Why don’t we trust health websites that help us help each other? An analysis of online peer-to-peer healthcare

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ABSTRACT
Shared patient experience (PEx) has become common on the medical Internet and is a potentially valuable source of health information and advice, but little is known about how we choose to incorporate PEx in our information gathering and health decision-making. An online questionnaire revealed a paradox: patients like PEx and are drawn to sites containing PEx, but are then less likely to trust the information and advice they find there. Subsequent analysis suggests that this paradox may be related to the prevalence of advertising as a funding-model for online patient communities. To better understand these issues we explored one health domain (smoking cessation) in greater depth, inviting participants to search for relevant material and then discuss the different kinds of patient experience they found online. We report on the selection and rejection factors involved in choosing sites containing PEx and explore the notion of credible design in this space.

Author Keywords
eHealth, health informatics, trust, credibility, advertising, health, patient experience, patient communities, smoking cessation

ACM Classification Keywords
H.5.3 User Interfaces, web-based interaction  
H.3.3. Information Search and Retrieval  
H.3.5 Online Information Services, Web-based.

General Terms
Human Factors; Design

INTRODUCTION
We have transformed our understanding of how patients use the internet for health decision-making and support over the past decade. At the turn of the century the received wisdom was that patients would primarily seek-out a professional, authoritative source for health information and advice as a means to prepare themselves for a future consultation. However, by 2007 with the rise of user-led content, it was clear that people sought more than a physician opinion online and were becoming heavily influenced in their health decision-making by other, like-minded patients. Recent reports of health behaviors have shown a remarkable rise in the number of people seeking support and advice from their online peers, with an estimate that one in four Internet users living with a chronic condition, such as high blood pressure, diabetes, heart or lung problems, or cancer, seek others with similar health concerns online [1].

The process of finding ‘like-minded others’ online has become relatively straightforward, as patient communities have grown around almost every known health condition. This means that patients can now easily source their health information, support and advice from fellow patients [2]. But this raises a new set of questions for those involved in the design of health websites: Are patients explicitly drawn to those websites that offer patient experience (PEx) and if so, how readily do they trust the information and advice they find there? Is the patient voice likely to carry more weight than the healthcare professional? In this paper we address these questions and make five contributions: Firstly, following an online survey, we provide an up to date snapshot of the most popular health websites returned in online searches. Note, that this is in terms of their reported consultation with web material as opposed to simply sourcing data on site visits. Secondly, we document the kinds of PEx associated with these sites. Thirdly, we reveal a paradox: patients like PEx and are drawn to sites containing PEx, but are then less likely to trust the information and advice they find there. Fourthly, we report on the prevalence of advertising as a funding model for many peer-to-peer health communities and show, following a series of focus groups, why this might present a real problem for these communities. Finally, we summarize those design factors likely to influence the perceived credibility of PEx.

Background
Most Internet users have conducted health-related searches online [3,4,5] many as a specific aid to decision-making or as a means of preparing for a consultation with a physician, but some simply as a means of accessing information and support [6,7,8,9,10]. Increasingly, these searches are
returning large amounts of patient-authored content, much of it capturing patients’ own experiences of different health conditions or procedures [11,12,13]. The nature of these experiences can vary widely, not only because the message itself can take different forms, but also because the medium is highly variable. It is, for example, possible to source graphic and highly emotive patient narratives, describing, say, a long-term stay in hospital, just as it is possible to source short patient responses to a health question via a forum or collection of tweets. A number of health professionals have proposed that these patient contributions should complement professional knowledge [14, 15] as they may offer additional health benefits. It has been argued, for example, that honest patient narratives may support accurate decision making [16, 17] or may help patients come to terms with longer term health conditions, improving their adjustment to the disease [18].

Ziebland & Wyke [19] have argued that access to patients’ stories can help promote positive behavior change, potentially increasing the use of health services and improving patients’ ability to visualize outcomes and realize more fully the implications of their illness or health condition. They discuss the role of online PEx in terms of seven activities: (1) finding information, (2) feeling supported, (3) maintaining relationships with others, (4) experiencing health services, (5) learning to relate the story, (6) visualizing disease, and (7) affecting behavior.

