

**Assignment Cover Sheet**

**MSc in Cyberpsychology**

Student Number: \_\_\_\_N00094915\_\_\_\_

Assignment:

■ Research Project Dissertation – soft bound copy –

Word count main document 14,979

Date Submitted: \_\_\_\_16<sup>th</sup> April 2011\_\_\_\_

**Title**

**Prognoses for Diagnoses: Medical Search Online and “Cyberchondria by Proxy”**

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Dissertation submitted as a requirement for the degree of MSc in Cyberpsychology,  
Dunlaoghaire Institute of Art, Design and Technology, 2011.

## **Declaration**

This Dissertation is entirely my own work, and has not been previously submitted to this or any other third level institution

Signed: *Mary Aiken*

Date: 16/04/2011

### **Acknowledgements**

*Two years of MSc study is a demanding, albeit very enjoyable process. I would like to thank my supervisor Dr. Gráinne Kirwan, all of the department staff, and my fellow students at IADT for helping me in the pursuit of a Master of Science in Cyberpsychology. Additionally I would like to thank my very patient family; Peter, Laura, Kevin and my study companion James, for their support and encouragement. Finally I would like to thank my sister Cathy, for encouraging me to return to academia.*

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## **Abstract**

### **Prognoses for Diagnoses: Medical Search Online and “Cyberchondria by Proxy”**

The Internet is a source of valuable medical information, however the Web has the potential to increase anxiety when employed as a diagnostic procedure. This study seeks to identify motivation behind health related search online. A new distinct cohort has emerged, those who experience anxiety when conducting health related search for others; “cyberchondria by proxy” (CbP). The mixed design research methodology consists of focus groups (N=20) and case histories (N=2). Results indicate that health-related search behaviour is impacted by technology, gains are evident, additionally there is a significant positive correlation between those who search for self, and for others, that is cyberchondria, and CbP. This finding is relevant for healthcare professionals, particularly regarding patient care and management.

## Introduction

“Hungry Joe collected lists of fatal diseases and arranged them in alphabetical order so that he could put his finger without delay on any one he wanted to worry about” (Heller, 1961, p.182)

Joseph Heller’s satirical novel *Catch 22* predated the advent of the World Wide Web by almost two decades. However the sentiments as expressed; fingertip search, categorised lists and predisposition to worry resonate, particularly when considered in the context of medical search online and anxiety. The Internet appears to offer some valuable medical information, intuitive diagnostic Websites such as Webmd.com, or Diagnose-me.com can provide answers with regard to concerning symptoms, however *caveat quaeror* (let the “searcher beware”), “the Web has the potential to increase anxieties of people who have little or no medical training, especially when web search is employed as a diagnostic procedure” (White & Horvitz, 2009, p. 23:1).

Anxiety induced as a result of health related search online is an increasingly differentiated activity (Fox et al., 2000; Feldman, 2000; Lewis, 2006; Belling, 2006; Ravdin, 2008; White & Horvitz, 2009) and known in the field of *Cyberpsychology* as *Cyberchondria*. The relationship between those who search health related material for self online, and those who search for others (Fox et al., 2000; Lewis, 2006; White & Horvitz, 2009) will be examined, additionally underlying motives for health related search online will be considered, results analysed and discussed. There is a relationship between the somatoform disorder Munchausens, and Munchausens Syndrome by Proxy (MSbP) (Day & Moseley, 2010), gratification resulting from medical attention obtained “by proxy” (Day & Moseley, 2010; Criddle, 2010). Is there however, a relationship between anxiety resulting from search for self (cyberchondria), and anxiety resulting from search for others, or by proxy?

Knowledge, empowerment (Bastian, 2003), support, reassurance (Sillence & Briggs, 2007) and altruism (Adar & Huberman, 2000) may all be considered positive

aspects regarding health related search online, however the literature (Belling, 2006; Lewis, 2006; Ravdin, 2008; White & Horvitz, 2009 ) indicates that anxiety is likely to be a consequence of same, a loss as opposed to a gain. There is a relationship between health anxiety and hypochondria (Asmundson, Taylor & Cox, 2001; Salkovskis, Rimes, Warick & Clark, 2002). Health related search online can lead to escalation and anxiety (White & Horvitz , 2009), arguably there may be a relationship between anxiety, hypochondria and cyberchondria? this association will be explored in this study,

The role of media in health related search online (Bonner, 2003; Belling 2006) will be investigated, somatoform disorders (Asmundson et al., 2001; Day & Moseley, 2010; Criddle, 2010), the doctor-patient relationship ( Belling, 2006; Lewis, 2006), technology that determines search (White & Horvitz, 2009), self diagnosis online (Belling, 2006; Lewis, 2006; Ravdin, 2006; White & Horvitz, 2009), self revelation (Joinson, 2001) and disinhibition online (Suler, 2004), will all be considered in the context of this study.

Arguably open access to complex medical information may compromise the conventional gatekeepers of knowledge and diagnostic expertise, however can “Dr. Google” undertake to abide by the long established hippocratic oath? “Primum non nocere,” first do no harm.

### *Health Anxiety*

Asmundson et al. (2001) describe *Health Anxiety* as “fears and beliefs, based on interpretations, or perhaps more often, misinterpretations, of bodily signs and symptoms as being indicative of a serious illness” (p. 4), this description is supported by Warwick and Salkovskis (1990). Health anxiety frequently occurs transiently in normal populations (Kellner, 1987), however in a number of cases anxiety can interfere with relationships, employment and leisure pursuits (Asmundson et al., 2001). The highest scores on self-report measures of state anxiety, have been recorded from people awaiting the results of medical tests or diagnoses (Asmundson et al., 2001), an important consideration in the context of the pursuit of health information or *self diagnostics* online.

Many severe cases of health anxiety meet DSM-IV-TR and ICD-10 diagnostic criteria for *Hypochondriasis*, this condition has a prevalence of between four and nine percent in general medical practice, characterised by multiple and stubbornly held complaints of physical illness although typically no evidence of such illness can be found (Carson, Mineka & Butcher, 2000). “Hypochondriasis is equally common in women and men” (Asmundson et al., 2001, p. 18). Health Anxiety and Hypochondria can be considered in terms of a continuum. Salkovskis et al. (2002), developed the Health Anxiety Inventory, a scale for the measurement of health anxiety and hypochondriasis, claiming the scale not only differentiated between patients suffering from hypochondriasis and anxiety disorders but was also not elevated in patients with actual physical illness. The standard scale for assessment of hypochondria is the Whiteley index (Pilowsky, 1967), a standard measure of Anxiety is the Becks Anxiety Inventory (Beck, Epstein, Brown & Steer, 1988). Individuals with hypochondria will generally attempt to describe their perceived illness in terms of peculiar or uncomfortable bodily sensations, however they usually have trouble giving a precise description of their symptoms (Carson et al., 2000).

Hypochondriacal patients are likely to be avid readers of magazines and books on medical topics (Carson et al., 2000). The volume and accessibility of health related information online, coupled with search facility and intuitive medical diagnostic websites that prompt symptomatology, arguably make this medium particularly attractive for those of a hypochondriac disposition. Cline and Hayes (2001) suggest that public health professionals should be concerned about the extent of online health information seeking.

Hypochondriacs repeatedly seek medical advice (Barsky & Klerman, 1983) typically their concerns are not lessened by doctors reassurances (Belling, 2006), conversely they are likely to be disappointed when no physical problem is found, “and will anxiously ruminate about the possibility of...yet undiagnosed disease” (Eifert, Zvolensky & Lejuez, 2001, p. 277). To date there have been no large scale cyberpsychology studies on the effect of medical search online on hypochondria or related conditions. Given the fact that the Web has the potential to increase anxiety when employed as a diagnostic procedure (White & Horvitz, 2009), coupled with reported high state of anxiety in those waiting for diagnoses (Asmundson et al., 2001)

potentially health search online may in some cases exacerbate underlying hypochondriacal tendencies, this premise requires further research.

### *Age of Cyberchondria*

Arguably the Web is fertile ground for those who suffer from hypochondria and other potentially related phenomena such as cyberchondria; which has been decribed “the unfounded escalation of concerns about common symptomatology, based on the review of search results and literature on the Web” (White & Horvitz, 2009, p. 23:2). Escalations from common symptoms to serious health concerns may lead to unnecessary anxiety (White & Horvitz, 2009). The web may therefore be considered as an omnipresent facilitator, enabling detailed investigation into percieved conditions, for those with an interest in medical search online, notably regardless of underlying mental health condition, or iportantly the impact of online search on same.

“In this *age of cyberchondria* (emphasis added)... medical consumers appear at the clinician’s doorstep having researched their symptoms on the internet...the presence of symptoms with no medical explanation may be explained by somatisation” (Ravdin, 2008, p. 912). A question to be addressed is as follows; does cyberchondria exist as a distinct condition? And if so, then perhaps it can be explained in terms of a somatoform disorder as proposed by Ravdin (2008).

### *Somatoform Disorders*

Soma means “body,” Somatoform Disorders involve presentation of bodily symptoms suggestive of medical problems for which no organic basis can be found, such individuals are typically preoccupied with their health and presumed disorders or diseases (Carson et al., 2000). Somatoform Disorders comprise of a group of conditions including *Somatisation Disorder*, *Hypochondriasis*, *Pain Disorder* and *Conversion Disorder* involving physical complaints or disabilities that occur without any evidence of physical pathology as defined by the medical profession (Carson et al., 2000). Individuals concerned are usually preoccupied with their state of health and presumed disorder or disease, there has been much debate yet little systematic research into the underlying factors that contribute to somatoform conditions for

example; motive, primary, secondary gains (Butcher, Mineka & Hooley, 2010), and biological, psychosocial and socio cultural factors. Limited evidence suggests a modest genetic contribution, somatoform disorders are often accompanied by depression and anxiety disorders (Carson et al., 2000). Somatising patients experience widespread difficulties in their emotional lives; vulnerability and neuroticism are in turn associated with anxiety, self-consciousness and impulsiveness (Costa & Widgier, 1994).

### *Factitious Disorders*

Patients presenting with *Factitious Disorder*, that is persistent patterns of feigned symptoms to gain medical attention, such as *Munchausen's Syndrome*, are compelled to maintain the attention and concern of medical personnel, frequently surreptitiously altering their own physiology. DSM distinguishes between *Malingering* and Factitious disorder on the basis of apparent goals; persons who are malingering are motivated by external incentives such as financial compensation or work avoidance. Factitious disorder is diagnosed when the person intentionally produces psychological or physical symptoms, the goal being the benefits the sick role may provide, for example; attention from family or medical personnel (Butcher et al., 2010). A variant of factitious disorder is known as *Munchausen's Syndrome by Proxy* (MSbP) whereby the person falsely seeking medical attention intentionally feigns medical symptoms in another person under his or her care (Carson et al., 2000). The committee on Child Abuse and Neglect states: "Motivations for this bizarre behaviour continue to puzzle both medical and mental health professionals" (Sterling, 2007, p. 1026).

Day and Moseley (2010) assert that determining motivation for any behaviour can be difficult to establish from the behaviour itself, concerning MSbP many mother-perpetrators have health concerns themselves, in many cases similar to the child victim's. The majority of MSbP abusers are women, "mothers and other women in a guardian role are by far the most frequent reported perpetrators (93%)" (Criddle, 2010, p.49). The incidence of MSbP is estimated from 1 in a million children, to 2.8 in 100,000 children (Galvin, Newton & Vandeven, 2005), the vast discrepancy in these figures clearly indicates the need for further research. MSbP

abusers are usually very knowledgeable about medical treatment options “through experience as a patient, training as a child care, or health care provider, or through library and Internet research” (Criddle, 2010, p. 49).

Criddle (2010) describes MSbP gains as; “ sympathy and attention respect...by playing the role of a loving devoted mother” (p. 50), showing off medical knowledge by baffling experts, having a role/purpose and self image of doing good, and the social life of being part of a hospital “family” bonding with the families of other children (Criddle, 2010). Sometimes secondary gain is also significant, aid, housing, medications, donations, community support and media attention (Weston & Morelli, 1997).

### *Virtual Factitious Disorder*

One of the earliest mentions of somatoform disorders online occurred in the late nineties when Dr. Marc D. Feldman coined the terms “Virtual Factitious Disorder” and “Munchausen by Internet” (MIB) (Feldman, 2000), referring to people who carry out a form of factitious disorder deception online, instead of seeking care at numerous hospitals, they clicked from one support group to another. A recent report in the Guardian newspaper supports the MIB assertion, Dr Kanaan, consultant psychiatrist at London’s Maudsley Hospital argues that MIB may in fact make sense; getting sympathy from hundreds of people online may be much more powerful than getting it just from one person in a white coat (Kleeman, 2011). Nonetheless the validity of these “syndromes” must be questioned; attempts at classification to date appear tenuous and dubious, and importantly have not been supported or ratified by DSM. Additionally it has been argued that there is little relationship between health anxiety and psychoneuroses, the Smith, Gardiner and Lyles (2002) study found that only a minority of the so-called ‘worried well’ that is patients who are frequent users of primary care services, fitted the classic definition of a somatisation disorder



### Health Information Seeking Online

Fox et al. (2000) reported 57% of online health information seekers claimed they looked for information for someone else. “*Mumsnet*” a meeting point website for parents is known for prolific health discussions on its notice boards, claiming 1.2million visitors per month and 25,000 forum posts per day (Kleeman, 2011). In a study of health related search online (N=1400) it was found that the majority who searched (76%), were women (Sillence Briggs, Harris & Fishwick, 2006), notably a greater prevalence of female participants (93%) is also evident in the MSbP population (Criddle, 2010).

Online health information seekers often rate a website by its attractive design (Sillence & Briggs, 2007). It has been suggested that “seals of approval or trustmarks” (Sillence & Briggs, 2007, p.350) may be a more empirical method of establishing credibility. Individuals often feel comfortable about revealing information about themselves online (Fox et al., 2000). Joinson (2001) supports this view arguing that the internet provides a comfortable space for self disclosure; this coupled with the anonymous nature of the internet (Turtle, 1995) undoubtedly contributes to open discussion in online health chat forums.

Trust however remains a key issue online “not being certain of a person’s identity...leads to lower confidence...leads to lower trust” (Green, 2007, p.46). Ambient conditions in online health forums may encourage disclosure (Turtle, 1995; Fox et al., 2000; Joinson, 2001), but recipients may not trust the available information. Green (2007), warns of potential additional cost “if information is incorrect, a variety of costs may be incurred” (p. 44). Additionally Amichai- Hamburger (2007) cautions that based on our knowledge of Freudian theory “surfing parts of the Internet may have serious consequences for people have received a severe trauma and have not received treatment for it” (p. 192).

