



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

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### ABSTRACT

**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.

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### 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

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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. Methods

### 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 it is for that reason participants during this 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 h) 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 behaviours, and looking forward, have the potential to underpin longer term behaviour change and provide access to social support. This staged process of engagement is outlined in Table 1 and is described in more detail below.

### 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 and who could offer

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