The story is not entirely positive: Some authors report concerns that some online testimony contains very strong emotional content that can be off-putting and is not always directly relevant [19] while others argue that an increasing sense of isolation could derive from the belief that only those who have personally dealt with the condition could possible know what it feels like [20]. Finally, the quality and credibility of online patient experiences are highly variable, with some testimonies explicitly included for commercial gain, so there are interesting issues here about how users decide to trust the information and advice they are offered by others.

In this study, we report the results of a survey that asks patients to report their experiences of the last time they went online for information and advice. Questions pertaining to the availability and quality of patient experience were included as well as questions concerning the design and credibility of the site visited. This survey is the third in series of three, undertaken every five years in order to explore changing patterns of health information [21]. The explicit inclusion of patient experience here was prompted in part by the finding, in the previous survey, that the presence of some kind of patient voice was influential in persuading users to follow the advice they found online.

However, it was also prompted by a recognizable shift in the kind of patient experience becoming available online. The rise of blogging, life-logging and social disclosure through networks of various kinds has been labeled in terms of the development of a new kind of ‘personal health informatics’ [22]. Certainly, studies published over the last two years have shown how different patient communities have grown with the explicit aim of offering help and support to their peers. This was reflected in the 2010 Pew Internet survey [1], which reported extensive patient-to-patient help among people living with chronic conditions. For people living with diabetes or high blood pressure for example the need to share stories was found to be a driver of health related Internet use. It was also reflected in a series of studies exploring how people seek mental health information online e.g. [23, 24] where people said that one of their prime motivations for going online was to find experiential information from others with similar problems. These patients typically reported increased hope on finding others that had shown good recovery and also reported taking comfort in knowing that they were not alone.

**STUDY 1**

**Method**

An Internet survey was designed as a development of two earlier eHealth investigations [25, 26], in which people with a range of health concerns were asked to describe their experience of a health site used recently. The survey was promoted on the hungersite.com website, a site which makes a donation to the UN World Food Program for each click-through. The URL for the questionnaire was also submitted to Yahoo and distributed to local print media. Participants were asked whether they had sought advice online about health. Those responding ‘yes’ were asked about previous searches and their reasons for searching online, as well as demographic information including age, gender, Internet experience, education and location, elements of which is captured in Table 1, below.

<table>
<thead>
<tr>
<th>Age</th>
<th>18-24</th>
<th>25-35</th>
<th>36-44</th>
<th>45-54</th>
<th>55-64</th>
<th>65+</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>8%</td>
<td>17%</td>
<td>12%</td>
<td>20%</td>
<td>27%</td>
<td>14%</td>
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</tbody>
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<table>
<thead>
<tr>
<th>Highest level of Education</th>
<th>High school</th>
<th>College</th>
<th>University</th>
<th>Postgraduate</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>17%</td>
<td>27%</td>
<td>27%</td>
<td>29%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Location</th>
<th>USA</th>
<th>Canada</th>
<th>UK</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>61%</td>
<td>3%</td>
<td>23%</td>
</tr>
</tbody>
</table>

Table 1: Demographic data for the questionnaire study

Participants were then asked about the nature of one specific website, describing its content and the presence or absence of any PEx before completing a set of five point Likert scales that captured attitudes to the site.
Results
The questionnaire data was cleaned to remove incomplete responses. Items reporting attitude to the online material was subject to a factor analysis which revealed a three factor structure. These factors were then entered into a hierarchical regression to see which if any factors predicted patients liking of and trust in the websites and also which predicted intention to change behavior.