Bonner (2003) and Lewis (2006) commented on the role of media and the rise of lifestyle television, where health and well being are “persuasive discourses”. However some have argued that rates of internet use for health information have been inflated (Baker, Wagner, Singer & Bundorf, 2003). Arguably there has been a shift in responsibility for health management; “In the new health paradigm, citizens are

encouraged to direct and shape their own health biographies ...individualised technologies like the Internet would seem to be the perfect medium for the self-managing healthy citizen” Lewis (2006, p. 522). Hence health search and the Internet appear to have syndicated in a readily available, informative, and empowering but potentially anxiety inducing alliance.

### Hypochondriac Hermeneutics

Is the time-honoured process of the doctor-patient relationship at risk? Bordin (1979) discusses the importance of the doctor-patient consultation relationship in terms of a *therapeutic alliance*. However Belling (2006) is sceptical with regard to the traditional medical consultation process, labelling it an “interpretive activity” arguing that medicine itself is a hermeneutic and therefore potentially hypochondriac enterprise. Is there a need to acknowledge the “potential rationality” of hypochondria? Moreover will better visual access eventually find all disease lurking inside us?

Belling (2006) cites the case of Dr. Harvey Eisenberg and the team at the Health View Centre for Preventative Medicine in California, where full body CT scans are routinely performed on hundreds of the so called “*worried-well*”, Dr Eisenberg has scanned more than 15,000 patients, interestingly evidence of evolving pathology had been found in every case. Could this mean the worried well are not simply *malinger*ing but have due cause for their anxiety? However no data is available on scans of the “non-worried well”, the lack of a control group relating to this data is a cause for concern. Additionally Dr. Dave Harvey has cautioned against this type of aggressive investigative approach arguing that people should not be exposed to ionising radiation unless absolutely necessary, as scanning carries a health risk in itself (Bowes, 2001).

Belling (2006) surmises that medicines response to somatoform type disorders is that enough investigation will eventually banish uncertainty, even if it does so by discovering that everyone is sick. This is perhaps an extreme view, people are often naturally concerned about health issues (Kellner, 1987), and they seek information in a responsible manner, and accept outcomes with minimal levels of anxiety, arguably thus differentiating themselves from the somatoform population. Nevertheless there

is an argument that lack of knowledge or experience by the medical profession may equally be an important factor in the failure of diagnostic processes, clearly “medicine cannot cure everything...physicians cannot know everything” (Belling, 2006, p.379).

### *Doctor-Patient relationship*

According to Sillence and Briggs (2007), people search online for health related information for a number of reasons, information, and preparation for an appointment, answers, support or reassurance. “Time constraints in the consulting room have led to an increase in online searching” (Sillence & Briggs, 2007, p.348) authors noted that the average consultation with a family practitioner was about eight minutes. Bastian (2003), found that the knowledgeable patient took up more of the physicians time, arguably medical search prior to an appointment could provide an economic gain, more time with a physician, more value for money.

In terms of diagnostic consideration, Dr. Meisel stated that he welcomed the “Google stack” in his doctor patient consultations, believing that patients benefit from going online before visiting the doctor, he cited an incident whereby a patient had accurately identified her atypical skin condition through online search, and had brought pictures to the consultation that facilitated the diagnosis, he claims that many health providers support his disposition (Meisel, 2011). However this collaborative internet friendly perspective may not be shared by all medical healthcare providers (McDaid & Park, 2011). Belling (2006) describes the role of the media in spreading information about new conditions, and increased patient autonomy resulting from better access to information, stating that “patients are more likely to be hypochondriac” (p.386). These hypochondriacal patient tendencies do not augur well for the doctor patient relationship, Belling (2006) gives an account a level of medical antipathy towards hypochondriacs, described as follows; “an infernal nuisance...a quite violent hatred...I wanted to hit him (the patient)” (p.381). Hart, Henwood and Wyatt (2004) propose a conciliatory approach, proposing that doctors must be prepared to discuss information concerning symptoms or health that patients present,

they should endeavour to process information rather than simply be the providers of same. It would perhaps be illuminating to conduct an attitudinal research study of frontline healthcare professionals regarding health information seeking online.

### Ranking Algorithms

Health search technology impacts how information is disseminated and can cause unnecessary anxiety (White & Horvitz, 2009). Therefore psycho-somatic factors must be considered in terms of the availability and presentation of health related information online. Currently health related word search is a flawed diagnostic process (White & Horvitz, 2009), and is in fact based on advertising search models. Results are ranked by frequency of search, and users have a tendency to escalate to search extreme results, thus impacting on rankings (White & Horvitz, 2009). Evidently there are challenges that need to be addressed in terms of the ranking algorithms used by search engines specifically in terms of health related search, morbid diagnoses should be mediated with statistical probability, leading to informed and educated assumptions, which may in turn lead to less health anxiety.

Increasing access to information, diagnostic internet sites, global health scares such as swine flu dominating media, and television shows demonstrating surgery can perhaps lead to a media induced medical knowledge overload. "The more the patient learns in the search for reassurance...the more there is to imagine and thus worry about...Cyberchondria, health anxiety exacerbated by exposure to Internet information, has almost become a formal diagnosis" Belling (2006, p. 536). Clearly there is a danger that this issue will fall into either/or rhetoric; lay people are either empowered medically literate consumers, or potentially the victims of cyberchondria.

There is little formal research on this subject, there is however one large scale recent key study (White & Horvitz, 2009). The study is based on review of search results, representative crawls of some 40 million web pages were processed for medical queries, of which 10,000 were manually analysed. Surprisingly high rates of linkage of rare, concerning diseases, for example 'brain tumour', to common symptoms such as 'headache' were detected. An additional survey by White and Horvitz (2009) "Health Related Search Habits" was distributed in the Microsoft Corporation to 5000 randomly selected employees, participation rate was 10.3%,

(N= 515), 350 males, 165 females, average age 36.3 years. The survey contained open and closed questions, and confirmed the prevalence of escalation of concern and web-induced medical anxiety. Online response rates of 70% have been quoted by some authors (Robson, 2002) therefore 10.3% may be considered a low response rate, perhaps indicating a level of suspicion by employees, privacy concerns regarding health information or survey fatigue/work overload. Arguably the computer and web literate Microsoft employee may not be considered as typically representative of an online population; to address this problem an Internet proficiency/use variable could be considered in future research design.

### Heuristics

The *availability heuristic* (Tversky & Kahneman, 1974) was investigated by Microsoft researchers White and Horvitz (2009); that is the influence recent exposure to events on subject's assessments of probabilities of the events, decisions are based on beliefs about the likelihood of uncertain events. The researchers noted that reliance on the rankings of web search results contributed to a similar bias in judgements people make about illness. "People tend to look at the first couple of results" Horvitz stated "if they find 'brain tumour'...that's their launching point" (Markoff, 2008, p.83). Findings of particular interest in the "Health Related Search Habits" survey (White & Horvitz, 2009) in the context of formulating this research proposal are detailed in Table I (Appendix A). When asked "Who are your health-related Web searches primarily for?" Results indicated that 58% of search was for self and 42% of search was for others (N=515). White and Horvitz (2009) concluded that people primarily search for themselves, and/or for relatives/others, which is consistent with the work of Fox et al. (2000). These findings are of particular significance for research.

### Cyberchondria by Proxy

A series of in-depth interviews with young adults revealed that they searched the Internet not just for themselves, but also for details of how to manage the health of relatives and friends (Lewis, 2006), this finding is supported by Sillence and Briggs (2007). Research to date on Cyberchondria is limited, and has concentrated on the individual. However there has been no specific research into the underlying

motivation to diagnose the symptoms of others online, despite the recurring reports of this occurrence (Fox et al., 2000; Lewis, 2006; White & Horvitz, 2009) hence there may exist a gap in the literature requiring further study.

Patients presenting with MSbP inflict harm for personal gain, and comprise a distinct classification. Hypothetically those searching symptomatology 'by proxy', could potentially be classified as manifesting '*Cyberchondria by Proxy*' type behaviour (CbP). Day and Moseley (2010) report similarities between Munchausens and MSbP. "Munchausens syndrome" is the label applied to adult patients who seek treatment for fabricated symptoms, they are also known as "hospital addicts" (Day & Moseley, 2010). "It has been hypothesised that the motivation for such patients behaviour is to obtain some sort of emotional gratification from the deceptive relationship between the patient and the doctor" (Day & Moseley, 2010, p.14). Similarly in terms of gain, MSbP is a "form of child abuse in which a caretaker, usually a mother fabricates and/or induces illness in a child or proxy for the purpose of obtaining emotional or psychological benefit" (Day & Moseley, 2010, p.14). The goal of this behaviour is "to assume the sick role by proxy" (Day & Moseley, 2010, p.14), Criddle (2010) supports this view stating the aim of the MSbP perpetrator "is to draw recognition...an insatiable need for social and emotional gain" (p.49). It is however notable that external incentives for MSbP type behaviour, for example; economic gain are absent (Day & Moseley, 2010).

Over reporting of symptoms is an identifying trait of MSbP perpetrators, other factors may include a family history of frequent and unusual illness behaviour (Day & Moseley, 2010). This view is supported by Criddle (2010) describing MSbP as potentially "a lifelong generational disorder" (p. 49), arguing that many MSbP victims can develop into Munchausen syndrome patients, the seeking/achieving gratification through illness behaviour may become rooted, learned behaviour in a zone of proximal development. Additionally Criddle (2010) notes that MSbP abusers enjoy "showing off their medical knowledge" escape from "other responsibilities" and having a purpose "doing... important and interesting things" (p. 50). Can the same be said of cyberchondria and hypothetically CbP, are there gains, and if so, what is the underlying motivation to pursue same?

What is the line between normal health anxiety regarding dependents, and abnormal type behaviours? Criddle (2010) argues that all parents “present somewhere on a continuum of medical neediness” (p.52), pointing out that many parents worry, are hypervigilant, misinterpret and exaggerate behaviours, however illness fabrication lies at the extreme edge of the spectrum. Criddle (2010) describes MSbP as “an escalating disorder” (p.48), stating that “the goal of the perpetrator is to create symptoms” at what point does extensive medical search for others (CbP), symptom search, symptom cluster creation, and escalation to review of serious medical content begin to become extreme? perhaps to a point of potential overlap with serious MSbP type traits.

### Health Search Behaviour

Somatoform disorders are highly complex psychological phenomena, contemporary use of emerging technology as considered in the discipline of cyberpsychology is similarly complicated, as witnessed by the current debate on the concept of Internet addiction (Young, 1998; Byun et al., 2009) and impulsivity online (Greenfield, 2010). In terms of online activity Greenfield describes the concept of *intermittent reinforcement* a form of lottery intermittently delivering a rewarding result. Perhaps symptom search and the potential excitement of reaching a diagnosis may be fuelled by intermittent reinforcement drivers, this concept requires further study. It should be noted that impulsivity has also been associated with somatoform disorders (Costa & Widgier, 1994). Is researching of symptomatology online a compulsive act of internet related addictive and reinforced activity? (Young, 1998; Byun et al., 2009; Greenfield, 2010), or is search for knowledge merely a heightened form of *information seeking*, basic *mammalian instinct* as proposed by Panksepp (2004).

Scholarship and reports to date indicate that media and use of new technology increasingly influences behaviour, particularly with regard to health anxiety (Fox et al., 2000; Feldman, 2000; Lewis, 2006; Belling, 2006; Ravdin, 2008; White & Horvitz, 2009; Kleenman, 2011; Moses, 2011; American Psychiatric Association, 2011). However some have argued that estimates of internet use for health related information seeking have been inflated (Baker et al., 2003), and that the vast majority of the “worried well” do not in fact fit the classic psychological profile

of somatisation disorder (Smith et al., 2002). This divergence of opinion creates an interesting gap in the knowledge related to this subject area, and a requirement to address same in terms of further research.

### Self - diagnostics

Doctors are warning of catastrophic consequences (Moses, 2011) following publication of an international survey conducted by the global health insurance provider Bupa (McDaid & Park, 2011). The research revealed that four out of five Australians are turning to the web for health information. Alarming nearly half of those surveyed are using the search engine *Google* to make a self-diagnosis. The survey was global (N=12,000), 68 per cent of respondents used the net to look for information about a medicine, 46 per cent to make a self-diagnosis, and 36 per cent were seeking other patients experiences, these findings are consistent with those reported in a recent study (Fox & Jones, 2009).

The Bupa survey does not provide any data on participant search for others, however there are some informative statistics in terms of accuracy of content; government websites were found to always provide accurate information, followed by educational sites 80 percent and news sites 55 per cent of the time, no sponsored sites were found to present accurate information. The reliability aspect of health related information online would appear to be supported by Scullard, Peacock and Davies (2010) reporting on searches regarding children's health using Google, and the reliability of medical advice on the internet, findings showed that by using Google to identify sites, only 39 per cent of 500 sites examined provided appropriate information, 11 per cent were incorrect and 49 percent failed to answer the question put to them.

Following publication of the Bupa report Dr Brian Morton, former president of the Australian Medical Association (AMA) reported a case whereby a patient had presented with symptoms of temporal arteritis, inflammation and damage to blood vessels that supply the head area, the condition can lead to catastrophic blindness. The 70-year-old man's son had searched for symptoms, and stopped his father's cholesterol lowering medication, thereby causing the temporal inflammation. "There is potential for 'Dr Google' and well-meaning family members to cause catastrophe,"



according to Dr. Morton (Moses, 2011), this statement provides support for this research projects CbP assertion, and the need for further investigation.

### *Motivation to Search*

Asmundson et al. (2001) note that concerns regarding health of relatives and friends can cause considerable anxiety, however prevalence of health-related search for dependants and relatives (Fox et al., 2000; Lewis 2006; White & Horvitz , 2009) despite the probability of escalated anxiety (White & Horvitz , 2009), causes concern. Cyberchondria may be a maladaptive strategy to self-manage health in a changing society (Lewis, 2006; Belling, 2006; Ravdin, 2008), or perhaps an avoidance of the cost/disruption associated with formalised medical consultation.

Health information seeking online may fall in the abnormal psychology category of somatoform disorders, such as hypochondria typically characterised by primary and secondary gains (Asmundson et al., 2001). However the current DSM-V work group reports that it may in fact abolish the term hypochondria and replace same by a more general classification of “*Illness Anxiety Disorder*” notably including online symptom checking (American Psychiatric Association, 2011). This recent development does in fact support an argument for the impact of technology on health information seeking online and associated anxiety, the question is what is the extent and nature of that impact.

