

Assessing the Quality and Usability of Anxiety-Related and
Panic Disorder Websites:

A Study Incorporating an Evaluation of User Needs and
Anxiety-Related, Panic Disorder and Health Information
Websites.

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Abstract

The aim of this study is to cover an area of health information that has, for the most part, been overlooked. This research looks at the quality of online information relating to the conditions of panic disorder and anxiety-related illness and the needs of sufferers using the World Wide Web as an aid to their condition. The objectives of this study are to evaluate current Web content relating to the aforementioned conditions in addition to health consumer practices with the intention of providing a guide for both websites and Web users.

The study is broken down in two major components, part one is an evaluation of a sample of 25 generic health and specialist anxiety-related websites. The sampled websites were broken down into two groups. The first and smallest group is made up of health websites that are not specific to anxiety-related illnesses, but do provide information on the condition. The second group is made up from websites that do offer a variety of services to sufferers of panic disorder and anxiety-related conditions.

In tandem with this evaluation, a questionnaire was run involving a number of the sample group that looked at how some websites source and evaluate their own health information. The second major part of the study looked at the particular needs of sufferers of these conditions and their experiences from using the Web for obtaining information relating to their conditions.

The research showed that there is some variation in the quality of health websites as well as the techniques employed by those using them. Evidence shows that over half of the websites evaluated in this study do provide a quality information service. Nevertheless, the evidence also suggests that there are a number of websites failing to achieve the minimum standard required in the provision of good quality health information and that there is a significant gap between the good and the bad quality.

The research concludes that there is a need for health websites to align themselves to initiatives such as the Health On the Net Code, or adopt certain quality practices and standards. There is a need for health consumers to become more adept at evaluating and diversifying their search techniques and strategies. Whilst the relationship between medical professionals and consumers needs to develop and take into account the information regarding health that is now freely available on the Internet.

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Chapter 1: Background to the Study

1.1 Background to the Study

The objective of this study is to assess the quality of online health information and the needs of consumers, in particular those suffering from anxiety-related and panic disorder conditions. From the findings of this study, the intention is to devise a set of guidelines for health websites providing information for sufferers of these conditions and their families. The guidelines will act as a checklist for quality assurance for those seeking and providing online information about anxiety-related and panic disorder conditions.

1.2 Research Methodology

The research methodology was focused towards an inductive approach. The intention was to look at the problem of health misinformation and the condition of anxiety-related and panic disorder conditions and how users make choices on which sources to use and how they come to their decisions. Firstly, using a combination of data from participating health websites and sufferers of anxiety-related and panic disorder conditions; the intention was to find out what sufferers of these illnesses want from health information websites. Secondly to evaluate the quality of current high-profile health and anxiety information websites and draw conclusions on their editorial practices and information content choices.

The study uses a combination of qualitative and quantitative approaches. The quantitative approach measured the quality of the sampled websites by utilising a Web evaluation tool, specially designed for this study. Its purpose was to assess the

content of selected health websites to discover if there are patterns in practice. The qualitative approach looked at the users who search for health information and analyse their searching habits; for example, do they use a certain search engine? What keywords do they employ? It also looked at the practices of Web editors and authors with regards to the processes utilised by them in supplying health information online.

1.3 Subject Matter

There are several reasons for choosing the condition of anxiety-related and panic disorders as the focus of the study. Firstly, as these conditions have a widespread affect and major impact on the modern society in its various forms. Today in society many people claim to be feeling stressed out, anxious, and mentally exhausted amongst various other terms. Along with mental illness as a whole, it is a condition that still carries a stigma within society and therefore many of those suffering from it are as likely to search for information online in the privacy of their own home or workplace as they are to go and visit their local doctor. The criteria of what makes up anxiety-related and panic disorder conditions can vary as there are several related forms of these conditions which in turn have relations and cross boundaries with a host of other mental health issues. For the purpose of this research, anxiety-related and panic disorders will include the conditions, general anxiety, social anxiety, and panic disorder. These conditions among with other associated illnesses are estimated to affect millions of people in the UK alone at any given time, with varying degrees of severity.

Due to the ambiguous nature of the condition, it was important to construct a set of guidelines to help users make better and more informed decisions on how to find quality information. Like many conditions and illnesses, there is no shortage of mythical information posted on the Internet, which is often infused with the better quality factual resources. This study does not attempt to set out what is fact or fiction, as time constraints and specialised medical knowledge restrict such an investigation. Instead it looked to detect and identify a system of good practice throughout the websites, which in turn will hopefully act as signposts for health information searchers.

The interest in this research has also stemmed from that most people, using the Internet, at some point in their lives access health information on the Web.

According to figures released by the Pew Internet (2006) Online Health Search 2006 survey as much as 80% of Americans using the Internet have accessed health-related websites at some point in their lives. In addition to these figures, the same survey estimates that 22% of Americans have searched for the specific conditions of depression, anxiety, stress, or mental health issues.

Sadly, much of the information available suffers from a variety of problems ranging from being inaccurate to out of date. There are also issues of commercial interests from drug companies, information overload and poorly worded websites. With a large proportion of the UK population now accessing the Internet on a regular basis and with many of these users having limited search skills; there is a need to provide signposts and guidelines to ensure what they find is accurate and is up to date. The intention was to devise a set of guidelines that can be used by those not only visiting

anxiety disorder related websites but those authoring them. The Pew Internet Online Health Search 2006 (2006) states on the report front page that; “Most Internet users start at a search engine when looking for health information online. Very few check the source and date of the information they find.”

1.4 Research Focus

The process of research is two-fold. Firstly, to evaluate health information websites, including not only those focused on anxiety-based illnesses, but also popular general health information websites. This evaluation was carried out from two angles. The first of these is by using a website evaluation tool which has been devised for the purpose of this study and secondly through contact with a small sample of information professionals and editors from various health information websites.

The second major component of this research was to design and carry out a questionnaire for those searching for information regarding the conditions of anxiety and panic disorder. It is important to note at this stage that this would have involved NHS staff and patients, but due to the long process of obtaining NHS ethical approval, it has not been possible.

1.5 Aims and Objectives

It is believed that the results of this research will be useful to novice in addition, experienced health information websites who wish to publish online health information. By creating a benchmark on what users need to look for, it will make the process of finding health information for the patient and their families easier and hopefully more fruitful. This in turn will help the patient-practitioner relationship; which can suffer due to some of the poor quality information available on the Internet.

- To carry out an extensive search and review of literature relating to online health information.
- To design a new Web evaluation tool to use as part of this study.
- To assess the quality of online information, especially websites relating to the conditions of anxiety-related conditions and panic disorder.
- To investigate the processes employed by users in searches for anxiety-related and panic disorder information.
- To investigate the practices employed by the sample group of websites and how they provide online health information.
- To devise a set of guidelines for website authors, owners and editors.
- To devise a set of guidelines for Internet users to aid them in the decision making process as to what is credible and quality health resources.

Chapter 2: The Literature Review

2.1 Introduction

The literature review was split into two strands, firstly literature relating to online health information, this included previous studies focused on health-related websites. The second part of the search focused on the medical conditions concerned with this study. Considering the nature of these conditions, in that the diversity and large amount of material available meant that a tighter editing process was required. Much of the material that was sourced, including many websites, was used to gain an overall knowledge on these conditions and their respective treatments.

After extensive searches, it became apparent that there was a clear lack of studies carried out that looked at the specific problem of information retrieval and content with relation to the conditions this study looks at. This was a positive outcome as it outlined the need for such a study.

2.2 The Use of the Web by Consumers to Access Health Information

In 2005 Gray et al carried out research looking at the health information seeking habits of adolescents in England. Gray et al (2005) concluded that the Internet supplemented traditional methods of obtaining health information from peers and adults, and had become an important source of information. Gray et al (2005:1467) notes that; “It is recognised that young people have difficulties accessing traditional health services; in theory, the Internet offers them confidential

and convenient access to an unprecedented level of information about a diverse range of subjects.”

In contrast, an American study carried out by Campbell & Nolfi (2005) which looked at the information searching behaviour of elderly adults found different results. Their study which looked at the sample group before and after skills training on Internet searching found that there was a willingness to utilise the Internet for general health care. Despite this, most of the group still adhered to the traditional model of the physician-centred model of care.

A study by Morahan-Martin (2004) reviewed relevant research on how health information is retrieved, evaluated and used. Morahan-Martin (2004) came to many useful conclusions which were that firstly, searchers very rarely go beyond the first page of a website. Secondly, that they use search engines with only keyword or short phrases, which are often misspelled. It is important to note that the misspelling of words is not uncommon with regards to health information retrieval due to the complicated terminology used. Thirdly, Morahan-Martin (2004) noted that most health information searchers have limited search and evaluation skills, although they are usually concerned about the quality of online information. As a rule most avoid websites that are overtly tied to commercialism and on a more worrying note do not pay attention to indicators of credibility.

Nicholas (2005) carried out research on behalf of the BBC’s health pages and compared them to its closet rival the NHS. The methodology employed was to evaluate the results from a questionnaire that was completed by 923 readers of the

Independent newspaper. Nicholas (2005) study found that both websites were well ahead of other online health information providers by some way. A third of the respondents had used both websites in the previous year, whilst one quarter of those surveyed had used neither websites.

Research carried out by Hong (2006) looked at the importance of perceived credibility of health websites and the influence it can have on information seeking. Hong (2006:161) concluded that; “The findings suggest that there is a strong relationship between the perceived credibility of a health-related website and the intention to revisit the site.”

Huntington et al (2006) carried out a survey to discover where people went online for their health information, why they went there and what levels of success they had. The research focused on two of the better known providers of online health information, NHS Direct Online and the BBC. The main findings that came out of this survey were that the NHS Direct Online and the BBC websites were not fulfilling the needs of some information seekers. Amongst the points that Huntington et al (2006:65) touched on for future research was; “To obtain a greater understanding of information provision between the three broad groupings of health information providers: national services, commercial, and lastly the voluntary services providers.”

The problem of misinformation is looked at by Kogan et al (2006) and found the problems of information retrieval fell into three categories. Firstly there were the issues relating to patients failing to formulate the right questions; whether this was

due to not knowing what their problem was, not being able to articulate their problem, or by making mistakes in their query. The second group of problems related to the obtaining of results. Issues included the query not matching the content resource, the content if poorly organised or indexed and that the information source lacked content. The third issue relates to the results from the patient queries. These can be due to patients not being able to comprehend the content due to it being medical jargon, or that they misinterpret the query results and finally there may be too many or too little query results.

The ability of consumers and using the Internet for health information was studied by Blackwelder et al (2003) found that many users had no knowledge how to assess the quality of the information they found. Blackwelder et al (2003) looked at the results from a survey following classes to aid the public on finding quality health information on the Internet. Blackwelder et al (2003:58) found that; “Classes directed at the public assisted them in learning how to retrieve and identify quality consumer health information.” As a result it is also interesting to note that Blackwelder et al (2003:58) found that; “Empowered by this skill, consumers used this information to improve communication and interactions with their health care provider.”

Research carried out by Eysenbach & Kohler (2002) looked at the techniques used by consumers for health information retrieval and appraisal. The study employed 21 participants who were split into three focus group sessions. Eysenbach and Kohler (2002:573) found that; “Participants in focus groups said that when assessing the credibility of a website they primarily looked for the source, a

professional design, a scientific or official touch, language or ease of use.”

Eysenbach & Kohler (2002:573) interestingly also point out that; “However, in the observational study, no participants check any ‘about us’ sections of websites.”

2.3 General Information Needs of Users of Health Websites

Crystal & Greenberg (2006) focused on the relevance judgements made by searchers looking for health information. As part of their study they asked a group of users to select the criteria they used to assess the relevance in Web search surrogates and full-text Web documents. Crystal & Greenberg’s (2006:1368) found that; “The key criteria identified (in order of frequency of appearance) research, topic, scope, data, influence, affiliation, Web characteristics, and authority/person.”

A large study carried out by Sillence et al (2007) compared data from 2000 and 2005 with the focus on online health information and users’ experiences. The first study used the data collected from 3000 participants whilst the later study had 2000. Sillence et al (2007) found a number of similarities from the two sets of data. Sillence et al (2007:8) stated that; “An important finding was that women are still the predominant users of the Internet for health advice.” Sillence et al (2007) points out that this statistic, as a rule, goes against the general trend in Internet user demographics. The key findings of the research carried out by Sillence et al (2007) was that there was a major difference between the two sets of data in which there had been a rise in the use of ‘less regulated’ health sites. Sillence et al (2007:8) refers to these as being; “Those run by individuals or by retail companies.” As a result this leads Sillence et al (2007:8) to the conclusion that; “This reflects the desire for

people to locate specialised Web material in order to generate and test theories about their personal health concerns.” Sillence et al (2007) concludes that the evidence shows that five years on, consumers are as keen to search for online health information and in turn trusting such sites and acting upon their advice.

2.4 Information Needs of People with Anxiety-Related and Panic Disorder

A study by Erwin et al (2003) looked at a sample group of 434 individuals and their experiences of using the Internet to seek out information on the condition of social anxiety. The results found that only one third of those questioned had reported receiving psychotherapy and pharmacotherapy to aid their condition. More interestingly Erwin et al (2003:629) found that; “Those with the most severe social interaction anxiety and who spent the most time interacting on the Internet endorsed positive effects of Internet use. However, a significant number of negative effects also were endorsed.”

Work carried out by Easton et al (2006) tried to tie up the relationship between online health information seeking and health care utilisation such as visiting a doctor. Despite this research not directly looking at the condition of anxiety, but more to the anxiety caused by other conditions, it is still worthy of note in this literature review. Easton’s et al (2006:497) key findings were that; “Individuals with even moderate levels of anxiety seek higher amounts of online health information. Frequent online seekers also tend to make more medical appointments based on information found online.” The study concluded that more research was needed in this field and Easton et al suggests that; “this line of research should investigate the

relationship among health anxiety, face-to-face interactions about health issues, and behavioural outcomes.”

2.5 Studies Evaluating Health Information Quality on the Web

Meiczakowski et al (2007) carried out a study looking at the quality of 303 primary care trust websites in England. Meiczakowski et al (2007:20) stated that; “Our results indicate that users expect PCT websites to convey accurate, timely, and reliable information on diverse corporate, clinical and community-oriented matters and to be navigable by means of intuitive and attractive design.” To aid this ideal model, Meiczakowski et al (2007) developed the 3C Compliance Model (the ‘Clinical – Community – Corporate’ Compliance Model). The aim of this framework is to improve the quality of design and content on PCT websites.

A study by Abbott (2000) looked into the quality of online information relating to the MMR jab found considerable evidence of the large amount of poor quality information on the Web. Abbott (2000) carried out an extensive search of the Web using two search engines and the search term ‘mmr vaccine’ and analysed the results using a standard proforma. Abbott (2000:191) pointed out that; “The proforma looked at the information the pages contained in terms of three categories: content; authorship and aesthetics.” The results of the study fell into line with that of other researchers and found that there is a worrying amount of misinformation on the Internet. Abbott (2000:194) found that; “60 percent of pages giving inaccurate or unbalanced information on MMR vaccine in my sample. If this applies generally then the scope for being medically misinformed is considerable.”

An early study looking at the Health On the Net Code (HONcode) by Boyer et al (1998) found that there was a need for guidelines to help standardise the varying qualities of online health information. Boyer et al (1998) argued that with the growing number of health websites it had become increasingly difficult for users of such websites to evaluate what was good and bad information on the Internet.

A study conducted by Fogg et al (2001) sampled over 1400 people, using 51 different elements to evaluate websites. Fogg et al (2001:61) found data which; “showed which elements boost and which elements hurt perceptions of Web credibility.” Their results showed that these elements fell into seven categories. Fogg et al (2001:61) reported that; “In order of impact, the five types of elements that increased credibility perceptions were ‘real-world feel,’ ‘ease of use,’ ‘expertise,’ ‘trustworthiness,’ and ‘tailoring.’” The two elements that Fogg et al (2001) found to hurt credibility were ‘commercial implications’ and ‘amateurism.’

A study by Benigeri & Pluye (2003) looked at health information on the Web and the problem of knowledge transfer. Benigeri & Pluye (2003) pointed to several shortcomings, which they regarded as ‘hidden’. Benigeri & Pluye (2003) list these shortcomings as; “(i) uneven quality of medical information available on the Internet; (ii) difficulties in finding, understanding and using this information; (iii) lack of access for the unconnected population; and (iv) the potential for harm risks of over-consumption.”

Benigeri & Pluye (2003) recommend that the remedy for such problems is that public health practitioners and health professionals oversee the design, dissemination and evaluation of online health and medical information.

2.6 Methods for Assessing the Quality of Health Information on the Web

Wilson (2002) carried out a review in the BMJ looking at the various tools available on the Internet to aid users find the good information and avoid the bad. The paper looked at a variety of different tools which included those for assessing the quality, filtering of information, organisations responsible for codes of conduct, user guidance systems and finally, third party quality and accreditation labels. Since Wilson's (2002) paper there have been newer initiatives, organisations and websites trying to offer the same advice to consumers. It is interesting to note that many of the websites identified by Wilson (2002) are no longer in operation, or have been superseded. Wilson (2002:600) points out that; "The greatest challenge is not to develop yet more rating tools, but to encourage consumers to seek out information critically, and to encourage them to see time invested in critical searching as beneficial." Wilson (2002) makes the interesting connection between websites and advertising, working on the premise that most consumers have become aware of what is good and bad advertising, in time more and more will learn what makes a good quality website and what makes a bad one.

In the same issue of the BMJ, Risk (2002) wrote a commentary regarding the subject of quality of health information on the Internet. Risk (2000) pointed at the way the Google search engine works by ranking items on the number of inbound

links given to any site. Risk (2002:602) states that; “Perhaps here lies the answer to the question of how to get good health information on the Internet: do what we do in the rest of our lives, and rely on reputation, sometimes.”

Zeng et al (2006) developed a tool to aid health consumers to search for good health information online. The tool, which is called the Health Information Query Assistant (HIQuA), was tested by 213 subjects which were split into two randomised. One of the two groups was given query recommendations whilst the second group was not. The results of the trial found that those using the HIQuA recommendations received statistically significantly higher rates of successful queries. Zeng et al (2006:80) found that; “Providing semantic-distance-based query recommendations can help consumers with query formation during health information retrieval.”

A study carried out by Bernstam et al (2004) searched and tested quality-rating instruments which can be used by health care consumers to assess health information websites. They discovered 273 unique instruments, of which Bernstam et al (2004:15) pointed out that; “178 (65%) were some kind of award or kite mark whose criteria were never intended to be applied by Internet users.” More interestingly, only 80 (29%) of the 273 websites publicly disclosed their criteria. Bernstam et al (2004:19) concluded that; “Future research should focus on developing instruments and/or techniques that allows consumers to evaluate online health information.”

Work carried out by Jadad & Gagliardi (1998) looked at 47 rating instruments for aiding users to evaluate health information and found that many of

them were incomplete. Jadad & Gagliardi (1998:611) suggest that; “It is unclear, however, whether they should exist in the first place, whether they measure what they claim to measure, or whether they lead to more good than harm.”

A later study in 2002 by Gagliardi & Jadad (2002) looked at 98 instruments including 51 new ones, although many of the original ones no longer existed. Gagliardi & Jadad (2002:569) results were that of the earlier study and found that; “whether they are needed or sustainable and whether they make a difference remain to be shown.”

Research by Boyer et al (1998) looked at the Health On the Net Code of Conduct for medical and health Web sites since its conception 1996. Boyer et al (1998:1165) found that; “World wide owners of medical/health Web sites are aware of the need to unify the quality, to ensure that accurate, unbiased, ethical health/medical information prevail on the Internet.” Boyer et al (1998) concluded that for websites to achieve this there needed to be a system of self governance through a widely agreed set of principles which in turn would improve the quality of online health information.

Winker et al (2000) reported measures taken by the American Medical Association to tackle the issue of misinformation on their websites. Winker et al (2000:1600) pointed out the aims of the project to; “Guide development and posting of Web site content, govern acquisition and posting of online advertising and sponsorship, ensure site visitors’ and patients’ rights to privacy and confidentiality, and provide effective and secure means of e-commerce.” Winker et al (2000) found

that while these guidelines were for the American Medical Association, there was no reason why they may not be of use to other providers and users of online health information.

Research conducted by Griffiths et al (2005) looked at the possibilities of using automated assessment techniques for online health evaluation. The research focused at the automated evaluation of depression websites. Griffiths et al (2005) believed that the manual assessment tools that have been used in the past to aid consumers rate medical information were poorly validated and often impractical. Griffiths et al (2005) found that; “Depression websites of different evidence-based quality can be differentiated using an automated system.” Griffiths et al (2005) also found that if replicable, this automation system could be applied to other health conditions and deployed in a user-friendly form.

2.7 Summary

From the literature review it is quite apparent that the area of health information on the World Wide Web is very much a growing one. There are a plethora of studies looking at the quality of health information in addition to the areas of user needs and their experiences. There is on the other hand no specific studies that look at measuring health information with regards to the conditions of anxiety-related illnesses and panic disorder on the Web.

