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A Rare Disease Perspective: Understanding the Relationship Between Online Health Information Services, Health Anxiety, and Trust

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Abstract

Approximately 30 million people in the EU, which equates to 1 in 15 people, have been or will be affected by a rare disease [21]. Rare disease patients are often misdiagnosed or undiagnosed, likely due to their health care providers' lack of knowledge and experience with rare diseases [57]. Therefore, rare disease patients may be more inclined to research into their health than the general public. A popular method of looking into health information is through online and digital health information services. These services can empower patients to take greater control of their health, however, they can also increase health anxiety and harm users' emotional state. Therefore, a few researchers have considered how to reduce the effects online health information services have on health anxiety. However, while people often talk about the worried well when considering health anxiety, they may unknowingly neglect the worried *unwell*. While it is important to reduce unfounded health concerns in order to promote patients' well being, it is also important that it does not prevent those who are unwell from acting on the information found.

This study will analyse methods of reducing health anxiety and evaluate whether these methods prevent users from seeking their health care providers. Furthermore, the experiences of rare disease patients regarding online health information will be contrasted and compared to the experiences of the general public. This will be done using a questionnaire and three interviews analysed thematically. Findings showed a number of effective design concepts to reduce health anxiety without preventing action. The most promising design concepts proposed are firstly detecting and down weighting escalatory websites from search results. Secondly, the use of visual analytics such as graphs reduces health anxiety caused by confusion. Finally, listing symptoms such that symptoms inputted present the resulting condition as more likely while symptoms not inputted (which are associated with that condition) present the condition as less likely reduces health anxiety by encouraging balanced thinking.

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1 Introduction

1.1 Rare Diseases

In the United Kingdom, a disease is said to be rare if it affects less than 1 in 2,000 people [20]. Due to their low prevalence, rare diseases take a long time to diagnose [11, 49], even up to 30 years [22]. "Late diagnoses delay the beginning of adapted treatments and can have severe irreversible, debilitating and life-threatening consequences" [34]. Furthermore, the diagnostic process for rare diseases between 2008 and 2018 cost the National Health Service (NHS) in excess of £3.4 billion [42], thus a faster diagnosis would not only significantly improve the health care of individuals, but it would also aid the health care service as a whole.

Therefore, it is important to provide resources to speed up the diagnosis, and since "the vast majority of patients with rare diseases actively seek information" [11], the use of online health information services may empower patients to speed up this process and to have greater control of their health journey. Furthermore, nearly 1 in 5 rare disease patients suggested the possibility of a rare disease to their healthcare professionals [34], and since rare disease patients often become 'experts' in their disease [11], empowering them to have a greater involvement in the diagnostic process will initiate this process sooner and utilise their desire to seek information to encourage early interventions.

1.2 Online Health Information Services

In March 1998, the NHS launched NHS Direct, a telephone service help line staffed by nurses in order to provide easily accessible health information and as a result, reduce the demands on general practitioners (GPs) as well as accident and emergency departments [48]. After its initial success, the NHS launched an additional website which was implemented in December 1999 to further support the NHS Direct service. In August 2010, it was announced that NHS Direct was to be replaced with NHS 111 so that the number was not only easier to remember, but also free of charge, unlike the previous 0845

number [48]. NHS 111 Online is still a popular resource for health information in the UK today along with other NHS websites and applications.

Many other health related websites were also developed in the 90s [56] and this newly found resource for health information introduced the possibility to empower patients to have greater control over their health. Since then, the use of the internet for health information has exponentially increased so much so that by 2011, 80% of internet users had looked online for health information [26].

1.3   Health Anxiety

Most people have experienced health anxiety of some level, although it is usually adaptive and prompts people to seek appropriate medical care [67]. However, health anxiety can harm individuals' well-being when it becomes maladaptive (disproportionately low) or excessive (disproportionately high). Health anxiety disorders, such as hypochondria, are characterised by excessive health anxiety.

Common thought patterns of health anxiety disorders include disease conviction, the belief that one suffers from a disease; disease preoccupation, repeated thoughts and images of diseases and death; high sensitivity to bodily changes; and difficulty believing reassurance. These thought patterns often lead to, and often stem from, fears of having or of contracting a disease as well as increased fear or anxiety from disease related stimuli. This often leads to, and often stems from, repeated checking of one's body; reassurance seeking; requesting medical tests repeatedly; researching medical information (e.g. Internet searches, reading medical books); and avoiding stimuli related to diseases [4, 47, 67]. These behaviours then lead to negative thought patterns and feelings. Thus, health anxiety disorder follows the vicious cycle of anxiety [1, 33, 43, 67] as described in cognitive behavioural models of anxiety, see Figure 1. This is a significant part of health anxiety and it is important to understand in order to consider methods which could break
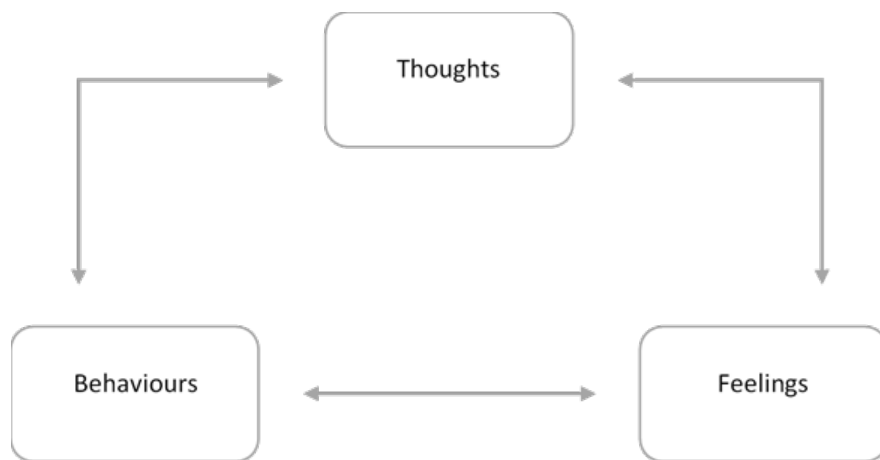
Figure 1: The Vicious Cycle of Anxiety

this cycle. Furthermore, this shows how reassurance seeking through online health information services can lead to negative thoughts and feelings which perpetuate the cycle of anxiety.

Due to the viscous cycle being a core part of sustaining and increasing health anxiety, the most common treatment for health anxiety disorders is cognitive behavioural therapy (CBT). This is a form of therapy which teaches practical skills to break this cycle by changing negative thought patterns and behaviour [7, 38, 46]. In a cognitive behavioural model, hypochondriasis is portrayed as an episodic disorder with discrete events [37]. In other words, people with hypochondriasis experience individual episodes of extreme health anxiety.

There has been a significant amount of research conducted on the effects online health information has on health anxiety, with many of them showing the associated challenges faced by individuals susceptible to health anxiety [35, 45, 60, 63, 75]. However, these issues focus on the 'worried well', whereas, those suffering from rare diseases might follow similar anxious behaviour trends before their diagnosis, but their concern is in fact justified. Thus, methods of addressing and reducing the implications of online health information on health anxiety must be evaluated in order to prevent not only

excessive, but also maladaptive health anxiety.

1.4   Trust

Trust is an essential part of the way society functions [8, 25, 27, 36]. This is particularly important for health care [24, 30, 51] as a lack of trust in health care professionals or in health information may hinder patients' ability to seek medical help through these means.

In order to design online health information services responsibly, their effects on health anxiety must be considered and addressed if possible. Whilst some studies have examined this, very few considered how these changes might impact users' trust in the information, how it affects doctor-patient relationships, and whether medical professionals would trust patient found information. Any changes to online health information services in order to prevent its impact on health anxiety may hinder users' trust in the information, and therefore, may prevent users from acting on the information they find. Hence, it is important to evaluate how best to reduce health anxiety, whilst maintaining and maximising users' trust in the information.

1.5   Motivation

Online health information has increasingly been used as a resource to empower patients to take better control of their health [26, 31, 50, 52]. This is particularly important and effective for rare disease patients [3, 9, 16, 17, 54] as they often experience a long diagnostic period and 2 in 5 rare disease patients are misdiagnosed before the correct diagnosis is given [34]. Therefore, rare disease patients are more likely to want to research into their health problems and it is highly important to empower them to take control of their health care. Furthermore, Bouwman et al. [9] state that when "regarding rare diseases, the use of the internet may be an important tool in the diagnostic process".

However, many studies have suggested that health information on the internet has a negative effect on health anxiety [6, 35, 45, 63, 74, 75]. This dissertation will consider the ways in which online health information services affect health anxiety and whether methods that prevent this hinder trust. This will be done by examining the literature not only within computer science, but also within psychology to explore methods which prevent online health tools from increasing health anxiety. Expanding on this, further research will be conducted through a questionnaire and interviews in order to identify how online health information services affect the general public as well as rare disease patients; to consider methods which address potential anxiety provoking factors of online health information and to determine how these methods affect users' trust in the information. These interviews will be analysed thematically in order to identify common trends and to extract meaningful information, pointing towards potential solutions which prevent health anxiety within online health information services without hindering trust.

1.6   Aims and Objectives

There are three main aims of this dissertation. Firstly, to design and conduct a study on the methods of reducing the negative impacts that online health information services have on health anxiety and well being. Secondly, to analyse and extract from this study the methods which are most suited to address this. And finally, to narrow down these methods and suggest additional new methods in order to create a design space which is human centred, addresses some of the negative impacts of online health information services as well as reducing the methods which may prevent patients from seeking medical help.

1.7   Responsible Innovation

This project is entirely underpinned by responsible innovation as it aims to consider the negative impacts of online health information, as well as methods which might address these issues. This dissertation can inform

future designers of health related websites of the areas to consider in order to ensure that website designs are responsible.

2 Literature Review

2.1 Online Health Information Services and Users

Cotten and Gupta [13] found that 64% of online health information users were female, with a mean average age of 40.4 years. This shows that many people, not just those who grew up during the 'internet age', use online health information services, and therefore, its users may have a range of different abilities when using online services. They also found that online health information users are generally healthier and happier than those that exclusively use offline health information. Motivations to use of online health information services include seeking reassurance; searching for a second opinion; desire for supplementary information; and difficulties pursuing health information through other means [52]. These motivations may be a result of curiosity, worry, and remedy-seeking [61].

There are a number of different platforms for online health information including academic literature, symptom checkers, blogs, chat rooms and mobile applications. Also, people searching for online health information often use websites that are not primarily designed for online health information such as social media platforms [15, 41], or search engines such as Google [15, 66].

Academic literature is generally highly accurate and informative, however, it is not patient-friendly because it is aimed at medical professionals and hence, it will use many complex technical terms which are often difficult for non-experts to understand.

Symptom checkers often consist of a search bar or a list of symptoms to choose from. These services are generally straight forward and provide an easy method of finding a number of conditions related to symptoms. However, common symptom checkers often evoke panic as benign symptoms may

lead symptom checkers to suggest fatal conditions as the cause.

Health blogs often consist of an individual's health journey. This can offer emotional support to peers and can give an idea of what to expect from certain conditions. However, blogs are unlikely to help patients find potential conditions, so it fulfils a different purpose to symptom checkers. Furthermore, because it is just one person's experience, it has a very low external validity.

Chat rooms, like health blogs, can often offer emotional support and advice. It can be very useful for patients to share common experiences, however, there is no guarantee that the conversations are credible, and may be less informative than other sites.

Mobile applications with a range of different functions, including the ones named above, are available to users who prefer to seek online health information on their mobile phone. Using a phone to browse information may be useful when away from a computer, however, it may not display information as clearly as a PC due to its smaller screen.

Social media pages containing health information can be helpful and some organisations use social media to spread health information. However, generally this is not particularly useful for users looking for specific information and there is a vast amount of inaccurate information on social media [55, 65, 76]. Furthermore, this information may impact health decisions, even if the information is recognised as unreliable [53].

Google is a commonly used tool for seeking online health information and is usually effective at finding health-related websites. However, it may not be as suitable for finding health information as a search engine that is designed specifically for health information. This is because it is more likely to find an inaccurate source as the most popular relevant websites will be listed first, rather than ones with higher credibility. On the other hand, due to users' familiarity with Google, they are less likely to use other search engines

when seeking health information. Furthermore, Siempos et al. [58] found that young, experienced, non-expert users of online health information found a correct diagnosis for assigned cases one fifth of the time when using Google.

2.1.1 Online Health Information for Rare Disease Patients

Some researchers have considered how online health information services can be more suited to rare disease patients. For example, Dragusin et al. [16] created FindZebra, a search engine for rare diseases aimed at medical professionals, in order to evaluate whether the diagnostic quality of search engines could be improved by only searching for rare disease information from specialised and accurate resources. They found that FindZebra was significantly more effective than Google or PubMed at finding the correct diagnosis for 56 rare disease cases. Therefore, this shows that online health information could significantly help speed up the diagnosis of rare disease patients. However, since this search engine is aimed at medical professionals, it is likely to be less useful for undiagnosed rare disease patients researching their symptoms. Hence, because rare disease patients often play an active role in their health care [11], there should be more patient-centred tools to help with patients' research during the diagnostic process.

Ronicke et al. [54] also considered how digital methods can reduce the diagnostic time of rare disease patients by comparing the time taken by doctors to diagnose rare diseases with that of Ada DX, a diagnostic decision support system. They found that Ada DX suggested the correct diagnosis in the top five suggestions faster than the clinical diagnosis time for 53.8% of cases. This again shows how digital methods are well suited to support rare disease diagnosis. This may be because GPs are unlikely to have previous experience diagnosing rare diseases, and therefore, their ability to diagnose rare disease patients will be diminished as a result of their lack of experience. This is why digital methods are ideal for rare disease patients as digital tools can utilise significantly more information.