Factor Analysis
A factor analysis of the items describing the web materials and patients responses to that material revealed three factors:

Factor 1 ($\alpha = .92$), labelled 'patient experience' brought together items mainly describing the importance of tailored information and the ability to interact with “like minded people” on the Web site. Specific items grouped under this factor were:
- The site offered powerful accounts of health experiences
- The site contained accounts of other peoples experiences
- It felt like the advice was tailored to me personally
- On the site I was offered the chance to see experiences from people just like me
- The site contained contributions from like minded people
- I was able to contribute to content on the site

Factor 2 ($\alpha = .85$), labelled 'impartiality', brought together items describing the extent to which the advice on the Web site appeared impartial and objective:
- The site told me most of what I would I need to know
- The advice was offered in my best interests
- The advice seemed objective i.e. no hidden agenda
- The site helped me understand the issue better
- The site was free from adverts
- The advice was impartial and independent
- The reasoning behind the advice was explained to me
- The advice seemed credible

Factor 3 ($\alpha = .84$), labelled 'credible design', brought together items describing the extent to which the site had credible design features and was easy to use:
- The language on the site made it easy to understand
- The site was easy to use
- The advice appeared to be prepared by an expert
- The site was owned by a well known organization

Hierarchical regressions were then conducted to examine which factors predicted the extent to which participants liked and trusted the website and the advice and acted upon the advice given by the site. The findings (see Table 2) show that impartiality, credible design and PEx all positively predict whether people like the website and impartiality alone was a predictor of intention to act on the advice. More surprisingly, in terms of trusting the information online, the two factors impartiality and credible design positively predicted trust in the website, as expected; whereas inclusion of patient experience was negatively associated with trust in the website. This was a surprising finding and left us with a paradox. Earlier literature was explicit in indicating that the presence of patient authored experiences could attract patients to health websites and that this kind of patient voice was associated with trust. Our analysis supported the first observation but not the second - people liked websites that contained PEx, but they didn’t trust them.

Content Analysis of Websites Visited
In order to explore this issue further a preliminary content analysis of the sites participants reported visiting was conducted. Firstly, the prevalence of different types of health searches was compared to see whether the health domains of interest had changed significantly over the decade. In fact, little has changed and the current survey show a remarkably similar pattern to those reported in the 2000 and 2005 studies [25,26,27] (Table 3).

<table>
<thead>
<tr>
<th>2000</th>
<th>2005</th>
<th>2011</th>
</tr>
</thead>
<tbody>
<tr>
<td>5. Allergies</td>
<td>5. Arthritis</td>
<td>5. Diet / Slimming</td>
</tr>
</tbody>
</table>

Table 3: Top five health searches by year of survey

Next we wished to look in more depth at the nature of online patient experience encountered by our participants, but to do this, we firstly had to identify a subset of sites containing PEx, where we believed, with some confidence
that patients had actually engaged with that available PEx. So we isolated those sites that were reported by a subset of individuals (n=40) who had both (i) scored highly on a question about their motivation to seek PEx online and (ii) could remember enough details about the site they visited for us to access it for analysis. A content summary of the resulting sites is provided in Table 3. These sites vary enormously in terms of their approach to PEx, although they can be roughly classified into three types. Firstly, there are some sites that are designed specifically for the provision of PEx. On these sites visitors are able to negotiate a portfolio of different experiences – with an example being patientslikeme, shown below (figure 1).

Figure 1: A site devoted to patient experience where different categories of experience are referenced from the home page.

Secondly, community-based sites often use PEx message boards and stories interwoven with information and advice from other sources. The sites typically relate to niche health fields and examples include hystersisters and twoweekwait (see figure 2 below). Here, the PEx material is readily accessible from the home page and can take a variety of forms but is largely supportive in tone and generally moderated, but unedited. More unusually some of these communities keep the PEx material housed separately within a separate site, two examples being Aspergillosis and autism speaks. The former uses a yahoo group to host its forum activity whilst the latter makes extensive use of social network media such as facebook and twitter to increase the scope and interactivity of their PEx.

