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**TITLE: How do people with asthma use Internet sites containing patient experiences?**

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## **How do people with asthma use Internet sites containing patient experiences?**

**Objective:** To understand how people engage with websites containing patient authored accounts of health and illness. To examine how people with asthma navigate their way through this information and make use of the patient experiences they find.

**Methods:** Twenty-nine patients with diagnoses ranging from mild to severe asthma were shown a range of websites, some containing patient experiences, and selected two sites to explore further. They discussed their choices in a series of focus groups and interviews.

**Results:** Participants were influenced initially by the design quality of the sites and were subsequently drawn to websites containing patient experiences but only when contributions were from similar people offering 'relevant stories'. The experiences reminded participants of the serious nature of the disease, provided new insights into the condition and an opportunity to reflect upon the role of the disease in their lives.

**Conclusion:** For people with asthma websites containing other patients' personal experiences can serve as a useful information resource, refresh their knowledge and ensure their health behaviours are appropriate and up-to-date.

**Practice Implications:** Health professionals should consider referring asthma patients to appropriate websites whilst being aware that online experiences are most engaging when they resonate with the participants own situation.

## **1. Introduction**

The World Health Organisation estimates that 235 million people worldwide suffer from asthma [1]. In the UK there are currently 5.4 million people receiving treatment for asthma, with an average of 3 people per day dying from the condition [2]. Asthma control is seen as the primary goal of asthma treatment with patients playing an important role in managing or controlling the condition day to day [3]. The aim behind active asthma management is to improve long-term control of the condition and to reduce the need for emergency treatment [4], as better management has been associated with improved outcomes [3].

The literature suggests that self-management is often poor with some patients failing to take their medication appropriately. There are a number of reasons for this, including forgetfulness [5], failure to accept being an asthma sufferer [6], and an over reliance on medical self management plans that fail to take account of the patients' experiential knowledge and the context of their daily lives [7]. There is little agreement, even between clinicians, about what good asthma control entails [8]; however knowledge appears to be important [9]. Whilst asthma patients typically report a desire to have more information there are individual differences in terms of information needs and differences in relation to asthma severity [10].

For many conditions, the Internet provides a major source of health information [11, 12]. Yet early reviews of asthma websites revealed problems with accessibility, as well as poor quality, and content that failed to meet the needs of asthma patients [13]. Subsequently, both the source and the nature of e-health content have changed rapidly, with much more patient-focussed content [14]. Indeed, patients themselves now provide a crucial source of online health material and the number of people accessing patient-authored content, in particular

those with chronic conditions, has greatly increased [15]. **There is increasing evidence that the sharing of patient experiences forms an important part of health-related Internet use [16] and we know that for some patient groups, access to practical and experiential information from other patients is highly valued [17-19]. The supportive functions of online patient experiences have also been noted across a number of health conditions (e.g. HIV/AIDS, [16], Huntington's disease, [18] and arthritis and fibromyalgia [20]. Simply reading or hearing about other patients' experiences can provide people with a sense of 'being supported' [21].**

Despite this, little is known, about how people with asthma view online patient experiences and how they make use of the information they find, even though there are a number of interesting issues that may influence sufferers' use of online patient experiences. Firstly, as the condition is often diagnosed in childhood, many patients may feel they have passed the critical point at which they needed relevant information about asthma. Secondly, the condition varies widely in terms of severity and triggers, which means that patients can differ greatly both in terms of their experiences and contact with health professionals. Finally, the extent to which people view themselves as being someone 'with asthma' also varies, raising questions about how patient identity influences the decision to interact with online patient experiences.

In this study we explore how people with asthma navigate their way through online information and make use of the shared patient experiences they find. We explore the types of experiences they are initially drawn to and ask what makes them choose to engage with certain experiences whilst rejecting others. We also examine how they view, value, and use the information they glean from online patient experiences.

## 2. Method

### 2. 1. Participants

A total of 29 asthma sufferers, (12 men, 17 women, aged 19-64 years) with experience of using the Internet, took part. Participants were recruited through a number of sources, including newsletters, flyers, and by contacting various health support groups across the UK. Asthma severity and length of condition also varied. The sample had been diagnosed with asthma for periods ranging from 3 months to 56 years ( $M = 14.6$  years). Overall, 13 rated their asthma as mild, 12 as moderate and two as severe (two participants did not disclose the severity of their condition).