2.2 Cyberchondria and Online Health Information Seeking

As online health information became more easily accessible, developers gradually became more aware of the phenomenon 'cyberchondria'. The term, coined by the media, is not an anxiety disorder or a mental health condition, but a behaviour pattern characterised by excessive or repeated searches for health-related information online [40, 63, 67]. This behaviour can contribute to the vicious cycle associated with health anxiety disorder and can hinder the well being of health anxious individuals [6, 23, 45, 63, 67]. The exposure of cyberchondria in the media prompted a number of researchers to look for empirical evidence to evaluate the relationship between health anxiety and online health information. Many studies showed that individuals with higher health anxiety found searching for health information significantly more distressing than those with lower levels of health anxiety [45, 60, 63, 75]. Furthermore, even individuals with low levels of health anxiety may experience increased anxiety after using online health information services [60,61,69,72].

Whilst searching for health information online can be distressing, it can also empower people to have greater control of their health and their diagnostic journeys. For example, although Usherwood [70] found that increased knowledge of health information from a booklet results in significantly more out of hours consultations, there were still 28% fewer home visits. Thus additional health information results in both the increase and decrease in health anxiety. Furthermore, approximately 50% of people reported that online health information decreased anxiety whilst only 40% of people reported increased anxiety after seeking online health information [75]. Thus, these services should not be disregarded or thought of pessimistically, but they must be adapted and improved to address the issues they have, whilst ensuring any adaptations still provide this support. Thus, let us consider and evaluate the methods discussed in literature to reduce the implications online health information services have on health anxiety.

2.3 Preventing Online Health Information from Increasing Health Anxiety

Since "increased knowledge about diseases can lead to transient increases in health anxiety" [67], it is not possible to prevent online health information services from increasing health anxiety altogether. However, it is worth discussing what other aspects of online health information unnecessarily increase health anxiety in order to reduce these implications.

Workshops on assessing website validity. One aspect of online health information which contributes to the heightened anxiety of around three in ten survey respondents is the unreliability of websites and the content of search results [32, 62, 74]. This may be because intolerance of uncertainty plays a key part in reinforcing and maintaining cyberchondria [23, 64, 72]. One method that could enable users to disregard unreliable websites more easily is to provide workshops and advice from general practitioners to educate internet users in order to enable them to critically appraise online health information and to interpret the results effectively, so that they disregard irrelevant and anxiety provoking information [19, 29, 35, 63]. This would be effective because although online health information seekers often use "strategies to filter and validate information" [39], they may not have a high enough health literacy to do this effectively. For example, users 'may reject many clinically credible sites simply on the basis of poor design and may trust less medically accurate sites solely because they resonate with their own lives' [59]. Furthermore, Menon et al. found that proper education can address intolerance of uncertainty and high anxiety sensitivity and that health education is an effective strategy to prevent cyberchondria [43]. Moreover, Gray et al. [29] ran an interactive workshop on how to find and use evidence-based health information online and found that it had a positive impact on the way the participants looked for and used health information after the workshop. Therefore, educating internet users improves their ability to deal with unreliable websites, and therefore, will reduce the implications of unreliable websites on their anxiety. However, workshops and training sessions are time consuming and generally expensive to run, furthermore, many

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individuals will not choose to participate in them. Therefore, although this may help to address the issue, it would be more suitable to use other more practical methods either instead of this, or in addition to this.

Visual representations of information. Conflicting and confusing health information is often distressing since a search for answers may result in more questions, and as a result, may increase anxiety for one's health. In order to provide more clarity, it may be useful for online health information to include insightful flowcharts or decision trees [74]. This would be effective because it uses methods more suitable for conveying health information to non-experts and may provide more clarity on the likelihood of different health problems. However, it will be challenging, and potentially impossible, to create flowcharts and decision trees which are flexible enough to provide clear and accurate information for a number of different conditions. Furthermore, users will not always know answers to specific health questions, and therefore, these methods may increase their anxiety and may not prove effective or useful. However, there are many other visual analytics and visualisation techniques which may be suitable. Flowcharts and decision trees may not necessarily suit the users as well as other techniques, and therefore, in order to ensure methods are human-centred and best suited for the users, a number of different methods should be evaluated through user studies.

Monitoring escalatory behaviour. Alternatively, search engine providers could monitor escalatory behaviour, click-through frequency and dwell time in order to identify which health-related websites are more alarming, anxiety provoking and irrelevant [74]. Then websites can either be reviewed by experts or down weighted in the ranking algorithm [74]. Reviewers could then suggest modifications to the websites to remove escalatory language, down weight websites, or mark websites as non-escalatory. This method would prove particularly effective since most users will not look further than the first page of search results [44] and exposure to a credible source of online health information is associated with higher levels of health literacy [28], thus this method could significantly improve users' understanding and utilisation of online health information. Moreover, since many popular search engines

are not designed for health information searches, there is significant room for improvement with search and ranking algorithms [16]. However, this method may have negative impacts on websites which are necessarily escalatory due to their purpose, for example, a cancer information website may be useful for cancer patients but will be escalatory for others. Furthermore, it may promote low maladaptive health anxiety, and prevent people from seeking medical care when they need it. Hence, these websites should not be down weighted to the point that cancer patients do not come across them, or users never see this information. However, provided this method is not the only factor for sorting search results it will likely prove effective at reducing health anxiety without disparaging websites that are escalatory by necessity.

Sorting health information by likelihood. Another issue with search results is that "availability is interpreted as probabilities" [74], and therefore, users will think that search results which are higher in the rank order are more likely. This may lead to elevated anxiety for health conditions due to the perceived likelihood of them. Therefore, another approach is to sort search results in order of likelihood [74]. However, this would make it almost impossible to find information regarding rare diseases, and therefore, may not provide useful information for a number of people. This could be addressed by categorising search results such that multiple websites on the same condition would be grouped together in order to enable the user to view many more potential conditions at once. Furthermore, incorporating personalised content within search engines for health queries by storing data such as gender, age, previous health searches and other information could also narrow down the search results to more suitable conditions. This would be effective as it would reduce the likelihood of increased anxiety over unlikely health problems and would present more relevant and likely causes to symptoms, thus enabling more useful searches. However, this clearly has privacy issues and as a result, not everyone would want to use this. Therefore, there must be an option to opt-out of this, and still use the search engine.

Provide both reasons why and why you may not have a condition. One technique within CBT to overcome negative thought patterns

associated with health anxiety and to break the vicious cycle is to consider 'more balanced thoughts' or opposing thoughts to those based on anxiety when worried about one's health [47]. Therefore, it would be helpful if symptom checker websites provide both the list of present symptoms which suggests why users may suffer from a particular condition in addition to symptoms not entered which may imply that they do not suffer from a particular condition. This should be laid out clearly to encourage users to think of opposing thoughts in order to help balance anxious ones. Furthermore, this may help to provide a deeper understanding of the health conditions users find online in order to recognise the likelihood (or improbability) of having these conditions based on the presenting symptoms. This suggests that providing such discussions on websites could reduce the implications of online health information on health anxiety.

Providing likelihood percentage. Another method of encouraging balanced thinking is to simply display the likelihood of each condition alongside search results from symptom checkers, potentially based on personalised statistics from users' demographics. Unlike search results sorted in order of likelihood, this method may be effective because it still portrays this meaning, but it would reduce the prospect of rare disease patients from being unable to find relevant conditions due to their lack of prevalence. Furthermore, users of online health information services may dismiss escalatory content more easily if they are aware how unlikely it is. This may be effective since "perceptions of personal risk (i.e. risk likelihood) occupy a central role in theories of individual health behavior" [73], and therefore, the use of percentages may help online health users to make more informed decisions. However, if users are more focused on the severity of conditions than on the likelihood, this may not reduce the probability of escalation.

Providing discussions of benign causes. Additionally, implications on health anxiety may be reduced by providing discussions on websites or at the top of search engine sites about the likelihoods of more common, less serious illnesses [74]. This could provide answers for those seeking to understand reasons behind benign symptoms, however, this may prevent people

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with health problems which need to be addressed from seeking help. Therefore, since most benign symptoms do not continue for more than two weeks, it may be worth recommending readers to seek medical help if symptoms do not resolve within this time. Furthermore, this method must be tested on users to check that it reduces health anxiety, whilst also ensuring people still act on health problems if they need to. However, it is less likely to help users who have difficulty believing reassurance which is a common problem of health anxiety disorder. This would be effective as it also follows the CBT technique mentioned above.

Precise and user-friendly descriptions. Furthermore, online health information "has the potential to increase the anxieties of people who have little or no medical training, especially when Web search is employed as a diagnostic procedure" [74]. This is likely due to the fact that users may not have the expertise to distinguish between benign symptoms and serious, concerning variants of these symptoms. Therefore, more precise descriptions of symptoms using language easily understood by non-experts would reduce the implications online health information has on health anxiety since users would be able to distinguish benign symptoms more easily, and thus prevent increased anxiety.

In summary of this section, there are a number of methods which may reduce the implications of health anxiety including:

- Promoting credible and demoting escalatory websites

- Using flowcharts, decision trees and other visualisation techniques

- Providing workshops and GP advice to recognise whether online information is credible

- Monitoring and detecting escalatory behaviour in order to address and prevent it

- Sorting search results in order of likelihood

- Providing personalised search results based on demographics and related information

- Using percentages or other metrics to show the likelihood (and improbability) of conditions

- Categorising search results to group multiple websites on the same condition together

- Providing discussions of less serious/benign explanations of symptoms

- Listing symptoms of conditions such that both the symptoms inputted and the symptoms not inputted are shown to present reasons why it might be a certain condition as well as reasons why it might not be

- Using precise, user friendly language and descriptions to convey information more clearly to non-experts

However, although these methods seem suitable in theory, they must be tested in order to ensure that future designs of online health information are human-centred as otherwise future designs may not be best suited to help the users. This leads us on to the study conducted for this dissertation.

3 Methodology

3.1 Questionnaire

A questionnaire (see Appendix A, Figure 14) was sent out by email to Swansea University students as well as on a number of different social media rare disease groups and pages. These pages were chosen because members actively participated in the posts and they were popular within the rare disease community. That is rare disease patients, families or friends of rare disease patients, as well as those interested in raising awareness of rare diseases. These pages are centred around rare diseases, have a large number of participants (the number of members in total for all pages and groups is over 5,500 members), and many of their members are active in liking, commenting, sharing and responding to posts in other ways. Therefore, posting on
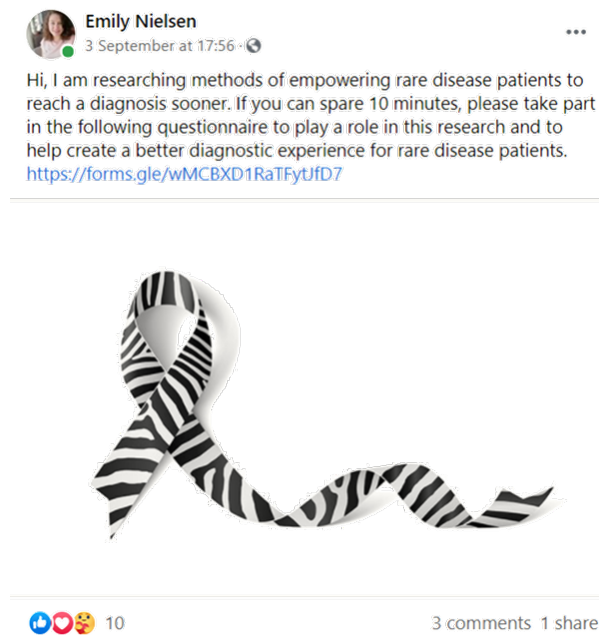
Figure 2: Facebook Post

these pages is an effective method of reaching the rare disease community. In order to achieve higher responses, the survey was posted multiple times in each page on a Thursday afternoon because this time increases positive engagement on Facebook [71]. Furthermore, since the duration of interaction is generally longer on posts with a picture [14], the post (Figure 2) included a picture of a rare disease awareness ribbon and text briefly describing the study and why readers should participate in the study. This picture [18] was chosen because it is aesthetically pleasing and looks professional alongside the post, but also because it is significant in the rare disease community and presented the fact that the survey is researching into methods which support rare disease patients.

3.2 Interview

At the end of the questionnaire, participants could leave contact details to participate in follow up interviews (see Appendix B, Figure 15). This allowed the collection of additional rich data to provide a more in-depth understand-

ing in order to support the questionnaire. These interviews were conducted online on Zoom because this study took place during the COVID-19 pandemic. It was semi-structured by design as the structure provided a strong foundation of knowledge, ensuring that the necessary questions were covered, but it also had the freedom to allow the discussion to lead into other interesting, relevant or unforeseen topics.

3.3 Design Concept Questions

The key questions both for the interviews and the questionnaire built upon the work discussed in Section 2.3, with a particular focus on the research conducted by White and Horvitz [74], but taking a human-centred approach to evaluate the effectiveness of the proposed techniques. Furthermore, since there were so many different methods and approaches suggested and there have been so few user studies to evaluate these methods, this study aimed to provide some preliminary research into which methods are most suited and are worth researching further. Therefore, the questionnaire and interviews only considered the key concepts from Section 2.3:

1. The use of visualisation techniques

2. Workshops on how to assess website credibility

3. Detection and demotion of escalatory websites

4. Search results sorted in order of likelihood

5. Likelihood of resulting conditions shown alongside them

6. Personalised search results using data from previous searches

7. Showing symptoms inputted as reasons a condition is likely and any symptoms not inputted (which are associated with that condition) as reasons it may be unlikely

3.3.1 Prototypes

Most of these concepts could be easily understood with a short description, and therefore could be evaluated quickly using a Likert scale. However, the fifth and seventh concepts were much harder to convey or visualise. Therefore, in order to convey these concepts more clearly, three rough prototypes were created (see Appendix C, Figures 16 - 18), one of each design concept separately, and one to show the two design concepts combined. Furthermore, since both of these concepts were based on CBT approaches (as discussed in Section 2.3), they may prove more effective than other techniques.