Figure 2: A community PEx site showing advertising content in a banner on the right-hand side

The commitment to PEx is less obvious within the third type of site: larger health portals such as healthline and webmd (see figure 3) which contain relatively little PEx material and seem to use it largely as an ‘add on’ feature to providing a feel good factor for the site. The quality and depth of PEx on these major health portals can be limited and is often centered on read-only material which does not facilitate peer sharing. The patient stories are often heavily edited and written up as magazine style articles rather than as first person narratives.

Figure 3: A mainstream health portal, with no obvious links to patient experience from the home page
Looking at Table 4, what is particularly interesting is the prevalence of advertising as a funding model for PEx-heavy sites. We know, from a range of previous studies [21, 28] that the presence of advertising on a site can lead to a negative first impression and can lead to either immediate disengagement or to subsequent mistrust of the messages on that site. In a recent study, for example, [29] the presence of advertising on a website showing the link between drinking and breast cancer had no immediate effect on drinkers’ overall attitude to the site, but did subsequently affect health behaviors: those who drank heavily reported a reduction in drinking following exposure to the non-commercial site, but no reduction in drinking when a more ‘commercial’ site presented them with the same health message, but accompanied by advertising. Could this be the factor that accounts for our finding that, while patients are drawn to PEx online, they find sites containing PEx difficult to trust? In order to explore this specific issue in more detail, we conducted a second, qualitative investigation in which we invited four small groups of people with particular health concerns (smokers wondering whether to quit) into the lab to search for relevant health information online and to share their views about the kinds of material they found there.

### Table 4: Websites and their funding source and types of PEx they contain

<table>
<thead>
<tr>
<th>Description of website</th>
<th>Funding</th>
<th>iPEx types</th>
</tr>
</thead>
<tbody>
<tr>
<td>Autism speaks (<a href="http://www.autismspeaks.org/">http://www.autismspeaks.org/</a>)</td>
<td>Donation</td>
<td>Social network messages e.g. tweets</td>
</tr>
<tr>
<td>Healthline (<a href="http://www.healthline.com/">http://www.healthline.com/</a>)</td>
<td>Advertising</td>
<td>Videos of health experiences</td>
</tr>
<tr>
<td>HysterSysters (<a href="http://www.hystersisters.com/vb2/">http://www.hystersisters.com/vb2/</a>)</td>
<td>Advertising</td>
<td>Forums, Blogs, journals, chatroom, photographs</td>
</tr>
<tr>
<td>MayoClinic (<a href="http://www.mayoclinic.org">www.mayoclinic.org</a>)</td>
<td>Clinic</td>
<td>Patient stories</td>
</tr>
<tr>
<td>PatientsLikeme (<a href="http://www.patientslikeme.com">www.patientslikeme.com</a>)</td>
<td>Selling data</td>
<td>Patient summaries and data, Forums</td>
</tr>
<tr>
<td>SurfaceHippy (<a href="http://www.surfacehippy.info/index.php">http://www.surfacehippy.info/index.php</a>)</td>
<td>Advertising</td>
<td>Forums, Patient stories</td>
</tr>
<tr>
<td>Twoweekwait (<a href="http://www.twoweekwait.com">www.twoweekwait.com</a>)</td>
<td>Advertising</td>
<td>Forums, Patient stories</td>
</tr>
<tr>
<td>WebMD (<a href="http://www.webmd.com">www.webmd.com</a>)</td>
<td>Advertising/sponsorship</td>
<td>Forums</td>
</tr>
</tbody>
</table>

### STUDY 2

#### Method

Fifteen smokers were recruited to take part in a follow-up study in which they were invited to search for health-related smoking material online. Participants were recruited via a number of sources including council newsletters, leaflets and flyers.

#### Smokers

The fifteen smokers (7 male, 8 female, mean age of 23 years) were all experienced Internet users. They had been smoking on average for 7 years and smoked an average of 11 cigarettes per day.

#### Procedure

Each participant was allocated to one of four focus groups and asked to attend a 2-hour session held in an Internet café styled lab in Newcastle-upon-Tyne, UK. During the first hour of the session, participants were invited to search the Internet freely, looking for information and advice on smoking and health. Sites visited were automatically logged, but participants were also asked to record their perceptions of each site manually via a logbook and use this
information during a subsequent group discussion with a facilitator. Group discussions covered four main themes: 1) Selection and rejection factors 2) liked and disliked websites, 3) patient experience/account features 4) trust and behavior.