### 2. 2. Design

**Having received ethical approval for the research project from the School's ethics committee the data was then collected over two time periods. During the first data collection period participants took part in focus groups. The second data collection period ran concurrently with a larger study that gathered additional data reported elsewhere (in prep) and for that reason participants in that collection period took part in individual interviews.** Both studies had a similar general format (that we have successfully used previously, [22] in which participants used the Internet to search for and select websites of interest within a restricted search. **All participants were given a participant information sheet to read before providing their informed consent.** Those that took part in the focus groups were shown seven pre-determined sites, representing a range of asthma information sites and experiences. Every site contained patient-relevant

material, but only four of the seven sites contained patient experiences. Participants that took part in the individual interviews were shown seven sites all containing patient experiences in different formats e.g. blogs and forum messages. This allowed us to explore further user preferences for different types of experience. All participants were given an hour to explore these sites freely. Following their initial exploration, during which they recorded first impressions in a paper-and-pencil logbook, participants were asked to choose two sites to explore in more detail. Asking participants to select sites to examine further allows their engagement or rejection factors to be studied in greater detail. During this time, participants again completed logbooks to record their general impressions of the sites they looked at, as well as their likes and dislikes for each site to use during subsequent discussions. Next, participants engaged in either a focus group discussion or an individual interview (1-1.5 hours) to discuss their findings and preferences. Finally, 23 of the participants took part in follow up telephone interviews 2 weeks later. **Drop out at this stage was mainly due to participants' time constraints and difficulties in making contact. All of the original 29 participants were included in the analysis at the appropriate stages** and all the interviews and discussions were audio recorded and transcribed for analysis.

### **2. 3. Analysis**

**All transcripts were read and re-read separately by the first two authors and then were subject to thematic methods [23] to identify both anticipated themes, for examples design and reputation factors, and emergent issues such as comparison processes. The themes were then subject to discussion with remaining authors to ensure validity in the interpretation and representation of data. For ethical reasons all participants were given a participant number and all quotations used in the results have been stripped of any information that could potentially identify the participant.**

### 3. Results

#### 3.1. Overall findings

The results paint a picture of how people with asthma navigate their way through online patient experiences and engage with the material they find. In broad terms patient experiences are viewed in a positive manner within the boundaries of well-designed websites. As people step through the engagement process they select sites that contain relevant experiences those that provide value to people searching for information and support. Online patient experiences are used in a fairly immediate sense to re-engage with issues and to re-establish behaviors, and looking forward have the potential to underpin longer term behavior change and provide access to social support. This staged process of engagement is outlined in Table 1 and is described in more detail below.

<insert Table1>

Key theme	Description of theme
Selecting sites	<ul style="list-style-type: none"><li>• People screen out low trust sites.</li><li>• Good, clear design and positive reputation are important factors in relation to trust.</li><li>• Patient experiences enhance the visual appeal of the website.</li></ul>
Finding relevant patient experiences	<ul style="list-style-type: none"><li>• People seek online authors who resonate in terms of age gender and background.</li><li>• People prefer stories that match their own experiences,</li></ul>

	<p><b>understanding or outlook.</b></p> <ul style="list-style-type: none"> <li>• <b>Higher engagement evident with directly relevant content.</b></li> </ul>
<b>Drawing comparisons</b>	<ul style="list-style-type: none"> <li>• <b>Patient accounts allow people to compare and contrast different asthma journeys.</b></li> <li>• <b>Encourage people to re-engage with the seriousness of the condition.</b></li> <li>• <b>Stories reinforce facts that were already known or provide new information.</b></li> </ul>
<b>Using online patient experiences</b>	<p><b>Led to people re-establishing familiar behaviors e.g. inhaler use.</b></p> <p><b>Encourages discussions about asthma and asthma self management with friends and family.</b></p> <p><b>People envisaged the future potential of online patient experiences e.g. providing social and emotional support.</b></p>

### **3.2. Navigating and selecting sites**

As in previous studies [22, 24], patients' initial impressions of all the sites were influenced by the design quality of the site they visited. Participants preferred sites that were well laid out and easy to navigate. They also showed a strong preference for familiar sites and those with a credible, impartial reputation. Participants believed that patient experiences enhanced the visual appeal of the site and brought the information 'closer' to the reader.

