# Modeling Patient Engagement in Peer-to-Peer Healthcare

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## **ABSTRACT**

Patients now turn to other patients online for health information and advice in a phenomenon known as peer-to-peer healthcare. This paper describes a model of patients' peer-to-peer engagement, based upon qualitative studies of three patient or carer groups searching for online information and advice from their health peers. We describe a three-phase process through which patients engage with peer experience (PEx). In phase I (gating) patients determine the suitability and trustworthiness of the material they encounter; in phase II (engagement) they search out information, support and/or advice from others with similar or relevant experience; and in phase III (evaluation) they make judgments about the costs and benefits of engaging with particular websites in the longer term. This model provides a useful framework for understanding web based interactions in different patient groups.

# **Categories and Subject Descriptors**

H.5.3 [Group and Organization Interfaces]: Web-based interaction; J.3 [Life and Medical Sciences]: Health; K.4.1 [Public Policy Issues]: Computer-related health;

## **Keywords**

Peer-to-peer healthcare; online patient experiences; engagement; trust; asthma; smoking cessation; multiple sclerosis carers; design guidelines

## 1. INTRODUCTION

The Internet is well established as a major source of health information [8, 26], but both the source and the nature of e-health content has changed rapidly over the past few years. Patients are increasingly the first source of information and advice for other patients in a new peer-to-peer process in which patients are turning to others like themselves for advice and support and where detailed patient experiences (PEx) are offered online and used to inform health decisions [30].

The changing nature of e-health raises a number of important research questions around the new types of peer-generated information, support, and advice that are available. How do individuals select from this shared data, stories and experiences, and how might we support them in this process? In this paper we

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ACM 978-1-4503-2745-9/14/04. http://dx.doi.org/10.1145/2567948.2576937 address both questions, presenting a framework that captures not only the different kinds of patient experience available online, but also the decision process by which patients chose one source of information over another.

## 2. BACKGROUND LITERATURE

There is increasing evidence that shared peer experience forms an important part of health-related Internet use [19]. Online patient experiences are particularly prevalent for health conditions that are life threatening, chronic, or less mainstream and examples explored in the research literature include HIV/AIDS [19], antenatal diagnostic testing [14] and infertility [15]. Carers are also using the Internet to find and proffer information, share experiences and opinions, and provide encouragement and support across a range of conditions and issues, including cancer [16] and parents caring for children with special health care needs [1]. The Internet is also a popular place to provide support for behavioral and lifestyle changes, such as weight loss and smoking cessation, through the use of tailored interventions, reminders and online support groups [28].

Patient experiences can be used to inform health decisions [12], but they also offer opportunities for social comparison, helping patients understand how well they are coping with a particular illness [17]. Patients may draw on others' accounts of their experiences of disease in order to become more optimistic about their own condition [22] or to adjust to the reality of the disease in order to prepare them for what is to come, but in either case, others' experiences can seem to leave them feeling less isolated in their "patient journey" [30]. Not surprisingly, then, the latest Pew data on peer-to-peer health care shows that those living with chronic conditions are most likely to go online to find others with similar health concerns [11].

The story is not entirely positive, as the ability to harvest health experiences with no online 'quality control' can cause problems. Individuals may struggle with experiences that contain very strong emotional content, or be left feeling that their condition will isolate them from other healthy individuals when accounts suggest that only those who have personally dealt with the condition could possibly know what it feels like [15]. The findings from some studies suggest that online groups can also exacerbate a process in which an illness comes to define the individual [17].

A key point is that the patient is faced with diverse experiences online and must therefore engage in a sampling or selection process, making decisions about which experiences seem relevant or useful. This, in turn, raises the important question of what drives this sampling process? From a theoretical standpoint we already know something about how patients come to select one health website over another. For example, we have evidence that it is a staged process that involves (i) a heuristic decision that is influenced by web design factors affecting the initial 'look and feel' of the site; (ii) an analytic decision that involves a careful

exploration of the content of the online material; and (iii) a longer term consultation and integration process in which diverse information sources (on and off-line) are reconciled [27]. We also know that in selecting a website patients are drawn to material offered by and written for 'people like me' [27,28] and there is evidence that such narrative accounts may enhance message uptake and responsiveness [4].