Chapter 3: Panic Disorder, Anxiety-Related Conditions and the Internet

3.1 Introduction

Anxiety-related illness covers a large variety of conditions, and can for some sufferers be an amalgamation of one or more of these. Conditions range from that of general anxiety, social anxiety and panic disorder to name but a few. The range of symptoms relating to these conditions can be extremely various and quite debilitating. Some sufferers of anxiety-related illnesses can have only the mildest of symptoms which include sweaty palms, nausea and shortness of breath; of course such symptoms can prevent a person from functioning in day to day situations. Manthorpe & Iliffe (2006:26) points out that; “The seemingly large variety of types of anxiety, and the fact that anxiety symptoms are commonplace, makes the diagnosis controversial.”

3.1 The Problem of Health and the Internet

The growing problem of incorrect or out of date online health information is considerably large and as a result cannot be underestimated. The BMJ’s Web Editor, Tony Delamothe (2000:843) warned that; “There’s a lot of harmful medical information on the Internet. Something needs to be done.” Delamothe’s (2000) solution was to provide users with some sort of quality rating, which would be guaranteed by some trusted third party. In fact Delamothe (2000) highlighted the fact that there are dozens of instruments for rating health information and helping consumers find good quality online health information, but none had been tested for

reliability or validity at the time of writing. The problem is still very large and as of yet there has been no universally accepted solution.

Delamothe (2000:843) states that the problem is due to the fact that; “No omniscient detached observer exists who can simultaneously view an article through the eyes of a specialist researcher, doctor, patient, and a member of the public, let alone take into account the different perspectives of orthodox and complimentary medicine.”

Murray (1998:144) points out regarding the Internet that; “Despite its drawbacks, the Internet is open 24 hours a day and can be accessed from the convenience of the home.” This in reality is a double edged sword, as we now have immediate access to our possible solutions; and it is fair to say that we have immediate access to our problems. Wood (1997:59) asks of the Internet; “Is it the ultimate public library with free access to any kind of information to anyone?” Ten years on from Wood’s (1997) paper, the answer is most certainly yes.

The reality as Fritch & Cromwell (2001:499) point out is that; “Many people fail to evaluate Internet information. This is often due to a lack of understanding of the issues surrounding evaluation and authority and, more specifically, lack of understanding of the structure and modi operandi of the Internet and the Domain Name System.”

Thanks to the growth in online health information websites it is almost impossible to name any Western medical condition that does not have any coverage of one sort and in turn it is right to presume that much of the older, biased or less critical information not only detracts users from the right answers but also prevents information seekers from finding the right medical attention. Wood's (1997:59) answer to his earlier question touches on this, as he states; "Unlike television or marketing, it is mostly unregulated, and unlike the library, its classification schemes are decidedly hit-and-miss."

Haddow (2003:169) points out that; "The quality of information is extremely variable. In health information, where quality can mean the difference between effective management of a health problem and potentially dangerous treatments, tools to assess quality are imperative."

Eysenbach and Diepgen (1998:1496) equate the problem simply as; "The quality of medical information is particularly important because misinformation could be a matter of life or death." Haddow's (2003) study acknowledges that just as there are the many comprehensive and professional websites offering unbiased medical information, there are others that don't. Whether these are through an online peer-reviewed journal or a personal blog, the Internet has every angle covered concerning health information in some form or fashion. The quality of this information as Eysenbach & Diepgen (1999) pointed out nearly a decade ago and little has changed since. Eysenbach & Diepgen (1999:80) states that; "The Internet offers a mixture of Web pages, bulletin boards and databases, covering an enormous scope for information which ranges from the highly significant through to the trivial

and obscene.” Dearness et al (2001) backs this argument up specifically with regards to health websites and the amount of information available to the consumer.

Dearness (2001:167) states; “The scope and depth of each site is unique and this serves to contribute to the difficulty of finding reliable, high quality literature.”

Wyatt (1997:1880) adds that; “Although surfing the Web provides an excellent method for patients and professionals to access clinical knowledge, unless we evaluate the quality of clinical sites and their effects on users, we risk drowning in a sea of poor quality information.” Wyatt (1997) also notes that improved technology is not the solution, but instead there is a need for better methods of measurement in addition to a rigorous evaluation of online information.

McLellan (1998:39) highlights the worrying notion that; “Trying to get health information from the Internet is like drinking from a firehouse, and you don’t even know what the source of water is.” Graves & Scoville (2001:32) adds a worthy note by saying; “While false and misleading information exists on the Internet, a wealth of excellent sites also appear. In fact, the more pressing problem is not necessarily avoiding the ‘snake-oil salesman,’ but cutting through and filtering to obtain the best information.” In contrast, Grandinetti (2000) argues that; “Many patients today are just as well educated as their physicians. They know how to research, evaluate information, and make their own decisions.”

Sonnenberg (1997:151) makes the point that; “There are a number of potential problems with patients seeking health-related information on the World Wide Web. First and foremost, there is no editorial control on the information on the

Internet. Literally anyone with control of a web site can claim to be a medical expert.”

Morahan-Martin & Anderson (2000:732) point out that; “Finding information online is inexpensive and relatively easy to use. Individuals are also exposed to a diversity of views because the Web has dramatically lowered the barriers to entry for people and organisations that want to spread their message.”

Delamothe (2000:843) pertinently hits the nail on the head with regards to controlling content on the Internet by stating; “By design, the Internet has no centre and therefore resists attempts at central control. Initiatives that go with its grain have a chance of success; those that go against it usually fail. Worse than failing, however is having unintended harmful effects.”

Roberts & Copeland (2001:186) points out that; “Sites that are ill-defined in their purpose or do not declare their intended audience are failing to capitalise on their potential and also could jeopardise confidence in the Internet as a medium for health-related advice and knowledge.”

Eng et al (1998:374) points out that; “Technology, if used appropriately, can help people increase their knowledge of health, enhance their ability to negotiate the health care system, understand and modify their health risk behaviours and acquire coping skills and social support.”

3.2 The Growth of Health Information on the Internet

As more and more people gain access to the World Wide Web, it is arguable that more and more people are searching for health information. This is especially so in a modern society that is focused heavily towards quality in health care. The National Statistics Online (2006) latest figures on Internet usage in Great Britain estimate that; “13.9 million households (57 per cent) in Great Britain could access the Internet from home between January and April 2006. This is an increase of 2.9 million households (26 per cent) since 2002, and 0.6 million (5 per cent) over the last year.”

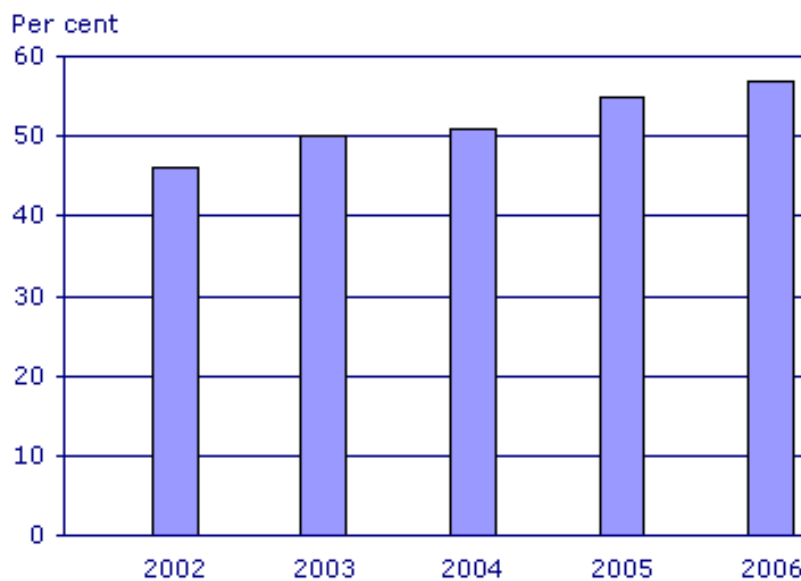


Fig 3.1. Households with access to the Internet, GB.
Source: National Statistics Online (2006)

The percentage of Internet users searching for health information in Great Britain is hard to gauge, as there are no published figures. Nevertheless it is fair to say that it would be similar to those of the US where the Pew Internet and American Life Project estimates 80% of Americans have search for health information online. Partially this is due to the reason pointed out by Lewis (2006:535) that; “Public

health within many Western nations has undergone a shift towards encouraging individuals to take responsibility for and manage their own health.”

3.3 About Panic Disorder and Anxiety-Related Illness

These conditions have only just started to be acknowledged as a serious illness in recent decades. As a consequence, it is only since the establishment of the World Wide Web that exposure and discussion on their effects and treatment have come into the public domain. Nevertheless, as Blenkinsopp (2007:5) so succinctly puts it: “Mental health is a topic that affects us all, perhaps more than we think.”

The Centre for Economic Performance’s Mental Health Policy Group’s (2006:1) report on Depression highlighted that; “Crippling depression and chronic anxiety are the biggest causes of misery in Britain today. They are the great submerged problem, which shame keeps out of site. But if you mention them, you soon discover how many families are affected.”

The Mental Health Policy Group estimated that 16.5% of the UK population between the ages of 16 and 75 suffer from some form of mental illness as shown by Fig.3.2 below.

Percentage of people currently suffering from mental illness (people aged 16-75)	
Schizophrenia	½
Depression	2 ½
Anxiety disorders	
Generalised anxiety	4½
Social phobia, agoraphobia, etc	2
Obsessive compulsive disorder	1
Panic disorder	1
Mixed depression and anxiety	5½
Total	16½

Fig 3.2. Percentage of People Currently Suffering from Mental Illness (People aged 16-75)

Source: The Centre for Economic Performance’s Mental Health Policy Group (2006:4)

The Mental Health Foundation highlight figures from The Office for National Statistics Psychiatric Morbidity Report in 2001 that; “1 in 4 British adults experience at least one diagnosable mental health problem in any one year, and one in six experiences this at any given time.”

There is not only the cost of anxiety-related illness to the sufferer but also to the workplace and economy as working days are lost to illness. A study carried out by The Sainsbury Centre for Mental Health looked at the economic and social costs of mental health as a whole. It found as a result that the cost of mental illness in England amounted to somewhere in the region of 77 billion pounds. The Mental

Health Policy Group (2006:5) point out that; “While depression and anxiety account for a third of all disability, they attract only about 2 per cent of NHS expenditure.”

The Sainsbury Centre for Mental Health (2003:2) report stated that; “By any yardstick mental illness imposes an enormous burden, on individuals, on families and on society.”

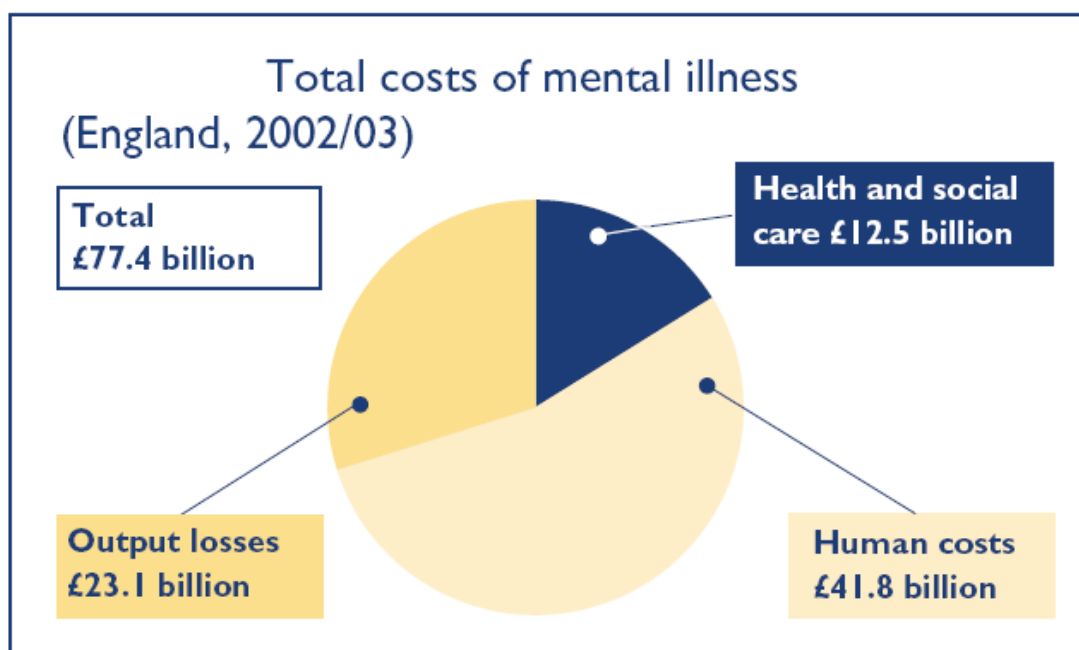


Fig 3.3. The Total Cost of Mental Illness (England 2002/03)
Source: The Sainsbury Centre for Mental Health: The Economic and Social Costs of Mental Illness (2003)

The Office for National Statistics figures for 2000 stated that 1 in 6 adults in Great Britain have a neurotic disorder which includes anxiety and depression. The breakdown of these disorders can be found in the table below, and it is worth noting that anxiety disorders are the most prevalent of the conditions.

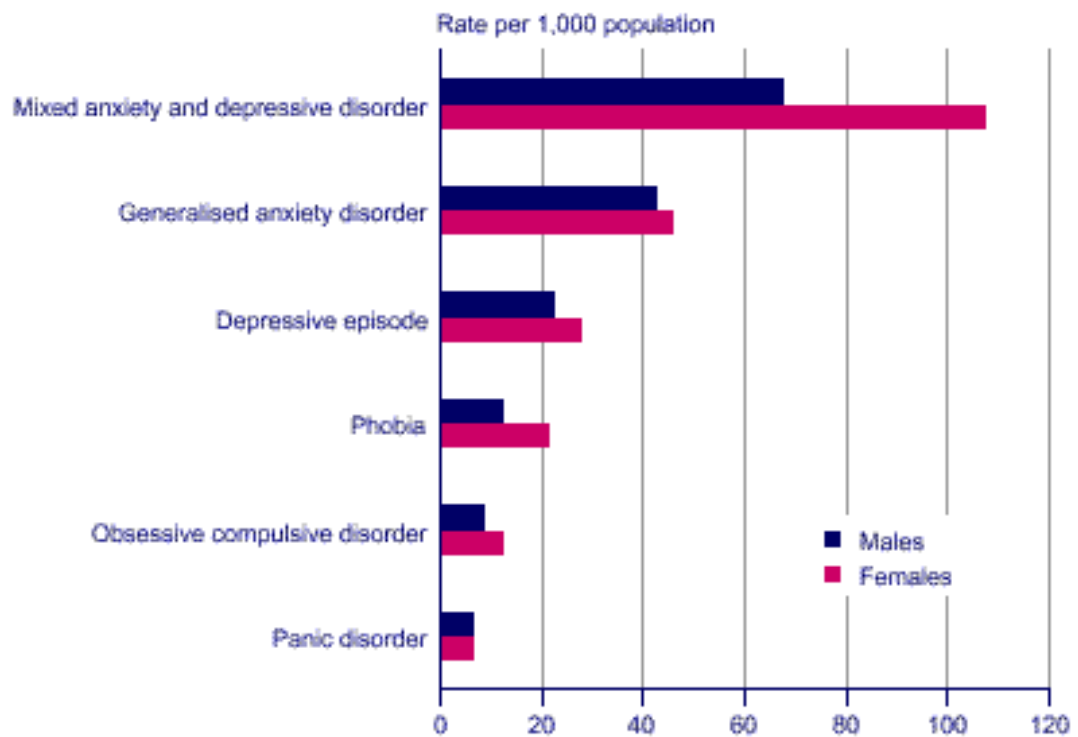


Fig 3.4. Weekly prevalence of neurotic disorders: by sex, (2000) GB
Source: The Office for National Statistics.

On a wider scale, figures provided by the National Institute of Mental Health in 2006 state that 40 millions American adults are affected by anxiety disorders, about 18% of the population, in any given year. Whilst on a global scale, the World Health Organisation estimated in 2001 that there were approximately 450 million people worldwide with a mental health problem.

3.4 Panic Disorder.

Panic disorder is a highly debilitating condition that can result in the sufferer having a series of intense episodes of extreme anxiety. It is worth noting at this point that because of these symptoms it is important to include this condition along with the other anxiety-related conditions, but make reference to it as a separate condition in its own right. These anxiety attacks are known as panic attacks and as a result they can last from several minutes to hours and in turn can vary in their intensity. The specific physical symptoms can also vary from one attack to another, and may include perspiration, dizziness, trembling, palpitations, dyspnea and a psychological experience of uncontrollable fear. Some sufferers refer to a panic attack as having a sense of impending doom. Sufferers can experience panic attacks on a regular basis, ranging from daily to weekly occurrences. The longer term effects of panic disorder may also vary on the sufferer as the symptoms may also lead to other problems such as agoraphobia. In addition to consequences such as agoraphobia, there are also the negative social experiences including embarrassment and social stigma. There are also the other risks relating to any kind of mental illness including a tendency to develop conditions such as agoraphobia, avoidance issues and depression; in addition to lifestyle complications such as drug and alcohol abuse to name but a few.

A study carried out by Markowitz et al (1989) on Panic Disorder and mental health concluded that there was significant change in the sufferer's quality of life.

Markowitz et al (1989:990) stated that; "Both Panic Disorder and major depression are associated with an increased risk of subjective feelings of poor physical and emotional health, alcohol and other drug abuse, suicide attempts, decreased time on hobbies, poorer marital functioning, increased financial

dependency, increased use of general medical and/or psychiatric professionals, increased use of minor tranquillizers and antidepressants, and increased use of the emergency department.”

Panic disorder can affect sufferers for prolonged periods of time, ranging from months to even years. The length of time can vary much depending on when the sufferer seeks out help and advice. If left untreated the condition can seriously impair the sufferer’s quality of life.

3.5 Generalised Anxiety Disorder (GAD)

Like panic disorder, Generalised Anxiety Disorder (GAD) is a highly debilitating condition. The main symptoms associated with this condition are that the sufferer has an uncontrollable and often irrational worry about everyday things. These worries are usually identified as being disproportionate to the actual source of worry.

Such excessive worry can as a result affect the sufferer’s daily functioning as individuals suffering GAD become overly worried about issues such as health, family and money. The extent of the sufferer’s worry can be that they typically anticipate negative outcomes in the form of disaster and catastrophe. Physical symptoms include headaches, fatigue, muscle tension and muscle aching; irritability, lack of concentration, hot flushes and sweating in addition to trembling and twitching.

Tyler & Baldwin (2006:2163) point out that GAD has; “strong genetic and environmental precursors and often becomes noticeable in early adult life. Generalised anxiety is relatively easy to detect and most management should be done in primary care.”

3.6 Social Anxiety Disorder

Social Anxiety Disorder (SAD), which is also referred to as Social Phobia, as expressed in the title; is the fear regarding social situations in addition to the perception of the sufferer by others. There is a relation between social anxiety and shyness and can be experienced by those who may have to undergo such things as interviews, public speaking or performances.

The symptoms can range from the physical such as sweating, blushing and nausea to cognitive such as the belief that the sufferer will be judged negatively. As with the other conditions previously mentioned, there can be avoidance issues for the sufferer. If untreated, social anxiety disorder can lead to the sufferer using alcohol and other drugs to help them cope at social events; there is also the chance that other conditions may arise such as depression.

The treatment of social anxiety disorder, again like other similar conditions, can be treated by either psychotherapy or medication. Psychotherapy may take the form of cognitive-behavioural therapy (CBT) with the aim of changing the sufferer’s thought patterns; this can be achieved in either a group or individual setting. Medication is in the form of antidepressants and come as two different types,

selective serotonin reuptake inhibitors (SSRIs) and serotonin-norepinephrine reuptake inhibitors (SNRIs).

3.7 Panic Disorder and Anxiety-Related Conditions Information Needs

Sufferers of anxiety related disorders need many things to aid them to overcome their condition. Firstly they need a cure, and as previously mentioned this can come via various methods, most notably cognitive-behavioural therapy and medication. Alongside the treatment route, there is also the need for help and support. This may come in the form of professional help through such organisations such as the NHS or BUPA, or through charities and self-help groups such as SANE and Mind.org.uk.

For many, the process of recovering from mental health can be a long and painful journey, which can take several years. There are those of course who are never totally free from mental health conditions, but may at some points of their life have periods of recovery. For those suffering from anxiety-related and panic disorder conditions, there is often a need for information. In addition, there is a need for people to discuss and relate their condition to fellow sufferers. The reason for this is not only to gain information about their condition, but to impart it to others as well as remove the feeling of not being alone.

The very nature of these conditions affects many sufferers in their daily activities and as a result can impair the treatment routes they may choose to follow. As previously mentioned one major problem relating to mental health conditions has

been the stigma attached to it. Only until recent times have some people found it comfortable to discuss openly their mental health issues. This has been very much the case with anxiety-related and panic disorder conditions, which has for so many years been quite often banded under the single umbrella named stress.