These prototypes represent the display users would see after searching symptoms into a symptom checker. The resulting conditions were deliberately provocative because it needed to include some escalatory content in order to assess whether these concepts can reduce any health anxiety caused. They were also based on Mayo Clinic's website [12]. This is because this website has a typical symptom checker layout, and therefore, the prototypes could follow the standard layout for an online health information website with the addition of the design concepts by altering the existing design. This would allow participants to imagine using the alternative designs more easily because they would look more like a website than if the concepts were shown without the surrounding website design. Furthermore, the design concepts were outlined in a red box to make sure that participants focused on the relevant parts of the image.

3.4 Analysis

The qualitative data from both the questionnaire and the interviews were analysed thematically according to the Braun-Clarke method [10]. This was chosen because it is rigorous and methodical, but it is also a reflexive approach to thematic analysis. Therefore, unlike coding reliability or code book approaches, it develops much more naturally from the data.

3.5 Human-Centred Approach

One of the key aims of this research is to conduct preliminary research into how online health information can become more human centred. In particular, this research is narrowing down which existing strategies and designs are most useful to end users, whether they reduce health anxiety, and establishing any new strategies which might be helpful.

4 Results

4.1 Participant Demographics
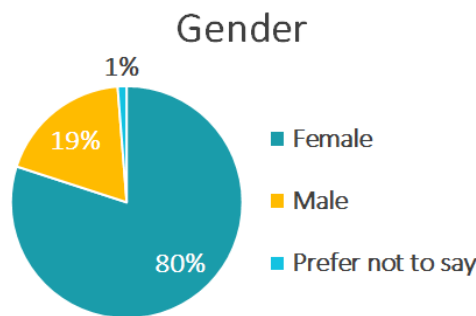
Figure 3: Gender of Participants
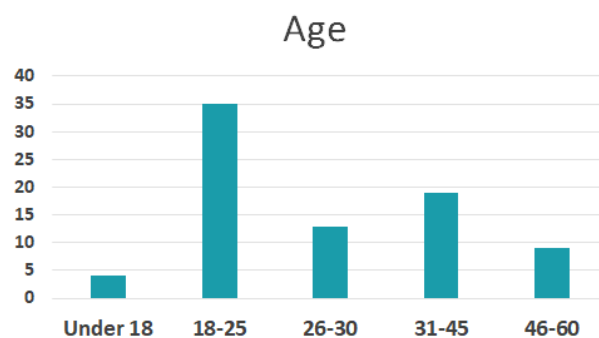
Figure 4: Age of Participants

In total, a sample of 80 participants completed the questionnaire. This sample consisted of 15 males and 64 females with the majority aged 18-25,

see Figures 3, 4. Therefore, since the demographic is predominantly young adults, they are likely to be more comfortable, proficient and well-practised in using the internet in general, and therefore, in using online health information services. Other demographics may face stresses or struggles due to challenges regarding technology.
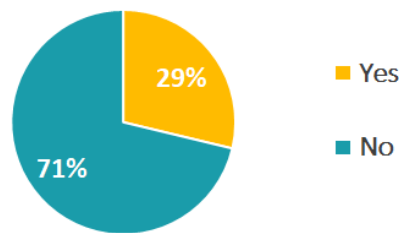
Figure 5: Number of Rare Disease Patients in the Study
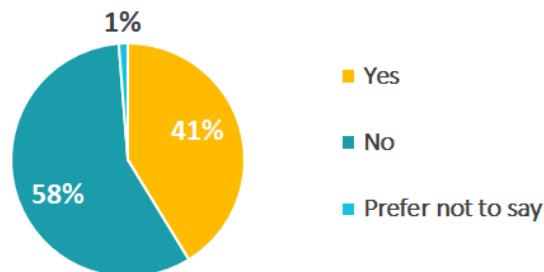
Figure 6: Participants With Long Term Health Problems

Out of the 80 participants, 23 were diagnosed with a rare disease, see Figure 5 and 33 suffered from long term health problems, see Figure 6. Comparing the perspectives of participants with rare diseases or long term health problems to those without may be useful to see how the general public's experiences differ, and how best to cater for both the worried well and the worried unwell.

Following the questionnaire, a total of three participants took part in the interview. Of those participants there was one male and two female, one of whom suffered from King-Denborough syndrome (KDS), a rare genetic disorder and Central Core Disease which is often associated with KDS.

4.2   Questionnaire Statistics

For over half of the rare disease patients in this study, it took more than 5 years to reach a diagnosis after their first symptoms (see Figure 7) and it took 52% of rare disease patients over 2 years after they had first sought medical help (see Figure 8). This shows the long diagnostic period of rare disease patients, and gives a small insight into their diagnostic journey.
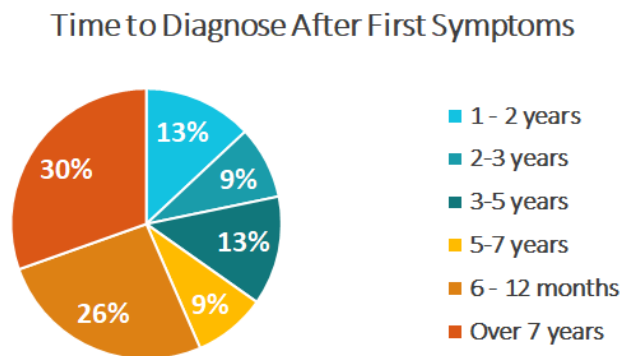
Figure 7: Time to Diagnose Rare Disease After Symptoms

Many of the participants were diagnosed recently: 30% of participants who said they had a rare disease were diagnosed this year with 17% in 2019, 22% in 2018, and less than a third (31%) were diagnosed before 2018, and only one participant was diagnosed before 2012. Therefore, the majority of rare disease patients participating in this study will have been able to use online health information services before their diagnosis.

The results from the questionnaire show that the most common motivation for looking at online health information is to find out more about a condition, the second being to find a diagnosis or research one's symptoms,

Figure 8: Time to Diagnose Rare Disease After Seeking Medical Help
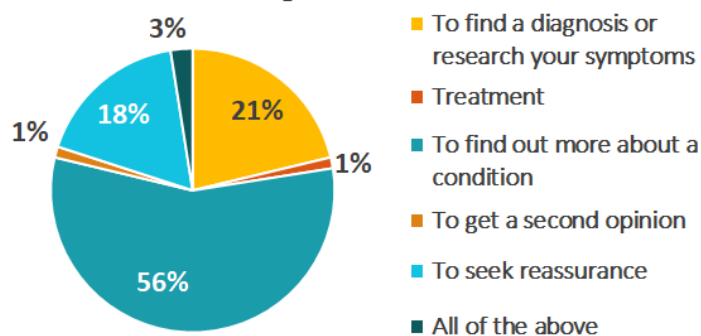
Figure 9: Motivations for Using Online Health Information Services

and the third most common motivation is to seek reassurance, see Figure 9.

Figure 10 shows the frequency of health information searches for participants with a rare disease, participants with long term health problems and for participants who do not have a rare disease or a long term health problem. From this, we can clearly see that participants who had a rare disease or a long term health problem looked at health information significantly more frequently that those who did not.

Furthermore, Figure 11 shows that participants with a rare disease or a long term health problem spend significantly longer when looking for online health information.

Frequency of Health Information Searches
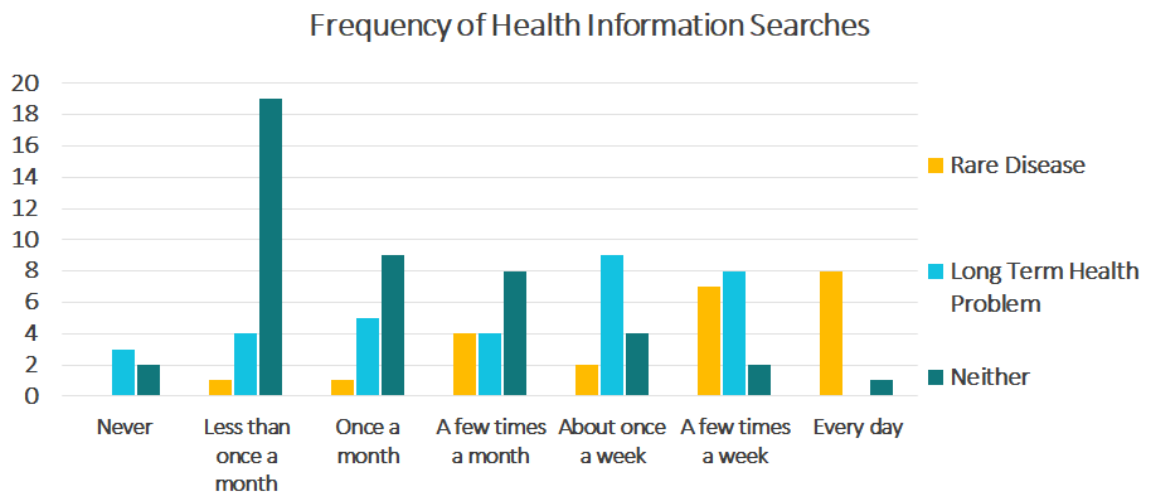
Figure 10: Frequency of Use of Online Health Information Services

Time Spent Looking for Health Information
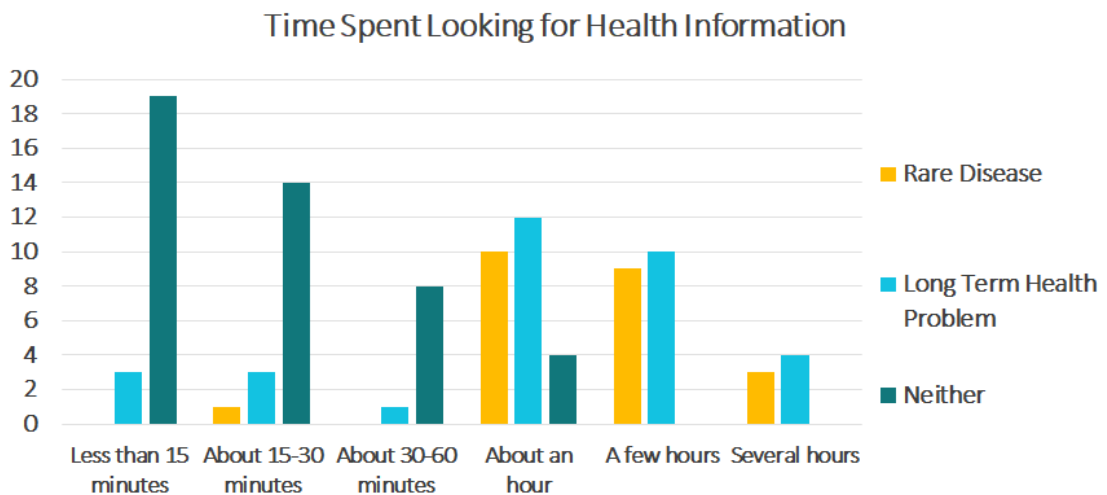
Figure 11: Time Spent Using Online Health Information Services

83% of participants said that their online health information goals (as seen in Figure 9) are at least somewhat hard to achieve, and 42% said that they were at least mostly hard to achieve. This shows that a large number of people are not completely satisfied with online health information. See Figure 12 for chart.

When looking online, are your goals hard to achieve?

Yes 11%
Mostly 31%
Somewhat 41%
Not at all 16%

Figure 12: Achievability of Online Health Information Goals

In Figure 13, we can see a comparison, using a Likert scale, of five different suggested approaches with described in Section 2.3. The base scale shows how helpful existing online health information services are. Using this, we can see which proposed methods would be more useful and which would be less useful than existing online health information services. Clearly, the monitoring of escalatory websites; search results sorted in order of likelihood; and the use of visual information to convey health information would be more helpful to users than existing services. However, utilising users' data to make results more accurate and running workshops on website credibility assessments were less helpful.

I would find it helpful if online health information services

	Strongly disagree	Disagree	neither agree nor disagree	Agree	Strongly agree
Monitored escalatory sites	3	4	22	23	28
Used my data to get personalised results	15	15	13	18	19
Sorted results in order of likelihood	3	3	21	28	25
Ran workshops on website credibility assessment		7	20	24	16	13
Included visual information (i.e. pie charts)	4	5	28	28	15
Base (no change)		11	30	27	11

Figure 13: Preferred Variations of Online Health Information Services

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4.3 Themes

After analysing the questionnaire and interview responses, five main themes of participants' thoughts and feelings before, during and after browsing health information emerged along with four themes that were less predominant.

4.3.1 Thoughts and Feelings Before, During and After Browsing Health Information

Desire for knowledge. The most prevalent theme was a desire for knowledge, particularly before looking for health information. That is that people were motivated to use online health information due to their curiosity and an eagerness to understand their own and their loved ones' health better. This theme generally encompassed logical and analytical thinking, and did not imply an increase in anxiety or stress.