We do know that patients and carers may have complex, unspecified needs extending beyond the remit of traditional information seeking such as described by Ellis [5] or Evans & Chi [7]. While we might assume that factors such as the credibility, trustworthiness and relevance of patient stories will play a role in the sites they select [10], we know little about how these and other factors may interact at different stages of the patient journey. In this paper, then, we seek to understand more about the ways in which patients access and assess information and advice from their peers.

## 3. METHOD

Research participants were drawn from three different populations, chosen to reflect three very different health challenges: (i) patients with a chronic health condition (asthma); (ii) individuals considering a health behavior change (smoking); and (iii) individuals supporting someone with a serious health condition (MS carers). In total there were 36 participants: 20 male and 16 female with a mean age of 38.71 years, range 20-65 years. There were 10 smokers, 15 people with mild to severe asthma and 11 MS carers, all experienced Internet users (9.92 average years using the Internet). Twenty-two participants (61.11%) had previously looked for information about their respective health condition on the Internet (11 of the MS carers; 5 of the smoking sample; 6 of the asthma sample).

Participants were invited to the lab and asked to search a subset of the health materials available on the Internet for approximately one hour, seeking information and advice on issues relevant to their own circumstances. This was followed by a facilitated group discussion. Each participant was given access to seven predetermined sites during the search phase. Every site contained patient-relevant material, but only four of the seven sites contained patient experiences. Following the initial search, participants were asked to choose two sites to explore in more detail. Subsequent group discussions covered the following main areas: (1) site selection and rejection; (2) site likes and dislikes; (3) aspects of patient experience; and (4) trusted elements.

Participants were then directed to patient experiences sections on two further websites to examine any remaining issues and a final discussion on the content of these last two sites addressed: (1) recall of experiential material; (2) level of interest and usefulness of patient experiences; (3) variety and type of patient experiences (i.e. individual accounts such as blogs testimonials versus interactive forum style content containing multiple experiences); and (4) trust in the material. Two weeks later, 16 participants took part in a one hour semi-structured telephone interview addressing: (a) information searching behaviors since phase 1; (b) recall of the websites and their content; (c) information sharing activities; and (d) decision making and current behavioral intentions.

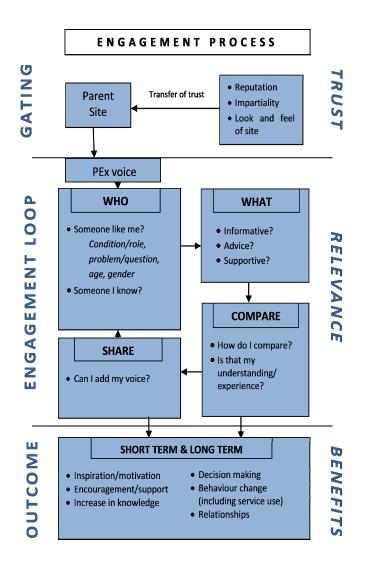


Figure 1: A framework that captures patient engagement with peer information online

## 4. RESULTS

A thematic analysis using a mixed qualitative methodology [3] supported a three phase process by which users engage with online patient experiences (Fig.1). We describe each of these phases and their sub-components below.

# 4.1 Phase I – Gating

During participants' initial encounter with a site, they reported making a rapid judgment about whether or not to engage further with that site or move swiftly on to an alternative. Participants made rapid 'gating' decisions based on either the known reputation of the site provider (i.e. is the site hosted by a credible and impartial agency) or based on the 'look and feel' of the site [cf 11]. We describe these as 'reputation' and 'design' factors.

