Advertising as a trustbuster in online peer-to-peer healthcare

Pam Briggs
Northumbria University
Newcastle upon Tyne
NE2 1NR
p.briggs@northumbria.ac.uk

Elizabeth Sillence
Northumbria University
Newcastle upon Tyne
NE2 1NR
elizabeth.sillence@northumbria.ac.uk

Claire Hardy
Northumbria University
Newcastle upon Tyne
NE2 1NR
claire2.hardy@northumbria.ac.uk

ABSTRACT

Websites offering peer-based healthcare potentially offer valuable new sources of health information and advice, but how do we decide which peer-to-peer sites to trust? We explore those sites offering different forms of peer-based patient experience (PEx) via an online questionnaire. The 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.

Categories and Subject Descriptors

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

Design, Human Factors

Keywords

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

1. INTRODUCTION

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.

1.1 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

	Like R^2 .57	**Trust R^2 .59**	**Intention R^2 .24**
Impartiality	β.494, t 9.61, p<.001	β.593, t 11.84, p<.001	β.492, t 9.49, p<.001
Credible design	β.295, t 5.82, p<.001	β.271, t 5.48, p=.000	Non-significant
PEx	β.110, t 2.71, p<.01	β.-.137, t -3.5, p≤.001	Non-significant

Table 2: Hierarchical regression outputs

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.

2. 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 are captured in Table 1, below. 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.

Age	18-24	8%
	25-35	17%
	36-44	12%
	45-54	20%
	55-64	27%
	65+	14%
Highest level of Education	High school	17%
	College	27%
	University	27%
	Postgraduate	29%
Location	USA	61%
	Canada	3%
	UK	23%

Table 1: Demographic data for the questionnaire study

3. 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.

3.1 Factor Analysis

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

Factor 1 (α=.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 (α = .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 (α=.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
- The site had a professional design
- The layout was consistent with other sites

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*.

3.2 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 results of the current survey show a remarkably similar pattern to those reported in the 2000 and 2005 studies [25,26,27] (Table 3).

2000	2005	2011
1. Alternative medicine	1. Womens health	1. Womens health
2. Diet / Slimming	2. Alternative medicine	2. Alternative medicine
3. Cancer	3. Fitness	3. Cancer
4. Fitness	4. Diet / Slimming	4. Arthritis
5. Allergies	5. Arthritis	5. Diet / Slimming

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 4. 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)**.

The more you share, the easier it will be to find patients like you. Start by adding a condition, symptom or treatment.

"I don't think all the money in the world could replace what I've learned here."
—PatientsLikeMe member

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 ***twoweekwait*** (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. Note 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.

Welcome to www.TwoWeekWait.com

Real-Life Early Pregnancy Symptoms

TwoWeekWait.com has the largest database of actual early pregnancy symptoms submitted from newly pregnant women. We update the site frequently with fresh new symptoms and stories! [View All Early Pregnancy Symptoms Here]

Recent BFP Stories

The Tale of 3 BFPs
BFP!
BFP on 12 DPO!! Very excited!!
Finally get to post to the site I have been stalking for 4 years!!!
Finally my very own BFP!!!
LONG! Unexpected success after 2nd HSG
BFP when I least expected it!

"Am I Pregnant?"

We added a new section to TwoWeekWait.com! Its called Do You Think I'm Pregnant? and its for all the women who are trying to conceive and haven't got that BFP yet! Check it out and wish these ladies good luck and send a little baby dust their way! Click here to read more.

"I was a real TTC novice until I came here. Everyone is encouraging, optimistic, and best of all willing to give away their secrets! I'm on this site every day."
--Jessica

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

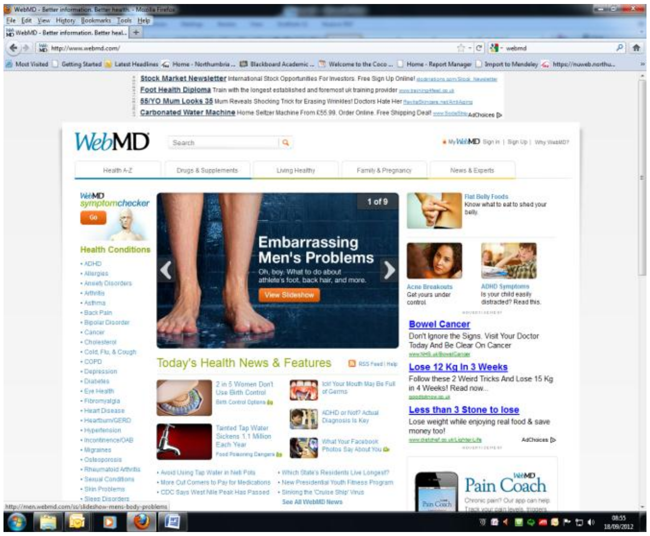

Figure 3: A mainstream health portal, with no obvious links to patient experience from the home page

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 use it largely to provide 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. 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 was accompanied by advertising. Online advertising. then, would seem to be a significant trustbuster in eHealth and may well be an underlying factor in our results – accounting for our seemingly paradoxical finding that, while patients are drawn to PEx online, they find sites containing PEx difficult to trust.