Impaired Emotional State. The second most prominent theme was an impaired emotional state when looking for health information. This describes negative and even depressive feelings (except feelings of fear and anxiety) before during and after looking for health information. This theme occurred much more after using online health information services than before or during.

Fear and Anxiety. This theme describes feelings and thoughts motivated by fear such as anxiety, concern and worry. Although this could be part of the impaired emotional state theme, it has been separated into its own theme because there were significantly higher reports of fear and anxiety than any other emotion. This theme remained high before, during and after using online health information services.

Reassurance. Many participants hoped for, expected or received reassurance or satisfaction from seeking online health information. This theme was much more prominent after using online health information services.

Validity Concern and Awareness. This theme describes the recognition of validity issues online in addition to strategic search methods in order to distinguish between reliable and unreliable sources. This theme occurred more frequently before and during the use of online health information services than it did after.

Other Themes. Other less prominent, but noteworthy themes include:

- **Informed Actions.** The intention of using online health information to make informed choices to improve their health such as whether to seek advice from their health care provider, to find over the counter remedies, etc.

- **Difficulties and Confusion.** Difficulty finding and/or interpreting online health information. This usually results in confusion regarding what online health information means, mostly due to the use of complex medical language as well as the vast amount and wide range of (often conflicting) information.

- **Convenience and Ease of Use.** Advantages of using online health information, such as speed and convenience.

- **Issues or Disadvantages of Health Care Providers.** The perceived necessity of using online health information due to the belief that health care providers are not delivering the help needed.

4.3.2   Response to Prototypes

Overall, participants generally responded well to all of the prototypes as over 60% of the points made were positive, whilst about 30% of the points made were negative. The analysis of these responses showed eight themes regarding participants' reactions to the prototypes.

More Information and Clearer Understanding. The most prevalent theme by far for each of the prototypes was that they provided more information than other online health information services and that this would

help provide a clearer understanding in order to draw conclusions from the information and how it relates to their symptoms and their health.

Reassurance. Many participants described the prototypes to be reassuring. This theme was much more prominent for the first two designs (Appendix C, Figures 16 and 17), than the third design (Appendix C, Figure 18) which combined both concepts.

Uncertainty and Confusion. Despite many participants finding the information clearer, some however found it more confusing and would find it harder to draw conclusions from health information. This confusion was equally apparent in each of the prototypes.

Increased Trust in Information Validity. A number of participants trusted the information more when presented in this format. This theme was higher in the first and last design (Appendix C, Figures 16 and 18) than in the second design (Appendix C, Figure 17) which showed the likelihood of each resulting condition.

Validity Concern and Awareness. However, some participants were concerned about validity issues online and would use strategic search methods in order to evaluate the reliability of the website. Validity concern was much higher in the second prototype (showing the likelihood) and lowest in the last prototype (the combined design).

Evidence. This theme describes the intention of using the information as evidence to either bring to their health care provider or to inform their actions and future searches. This theme only occurred in the prototype showing the likelihood of each condition.

Not Ideal for Rare Disease Patients. Some participants said that the prototypes were not as useful or even were completely useless for rare disease patients.

Fear and Anxiety. This theme describes feelings and thoughts motivated by fear such as anxiety, concern and worry. This theme only occurred in the first and second design and it was more prevalent in the second design.

5 Discussion

5.1 Thoughts and Feelings Before, During and After Browsing Online Health Information

5.1.1 Desire for Knowledge

The participants' curiosity and desire for knowledge was a major thought process when looking for health information online. The fact that this theme was much more apparent in the beginning implies that it is a common motivation for using online health information services. This theme shows the participants' interest and desire to pursue health improvement and an inclination to take an active role in their health care. Thus, this implies that online health information has the potential to decrease the pressure on the NHS and other health care services due to its high uptake by users. However, this potential may be greatly diminished by the inaccuracy of websites; by escalatory content (as this would increase pressure on health care services) and by the lack of non-expert user centred content. Hence, we can see the importance of researching into methods which address these issues.

While most of the responses within this theme showed interest without any emotional challenges, some responses showed participants' intolerance of uncertainty and desperation for answers.

> *"I am the type of person that needs an answer to a problem, or I will never move on."*

(Participant 64)

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Intolerance of uncertainty is generally associated with health anxiety, however it only occurred for participants who are either rare disease patients or parents of rare disease patients. Thus this may partly be due to their experiences as rare disease patients, and so an increase in health anxiety is not unfounded considering most rare disease patients will experience severe symptoms for an extended period of time without answers. For example, in Figure 7, we can see that 71% of rare disease patients in this study had symptoms for over three years before they were diagnosed. This will raise health anxiety, but this may be what motivates them to seek the help they need.

Furthermore, this may also be due to the belief that health care providers are not delivering the help needed. Rare diseases are very hard to diagnose, and therefore, rare disease patients may actively seek information due to the lack of help from visits to their health care provider.

> *"don't be discouraged when your doctors don't find answers. you know your body best. advocate for yourself and find your diagnosis"*

(Participant 24)

However, doctors may be hesitant to believe findings from the internet due to patients' lack of medical knowledge and the vast amount of misleading and escalatory information.

> *"I would take them [findings from online health information] to my primary care physician, yeah. He got really frustrated with me though. He kept saying everybody hurts, you know, everybody's weak and, and then when I started getting when you could see it physically, when I started going down in like, 2008, he went, Whoa. Okay, now I understand."*

(Interviewee 3)

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Therefore, this highlights a key issue with online health information. If doctors and other medical professionals disregard this information, it could render effective, good quality research useless. Furthermore, although not all information will be accurate or relevant, it is important that patients feel that their concerns are being acknowledged by their doctors. This is not only because it would maintain patients' trust with the health care system, but also, patients' health anxiety may increase if they do not feel that their health concerns are taken seriously. Therefore, improving the reputation of online health information and of non-expert users' ability to research effectively will be key to utilising this tool as a patient aid.

5.1.2 Impaired Emotional State

Many participants often experience an impaired emotional state during and after searches. In particular, participants are often discouraged, frustrated or overwhelmed after searching for health information. One likely cause of this may be due to participants' difficulties of understanding the information and struggling to disregard conditions due to symptom similarity.

> *"Sometimes I am annoyed that there is no clear answer and the concern could be diagnosed in so many ways"*

> (Participant 26)

Therefore, this could be improved by explaining symptoms and conditions more precisely in user friendly terminology. Furthermore, while the use of precise wording can prove to be effective, using visual methods in addition to this may convey information more clearly.

Furthermore, an impaired emotional state could also be due to excessive amounts of information.

> *"So and like if my goal is to diagnose a concern, and I go online,*

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I get, like 25 diagnoses for those symptoms. So how would I know which one it is?"

<div align="right">(Interviewee 2)</div>

Therefore, it may decrease health anxiety to show less conditions on health information websites as this could reduce the feeling of being overwhelmed by the high quantity of different, and potentially fear provoking, conditions. Furthermore, since people can often hold about eight 'chunks' of information in their short term memory [5], there should be a maximum of about eight conditions shown. This would mean that they would not need to remember all of the information in their long term memory, or write the conditions down, making it easier for users to evaluate conditions more effectively. However, this may reduce the chances of a successful search as some relevant conditions may not appear initially and could potentially increase the likelihood of misdiagnosis. Furthermore, if online health information services only showed the first five most likely causes of symptoms, rare diseases would be very unlikely to come up. On the other hand, whilst a single symptom may be associated with thousands of conditions, a combination of symptoms, may be associated with significantly fewer conditions. Therefore, a search engine with multiple sections for different symptoms may produce more relevant and specific conditions.

An impaired emotional state was much more prominent after searches. Therefore, this is probably as a result of unsuccessful or escalatory health information searches.

"sometimes it [online health information] creates more questions rather than answers."

<div align="right">(Participant 58)</div>

One possibility which could address this would be to monitor which websites evoke more negative feelings by using feedback emojis. Furthermore, it might also be possible to detect distressing websites by monitoring and

analysing user behaviour such as click through frequency.

Proportionally, more rare disease patients described an impaired emotional state after using online health information services than other participants. This may be because they are more likely to have an unsuccessful search since for many rare diseases, there is not much information available. Moreover, even when their searches are successful, it is less likely to be reassuring as most rare diseases lack effective treatments [21].

> *"It's very, it's very sad that the there's just nothing for me to reference to. Yeah, I'm very frust- It's very frustrating."*
> *...*
> *"I'm on a support group... [for] patients with rare diseases ... [and it is] the same level of frustration with each and every one of these people that I talked to, like once a week that they cannot find any information about it [their rare disease]."*

<div align="right">(Interviewee 3)</div>

Therefore, to improve the effectiveness of online health information and to reduce health anxiety for rare disease patients, the information online should be as up to date as possible. Although new studies and findings may be highly technical and difficult to understand, it may nevertheless be useful to ensure any findings for rare diseases are freely available to patients as well as doctors. This is because there is very little information on rare diseases and the challenges of interpreting the information will probably have a less severe impact on users' emotions than the impact of knowing that there is information out there, but being unable to see it.

> *"If I were a doctor, I could enter in my information, and I could receive more information, but I don't have that. As a patient, I don't I can't get any further than that."*

<div align="right">(Interviewee 3)</div>

5.1.3 Fear and Anxiety

Despite the fact that fear and anxiety could have been taken as part of the impaired emotional state theme, it was significantly more prominent than all other emotions, and therefore, it is worth analysing separately to better understand the causes and patterns associated with fear and anxiety.

This theme occurred consistently before, during and after searches, and was slightly more prominent before searches. This implies that the presence of health anxiety is a common motivation for looking for health information online. Hence, it is likely that users of online health information services hope or aim to seek reassurance or other forms of closure, such as a resolution of the cause.

> *"I'm normally anxious and looking for reassurance or ways I can deal with my symptoms without having to go to the doctor."*

(Participant 33)

Surprisingly, the theme of fear and anxiety was not more prominent after searching for health information than before, however, this may suggest that online health information increases existing worries, rather than introducing new ones. This is likely since only four participants described being anxious after using online health information services who did not show anxiety before hand.

> *"Usually a mixture of concern and anxiety relation to the disorder/health issue."*

(Participant 21 — Before search)

> *"I am left feeling more confused and concerned than I was before I began my deep dive into online writings on my health problems."*

(Participant 21 — After search)

Therefore, it may be possible to detect users with pre-existing anxiety from search language and behaviour, and thus, escalations may be prevented by adapting the content to contain more reassuring and less escalatory components.

Fear is often increased when more serious conditions are presented, this is particularly strong with cancer as most people already know about cancer and are very aware of its severity.

> *"So like when she [the participants' daughter] was little, and she had a lump on her jaw line, we got really scared about that, because that could be eventually cancer or anything or limb disorder or whatever. So we were running around them and emergency rooms and stuff like that. And it turned out it was just for the forceps from the forceps. So but yeah, but you know, sometimes it can be really scary what you find online."*

<div align="right">(Interviewee 2)</div>

This is a difficult issue to resolve because it is important to diagnose cancer as early as possible because cancers are generally degenerative, and therefore, patients should not dismiss the possibility. Thus, unnecessary stress over the possibility of cancer is not as damaging as undiagnosed cancer.

5.1.4 Reassurance

Many participants found online health information reassuring, additionally, many were motivated by reassurance or hoped to receive reassurance before and during online health information searches.

> *"Mostly just seeking reassurance from shared experiences, to quell any anxiety relating to the issue. I use it as a coping mechanism."*

<div align="right">(Participant 21)</div>

Using online health information to seek reassurance is a common behaviour pattern associated with cyberchondria and is considered a contributing factor of the vicious cycle associated with health anxiety. This is because reassurance is often short-lived and sometimes searches are not reassuring, but instead are escalatory.

> *"So, most of the time I find information that tells me that there is nothing wrong, and then I can just chill. And sometimes they scare me. And like, okay, so she [the participant's daughter] has brain cancer - quite a negative feeling"*
>
> (Interviewee 2)

> *"Sometimes it [online health information] makes me anxious and stressed over small concerns, because someone had a major problem from it."*
>
> (Participant 26)

Therefore, excessive anxiety may be reduced by predicting escalations and estimating users' predisposition of escalations through log analyses of previous escalations from online health information [74]. Thus, predicted escalations may be prevented by including more reassuring content and reducing escalatory components. Furthermore, this could be optimised by detecting which factors trigger and prevent escalations for specific users and to personalise content. For example, some people may find large amounts of text stressful to look through, whilst others may find numerical information anxiety provoking.

Many participants who described feeling reassured after looking for online health information, also found online health information distressing, depending on the outcome of the search and how successful it was.

> *"Sometimes relieved and sometimes still confused or irritated."*
>
> (Participant 59)

This implies online health information users would have lower health anxiety if information was presented more effectively in order to make it more easily understood by non-expert users and to help them to distinguish between serious symptoms and benign symptoms which may appear similar on the surface. Thus this shows the importance of using human-centred approaches when designing online health information to understand what methods convey information more clearly and as a result reduce health anxiety.

5.1.5 Validity Concern and Awareness

Many participants showed a strong awareness of validity issues online and approaches. This implies that users of online health information services are likely to question or disregard misinformation. Therefore, participants using suitable strategies are unlikely to become anxious over inaccurate information.

> *"Before searching, my thoughts are very analytical, I know I'll be looking for a variety of reliable sources from websites that have positive feedback in order to compare the information "*

> (Participant 32)

However, many people using online health information services will not have been taught how to assess credible information, and therefore, they might use strategies which are not very effective, for example, they may judge the accuracy of the website based on its appearance.

> *"Yeah, I guess it looks quite professional."*

> (Interviewee 2 — Would you trust the information?)