# 4.1.1 Reputation

Participants' first impressions were influenced by the knowledge they brought with them. Participants were initially prepared to trust in the information provided on site provided that they recognized the organization as being both credible and impartial: So yeah, I probably like the NHS and the Asthma UK site. They were both obviously well established and really really well liked.. And the British Lung Foundation as well 'cos they're a charity. (Asthma, Participant 5)

I'm familiar with it, with the logo as well [...] so I have an involvement if you like, so therefore I would trust it. (MS, Participant 2)

Websites that had commercial overtones created very negative first impressions and, consequently, participants often felt that information contained on such sites would not be impartial or trustworthy:

Advertising and private sector sponsorship branding all over the homepage made it feel less 'neutral' and independent, which made me wary that the info would be impartial. (Asthma, Participant 7)

You don't know what they're promoting and what they're not promoting; whereas if you look at something like NHS Choices it should be more open, it should be more level pegged. (Asthma, Participant 13)

The site is clearly built to make money, though the story of Allen Carr1 may or may not be true. I would not be swayed by a site that offers a 'simple fix' to something that I know to be difficult for many. (Smoking, Participant 10)

## 4.1.2 Design

Participants from all three health groups liked sites that looked clear, attractive, and professional. They also liked a site that was easy to navigate:

It was very easy to access what you wanted [...]whereas some of the other ones you got lost .. into perhaps something else you didn't want to get into or wasn't really appropriate. (MS, Participant 9)

Straight-forward layout. Clear headings for information. No advertising to distract from text/information. (Asthma, Participant 1)

Looks like very informative but also attractive and easy to use. Good access to lots of information and advice. Doesn't appear like a sales pitch or judgmental of smokers. (Smoking, Participant 7)

The converse was also true; participants particularly disliked sites that appeared at first glance to be informative but were then difficult to navigate because of poor or thoughtless organization:

I wouldn't give it the time of day for that, lazy with the layout, throw everything into one page, instead of being creative. (Asthma, Participant 4)

#### 4.2 Phase II: Engagement Loop

Having made their initial selections, participants examined the content of the websites and the patient experiences in more detail. For those in all three health groups, this involved an iterative process during which they discovered who was making the contribution, and assessed what was being said. Participants then compared the online stories with their own experiences, in part to see how credible the material was, while also assessing the extent to which they could add their own stories. These four processes – who, what, compare, share – were critical to meaningful engagement with patient experiences.

# 4.2.1 Who

Patient experiences say something about the person posting the experience and participants were keen to understand who that person was. They were quick to reject experiences that came from an individual who seemed different from themselves, either because they came from a different age group, region, or other demographic, or because the match to their health profile or severity of condition was poor. Sometimes these judgments were made on the basis of quite superficial information (such as the photograph of the story-teller); on other occasions the judgments reflected a more nuanced interpretation of the underlying patient 'voice'. Differences in age and severity of condition were the main reasons for rejecting an account of an experience altogether:

They were interesting but they weren't really applicable to our age group. Like on the NHS Choices one the people were 49, 56 and 69. So it's good if you're an old person but for me, I'm 21, it's got like nothing to do with my age group. (Asthma, Participant 3)

The first one, the three stories, they were older people. I think they were a little bit extreme. I don't they're typical of an everyday asthma sufferer ... So I don't see the relevance of those particular ones. (Asthma, Participant 15)

So I don't know if it's helpful because I can't really relate to it. I couldn't really relate to those people. I can't say how. Definitely not Maria from Michigan (laughs). (Smoking, Participant 7)

#### 4.2.2 What

Participants appeared to be searching for different kinds of resources from the online patient experiences. Some were seeking out basic information, others advice on how to proceed, make changes or decisions, and some were simply acknowledging the social and emotional support on offer. Participants rejected information offered by their peers if it did not resonate with their own understanding of the condition or if the mixture of information, advice and support on offer was unbalanced or a poor match to their needs. However, even those who claimed to be quite knowledgeable about their condition were generally interested in the different kinds of patient "journey" that others had experienced:

There was one... the MS Trust one I think ... it got a load of photos of people ... and when you click on those there was a little sort of their own personal story of what happened to them. And it gave it quite an edge. (MS, Participant 2)