The growth in health information available on the Web has opened up an information world to many. Most people with an Internet connection will have, at some point in their lives, searched for information relating to health. Much of the information is of good quality, but the reality is that there is a substantial amount of information that is not only out of date, but poorly communicated and even false. As a result of this, it is extremely important that those searching for health information on the Internet have some idea what to look out for when carrying out their searches. This is especially important considering two key factors. Firstly, more and more people are using the Internet and in turn using it to search for health information. Secondly, there is more and more health information being published on the World Wide Web than ever. So in that case, it should go without saying, that there needs to be a greater awareness for users and better moderation for information providers.

Chapter 4: Methodology

4.1 Introduction

The research methodology is focused towards an inductive approach. The study looked at the problem of misinformation on the condition of panic disorder and anxiety-related illnesses and how online content on this condition is edited and written. Due to the conditions' ambiguous nature and symptoms, it was decided that research of this kind required a three-pronged approach. It had been noted in many other previous studies that there was firstly a focus on the information seeker and secondly the information provider, although most studies did not cover both groups comprehensively. Many studies had taken a two-pronged approach to gather their findings. The two-pronged approach is designed for, firstly that of assessing the characteristics and ability of the information seeker, and secondly the quality of information held on Internet websites. The first part was usually carried out with the aid of a questionnaire, whilst the second part was analysed with the aid of a website evaluation tool.

Once again, considering the nature of this particular study, it is important that a third dimension was added to the methodology employed. Considering that most studies had looked at the users' abilities and websites' content, it was also important to consider the processes that go into deciding the latter. By just carrying out website evaluations using evaluation tools would just be looking at one part of the problem and not necessarily getting to the bottom of it.

Initially, the decision was to carry out formal interviews with web editors and authors who were willing to help out with this study. After making initial contacts with the sample group, it was noted early on in the study that this would be harder than first suggested due to several reasons which will be touched on in more depth later on. After compiling the final list of the 25 websites (See Appendix J) the task of recording their contact details was conducted. This was not easy as first thought as some websites had no contact details at all, which in turn provided evidence of their various states of quality.

The study uses a combination of qualitative and quantitative approaches. The quantitative approach will measure the quality of the sampled websites. It will look at the different websites to discover if there are patterns in practice. The qualitative aspect of the study intends to look at those searching for health information and analyse their searching habits for their respective conditions. For example, what kind of key words are they using? This is achieved with the aid of an online anonymous questionnaire. Ideally this study would have involved NHS staff and patients, but due to the convoluted process of obtaining NHS ethical approval, this has not been possible due to the limited timescale of this study. Instead the sample group is taken from participants of online forums and discussion lists from the sampled health websites.

4.2 Literature Search Strategy

Literature searches were carried out on the medical reference database Medline and on the Psychiatry database PsychINFO. Information related papers were retrieved by using the Library and Information Science Abstracts database (LISA). Keywords within journal articles were searched for, these were; anxiety, panic, disorder, doctor, health, website or Internet and information. Reference Tracking was by far the most successful of the search tactics employed. One outcome of utilising this method was that not only did it lead to finding very good articles but that these papers were flagged up time after time thus increasing their credence for this study.

4.3 Selection of Anxiety-Related, Panic Disorder and General Health Websites

The websites that are sampled originate from two groups. The first group of websites that were selected are not focused on anxiety disorders and instead concentrate on a whole range of health conditions. The methodology for selecting the second group websites was conducted by using arguably the most popular search engine and directory search engine, Google and Yahoo. Other popular search engines, such as MSN, Ask Jeeves, Netscape and Altavista were also employed in addition to other popular directories and meta crawlers; although it is important to note that they did not add anything substantial to the search results. The decision to focus on the two main search engines was based on the premise that Google and Yahoo are currently the most respected and well used of such websites; and have overwhelming popularity within the Internet community.

4.3.1 Website Search Strategy

Both sets of searches were carried out on UK-based websites only. The search using Google was modified by selecting the 'pages via the UK' option on the main search page. Whilst Yahoo's search was modified by selecting advanced search tab and instructing the search to look for only pages in the UK. The reason for using this method was to ensure that the anxiety-based websites were selected on the same grounds as the non-specific health websites. The decision to focus the research on just UK based websites was due to the huge amount of non-specific health information websites, in addition to those focusing on anxiety disorders based in the U.S. and Europe.

4.3.2 Non-Specific Health Websites

In total 25 websites were chosen to sample. Out of which six non-specific health information websites were chosen for evaluation. These were selected through a series of criteria. Firstly their popularity, websites such as BUPA, The BBC's health pages, and NHS Choices are household names and therefore it is fair to presume that they are accessed by a large amount of people seeking health information. In addition to the mentioned websites, Patient UK was selected after featuring in the top five results for Yahoo and Google; following a search for the term "health information". Patient UK is not a health information website in the traditional sense; but it does act as a hub for numerous sources different types of information, including anxiety disorders. Netdoctor.co.uk was also added to the study because of its high online profile. Whilst Surgery Door also ranked highly in the search results. It is interesting to note that Best Treatments, which is run by the British Medical Association, was initially considered as the website's remit is to help

patients make better health decisions. After closer inspection this website was ruled out due the decision processes it refers to are not online health information choices, but those made in the hospital or Doctor’s surgery.

Table 4.1 - Non-Specific Health Information Websites

Website	URL Address
BBC Health Pages	http://www.bbc.co.uk/health/
BUPA	http://www.bupa.co.uk/
Net Doctor	http://www.netdoctor.co.uk/
NHS Choices	http://www.nhs.uk/Pages/homepage.aspx
Patient	http://www.patient.co.uk/
Surgery Door	http://www.surgerydoor.co.uk/

4.3.3. Specialist mental health, anxiety-related and panic disorder websites

The remaining selected websites are a mixture of anxiety-related and panic disorder information websites and mental health websites.

The Royal College of Psychiatrists and the Mental Health Foundation were chosen for their wide coverage of mental health illnesses, and although they may not be an obvious first point of reference for many information seekers, they are leading websites in the field of mental health.

The remaining 17 websites were selected after carrying out several searches on Google and Yahoo. The search terms employed were; “anxiety”, “anxiety disorder”, “panic disorder”, “social anxiety”, and “general anxiety”. All of the websites appeared in the first two pages of each search result and it was noted that most of the sampled websites appeared on frequent occasions, cementing their participation in this study. A couple of the anxiety disorder websites were chosen not only because of their content but also taking into consideration their links with the bigger non-specific health websites. Websites were also selected from the

‘sponsored links’ section of the search pages. Despite such websites not always having the credibility of some of the other websites, they are still very much in the public domain and therefore can be visited by many health information seekers. Any websites backed by pharmaceutical companies were still taken into consideration if they appeared in the primary search result pages. A couple of the sample groups were individually run websites; these were selected to sample due to their high rankings in the search results, in addition to maintaining a variety of sampled websites.

The study also analysed health information and related websites covering Phobias, obsessive-compulsive disorder and post traumatic stress disorder (PTSD). The reason for this was that many of these conditions are covered by anxiety-related websites, but as a whole most of these conditions have websites specific to them and inclusion of those excluding the National Phobic Society website would have broadened this study too far beyond its original remit.

Table 4.2 - Specialist mental health, anxiety-related and panic disorder websites

Website	URL Address
Royal Collage of Psychiatrists	http://www.rcpsych.ac.uk/
Mental Health Foundation	http://www.mentalhealth.org.uk/
The Centre for Anxiety Disorders and Trauma	http://psychology.iop.kcl.ac.uk/cadat/
Social Anxiety UK	http://www.social-anxiety.org.uk/
No Panic	http://www.nopanic.org.uk/
Anxiety Care	http://www.anxietycare.org.uk/
Help For	http://www.help-for.com/
Anxiety 2 Calm	http://www.anxiety2calm.com/
The Linden Method	http://www.thelindenmethod.co.uk/
No More Panic	http://www.nomorepanic.co.uk/
End Social Anxiety	http://end-social-anxiety.50webs.com/
Sane	http://www.sane.org.uk/public_html/index.shtml
Panic Attacks	http://www.panic-attacks.co.uk/

Stress	http://www.stress.org.uk/
Phobic Society	http://www.phobics-society.org.uk/
Destigmatize	http://www.destigmatize.org.uk/
Social Fear	http://www.socialfear.com/
Stress Watch Scotland	http://www.stresswatchscotland.org/
Stressbusting	http://www.stressbusting.co.uk/

4.4 Identification and Choice of Evaluation Tools

As part of this study, there were a few existing website evaluation tools considered but the vast majority were deemed unsuitable, not comprehensive enough or just not relevant. Many of the tools that this study investigated did not test the reliability or validity of health information and were instead designed to test the readability of the text for partially-sighted or the blind. Others were basic check sheets for school and higher education students to check the quality of websites and in turn offered no overall rating score of the information.

4.4.1 Health On the Net Code

The two evaluation tools that were given greater consideration for their utilisation in this study were firstly, the one created by the Health On the Net organisation based in Geneva, Switzerland and their HON Code. The evaluation form is constructed of a series of 14 multi-optional questions. This tool was discounted from the study due to it only being able for first party evaluation. A good score means gaining accreditation from the HON Code, a poor score means that the website needs to improve some of the areas it has failed on. Contact was made with the Health On the Net organisation a couple of occasions to enquire whether there was any way of conducting third party evaluations, but there was no reply from them.

The intention was to test the validity of the sampled websites by using their HONcode Site evaluation form, which can be found at;

http://www.hon.ch/HONcode/Check/HONcode_membership2.html

The purpose of the 14 questions is not to give an overall score but to give feedback on each area of the evaluation where the website has failed. The less feedback a website receives, the less likely it will have failed the test. It was decided that due to the third party issue and the limitations of just 14 questions that the HON Code was unable to provide a solution and was therefore discounted from the study.

4.4.2 The Mitretek Information Quality Tool

The second evaluation tool was the Information Quality Tool created by Mitretek. This evaluation tool was used in a previous Information Management MSc research dissertation carried out at The University of Sheffield by Harland (2004). Harland (2004) used the Mitretek tool to score Multiple Sclerosis websites on their quality of health information and reliability. The Information Quality Tool can be found at; <http://hitiweb.mitretek.org/iq/iqmain.asp>. The tool was developed by Mitretek Systems and supported The Health Summit Working Group's (1997) "Criteria for assessing the quality of health information on the Internet". The IQ Tool is designed for consumers to help them ask the right questions about the quality and validity of the information found on health websites. Based on the tool's results the IQ Tool will evaluate the sampled website's strengths and weaknesses. The tool uses a system of 21 questions to score the quality of the sampled website and gives most of the answers a weight of 5.8 percent for a positive answer to the majority of

the questions, with some getting a lower weighting of 3.6 percent. If the sampled website gets positive results to all 21 questions then a maximum score of 100 percent can be given. The two main reasons for not using this tool were that firstly, the tool has not been supported since 2001. The second reason was that three of the questions only offered a score of 0 for a positive answer and no overall score for the test for a negative answer, which prevented most of the websites initially sampled from getting a final score. The inability to give an overall score for each website was a problem for the purpose of the study in addition to there being no reason given as to why these three questions should be rated so. It was decided that these two reasons given earlier were good enough to discount this tool from the study and that a new tool should be developed by combining properties from the aforementioned websites in addition to others the study came across.

4.5 Development of a New Evaluation Tool

The intention of this study from the outset was to devise a set of guidelines for sufferers of anxiety-related and panic disorder conditions. As established previously, that a new Web evaluation tool would be have to be developed to aid this research. From exploring existing tools and carrying out an extensive literature review it was concluded that a new evaluation tool would need to be developed.

The criteria for this tool would be similar to that of the Information Quality Tool, in that so much it would give weights to positive and negative answers, although unlike the Mitretek model there would be a final score respective of the answers.

4.5.1 Website Evaluation Questions

In total 25 questions were composed (See Appendix H) which were collated from a number of previous tools and website evaluation checklists (See Appendix I). The 25 questions were all given a range of eight which went from 4 for a positive score and -4 for a negative score. This meant that each website evaluated had a potential to get a score of between 100 and -100, although both scores were highly unlikely. The majority of the questions had simple yes, no or not known answers which were rated with a score of 0. 10 of the questions had 9 possible scores that went from 4 (highest score) going down in single steps to -4 (lowest score) giving the potential to score the website on how well it performed on each component.

4.6 Development, Construction and Implementation of the Web User Survey

The second major component of this study was that of health information users and their experiences of searching for online information regarding anxiety-related and panic disorder conditions. A set of ten questions were devised and hosted on the questionnaire website Survey Monkey (See Appendix E). The participants were all asked to agree to the terms and conditions involved in the study and were given supplementary information and contact details regarding the study (See Appendixes A and D). The questionnaire was promoted by posting links to it on the 25 sampled websites and their forums, it is important to note that permission was asked where necessary to do this. Social Anxiety UK, No Panic and National Phobic Society also promoted this study on their websites (See Appendix A). As a footnote to this, it is important to point out that a couple of the forums were incredibly

underused, with at least two of the websites containing several spammed posts of a sensitive nature.

4.7 Development and Construction and Implementation of the Web Editor Survey

This survey formed the supplement part to the web user survey and despite the limitations of this questionnaire in so much as there is a much smaller target audience, its importance can not be ignored as an important part of this study. Again this was an anonymous questionnaire which was hosted on Survey Monkey (See Appendix F). As with the previous questionnaire the participants were asked to agree to the terms and conditions and were given supplementary information and contact details regarding the study (See Appendixes B and C). All of the 25 sampled websites were contacted on several occasions to ask them to participate in this survey. A positive outcome from this was that it opened up channels of communication which in turn led to some interest in a study such as this being conducted. In addition some of the sampled websites asked for a copy of this finished work.

Chapter 5: Results and Analysis

5.1 Introduction

The three following evaluations looked at both sides of online health information, those being the website and the health consumer. The evaluation of these two processes were carried out utilising an online anonymous questionnaire and were run over a six month period at the beginning of 2007. The third component of these results was the Web evaluation utilising a 25 question tool which rated the quality of various aspects of information quality. These were authorship, sponsorship and bias, information quality and finally, interactivity and usability.

Research carried out by Adelhard & Ost (1999) collated information from other website evaluations. They concluded that the criteria for evaluating websites fell into six main categories.

These are:

Authority and objectivity, which means that the author's name is also given in addition to their affiliation.

Currency and methods of revision, this means that due to the nature of the Internet and its ability to provide up to date information, websites should indicate the frequency their information is updated.




Evidence and accuracy, very much like the previous criteria, there is a strong need to back up the information with references to other publications and the usage of clinical studies to add credence to any health information online.

Access and ease of use, this criteria not only relates to the ease of connectivity but to the design of the website including the ability for free text searching for the website's content.

User support. By achieving this criterion the website must allow the possibility of exchanging emails in addition to there being a good ability for website updating where necessary.

Intended audience, which means that the context of the information must be easily recognisable. Adelhard & Ost (1999:76) state that; "The user must be able to perceive the relevance and usefulness for his purpose."

5.2 Scores for Customised Web Evaluation Tool

The scores for the Web evaluation were collated into four matrix tables (See Appendix H) and give an overview of how each website performed in each of the criteria. The websites that achieved a positive score of 1 to 4 were shown with a  symbol, those that failed to achieve the criteria and were scored -1 to -4 were given a  symbol and finally a neutral or no score was indicated by the symbol . The three symbols are coloured as to give an immediate grasp of the data from these tables.

5.2.1 General Comments

The Web evaluation was split into four sections, authorship, bias and sponsorship, information quality and finally interactivity and usability. From looking at the four matrix tables (See Appendix H) there are some notable points worth highlighting.

- **Authorship Criteria**

An important criteria for the provision of quality health information is that of authorship and as indicated by the red areas, there are a lot of websites failing badly in their provision of this set of simple rules.

- **Bias and Sponsorship**

In stark contrast, most of the websites were indicated as not having a lot of bias in their content, this is a positive outcome.

- **Information Quality**

A large number of the websites did succeed in having the right criteria for the provision of good quality health information.

- **Interactivity and Usability**

The fourth set of results showed that the majority of websites did succeed in these criteria, although there were three questions which a large number of the websites failed in.

5.2.2 Web Evaluation (By Question)

Q1 Is the author identified in the article?

The results from question one highlighted a large problem relating to health information on the Internet. This means that a lot of information does not have an author and therefore could in theory have been written by anyone.

😊	😐	😞
9	0	16
36%	0%	64%

Q2 When the author refers to another source, are appropriate references provided?

For most of the information that this study looked at, there was a distinct absence of references to other sources. This may be due to a multitude of reasons from worry over copyright issues to the website not knowing that they can reference other material.

		
8	15	2
32%	60%	8%

Q3 If the author is not referring to a source, does he/she clearly state that it is only his/her opinion?

This was the one question from the evaluation tool which failed totally in its purpose. For the most instances, as explained in the previous question, most of the information this study sampled did not appear to reference other material, whilst for the rest it was impossible to gauge either way.

		
0	25	0
0%	100%	0%

Q4 Are the site author's credentials listed?

Almost half of the sample group did give the author's credentials, which for the most part was positive. Nevertheless, there were a couple of websites where the author's credentials were not totally connected to the particular field of expertise, neither were they from medical backgrounds. Despite this honest and open approach, there is the fear that some users will accept their information regardless of the author's credibility.

		
11	0	14
44%	0%	56%

Q5 Does the site author's credentials relate to the knowledge of the field that is required for the site's subject discussions?

This question looked at the author's credentials and whether it related to the subject of health. The most worrying aspect is that 20% of the authors sampled did not relate to the subject they were writing about. The author of the website End Social Anxiety openly admits to having no medical experience beyond overcoming the condition they are writing about. There was also a degree of ambiguity regarding the author's credentials, such as the Stressbusting.co.uk website, where information is written by their workplace stress guru. Reasons for this can vary from one man operations offering subjective guidance on the subject, usually from anecdotal experiences. There is also the issue relating to the selling of a product where the medical information is usually supplementary to eventually selling a cure.

		
9	11	5
36%	44%	20%

Q6 Are the author's experiences relevant to the topic?

Over half of the content evaluated was shown to be written by people with experience relevant to the subject. This group included doctors, psychiatrists in addition to academics from that particular field of research. Only one sample failed to have a background in the subject, which was pointed out as a disclaimer.

		
13	11	1
52%	44%	4%


Q7 Is a means provided to contact the author directly?

The vast majority of the websites had some means to contact the website directly, but only a small percentage of these gave a direct contact for the author. For some this was indication of the website being a small time project, but other larger organisations direct email addresses were still employed regardless.

		
16	0	9
64%	0%	36%

Q8 Can you determine who has paid for or sponsored this website?

This does not mean is there commercial sponsorship, but is there is any easily identified backing which can include charitable, commercial, governmental or private funding. For the vast majority the answer was yes, much of this information was gained from the ‘about us’ pages held on the website.

		
19	3	3
76%	12%	12%

Q9 Is there any financial conflict or bias? (Yes -4 No 4)

This is a much harder question to give a definitive answer, as financial bias and its respective conflicts can be undisclosed, hidden or worded in ambiguous language. A positive answer to this question gained a negative score as non commercial bias and conflict is a positive outcome from this evaluation.

		
15	4	6
60%	16%	24%

Q10 Does the site state that contributors or sponsors have no control over content?

This was very hard to gauge, as it meant going through a lot of information and there was no assurance that it would be declared. Only three websites declared commercial influences, although it would be arguable to say that the majority of the websites sampled would answer yes, but without clear evidence it was impossible to score it either way.

		
3	22	0
12%	88%	0%

Q11 Is there a means to determine how current the information in the website is, for example - date of last update or posted date?

There were only two answers for this question, yes or no; with the slight majority not giving their health information a date of publish. Again, like question 10, it is arguable to conclude that most of the sampled websites did have a positive outcome by having fresh information, but without a date stamp it was impossible to score positively

		
11	0	14
44%	0%	56%

Q12 Is the information current? (Updated in the last 6 months)

The majority of the sample group passed this test as it was obvious that the majority of the websites had been updated in the recent months. This was obvious to date stamps on the information, fresh news items and updates on the home page.

		
21	0	4
84%	0%	16%


Q13 Is the information still relevant? (for example a new treatment posted two years ago may no longer be the most appropriate treatment today)

To give a precise answer to this question requires background knowledge in the conditions studied in this dissertation. From limited knowledge and research it appeared that the vast majority (92%) did pass this criteria.

		
23	0	2
92%	0%	8%

Q14 From your own knowledge and experience, does this site give quality medical information?

Part criteria for answering this question came from six years of working in a medical research library and familiar knowledge with some of the sample websites. This question has a level of subjectivity which must be taken into account.

		
22	0	3
88%	0%	12%




Q15 Is the medical information presented in a balanced and neutral form?

Previous journalistic experience was used to critically appraise the information and it was found that the vast majority (88%) of the sampled websites did present their information in a balanced format. The three websites that failed either contained information that was emotive in content or tried to push a sales product rather at the expense of quality information.

		
22	0	3
88%	0%	12%




Q16 Are the linked sites current?

All of the sampled websites had their links checked to see how many were kept up to date. 80% of the sample group had fully working links, but more surprisingly one in five did not, which considering the amount of work required to rectify this, which was poor.