Therefore, despite evaluating the reliability, some individuals may believe misinformation on websites because they appear to be credible. This may

lead to escalation or a misdiagnosis. In order to prevent this, medical professionals could evaluate the credibility of a number of different websites, and this rating could be shown on search results, or websites with low credibility could be removed from search results or down weighted in the sorting algorithm. Alternatively, users could be taught techniques of evaluating website credibility. However, only 29% of participants said they would find it helpful to attend workshops on how to evaluate the credibility of websites, and furthermore, many participants will be unaware if their strategies are not very effective. Therefore, rather than purely running opt-in workshops, GPs should be encouraged to explain how to assess the credibility of sources or to recommend more credible websites to stick to. Although this may seem time consuming, especially considering GPs are often pushed for time, it may save time long term as people are less likely to seek medical help due to misinformation.

Furthermore, some online health information seekers' anxiety may increase if they are not confident or are unsure of how to assess the reliability of websites. Firstly, this is likely to be because they may not disregard inaccurate information which is escalatory. Secondly, this may be because they may find evaluating the validity of online health information stressful as they may doubt their conclusions because they are unsure which information is valid, and thus, they would become confused and any potential reassurance would be prevented by the lack of clear answers.

> *"Apprehension about the validity of the site. Usually only trust NHS ones"*

(Participant 22)

Therefore, they would be helped both by the methods discussed above and by running workshops on how to assess the credibility of websites. This would reduce their anxiety and uncertainty as they would be able to trust reliable information more and disregard misinformation more easily and with more confidence.

5.1.6 Other Themes

- **Informed Actions.** A number of participants used online health information to decide whether to and/or how to act on their health problems. Mostly this was to decide whether they needed to see their GP, or to avoid a trip to their primary health care provider.

> *"I'm normally ... looking for ... ways I can deal with my symptoms without having to go to the doctor."*
>
> (Participant 33)

Although reducing unnecessary visits to one's doctor is a positive outcome of using online health information services, it may be difficult to assess how necessary visits are. Therefore, it is possible for patients to disregard serious symptoms as benign, or even attempt to treat an incorrect diagnosis. Both of these could seriously harm patients' health. Therefore, in order to resolve this issue, online health information services could use a disclaimer to tell people to seek medical attention if symptoms do not resolve within two weeks.

> *"Sometimes I find an "over the counter" cure for the concern and I solve the problem with that."*
>
> (Participant 26)

Another response to online health information is to discuss it with other peers and support groups. This may help to alleviate any health anxiety that has occurred as a result of online health information and may also provide advice and support based on other people's experiences regarding what to do with the information and what it means.

> *"I ask people in my support groups for advice"*
>
> (Participant 57)

This response would be particularly helpful for rare disease patients as it can be hard to find health care professionals who specialise in certain rare diseases and often rare disease patients become experts in their disease [11]. Thus, the information found is likely to be credible and well informed.

- **Difficulties and Confusion.** A number of participants found finding or interpreting information difficult. This may be due to complex medical terminology used, lack of (non-expert friendly) detailed information, difficulty ruling out conditions or simply just a lack of information altogether.

> *"I find it difficult to filter all the information available online concerning health"*
>
> (Participant 48)

Participants who have difficulty ruling out conditions, or narrowing down their search are more likely to experience anxiety and an impaired emotional state after searching. This is because a lack of clarity can often be stressful, confusing and frustrating. Therefore, online health information services should be designed using human-centred methods to assess their ease of use. For example, evaluating whether using visual aids to communicate complex information helps users to understand more easily and which visual aids are most suitable; assessing which terminology is user-friendly and easy to understand; or analysing the effectiveness of videos of health care professionals explaining health information.

> *"[I] Need [an] explanation for medical or scientific terms."*
>
> (Participant 71)

While medical terms are precise and their specificity is useful for medical professionals, it can be confusing, and challenging to understand the meaning for non-expert users. Therefore, where there are suitable non-expert synonyms for these terms, they should be used instead, however, many technical terms will lose meaning when using synonyms. Hence, these terms should have a definition displayed when users hover or click on it, and/or clearly show a list of all technical terms used on the website page.

Furthermore, this may help alleviate any stresses caused by seemingly conflicting definitions of medical terms. This is because any medical terms used on websites should be consistent with their own definition. Therefore, this would prevent confusion and increase users' understanding of the health information presented.

> *" I would like write down the technical term, and then look it up and it would give me like, 150 choices, and I don't I just want this one. And they all said something different."*

(Interviewee 3)

It is often hard for a non-expert to differentiate between benign symptoms and serious ones.

> *"It's usually to look up symptoms and make sure its nothing serious, problem is that often same symptons [sic] are associated with very different reasons that span from serious to not"*

(Participant 12)

This then makes it hard for users to be reassured for benign symptoms, and may potentially make users with serious symptoms disregard them as benign. Therefore, it is highly important to differentiate between

similar symptoms. This can be done through clear explanations and including pictures where similar symptoms are visually different. Furthermore, interactive and collaborative websites may convey health information more clearly to non-experts [2].

Rare disease patients often have difficulties finding relevant online health information.

> "There's just so little information, they always lead me to the same sites. Every time I type in King-Denborough syndrome, I get the exact same information. And there's only about five or six articles, but they always are the same. So I haven't found any, anything besides that. I went to every website... I've even contacted the places where I found information, and they have called me. But all they wanted. All they know about is malignant hyperthermia, or central core disease. When I get to King-Denborough, they're like, we don't know."

> (Interviewee 3)

This may cause frustration and anxiety, and therefore, there needs to be more content online regarding rare diseases. However, the lack of information online is likely due to a lack of information in general, and therefore, this problem is not easily solved.

- **Convenience and Ease of Use.** The main attraction for using online health information services is because it is convenient and fast.

> "It's that you get a quick answer. You get a wide range of answers. So, you can kind of it gives you a starting point, to do your research more deeply into one area or more. It

*gives you a solutions that might work might not, but there is
something you can at least try."*

<div align="right">(Interviewee 2)</div>

This is useful as individuals with benign health concerns do not have to wait to see a doctor in order to get reassurance, thus reducing health anxiety quickly.

- **Issues or Disadvantages of Health Care Providers.** Another motivation for seeking information online as opposed to visiting a GP is because of perceived disadvantages of health care providers or a lack of trust in the health care system.

Many participants felt like their doctors disregarded their medical concerns and did not provide suitable health care.

*"I am saddened by the fact that I have to look online for
health information. We are taught to trust our physicians,
but what do you do when they can't help you or are unwilling
to help. It's exhausting suffering without an answer so I do
my own research."*

<div align="right">(Participant 64)</div>

This erodes the trust between doctors and patients, makes patients more likely to avoid seeking professional medical help and can make patients more anxious and emotional about their health. This is because they may feel that since the doctors are not helping them, the responsibility of finding a diagnosis or treatment lies on them.

*"I feel desperate as I feel very sick and doctors are refusing
to diagnose me"*

<div align="right">(Participant 10)</div>

<div align="center">45</div>

Furthermore, some participants found that doctors would not listen to their findings from online health information searches.

> *When discussing findings with healthcare provider "they most often look at me like I'm crazy"*
>
> (Interviewee 2)

This may be because doctors perceive online health information to be inaccurate; consider the patients' expertise to be insufficient to find appropriate conditions; or because the specific findings presented seem unlikely. This will likely deteriorate the doctor-patient relationship, especially if it is because of the first two reasons. However, this effect may be reduced or prevented if the doctor explains why they disbelieve the information and shows consideration and listens intently to the patients' health concerns to find a more suitable diagnosis.

The distrust of online health information or of patients' findings in general could be particularly detrimental for rare disease patients because they often play an active role in their health care. For example, in Britain, 31% of patients suggested the possibility of a rare disease to their doctor [34].

> *"My family has a rare genetic mutation, and I am a carrier for a rare genetic illness. If I did not do my research, we would have never found a doctor willing to help make sense of my mysterious symptoms."*
>
> (Participant 64)

It is highly important that doctors trust online health information and patients' findings (within reason) in order to maintain doctor-patient trust and to make use of patients' research where possible.

5.2 Responses to Design Concepts

Out of the five design concepts evaluated using a Likert scale, three of them proved more effective than existing methods. Sorting search results in order of likelihood was rated the most helpful by participants. This is likely because it increases the likelihood of a successful search, and reduces the chance of seeing unlikely escalatory content. It was also popular with participants who have been diagnosed with a rare disease. This was unexpected as this may make it harder to find content regarding rare diseases. However, this may still be effective for rare disease patients if searches are specific enough. This is difficult with current search engines as they do not deal with multiple phrases well. Therefore, this technique may be yet more effective if it is possible to add segments in a search bar to enable searches for multiple symptoms simultaneously. This could make it easier to find more obscure conditions as there would be fewer conditions that present a particular combination of symptoms.

Participants said that the second most useful concept was for search engines to detect escalatory websites by monitoring user activity, escalatory content, dwell time and click through frequency and using this to down weight unreliable or anxiety provoking websites. Furthermore, problematic websites could be reviewed and any flagged websites in which escalatory content is deemed necessary (such as cancer websites) may be 'approved' to prevent it from being down weighted, or relevant modifications could be suggested to website designers in order to reduce chances of escalation.

The use of visual analytics in website design was also considered more helpful than existing online health information services. This is very vague and non-specific, but provides some direction to show that it would be worth looking into how to use visual guides in order to present health information more effectively. This was the most popular design concept within the rare disease group of participants. Therefore, this may be particularly helpful for complex conditions; it may help to improve clarity and understanding, and therefore reduce health anxiety; and it would not reduce the chances of rare

disease patients finding health information regarding their conditions.

However, participants said that workshops on website credibility assessment would be less helpful than existing online health information services. This may be because workshops can be very time consuming, and people who have ineffective techniques to evaluate sources may not realise that they could benefit from workshops. Alternatively, when GPs receive patients who bring inaccurate findings from online health information, they could briefly teach some effective techniques for evaluating source credibility and/or recommend more suitable websites for users to stick to.

Participants also said that they would not find it helpful if search engines used their data to find resulting conditions which are more likely. This may be because of the privacy issues related to collecting this data, indeed, 60% of participants said that they would be worried about sharing their data with search engines to find health conditions that are more likely and more relevant to them. However, an alternative would be to use cookies to ensure that any data used is stored on the users' PC, rather than in a database, and furthermore, make sure that cookie collection is optional, and search engines are still usable without collecting cookies on health searches.

5.3   Responses to Prototypes

Generally, responses to the prototypes were positive, with many participants preferring these design concepts to other existing designs.

> "I am very likely to use this format over other websites, but if I don't know about it from an advertisement etc, I'd never know what I am missing out on. This looks great!"

(Participant 52)

However, let us consider the feedback with specific and constructive comments in order to improve these designs further.

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5.3.1 More Information and Clearer Understanding

Participants found that each of the three designs provided more insight and a clearer understanding than other online health information services.

> *"I would feel much more informed and less stressed jumping to conclusion from information that does not present the whole picture."*

> (Participant 29 — Prototype 1)

> *"I think that is quite good to know because sometimes I could be everything, so the percentage would help to sort through all the possibilities"*

> (Participant 46 — Prototype 2)

> *"This is more comprehensive than what was before, and accompanied by the extra information on symptoms would make me more likely to look at this website."*

> (Participant 28 — Prototype 3)

Clearer information and understanding may reduce unfounded health anxiety as it will enable users to disregard anxiety provoking conditions more easily. Furthermore, it would reduce the chances of an impaired emotional state as participants will be less frustrated if they can sort through information more easily.

> *"id [sic] take this more seriously as it has clear symptoms for health problems as well as things that will discredit worry that you have a paticular [sic] health problem"*

> (Participant 36 — Prototype 1)

5.3.2 Reassurance

A large number of participants found the prototypes reassuring. However, this was much more prominent for the first two prototypes than it was for the third.

"it's, it's more reassuring than anything, because you're, you're eliminating any sort of severity of what the actual illness or disease could be."

(Interviewee 1 — Prototype 1)

"Much better the percentage chance can settle you if it's nothing serious and alert you to check if it isnt [sic]"

(Participant 43 — Prototype 2)

"Much less intimidating"

(Participant 26 — Prototype 3)

5.3.3 Uncertainty and Confusion

Even though the vast majority of participants found the prototypes clearer to understand, there were also a number of participants who found it more confusing.

"I have a hard time understanding most of it"

(Participant 53 — Prototype 1)

"Percentage is weird to comprehend in regards to illness."

(Participant 23 — Prototype 2)

"I think it all just needs to be easier for a non Dr to read"

(Participant 53 — Prototype 3)

Clearly, it is stressful when health information is confusing, and therefore it is important to reduce this confusion. However, many of the participants who did not like prototype 1, were much more fond of prototype 2 and vice versa. So, this could be down to individual preferences and inclinations towards certain formats. Thus, these two different concepts should be available to view or hide for symptom checkers.

Furthermore, it may be useful to view and in order to see less 'text heavy' content for the initial search, and then to view the text after narrowing down the results.

> *"If this was a drop-down option from the image above (the one with percentages), this would be immensely helpful."*

> (Participant 29 — Prototype 3)

5.3.4   Increased Trust in Information Validity

Some participants said that they would trust a website more if it had a similar design to the prototypes.

> *"I would considerate as reliable, and probably I would need to do less search in other websites to validate this information"*

> (Participant 32 — Prototype 1)

> *"Having a numerical figure to measure the likelihood assures me more that the information is reliable."*

> (Participant 47 — Prototype 2)

> *"I think this is concise and well laid out and makes it look like a more professional webpage and id [sic] be more likely to believe the facts stated."*

> (Participant 24 — Prototype 3)

However, this was much lower for the second prototype. This is likely because people may distrust the percentages as they may want to have information on how they are calculated.