I feel quite confident in what I actually know about it in terms of just the base level of information but I found I learned a lot more from actually listening to, and reading about the other peoples experiences, and how they handle different situations in comparison to how I do and also just the different range of treatments. (Asthma, Participant 6)

# 4.2.3 Compare

Some participants saw clear and direct comparisons between their situations and the online patient experiences:

The first one about 47-aged smoking for 30 years. But she got this, she got stroke, and I was thinking, when I read it I thought, well it's me. I couldn't sleep because my chest is hurting, it could be me! That kind of that experience and you can share it, and when I read that experience I thought yes, 30 years of smoking, she is younger than me, I year younger than me, and she got stroke, it could be me. (Smoking, Participant 9)

Other comparisons were less easy to draw, such as when the severity of the online patients' condition was very different to the participant's:

It's hard to compare myself directly and say that I've learnt a lot from that because I can't really ... I'm not at that stage. (Asthma, Participant 5)

People differed in the extent to which they could cope with their varying circumstances and said they found it difficult to read about others whose stories perhaps challenged their own worldview or outlook. The MS carers were particularly vulnerable here, as they found that reading about other peoples' situations could highlight imagined futures that they simply did not want to consider:

you've got to keep yourself upbeat and if that kind of thing is put in front of me I'd be thinking 'that's not going to make me upbeat' it's going to make me go down and I just can't afford to be down. (MS, Participant 9)

On the other hand, unrealistically positive experiences were also rejected by MS carers and by smokers:

Sometimes that has in 'I've got MS but I still managed to climb Mount Everest' and you think, and that's the other end of the scale, and you think well I can never replicate that I must be a bloody failure. (MS, Participant 8)

It's quite sickening the group [on NHS smokefree website] it's detached from real life... it's just too nice. (Smoking, Participant 5)

#### 4.2.4 Share

For some participants, the presence of a forum or some means whereby patients could share information directly was important as it provided the opportunity to interact directly with others with similar health conditions and histories, and get to know more about the people who were sharing. The presence of a forum could lend the site greater credibility, as the stories were more variable and less like artificial or scripted patient testimonials:

The forums are better than the real life stories because we can interact with other people and share their experiences with us and we can gain some knowledge. (Asthma, Participant 6)

On the Asthma UK one, they had on the home page this thing, like a campaign 'put your story on the map' which you went into and it got lots of people's stories. Some were happy, some were angry stories, some were sad stories and they'd got them all, you know different areas ... It was quite powerful, you had a chance to put your story on there. (Asthma, Participant 11)

For the MS carers, in particular, it was helpful for them to envisage a future in which they not only read other peoples' accounts but could be moved to share their own experiences as well, either as a response to the online narrative or as a way of seeking more specific information:

To begin with it was just absorb, it was just read it, but then fairly soon she [partner with MS] was putting questions out, 'This has just happened, has anyone else had this?', I think especially with erm treatment. (MS, Participant 2)

## 4.3 Phase III: Evaluation and Outcomes

Participants expected – and in some cases had already experienced – a range of outcomes resulting from their interactions with online experiences. The advantages and disadvantages described by our

participants mapped well onto the domains described in the recent literature [30]. We found that patient experiences provided participants with the opportunity to learn more about their condition, to acquire knowledge about the practicalities of managing their condition or about dealing with health services, to understand more about what they might expect, to motivate themselves using positive stories, or to remind themselves about the seriousness of their condition or outlook, and to develop supportive relationships with others. We have clustered these into two headings reflecting the time-course of a particular disease, involving firstly 'information and understanding'; and secondly 'peer support, motivation and behavior change'.