		
20	2	3
80%	8%	12%




Q17 Do the linked sites give good medical information?

For the most part, the majority of these websites did have good quality links, and many of these websites did link to each other. Three websites gave inconclusive results, whilst another three linked to websites containing poor or dubious information. Many of these links were sales sites promoting various cures for conditions of anxiety and panic disorder.

		
19	3	3
76%	12%	12%

Q18 If you are allowed to input information or submit queries, is a statement provided that explains whether or not this information is confidential and secure?

Only 12% of the websites fulfilled these criteria, whilst another 52% allowed the inputting of queries, they did not state any details regarding privacy.

		
3	13	9
12%	52%	36%

Q19 Is the site easily navigable and presented in an organised manner?

The results to the question were very positive, 92% of all the websites evaluated were presented in a clear and organized manner. The Internet and its practices are now firmly established in modern culture and as a consequence it is unacceptable for websites, certainly those providing health information, to exist in an unstructured and chaotic format. Nevertheless, this research did find two websites that did provide their content in an unstructured and unclear way.

		
23	0	2
92%	0%	8%

Q20 Is a search engine provided?

This element is even more crucial for websites that provides a lot of content. For the 48% that failed it is not always essential for a search engine to exist, especially the smaller websites as content is usually easier to find. For the larger websites, a search engine is desirable and for the most part these websites succeeded in their capability to provide one.

		
13	0	12
52%	0%	48%

Q21 Does the search engine assist you in using the site?

48% of the websites sampled did not have a search facility so it was impossible to score them either way on this question. For the 52% that did, as identified in question 20, 40% did assist in aiding the finding of information. The remaining 12% failed in this assessment.

		
10	12	3
40%	48%	12%

Q22 The information is consistent with that of other similar websites?

92% of the sample group did have consistent information, insomuch that they gave the same information regarding courses of treatment and support. The two remaining websites failed to offer information consistent with the sample group.

		
23	0	2
92%	0%	8%


Q23 The website provides interactivity that increases its value?

This is particularly important with regards to the conditions that this research focuses on. Certainly for health information websites, the importance of interactivity and peer support is crucial in aiding the recovery process. Over half of the sampled websites succeeded in this, whether through the forms of a working forum or through telephone or email support and feedback.

		
13	1	11
52%	4%	44%

Q24 The information is easy to understand?

This very much depends on the ability of the user and can relate not only to their grasp of English, but the terminology employed. The positive outcome from this evaluation was that, except one, all of the websites evaluated had easy to understand information.

		
24	0	1
96%	0%	4%

Q25 The purpose of the site is clear, i.e., business/commercial, news, personal page?

Again, like the previous question, only one website failed on this question.

The majority of the websites fell into the category of either charity, recognised as private or publicly funded bodies or personal Web pages. Only one website was so ambiguous that it was impossible to tell of its nature.

		
24	0	1
96%	0%	4%

5.2.3 Complete Web Evaluation Score

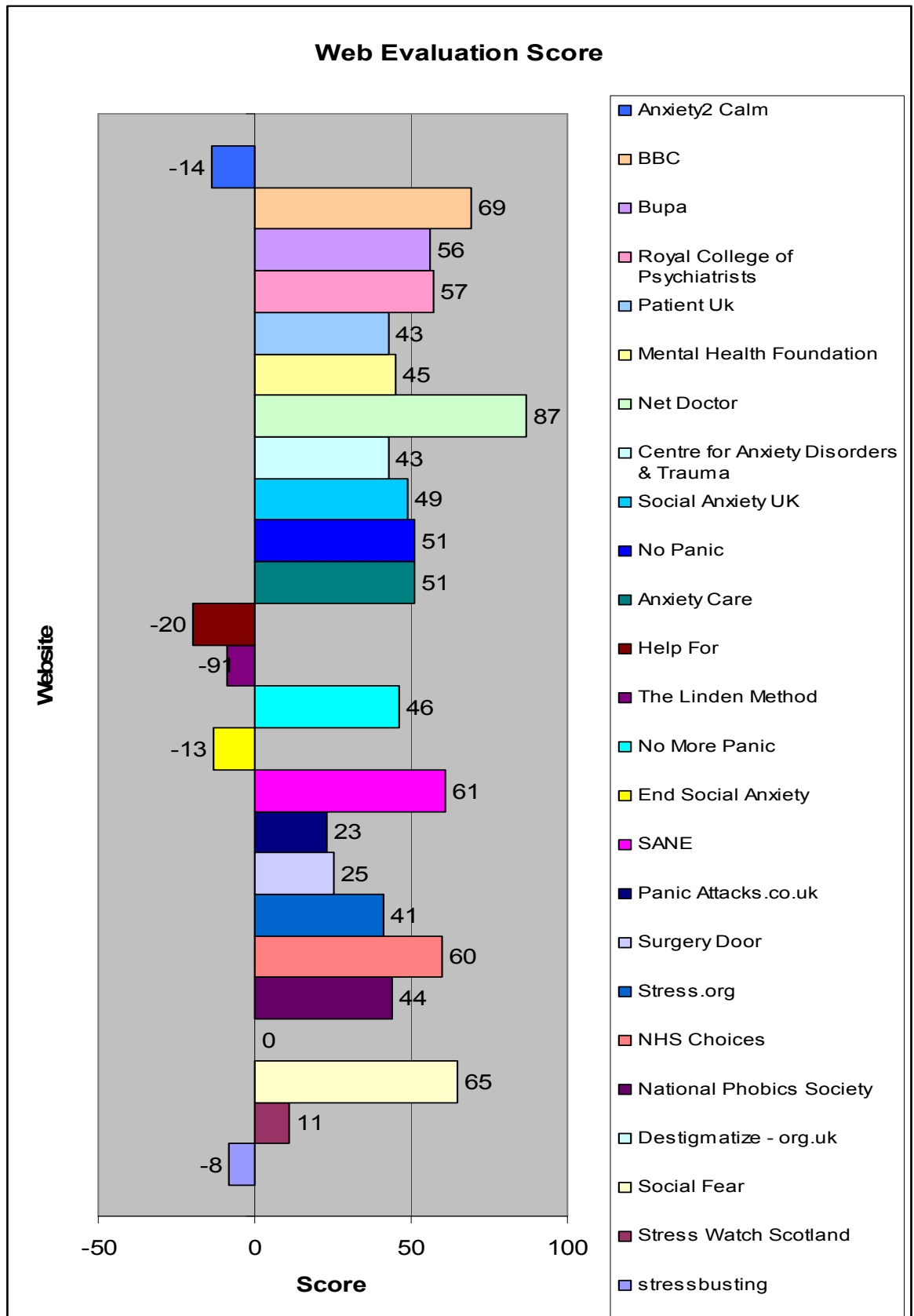


Fig 5.0 Web evaluation scores by website

The previous chart shows widely contrasting results from the Web evaluation. Of the 25 websites that were sampled, 76% of them achieved a positive score but most notably is that 20% of the tested websites received a negative score.

5.2.4 Best and Worst Performers

This table highlights how well the generic health websites fared in comparison to the specific anxiety-related and panic disorder websites. Out of the top five only SANE and Social Fear managed to achieve a high score, although it is worth pointing out that SANE covers a wide range of mental health issues.

Website	Top 5 Websites Score
Net Doctor	87%
BBC Health	69%
Social Fear	65%
SANE	61%
NHS Choices	60%

The below table contains websites that focus specifically on anxiety-related conditions. All five websites achieved scores below zero for a variety of reasons. Help For's lack of content and authority and poor information quality resulted in it finishing bottom of the evaluation. Anxiety 2 Calm fared very poorly with regards to authorship, whilst End Social Anxiety also performed badly with regards to authorship as well as having problems with interactivity and usability.

Website	Bottom 5 Websites Score
Help For	-20
Anxiety 2 Calm	-14
End Social Anxiety	-13
The Linden Method	-9
Stressbusting.co.uk	-8

5.2.5 Web Evaluation by Score

The positive outcome of this evaluation is that the majority of websites that were sampled did manage to achieve a moderate to good score. Over one third, 36% did manage to achieve over 50% which should be considered as a bare minimum for any website wishing to provide online health information. A further 28% of websites just fell below the halfway mark scoring in the region of between 40-50% in the Web evaluation. The table below gives a breakdown of scores for the 25 websites.

5.2.6 Evaluation Scores and Type of Website

Average Scores (by website type)

<u>Type of Website</u>	<u>Average Score</u>
All (25 Websites)	34.52
Generic Health Websites (6 Websites)	56.66
Anxiety-Related and Panic Disorder Websites (19 Websites)	27.52

5.2.7 Website Evaluation Scores (Scatter Diagram)

The below scatter diagram indicates how well the six non-specific health websites fared in the Web evaluation. Five of the six websites (indicated in red) achieved a score of 40% or higher whilst only Surgery Door failed to achieve this with a score of 25%. The table reflects the wider result that over half of the tested websites achieved a score of 40% or higher, with only three websites scoring between 0 and 40%.

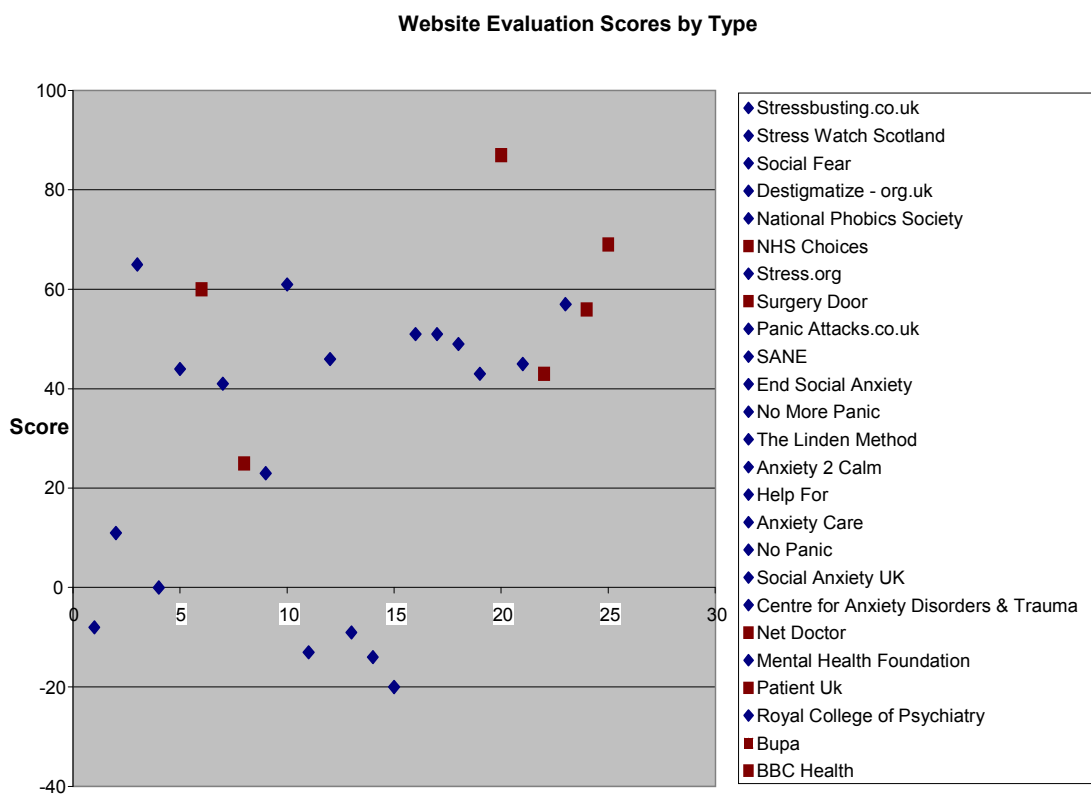


Fig 5.1 Web evaluation by website type

Key:

- Generic Health Websites (in order from left to right – NHS Choices, Surgery Door, Net Doctor, Patient UK, BUPA, BBC Health)
- Mental health, Anxiety and Panic Disorder websites

5.2.8 Website Evaluation (by score range)

The table below shows where the peaks are troughs are in terms of scores from the evaluation. The table clearly shows that the majority of websites did manage to achieve a score of at least 40%.

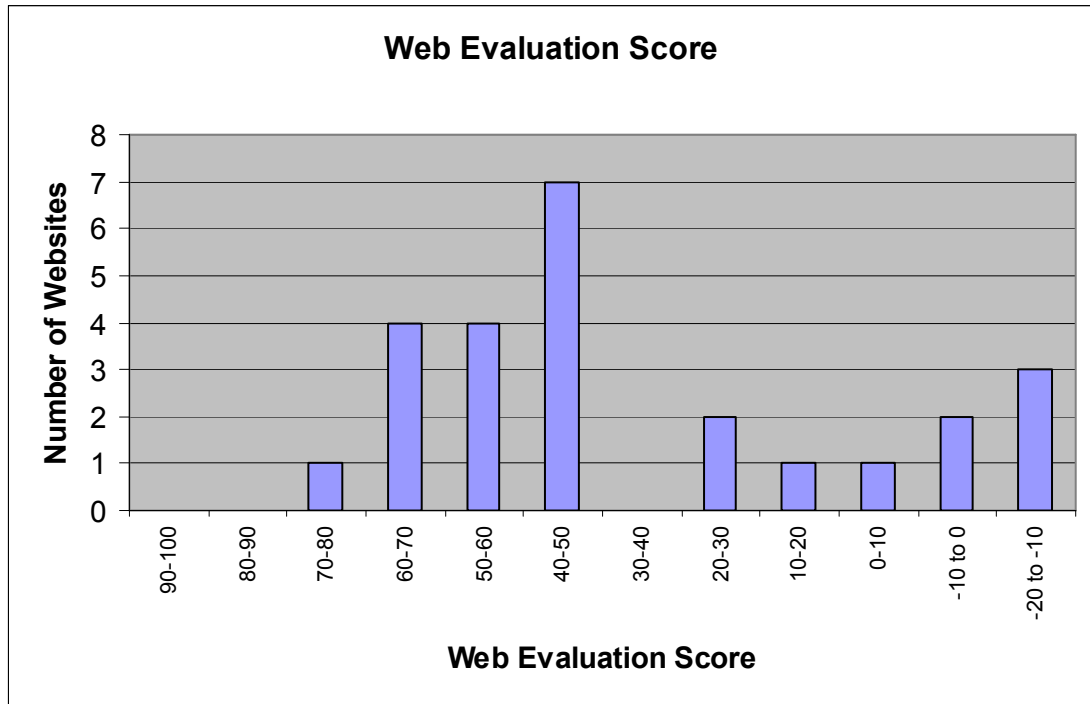


Fig 5.2 Evaluation score (by range)

5.2.9 Summary of the Web Evaluation

The evaluation was successive in highlighting many areas where health websites do succeed in supplying high quality, balanced information. Information quality and the minimum amount of interference from external, particularly commercial, influences is a positive outcome. Authorship is still an area for improvement as many websites fail in tagging much of their more delicate information with a name. The area of interactivity and usability remains inconclusive, some websites have a greater need for this component, but this study shows that certain organisations need to improve in this area.

5.3 User Needs Survey

The user needs survey was posted on three of the 25 sampled websites. No Panic, The National Phobic Society and Social Anxiety UK all agreed to post the research on their news and research pages (see Appendix A) for people to anonymously answer; giving their experiences of using the Internet to search for information relating to the conditions of anxiety and panic disorder. In all there were 111 responses to the questionnaire over a six month period, with not all respondents answering all the questions, although it is important to note that this number was just a tiny minority. Ten questions were asked that looked at what websites people used, what search terms were employed; their preferences for the information content and finally how well they rated their experience of using the Internet to obtain health information.

5.3.1 Scores for the User Needs Survey

Question 1.

Which website do you use the most for obtaining health information?

This looked at the most popular and established health websites used by health consumers.

Website	Total
1. NHS Direct	49
2. BBC Health	27
3. Other	21
4. Netdoctor	10
5. BUPA	1
Total Respondents	108

The evidence shows that almost half of the respondents use NHS Direct as a first point of call for their health information. This was a positive outcome as NHS Choices, the new website for health consumers had fared very well in the Web evaluation by coming in the top five of the results with a score of 60%.

The second website was the BBC's health pages, and it is by no coincidence that both organisations have huge presences outside of the domain of the Internet. The BBC and the NHS are both renowned for providing good quality information and this is reflected in both the questionnaire and the Web evaluation. Out of the 21 'other' response, no single website stood out, it is important to note that many of the 21 websites were not websites but actually search engines or terms.

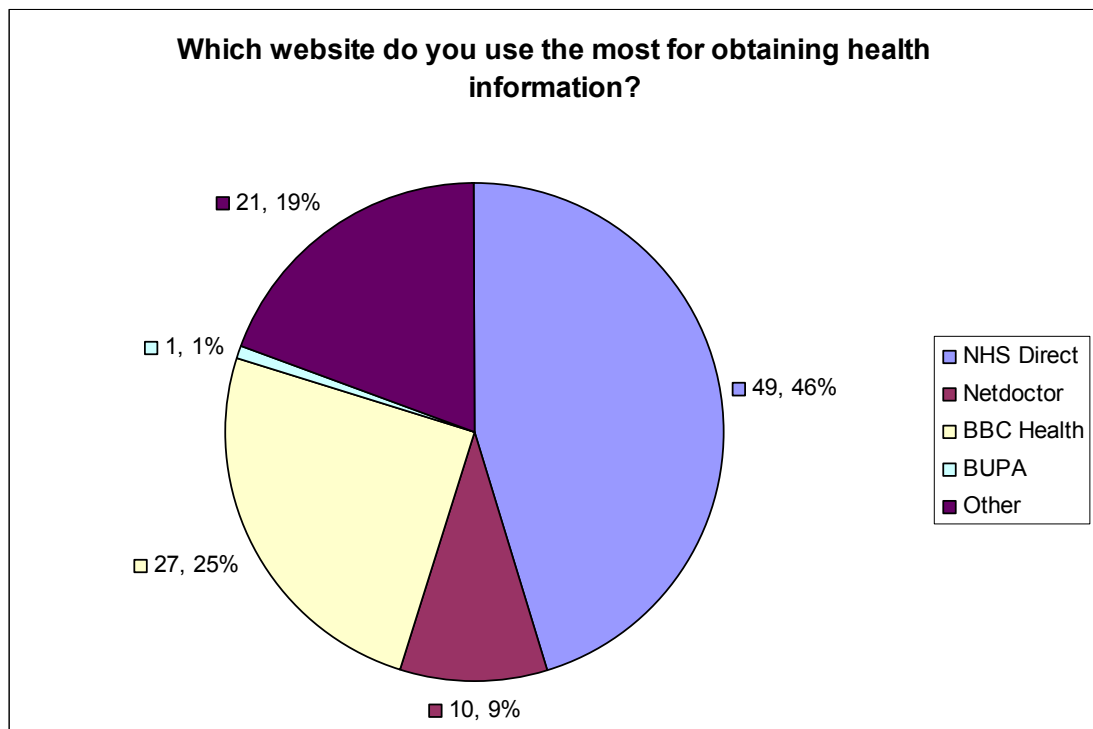


Fig 5.3 Choice of non-specific health website (value and percentage)

Question 2. Which Website do you use most for information concerning anxiety, panic attacks or stress?

The results were quite conclusive from the five options that were offered to the participants. Four mental health websites and an ‘other’ option were provided with the top three making up 90% of the share. It is interesting to note that of the 35 respondents who answered ‘other’ 24 gave the names of websites that they use as a first point of call. Of those 15 (64%) named No More Panic as a website of choice, this will be touched on later in this chapter.

Website	Total
1. Other	35
=2. No Panic	34
=2. Social Anxiety	34
4. Anxiety Care	3
5. SANE	1
Total Respondents	107

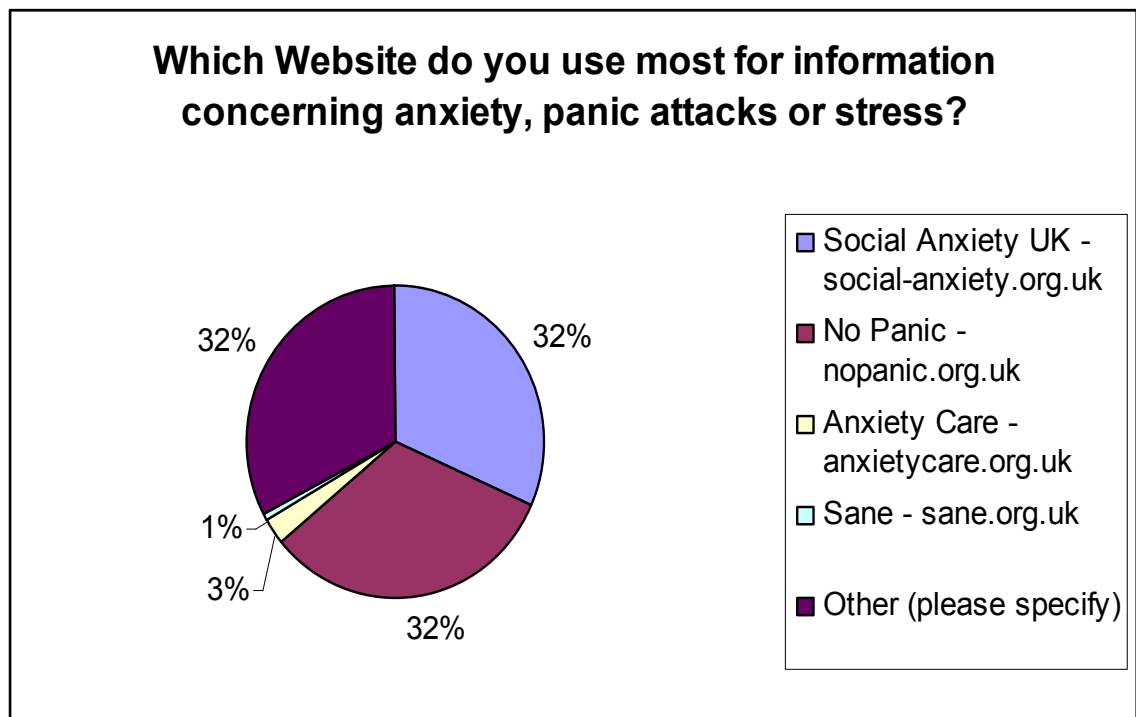


Fig 5.4 Choice of specific health website (percentage)

As previously mentioned of the 35 respondents who answered ‘other’ as the specialist website that they choose to obtain information, 24 gave references to the

actual websites. The majority of these, 15 respondents (64%), pointed to the No More Panic website as a specialist source of information relating to their condition.