Symptom search for dependants may be related to protective/preventative carer instinct (Lewis, 2006). Severe health anxiety can lead to hypochondriasis (Asmundson et al., 2001) the question is; what is the impact of emerging technology on abnormal psychology conditions particularly those in the range of somatoform disorders? Research to date has identified the fact that people search for medical information online for self, and for others (Fox et al., 2000; Lewis 2006; White & Horvitz , 2009), the question to be addressed is; what is the difference between health related search for self online and search for others? This point will be investigated in this research.

Symptom search may be a consequence of a compulsive, addictive, rewarding and engaging technology (Young, 1998; Byun et al., 2009; Meerkerk, Van Den

Eijnden, Vermulst & Garretsen, 2009; Greenfield, 2010), the role of technology in terms of health related information seeking on line will be investigated.

Inquisitiveness/seeking (Panksepp, 2004), online anonymity (Turkle, 1995) disinhibition (Suler, 2004), may play a role. The research will investigate curiosity and seeking online, and will search for examples of benign disinhibition and self disclosure (Joinson, 2001), that is online exchanges and forums where people feel comfortable discussing and revealing (Fox et al., 2000) very personal and private health related information. Compulsive entities such as Internet addiction Young (1998) and intermittent reinforcement online (Greenfield, 2010) will also be considered. Altruism a trait identified in cyberpsychology research (Adar & Huberman, 2000) may explain search for others, and may also be a factor in terms of exchanges and/or the sharing of information in medical chat rooms. Anxiety may be a predictive factor, or may in fact be an undesirable side effect of medical search online (White & Horvitz, 2009); this relationship will be explored in the research. Equally cyberchondria may be related to hypochondria, or even Munchausen's manifested online, and CbP may potentially share characteristics with MSbP, or not.

### *Hypotheses and Research Questions*

Literature to date outlined the fact that people participated in medical search for self and for others (Fox et al., 2000; Lewis 2006; White & Horvitz , 2009). However this research did not indicate if there was a distinct relationship between these activities, and if anxiety associated with escalation regarding medical search for self online, cyberchondria (White & Horvitz , 2009) was also evident in those who searched for others; that is, cyberchondria by proxy. In terms of abnormal psychology conditions regarding illness anxiety disorders there is a relationship between the somatoform disorder Munchausens and MSbP (Day & Moseley, 2010), a form of emotional gratification resulting from medical attention (Day & Moseley, 2010; Criddle, 2010). What therefore is the relationship between cyberchondria and CbP? is there a psychological or tangible reward for engaging in this behaviour, and if so how is it characterised? This led to the generation of the following research question and hypothesis:

RQ. 1: Is there a relationship between health-related information search online for self, and for dependents?

H1: There will be a correlation between medical search online for self (cyberchondria) and for others (CbP).

Health information seeking online is a prevalent activity (Fox et al., 2000; Feldman, 2000; Lewis, 2006; Belling, 2006; Ravdin, 2008; White & Horvitz, 2009; Kleenman, 2011; Moses, 2011; McDavid & Park, 2011). Anxiety regarding health can occur in normal populations (Kellner, 1987, Lewis, 2006; Belling, 2006; White & Horvitz, 2009; Criddle, 2010). Research to date has identified a relationship between health anxiety and hypochondria (Asmundson et al., 2001; Salkovskis et al., 2002). It has been established that health related search online can lead to escalation and anxiety (White & Horvitz , 2009), the question is; can pre-existing anxiety or hypochondriac type conditions play a role in cyberchondria? This led to the generation of the following research question and hypothesis:

RQ. 2: Can cyberchondria be predicted by means of anxiety and/or hypochondria?,

H2: There is a correlation between anxiety, hypochondria and cyberchondria

Finally, the internet is both a push (media providing), and pull (information seeking) medium, this study will consider the impact of media (Bonner, 2003; Belling 2006; Moses; 2011) on the online health information seeking process, important given the Internet role as a news provider and information seeking platform. Health search online may be prompted by media news stories carried both on and off the internet. However given that the Internet is a form of media in its own right, consideration will be given to all aspects of online behaviour that may impact on health related search online (Turkle, 1995; Young, 1998; Adar & Huberman, 2000; Fox et al., 2000; Joinson, 2001; Suler, 2004; Green, 2007; Sillence & Briggs, 2007; Greenfield, 2010), leading to the research question:

RQ. 3: What role does media play in influencing the process?

## **Method-Study One**

### **Research design**

The research methodology was mixed methods design, quantitative and qualitative, In terms of research design several options were considered, an online survey would have produced a greater amount of data, however ethical considerations in terms of vulnerable populations ruled out this option. Observational methods were considered and then deemed not workable, due to potential influence of the *Hawthorne effect*. Case history methodology was selected for research design purposes. Case histories were collected during a semi-structured interview, an *interview script* was used in order to stay in control of the process, Powney and Watts (1987, ch.2) describe this procedure as a *respondent interview*, the point being that the interviewer drives and controls the agenda, thereby obtaining an optimum level of information.

The research was broken up into two studies; Study one consisted of Case histories (N=2), Study Two consisted of focus group studies (see p.34 for details).

## **Study One**

### **Case History One - Participant One:**

*Participant:* Participant One was a 34 year old English female, married with two young children. At the time of interview she was resident overseas. Participant one was recruited by snowballing; she was described as having an interest in online health related information.

*Measures/Materials:* a recording device was used to record the interviews no measures were applied. An interview script (Appendix B) was developed according to semi-structured interview guidelines (Powney & Watts, 1987) to control the flow of discussion. The subject prompts in the script reflected areas of research interest such as; responsibility for health management, online medical information seeking and attitudes towards search for self and search for others. An e-version of the interview consent form (Appendix C) and debrief form (Appendix D) were utilised. Video facility, large screen monitor, webcam and *4Hn zoom* recording device were also employed. Pilot testing of recording device and the webcam set up confirmed that all equipment was functional.

*Procedure:* Interview consent form (Appendix C) was emailed to Participant One, signed and returned to researcher prior to commencement of video interview, video as opposed to voice call methodology was selected to enhance the interview communication process, and to enable researcher to observe the facial expressions of participant. Participant was advised to nominate a suitable time and to take the video call in a private room. The interview session commenced with a general greeting, explanation of the interview process and the general subject matter for discussion, followed by a reading of the interview consent forms to remind participant of their rights. Interview session lasted for approximately one hour and 15 minutes. An interview prompt Script (Appendix B), was used to ensure continuity of discussion. Session was concluded with an opportunity for the participant to ask questions, none were raised, followed by a reading of the debrief form (Appendix D), which had also been emailed to participant. Participant One was not paid for input; a small donation of €5 was made to a nominated charity.

Strict ethical guidelines as issued by the British Psychological Society (BPS), the Psychology Society of Ireland (PSI) were adhered to at all stages of the interview process.

The interview was recorded and data collected was transcribed. The Miles and Huberman (1994) approach was employed in terms of organising the data in preparation for analysis; materials were coded and reflections were captured in the form of memos at the time of interview, all data was considered and analysed, significant themes that emerged were reported, all themes were supported by direct quotes.

#### *Case History Two - Participant two:*

*Participant:* Participant Two was a 39 year old Irish professional male who lives with his partner and young child. Participant Two displayed a keen interest in online health related information seeking during his focus group discussion session, and was subsequently recruited for a case history interview following the focus group session. Refer to “*Flow of Participants*” diagram for details of selection/ recruitment process (Figure 1. Appendix E)

*Measures/Materials:* The 4Hn zoom recording device was used to record the interview (measures were applied in focus group session). The interview script ((Appendix B) was utilised to control the flow of discussion and to facilitate inter interview continuity (Powney & Watts, 1987), the interview consent form (Appendix C) and debrief form (Appendix D) were also used. Pilot testing of the recording device confirmed that equipment was functional.

*Procedure:* Interview *session* commenced with a general greeting, explanation of the interview process and the general subject matter for discussion. The interview consent forms was then discussed and signed. Interview session lasted for approximately 45 minutes. An interview prompt Script (Appendix B) was used to facilitate flow of discussion. Session was concluded with an opportunity for the participant to ask questions, none were raised, followed by an explanation and signing of the debrief form (Appendix D) Participant Two was not paid for input; a small donation of €5 was made to a nominated charity.

Ethical guidelines, interview methodology, data capture and analysis followed the same Study One format (see Case history one, Participant One for details p. 21).

## **Results: Study One**

In terms of qualitative case history, all transcribed data was organised and analysed by means of a *Template approach* and *Matrix analysis* (Robson, 2002; Miles & Huberman, 1994)). Data was coded, memos noted, phrases, patterns, themes and sequences were explored for frequency, overlap, relationships and contradiction. Processes of verification, reduction and interpretation were used to generate specific thematic headings that followed the narrative discourse style of the Case history interview data. Some representative quotations are listed, the balance can be found in appendices section (Appendix E).

Study One comprises of two case history studies conducted independently of each other. Participant One (Case History One) features a 34 year old female who was interviewed via a conference facility. Participant Two (Case History Two) features a 39 year old male, interviewed face to face.

### **Case History One**

Participant One (P1) was interviewed on the 5<sup>th</sup> February 2011 via a pre-arranged video conference call. Participant One is married with two young children. She is resident overseas; her husband has a job which involves extensive travel and frequent periods of separation from the family. The family have a limited local family support system; however Participant one has the support of home help. The interview consisted of a semi-structured discussion regarding health-related search online. No measures were applied given the video conference format of the interview.

### **Responsibility/protection**

Participant One felt that healthcare management of children was the joint responsibility of medical professionals, parents and individuals.



### Doctor – Patient relationship

Participant one was a first time mother whose relationship with various medical personnel was strained; she frequently brought printouts to consultations and encountered negative responses:

**P1/133 -134:**

“Doctors who just said, ‘Oh, its rubbish....It’s just nonsense”

### Pivotal anxiety inducing event

Participant One described an apparent near miss regarding her child’s health, which was followed by feelings of anger and relief:

**P1/208 -213:**

“We can’t even believe he’s almost alive”

**P1/232 -234:**

“Obviously annoyed...but kind of a relief”

### Health related anxiety

Participant One confirmed feelings of anxiety, and reconfirmed parental responsibility:

**P1/246 -252:**

“Oh absolutely... especially with small children...you are the primary person responsible for their health maintenance”

### Medical information seeking online

Participant One confirmed that she was a consistent user of online medical information facilities, and had in fact built up trust with a medical website hosted by a renowned Doctor:

**P1/324 – 327:**

“I have built trust with a virtual doctor”

When asked if she felt that her medical knowledge had increased as a result of consulting the internet, Participant One confirmed same.

#### Medical website selection criteria

Participant One had a system of validating medical websites, she did acknowledge that some sites were not reputable or could be out of date:

**P1/394 -399:**

“I would go to their (*medical condition*) page”

#### Online medical information sharing

Participant One reported significant medical information sharing online, believing there were cost efficiencies to be gained by gathering information online to avoid paying for a visit to a doctor:

**P1/455 -465**

“Sometimes you’re getting 20 different mothers saying different things”

#### Medicating dependents

Participant One cited an amount of peer pressure from other mothers to “fix” child health related problems:

**P1/556 -566:**

“Swine flu and all that kind of thing... there’s peer pressure from other mothers”

#### The role of media

Participant one commented on the role of media if health related scares noting the requirement of reporting balance:

**P1/600 -606:**

“The media plays a huge role... it’s a double-edged sword I think...”

#### Self diagnosis

When asked about self diagnosis Participant one reported searching symptoms online and ensuing levels of anxiety associated with review of serious content:

**P1/728**

“It ranged from that... and then obviously to things like throat cancer”

**P1/771:**

“Yeah, anxious”

#### Diagnosis of others

When asked about diagnosis of others Participant One reported that it was difficult to assess illness in children, however with something straightforward she would go to a doctor, conversely for something more complex she would first search online:

**P1/801-853**

“With something basic, I would just go to the doctor and then search. If it was something more complex, I’d search”

#### Knowledge and empowerment

Participant one acknowledged that sourcing medical information online was empowering, indicating it would be very distressing if she could not perform search going forward:

**P1/864-865**

“If someone said to me, you know, you can’t look for anything online... it would just be a nightmare basically. I’d hate that.... it’s just, knowledge is power”

#### Time as a variable

Participant one emphasised the impact of consulting a Doctor in a fixed time slot noting the process was rushed and that people saved up issues to discuss:

**P1/1032-1041**

“I mean most GP’s...in and out in ten (*minutes*)”

### Future recommendations

Participant one was asked to make recommendations to improve medical search online, she suggested best site listings and segregation of sites by condition:

**P1/959-973**

“I think people need to know...the top ten reputable medical sites”.

### Case History Two

Participant Two (P2) was interviewed on the 9<sup>th</sup> February 2011. Participant Two lives with his partner and young child. The family are resident in Ireland and have an extended family support system. The interview consisted of a semi-structured discussion regarding health-related search online. Measures were applied to Participant Two during focus group session, details as follows; Participant's Becks score was 8, focus group (N=20) Becks mean score was 3.85, standard deviation 4.934, minimum score recorded 0, maximum 20. In terms of hypochondria, Participant Two had a score of 27, focus group mean score was 21.65 standard deviation 3.558, minimum score recorded on Whiteley was 17, and maximum was 30. A number of representative quotations are listed, the balance can be found in the appendices section (Appendix G).

### Medical information seeking online

Participant two stated that the positive of medical information seeking online was the facility to diagnose child health related issues:

**P2/76-85**

“Child is vomiting and hot, unable to breathe and coughing in a very disturbing manner... we called a doctor... we called some relatives ...we did Google”

### Medical website search validation

Participant two is technology literate, employing experience and technical know-how to differentiate between medical websites:

“You go onto the website... good website... official URL”

### Symptom search online

Participant two described the process of searching the child's symptoms online in the middle of a crisis situation; both Google and the medical websites "diagnosed" the condition and provided remedial information:

**"P2/208-253"**

P2: "I wasn't familiar with the word 'croup' at the time, so I was just really just... putting in sentences"

### Pivotal anxiety inducing event

Participant Two describes medical follow up where cot death was mentioned in relation to the croup event, he found this association very anxiety inducing.

**P2/357 - 366,**

"They did say...it could have been a cot death scenario"

### Diagnosis of others online

Participant 2 describes the use of forums, reading through detailed medical thread discussions (in addition to search), speaking of trusted communities.