Description of website	**Funding**	**iPEx types**
Aspergillosis Patient Support (http://www.aspergillus.org.uk/newpatients/index.php)	Advertising/ sponsorship	Patient stories, Forums, Videos of meetings
Autism speaks (http://www.autismspeaks.org/)	Donation	Social network messages e.g. tweets
Healthline (http://www.healthline.com/)	Advertising	Videos of health experiences
HysterSysters (http://www.hystersisters.com/vb2/)	Advertising	Forums, Blogs, journals, chatroom, photographs
MayoClinic (www.mayoclinic.org)	Clinic	Patient stories
NHS choices (http://www.nhs.uk/Pages/HomePage.aspx)	Government	Patient stories (videos/text)
PatientsLikeme (www.patientslikeme.com)	Selling data	Patient summaries and data, Forums
SurfaceHippy (http://www.surfacehippy.info/index.php)	Advertising	Forums, Patient stories
Twoweekwait (www.twoweekwait.com)	Advertising	Forums, Patient stories
WebMD (www.webmd.com)	Advertising/ sponsorship	Forums

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

4. DISCUSSION

The trust issues raised in this paper are important for understanding the future of PEx in peer-to-peer healthcare. We know this 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.

5. ACKNOWLEDGEMENTS

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

6. REFERENCES

[1] Fox, S. The social life of health information. *Pew Internet and American Life*, (2011), http://www.pewinternet.org/Reports/2011/Social-Life-of-Health-Infor-Summary-of-Findings.aspx

[2] Mo, P.K.H. and Coulson, N.S. Exploring the communication of social support within virtual communities: A content analysis of messages posted to an online HIV/AIDS support group. *CyberPsychology & Behavior 11*, (2008), 371-374.

[3] Brann, M. and Anderson, J.G. E-Medicine and health care consumers: Recognizing current problems and possible resolutions for a safer environment. *Health Care Analysis 10*, (2002), 403-415.

[4] Christensen, H. and Griffiths, K. The internet and mental health practice. *Evidence-Based Mental Health 6*, (2003), 66-69.

[5] Laurent, M. and Vickers, T.J. Seeking health information online: Does Wikipedia matter? *Journal of the American Medical Informatics Association 16*, (2009), 471-479.

[6] Anderson, J.G., Rainey, M.R., and Eysenbach, G. The impact of CyberHealthcare on the physician-patient relationship. *Journal of Medical Systems 27, (*2003), 67-84.

[7] Berland, G.K., Elliott, M.N., Morales, L.S., Algazy, J.I., Kravitz, R.L., Broder, M.S., et al. Health information on the Internet: Accessibility, quality, and readability in English and Spanish. *Journal of the American Medical Association 23*, (2001), 2612-2621.

[8] Fox, S. and Rainie, L. *Vital decisions: How Internet users decide what information to trust when they or their loved ones are sick.* Washington, DC: Pew Internet & American Life Project, 2002.

[9] Friedewald, V.E. Jr. The Internet's influence on the doctor-patient relationship. *Health Management Technology 21*, 11 (2000), 79-80.

[10] Pemberton, P. J. and Goldblatt, J. The Internet and the changing roles of doctors, patients and families. *Medical Journal of Australia 169*, (1998), 594-595.

[11] Eysenbach, G. The impact of the Internet on cancer outcomes. *CA: A Cancer Journal for Clinicians 53*, (2003), 356-371.

[12]. Frost, J. Social uses of personal health information within PatientsLikeMe, an online patient community: What can happen when patients have access to one another's data. *Journal of Medical Internet Research 10*, (2008), e15.

[13] Ziebland, S., Chapple, A., Dumelow, C., Evans, J., Prinjha, S. and Rozmovits, L. How the internet affects patients' experience of cancer: A qualitative study. *British Medical Journal 328*, 7439, (2004), 564.

[14] Caron-Flinterman, J.F., Broerse, J.E.W. and Bunders, J.F.G. The experiential knowledge of patients: A new resource for biomedical research? *Social Science & Medicine 60*, (2005), 2575-2584.