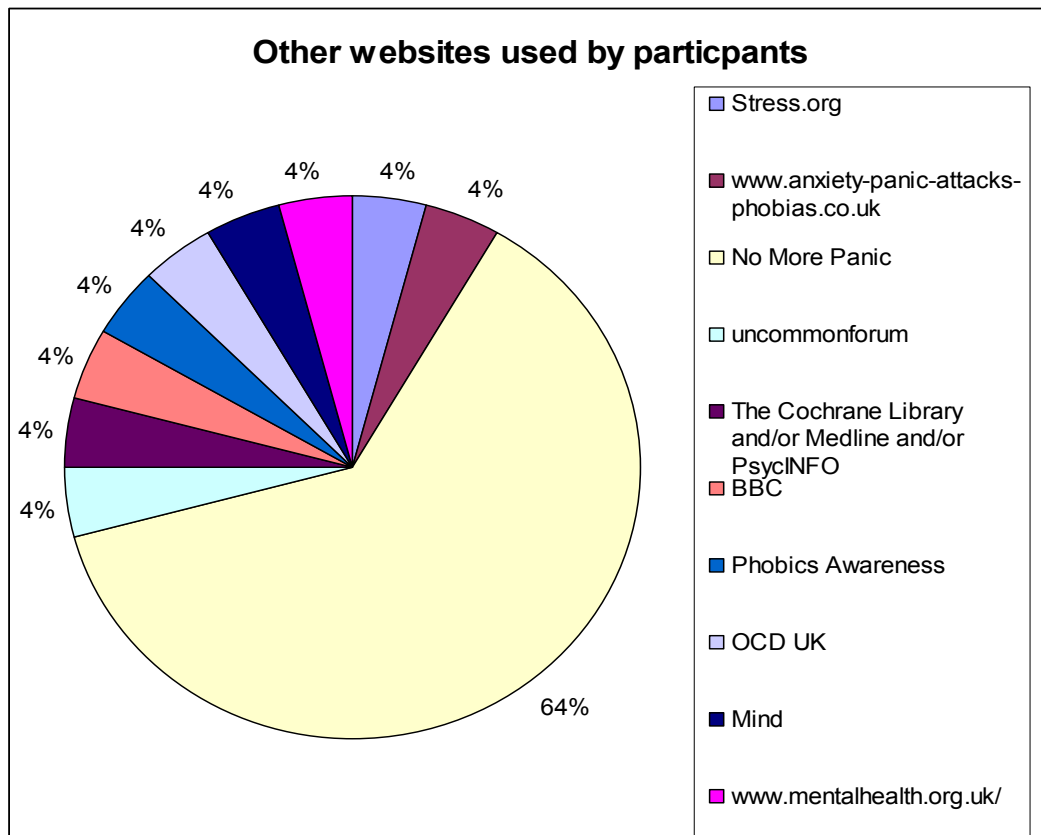


Fig 5.5 Other websites used by participants (percentage)

Question 3. Placing them in order, what are the most important reasons for visiting health/anxiety websites? Please ensure that you do not give each option the same ranking.

The five options were as follows:

- i) Interactions with/through the forums and chat rooms
- ii) Information on a specific condition
- iii) Professional contact information
- iv) Medication information and sales
- v) Links to other organisations and websites

Not all respondents ranked all five options, with just 7 out of the 111 replies not being completed, with some only ranking the first, whilst others ranking just 1 to 4.

<u>First Choice Option</u>	<u>Number of Respondents</u>
1 Information on a specific condition	72
2 Interactions with/through the forums and chat rooms	31
3 Professional contact information	8
4 Links to other organisations and websites	5
5 Medication information and sales	3
Total Respondents	111

It is important to note that, although there are a total of 119 responses from 111 respondents, this results from some people selected two options equally as their first choice. In fact, on three occasions are the first two most popular options are ranked equally first, which perhaps shows the importance of these two facilities compared to the rest as provided by websites. The importance of these two reasons is also highlighted by the second choice results which can be seen in the table below.

<u>Second Choice Option</u>	<u>Number of Respondents</u>
1 Links to other organisations and websites	29
2 Information on a specific condition	25
=3 Professional contact information	20
=3 Interactions with/through the forums and chat rooms	20
5 Medication information and sales	15

Again it is important to note that the second choice selection, along with the first, received more than 111 votes as some respondents equally rated two options. From the previous two tables it is obvious that people rate information on a specific condition as being the most important reason to visit a health website. Almost three-quarters of the respondents felt that this was the most important reason to use a health website, whilst a large number of the remainder rated this as being the second most important reason. Despite it not being a popular reason to visit a health website, links to other organisations and websites was deemed an important reason to use them. With specific regards to health information, it is quite important that consumers do not get reliant on just one website and in particular one opinion, especially if it is of dubious nature.

The fifth and least popular of the options, medication information and sales, must not be discounted. A major problem that health consumers face is that of organisations and websites trying to sell them medication which may not be a

prescribed cure for their illness. The fact that three respondents placed this as the highest of importance may not necessarily mean they are actively seeking medication online; but it is without doubt an important issue to flag up. There is no shortage of online information relating to legally prescribed medication, but there are also several websites that are keen to sell their own less official product.

The scatter diagram below reflects how the importance of information contrasts with medication information sales. By the time respondents make their third choice, the two options have changed places in their ranking.

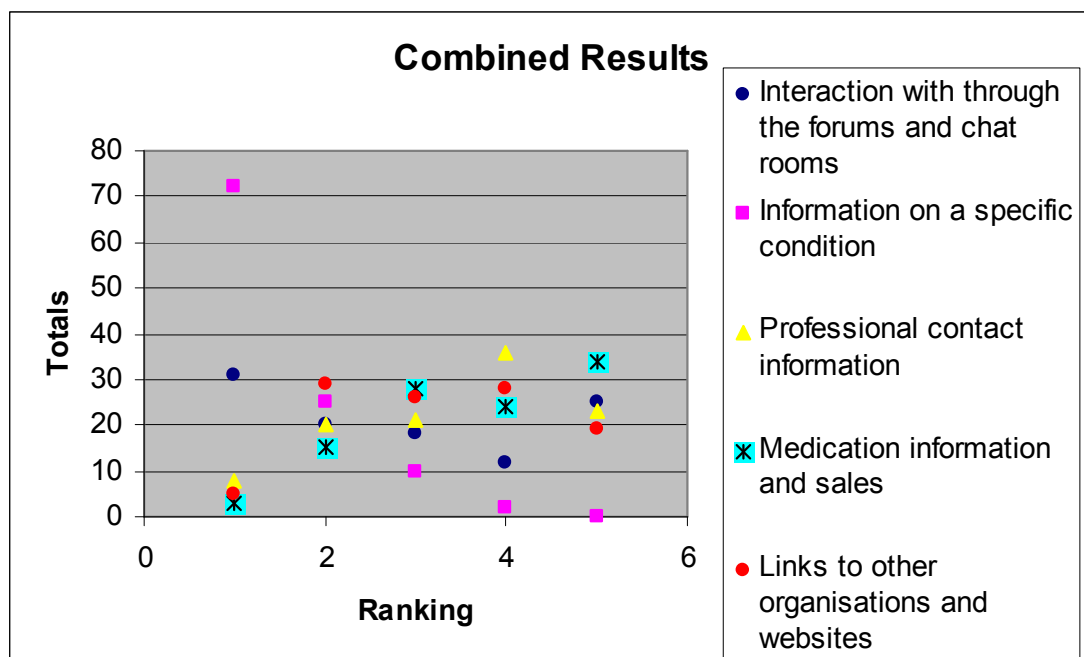


Fig 5.6 Reasons for visiting health and anxiety websites

The table that follows shows the average response for each option. Most options received at least 104 responses out of a total 111 (93.6%). The table shows that, as previously stated, information on a specific condition is by far the most popular reason for people to visit a health website. Second option is that of interactions with/through the forums and chat rooms. It is worthy to note that this is even more important considering the particular conditions in this study which

acknowledge the importance of support mechanisms both online and in the real world in helping sufferers to overcome their illness.

Average Rating

Option	Response Count	Rating Average
Information on a specific condition	109	1.47
Interactions with/through the forums and chat rooms	106	2.81
Professional contact information	108	3.43
Links to other organisations and websites	107	3.25
Medication information and sales	104	3.68
Total Respondents	111	

Question 4. What keyword search terms do you use to find your website? Please tick all those that apply.

Respondents were asked to select from a list what search terms did they use to retrieve information on their conditions. The most popular term was ‘anxiety’, with four out five of the respondents, in 89 from a possible 111 participants selecting this term. The second most popular term was chosen by just under half of the respondents who chose ‘panic’ as a search term. Obviously the conditions of anxiety and panic are quite different in their make up; whilst some sufferers will regard both terms equally as important as those suffering from panic-disorder usually suffer from different levels of anxiety. ‘Stress’ and ‘disorder’ both received a similar number of responses, almost one fifth of all the respondents selected this term. It is important to note that the term stress may not be as popular as it used to be. This may be due to the stigma tied to word and that more people are becoming informed as to what the correct terms are for the varying conditions relating to this word. On the other hand, ‘disorder’ is obviously related to ‘panic’ and therefore has a degree of popularity. Despite this, it is necessary to note that both ‘panic’ and ‘disorder’ relate to one

specific condition and it is fair to suggest that respondents searching for ‘anxiety’ are less likely to search for ‘panic’ than those searching for ‘panic’ along with ‘anxiety’.

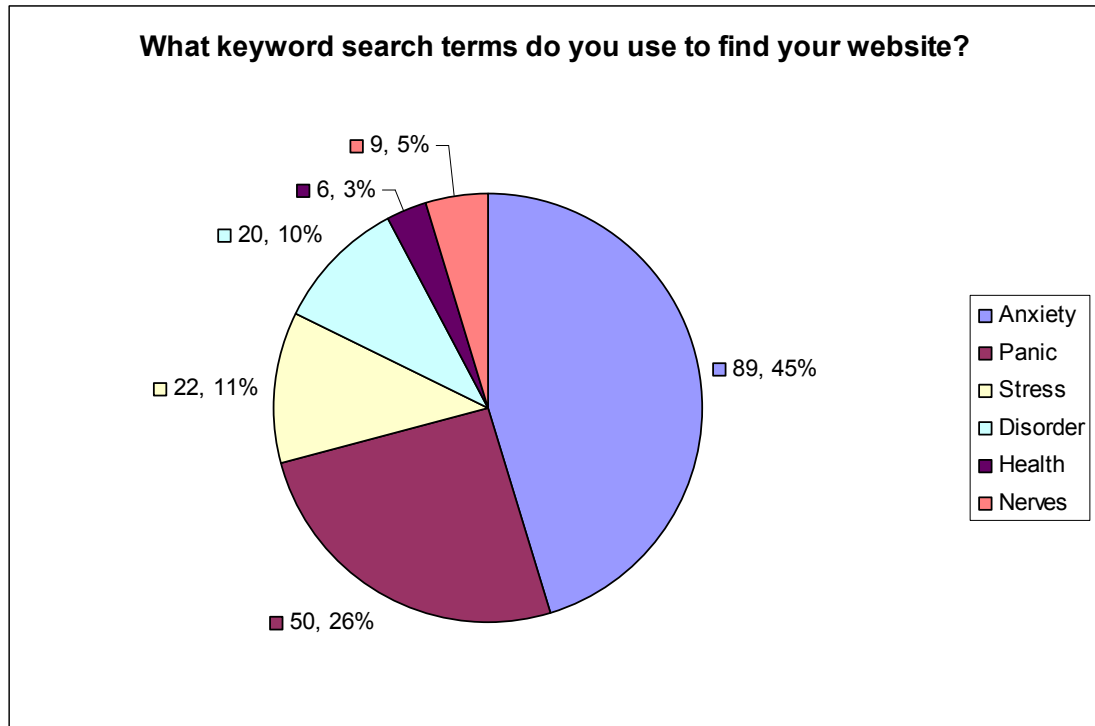


Fig 5.7 Keyword search terms used to find websites (value and percentage)

Of the other search terms used, which accounted for one quarter of all respondents, 27 pointed out that ‘social anxiety’ was used as a search term. The other notable search term was ‘social’ which was suggested by five of the respondents.

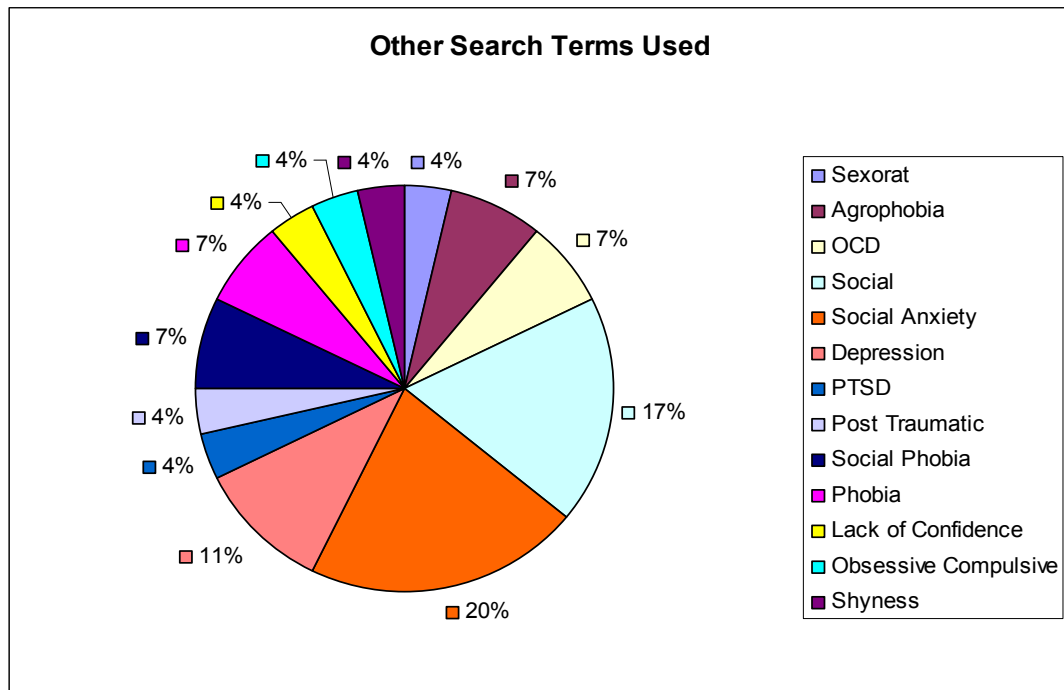


Fig 5.8 Other search terms used. (percentage)

Question 5. Where do you begin searching for health information on the Web?

Respondents were asked to provide information on where they begin to search for information. The response clearly reinforced the dominance of the modern day search engine. 82.9% said that they used a search engine such as Google or Ask as a starting point to find information on their condition. 10.8% of the respondents stated that they already know the website they are looking for which arguably shows that they have some familiarity with certain online health resources.

Answers	Response Percent	Response Count
From using a search engine such as Google or Ask	82.9%	92
By using a directory search engine such as Yahoo	4.5%	5
I already know the website home page address	10.8%	12
I have been recommended a website	1.8%	2
Other (please specify)	0%	0
Total Respondents		111

Question 6. How do you assess that a website contains credible information regarding health?

A total of a 109 respondents completed this question regarding how they evaluate online health information. The participants were asked to select which methods they employ in evaluating the information they find online relating to their condition. Two thirds of respondents stated that they visited many sites and evaluated content by comparing it to other sites. Hopefully as more and more people become familiar with the Internet, the chances are that they will become more selective to what resources they use and by means of editorial process they will start to build up a collection of credible resources. Almost a third of the participants looked at the quality of the writing on the web site as a way of deciding on its quality. Whilst almost a third assessed a websites quality on its appearance, if it is run by health professionals and if they were already familiar with the website. Obviously these four options are not without their pitfalls. Firstly, good writing does not necessarily mean good quality health information. Secondly, appearances can be deceiving, anyone can make a flashy looking website these days, the rule should be content over style, that's not to say of course that a website can look pretty as well as have brains. Thirdly, websites run by health professionals will usually be of good quality, but users need to acknowledge that not everyone on the Internet is who they claim to be. In addition, there is the concern that there are those working on the

outskirts of medical knowledge, providing loose or even incorrect information.

Finally, familiarity does not always mean quality, some users may become attached to a website because it feels comfortable and it offers reassurance. Health consumers need to be aware that there are always other websites and it is important to consider a cross section before giving their allegiance to just one.

Quite interestingly, four of the five respondents who selected that ‘they don’t assess’ the information did not select any of the other options. Taking into consideration that millions of people search for health information online every week, the number of those not taking serious note of the quality of the information may run into the tens of thousands. Another point to consider is the amount of respondents who gave the answer; ‘because it reassures me with the right answers’, considering the nature of the conditions that this study is concerned with, reassurance plays a large part in the healing process. Nevertheless, it is arguable that reassurance may not be enough and in turn can lead the sufferer from getting the right treatment from a website that may provide incorrect or misleading information. It is also interesting to note that 18.4% stated that they use word of mouth in their assessment of health websites. Of the ten respondents who gave other answers, the most noteworthy are ‘from reading books on the condition’, ‘from press recommendations’ and it is ‘referenced by an official government or charity body’.

Answer	Percentage	Number
1. By visiting many sites and evaluating their content	60.6%	66
2. The quality of writing on the website	32.1%	35
3. I already know about the website and trust it	29.4%	32
=4. The people who run it are health professionals	28.4%	31
=4. It looks like an official information source	28.4%	31
=6. Because it reassures me with the right answers	18.4%	20
=6. From what other people say about it	18.4%	20
8. By the amount of content on it	13.8%	15
9. Other (please specify)	9.20%	10
10. I don't assess it	4.6%	5
Total Respondents		109

Question 7. How often do you use the Internet to obtain information about anxiety-related issues?

The results from this question point to very different levels of usage by health consumers. Just over half use the Internet on a weekly basis, with almost one third of those using it on a daily basis. The other 49.5% are almost split equally between weekly monthly visits and less than a month.

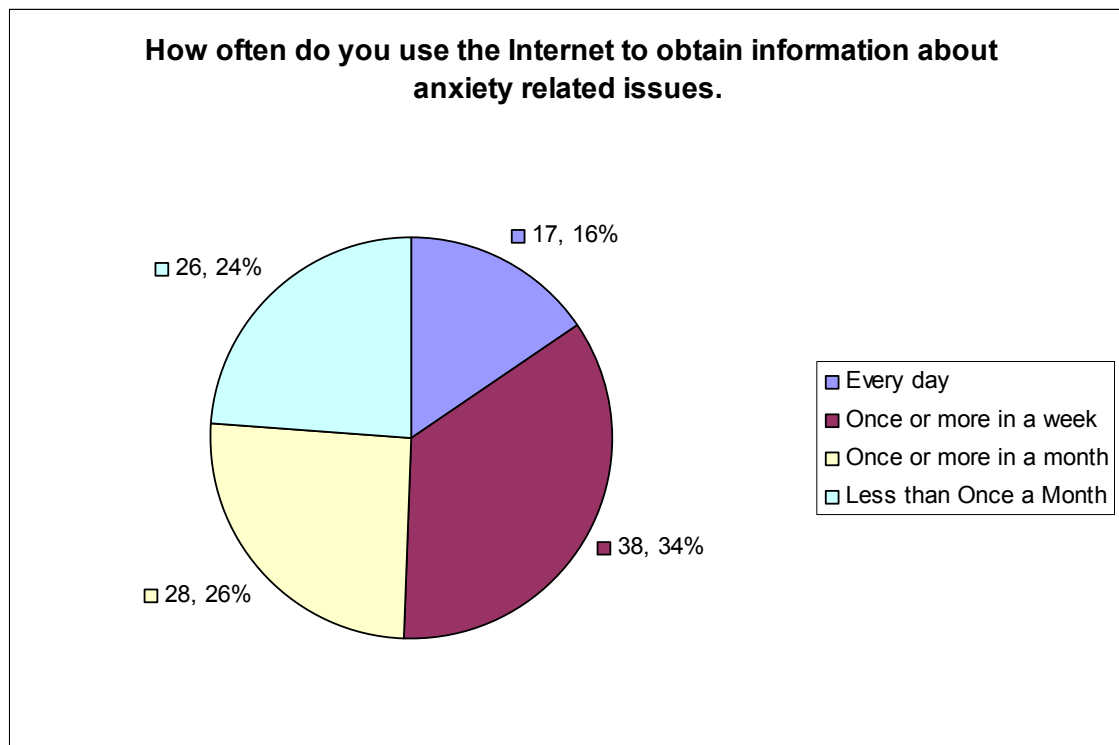


Fig 5.9 Frequency of visits by participants to anxiety-related websites (value and percentage)

Question 8. How satisfied are you with the information you find relating to your condition

Participants were asked to rate their experiences of using the Internet to obtain health information. Over half of the respondents stated as a whole that their experiences were for the most part positive. Although a third were only happy with the information they found half of the time, which obviously means that there are a large proportion of users are unhappy half of the time. Another statistic to take note of is that 9.3% of the respondents were unhappy with the content they found for at least most of the time, added with the previous group this makes for a large number of users having negative experiences searching for health information.