**P2430 - 441**

"We consulted a number of different sites...others that have forums within the site so you're speaking with other parents who are experienced"

### Self diagnosis online

Participant Two reported a previous history of attempting self diagnosis online, however conceded that this was not constructive; he had begun to imagine that he had various illnesses. He described himself as having an anxious disposition, which he claims was caused by his mother's anxiety regarding his health and welfare as a child:

**P2/473-486**

"I started to think I had things that I didn't have

**P2** 491 – 498:

**P2:** “I would be someone who suffers from anxiety to a certain degree...from my mother”

### **Discussion: Study One**

Both Participants gave highly informative interviews covering a range of subject related topics. The semi-structured discussion allowed the Participants to discuss same in detail. The results of the interviews have been considered and analysed in the context of the available literature, findings are as follows:

The study aimed to identify the existence of a relationship between health related search for self and for others, both of the case history Participants confirmed that they did in fact search for self, and for others, specifically their dependent children. In terms of the primary hypothesis one “There will be a correlation between medical search online for self (cyberchondria) and for others (CbP)” both Participants acknowledged that they suffered anxiety as a result of health related search online, which supports this hypothesis. Additionally both Participants reported anxiety following escalation to review of serious content online, a characteristic of cyberchondria (White & Horvitz, 2009). It should be noted that results of search are often interpreted as a diagnosis (White & Horvitz, 2009), and that highest levels of anxiety often occur in those awaiting diagnosis (Asmundson et al., 2001).

In terms of motive to search for health related information for dependents online, a number of significant themes emerged. Parental anxiety related to responsibility and duty of care regarding children (Criddle, 2010), appears to have been a significant driver in both cases. This tendency to search for dependents is supported in the literature (Fox et al., 2000; Lewis, 2006; White & Horvitz, 2009). Search habits may have been compounded by the fact that both Participants gave unprompted accounts of apparent “near misses” regarding their child’s health. The near miss may have in turn initiated extensive search online, or may simply have reinforced the pre-existing search behaviour. Undoubtedly Participants were perturbed by the pivotal traumatic event, perhaps seeking reassurance in ongoing search, however Amichi-Hambruger (2007) cautions against traumatised, untreated individuals, surfing the Internet.

Information seeking and knowledge acquisition were cited by both Participants as reasons to perform medical search, this tendency is supported by Sillence and Briggs (2007) and Meisel (2011), an advocate of self-help online.

However Moses (2011) does warn of potential catastrophic consequences regarding medical search for dependents particularly in terms of diagnostics online, this causes concern particularly given Participant One's preference to take children to the doctor for issues but to conduct search in terms of serious issues, this "by-passing" of medical staff finding is supported by Cline and Hayes (2001), who state that medical professionals should be very concerned about online medical search.

In terms of the second hypothesis "there is a correlation between anxiety, hypochondria and cyberchondria" both Participants admitted to feelings of anxiety, no measures were applied to Participant One given the video conference format. Participant One reported a strained relationship with doctors following presentation of printouts at consultation, reporting feeling marginalised by the encounter, and speaking of "stigma". This is an insightful observation, the stigma the Participant describes may be evidence of a hostile attitude known to exist in the medical profession towards patients that appear to display hypochondriacal or related tendencies (Belling, 2006), however in this case there is no evidence to support hypochondria, in fact Participant One health related search efforts were directed towards a dependent, a proxy.

Participant Two's Becks score was 8, and indicative of mild anxiety (Becks et al., 1988). In terms of hypochondria, Participant two had a score of 27, it should be noted that this score lies at the upper end of the Whiteley scale, which may be indicative of hypochondriacal tendencies.

Participant Two acknowledged experiencing anxiety whilst conducting search for self online, a trait of cyberchondria (White & Horvitz, 2009), additionally Participant Two spoke of "imagined illnesses", a characteristic of hypochondria (Asmundson et al., 2001; Eifert et al., 2001). Data relating to Participant Two would appear to support the second Hypothesis that is the potential relationship between anxiety, hypochondria and cyberchondria, however further research is required to substantiate any correlation.

In terms of the third research question; the role of media in influencing health related online search, both participants were aware of the impact of media, Participant One referred to traditional media such as newspapers, and was aware of



the necessity of balance in reporting. Participant Two was more technology literate and preferred to search for health related news online. The incidence of extensive personal content in blogs and chat forums is supported by the literature in terms of self revelation online (Joinson, 2001), disinhibition online (Suler, 2004), and altruism (Adar & Huberman, 2000). Additionally anonymity (Turkle, 1995) may also be a factor, however Feldman (2000) warns of factitious disorder online, and the deviants that can populate medical chat rooms.

Regarding other findings, both Participants had developed skills to authenticate or trust websites based on appearance and content, this finding is supported by Sillence and Briggs (2007) and Green (2007). Participant one indicated it would be very distressing if she could not perform search going forward, this may be indicative of a level of technology induced compulsion (Greenfield, 2010) and/or dependence (Young, 1998). Participant Two admitted to having an anxious disposition, which he claims was caused by his mothers anxiety regarding his health as a child, possible generational transfer of health anxiety (Criddle, 2010; Day & Moseley, 2010) is beyond this scope of this study.

The implications of the findings are as follows; given the likely existence of a relationship between cyberchondria and cyberchondria by proxy, more analysis of data with a larger group would be required to substantiate this relationship. This research is timely and potentially important given the current DSM review of the classification of somatoform disorders and the advent of symptom checking/health related search online. From a theoretical perspective the study findings in general are supported by previous research and literature, however the verification of anxiety related to search for dependents online, that is CbP, is in fact a significant new finding, which will be further explored in the focus group studies.

In terms of practical implications, the fact that patients are seeking to self diagnose online has serious implications for the healthcare industry. Medical search online is largely unregulated, the literature warns of the dangers of same (Mc Daid & Park, 2011, Moses, 2011), however given the involvement of vulnerable populations such as dependents, this is an area that now merits serious consideration. Perhaps a fundamental redesign of medical search online is required, stating that search results are word clusters, and definitively not a diagnosis. Additionally medical practitioners

may need advice on best practice when dealing with patients who present with internet sourced information, challenging the opinion and status of the Doctor. Parents in particular may require advice from health advisors regarding escalation and anxiety relating to medical search online, in order to avoid reaching the edge of the parental health anxiety continuum as described by Criddle (2010) concerning health anxiety (Kellner, 1987; Asmundson et al., 2001).

Additionally extensive search and connectivity with online health forums where escalated health matters are commonly discussed may exacerbate existing anxiety (White & Horvitz, 2009). This study highlighted the fact that search focus has apparently transferred from Participants (search for self) to their children (search for other); perhaps a case of transfer of internet related health anxiety behaviour, potentially a form of cyberchondria by proxy? However while a numbers of drivers have been indicated, specific motive or rationale for doing same has not been established, this area requires future study.

The limitations of the study are as follows; small number of Participants (N=2), similar socio economic and professional demographic, common age group, both with young children, additionally no measures were applied to Participant one (video interview). The present study was also limited by the ethics stipulation that any Participant presenting with severe anxiety or hypochondria (as deemed by the appropriate measures) should not participate in the study, therefore any such population would be screened out by same. Nonetheless in terms of future study, it would perhaps be informative to conduct case history interviews with patients clinically diagnosed with a somatoform disorder, to investigate whether cyberchondria or CbP is in fact evident in this population.

In terms of future research a large sample potentially accessed through an online survey could test the generalisability of the findings. Additionally it would be helpful to gauge medical opinion in a survey regarding health related search online, and the impact of same on the traditional doctor patient relationship, finally it would be very constructive to design a measure that could accurately assess cyberchondria and CbP tendencies, a scale that may be very useful in a practical context for the medical practitioner community.

## **Method: Study Two**

### **Study Two –Focus Groups**

Study two consisted of focus group studies (N=20), there were four focus groups in total, two measures and a survey were applied, additionally all Participants took part in focus group discussions. Focus group methodology was also selected for the following reasons; efficiency in terms of collecting data from several people at once, group dynamics can help to focus on important topics, participants tend to enjoy the experience and the method is inexpensive, typically fewer than ten topics can be covered in an hour however this limitation suited the research design in this instance. Confidentiality can be an issue and facilitating the process requires skill (Robson, 2002).

The four focus group sessions took place between 15<sup>th</sup> February and 1<sup>st</sup> March 2011. See Table 2 for breakdown and coding of participants, codes will be used to identify participants in the reporting of qualitative thematic data gathered during the focus group discussion sessions.

Table 2. Focus group breakdown and coding of participants

Focus group A	Focus group B	Focus group C	Focus group D
Participants (n=5)	Participants (n=5)	Participants (n=6)	Participants (n=4)
A1	B1	C1	D1
A2	B2	C2	D2
A3	B3	C3	D3
A4	B4	C4	D4
A5	B5	C5	
		C6	

### Participants

All participants in focus group studies were aged 18 years or older and all had a good command of the English language. Total sample gender split as follows: seven males, and thirteen females. Sample age range; minimum 19, maximum 58, mean 34.65, standard deviation 11.061.

Pilot group testing indicated that a better quality of discussion, particularly concerning personal health related information would be achieved by grouping participants of similar age and interests together to form a *homogeneous group*, facilitating communication, promoting exchange of ideas, giving a sense of safety. However this harmonious situation “may result in ‘groupthink’ an unquestioning similarity of position or views” (Robson, 2002, p 286). Focus groups were organised as follows;

*Focus group A* (n=5): urban based, mixed group of working professionals in the marketing and advertising services sector, three reported child dependents, all had completed secondary school, three had completed an undergraduate qualification, all reported being frequent users of the internet. Gender split three females and two males, age range; minimum 29, maximum 47, mean 39.40, standard deviation 7.092.

*Focus group B* (n=5): urban based, mixed group of students, no child dependents reported, one however did express concern for an elderly dependent. All had completed secondary school, all five were pursuing undergraduate qualifications, and all reported being frequent users of the internet. Gender split one female and four males, age range; minimum 19, maximum 20, mean 19.40, standard deviation .548.

*Focus group C* (n=6): suburban based, group of female only participants belonging to a local mother and toddler group, three of the mothers worked part time, all six participants reported child dependents. All had completed secondary school, four had completed an undergraduate qualification, two had progressed to a postgraduate qualification, and all reported being frequent users of the internet. Age range; minimum 37, maximum 47, mean 39.67, standard deviation 3.933.

*Focus group D* (n=4): urban based, mixed group of working professionals in general business administration sector, two reported child dependents. All had completed secondary school, three had completed a postgraduate qualification, and all

reported being frequent users of the internet. Gender split three females and one male, age range; minimum 28, maximum 58, mean 40.25, standard deviation 12.816.

*Recruitment:* Candidates were recruited by local advertising; notices in shops, offices, schools and playgroups in order to obtain a broad socio economic demographic and gender split. Snowballing methodology was also employed.

*Measures/Materials:*

The focus group pilot study provided a number of learning's in terms of handling materials, firstly all materials were prepared and made ready in advance of each session, and secondly all materials were coded with both the focus group and participant codes to facilitate traceability of data.

The research will test the primary hypothesis (H1) and the third Research question (RQ.3) by means of a *survey questionnaire* (Appendix H), The research will also test the secondary hypothesis (H2), by means of two separate measures; the *Becks Anxiety Inventory* (Appendix I) and the *Whiteley Index* (Appendix J), established anxiety and hypochondria measures. A number of alternative measures were considered including the Health Anxiety Inventory (Salkovskis et al., 2002), a combined scale for the measurement of health anxiety and hypochondriasis, however it was considered more useful at this research stage to consider anxiety and hypocondria as related, yet distinct variables.

*Badges:* all participants were issued with identity badges "Participant One, Participant Two". Badges had a dual purpose; to preserve anonymity and to facilitate speaker identification on transcription of data.

*Focus Group Consent form* (Appendix K) this form was designed to inform participants of the nature of the research, advise them of their rights and record their age and written consent.

*The Beck Anxiety Inventory* (BAI) (Appendix I) developed by Beck et al. (1988) a 21 item scale that measures the severity of anxiety in adults and adolescents. Scores of 0-7 are considered minimal, scores of 8-15 are considered in the mild anxiety range, scores of 16-25 are classified as moderate anxiety, and scores of 26-63 are described as severe. Beck et al. (1988) reported that the BAI had high internal

consistency reliability (Cronbach coefficient  $\alpha=.92$ ). Content, concurrent, construct, discriminant and factorial validity for BAI were also considered (Becks & Steer, 1990).

*Whiteley Index*, (Appendix J), developed by Pilowsky (1967) to measure health related worries and core features of hypochondria, consisting of a 14 item true or false measure. According to the Whiteley index people without health anxiety generally have a score of  $21 \pm 7$  (14 to 28). Patients with hypochondria are found to have a score of  $44 \pm 11$  (32 to 55). Most studies conducted using this measure indicate good reliability and validity (Barsky et al., 1992; Pilowsky, 1967).

*Survey questionnaire* (Appendix H) a broad data collection tool combining Likert scales with open and closed question formats investigating attitudes to health, medical search online for self and for others, self reports of anxiety, and sources of medical knowledge. Questions relating to online search and health anxiety used in the White and Horvitz (2009) study were reviewed and amended for inclusion in the survey questionnaire, Sample survey questions as follows:

*Question 8. Do you use the Internet?*

*Question 11. Do you worry about your physical health?*

The survey questionnaire has not as yet been tested for reliability or validity.

*Prompt script* (Appendix L) a prompt script was developed to ensure continuity of discussion within each focus group and continuity of themes discussed between focus groups, all themes were relevant to the research questions and hypotheses, sample theme as follows:

*“Discuss health related information seeking for self or for family - what happens pre- search and post- search?”*

*Focus Group Debrief Form* (Appendix M), this form was designed to thank participants for participating in the research, give them contact details of the researcher and supervisor should they have any post focus group queries, and to provide a list of organisations they could refer to if they felt they had been affected by the research process.

### Procedure

Pilot testing was useful in establishing timings for the focus group sessions given the number of stages were involved. As directed by ethics focus groups candidates were screened by means of Becks Inventory and the Whiteley index. The measures were applied at the beginning of the session following introduction and signing of the consent form (Appendix K), results were then screened by the supervising psychologist who deemed suitability of participants to continue with the focus group process, 30 minutes was allowed for this stage.