[15] Entwistle, V.A., Renfrew, M.J., Yearley, S., Forrester, J. and Lamont, T. Lay perspectives: Advantages for health research. *British Medical Journal 316*, 7129, (1998), 463-466.

[16] France, E.F., Wyke, S., Ziebland, S.; Entwistle, V.A. and Hunt, K. How personal experiences feature in women's accounts of use of information for decisions about antenatal diagnostic testing for foetal abnormality. *Social Science & Medicine 72*, (2011), 755-762.

[17] Entwistle, V.A., France, E.F., Wyke, S., Jepson, R., Hunt, K., Ziebland, S. and Thompson, A. How information about other people's personal experiences can help with healthcare decision-making: A qualitative study. *Patient Education and Counseling 85*, (2011), 291-298.

[18] Wicks, P., Massagli, M., Frost, J., Brownstein, C., Okun, S., Vaughan, T., et al. Sharing health data for better outcomes on PatientsLikeMe. *Journal of Medical Internet Research 12*, 2 (2010), e19.

[19] Ziebland, S. and Wyke, S. Health and illness in a connected world: How might sharing experiences on the Internet affect people's health? *Millbank Quarterly 90*, 2 (2012), 219-249.

[20] Hinton, L., Kurinczuk, J.J., and Ziebland, S. Infertility; isolation and the Internet: A qualitative interview study. *Patient Education and Counseling 81*, (2010), 436-41.

[21] Sillence, E.; Briggs, P.; Harris, P. and Fishwick, L. Going online for health advice: Changes in usage and trust practices over

the last five years. *Interacting with Computers 19*, (2007), 397-406.

[22] Kamal, N., Fels, S. and Ho, K. Online social networks for personal informatics to promote positive health behavior. In *Proc. of the 2nd ACM SIGMM Workshop on Social Media* (Firenze, Italy), (2010), 47-52.

[23] Powell J. and Clarke, A. Information in mental health: qualitative study of mental health service users. *Health Expectations* 9, (2006), 359-365.

[24] Powell J., and Clarke, A. Internet information seeking in mental health: population survey. *British Journal of Psychiatry 189*, (2006), 273-277.

[25] Briggs, P., Burford, B., De Angeli, A. and Lynch, P. Trust in online advice. *Social Science Computer Review* 20, 3 (2002), 321-332.

[26] Harris, P.R., Sillence, E. and Briggs, P. Perceived threat and corroboration: Key factors that improve a predictive model of trust in Internet-based health information and advice. *Journal of Medical Internet Research 13,* 3 (2011), e51.

[27] Sillence, E. Briggs, P. Harris, P. & Fishwick, L. Changes in online health usage over the last 5 years. *Ex Abstracts CHI 2006 ACM Press (2006).*

[28] Sillence, E., Briggs, P., Fishwick, L. and Harris, P. Trust and mistrust of online health Sites. *Ex Abstracts CHI 2004 ACM Press (2004).*

[29] Harris, P. R., Sillence, E. and Briggs, P. The effect of trust-related design cues on responses to a web-based message about the breast cancer risks from alcohol. *Journal of Medical Internet Research* 11, 3 (2009), e37.

[30] Braun, V. & Clarke, V. Using thematic analysis in psychology. *Qualitative Research in Psychology* 3, 2 (2006), 77-101.

[31] Wangberg, S.C., Nilsen, O., Antypas, K., and Gram, I.T. Effect of tailoring in an Internet-based intervention for smoking cessation: Randomized controlled trial. *Journal of Medical Internet Research* 13, (2011), e121.

[32] van Genugten, L., van Empelen, P., Boon, B., Borsboom, G., Visscher, T. and Oenema, A. Results from an online computer-tailored weight management intervention for overweight adults: Randomized controlled trial. *Journal of Medical Internet Research* 14, (2012), e44.

[33] Peels, D.A., van Stralen, M.M., Bolman, C., Golsteijn, R.H.J., de Vries, H., Mudde, A.N. and Lechner, L. Development of web-based computer-tailored advice to promote physical activity among people older than 50 years. *Journal of Medical Internet Research 14*, (2012), e39.

[34] Cobb, N.K., Graham, A.L., Byron, M.J., Niaura, R.S. and Abrams, D.B. Online social networks and smoking cessation: A scientific research agenda. *Journal of Medical Internet Research 13*, (2011), e119.

[35] Department of Health. *Equity and excellence: Liberating the NHS (White Paper-Cm7781)* (2010).