Answers	Response Percent	Response Count
Always	2.8%	3
Most occasions 75%	55.6%	60
Half of the time	32.4%	35
Very rarely 25%	7.4%	8
Never	1.9%	2
Total Respondents	108	

Question 9. Do you think that the health information on these websites help you understand and treat your condition better?

Participants were asked to give a judgment on whether their online experiences helped aid them understand their condition better. Again, fewer than 10% pointed out that it rarely or did not help them understand their condition better. On a positive note, over one third had very positive experiences, whilst 53% had mild to positive outcomes.

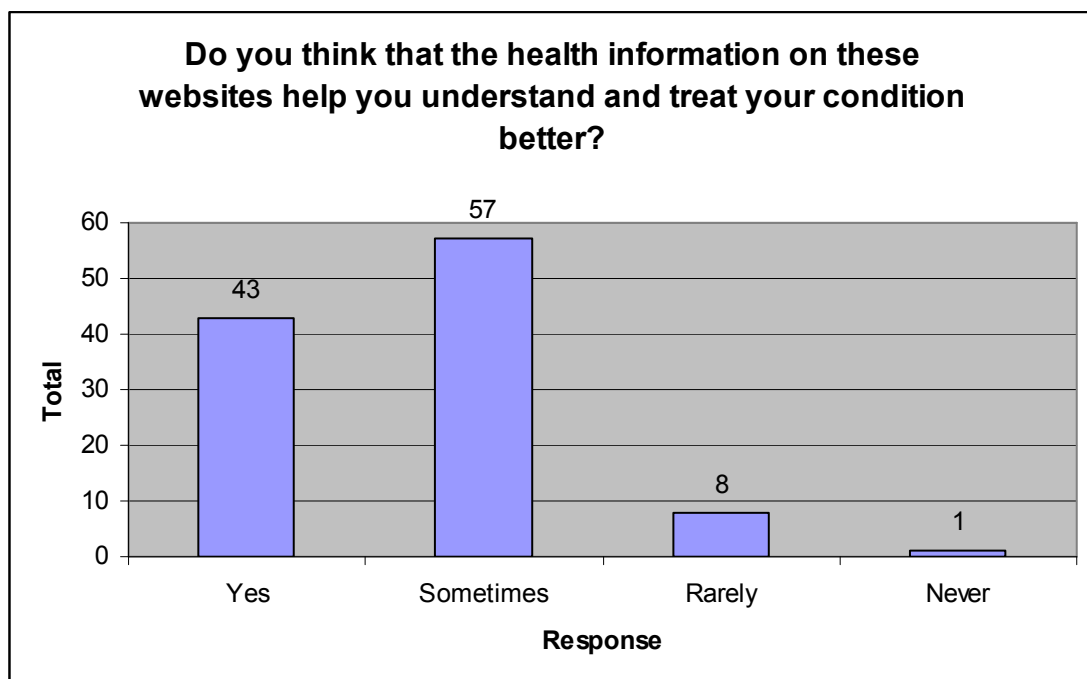


Fig 5.10 User's experiences of using online health information

Question 10.

I would say that my experiences of using online health information are...

97 participants responded to this question, mainly with one word answers.

For the full list of answers please refer to Appendix G at the end of this dissertation, although some of the more insightful comments are listed below. In addition to this, the comments were split into three groups, good experiences, mediocre experiences and bad experiences.

Good Experiences	Mediocre Experiences	Bad Experiences
65	20	12

5.3.2 Selected User Comments

Good experiences

- Excellent, as long as you savvy enough to know when a website is dodgy or not, and as long as you don't let it become a source of panic (e.g. self diagnosing yourself with the worse health scenario)
- Very good. I was able to approach my GP as a direct result of what I read on the websites.
- Usually positive, though I stick to one or two trusted sources, e.g. bbc/nhsdirect

Mediocre Experiences

- OK its hard to find things to help, lots are full of useless information.
- Reasonable, anxiety probably affects different people to different degrees and that's why finding information that relates to me is sometimes hard.
- It provides reassurance for a brief time but anxiety for a much longer period

Poor Experiences

- Poor - can actually make my health anxiety worse!!
- Not helpful compared to a doctor but they can be reassuring, provide a sense of perspective on your condition, alleviate a sense of isolation as a sufferer of a condition, and help seek further treatment
- At the moment not very good as anxiety has many other things attached to it and most sites are only covering the basics which leaves people like me feeling let down

5.3.3 Summary of User Survey

Much of the result data backed up earlier preconceptions of certain website types and their information quality. Non specific health websites, which for the most part, are entrenched in the Internet community fared very well in this questionnaire. Some of the second group of specific health websites fared very well and taking into account how these particular websites did in the Web evaluation implies that the majority of the participants have a good working knowledge of the online health information and have also gained a good level of familiarity with these websites. Areas where there are a need for concern is that many of the participants were unhappy regarding the quality of information they access, whilst there is also a pattern of reassurance over cure. On the other hand, many users acknowledged that the Internet is not a replacement for traditional medical care.

5.4 Web Editors Survey

The Web editors' survey was emailed to each of the 25 sampled websites, in addition to supporting information about this study (See Appendixes B, C & E). The websites were contacted on three separate occasions to ensure that the maximum number of responses was received. In total 7 (28%) websites responded to the anonymous questionnaire. Nine questions were asked which looked at the practices employed by websites in the provision of online health information.

5.4.1 Results for the Web Editors' Survey

Question 1. What is your role for the website?

Role	Response
Editor	3
Web Editor	2
CEO	1
Director	1

Question 2. Placing them in order, what are the principle functions of your website?

The important result from this was that all of the sampled websites stated that the most important function of their website was to provide information on a particular condition as Fig 5.15 indicates below.

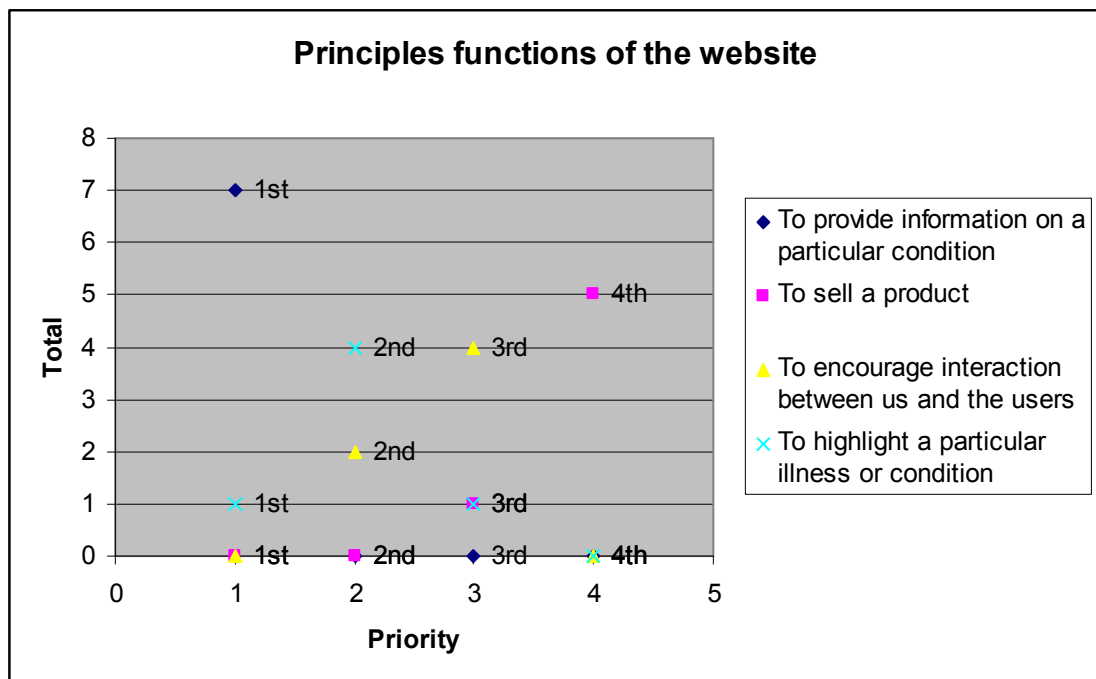


Fig 5.11 Principle functions of the website.

Question 3. What would you estimate is the most visited part of your website?

Again following on from question two, the vast majority 85.71% felt that most people visited their website to obtain information on a condition or illness.

Answer Options	Response Percent	Response Count
News	0%	0
Forum	14.29%	1
Contact details	0%	0
Information (on a condition or illness)	85.71%	6
Other (please specify)	0%	0

Question 4. Where do you obtain your health information? (Please tick all that apply)

The most notable statistic from this response was that 71.42% of websites obtain their information from medical professionals. The other two options that were highlighted were ‘In-house systematic review database Clinical Evidence’ and ‘via our patron team’. The area of ‘own knowledge’ needs further investigation to establish the the quality and validity of such sources.

Answer Options	Response Percent	Response Count
News wire	0%	0
Other website	14.29%	1
Medical publications	42.86%	3
Own knowledge	57.12%	4
From medical professionals	71.42%	5
Other (please specify)	28.58%	2

Question 5. From which sources do you obtain information that you post on to your website? Please tick all that apply.

The majority of the respondents (71.42%) replied stating that they obtained their information from published sources. This outcome is quite positive on the assumption that they are referring to information that has had to undergo a review process and therefore should be of good quality.

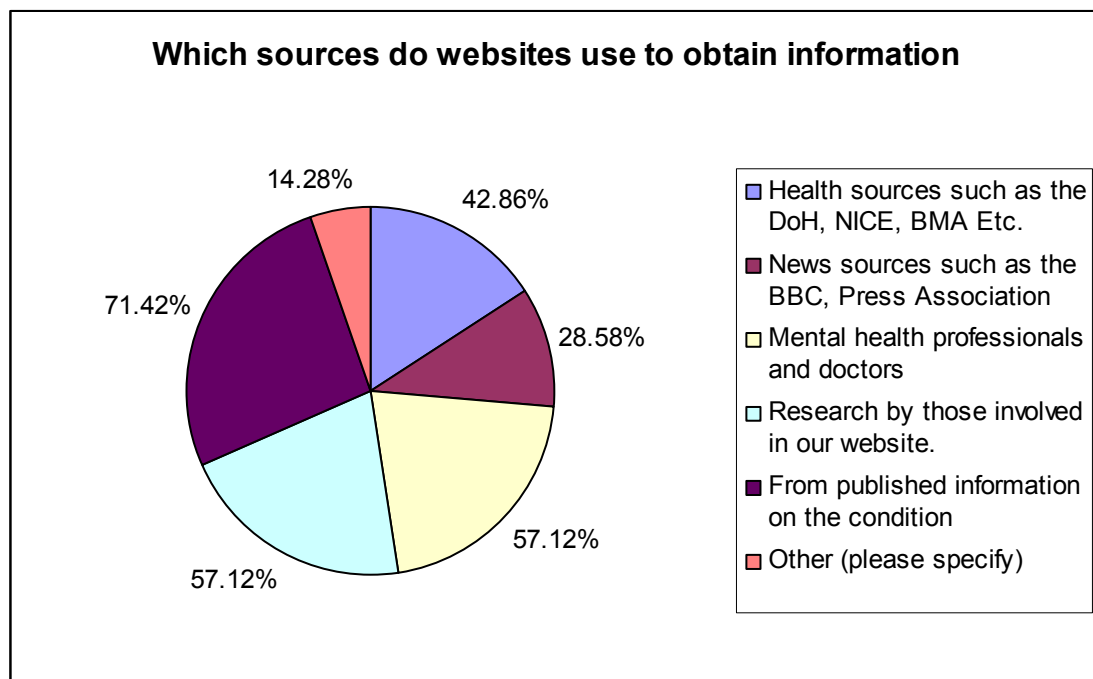


Fig 5.12 Sources used by websites to obtain information. (percentage)

Question 6. How often do you edit or update your information?

The answer to this question very much depends on the nature of the website and the traffic it experiences. 71.42% stated that they update their information at least once a month.

Answer Options	Response Percent	Response Count
Daily	14.29%	1
Every week	14.29%	1
Every month	42.86%	3
Less than once a month	28.58%	2

Question 7. Do you get people contacting you directly with health-related enquiries?

The results to this perhaps have some cause in effect, as it is arguable to say that the fact these seven websites took time to carry out this questionnaire perhaps points to them being manned on a regular basis. This in turn means that they are more likely to receive correspondents, who can usually see it is an active site, from visitors interested in the conditions supported there.

Answer Options	Response Percent	Response Count
At least once a day	28.58%	2
At least once a week	42.86%	3
At least once a month	28.58%	2
Rarely	0%	0
Never	0%	0

Question 8. Do you ever liaise with other associated websites to share and obtain information?

The positive outcome from this question was that all of the websites questioned did have at least some contact with other websites. By building up and establishing a network of good health contacts can the information they hold be better shared and in turn be of higher quality.

Answer Options	Response Percent	Response Count
Quite often	0%	0
Sometimes	57.14%	4
Rarely	42.86%	3
Never	0%	0

Question 9. Do you ever carry out any self-evaluation of your content with tools such as those available by the Health on the Net Foundation?

<http://www.hon.ch/Project/HONcode.html>

The chances of every health information website ever signing up to some code of conduct as offered by HON are extremely unlikely. The fact that only 28.58% had already done so may be an indication of naivety on the part of the others. There is also the issue of what is to be gained from joining such a scheme when most health consumers are unaware of the accreditations that are available.

Answer Options	Response Percent	Response Count
Yes	28.58%	2
No	71.42%	5

5.4.2 Summary of Web Editors Survey

Despite the limitations of this survey in that only 7 websites participated, there were certain patterns of practice that are important to highlight. All of the sampled websites showed that their main concern was that of the health consumer. Obviously there are those websites, including a couple in this study, which exist purely for ulterior motives other than the provision of health information, but these results backed up the notion that the majority of the sample group exist purely as a support mechanism for sufferers of health conditions.

Another positive aspect was that most of the information the sampled group sourced is from credible medical sources and medical professionals working for their websites. On the other hand, only two of the websites had carried out a self-evaluation of their websites using such as the HON Code. Considering the amount of work needed to undertake this evaluation, it is regarded as an area for much improvement.

Chapter 6: Discussion

6.1 Introduction

The results from the two surveys and Web evaluation do produce some interesting information regarding the quality of online information relating to anxiety-related and panic disorder conditions. Not only are the findings interesting regarding the conditions this study focuses on but the practices employed by health consumers and health providers.

6.2 The Experiences of Health Consumers on the Internet

From the evidence gathered from the user questionnaires, it is apparent that the majority of consumers are knowledgeable about health information and where to obtain it and how to assess its quality. Nevertheless it is important to note Morahan-Martin's (2004) research which highlighted that many searchers go beyond the first page of a website. There is also strong evidence that the participants of this study use the Internet to obtain health information on a regular basis. The major concern that comes from this particular aspect of the study is that some participants use the Internet for health information for reasons not entirely beneficial to their recovery.

The reasons are listed below:

- That they use health websites to purchase medications or cures.
- That online health information is used purely for reassurance and further investigation towards treatment is not carried out as a result.
- That some participants are not prepared to cross reference information from other websites.
- That some consumers do not interact with this websites and only use them on a surface level despite there being interactive services to aid their recovery.

6.2.1 Health Consumers, the Internet and Doctors.

The missing component from this part of the research is that of the medical professional. For websites to be used in their maximum capacity there needs to be more interaction between doctor and patient and this relationship must work both ways. Firstly, by consumers questioning and investigating what they read from the Internet with their doctor and in turn their doctor gaining a greater knowledge of what is on the Web. From there, the medical professional can advise the patient which websites are the most trustworthy. Morahan-Martin's (2004:497) research on how users find, evaluate and use online health information made three recommendations to aid users by proposing that; "Professionals should recommend sites. Professionals should promote more effective search and evaluation techniques. Professionals should be involved in developing and promoting uniform standards for health and mental health sites." It is also important to note the findings of Easton et al (2006) who detected a link between the frequency of online health searches and increased medical appointments.

If people are to make the best of health information on the Internet they need to not only undertake the same enthusiasm for finding information but for the evaluation of it. There is only so much that can be done by organisations, health authorities and charities to regulate and disseminate their information. Hopefully as the Internet matures the editorial processes that ties into it will mature and systems will develop to ensure that the amount of poor quality information is kept to a minimum. Ideally all health information published on the Internet would go through some professional editorial process.

6.3 Improving Information Quality

Health information on the Internet as a whole is still an area for great improvement. As Van Der Weyden (1997) argues that; “There is no reason that medical information on the Web should not receive the same scrutiny for its impact on clinical outcome and cost effectiveness as other methods of delivering the same information.”

With regards to the conditions of panic disorder and anxiety-related conditions this very much applies. Boyer et al (1998) highlighted the importance of websites aligning themselves with organisations such as Health On the Net and it is a recommendation of this study that this is still very much the case.

As with Roberts & Copeland (2001) suggestion it is imperative that websites have a clear and open policy regarding the nature of their organisation or risk jeopardising the confidence of health consumers. This is even more crucial considering the stigma that still affects any mental health conditions and its sufferers, it is important that websites make great efforts to gain the full confidence of health consumers. For this to happen there needs to be several things to happen:

- That health websites gain accreditation with organisations such as the Health On the Net Initiative.
- That health websites carry out regular self and third party evaluation and testing to ensure that they meet with certain standards of quality and usability.
- That the correct system of referencing sources of information is carried out, including the naming of authors and their credentials.
- That any commercial bias or sponsorship be clearly labelled on the website.

Gilliam et al (2003:44) makes the important conclusion that; “Assessing quality Internet health information is very time consuming. Recommended websites that provide the best information would help patients avoid being overwhelmed with irrelevant and confusing literature.”

6.4 Guidelines for Health Consumers

For the growing number of health consumers to navigate the Internet safely there needs to be a greater awareness of the pitfalls they may encounter in their search for information. This concern was highlighted by Blackwelder et al (2003) that many users had no knowledge on how to assess the quality of information. Not only is it the duty of websites to achieve a high quality of standards and ethics, but it is important that health consumers learn evaluation and appraisal skills to aid them sort the wheat from the chaff. As found in this study there is a high level of perceived credibility that affects which websites are the most popular. This ties up with Hong's (2006) theory that perceived credibility of a website increases the possibility of multiple visits from health consumers.

The guidelines below act as a checklist to aid health consumers assess the quality of online health information.

- Ensure that the information is up to date and relevant to your condition.
- Cross reference information on one website with another where possible.
- Do not be afraid to contact the website, if there are no obvious contact details you are using the wrong website.
- Ensure that the information has an author, or at least has medical experts writing for the website.
- Do not be afraid to question the author's credentials, people are not always who they say they are.
- Ensure that the website is not just a selling tool for a medical product.
- Try to post messages on the website's forum, if it has one. The more active the forum is the better chance it is a respected and quality information source.
- Try to find out more about the website or organisation you are obtaining information from their 'about us' webpage.

As with Eysenbach & Kohler's (2002) findings it is important that users learn the importance of the 'about us' part of any website.

6.5 Strengths, Weaknesses and Limitations of this Study

The results highlighted several areas where this study was successful in gaining a snapshot of current practices as well as assessing the state of the some health websites which are the conduit between health expert and health consumer. Despite this, there are also areas where this study fell short and on occasion failed.

6.6 Strengths of the Study

Unlike many previous studies, where the quality of online health information had been assessed by the use of a Web evaluation tool; or ones which had looked at the beliefs, practices and cultures of health consumers, this study looked at them all.