Following the measures, Participants completed the research questionnaire (Appendix H), 10 minutes was allowed for this stage. Recommendations adapted from Donaghy (1990) (Appendix N), on ways to build a comfortable focus group discussion climate were employed. Focus group sessions were controlled by use of a focus group prompt script (Appendix K), comprising of a series of subject related questions, designed to elicit and capture deep underlying behavioural motivation and attitudes in terms of subject research. A maximum of 40 minutes was allowed for the discussion stage. Participants were issued a debrief form (Appendix M) on completion of the focus group session. No Participants were excluded from discussion based on results of the Becks or Whiteley measures. All Participants accepted a donation to a nominated charity. Focus group sessions were conducted in comfortable private room, refreshments were provided, all focus group sessions were supervised at all times by a clinical psychologist, There were no clinical issues raised by the psychometric tests, no follow up by the psychologist was required.

Strict ethical guidelines as issued by the British Psychological Society (BPS), the Psychology Society of Ireland (PSI) were adhered to at all stages of the focus group process. On occasion some Participants began to discuss very personal or private health related matters, they were reminded that they should speak only in general terms, and did not have to reveal private information in a group session.

## Results: Study Two (A: quantitative)

### Search for Self and Search for Others

Fifty five percent of participants (n=11) searched for health related information for self online, 55% of participants (n=11) searched for others. 30% of participants (n=6) searched for self and for others, and of that cohort the majority (n=5) or 83.3% searched for others who were relatives or dependents. Health related information search for self (SFS) and search for others (SFO) were considered in the Table 3, cross *tabulation* grid.

Table 3. Search for Self and Search for Others: Cross tabulation

			SFO		Total
			no	yes	
SFS	no	Count	4	5	9
		Expected Count	4.1	5.0	9.0
	yes	Count	5	6	11
		Expected Count	5.0	6.1	11.0
Total	Count		9	11	20
	Expected Count		9.0	11.0	20.0

SFS and SFO were investigated by means of a chi-square test. Since the analysis showed that 75% of the cells had an expected frequency of less than 5, the appropriate statistical test was Fisher's Exact Probability. The relationship between SFS and SFO was:  $\chi^2$  (1, N = 20) = .002, exact  $p$  = .964). The value of Cramer's V was .010 ( $p$  = .964). Descriptive statistics are outlined in Table 4.

Table 4. Descriptive Statistics

	N	Minimum	Maximum	Mean	Std. Deviation
Age	20	19	58	34.65	11.061
Anxiety search for self online	20	2	7	4.25	1.251
Anxiety search for others online	20	2	7	3.70	1.809
Media score	20	17	27	21.90	3.227
Whiteley	20	17	30	21.65	3.558
Becks	20	0	20	3.85	4.934
Valid N					



### Cyberchondria and Cyberchondria by Proxy

A number of questions in the survey were introduced to measure levels of anxiety induced as a result of health related search for self, and search for others online (see questions 17, 18, 19 and 20 in Appendix B). There was a significant positive correlation between *anxiety resulting from search for self* online (AnxSFS) and *anxiety resulting from search for others* online (AnxSFO), ( $r = .500$ ,  $N = 20$ ,  $p = .025$ , two tailed), see Table 4 (p. 39) for descriptive statistics, and Table 5 for correlation.

Table 5. Anxiety and health related search online correlation matrix

Correlations								
		Anxiety search self online	Anxiety search others online	review serious content online	rate online diagnosis	online compulsive	online interesting	Whiteley
Anxiety search self online	Pearson Correlation	1	.500*	.615**	.309	.564**	.344	.541
	Sig. (2-tailed)		.025	.004	.185	.010	.137	.014
Anxiety search others online	Pearson Correlation	.500	1	.695**	.148	.482*	.012	.261
	Sig. (2-tailed)	.025		.001	.532	.031	.960	.267
review serious content online	Pearson Correlation	.615*	.695**	1	.535	.531*	.385	.292
	Sig. (2-tailed)	.004	.001		.015	.016	.094	.212
rate online diagnosis	Pearson Correlation	.309	.148	.535	1	.486*	.550	-.026
	Sig. (2-tailed)	.185	.532	.015		.030	.012	.912
online compulsive	Pearson Correlation	.564*	.482*	.531*	.486	1	.341	.256
	Sig. (2-tailed)	.010	.031	.016	.030		.141	.276
online interesting	Pearson Correlation	.344	.012	.385	.550	.341	1	.446
	Sig. (2-tailed)	.137	.960	.094	.012	.141		.049
Whiteley	Pearson Correlation	.541*	.261	.292	-.026	.256	.446	1
	Sig. (2-tailed)	.014	.267	.212	.912	.276	.049	
	N	20	20	20	20	20	20	20

Note: \* Correlation is significant at the 0.05 level (2 tailed)

\*\* Correlation is significant at the 0.01 level (2 tailed)

The AnxSFS score was calculated by a formula comprising of questions 17 and 19, the AnxSFO score was calculated by a formula comprising of questions 18 and 20, reference questionnaire (Appendix B).

Additionally significant correlations were noted between anxiety resulting from search for self online scores and review of serious content online; ( $r = .615$ ,  $N = 20$ ,  $p = .004$ , two tailed), anxiety resulting from search for self online scores and finding online search compulsive; ( $r = .564$ ,  $N = 20$ ,  $p = .010$ , two tailed) and anxiety resulting from search for self online scores and the Whiteley score; ( $r = .541$ ,  $N = 20$ ,  $p = .014$ , two tailed). Moreover significant correlations were noted between anxiety resulting from search for others online scores and review of serious content online; ( $r = .695$ ,  $N = 20$ ,  $p = .001$ , two tailed), and between anxiety resulting from search for others online scores and finding online search compulsive; ( $r = .482$ ,  $N = 20$ ,  $p = .031$ , two tailed). (See Table 5. p. 40)

#### Prediction of Cyberchondria

No association was found between Becks scores and scores reporting anxiety resulting from search for self online, ( $r = .211$ ,  $N = 20$ ,  $p = .372$ , two tailed), similarly no association was found between Becks scores and scores reporting anxiety resulting from search for others online; ( $r = -.306$ ,  $N = 20$ ,  $p = .190$ , two tailed). There was however a positive correlation between Whiteley scores and anxiety induced by search for self (AnxSFS score) reported as follows: ( $r = .541$ ,  $N = 20$ ,  $p = .014$ , two tailed).

#### Becks and Whiteley measures

There was a significant positive correlation between the Becks Inventory and Whiteley scores ( $r = .587$ ,  $N = 20$ ,  $p = .006$ , two tailed), see Table.4 (p.41) for descriptive statistics). Ninety percent of Becks Participant scores were in the mild anxiety category, 10% ( $n = 2$ ) fell in the moderate anxiety category. No Participants met the official criteria for hypochondria according to the Whiteley scale.

### Non significant results

No relationship was found between the media score (and scores reported under AnxSFS ( $r = .319$ ,  $N = 20$ ,  $p = .170$ , two tailed) see Table 4 (p. 39) for descriptive statistics, equally no relationship was found between the media score and AnxSFO ( $r = -.005$ ,  $N = 20$ ,  $p = .982$ , two tailed).

## **Results: Study Two (B: qualitative)**

### **Thematic Analysis**

Thematic analysis of the qualitative data captured in focus group discussion sessions is reported under three main headings. Themes identified are listed in Table 6, some representative quotations are listed, the balance can be found in Appendix O. Additionally findings have been mapped (Appendix P) in a discussion model regarding medical search online.

Table 6. Thematic Analysis of focus group discussion content

Major over lapping themes	Minor overlapping themes	Subject specific themes
Curiosity/information seeking	Escalation	Diagnostics
Availability	Reassurance	Doctor-patient relationship
Media	Empowerment	Intervention
Anxiety		Medicating
Trust		Forums
Cost		The future

### **Major over lapping themes**

#### **Curiosity/information seeking**

Focus group Participants reported levels of curiosity regarding medical information seeking. Those with a medical family background reported resisting propensity to search for information online:

**A1/519-523:** “If I heard of like someone close to me with an illness or something I would be curious about it”

**D4/150:** “you can spend a lot of time searching for stuff online”

### Availability of information and the Internet

Participants stated that they searched for health related information online, because it was easier, immediate, more available and quicker than going to a doctor:

**A1/312:** “Just the easy access of it, that it’s so freely available”

**B4/190-195:** “it’s really handy... You’ve a computer in front of you all day”

### Media

Participants spoke of the role of media regarding health information reporting elements of mass hysteria and sensationalism concerning health scares:

**A4/ 226:** “Well... it was like a mass hysteria thing, through the newspaper”

**B2/176:** “So there’s a lot of information on the radio about cancer at the moment”

### Anxiety/concern

Participants reported anxiety and concern regarding health related search online, review of severe conditions such as cancer were reported as increasing anxiety:

**B4/144-149:** “obviously things like cancer ... you do kind of worry”

**B1/534:** “Yeah, it (medical search online) can generate anxiety. It can generate hypochondria and misinformation”

### Trust

Some Participants did not trust the web; however others had developed trusted communities:

**A2/553-559** “the Internet’s a great medium ... but I mean, it’s not always accurate”

### Cost

Participants agreed that there were strong financial incentives to search for medical information online, potentially avoiding cost of GP or specialist consultations:

**C5/280-281:** “I hate going to a doctor to be told, ‘Oh, it’s something viral. Go home ... there you are €50”

### **Minor overlapping themes**

#### Escalation

Participants reported escalation of health concerns following medical search online for self and for dependants:

**A5/ 267-271** “I have a headache and I’m dizzy... It could just be stress... (Online) It’s always going to be more severe”

#### Reassurance

Participants noted that medical search online could provide reassurance, others noted that they required face to face contact:

**C1/1506 -1512:** “It’s (nurse line) a calming voice ...with Google, you don’t get that”

#### Empowerment/knowledge

Participants noted that medical knowledge gained online could be empowering in terms of ability to self diagnose, compare notes and to compete with medical professionals:

**C3/756-758** “I think it’s they think that by looking on the Internet, they know as much as the doctor”

## **Subject specific themes**

### **Diagnostics**

Participants noted the ease with which people could diagnose online, commenting that those who engaged in self diagnosis online were typically of a negative disposition, appeared to be hypersensitive to symptoms and had hypochondriac type tendencies:

**C3/1183-1188:** - “people I’ve come across who do a lot of Internet research tend to be hypersensitive to the symptoms and they just get carried away”

### **Doctor-patient relationship**

Some Participants believed Google search/printouts could speed up diagnosis, referring to search as a “second and third opinions”; others thought that dealing with same was stressful for doctors. However most reported very negative feedback from doctors when results of online search were presented. They reported doctor’s attitudes as disdainful, dismissive and irritated.

**A5/657-660:** “Sometimes I think it (internet printouts) could speed up a diagnosis”

**D1/378:** “people use it (the internet) for second and even third opinions”

### **Intervention/problem solving**

Participants noted use of online search to support dependents, additionally as a useful tool in problem solving:

**B3/412-416:** “definitely you would hope for an answer that would lead to a solution”

### **Medicating**

A participant noted an event whereby her husband was diagnosed and given medication by his mother (described as a hypochondriac), when checked with a

professional the dose provided was an overdose. Participants reported self medicating, and medicating children with analgesics, codeine and paracetamol:

**C3/ 630:** “She’s given him an overdose. They’re the same drug”

### Chat rooms/forums

Some participants promoted the use of online forums, stating benefits as shared experience, anonymity, it was noted that there are forums where doctors participate:

**A4/634-637:** “I think it’s good the way they’re anonymous”

### The future

Participants advocated a continuing role for doctors in terms of future health care. Regulation, filtering, monitoring, referencing and policing were all mentioned as key requirements of online health information services of the future:

**A1/933:** “filter it and monitor it online”

**C4/1357:** “They’ll have to regulate”

**C5/1382:** “I’d love to see it policed more”



## **Discussion: Study Two**

Focus group discussions were productive in terms of generating a large amount of information. Information discussed was generally less intimate than the case history sessions; however this was expected in terms of the difference in data collection methodology. Nonetheless interesting content was captured, the results of the focus group studies have been considered and analysed in the context of the literature reviewed, and findings are as follows:

### **Cyberchondria and Cyberchondria by Proxy**

There was a significant positive correlation between *anxiety resulting from search for self* online (AnxSFS) and *anxiety resulting from search for others* online (AnxSFO) thus supporting the primary hypothesis “there will be a correlation between medical search online for self (cyberchondria) and search for others (cyberchondria by proxy). This finding is also reflected in the focus group discussion where Participants reported use of online search to support dependents (Fox et al., 2000; Lewis, 2006; White and Horvitz, 2009), Participants also reported escalation of health concerns following medical search online for self (White & Horvitz, 2009) and for dependants.

Economic motives were expressed in terms of search for others, to avoid the cost of GP or specialist consultations, presenting a possible primary gain (Butcher et al., 2010; Criddle, 2010). Some expressed concerns regarding attempts to diagnose online, particularly concerning minors, an indication of concern regarding search by proxy. Additionally Participants reported curiosity, temptation and interest regarding medical information seeking for self and others online, this finding is supported by Sillence and Briggs (2007). Temptation may imply a level of compulsion (Greenfield, 2010) and addictive tendencies (Young, 2004). However it should be noted that Participants with a medical family background reported resisting search, Belling (2006) reports antipathy in the medical community regarding online search, which supports the discussion findings.

Additionally significant correlations were noted in a cluster of co-morbid tendencies; between anxiety resulting from search for self online scores and review of serious content online, a feature of cyberchondria (White & Horvitz, 2009). This

finding is supported in the focus group discussions where Participants reported anxiety and concern regarding health related search online, review of severe conditions such as cancer were reported as increasing anxiety, conforming to criteria for cyberchondria (White & Horvitz , 2009)

Positive correlations was found between anxiety resulting from search for self online , searching for others online, and finding online search compulsive, potential Internet addiction (Young, 2004) and compulsiveness (Greenfield, 2010) traits. The compulsive aspect (Greenfield, 2010), perhaps providing insight into intermittent reinforcement aspects of search online, and importantly motivation to engage in this activity.

A positive correlation was also found between anxiety resulting from search for self online scores and the Whiteley score; consistent with current research into hypochondriacal tendencies online (American Psychiatric Association, 2011). Moreover significant correlations were noted between anxiety resulting from search for others online scores, and review of serious contents online, potentially a characteristic of cyberchondria by proxy. A participant reported an incident whereby her husband was given medication by his mother who had searched online, the dose provided was an overdose, evidence of “by proxy” activity (Moses, 2011), normally found in somatoform populations (Day & Moseley, 2010, Criddle, 2010).