**Analysis**

Focus group comments were transcribed and then read and reread by two coders who compared emerging themes prior to undertaking a more thorough independent thematic analysis following the guidelines of Braun and Clarke [30], in conjunction with the data derived from participant logbooks. Coders were primed to highlight comments in relation to trust or mistrust, like or dislike of sites and were also interested in the presence or absence of a ‘commercial voice’.

"I just went on the NHS one and typed smoking in the search thing." (Focus group 1, Participant 6)

As we would expect, from the survey data, we did find that people really liked having access to other people’s experiences online.

"Well the patient UK one did have experiences of people who’ve smoked and who’ve quit and health issues that they’ve had whilst smoking and once giving up and things like that and that was quite good I think - reading about other people’s experiences." (Focus group 1, Participant 3)

"Who is better to tell you to about it than someone who’s already done it? in my opinion… So I quite like it (the PEx)." (Focus group 3, Participant 9)

We also found support for the claims that such experiences can help make the health issues seem more real and engaging as people felt that they could relate more to other people who are in similar situations.

"[It’s more helpful] If they’re more realistic if they’re not just literally a doctor’s sat and written it like ‘Mrs C has done this’. If it’s an actual person saying ‘look it’s really hard. I’ve shouted a lot. I’ve done this. I’ve done that’ then you can relate to them." (Focus group 1, Participant 2)

"It makes sure it relates to the individual doesn’t it? If your doctor tells you to stop smoking the chance is they never smoke, so they don’t, I don’t think they understand, they can’t understand the position we are in, because they never smoke, whereas somebody has smoked, they smoked for eight years, they quitted, and they got a successful story, it will make me think, wait a minute, they know how it is to smoke, they also know how it is not to smoke, so it kinds of applies to you to stop smoke and makes you feel like you should." (Focus group 1, Participant 4)

However, the presence of advertising was almost universally raised as something that was disliked about some of the sites.

"There’s lots of adverts as well which annoyed me. It’s like they get some form of gain out of telling people to quit. There’s adverts and even some adverts weren’t even related to smoking." Focus group 1, participant 2)

Too many adverts. Looks like websites gets money out of advice” (Focus group 1, Participant 2)

As predicted, we found considerable evidence that users were suspicious about site content and advertising had an important role to play here. Sites that appeared to be selling a product or that were otherwise viewed as commercial created very negative first impressions in the sample, and participants often felt that information contained on a site such as this would not be impartial or trustworthy.

"I have a website that I really don’t like, it’s more, it seems like a business setup. It was more like, smoking is really bad, smoking is really bad, buy something off us and we

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**Figure 4:** An example of an NHS sponsored smoking cessation site containing PEx, but no advertising
going to make money out of you. That kind of make me feel like fall into this massive money making scheme.” (Focus group 4, Participant 13)

“Seemed like a money maker - forcing pricey products. Business set up.” (Logbook, Participant 15)

More tellingly, participants became particularly suspicious if it seemed that the PEx had been used cynically to advertise a particular product or manipulate beliefs.

“There is one particular one that got like a few ... a review of stories of how people are doing with the product, but I think those websites try to sell their products rather than they are really trying to be help.” (Focus group 3, Participant 9)

“They [are] sort of using it [in a] commercial way, like I can see information on TV there, but if its someone not trying to sell you anything just sharing their experience I would find them quite helpful” (Focus group 3, Participant 10)

“No it seems to be a commercial way I don’t usually believe it!” (Focus group 3, Participant 10)

These discussion points are revealing as they highlight the liking of PEx material, but indicate how they can be mistrusted if used in a seemingly commercial way, to the point that users may actually question the genuineness of the PEx. As noted earlier, the issue of advertising or using PEx for some kind of commercial gain is a particularly interesting one for online health communities. Harris and colleagues [29] found that the mere presence of advertising online can generate mistrust, which can lead to defensive responding to unpalatable material [26]. This is worrying when we consider that the funding models for so many well-intentioned social health enterprises are advertising based. With this in mind, we end with a discussion of how our findings might suggest ways in which PEx design can be improved in order to have maximal effect.