The purpose of this research was that all three aspects, the users, the provider and the medium, would be covered. Due to the sensitive nature of health information this wide approach was even more important. Depending on the condition, there is a high degree of emotiveness in health content and this is especially the case with retards to online information. The study successfully employed the beliefs and opinions of the specific target group, being those who use anxiety-related websites. It is important to stress this factor, that everyone in the target group are sufferers of the conditions and in turn used websites from the 25 that this study evaluated.

6.6.1 Strengths of the Web Evaluation

For the most part the Web evaluation did work, which was achieved through a series of validity tests, to ensure that it scored fairly and accurately. Websites that were widely regarded as being good resources did fare well in the test, while other lesser known websites received lower scores. It is interesting to note that websites that were ranked highly in the searches did achieve higher scores than the lower

ranked websites. This study does look at the key players in not only anxiety-related conditions, but health information as a whole. The sample group is as comprehensive as it could be at this particular time.

6.6.2 Strengths of the User Questionnaires

As covered later on as a weakness of this study, it is important to note that that the careful selection of websites used in the user questionnaire was for the most part successful. The websites that were provided as choices were highly selected, which was more a result of careful selection than cause and effect. The questionnaires gained some important information on the nature of health information retrieval as well as its creation.

6.7 Weaknesses of the Study

A large problem this study faced from the offset was that no previous study of this nature existed. The lack of a yardstick meant that there was a degree of trial and error in the creation of a Web evaluation and user questionnaire. Throughout this test period, several issues were identified and rectified, whilst others became apparent at the results stage.

6.7.1 Weaknesses of the Web Evaluation

Future studies of this kind will need to carefully reassess how they evaluate websites with the aid of evaluation tools, such as the one created for this study. For the most part, the Web evaluation did achieve much of what it set out to do; nevertheless, following extensive use on the 25 sampled websites, it is apparent that this tool requires a level of adjustment. Certain criteria need adjusting to take into account its importance in the overall evaluation process. It is arguable that certain aspects of a website's functionality are more important than others. For instance, the

quality of information is far more important than the layout of a website of whether its links work. The evaluation carried an equal rating scale for all 25 questions, and perhaps this scale should be widened to allow a higher score of four for some aspects, such as information quality, and a lower possible score for links.

6.7.2 Weaknesses of the User Questionnaire

As for the user questionnaire, there are areas where this study could have worked better. This was the limited number of options some of the questions had, which in turn led to some users identifying 'other' as an choice. This was particularly the case with regards to participant's experiences of websites, as they were only given a limited selection to choose from. Future studies would be well advised to extend the list of websites up to a wider selection.

Another are that this study could have been improved was the use of open-ended questions for both questionnaires. The majority of the questions were multiple choices and, which is not necessarily a bad thing, but the use of open-ended questions would have provided supplementary evidence of user's experiences and website practices.

Considering that this study focused on a health-related subject, it would have been preferable to conduct the user and editor surveys with patients and staff of the NHS. Due to the lengthy and complicated ethical approval process and the time limits associated with this study, this was not possible. Future studies would benefit from the involvement of these two groups.

6.8 Limitations of the Study

The major limitation of this study was that it was carried out by a single person over a limited time period. Also as mentioned in the previous section, the exclusion of NHS staff and patients limited the scope of this study, especially as many sufferers go through the NHS as part of their treatment.

6.8.1 Limitations of the Web Evaluation

As expressed earlier, the major limitation of this study was that it was carried out by a single person. Despite a high level of objectivity employed throughout the study it is fair to argue that preconceptions can potentially influence and in turn affect the scoring process. Websites that are familiar to the scorer may score better than those which are less known or popular. The way to limit this influence is to increase the validation of the scores by widening the evaluation out to a larger group. Nevertheless, regardless of the number of participants scoring the websites the potential for bias and influence will always be an issue, even if just a small one. A second limitation concerning the Web evaluation was that it only looked at key Web pages, which were those that contained information on the featured conditions. This part of the study therefore requires a more in depth evaluation that digs deeper in to each website and in turn evaluates multiple pages.

6.8.2 Limitations of the User Questionnaire

Despite the good number of participants for the user questionnaire, a study of this nature would benefit from a higher number of respondents. This could be achieved by greater liaison with the participating websites which could lead to wider advertisement of the study and in turn produce more data from completed

questionnaires. It is also worth noting that some of the websites that were approached to help with this study did not wish to, despite carrying out health research of their own. There is also ethical considerations to take into account regarding a study of this nature, in that, some websites would only allow posts on their forums from sufferers of the conditions, this request was respected.

Chapter 7: Conclusion

This study found that there is no shortage of information on the Web for sufferers of mental illness, especially those suffering from anxiety-related conditions. Each condition that is covered in this study has at least one website that covers that specific illness. The quality of these websites does vary as a whole, but the most popular websites as identified in the user questionnaire are also of the best quality according to the Web evaluation.

The overall ability of health consumers and their experiences with information retrieval were on the whole positive. For the most part, health consumers, as with the natural pattern of Internet users as a whole, have a good grasp of the Internet. Certain areas of worry still remain, with a minority of health consumers unwilling to validate information they access in addition to using familiar modes of practice which may be outdated. The most important outcome from the user survey was that a large number of participants are dissatisfied or partially satisfied with regards to the information they retrieve. It is important to note the relevance of this considering the delicate nature of the subject matter.

The research did achieve all of its original objectives and goals with the aid of a new Web evaluation tool and through the utilisation of the user questionnaires. Nevertheless the processes of online health information creation and retrieval do require further in depth investigation.

This study shows that there is still extensive scope for further research, not only with regards to the conditions that this research focuses on but health

information as a whole. Websites that provide health information can only benefit from such research and as such should be encouraged to participate with any future studies. The positive outcomes of such research can only be passed onto the health consumer, who should be the focus of interest for both parties concerned. Future studies would benefit greatly from a wider validity testing of the tools employed in this study and in turn the creation of future more complex and adaptable tools should not be ruled out. This in turn should lead to an eventual scenario where all active health information websites undergo either third-party or self testing and in turn receive a quality kite mark. This can only aid health consumers retrieve the best possible information with the least possible fuss and effort.

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Appendix A

The news page item from the Social Anxiety UK website highlighting this study.

(Please note that the National Phobic Society and No Panic websites had removed the news item relating to this research by the time this work was written)



Appendix B

Email and forum post sent to anxiety-related and panic disorder websites in addition to the website authors and editors.

Hi,

My name is Andrew Tattersall and currently I work for The University of Sheffield as an Information Officer at the School of Health and Related Research (ScHARR).

I am currently undertaking my MSc in Information Management and in the process of writing my dissertation which is on the subject of anxiety-related illnesses and the use of information on websites by information seekers relating to the condition of anxiety and other related illnesses.

I wondered if you could take a few minutes to answer my online questionnaire, all information you supply will be treated in strict confidence and will remain anonymous as no personal details will be taken.

Your assistance will hopefully go a long way to help me completing a competent and useful piece of research on this condition.

If you have any questions regarding my research, I would be very happy to answer them.

The questionnaire is very short and should take no longer than a couple of minutes. To access the questionnaire, please go to:

<http://eurovision.shef.ac.uk/~cloughie/students/andy/expert-introduction.html>

Any questions, please email me at: a.tattersall@shef.ac.uk

Appendix C

Participation sheet for Web Editors and Information Professionals

Model Information Sheet (For web editors and information professionals)

1. **Research Project Title:**

Guidelines for Good Practice for Websites Providing Information on Anxiety Disorders. Incorporating an Evaluation of User's Needs and Current Health Information Websites.

2. **Invitation**

'You are being invited to take part in a research project. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.'

3. **What is the project's purpose?**

The purpose of the project is to assess the quality of online health websites, with the focus on information on anxiety disorders; these include general anxiety disorder (GAD), panic disorder, and social anxiety disorder (SAD). The aim is to assess and evaluate current decision making practices from the aspect of the information provider and information searcher.

4. **Why have I been chosen?**

You have been chosen because I am interested in the editorial processes that go into the decisions making that affects the content of health information on your website.

5. **Do I have to take part?**

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep (and be asked to sign an online consent form) and you can still withdraw at any time without it affecting any benefits that you are entitled to in any way. You do not have to give a reason."

6. **What will happen to me if I take part?**

You will be interviewed either via a short telephone call or by letter or email, whichever is the most suitable for you. This should not take more than five minutes of your time. The answers you give are expected to be totally honest.

7. **What do I have to do?**

You do not need to do anything except answer the questions honestly.

8. **What are the possible disadvantages and risks of taking part?**

There are no risks or disadvantages involved in taking part in this study.

9. **What are the possible benefits of taking part?**

‘Whilst there are no immediate benefits for those people participating in the project, it is hoped that this work will provide better information for people searching for information on anxiety disorders.

10. **Will my taking part in this project be kept confidential?**

‘No personal data including name and address will be needed. You will not be able to be identified in any reports or publications, only the name of the organisation you work for will be identified’.

11. **What will happen to the results of the research project?**

The research project is to be submitted as part of my MSc Information Management Degree. The dissertation will be completed by September 2006 and a copy of it will be held by the Information Management department in addition to a copy possibly being held in University of Sheffield Main Library.

12. **Who is organising and funding the research?**

The research is co-funded by myself and my employer the University of Sheffield.

13. **Who has ethically reviewed the project?**

This project has been ethically approved via the Department of Information Management ethics review procedure.

14. **Contact for further information**

You can contact Andy Tattersall on 01142 220702 or by email at a.tattersall@shef.ac.uk for further information.

Or I can be contacted by post at:

Andy Tattersall
Information Officer
Information Resources
ScHARR
Regent Court
30 Regent Street
Sheffield
South Yorkshire
S1 4DA

Please note, that you may download this information sheet for your own records.

Many thanks for your participation in this research.

Appendix D

Participation sheet for health information seekers

Model Information Sheet (For health information seekers)

1. **Research Project Title:**

Guidelines for Good Practice for Websites Providing Information on Anxiety Disorders. Incorporating an Evaluation of User's Needs and Current Health Information Websites.

2. **Invitation**

'You are being invited to take part in a research project. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.'

3. **What is the project's purpose?**

The purpose of the project is to assess the quality of online health websites, with the focus on information on anxiety disorders; these include general anxiety disorder (GAD), panic disorder, and social anxiety disorder (SAD). The aim is to assess and evaluate current decision making practices from the aspect of the information provider and information searcher.

4. **Why have I been chosen?**

You have been chosen as a random participant to give the study a widespread and diverse sample group.

5. **Do I have to take part?**

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep (and be asked to sign an online consent form) and you can still withdraw at any time without it affecting any benefits that you are entitled to in any way. You do not have to give a reason."

6. **What will happen to me if I take part?**

You will be asked to fill in an anonymous online questionnaire. This should not take more than five minutes to complete. You will only need to fill in the questionnaire just once. The answers you give are expected to be totally honest. The method of questionnaire will be based totally online and will feature a number of multiple choice questions.

7. **What do I have to do?**

You do not need to do anything except fill the questionnaire in honestly. Passing the link to the questionnaire onto other potential participants would be greatly appreciated to aid the comprehensiveness of the study.

8. What are the possible disadvantages and risks of taking part?

There are no risks or disadvantages involved in taking part in this study.

9. What are the possible benefits of taking part?

‘Whilst there are no immediate benefits for those people participating in the project, it is hoped that this work will provide better information for people searching for information on anxiety disorders.

10. Will my taking part in this project be kept confidential?

‘All the information that we collect about you during the course of the research will be kept strictly confidential, no personal data including name and address will be needed. You will not be able to be identified in any reports or publications’.

11. What will happen to the results of the research project?

The research project is to be submitted as part of my MSc Information Management Degree. The dissertation will be completed by September 2006 and a copy of it will be held by the Information Management department in addition to a copy possibly being held in University of Sheffield Main Library.

12. Who is organising and funding the research?

The research is co-funded by myself and my employer the University of Sheffield.

13. Who has ethically reviewed the project?

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14. Contact for further information

You can contact Andy Tattersall on 01142 220702 or by email at a.tattersall@shef.ac.uk for further information.

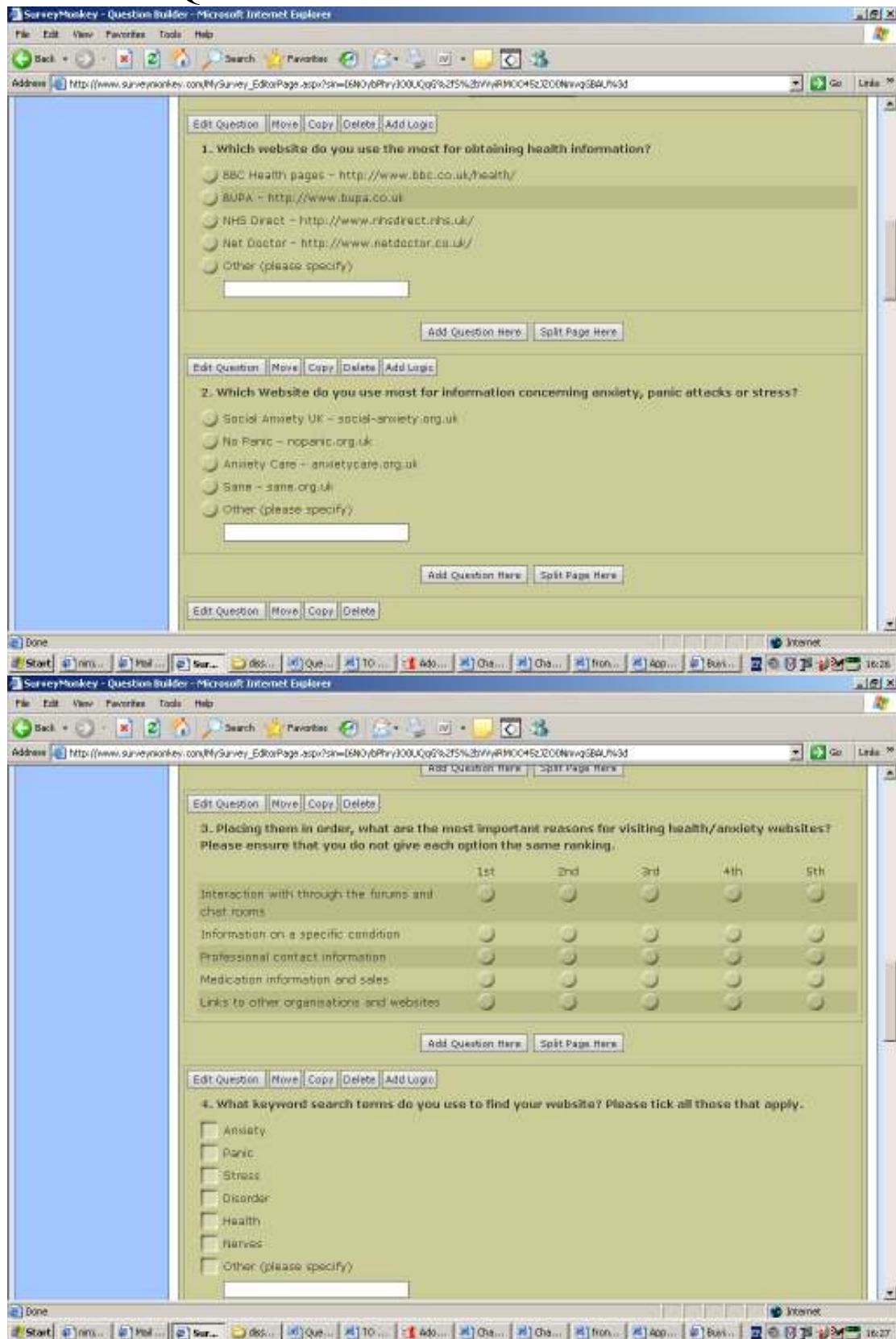
Or I can be contacted by post at:

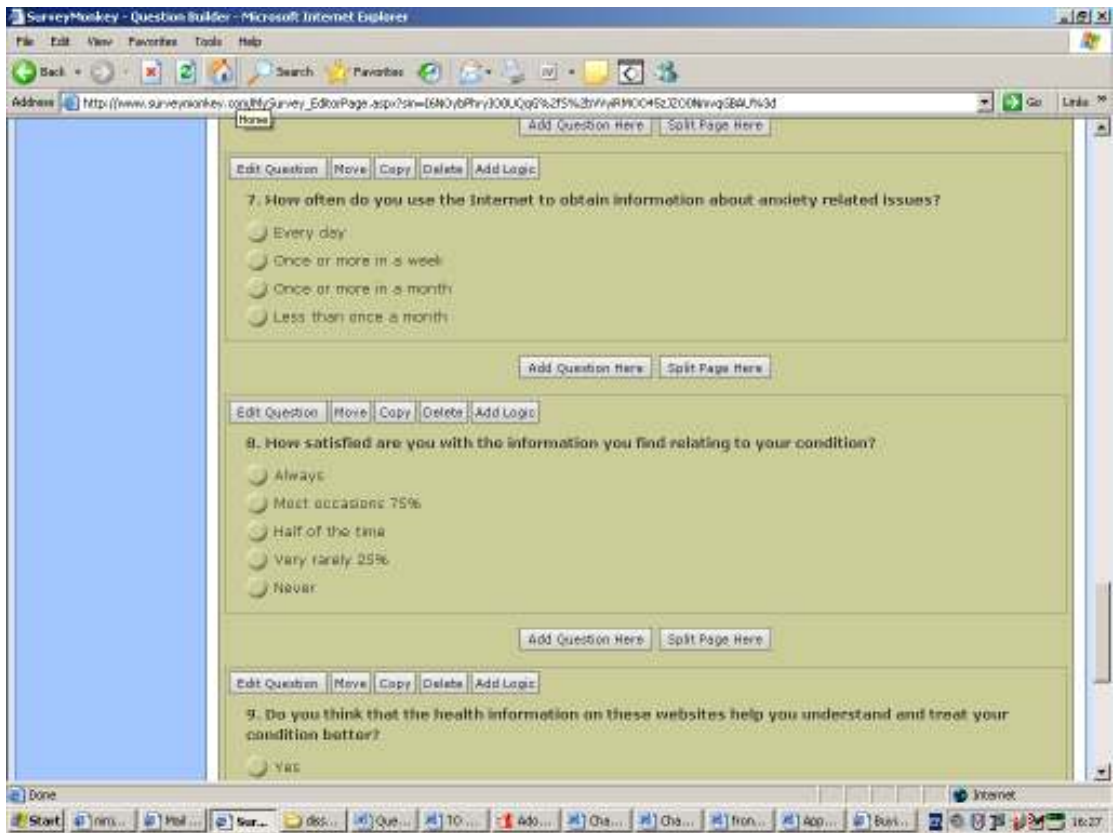
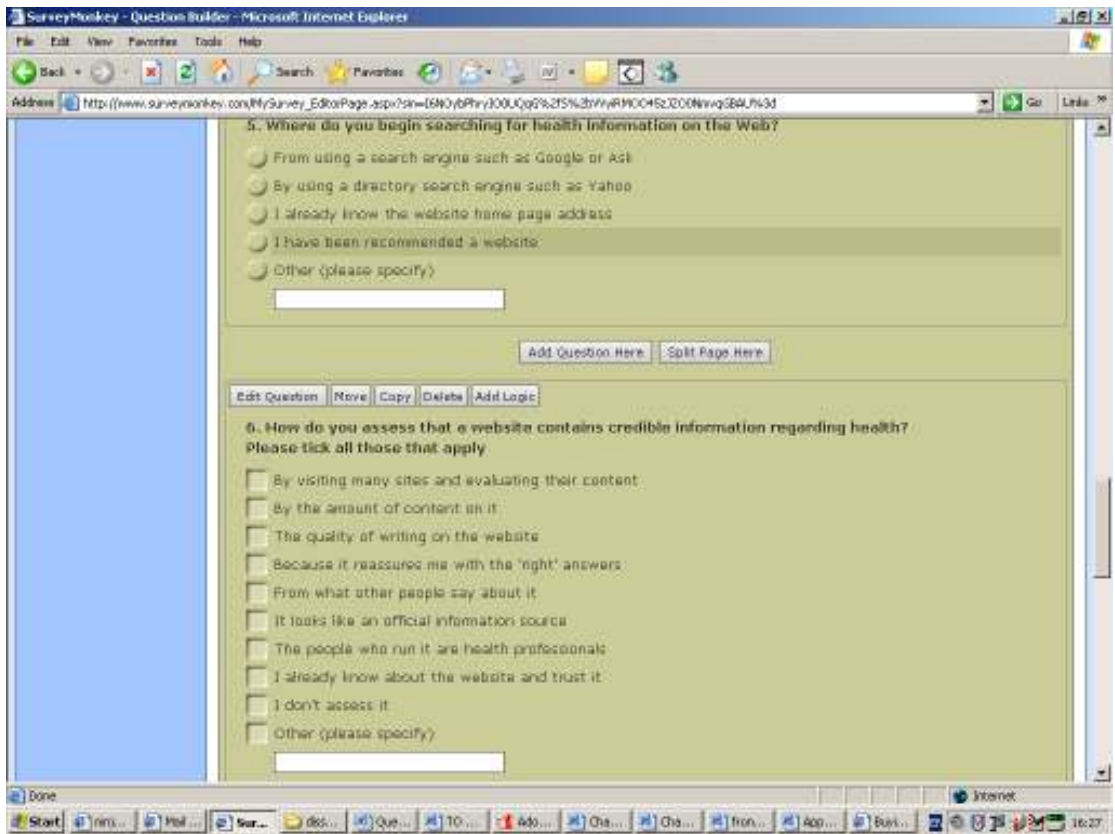
Andy Tattersall
Information Officer
Information Resources
ScHARR
Regent Court
30 Regent Street
Sheffield
South Yorkshire
S1 4DA