#### *Prediction of Cyberchondria*

Findings reported a significant positive correlation between the Becks Anxiety Inventory and the Whiteley index, however no association was found between Becks scores, and scores reporting anxiety resulting from search for self online. Similarly no association was found between Becks scores and scores reporting anxiety resulting from search for others online. Therefore it may be assumed that in terms of the second hypothesis “There is a correlation between Anxiety, Hypochondria and Cyberchondria” there would appear to be no apparent relation between anxiety as measured by Becks, and anxiety resulting from search for self, and/or search for others online. There was however a positive correlation between Whiteley scores and anxiety induced by search for self, thus indicating a possible association between Hypochondria and Cyberchondria, which would partly support the second hypothesis.

Participants noted the accessibility of online diagnostics (Sillence & Briggs, 2007) particularly regarding generic symptomatology, negative disposition, hypersensitivity to symptoms, and “hypochondriacal tendencies” were noted in those who engaged in diagnostic processes, consistent with findings of Asmundson et al. (2001).

### *Role of Media*

In terms of the third research question: “investigation of the role media plays in influencing the process” no relationship was found between the media score and scores reported under anxiety resulting from search for self, and anxiety resulting from search for others. However Participants did report some media induced mass hysteria, and sensationalism concerning health scares. Stating that people may be scared into believing they had an illness, media induced health anxiety is supported by Belling (2006). Additionally Participants noted that young mothers may be vulnerable, perhaps media induced anxiety may account for some elements of search “by proxy”.

### *General Discussion*

There was a significant positive correlation between the Becks Inventory and Whiteley scores this result was to be expected given the known relationship between Anxiety and hypochondria (Asmundson et al., 2001).

Participants noted that medical search online provided limited reassurance (Sillence & Briggs, 2007); failure to be reassured is a feature of hypochondria (Asmundson et al., 2001). Participants noted that medical knowledge gained online could be powerful (Bastian, 2003) representing an unwelcome threat to the medical community (Belling, 2006; Lewis 2006), however potentially bordering on somatoform presentation (Criddle, 2010). Some Participants trusted the web (Green, 2007), some did not trust their doctor and used search to bridge that trust, findings supported by Sillence and Briggs (2007). A number of Participants indicated that search/printouts could speed up diagnosis (Meisel, 2011), interestingly referring to search as a “second or third opinion”. Participants acknowledged that search could be stressful for doctors (Belling, 2006). However negative feedback was reported regarding presentation of search to doctors, attitudes described as “disdainful”,

“dismissive” and “irritated” findings supported by Belling, (2006) and McDaid and Park (2011). Participants supported the use of chat rooms for medical exchange, stating positives as altruistic shared experience (Adar & Huberman, 2000; Fox et al., 2000; Joinson, 2001) and anonymity (Turkle, 1995). Regulation, filtering, monitoring, and policing were all mentioned as key requirements of online health information services of the future, findings supported by Sillence and Briggs (2007).

There are implications regarding these findings from a theoretical perspective, firstly primary and secondary gains regarding somatoform disorders have been investigated (Asmundson et al., 2001; Criddle, 2010; Day & Moseley, 2010), however little or no research has been conducted into gains associated with cyberchondriac or CbP type activity, this finding requires further research. Secondly there appears to be an association between hypochondria and cyberchondria, further investigation of this linkage is required perhaps employing alternative measures such as the Health Anxiety Inventory (Salkovskis et al., 2002).

In terms of practical implications patients are now presenting at medical practices with a “Google stack” of information, the evidence suggests that the majority of practitioners are struggling to cope with same (Belling, 2006). Search online may generate anxiety, however that anxiety may be exacerbated rather than appeased by the current stance of the medical community, in practical terms this may lead to increased levels of health anxiety in the general population, a concern for mental health practitioners and the charities interfacing with this population.

A greater understanding of the actual role of technology in the process is required, from a practical perspective the ranking algorithms that currently underlie search would appear to compound the issue (White & Horvitz, 2009), however it is likely that a substantial evidenced based study, identifying the association between search presentation and consequential negative mental health impact, would be required before relevant companies may address the issue. Cyberchondriac activity “by proxy” is a cause for great concern, given the involvement of dependent vulnerable populations. The literature warns of impending catastrophes (McDaid & Park, 2011; Moses, 2011), findings in this study highlighted widespread syndication/exchange of medical information online amongst non-medical populations, diagnostics and self-medicating evidenced by a reported case of a

“potential overdose” documented in this study. In real terms these issues need to be addressed by further research, before as predicted, there are consequences.

The limitations of the study are as follows; limited number of participants (N=20), homogeneity of participants, limited time available to complete all measures and engage in in-depth discussion. Ethical requirements to protect participant confidentiality meant that personal and private experiences could not be freely discussed in the open focus group sessions. Additionally limited quantitative data was captured for analysis.

### *Study One and Study Two*

In terms of the primary hypothesis “there will be a correlation between medical search online for self (cyberchondria) and search for others (cyberchondria by proxy) both studies in fact supported the hypothesis, both finding evidence of anxiety resulting from online health related search for self and others, which is supported by the literature (Belling, 2006; White & Horvitz, 2009)

In terms of the secondary hypothesis, “There is a correlation between Anxiety, Hypochondria and Cyberchondria” Study One Participants confirmed that they experienced anxiety. One Participant in fact displayed hypochondriac tendencies, which would support this hypothesis. Additionally both Participants displayed “cyberchondriac and CbP tendencies”, in so far as could be assessed and measured by this limited study. In terms of the quantitative data, an association was found between hypochondria and cyberchondria, which would partly support this hypothesis, perhaps implementation of different measures in future study, may further support this finding.

Finally regarding the third research question, no evidence was found in either study to confirm the role of media in terms of health related search online. However evidence of interesting cyberpsychology related behaviours, which may consequentially impact on medical search online were noted. Given the Internet's increasing role as a form of media, this area should be addressed and perhaps regulated, participants from both studies made constructive recommendations in this regard.

In terms of overall implications of this research study a number of key areas have emerged, firstly motive to search for self, and for others, requires investigation.

A number of the study findings have been mapped (Appendix P) in a theoretical discussion model, illustrating possible end states resulting from medical search online. The model highlights motivational elements such as curiosity, concern, and economics leading subjects to commence search, and incur anxiety that can result from same. This was contrasted to hypochondriacal conditions, where motivation to seek health related information can commence with anxiety, and culminate in relief (Asmundson et al., 2001). This area requires further research; the model may provide a useful starting point for same. The present study was limited to those who did not suffer from pre-existing mental health conditions, however going forward it is important that these populations are included in any research.

Secondly challenge to medical opinion and knowledge empowerment (Bastian, 2003) offered by the internet via search, intuitive diagnostic websites, and online forums are undoubtedly problematic for medical practitioners (Belling, 2006). A limitation of the present study was the one dimensional “patient only” perspective of the study. In terms of future study it would be useful to quantify the problem from a medical practitioner/frontline medical healthcare staff perspective, where it is likely there will be major insights in terms of the day to day presentation of the problem, and the stress and complexity for practitioners associated with dealing with same.

Finally a much larger quantitative study is required to support the findings of this study, where interesting variables such as gender, age, socio economic demographic, ethnicity, culture and familial/generational influence could be explored. Criddle (2010) notes a greater female incidence of MSbP, Sillence et al (2006) note that the majority of those who search for health related information online are female.

Participant self-selection could be considered as a weakness of this study, a greater number of participants randomly selected would address this problem. Furthermore similar prompts in the case history and focus group scripts (Appendix B & L) may have resulted in homogeneity of themes explored, future research design should allow for open unprompted discussion which may lead to other important insights. Given Participants expressed preferences for open dialogue (Kleeman, 2011)

in online forums, it would perhaps be interesting to consider incorporating data capture from same in future study design.

### **Conclusion**

No evidence was found to support the hypothesis of a general relationship between health related search for self, and search for others online. However when anxiety was considered as a variable, a significant positive correlation was found, thus supporting the hypothesis of a relationship between cyberchondria and cyberchondria by proxy, the common trait being the resultant anxiety (White & Horvitz).

This finding addresses a gap in the literature in terms of indentifying the cohort who search for self and search for others, “by proxy” ( Fox et al, 2000; Lewis, 2006; White & Horvitz, 2009) and establishing a common measurable trait, anxiety. Whereas a number of interesting motives were found in terms of drivers to search for others, responsibility, protection, information seeking, availability, empowerment, economic factors and so forth, no definitive conclusions were reached in this regard, a separate study would be required to specifically address motive to search. Acute somatoform tendencies regarding challenging professionals, compulsive medical information seeking, escalation (White & Horvitz, 2009; Criddle, 2010), and symptom checking/creation (Criddle, 2010; Day & Moseley, 2010) were identified in this study. This apparent overlap of somatoform traits and cyberchondriacal type behaviour causes concern. Conversely economic motives to search were identified, this trait is not evident in the somatoform population (Day & Moseley, 2010), and the possible implications of these findings require further research.

Interesting cyberpsychology influences were noted regarding addiction (Young, 1998), compulsion (Greenfield, 2010), online disinhibition (Suler, 2004), self revelation (Joinson, 2001), altruism (Adar & Huberman, 2000) and trust (Turkle, 1995). No influence of media regarding health search was found. However the Internets capacity as a simultaneous delivery mechanism for media and medical search, ranking algorithms, word clusters interpreted as diagnosis, coupled with

subject's propensities to escalate online, makes a strong case for further study, perhaps involving an Internet addiction/compulsion measure.

Finally the medical profession should take note of findings. Doctor patient relationships, professional economic motives in terms of short/multiple appointments (Silence & Briggs, 2007), challenge to practitioner opinion (Criddle 2010), intolerance of information sourced online, and aggressive response to perceived hypochondriacal presentation (Belling, 2006), all would appear to be compounding rather than addressing (Hart et al., 2004, Meisel, 2011) the problem. Typically regarding any behavioural issue impacted by technology and left unaddressed, the problem is likely to become more pervasive, and amplified going forward.



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## **Appendices**

# Appendix A – Table 1. White and Horvitz (2009) Health related search habits

## Appendix A

23:16 • R. W. White and E. Horvitz

Table IV. Summary Statistics on Health-Related Search/Anxiety (per survey respondent)

<b>Health-Related Search Habits</b> ( <i>N</i> = 515)		
On average, how many health-related Web searches do you perform per month?	<i>M</i> = 10.22, <i>SD</i> = 45.58, Median = 2	
On average, how many health-related Web searches for professionally undiagnosed medical conditions do you perform per month?	<i>M</i> = 2.12, <i>SD</i> = 5.84, Median = 1	
Who are your health-related Web searches primarily for?	Yourself	58.1%
	Relative	36.9%
	Friend or work colleague	3.5%
	Other	1.6%
When you seek health-related information online you generally search for? (multiple responses permitted)	Information on symptoms (e.g., headache, chest pain)	85.8%
	Information on serious medical conditions (e.g., cancer, myocardial infarction)	49.1%
	Medical diagnoses	41.7%
	Forums or pages describing others' experiences with similar conditions to your own	38.1%
	Other	6.2%
<b>Health-Related Anxiety</b> ( <i>N</i> = 515)		
On a scale of 1 to 10, how would you rate your overall anxiety about potential medical conditions that are not present or currently undiagnosed (1 = don't worry about health issues, 10 = severe anxiety)?	<i>M</i> = 2.78, <i>SD</i> = 1.71, Median = 2	
Do you think that you are a hypochondriac?	Yes	3.5%
	No	96.5%
Have you ever been called a "hypochondriac" by friends, family, or a health professional (e.g., a physician)?	Yes	4.7%
	No	95.3%
Have you ever been concerned about having a serious medical condition based on your own observation of symptoms <i>when no condition was present</i> ?	Yes	39.4%
	No	60.6%
How often do your Web searches for symptoms / basic medical conditions lead to your review of content on serious illnesses?	Always	1.9%
	Often	19.0%
	Occasionally	42.3%
	Rarely	28.5%
	Never	8.2%

## Appendix B

### **Interview Prompt Script – Case history**

- Introduce subject area, ensure confidentiality – discuss subject details, age status, dependants etc
- General introduction – introduce concept of health related information seeking
- General health – discuss who is responsible for health management? for self and for family, for friends etc ask about any personal experience they might feel comfortable sharing.
- Discuss how do they find health related information – what do they find are the best/ most commonly used sources?
- Discuss the Internet and health related search online – assess pros & cons, any experiences of using online search for health related issues? – if so discuss,
- Discuss what exactly is available online – what forums does the participant use – if any?
- Discuss health related information seeking for self or family – what happens pre search and post search? Are there positives? Are there negatives?
- Discuss impact of health related knowledge from various sources on traditional doctor patient relationship – have they any experience in this area?
- Discuss the future of Health care system and availability of health related information – have they any suggestions?



## Appendix C

### **Interview Consent form**

**This interview will consider behaviour with regarding health-related information seeking. It is being carried out by Mary Aiken MSc student at Dun Laoghaire Institute of Art, Design and Technology, Ireland ([www.iadt.ie](http://www.iadt.ie)).**

**The session will take approximately 45 minutes to complete.**

**Take your time.** Please don't rush to answer questions.

**There are no right or wrong answers.** The best answer to choose is the one that you most identify with.

**Answer honestly.** As much as possible,

This interview session is voluntary and you are free to leave at any point if you wish.

Participation in this interview will not involve any known risks and data gathered in the study will be anonymous, confidential and for research purposes only. The findings of the research may be published in the form of journal articles and conference proceedings, but your individual data will not be identifiable in the published accounts. You are free to withdraw from the study at any time.

If you are 18 or over, understand the statements above and freely consent to participate in this interview please sign and date below.

Participant \_\_\_\_\_

Date \_\_\_\_ / \_\_\_\_ /2010

## Appendix D

### Interview Debrief form

#### **THANK YOU VERY MUCH FOR TAKING PART IN THIS INTERVIEW.**

The session in which you just participated was designed to investigate potential anxiety regarding health-related information seeking

If you have questions about this study or you wish to have your data removed from the study at any time, please contact Mary Aiken, at IADT at the following e-mail address: [mary.aiken@iadt.ie](mailto:mary.aiken@iadt.ie) or you may contact my supervisor Dr. Grainne Kirwan, at IADT at the following e-mail address: [grainne.kirwan@iadt.ie](mailto:grainne.kirwan@iadt.ie)

We thank you sincerely for contributing and assure you that your data is confidential and anonymous, and if published the data will not be in any way identifiable as yours. Your contribution is very useful for the investigation of health anxiety.