5.3.5 Validity Concern and Awareness

A number of people would be concerned about the validity of the prototypes if they were implemented. This may be partly because of the unfamiliarity of these designs and because they would distrust percentages if there isn't an explanation of how these were calculated.

> *"I may be dubious to believe the statment and check this with the NHS website."*

> (Participant 24 — Prototype 1)

> *"I wouldn't trust the percentage I may trust the cause they give me on the first- on the list."*

> (Interviewee 1 — Prototype 2)

> *"I'd react positively to this presentation but would like to gain more insight into how this output is calculated."*

> (Participant 41 — Prototype 3)

5.3.6 Evidence

A number of participants would use the percentages as evidence to guide further research or to back up any findings that are brought to their GP. This theme links into issues of health care workers listening to patients' findings.

> *"Its easier to suggest the outcome with specialists this way"*

> (Participant 4 — Prototype 2)

5.3.7 Not Ideal for Rare Disease Patients

Some participants said that these designs would not cater for rare disease patients.

> *"It's not helpful and only has an algorithm to find common diseases"*

> (Participant 10 — Prototype 1)

These prototypes are purely visual with outputs based on Mayo Clinic's existing algorithm. Therefore, this implies that current algorithms for online health information are not best suited to rare disease patients. Thus, a number of different algorithms should be tested in order to ensure that they are suitable for rare disease patients.

> *"Find it interesting but as we have a rare disease, likelihood doesn't always apply"*

> (Participant 54 — Prototype 2)

Showing likelihood may help to reassure participants, however, this would make it more likely for individuals with rare diseases to disregard their conditions if looking during their diagnostic process.

> *"While valid I wouldn't take this for granted. This seems a little like those doctors who overlook the smaller details for the obvious or easy solutions, and thus isn't always the case with chronic or rare disease... When you hear hoofbeats, it doesn't always mean it's a horse unless you see a horse"*

> (Participant 69 — Prototype 2 and 3)

5.3.8 Fear and Anxiety

A few participants described prototype 2 as fear provoking. This may be because many people do not like statistics or numerical information, moreover, many people may be stressed due to maths anxiety, that is "the panic, helplessness, paralysis, and mental disorganisation that arises among some people when they are required to solve a mathematical problem" [68].

> *"Percentages don't calm my anxiety... because there is no guarantee I am not in the 1% of anything. For the population the likelihood might be 1%... but for me, if I have the condition, then it's a 100%."*
>
> (Participant 26 — Prototype 2)

5.4 Reflections on the Process

This project was created during the COVID-19 pandemic, and therefore, all research had to be conducted online. This proved to be challenging as conducting interviews online was much more difficult due to connection issues and it was also harder to build a rapport with interviewees online. Furthermore, due to national lockdown, there was no access to libraries or to Swansea University's facilities until the last few weeks of this dissertation. This made it much more difficult to access sources that are not available online.

Another challenge of the project was recruiting participants. Two rare disease organisations were contacted to recruit their members, however, this recruitment was unsuccessful. This is likely due to the fact that many candidates had been overloaded with surveys over the past 5 months, and because recruitment occurred during the summer holidays. In order to overcome this, rare disease patients were recruited through social media groups and pages. For future work, the author will use both methods in addition to contacting participants from this study who said that they would be interested in future work relating to this research. This would maximise the potential for more

participants to be recruited.

6 Conclusion

6.1 Design Space

These findings show insight into which design concepts are worth considering implementing in future online health information services, and which should be disregarded. The design concepts evaluated in the project which seem the most promising is firstly, to detect and down weight escalatory websites from search results; secondly, to include visual prompts such as graphs in order to convey health information; thirdly, to use the layout shown in Prototype 1 (Figure 16) for symptom checker websites; and finally, to sort conditions in terms of likelihood. It also may be possible to prevent escalation by detecting anxious behaviour or predicting escalations from analysing logs from previous searches and then providing more reassuring content and reducing escalatory content.

This study also found new design concepts which may improve the experience of using online health information services by addressing issues that became apparent from the questionnaire. Firstly, in order to prevent confusion, and as a result stress, due to the vast number of seemingly relevant conditions, the number of conditions shown to online health information users should be reduced, initially only showing a maximum of about eight conditions.

A key challenge users face when searching for health information is difficulty understanding medical terminology. In order to resolve this, websites should replace technical terms with synonyms where possible. If this is not possible, a definition should appear when users hover over these terms or click on them.

In order to show more relevant conditions from initial results, search en-

gines could incorporate a multidimensional search such that it can search multiple phrases separately, and compare the separate lists for common conditions. This would reduce the resulting conditions to ones more applicable to the searcher.

One issue with online health information is that sometimes information is simply not available, particularly for rare disease patients. This cannot be solved entirely because it stems from a lack of information in general. However, new studies which are only available to view by medical professionals should be made more available if there is little existing information on the relevant condition.

Another challenge participants discussed regarding online health information usage is feeling distressed post search. Some websites may be more distressing than others, and therefore, search engines could use feedback emojis to monitor which websites are distressing to down weight distressing websites.

Another significant cause of health anxiety is validity and reliability issues. This is both due to the stress of not knowing which source to trust and of believing inaccurate escalatory content. In order to resolve this, websites could be reviewed by medical professionals to assess credibility and this rating could be shown on search results to assure users of online health information.

Since some users are keen to self-diagnose, and potentially even 'treat' their self-diagnosed problems, they could cause serious harm to themselves. Therefore, there should be a disclaimer on online health information to encourage users to seek their GP about symptoms if they are not resolved within two weeks and to advise patients not to treat themselves without seeking advice from a medical professional.

To summarise, designers of online health information services **should**:

- (Search engines) Detect and down weight escalatory websites

- Use visualisation tools such as graphs

- (Symptom checkers) Use layout shown in Prototype 1 (Figure 16)

- Analysing user logs and anxious behaviour to predict and prevent escalations

- (Search engines) Enable search of multiple distinct phrases

- (Search engines) Use feedback emojis for websites and demote websites which impair users' emotional state

- Provide disclaimers encouraging users to see their GP if symptoms do not go away within two weeks

- Provide definitions of medical terminology when users hover over these words

Designers of online health information services **should not**:

- (Symptom checkers) Initially show more than eight conditions

- Use complex medical terminology except where necessary

6.2 Future Work

One of the most challenging issues that arose in this dissertation is issues with doctor-patient relationships. In particular, a number of participants said that their doctor does not listen to them or disregards their online health information findings. In situations where doctors are right to dismiss their findings, it is important that they do it sensitively and explain how to find more credible information in future. Alternatively, this may be due to a lack of trust in the credibility of online health information, or a lack of trust in patients' abilities to interpret this information. In order to address this, online health information should be created with doctors in mind to ensure that the information is not only trusted by patients, but also by doctors. Therefore, future work should consider how to increase doctors' trust in online health information, and furthermore, how patients can bring information to their doctors in such a way that they believe the patient's findings.

Also, in order to convey information more clearly, future research should be conducted on the most appropriate methods for this including discovering which visual analytics techniques convey health information to non-experts effectively and other formats of communicating health information such as pictures and videos.

Furthermore, in order to find more specific health conditions, future work could study how to design and optimise a search engine specifically for online health information which can search multiple distinct phrases.

Finally, research should be conducted to investigate which methods and algorithms would be best suited to analyse and detect escalatory or distressed searches.

6.3   Limitations

It is worth noting a few limitations of the study. Firstly, due to the lack of participants in the study, the interviews may be biased towards those individuals. However, there were many more participants who took part in the questionnaire, and therefore, since the interview themes aligned with the themes in the questionnaire, it is less likely to be biased.

Since this study was held for an MSc dissertation, it had to be conducted independently, and therefore, codes and themes lack inter-code agreement. However, since many of these themes are in line with existing findings or themes in previous literature, these results are likely to be reliable.

Another limitation is both the questionnaire and the interview questions may be influenced by prior knowledge/preconceptions. However, in order to prevent this and to ensure this does not affect the research conducted, pilot studies were conducted with feedback taken from participants in order to detect and remove any issues or biases within the questions.

Despite these limitations, the author has conducted a study on the methods of reducing the negative impacts that online health information services have on health anxiety and well being, analysed and extracted the most suitable methods to address this and has narrowed down these methods in addition to suggesting new methods, thus creating a design space which is human centred, addresses some of the negative impacts of online health information services as well as reducing the methods which may prevent patients from seeking medical help. Therefore, the aims of the dissertation have been achieved and this research provides useful contributions to future designers of online health information, to health anxious individuals, and to the rare disease community.

References

[1] Jonathan S Abramowitz, Brett J Deacon, and David P Valentiner. 2007. The Short Health Anxiety Inventory: Psychometric properties and construct validity in a non-clinical sample. *Cognitive Therapy and Research* 31, 6 (2007), 871–883. `https://link.springer.com/article/10.1007/s10608-006-9058-1`

[2] Samantha A Adams. 2010. Revisiting the online health information reliability debate in the wake of "web 2.0": an inter-disciplinary literature and website review. *International journal of medical informatics* 79, 6 (2010), 391–400. `https://www.sciencedirect.com/science/article/pii/S1386505610000195`

[3] Stig Kjær Andersen. 2008. CEMARA: a Web Dynamic Application Within a N-tier Architecture for Rare Diseases. *eHealth beyond the horizon: Get IT there: Proceedings of MIE2008 the XXIst international congress of the European federation for medical informatics* (2008), 51–56. `http://ebooks.iospress.nl/volume/ehealth-beyond-the-horizon-get-it-there`

[4] Gordon JG Asmundson, Jonathon S Abramowitz, Ashley A Richter, and Margaret Whedon. 2010. Health anxiety: current perspectives and future directions. *Current psychiatry reports* 12, 4 (2010), 306–312. `https://link.springer.com/article/10.1007%2Fs11920-010-0123-9`

[5] Pierre Barrouillet, Simon Gorin, and Valérie Camos. 2020. Simple spans underestimate verbal working memory capacity. *Journal of Experimental Psychology: General* (2020). `https://psycnet.apa.org/record/2020-74576-001`

[6] Susanne E Baumgartner and Tilo Hartmann. 2011. The role of health anxiety in online health information search. *Cyberpsychology, behavior, and social networking* 14, 10 (2011), 613–618. `https://www.researchgate.net/publication/51104249_The_Role_of_Health_Anxiety_in_Online_Health_Information_Search`

[7] Aaron T Beck. 1964. Thinking and depression: II. Theory and therapy. *Archives of general psychiatry* 10, 6 (1964), 561–571. `https://jamane twork.com/journals/jamapsychiatry/article-abstract/488562`

[8] Ellen Berscheid. 1994. Interpersonal relationships. *Annual review of psychology* 45, 1 (1994), 79–129. `https://www.annualreviews.org/do i/abs/10.1146/annurev.ps.45.020194.000455?journalCode=psych`

[9] Machtelt G Bouwman, Quirine GA Teunissen, Frits A Wijburg, and Gabor E Linthorst. 2010. 'Doctor Google' ending the diagnostic odyssey in lysosomal storage disorders: parents using internet search engines as an efficient diagnostic strategy in rare diseases. *Archives of disease in childhood* 95, 8 (2010), 642–644. `https://adc.bmj.com/content/95/8 /642.long`

[10] Virginia Braun and Victoria Clarke. 2006. Using thematic analysis in psychology. *Qualitative Research in Psychology* 3, 2 (2006), 77–101. `ht tps://www.tandfonline.com/doi/abs/10.1191/1478088706qp063oa`

[11] Karolina Budych, Thomas M Helms, and Carsten Schultz. 2012. How do patients with rare diseases experience the medical encounter? Exploring role behavior and its impact on patient–physician interaction. *Health policy* 105, 2-3 (2012), 154–164. `https://www.sciencedirect.com/sc ience/article/pii/S0168851012000644`

[12] Mayo Clinic. n.d. *Mayo Foundation for Medical Education and Research* (n.d.). `https://www.mayoclinic.org/`

[13] Shelia R Cotten and Sipi S Gupta. 2004. Characteristics of online and offline health information seekers and factors that discriminate between them. *Social science & medicine* 59, 9 (2004), 1795–1806. `https://ww w.sciencedirect.com/science/article/pii/S0277953604000796`

[14] Irena Pletikosa Cvijikj, Erica Dubach Spiegler, and Florian Michahelles. 2011. The effect of post type, category and posting day on user interaction level on Facebook. In *2011 IEEE Third International Conference on Privacy, Security, Risk and Trust and 2011 IEEE Third In-*

ternational Conference on Social Computing. IEEE, 810–813. `https://ieeexplore.ieee.org/document/6113221`

[15] Munmun De Choudhury, Meredith Ringel Morris, and Ryen W White. 2014. Seeking and sharing health information online: comparing search engines and social media. In *Proceedings of the SIGCHI conference on human factors in computing systems*. 1365–1376.