# 4.3.1 Information and understanding

The majority of smokers felt that they were familiar with the facts about smoking and health and so did not rate the information content particularly highly. However, several appreciated the sharing of practical tips and new ideas to help them quit. For people with asthma the issues were often about acquiring hints and tips on management:

It just helps you, if someone telling you about the mistakes they have made and help you avoid it. That's the ideal for what forum is for really. That's why people are using because they are so useful. (Smoking, Participant 2)

I have learned something from looking at those sites that I didn't know. (Asthma, Participant 5)

Sometimes the information provided concerned the health service management of the disease or useful pointers as to how other people had interacted with their doctors and this, in turn, led to participants drawing up plans for their own use of health services:

It gave me a few places to look at myself when I get back home and some things my doctor or nurse next time might be able to review what's happening, maybe sort of help me. (Asthma, Participant 6)

They also reported shifts in understanding arising from these shared experiences and this could relate to the condition itself or the nature of the treatment. For example, one participant was pleased to read an experience that explained the true function (and names) of his inhalers:

[It showed me] the difference between prevention and relieving. I have not thought of that I know there are different inhalers with different colors but I didn't realize what the real difference was between them. (Asthma, Participant 2).

This shift in understanding was often described in terms of the ability to visualize the disease or problem or anticipate the future:

It was interesting to read the discussions and some of the stories of people who've been in hospital for a lengthy amount of time and how they deal with things and really how bad it can get. (Asthma, Participant 5)

We should note, however, that for those with longer-term experience of caring for patients with MS, visions of the future were problematic. Other peoples' experiences were sometimes regarded as too gloomy and few carers wished to be reminded of what was coming:

I got so far and then I started to feel really sickly because it was talking about the future and I really don't want to think about things in that way. (MS, Participant 7)

That said, for those MS carers with a recently diagnosed partner or child, the patient experiences satisfied a strong desire for basic information about the condition and allowed them to test out possible symptoms with other MS patient experiences in a more meaningful manner:

[The forums] are useful for both carers and sufferers ... if they get something that they haven't experienced before they can find out whether it's a symptom or not a symptom of the condition. (MS, Participant 1)

4.3.2 Peer support, motivation and behavior change. For many of our participants, the most significant longer-term potential of the Internet was in developing new supportive relationships that allowed them to talk openly about their health conditions:

It felt like people knew each other and they were saying so and so are you ok, I hear you've been in hospital and you can see that there would be that real peer support network, which for me, I suppose is the benefit of doing this kind of thing online. That could never happen just normally without the Internet. (Asthma, Participant 7)

It's good for communicating and letting off steam. (Asthma, Participant 6)

Peer support could also provide participants with the motivation to change behavior or maintain a treatment regime. Smokers in particular recognized the supportive or motivational function of patient experiences. For some smokers, simply knowing that other people (like them) fail but persist until they succeed was felt to be valuable:

I don't feel alone on the forum because there are different people who try to quit smoking. And it's kind of encouraging. (Smoking, Participant 3)

Forums is like you are actually talking to people not just like given a quote of someone said like 'I quitted 20 years ago'. They are actually typing out to say, oh, this happens and this keeps going on. (Smoking, Participant 2)

There's a certain personality to it [the inclusion of patient experiences] one you sort of connect to even at a very superficial level of reading. It still gives you kind of sort of hope and motivation that if other people can do it so can I. (Smoking, Participant 10)

There were some signs across the groups that the experiences had initiated behavior change. At the two week follow-up, for example, one of the MS carers, triggered by the experiences online, had begun applying for power of attorney (the authority to represent or act on another's behalf in legal matters), and another had sought more help and support from family members and requested a social worker.

## 5. DISCUSSION

Overall, the engagement framework supports findings from earlier research, reflecting the importance of good design, visual appeal, credibility, reputation and trust in Phase I [10, 27] and the recognition of a range of outcomes from engagement with patient stories in Phase III [30]. We have made the greatest contribution in developing the engagement loop in Phase II where we have clarified the kinds of questions different patients may ask of their peers. This can be a useful framework, then, for comparing the needs of different patient groups, as we imagine that some groups

may have needs that are more information driven and others may seek greater levels of support. We should recognize that previous research has been somewhat limited, typically drawing upon single user groups [19], individual websites [24], or studies focusing upon a discrete aspect of patient experience use (e.g., decision making, [25]). In this work we have tried to provide a unifying framework that captures the whole interaction process in order to facilitate the future design of websites that can fully support patients in their interactions with their peers.

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