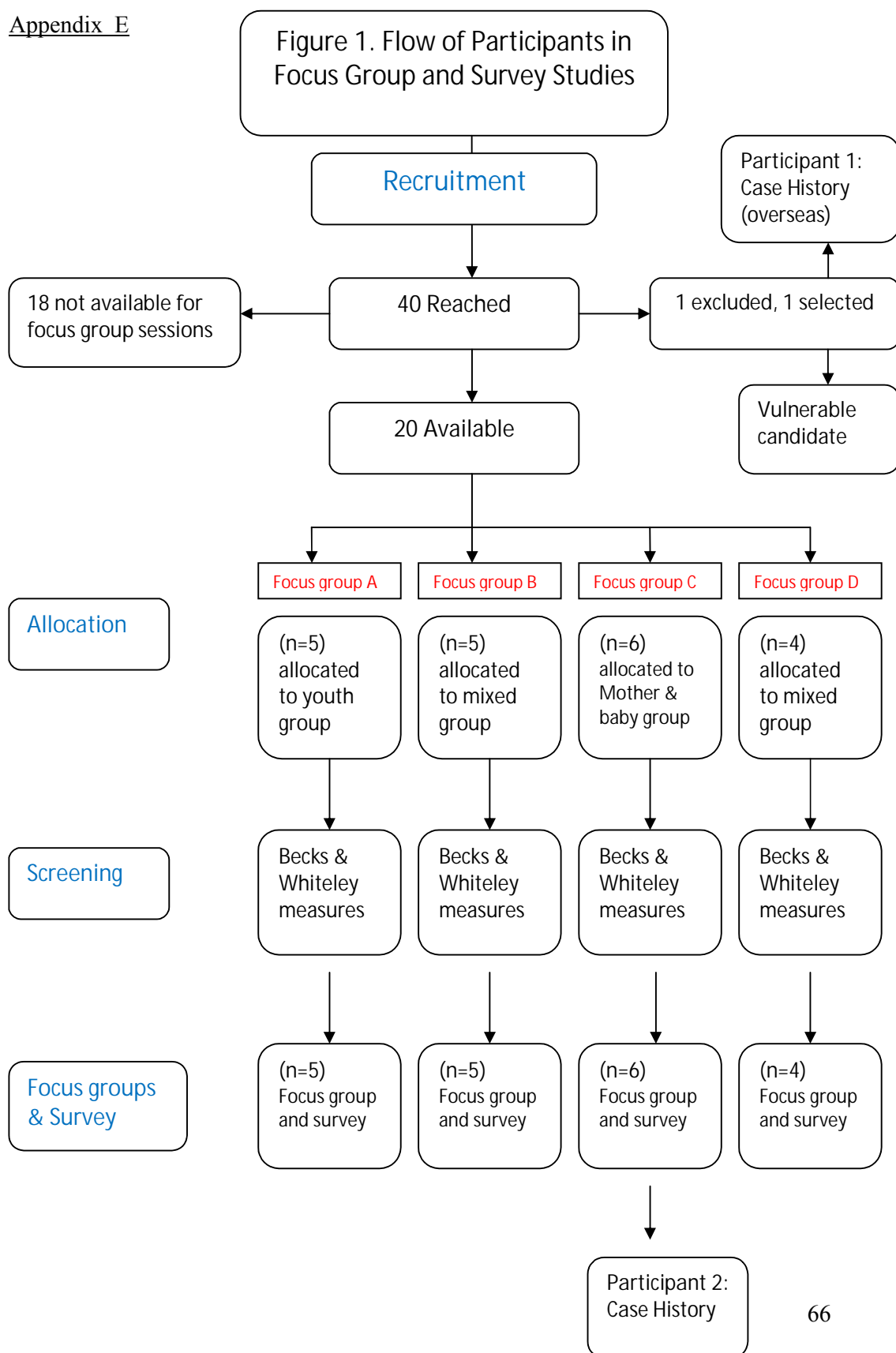
If you have been affected by the content of this study in any way, the organizations below may be of assistance:

**Aware:** support group for depression : phone 1890 303 302 : [www.aware.ie](http://www.aware.ie)

**Reach out:** support group to help with mental health and well being issues:  
phone 1800 66 66 66: [www.reachout.com](http://www.reachout.com)

**The Samaritans:** confidential and emotional support phone: 1850 60 90 90:  
[www.samaritans.org](http://www.samaritans.org)

Appendix E



## Appendix F

### **Quotations Participant One**

#### *Responsibility/protection*

**P1/31:**

“The medical professionals have some responsibility. Obviously they are professionals. And I think myself as a mother, as a wife, absolutely has responsibility for the children who are...obviously not old enough to look after themselves or make any medical decisions”

#### *Doctor – Patient relationship*

**P1/156 -172:**

“Male doctors don’t like to be challenged ...I do find there is stigma with any doctor”

“Sometimes you know more than they do on...because they studied 30 years ago...they’ve not kept up to date”

#### *Health related anxiety*

Participant one when asked specifically about investigation of her child’s health confirmed feelings of anxiety and reconfirmed parental responsibility:

**P1/246 -252:**

“Oh absolutely... especially with small children...you are the primary person responsible for their health maintenance”

#### *Medical information seeking online*

**P1/156 -172:** “If I went to the doctor for myself and a red flag was raised...and the doctor gave me a diagnosis, I would always double-check that diagnosis online, always”

**P1/324 – 327:**

“I have built trust with a virtual doctor”

**P1/336 – 337:**

“The other place I, I go on, which is helpful, because it’s other mothers, is the chat rooms”

#### *Medical website selection criteria*

**P1/394 -399:**

“I would go to their (*medical condition*) page. And if they didn’t know what they were talking about on that page, then I knew that they wouldn’t know”

**P1/422 -424:**

“Searching online can be a dangerous thing... there are websites that are out of date. There are websites that aren’t really reputable”

#### *Online medical information sharing*

**P1/455 -465**

“Sometimes you’re getting 20 different mothers saying different things”

**P1/455 -465:**

“It’s very confusing and conflicting... it could be really dangerous”

**P1/474 -494:**

“Some are saying, Well, I gave 10mls for that...You could try giving this”

“These people who are going to be looking online possibly because they’re not going to take a trip to the doctor because they actually can’t afford it”

#### *Medicating dependents*

**P1/556 -566:**

“Swine flu and all that kind of thing... there’s peer pressure from other mothers”

**P1/568 -578:**

*The role of media*

**P1/600 -606:**

“The media plays a huge role... it’s a double-edged sword I think..”

*Self diagnosis*

**P1/674 -686**

“ probably try and put a few (*symptoms*) together and probably Google it”

**P1/728**

“it ranged from that... and then obviously to things like throat cancer”

**P1/771:**

“Yeah, anxious”

*Diagnosis of others*

**P1/801-853**

“It’s harder when...they’re smaller... they can’t articulate”

“ with something basic, I would just go to the doctor and then search. If it was something more complex, I’d search”

*Knowledge and empowerment*

Participant one acknowledged that sourcing medical information online was empowering, indicating it would be very distressing if she could not perform search going forward:

“If someone said to me, you know, you can’t look for anything online... it would just be a nightmare basically. I’d hate that.... it’s just, knowledge is power”

*Future recommendations*

**P1/959-973**

“I think people need to know...the top ten reputable medical sites”.

“maybe break it down...into areas...if you have cancer... go to this site”.

*Time as a variable*

Participant one emphasised the impact of consulting a Doctor in a fixed time slot noting the process was rushed and that people saved up issues to discuss:

**P1/1032-1041**

“I mean most GPs... rushed in and out in ten (*minutes*)”

“it’s pretty rushed...most people save up their issues”

## Appendix G

### **Quotations Participant Two**

#### *Medical information seeking online*

**P2/76-85**

“Child is vomiting and hot, unable to breathe and coughing in a very disturbing manner... we called a doctor... we called some relatives ...we did Google”

**P2/96-102**

“It was a very scary thing... we were somewhat panic-stricken... from the Google result, we found that the child needed to be steamed”

#### *Medical website search validation*

**P2/149-160**

“I suppose just from using the Internet every day, you become accustomed ... you perceive to be something official.

“You go onto the website... good website... official URL”

#### *Symptom search online*

**“P2/208-253”**

P2: “I wasn’t familiar with the word ‘croup’ at the time, so I was just really just - putting in sentences almost”-

#### *Pivotal anxiety inducing event*

**P2/357 - 366**

“They did say...it could have been a cot death scenario”



### Diagnosis of others online

Participant 2 describes the use of forums, reading through detailed thread discussions (in addition to search) in terms of medical information seeking online.

**R/P2:** 430 - 441

**P2:** “we consulted a number of different sites...others that have forums within the site so you’re speaking with other parents who are experienced”

### Self diagnosis online

Participant 2 reported a previous history of attempting self diagnosis online however conceded that this was not constructive, from the perspective that he had begun to imagine that he had various illnesses; he also described himself as having an anxious disposition, which he claims was caused by his mother’s anxiety regarding his health and welfare as a child:

**P2/473-486**

“I started to think I had things that I didn’t have.... applying my symptoms to other illnesses and even if your symptoms don’t fully match, you kind of go... but I experienced like three out of five of those.’

**P2** 491 – 498:

**P2:** “I would be someone who suffers from anxiety to a certain degree...from my mother”

**P2** 538-539:

**P2:** “She suffers from anxiety I’d say in general, but she was specifically...worried about me”

Appendix H

**Survey questionnaire**

Date \_\_\_\_/\_\_\_\_/2011

Focus Group: \_\_\_\_

Participant: \_\_\_\_

Survey questionnaire – MSc thesis

Please tick box or write in answer where appropriate.

N/A – Stands for not applicable, please tick this box when the question does not apply to you

DKN – Stands for do not know

Please note all questions are optional.

**1. Age - How old are you?** \_\_\_\_\_

**2. Gender - What is your gender?** Male ☐ Female ☐

**3. Nationality - Where are you from?** \_\_\_\_\_

**4. Education - What is your highest level of qualification?**

Primary School ☐

Secondary School ☐

Undergraduate ☐

Postgraduate ☐

**5. Occupation - describes your area of employment:** \_\_\_\_\_

N/A ☐

**6. How often do you exercise?**

Daily ☐

2-3 times per week ☐

Once a week ☐

Less than once a week ☐

Never ☐

**7. Health - How would you describe your general physical health?**

Excellent ☐

Good ☐

Average ☐

Fair ☐

Poor ☐

**8. Do you use the Internet:**

Yes ☐

No ☐

**9. If yes when did you first start to use the Internet?**

Less than one year ago ☐

One to five years ago ☐

More than five years ago ☐

**10. If you use the Internet - How often do you go online? Select the option that most applies to you.**

Always online ☐

Several times a day ☐

At least daily ☐

Rarely ☐

Never ☐

**11. Do you worry about your physical health?**

Always ☐

Often ☐

Occasionally ☐

Rarely ☐

Never ☐

**12. Do you worry about the health of your family?**

Always ☐

Often ☐

Occasionally ☐

Rarely ☐

Never ☐

---

**13. What source do you use for health-related information? (Please tick any that are appropriate)**

Newspapers and Magazines ☐

Medical books ☐

Television ☐

Radio ☐

The Internet ☐

A medical professional ☐

Family ☐ Friends ☐

None ☐

DKN ☐

Other – please specify \_\_\_\_\_

---

**14. If you use the Internet, how many health-related Web searches do you perform a month?**

N/A ☐

Less than once per month ☐

Once per month ☐

Once or twice a week ☐

Daily ☐

Several times a day ☐

**15. Who are your health- related Web searches primarily for? (Tick as appropriate)**

Yourself ☐

Relative ☐

Friend or work colleague ☐

Other – please specify \_\_\_\_\_

**16. Which relatives do your search for (tick as appropriate - and indicate age)**

Child/children ☐

Partner ☐

Parent ☐

Other – please specify \_\_\_\_\_

N/A ☐

**17. Have you ever been concerned about having a serious medical condition based on results of online health search for yourself?**

Always ☐      Often ☐      Occasionally ☐      Rarely ☐      Never ☐      N/A ☐

**18. Have you ever been concerned about a serious medical condition based on results of online health search for your child?**

Always ☐      Often ☐      Occasionally ☐      Rarely ☐      Never ☐      N/A ☐

**19. Does health search on line of your own symptoms cause you anxiety?**

Always ☐      Often ☐      Occasionally ☐      Rarely ☐      Never ☐      N/A ☐

**20. Does health search on line of your child's symptoms cause you anxiety?**

Always ☐      Often ☐      Occasionally ☐      Rarely ☐      Never ☐      N/A ☐

---

**21. Do you find health-related information search online interesting?**

Always ☐      Often ☐      Occasionally ☐      Rarely ☐      Never ☐      N/A ☐

---

**22. Do you find health-related information search on line compulsive?**

Always ☐      Often ☐      Occasionally ☐      Rarely ☐      Never ☐      N/A ☐

---

**23. How often do your web searches for symptoms/basic medical conditions lead to review of content on serious illness?**

Always ☐      Often ☐      Occasionally ☐      Rarely ☐      Never ☐      N/A ☐

---

**24. How do you rate the Internet for diagnosing illness?**

Excellent ☐

Good ☐

Average ☐

Fair ☐

Poor ☐

N/A ☐

**25. Does consulting others sources (i.e. other than the Internet) for health-related information of your own symptoms cause you anxiety?**

Always ☐      Often ☐      Occasionally ☐      Rarely ☐      Never ☐      N/A ☐

---



**26. Does consulting others sources (i.e. other than the Internet) for health-related information of your child's symptoms cause you anxiety?**

Always ☐

Often ☐

Occasionally ☐

Rarely ☐

Never ☐ N/A ☐

---

## Appendix I



---

NAME \_\_\_\_\_ DATE \_\_\_\_\_

Below is a list of common symptoms of anxiety. Please carefully read each item in the list. Indicate how much you have been bothered by each symptom during the PAST WEEK, INCLUDING TODAY, by placing an X in the corresponding space in the column next to each symptom.

	NOT AT ALL	MILDLY It did not bother me much.	MODERATELY It was very unpleasant, but I could stand it.	SEVERELY I could barely stand it.
1. Numbness or tingling.				
2. Feeling hot.				
3. Wobbliness in legs.				
4. Unable to relax.				
5. Fear of the worst happening.				
6. Dizzy or lightheaded.				
7. Heart pounding or racing.				
8. Unsteady.				
9. Terrified.				
10. Nervous.				
11. Feelings of choking.				
12. Hands trembling.				
13. Shaky.				
14. Fear of losing control.				
15. Difficulty breathing.				
16. Fear of dying.				
17. Scared.				
18. Indigestion or discomfort in abdomen.				
19. Faint.				
20. Face flushed.				
21. Sweating (not due to heat).				