[16] Radu Dragusin, Paula Petcu, Christina Lioma, Birger Larsen, Henrik L Jørgensen, Ingemar J Cox, Lars Kai Hansen, Peter Ingwersen, and Ole Winther. 2013a. FindZebra: a search engine for rare diseases. *International Journal of Medical Informatics* 82, 6 (2013), 528–538. `https://www.sciencedirect.com/science/article/pii/S1386505613000166`

[17] Radu Dragusin, Paula Petcu, Christina Lioma, Birger Larsen, Henrik L Jørgensen, Ingemar J Cox, Lars Kai Hansen, Peter Ingwersen, and Ole Winther. 2013b. Specialized tools are needed when searching the web for rare disease diagnoses. *Rare Diseases* 1, 1 (2013), 528–38. `https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3932942/`

[18] Adobe Stock (Dvarg). 2020. *Ribbon Symbol*. `https://stock.adobe.com/search?creator_id=201848972&filters%5Bcontent_type%3Aphoto%5D=1&filters%5Bcontent_type%3Aillustration%5D=1&filters%5Bcontent_type%3Azip_vector%5D=1&filters%5Bcontent_type%3Avideo%5D=1&filters%5Bcontent_type%3Atemplate%5D=1&filters%5Bcontent_type%3A3d%5D=1&filters%5Bis_editorial%5D=all&filters%5Bcontent_type%3Aimage%5D=1&order=relevance&safe_search=1&k=rare+disease&search_page=1&search_type=usertyped&acp=&aco=rare+disease&get_facets=0`

[19] Matthew S Eastin. 2001. Credibility assessments of online health information: The effects of source expertise and knowledge of content. *Journal of Computer-Mediated Communication* 6, 4 (2001), JCMC643. `https://academic.oup.com/jcmc/article/6/4/JCMC643/4584226`

[20] Genomics England. 2016. Rare disease genomics. (May 2016). `https://www.genomicsengland.co.uk/understanding-genomics/rare-disease-genomics/`

[21] European Commission, The. 2020. *Rare diseases*. Technical Report. `https://ec.europa.eu/info/sites/info/files/research_and_innovation/research_by_area/documents/ec_rtd_eu-rare-diseases-research_factsheet.pdf`

[22] F Faurisson. 2004. Survey of the delay in diagnosis for 8 rare diseases in Europe: EurordisCare2. *European Organisation for Rare Diseases Web site* (2004). `https://www.eurordis.org/publication/survey-delay-diagnosis-8-rare-diseases-europe-%E2%80%98eurordiscare2%E2%80%99`

[23] Thomas A Fergus. 2013. Cyberchondria and intolerance of uncertainty: examining when individuals experience health anxiety in response to Internet searches for medical information. *Cyberpsychology, Behavior, and Social Networking* 16, 10 (2013), 735–739. `https://www.liebertpub.com/doi/10.1089/cyber.2012.0671`

[24] J Firth-Cozens. 2004. Organisational trust: the keystone to patient safety. *BMJ Quality & Safety* 13, 1 (2004), 56–61. `DOI:http://dx.doi.org/10.1136/qshc.2003.007971`

[25] Alan Fox. 1974. *Beyond contract: Work, power and trust relations*. Faber & Faber.

[26] Susannah Fox. 2011. *The social life of health information, 2011*. Pew Internet & American Life Project, Washington, DC.

[27] Diego Gambetta. 2000. Can we trust trust. *Trust: Making and breaking cooperative relations* 13 (2000), 213–237. `https://www.researchgate.net/publication/255682316_Can_We_Trust_Trust_Diego_Gambetta`

[28] Suad F Ghaddar, Melissa A Valerio, Carolyn M Garcia, and Lucy Hansen. 2012. Adolescent health literacy: the importance of credible

sources for online health information. *Journal of school health* 82, 1 (2012), 28–36.

[29] Kathleen Gray, Kristine Elliott, and Janet Wale. 2013. A community education initiative to improve using online health information: Participation and impact. *Informatics for Health and Social Care* 38, 3 (2013), 171–181. `https://www.tandfonline.com/doi/abs/10.3109/175381 57.2012.705201`

[30] Jamie Harrison, Rob Innes, and Tim D Van Zwanenberg. 2003. *Rebuilding trust in healthcare*. Radcliffe Publishing.

[31] Bradford W Hesse, David E Nelson, Gary L Kreps, Robert T Croyle, Neeraj K Arora, Barbara K Rimer, and Kasisomayajula Viswanath. 2005. Trust and sources of health information: the impact of the Internet and its implications for health care providers: findings from the first Health Information National Trends Survey. *Archives of internal medicine* 165, 22 (2005), 2618–2624. `https://jamanetwork.com/jour nals/jamainternalmedicine/fullarticle/766849`

[32] Eliza Ivanova and others. 2013. Internet addiction and cyberchondria-Their relationship with Well-Being. *The Journal of Education, Culture, and Society* 4, 1 (2013), 57–70. `https://jecs.pl/doi/10-15503-jec s20131-57-70/`

[33] Robert Kellner, Patrick Abbotf, Walter W Winslow, and Dorothy Pathak. 1989. Anxiety, depression, and somatization in DSM-III hypochondriasis. *Psychosomatics* 30, 1 (1989), 57–64. `https://www.sc iencedirect.com/science/article/abs/pii/S0033318289723185`

[34] Anna Kole and François Faurisson. 2009. *The voice of 12,000 patients. experiences and expectations of rare disease patients on diagnosis and care in Europe.* Eurordis-Rare Diseases Eu. `https://www.eurordis.o rg/publication/voice-12000-patients`

[35] Carolyn Lagoe and David Atkin. 2015. Health anxiety in the digital age: An exploration of psychological determinants of online health information seeking. *Computers in Human Behavior* 52 (2015), 484–491.

https://www.sciencedirect.com/science/article/pii/S0747563
215004392

[36] J David Lewis and Andrew Weigert. 1985. Trust as a social reality. *Social forces* 63, 4 (1985), 967–985. https://www.semanticscholar.org/paper/Trust-as-a-Social-Reality-Lewis-Weigert/7d3c196ca79a413ca59c0f6452bd8449127f0319

[37] David K Marcus, Jessica R Gurley, Melynda M Marchi, and Craig Bauer. 2007. Cognitive and perceptual variables in hypochondriasis and health anxiety: A systematic review. *Clinical psychology review* 27, 2 (2007), 127–139. https://www.sciencedirect.com/science/article/abs/pii/S0272735806001139

[38] Ben Martin. 2019. In-Depth: Cognitive Behavioral Therapy. (Jun 2019). https://psychcentral.com/lib/in-depth-cognitive-behavioral-therapy/

[39] Freda McManus, Christie Leung, Kate Muse, and J Mark G Williams. 2014. Understanding 'cyberchondria': an interpretive phenomenological analysis of the purpose, methods and impact of seeking health information online for those with health anxiety. *The Cognitive Behaviour Therapist* 7 (2014). https://www.cambridge.org/core/journals/the-cognitive-behaviour-therapist/article/understanding-cyberchondria-an-interpretive-phenomenological-analysis-of-the-purpose-methods-and-impact-of-seeking-health-information-online-for-those-with-health-anxiety/9CF314C9F9DD226A3F4E509541CFAE4D

[40] Ryan D McMullan, David Berle, Sandra Arnáez, and Vladan Starcevic. 2019. The relationships between health anxiety, online health information seeking, and cyberchondria: Systematic review and meta-analysis. *Journal of affective disorders* 245 (2019), 270–278. https://www.sciencedirect.com/science/article/abs/pii/S0165032718315775

[41] Christine McNab. 2009. *What social media offers to health professionals and citizens.* SciELO Public Health (Bulletin of the World Health

Organisation). `https://www.scielosp.org/article/bwho/2009.v87`
`n8/566-566/en/`

[42] Mendelian. 2018. A preliminary assessment of the potential impact of rare diseases on the NHS. (2018). `https://imperialcollegehealthp`
`artners.com/wp-content/uploads/2019/05/ICHP-RD-Report-Nov-`
`2018-APPROVED-002.pdf`

[43] Vikas Menon, Sujita Kumar Kar, Adarsh Tripathi, Naresh Nebhinani, and Natarajan Varadharajan. 2020. Cyberchondria: conceptual relation with health anxiety, assessment, management and prevention. *Asian Journal of Psychiatry* (2020), 102225. `https://www.sciencedirect.`
`com/science/article/pii/S1876201820303373`

[44] Janet M Morahan-Martin. 2004. How internet users find, evaluate, and use online health information: a cross-cultural review. *CyberPsychology & Behavior* 7, 5 (2004), 497–510. `https://www.liebertpub.com/doi`
`/abs/10.1089/cpb.2004.7.497`

[45] Kate Muse, Freda McManus, Christie Leung, Ben Meghreblian, and J Mark G Williams. 2012. Cyberchondriasis: fact or fiction? A preliminary examination of the relationship between health anxiety and searching for health information on the Internet. *Journal of anxiety disorders* 26, 1 (2012), 189–196. `https://www.sciencedirect.com/scie`
`nce/article/pii/S0887618511001794?via%3Dihub`

[46] National Health Service. 2007a. Cognitive behavioural therapy (CBT). (2007). `https://www.nhs.uk/conditions/cognitive-behavioural-`
`therapy-cbt/`

[47] National Health Service. 2007b. Health Anxiety. (2007). `https://ww`
`w.nhs.uk/conditions/health-anxiety/`

[48] National Health Service. 2008. History of NHS Direct. (2008). `https:`
`//web.archive.org/web/20081217040304/http://www.nhsdirect.`
`nhs.uk/article.aspx?name=HistoryOfNHSDirect`

[49] Department of Health. 2014. Rare diseases: UK strategy. (Feb 2014). `https://assets.publishing.service.gov.uk/government/upload s/system/uploads/attachment_data/file/260562/UK_Strategy_for _Rare_Diseases.pdf`

[50] Office for National Statistics. 2019. Internet access - households and individuals, Great Britain. (2019). `https://www.ons.gov.uk/peoplep opulationandcommunity/householdcharacteristics/homeinterne tandsocialmediausage/bulletins/internetaccesshouseholdsand individuals/2019`

[51] David Pilgrim, Floris Tomasini, and Ivaylo Vassilev. 2010. *Examining trust in healthcare: A multidisciplinary perspective*. Macmillan International Higher Education.

[52] John Powell, Nadia Inglis, Jennifer Ronnie, and Shirley Large. 2011. The characteristics and motivations of online health information seekers: cross-sectional survey and qualitative interview study. *Journal of medical Internet research* 13, 1 (2011), e20. `https://www.jmir.org/2 011/1/e20/`

[53] David N Rapp and Nikita A Salovich. 2018. Can't we just disregard fake news? The consequences of exposure to inaccurate information. *Policy Insights from the Behavioral and Brain Sciences* 5, 2 (2018), 232–239. `https://journals.sagepub.com/doi/10.1177/2372732218785193`

[54] Simon Ronicke, Martin C Hirsch, Ewelina Türk, Katharina Larionov, Daphne Tientcheu, and Annette D Wagner. 2019. Can a decision support system accelerate rare disease diagnosis? Evaluating the potential impact of Ada DX in a retrospective study. *Orphanet journal of rare diseases* 14, 1 (2019), 69. `https://ojrd.biomedcentral.com/artic les/10.1186/s13023-019-1040-6`

[55] Daniel Scanfeld, Vanessa Scanfeld, and Elaine L Larson. 2010. Dissemination of health information through social networks: Twitter and antibiotics. *American journal of infection control* 38, 3 (2010), 182–188.

[56] Alpesh Shah. 2012. Simple diagnosis, treatment and prescriptions now a click away. (Mar 2012). `https://njtopdocs.com/simple-diagnosis-treatment-and-prescriptions-now-a-click-away/`

[57] Feichen Shen, Sijia Liu, Yanshan Wang, Liwei Wang, Naveed Afzal, and Hongfang Liu. 2017. Leveraging collaborative filtering to accelerate rare disease diagnosis. In *AMIA Annual Symposium Proceedings*, Vol. 2017. American Medical Informatics Association, 1554. `https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5977716/`

[58] Ilias I Siempos, Alex Spanos, Evangelos A Issaris, Petros I Rafailidis, and Matthew E Falagas. 2008. Non-physicians may reach correct diagnoses by using Google: a pilot study. *Swiss medical weekly* 138, 4950 (2008). `https://pubmed.ncbi.nlm.nih.gov/19130327/`

[59] Elizabeth Sillence, Pam Briggs, Peter Richard Harris, and Lesley Fishwick. 2007. How do patients evaluate and make use of online health information? *Social science & medicine* 64, 9 (2007), 1853–1862. `https://www.sciencedirect.com/science/article/pii/S0277953607000160`

[60] Karmpaul Singh and Richard J Brown. 2016. From headache to tumour: An examination of health anxiety, health-related Internet use and 'query escalation'. *Journal of Health Psychology* 21, 9 (2016), 2008–2020. `https://pubmed.ncbi.nlm.nih.gov/25706333/`

[61] Karmpaul Singh, John RE Fox, and Richard J Brown. 2016. Health anxiety and Internet use: A thematic analysis. *Cyberpsychology: Journal of Psychosocial Research on Cyberspace* 10, 2 (2016). `https://cyberpsychology.eu/article/view/6177`

[62] Vladan Starcevic. 2017. Cyberchondria: challenges of problematic online searches for health-related information. *Psychotherapy and psychosomatics* 86, 3 (2017), 129–133. `https://www.karger.com/Article/FullText/465525`

[63] Vladan Starcevic and David Berle. 2013. Cyberchondria: towards a better understanding of excessive health-related Internet use. *Expert*

Review of Neurotherapeutics 13, 2 (2013), 205–213. `https://www.rese archgate.net/publication/235389719_Cyberchondria_Towards_a_b etter_understanding_of_excessive_health-related_Internet_use`

[64] Vladan Starcevic and David Berle. 2015. Cyberchondria: An old phenomenon in a new guise. *Mental health in the digital age: Grave dangers, great promise* (2015), 106–117. `https://www.researchgate.net/pub lication/277559120_Cyberchondria_An_Old_Phenomenon_in_a_New _Guise#:~:text=Cyberchondria%20refers%20to%20the%20excessi ve,anxiety%20and%20obsessive%2Dcompulsive%20symptoms.`

[65] Briony Swire, Ullrich KH Ecker, and Stephan Lewandowsky. 2017. The role of familiarity in correcting inaccurate information. *Journal of experimental psychology: learning, memory, and cognition* 43, 12 (2017), 1948. `https://psycnet.apa.org/doiLanding?doi=10.1037%2Fxlm00 00422`

[66] Hangwi Tang and Jennifer Hwee Kwoon Ng. 2006. Googling for a diagnosis—use of Google as a diagnostic aid: internet based study. *Bmj* 333, 7579 (2006), 1143–1145. `https://www.bmj.com/content/333/75 79/1143`

[67] Steven Taylor and Gordon JG Asmundson. 2004. *Treating health anxiety: A cognitive-behavioral approach.* Guilford Press.