*“I think [patient experiences] makes it more valuable. I think it’s good. I think without that it kinds of feels a bit distant and not as personal. Whereas putting it in, it’s showing that there are people in the same boat as you. It makes you feel kind of ...part of it rather than alone and isolated.”* (Focus group, P2)

### **3. 3. Finding relevant patient experiences**

**Having screened out poorly designed websites participants were then subsequently drawn to those sites containing patient experiences, but only if the contributions seemed to come from individuals judged to be similar to themselves, who could offer ‘relevant’ stories.** For those engaging with the online patient experiences, the main task was to find a resonating voice (i.e. an online author that was comparable in terms of age, gender and background) and a story they could relate to at some level. Likewise, engaging stories were those that matched the participants’ own experience, understanding, or outlook. In some situations, however, the voice and the story were simply likeable either because they drew empathy from the reader or connected with them through their written style, perceived manner, or some other idiosyncratic feature. The participants took care to compare the patients’ experiences with their own experience, understanding, or outlook. The ‘author’s’ characteristics were usually considered first. This including factors such as age, length of time since diagnosis and severity of asthma with participants preferring experiences which seemed more relevant to them in terms of these characteristics.

*“The first one, the three stories, they were older people. I think they were a little bit extreme. I don’t think they’re typical of an everyday asthma sufferer ... so I don’t see the relevance of those particular ones. I think it would probably be more useful to have younger people’s*

experiences, what triggers them more, how people have reacted if they needed help that kind of thing.” (Focus group, P15)

“I just thought they were completely irrelevant to me because *I haven't got severe asthma.*” (Interview, P4)

Other points of comparison centred upon the message content itself rather than the characteristics of the author. Consequently, participants engaged with patient experiences that provided them with applicable, relevant content.

“*Yeh I did read a few only the ones that were applicable to me, so the ones that were about coughing.*” (Interview, P11)

### **3. 4. Drawing comparisons**

Engaging with this careful comparison process led to a number of different outcomes for the participants. Some of those that had found ‘relevant stories’ online reported learning something new from the patient experiences. For others, the information presented through personal accounts also appeared to reinforce facts that were already known or, in some cases, provided a new slant on ‘the basics’ that they had originally learned from their doctor or nurse.

“*[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.*” (Focus group, P2)

“*But there was the kind of stuff, most of it you already knew from what I had been told by the doctor but then some of the stuff I didn't realise. I know that some people say that swimming*

*is really good for you, but I didn't realise that so many people said that it helped them when they were swimming because of their asthma.*"(Interview, P7)

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. They were able to use the patient experiences as a way of comparing their own knowledge and understanding of asthma with that of someone else.

*"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."* (Focus group, P6)

Another consequence of the comparison process was that participants invariably considered the people sharing their experiences online to be worse off than themselves. Engaging in this form of social comparison allowed the participants to reflect upon their own knowledge and experience, and to re-engage with the seriousness of asthma and its control mechanisms.

Whilst a few patient experiences were considered too extreme to be in any way relevant, others reminded people about the potential consequences of asthma. They served to heighten awareness of the condition and allowed participants to rehearse intentions regarding control mechanisms.

*"I think that now I've looked at erm and read some of the experiences it's helped me realise I should probably like take care of myself a bit more and should probably go and get a check up."* (Interview, P5)

### **3. 5. Making use of online patient experiences**

At the start of the study, participants reported a high level of knowledge about their condition and were unsure as to what new information about asthma, if any, they needed. At the follow up interview they maintained this overall position but did appear to have used the information within the patient experiences to re-establish familiar behaviours. These behavioural outcomes related to better self-management, either through improved inhaler use or arranging asthma reviews with the specialist nurse.

*“I suppose it’s made me a bit like more careful about it. I always check that I’ve got my inhaler in my bag now; I don’t want to be one of those crazy people in the blogs.”* (Interview, P10)

*“I’ve decided that I should probably go and get it checked up.... so I am going to sometime in December just to have an asthma check.”* (Interview, P5)

In addition, several participants had discussed the online patient experiences with their close friends and family. These discussions had helped the participants to construct a narrative around asthma that highlighted the seriousness of the condition, as well as allowing them to pass on practical guidance as to what to do in the case of emergency. Finally, even those patients who managed their asthma well tended to accept that online support was important to others or might be useful to them in the future.