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ISBN 015-4018-42-2



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## Appendix J

# Whitely Index

Date \_\_\_\_/\_\_\_\_/2011      Focus Group: \_\_\_\_      Participant: \_\_\_\_

Below is a list of questions about your health. For each one, please circle the number indicating how much this is true for you.

1 = Not at all

2 = A little bit

3 = Moderately

4 = Quite a bit

5 = A great deal

1: Do you worry a lot about your health?

1 2 3 4 5

2: Do you think there is something seriously wrong with your body?

1 2 3 4 5

3: Is it hard for you to forget about yourself and think about all sorts of other things?

1 2 3 4 5

4: If you feel ill and someone tells you that you are looking better, do you become annoyed?

1 2 3 4 5

5: Do you find that you are often aware of various things happening in your body?

1 2 3 4 5

6: Are you bothered by many aches and pains?

1 2 3 4 5

7: Are you afraid of illness?

1 2 3 4 5

8: Do you worry about your health more than most people?

1 2 3 4 5

9: Do you get the feeling that people are not taking your illnesses seriously enough?

1 2 3 4 5

10: Is it hard for you to believe the doctor when he/she tells you there is nothing for you to worry about?

1 2 3 4 5

11: Do you often worry about the possibility that you have a serious illness?

1 2 3 4 5

12: If a disease is brought to your attention (through the radio, TV, newspapers, or someone you know), do you worry about getting it yourself?

1 2 3 4 5

13: Do you find that you are bothered by many different symptoms?

1 2 3 4 5

14: Do you often have the symptoms of a very serious disease?

1 2 3 4 5

## Appendix K

### **Focus Group Consent form**

**This focus group session will consider behaviour with regarding health-related information seeking. It is being carried out by Mary Aiken MSc student at Dun Laoghaire Institute of Art, Design and Technology, Ireland ([www.iadt.ie](http://www.iadt.ie)).**

**The session will take approximately 60 minutes to complete.**

**Take your time.** Please don't rush to answer questions.

**There are no right or wrong answers.** The best answer to choose is the one that you most identify with.

**Answer honestly.** As much as possible, avoid the temptation to choose answers simply because they sound most desirable.

This focus group session is voluntary and you are free to leave at any point if you wish.

Participation in this focus group session will not involve any known risks and data gathered in the study will be anonymous, confidential and for research purposes only. The findings of the research may be published in the form of journal articles and conference proceedings, but your individual data will not be identifiable in the published accounts. You are free to withdraw from the study at any time.

If you are 18 or over, understand the statements above and freely consent to participate in this focus group session please sign and date below.

Participant \_\_\_\_\_

Date \_\_\_\_/\_\_\_\_/2010

## Appendix L

### **Prompt Script – Focus Group**

#### **Subject prompts**

- General introduction – introduce concept of health related information seeking  
If discussion is slow introduce subject related topic to start discussion, recent article or study.
- General health – discuss who is responsible for health management? for self and for family, for friends etc
- Discuss how to find health related information – what are the best/ most commonly used sources?
- Discuss the Internet and health related search online – assess pros & cons, any experiences n the group of using online search for health related issues – if so discuss,
- Discuss what exactly is available online – what forums do participants use – if any?
- Discuss health related information seeking for self or family – what happens pre search and post search? Are there positives? Are there negatives?
- Discuss impact of health related knowledge from various sources on traditional doctor patient relationship
- Discuss the future of Health care system and availability of health related information – any suggestions?

## Appendix M

### Debrief form

#### **THANK YOU VERY MUCH FOR TAKING PART IN THIS FOCUS GROUP.**

The session in which you just participated was designed to investigate potential anxiety regarding health-related information seeking

If you have questions about this study or you wish to have your data removed from the study at any time, please contact Mary Aiken, at IADT at the following e-mail address: [mary.aiken@iadt.ie](mailto:mary.aiken@iadt.ie) or you may contact my supervisor Dr. Grainne Kirwan, at IADT at the following e-mail address: [grainne.kirwan@iadt.ie](mailto:grainne.kirwan@iadt.ie)

We thank you sincerely for contributing and assure you that your data is confidential and anonymous, and if published the data will not be in any way identifiable as yours. Your contribution is very useful for the investigation of health anxiety.

If you have been affected by the content of this study in any way, the organizations below may be of assistance:

**Aware:** support group for depression : phone 1890 303 302 : [www.aware.ie](http://www.aware.ie)

**Reach out:** support group to help with mental health and well being issues:  
phone 1800 66 66 66: [www.reachout.com](http://www.reachout.com)

**The Samaritans:** confidential and emotional support phone: 1850 60 90 90:  
[www.samaritans.org](http://www.samaritans.org)

## Appendix N

Adapted from Donaghy (1990) – ‘ways to build a comfortable climate’

- Welcome participants
- Make sure consent forms are signed
- Introduce yourself spend a few minutes on small talk about some current issue or about the weather
- Offer refreshments
- Use a warm and friendly tone of voice
- Sit beside the participants in comfortable chairs
- Give the participant full orientation of the aims of your study
- Give an outline of the focus group session



## Appendix O

### Quotations Focus Groups

#### Major overlapping themes

##### Curiosity/information seeking

**A4/188-194:** “Well, there’s always going to be, like a pending period between, like even if you ring up the doctor..... sometimes when you feel you might be, suspect that you have one of these major illnesses, you know, you try and diagnose yourself quickly”

**A5/424-428** “I would read books more than I would go on the Internet”

**A4/450-467:** “Not for physical health, maybe for mental health... it’s curiosity more than anything”

**A1/519-523:** “If I heard of like someone close to me with an illness or something I would. be curious about it”

**B1/282-290:** “ when people have children... rather than calling a doctor every five minutes...they might be tempted to Google something”

**C3/145:** “I would never check online...my family are all medics, so I would always go to the doctor”

**D4/150:** “you can spend a lot of time searching for stuff online”

##### Availability of information and the Internet

**A1/312:** “Just the easy access of it, that it’s so freely available”

**A3/326:** “Quicker than having to go to a doctor, or make an appointment”

**A4/331-336:** “sorry, just because these things are quick and easy...readily available, it doesn’t necessarily mean they’re.... good things”

**B4/190-195:** “it’s really handy... You’ve a computer in front of you all day”

**A4/996-968:** “it’s just the whole readily available...thing”

**C2/1001:** “The web is through my veins”

**D2/300:** “it (the internet) can be dangerous)”

### Media

**A4/ 226:** “Well... it was like a mass hysteria thing, through the newspaper”

**A2/804:** “I think they (the media) definitely have to be careful - everyone was aware of it (swine flu). and everyone definitely thought they were going to catch it at one stage”

**A5/844-849:** “towards the end of the epidemic it was more sensationalised through ....people selling their stories”

**A4/1023:** “Yeah, because they advertise the pharmaceuticals beneath the diagnosis”

**B2/176:** “So there’s a lot of information on the radio about cancer at the moment”

**B1/854-859:** “I mean the media exploit anything like that (swine flu)... it’s sensationalised, it’s taken out of context. It feeds on the anxieties of people”

**B4 890- 906:** “Like the radio and TV. The amount of hospital dramas that are on at the moment”

**C3/467-469:** “They give you the headlines just to make you buy the paper”

**C6/496-499:** “But I think that the younger mums, it must be worrying. They’re reading all this”

### Anxiety/concern

**A3/586-589:** “There’d be so much information out there that you could just see something that might not be related to yourself but it could scare you to death”

**A4/ 291-294:** “the ambiguity is actually really bad...it might lead to more anxiety... really big words that only a doctor would understand”

**B4/144-149:** “obviously things like cancer ... you do kind of worry”

**C1/100-112:** - “I wouldn’t be totally in the knowledge of knowing what site is good and not good, so there’s no point, you know, scaring yourself”

**C4/124 -126:** “I used to Google stuff. I don’t anymore because I would get paranoid... and always the worst case scenario will jump out at you... I think it’s too scary”

**B1/534:** “Yeah, it (medical search online) can generate anxiety. It can generate hypochondria and misinformation”

### Trust

**A2/553-559** “the Internet’s a great medium ... but I mean, it’s not always accurate”

**A2/ 721-725:** “if it was kind of a local GP ... you’re more inclined to trust them whereas if it’s someone brand new and... you feel you can’t trust the person, then you come to them with this sheet”

**B1/482-488:** “narrowing down the randomness of the Internet by going to a specific medical forum that they trust... maybe have built up relationships with the other subscribers to that forum... if you use Twitter, then you’re more, you’re part of a more specific community”

**C2/33:** “they were misdiagnosed... I wouldn’t necessarily, necessarily trust my doctor 100%”

**C2/64-65:** “there are an awful lot of people who put up sites that don’t have a clue about anything... wouldn’t necessarily trust it 100%”

**C1/100-102:** “just because doctor tells you something, doesn’t necessarily mean it’s true”

**B2/532:** “Well, maybe they do take solace in finding an answer on the Internet that they can believe in”

**B3/199:** “It’s too impersonal to trust. Plus I think your health is a very personal thing”

### Cost

**A5/246-249:** “I think a lot of people get put off by going to a GP because it’s so expensive that they would kind of just go to a family member or go on the Internet”

**A5/1063:** [Interposing] I think we would more because the UK has the NHS which is free healthcare

**C5/280-281:** “I hate going to a doctor to be told, ‘Oh, it’s something viral. Go home ... there you are. €50”

**C3/ 350-352:** “that’s the danger I think with things like the Internet...they’ll read up and they’ll say, ‘my child has this’... do I need to bring them to the doctor?”

**C2/ 787-794:** “my mum has emphysema... but my mother’s consultant doesn’t say a lot for a consultant that you’re paying €150 an hour for, for five minutes... I looked up different things about emphysema online”

**C6/1405-1406:** “you’re worried...you want to go to the doctor. It is €50 plus the prescription...and its money you’re spending that could be spent on other things”

### **Minor overlapping themes**

#### Escalation

**A5/ 267-271** “I have a headache and I’m dizzy... It could just be stress... but it could say to you anaemia... it’s always going to be more severe”

**B3/225-227:** “I think the Internet has maybe multiplied, added to it” (a person’s hypochondria disposition)

**C3/704-708:** “you’ll get somebody else whose child maybe has... a slightly high temperature, but really it’s a cold. But they read into it that suddenly they have pneumonia”

#### Reassurance

**A4/1038-1040:** “you will feel better... is advertised beneath it”

**B5/312-315:** “I just like to... be dealing face-to-face with a professional who’s qualified... I don’t feel that security on the Internet”.

**C1/1506 -1512:** “It’s (nurse line) a calming voice ...with Google, you don’t get that”

*Empowerment/knowledge*

**A4/681-686:** I think that people find it empowering when they believe that they’ve diagnosed themselves.... it just all kind of comes back to the ego”

**D2/ 411:** “people learn by comparing notes online”

**C3/756-758** “ I think it’s they think that by looking on the Internet, they know as much as the doctor”

**Subject specific themes**

*Diagnostics*

**A4/ 284-286** “symptoms and everything for illnesses online... It’s always simple and accessible”

**A4/352-355** “But you never really hear people talk about self-diagnosis in a positive light”

**A4/812-817 :** “ those kinds of illnesses (swine flu)...have like eight symptoms... it’s all really basic things like a chesty cough and a swollen mouth...you could believe you have it”

**B3/207-210:** “I know a hypochondriac who any illness on the planet... he has it... Googling, he has it... He’d be on the Internet a lot”

**C3/1183-1188:** - “people I’ve come across who do a lot of Internet research tend to be hypersensitive to the symptoms and they just get carried away”

*Doctor-patient relationship*

**A4/ 383-393** Yeah, they (doctors) reassure you...there isn’t anyone patting you on the back if you find out you’ve some major illness, when you diagnose yourself online”

**A5/657-660:** “Sometimes I think it (internet printouts) could speed up a diagnosis”

**A4/688-692:** “it adds to the stress of a doctor, trying to either convince or unconvince this patient of something he’s holding in front of him (google stack)”

**A1/751-754:** “I think it kind of contradicts the whole reason for going to the doctor in the first place, bringing a second like opinion with you”

**D1/378:** “people use it (the internet) for second and even third opinions”

**B3/376-379:** “doctors aren’t great communicators”

**B5/384-398:** “it’s the fallibility thing for me”

**B1/710:** “Total disdain... you shouldn’t have done that”

**B2/739:** “the doctor requested that I didn’t use the Internet”

**C2/84-86** “What drug do I need to treat that?... they (doctors) don’t treat the person... they just treat the actual symptom”

**C3/603:** “A bit irritated”

**C2/859:** “dismissive, very dismissive”

### Intervention/problem solving

**A2/490-494:** “people are always inclined to worry about... grandparents or whatever. you might be inclined to look up for...people who you think aren’t capable”

**B3/412-416:** “definitely you would hope for an answer that would lead to a solution”

### Medicating

**C3/ 630:** “She’s given him an overdose. They’re the same drug”

**B3/88-93:** “you just endure or self medicate on a certain level... Solpadine kills everything”

**D3/451:** “ they self diagnose...and then self medicate”

**C3/1281-1284:** “If they’re crying, give them Calpol. They fall over, give them Calpol. They won’t sleep, give them Calpol”.

Chat rooms/forums

**A3/615 - 618:** They're more personal than just general searches though... It's, its real people"

**A4/634-637:** "I think it's good the way they're anonymous"

**C2/889-897:** " I go into forums ... and listen ( to people)... their experience... YouTube is my favourite"

**C2/1097:** "Well, there are some websites, or medical websites that actually have doctors"

**D4/607:** "they problem with forums... is that the people are anonymous"

The future

**A2/891-897:** "I think people have always looked to a physical person... in terms of helping you, even like thousands of years ago... Witch doctors...there's always going to be someone...who has more knowledge"

**A2/904-909:** "I think there's always going to have to be some kind of human interaction... doctors will become better with technology"

**A1/933:** "filter it and monitor it online"

**C2/1315-1320 :** " our children are all about technology and all about the Internet"

**C2/1348:** "a link will evolve because the pharmaceutical companies round the world are making absolutely billions"

**C4/1357:** "They'll have to regulate"

**C5/1382:** "I'd love to see it policed more"

**D2/711:** "Internet health related information should be referenced ...taken from approved websites"

**D1/754:** "Health boards should run the sites"

## Appendix P

Figure 2. **Mapping End State: Theoretical Model** ( following health-related search online)