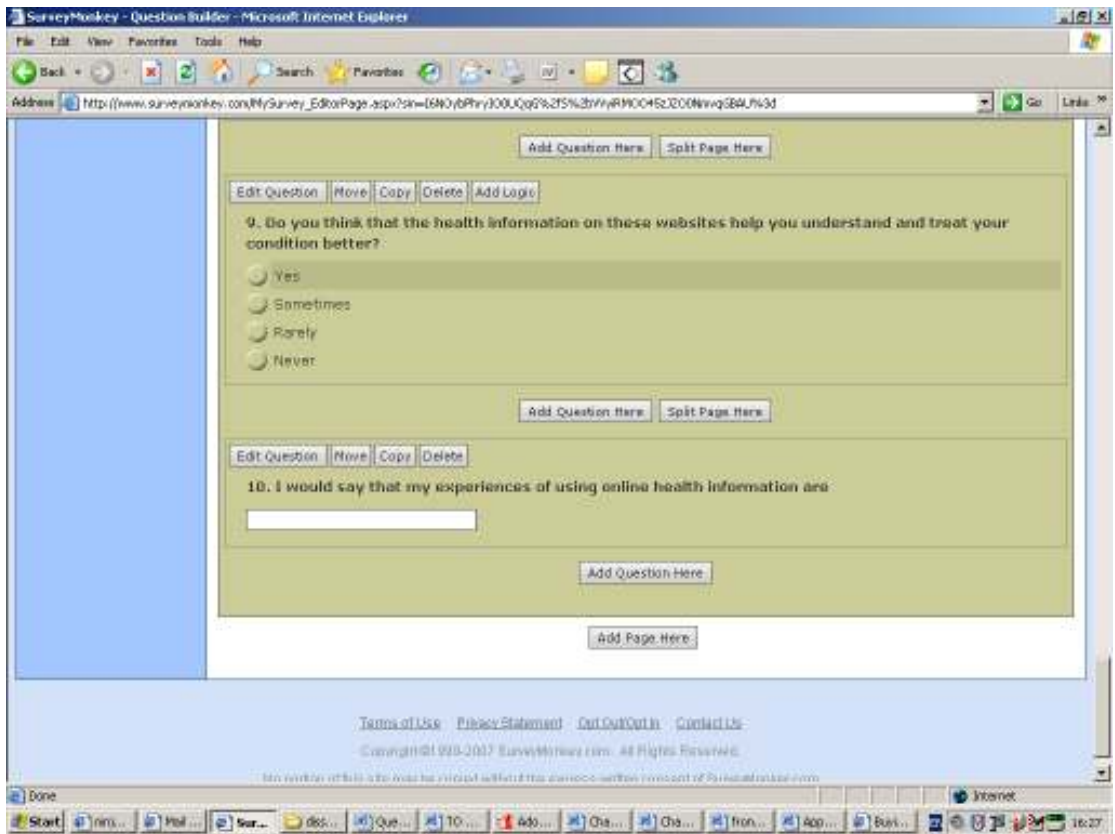
Please note, that you may download this information sheet for your own records.
Many thanks for your participation in this research.

Appendix E

Web User Questionnaire







Appendix F

Web Editors/Authors Questionnaire

Questions for Web Editors/Authors - Microsoft Internet Explorer

Address <http://www.surveymonkey.com/s.asp?sn=Q30FALYR00xJ3CQY%2FhwdfH4G%2BvW0PZITAgB4%3d>

Please email me at: a.tattersall@shef.ac.uk

1. What is your role for the website?

Editor
 Journalist
 Web editor
 Information officer
 Other (please specify)

2. Placing them in order, what are the principle functions of your website? Please ensure that you do not give each option the same ranking.

	1st	2nd	3rd	4th
To provide information on a particular condition	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
To sell a product	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
To encourage interaction between us and the users	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
To highlight a particular illness or condition	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

3. What would you estimate is the most visited part of your website?

News
 Forum
 Contact details
 Information (on a condition or illness)
 Other (please specify)

3. What would you estimate is the most visited part of your website?

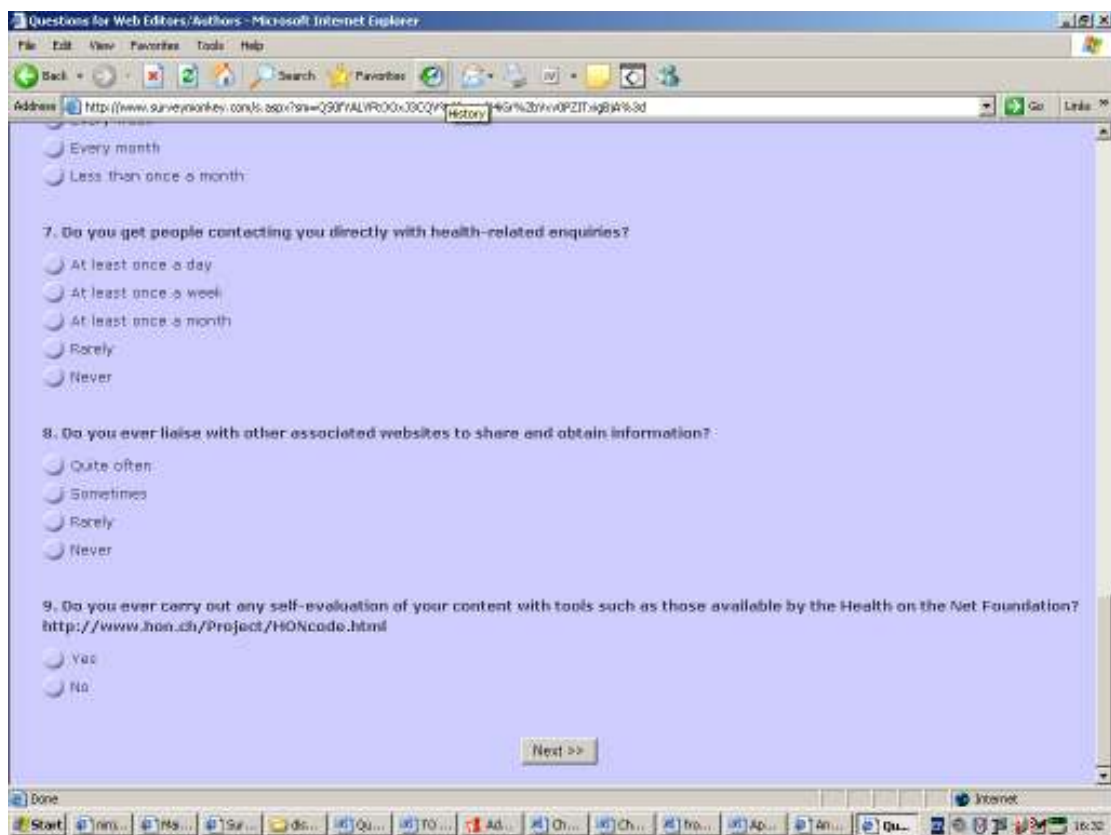
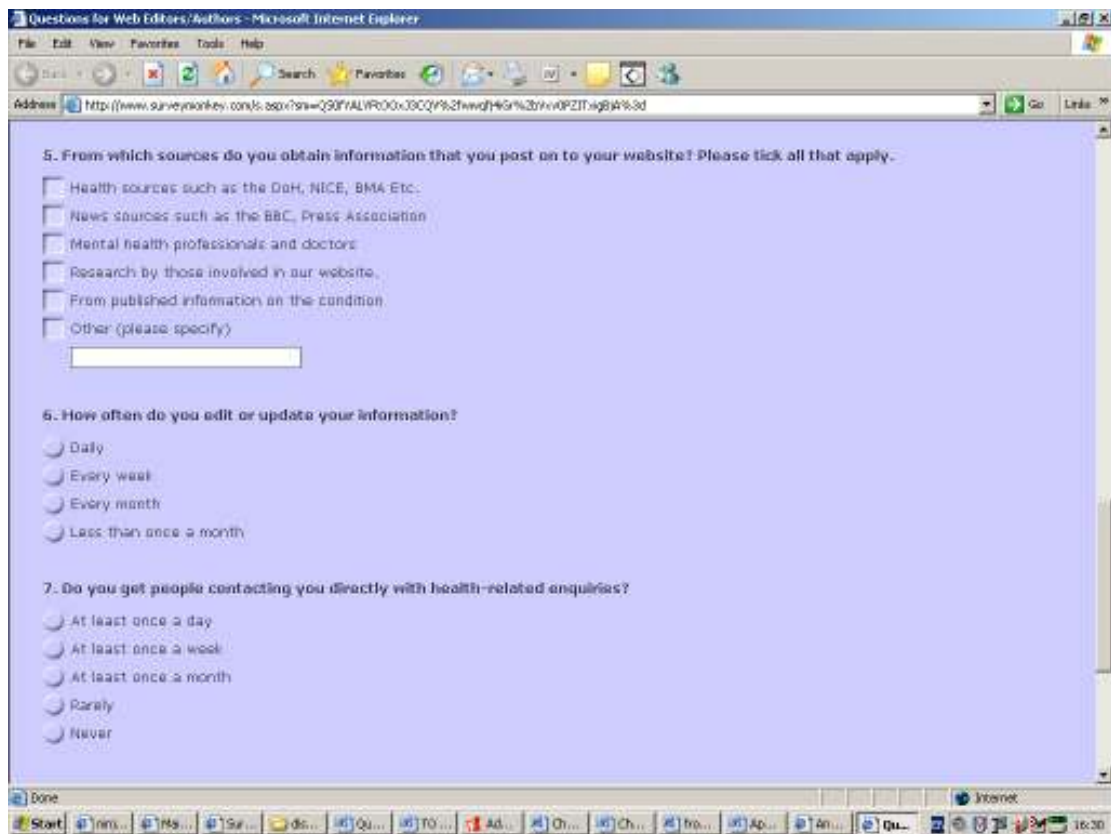
News
 Forum
 Contact details
 Information (on a condition or illness)
 Other (please specify)

4. Where do you obtain your health information? Please tick all that apply.

News wire
 Other website
 Medical publications
 Own knowledge
 From medical professionals
 Other (please specify)

5. From which sources do you obtain information that you post on to your website? Please tick all that apply.

Health sources such as the DoH, NICE, BMA Etc.
 News sources such as the BBC, Press Association
 Mental health professionals and doctors
 Research by those involved in our website.



Appendix G

Full list of user's experiences of searching for health information on the Internet (user questionnaire – question 10.)

Good experiences (65 Responses)

Very Good

Excellent

Good

Positive, although researching conditions online when you suffer from health anxiety is actually counterproductive!

Positive

Good.

Helpful & Understanding

Usually good

Good

Informative

Helpful

Good

It has helped me to understand why I suffer from anxiety

Excellent, as long as you savvy enough to know when a website is dodgy or not, and as long as you don't let it become a source of panic (e.g. self diagnosing yourself with the worse health scenario)

Very positive and helpful

Very good. I was able to approach my GP as a direct result of what I read on the websites.

Pretty good; it's helpful to see other people going through the same problem as me.

Good

Meeting others with same condition

Usually positive, though I stick to one or two trusted sources, e.g. bbc/nhsdirect

Fairly positive

Helpful

Good but no substitute for speaking to a real doctor or psychiatrist or therapist

Helpful

Good

Overall positive

Great. But ONLY through NoMorePanic (not to be confused with NoPanic). The support is amazing. As a sufferer, a Doctor or other health professional CANNOT offer this level of understanding.

Useful and have helped me progress with treatment

Very positive

On the whole very positive

Quite useful sometimes as an extra resource

Reassuring

Nopanic saved my life

Helping my anxiety

Have been extremely beneficial in managing my panic disorder

Very useful and full of information that I wouldn't probably be able to get hold of anywhere else without visiting GP

Usually very good.

Useful

Helpful
Helpful
Very good and informative
Reassuring
Good
Fairly good
Invaluable when it comes to SA
Very beneficial, providing varied and personal view points and information to act upon, can be used in an "emergency" when needing instant reminders that it's a panic attack and not imminent death
Very good and beneficial
Better than offline!
Good for a quick rough guide
Very positive and informative
Useful
Beneficial
Mostly beneficial
Helpful
Very helpful
Fairly Good
Positive. It lets you know that there are other people feeling the same way as you. more advantageous than seeing your GP as they do not have the time and knowledge in mental health issues
Good and informative
Good
Good
Reassuring
Very good

Mediocre Experiences (20 Responses)

OK its hard to find things to help, lots are full of useless information.
Reasonable, anxiety probably affects different people to different degrees and that's why finding information that relates to me is sometimes hard.
Helpful Sometimes
I have only found one good site so far
Helpful some of the time
Okay
More out of desire to learn more about my condition than to get help.
Partially satisfactory
Satisfactory
Useful but I need professional help to recover
Average and vague
Sometimes helpful
Adequate
Limited
Satisfactory
OK
Hit and miss
So so
Mixed

It provides reassurance for a brief time but anxiety for a much longer period

Poor Experiences (12 Responses)

Disappointing and too impersonal

Poor - can actually make my health anxiety worse!!

Not helpful compared to a doctor but they can be reassuring, provide a sense of perspective on your condition, alleviate a sense of isolation as a sufferer of a condition, and help seek further treatment

Poor

Lots of repetition and superficial

Pointless

Unsatisfactory

Confused

Difficult

For general use prior to seeing a GP

At the moment not very good as anxiety has many other things attached to it and most sites are only covering the basics which leaves people like me feeling let down

Sometimes make me a hypochondriac

Appendix H – Web Evaluation Tool

Website Evaluation Check Sheet					
Website name.....					
No.	Question	Yes (rating scale 1 to 4)	No (rating scale -1 - 4)	Not known	Score
1	Is the author identified in the article				
2	When the author refers to another source, are appropriate references provided				
3	If the author is not referring to a source, does he/she clearly state that it is only his/her opinion?				
4	Are the site author's credentials listed?				
5	Does the site author's credentials relate to the knowledge of the field that is required for the site's subject discussions?				
6	Are the author's experiences relevant to the topic?				
7	Is a means provided to contact the author directly				
8	Can you determine who has paid for or sponsored this website?				
9	Is there any financial conflict or bias? YES -4 NO 4				
10	Does the site state that contributors or sponsors have no control over content?				
11	Is there a means to determine how current the information in the website is, for example - date of last update or posted date?				

12	Is the information current? (Updated in the last 6 months)	1	2	3	4	-1 -4	-2	-3		
13	Is the information still relevant? (for example a new treatment posted two years ago may no longer be the most appropriate treatment today)	1	2	3	4	-1 -4	-2	-3		
14	From your own knowledge and experience, does this site give quality medical information?	1	2	3	4	-1 -4	-2	-3		
15	Is the medical information presented in a balanced and neutral form?	1	2	3	4	-1 -4	-2	-3		
16	Are the linked sites current?	1	2	3	4	-1 -4	-2	-3		
17	Do the linked sites give good medical information?	1	2	3	4	-1 -4	-2	-3		
18	If you are allowed to input information or submit queries, is a statement provided that explains whether or not this information is confidential and secure?									
19	Is the site easily navigable and presented in an organised manner?	1	2	3	4	-1 -4	-2	-3		
20	Is a search engine provided?									
21	Does the search engine assist you in using the site?									
22	The information is consistent with that of other similar websites.	1	2	3	4	-1 -4	-2	-3		
23	The website provides interactivity that increases its value									
24	The information is easy to understand	1	2	3	4	-1 -4	-2	-3		
25	The purpose of the site is clear, i.e., business or commercial, news, personal page	1	2	3	4	-1 -4	-2	-3		
Total										

Appendix I – Web Evaluation Tools and Guides

Health On the Net Code <http://www.hon.ch/HONcode/Conduct.html> [Last Accessed 10 August 2007]

Mitretek IQ Tool <http://hitiweb.mitretek.org/iq/iqmain.asp> [Last Accessed 10 August 2007]

New Mexico State University Library
<http://www-personal.umich.edu/~pfa/pro/courses/WebEvalNew.pdf>. [Last Accessed 10 August 2007]

UC Berkeley Library
<http://www.lib.berkeley.edu/TeachingLib/Guides/Internet/Evaluate.html> [Last Accessed 10 August 2007]

Appendix J – Complete List of 25 Sampled Websites

BBC Health Pages	http://www.bbc.co.uk/health/
BUPA	http://www.bupa.co.uk/
Net Doctor	http://www.netdoctor.co.uk/
NHS Choices	http://www.nhs.uk/Pages/homepage.aspx
Patient	http://www.patient.co.uk/
Surgery Door	http://www.surgerydoor.co.uk/
Royal Collage of Psychiatrists	http://www.rcpsych.ac.uk/
Mental Health Foundation	http://www.mentalhealth.org.uk/
The Centre for Anxiety Disorders and Trauma	http://psychology.iop.kcl.ac.uk/cadat/
Social Anxiety UK	http://www.social-anxiety.org.uk/
No Panic	http://www.nopanic.org.uk/
Anxiety Care	http://www.anxietycare.org.uk/
Help For	http://www.help-for.com/
Anxiety 2 Calm	http://www.anxiety2calm.com/
The Linden Method	http://www.thelindenmethod.co.uk/
No More Panic	http://www.nomorepanic.co.uk/
End Social Anxiety	http://end-social-anxiety.50webs.com/
Sane	http://www.sane.org.uk/public_html/index.shtml
Panic Attacks	http://www.panic-attacks.co.uk/
Stress	http://www.stress.org.uk/
Phobic Society	http://www.phobics-society.org.uk/
Destigmatize	http://www.destigmatize.org.uk/
Social Fear	http://www.socialfear.com/
Stress Watch Scotland	http://www.stresswatchscotland.org/
Stressbusting	http://www.stressbusting.co.uk/

Appendix H – Matrix Table of Web Evaluation Scores

Authorship Criteria	Q1	Q2	Q3	Q4	Q5	Q6	Q7
Stress Busting							
Stress Watch Scotland							
Social Fear							
Destigmatize - org.uk							
National Phobics Society							
NHS Choices							
Stress.org							
Surgery Door							
Panic Attacks.co.uk							
SANE							
End Social Anxiety							
No More Panic							
The Linden Method							
Help For							
Anxiety Care							
No Panic							
Social Anxiety UK							
Centre for Anxiety Disorders & Trauma							
Net Doctor							
Mental Health Foundation							
Patient UK							
Anxiety 2 Calm							
Royal College of Psychiatrists							
Bupa							
BBC Health							

Satisfies Criteria
Criteria














































































Not Known



Does not satisfy



	Q8	Q9	Q10
Bias and Sponsorship			
Stress Busting			
Stress Watch Scotland			
Social Fear			
Destigmatize - org.uk			
National Phobics Society			
NHS Choices			
Stress.org			
Surgery Door			
Panic Attacks.co.uk			
SANE			
End Social Anxiety			
No More Panic			
The Linden Method			
Help For			
Anxiety Care			
No Panic			
Social Anxiety UK			
Centre for Anxiety Disorders & Trauma			
Net Doctor			
Mental Health Foundation			
Patient UK			
Anxiety 2 Calm			
Royal College of Psychiatrists			
Bupa			
BBC Health			

Satisfies Criteria



Not Known



Does not satisfy Criteria



Information Quality	Q11	Q12	Q13	Q14	Q15	Q16	Q17	Q22
Stress Busting								
Stress Watch Scotland								
Social Fear								
Destigmatize - org.uk								
National Phobics Society								
NHS Choices								
Stress.org								
Surgery Door								
Panic Attacks.co.uk								
SANE								
End Social Anxiety								
No More Panic								
The Linden Method								
Help For								
Anxiety Care								
No Panic								
Social Anxiety UK								
Centre for Anxiety Disorders & Trauma								
Net Doctor								
Mental Health Foundation								
Patient UK								
Anxiety 2 calm								
Royal College of Psychiatrists								
Bupa								
BBC Health								

Satisfies Criteria
Criteria



Not Known



Does not satisfy



Interactivity and Usability	Q18	Q19	Q20	Q21	Q23	Q24	Q25
Stress Busting							
Stress Watch Scotland							
Social Fear							
Destigmatize - org.uk							
National Phobics Society							
NHS Choices							
Stress.org							
Surgery Door							
Panic Attacks.co.uk							
SANE							
End Social Anxiety							
No More Panic							
The Linden Method							
Help For							
Anxiety Care							
No Panic							
Social Anxiety UK							
Centre for Anxiety Disorders & Trauma							
Net Doctor							
Mental Health Foundation							
Patient UK							
Anxiety 2 calm							
Royal College of Psychiatrists							
Bupa							
BBC Health							

Satisfies Criteria
Criteria



Not Known



Does not satisfy