*“Yeah I think it’s good, good support, especially for people that sort of whose asthma’s quite bad and can’t get out as much as they’d like to and interact with people. It’s good for communicating and letting off steam.”* (Focus group, P6)

*“There were loads of people passing advice in terms of sleeping techniques; I particularly picked up on a couple of times. If I was to maybe ever struggle in those kinds of situations again I might use that in future.”* (Interview, P5)

## **4. Discussion and conclusion**

### **4. 1. Discussion**

This study examined how people with asthma navigate their way through online information and make use of the shared patient experiences they find. Participants were initially drawn to websites with good design quality. In line with previous studies [22, 24], we noted that participants preferred sites that were easy to navigate and looked professional. Participants were then subsequently drawn to those sites containing patient experiences, but only if the contributions seemed to come from individuals judged to be similar to themselves (e.g. age and length of time since diagnosis) and could offer ‘relevant’ stories.

Before the study, participants were unsure what else they could or should know about asthma but as they started to engage with the online patient experiences, many chose to explore certain stories in more detail through comparing their own experiences with those online. This comparison process allowed for recognition of their experiential asthma knowledge [7] with participants able to reflect upon the ways in which they had experienced and handled certain situations in regards to their asthma. Despite many participants reporting a high level of asthma knowledge prior to the study, many were still able to acquire hints and tips regarding the management of their condition. For others it was a case of confirming or even fine tuning their existing knowledge.

However, one consequence of this comparison process was that participants sometimes dismissed potentially useful hints and tips for managing their asthma on the grounds that the online experience was written by someone different to them. Most participants thought that

the online contributions came from people who were worse off or had more severe asthma than themselves. This process of downward social comparison has been noted in other health settings in which people under threat evaluate themselves favourably in comparison to others [25]. A consequence of this process is that for some, the patient experiences served as a reminder of the potentially serious nature of the condition and triggered some re-engagement with the self-management programme.

For people with certain kinds of chronic diseases, such as asthma, the access to information is relatively straightforward in comparison to other potential users of patient experiences, for example, carers of people with Multiple Sclerosis (MS) [26]. However, for the asthma patients sampled here, the sense in which they were 'asthmatics' had not been reinforced since their initial diagnosis when information had been made freely available. The time elapsed since diagnosis and the health information that accompanied it had often meant that participants had forgotten the potentially serious nature of the disease. Without a constant reminder of symptoms, they were unaware of the most up-to-date information and advice about asthma.

The potential uses of patient experiences described by our participants show some overlap with the domains noted in the recent literature. For example, Ziebland and Wyke [21] have argued that access to patients' stories is associated with, inter alia, finding information, feeling supported and behavior change. **Our findings give support to the notion that people can use online patient accounts in a number of different ways in relation to managing their chronic health conditions. In terms of limitations this study employed a relatively short follow up period. Whilst some signs of behavior change etc were observed at this point a longer term follow up would allow some of those behaviors to become better established and thus confirmed. In addition it may allow the development**

**of online supportive relationships that some participants suggested they could imagine utilizing as part of their future self management plans. This study involved a relatively small number of participants a larger scale project examining people with asthma and their use of online patient experiences is currently being undertaken as part of a multidisciplinary e-Health group research program. Using an online trial methodology, it will serve to test out some of this study's findings relating to asthma patient outcomes.**

#### **4. 2. Conclusion**

This study has provided an insight into how people with asthma engage with online patient experiences. The study has allowed us to examine how participants view, value, and use different patient experiences. For many asthma sufferers, engaging with the online patient experiences was associated with acquiring hints and tips on management and visualizing the potential seriousness of their condition. This had led some to re-examine their existing knowledge, services, or the usefulness of their self-management programmes. Follow up interviews showed that, for a number of participants, viewing other patient experiences had caused them to re-engage with asthma self-management, including improved use of inhalers, and arranging asthma reviews with health care professionals. Future research should focus on exploring the robustness of these findings in relation to specific groups of asthma patients, such as those with more severe asthma, or younger patients who may feel more isolated and stigmatised [27].

#### **4. 3. Practice implications**

People with asthma find patient experiences interesting and value their inclusion on information based websites. Health professionals can help people with asthma by referring them to appropriate websites, whilst being aware that online patient experiences are most

engaging when they resonate with the participants own situation and experience. Engaging with patient stories can increase knowledge and awareness of asthma and may help people re-engage with asthma self management. Designing health websites with these factors in mind would also be advantageous.

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