**DISCUSSION**

The trust issues raised in this paper are important for understanding the future of PEx. We know PEx is growing and is likely to be increasingly employed by those hoping to engineer positive health behavior change. A number of web based interventions focusing on, for example, smoking cessation, weight management and physical activity [31, 32, 33] use tailored programs of information and advice to facilitate behavior change and researchers are considering the ways in which online social networks could also be harnessed support smoking cessation [34].

We also know that people genuinely want to learn from others who have shared similar experiences, but are cautious because too many of those experiences seem credible. Given this, it is interesting that so little is being done to incorporate PEx into the large, mainstream eHealth sites and portals. From a health policy perspective, this surely needs to change: if genuine patient stories are an important health resource – then such stories should be integrated into the larger government and charity portals without recourse to advertising that may taint the message. In the UK, a 2010 White Paper ‘Equity and excellence: Liberating the NHS’ highlighted the government’s intention to ‘put patients at the heart of the NHS, through an information revolution and greater choice and control’ and to ensure that ‘patients will have access to the information they want, to make choices about their care’ [35]. The presence of good quality forums for health information and support that is ‘generated by the patients themselves’ is likely to be central to this information strategy and it is interesting that the NHS have not only incorporated patient videos into their NHS choices website, but have also entered into a collaboration with an external site ‘health unlocked’ helping patient groups to set up more interactive forums.
Based on the findings we report here, we would make the following specific recommendations in respect of PEx:

**Make PEx easy to find on the larger portals:** Ensure that the experiences are clearly labelled within the application and are directly accessible from the homepage or first screen of any application.

**Avoid commercial overtones:** PEx and commerce do not sit together comfortably. Product testimonials and advertising wrapped up as PEx reduce the value of PEx and the credibility of the application as a whole.

**Include a balance of PEx and medical facts and figures:** This balance should foster credibility and allows users to become familiar with a particular condition or treatment and then to follow up with questions or to read about peoples’ first hand experiences.

**Consider the trust issues associated with the site as a whole:** The look and feel of the site or application as a whole will have an important effect on the extent to which users trust and engage with the PEx provision. Consider issues such as the professionalism of the site’s design, familiar navigation and layout and branding and reputation factors.

**Think about the potential effects of PEx:** If the application is centered around the provision of support and relationship development designers will need to consider the level of interactivity possible and the type of PEx on offer. Is the application intended to assist with decision making? Will users exchange images or video material to facilitate visualization of the health condition? Not all users are looking for all of the seven potential benefits of PEx reported by Ziebland and Wyke,[19] so which benefits are most likely for your community?

**Consider whether PEx is right for this health domain.** This field is relatively young and yet it is already clear that different patient groups have very different needs. Further research would be useful to establish whether PEx is sought and deemed helpful across all health topics, or whether there are particular domain-specific benefits.

Studies now need to test whether these findings can be replicated in cultures, such as the US, where advertising of drugs and medical services is more mainstream.

**CONCLUSION**

PEx can provide patients with access to experiential information and advice, but it is most commonly found in health websites that use advertising as a funding model. This is not the ideal situation for the future of health communication, as it can create mistrust and gives patients cause to discount the information they find online. To offset this problem, greater attention should be paid to other trust indicators and the larger and more credible health portals should give more prominence to PEx material.

**ACKNOWLEDGEMENTS**

This publication presents independent research commissioned by the National Institute for Health Research (NIHR) under its Programme Grants for Applied Research programme (RP-PG-0608-10147). The views expressed in this publication are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health.

The authors would also like to thank Phoenix Mo for her involvement during the early stages of this research project.

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