[68] Sheila Tobias and Carol Weissbrod. 1980. Anxiety and mathematics: An update. *Harvard Educational Review* 50, 1 (1980), 63–70.

[69] Peter Tyrer, Sylvia Cooper, Helen Tyrer, Duolao Wang, and Paul Bassett. 2019. Increase in the prevalence of health anxiety in medical clinics: Possible cyberchondria. *International Journal of Social Psychiatry* 65, 7-8 (2019), 566–569. `https://journals.sagepub.com/doi/10.1177 /0020764019866231`

[70] TP Usherwood. 1991. Development and randomized controlled trial of a booklet of advice for parents. *British Journal of General Practice* 41, 343 (1991), 58–62. `https://bjgp.org/content/41/343/58.short`

[71] Jenely Villamediana, Inés Küster, and Natalia Vila. 2019. Destination engagement on Facebook: Time and seasonality. *Annals of Tourism Research* 79 (2019), 102747. `https://doi.org/10.1016/j.annals.2019.102747`

[72] Matteo Vismara, Valentina Caricasole, Vladan Starcevic, Eduardo Cinosi, Bernardo Dell'Osso, Giovanni Martinotti, and Naomi A Fineberg. 2020. Is cyberchondria a new transdiagnostic digital compulsive syndrome? A systematic review of the evidence. *Comprehensive Psychiatry* (2020), 152167. `https://www.sciencedirect.com/science/article/pii/S0010440X20300092`

[73] Neil D. Weinstein and Michael A. Diefenbach. 1997. Percentage and verbal category measures of risk likelihood. *Health Education Research* 12, 1 (03 1997), 139–141. `https://academic.oup.com/her/article/12/1/139/811187`

[74] Ryen W White and Eric Horvitz. 2009a. Cyberchondria: studies of the escalation of medical concerns in web search. *ACM Transactions on Information Systems (TOIS)* 27, 4 (2009), 1–37. `https://dl.acm.org/doi/10.1145/1629096.1629101`

[75] Ryen W White and Eric Horvitz. 2009b. Experiences with web search on medical concerns and self diagnosis. In *AMIA annual symposium proceedings*, Vol. 2009. American Medical Informatics Association, 696. `https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2815378/`

[76] Sean D Young. 2011. Recommendations for using online social networking technologies to reduce inaccurate online health information. *Online journal of health and allied sciences: OJHAS* 10, 2 (2011).

Appendices

A   Questionnaire Design

Online Health Information

Comparing a rare disease perspective of online health information with the general public
* Required

1.   What is your age? *

Mark only one oval.

   ◯ Under 18

   ◯ 18-25

   ◯ 26-30

   ◯ 31-45

   ◯ 46-60

   ◯ Over 60

   ◯ Prefer not to say

2.   What gender do you identify as? *

Mark only one oval.

   ◯ Female

   ◯ Male

   ◯ Other

   ◯ Prefer not to say

3.   Do you suffer from any long term health problems? *

Mark only one oval.

   ◯ Yes

   ◯ No

   ◯ Prefer not to say

4. Have you been diagnosed with a rare disease? *

   Mark only one oval.

   ( ) Yes

   ( ) No   *Skip to question 9*

   ( ) Prefer not to say   *Skip to question 9*

   About your diagnosis

5. What type of rare disease were you diagnosed with? *

   _____

6. When were you diagnosed? *

   _____

   Example: January 7, 2019

7. Approximately, how long did it take to reach a diagnosis after you first sought medical help? *

   Mark only one oval.

   ( ) Less than 6 months

   ( ) 6 - 12 months

   ( ) 1 - 2 years

   ( ) 2-3 years

   ( ) 3-5 years

   ( ) 5-7 years

   ( ) Over 7 years

8. Approximately, how long did it take to reach a diagnosis after you first had symptoms? *

   Mark only one oval.

   ⚬ Less than 6 months
   ⚬ 6 - 12 months
   ⚬ 1 - 2 years
   ⚬ 2-3 years
   ⚬ 3-5 years
   ⚬ 5-7 years
   ⚬ Over 7 years

   Online Health Information

9. How frequently do you look for health information online? *

   Mark only one oval.

   ⚬ Every day
   ⚬ A few times a week
   ⚬ About once a week
   ⚬ A few times a month
   ⚬ Once a month
   ⚬ Less than once a month
   ⚬ Never

10. How long do you normally spend when looking for health information? *

Mark only one oval.

◯ Several hours

◯ A few hours

◯ About an hour

◯ About 30-60 minutes

◯ About 15-30 minutes

◯ Less than 15 minutes

11. What methods/tools do you usually use when looking for health information? *

Check all that apply.

☐ Search Engine
☐ Symptom checker website
☐ Blog or Chatroom
Other: ☐ _____

12. How useful do you find these methods/tools? *

Mark only one oval.

	1	2	3	4	5	
Not at all useful	◯	◯	◯	◯	◯	Very useful

13. When looking for health information, what are you usually hoping to achieve? *

Mark only one oval.

◯ To find a diagnosis or research your symptoms

◯ To find out more about a condition

◯ To seek reassurance

◯ To get a second opinion

◯ Other: _____

14. Following on from the previous question, was this goal hard to achieve? *

Mark only one oval.

◯ Yes

◯ Mostly

◯ Somewhat

◯ Not at all

15. What are your thoughts and feelings when you decide to look online for health information? *

_____

_____

_____

_____

_____

16. What are your thoughts and feelings whilst you look online for health information? *

_____

_____

_____

_____

_____

17. What are your thoughts and feelings after you stop looking online for health information? *

_____

_____

_____

_____

_____

18. I would find it helpful if online health information was presented visually (e.g. pie charts, bar graphs, etc.) in addition to written information. *

Mark only one oval.

	1	2	3	4	5	
Strongly Disagree	◯	◯	◯	◯	◯	Strongly Agree

19. I would find it helpful to attend workshops to better understand how to recognise whether online information is credible. *

Mark only one oval.

	1	2	3	4	5	
Strongly Disagree	◯	◯	◯	◯	◯	Strongly Agree

20. When searching for health information, I would find it helpful if health conditions were sorted in order of likelihood. *

Mark only one oval.

	1	2	3	4	5	
Strongly Disagree	◯	◯	◯	◯	◯	Strongly Agree

21. I would find it helpful if search engines used my data to find health conditions that are more likely and more relevant to me. *

Mark only one oval.

	1	2	3	4	5	
Strongly Disagree	◯	◯	◯	◯	◯	Strongly Agree

22. I am worried about sharing my data with search engines to find health conditions that are more likely and more relevant to me. *

Mark only one oval.

	1	2	3	4	5	
Strongly Disagree	◯	◯	◯	◯	◯	Strongly Agree

23. I would find it helpful if search engines monitored website activity and content to detect and downweight unreliable or anxiety provoking websites. *

Mark only one oval.

	1	2	3	4	5	
Strongly Disagree	◯	◯	◯	◯	◯	Strongly Agree

24. This image shows one example of how a website might provide information regarding why it suggested a particular condition, in addition to why you may not suffer from this condition. How would you respond differently to this than to other online health information? *

_____

_____

_____

_____

_____

25. This image shows one example of how a website might show a percentage representing the likelihood (based on the symptoms inputted) that you have the suggested condition. How would you respond differently to this than to other online health information? *

26. This image shows one example of how a website might incorporate both designs. How would you respond differently to this than to other online health information? *

_____

_____

_____

_____

_____

27. Please write any further comments you have below.

_____
_____
_____
_____
_____

28. We would really appreciate it if you could take part in a follow up interview for this research. The interview will take 20 minutes over a video conference at a mutually agreed time over the next couple of weeks. If you are willing to contribute to this research in this way, please leave your email address and/or phone number below.

_____

Figure 14: Questionnaire Design

B Interview Questions

1. When did you first get symptoms of *KDS and Central Core Disease*? Tell me about your journey towards a diagnosis after that.
   a. When did you first seek medical help?
   b. Did you look for health information to assist with your diagnosis? Can you expand on that a little?

2. Tell me about a time during the journey towards your diagnosis when you have looked for health information.
   a. Have you ever used online tools during this time?
      i. Why/why not?
      ii. How useful was it? Can you talk a little about why that is?
      iii. In the questionnaire you said that when looking for health information, your goal was mostly hard to achieve, why is that?
   b. Tell me about your process, how did you go about doing it?
      i. What about this method works for you?
      ii. What sort of sites lead from your search?
      iii. It sounds like your thoughts and emotions were mostly negative, is that correct? Tell me a bit about that
      iv. Did you act on the results? If so, how?
         a. Why were you keen/hesitant to act on the information you found?
         b. Did you discuss findings with your health provider?
   c. How confident were you that you suffered from the condition that came up?
   d. How much did you trust the results?

3. What are the advantages and disadvantages of using technology for health information?

4. Is there anything you would change about the services online to better suit your needs when looking for health information?

5. In the questionnaire, you were shown this image and said that you were *Unsure* how you would respond differently. Can you expand on that?
   a. Why is that?
   b. Would you act on the results? If so, how?
   c. How would it make you feel?
   d. Would you prefer to have information presented in this way?
   e. How much would you trust the results?

6. With the second image, you said you were *Unsure* again. Can you expand on that?
   a. Why is that?
   b. Would you act on the results? If so, how?
   c. How would it make you feel?
   d. Would you prefer to have information presented in this way?
   e. How much would you trust the results?

7. Finally, you said that ***Probably in my case is rare.*** Can you expand on that?
   a. Why is that?
   b. Would you act on the results? If so, how?

  c. How would it make you feel?

  d. Would you prefer to have information presented in this way?

  e. How much would you trust the results?

8. Is there anything else you would like to add?

Figure 15: Interview Questions

C   Prototypes

Figure 16: Prototype 1

Figure 17: Prototype 2

Figure 18: Prototype 3

D   Questionnaire Responses

What is your age?	What gender do you identify as?	Do you suffer from any long term health problems?	Have you been diagnosed with a rare disease?	What type of rare disease were you diagnosed with?	When were you diagnosed?	Approximately, how long did it take to reach a diagnosis after you first sought medical help?	Approximately, how long did it take to reach a diagnosis after you first had symptoms?	How frequently do you look for health information online?	How long do you normally spend when looking for health information?	What methods/tools do you usually use when looking for health information?	How useful do you find these methods/tools?	When looking for health information, what are you usually hoping to achieve?	Following on from the previous question, was this goal hard to achieve?	What are your thoughts and feelings when you decide to look online for health information?	What are your thoughts and feelings whilst you look online for health information?	What are your thoughts and feelings after you stop looking online for health information?	I would find it helpful if online health information was presented visually (e.g. pie charts, bar graphs, etc.) in addition to written information.	I would find it helpful to attend workshops to better understand how to recognise whether online information is credible.	When searching for health information, I would find it helpful if health conditions were sorted in order of likelihood.	I would find it helpful if search engines used my data to find health conditions that are more likely and more relevant to me.	I am worried about sharing my data with search engines to find health conditions that are more likely and more relevant to me.	I would find it helpful if search engines monitored website activity and content to detect and downweight unreliable or anxiety provoking websites.	This image shows one example of how a website might provide information regarding why it suggested a particular condition, in addition to why you may not suffer from this condition. How would you respond differently to this than to other online health information?	This image shows one example of how a website might show a percentage representing the likelihood (based on the symptoms inputted) that you have the suggested condition. How would you respond differently to this than to other online health information?	This image shows one example of how a website might incorporate both designs. How would you respond differently to this than to other online health information?	Please write any further comments you have below.
31-45	Female	Yes	Yes	NMO	8/15/2020	3-5 years	3-5 years	Every day	A few hours	Search Engine, Symptom checker website, Blog or Chatroom	5	To find out more about a condition	Somewhat	Determined	Determined	Satisfied, overwhelmed	5	5	5	5	5	5	I wouldn't respond differently.	I wouldn't.	I wouldn't.	
Under 18	Male	Yes	Yes	Trisomy 18	05/03/2020	2-3 years	2-3 years	Every day	Several hours	Search Engine, Blog or Chatroom	3	To find out more about a condition	Yes	Looking for info to better help my child	Not enough info out there	Wish I found what I was looking for	3	4	5	4	3	3	It would be more helpful	It would carry more weight	Helpful	
26-30	Female	Yes	Yes	Moyamoya Disease	03/07/2019	Less than 6 months	Over 7 years	Every day	About an hour	Search Engine, Blog or Chatroom	4	To find out more about a condition	Mostly	Anxious	An ious	Still Anxious but more understanding	5	5	5	2	5	5	I'm unsure of the question?	Its easier to suggest the outcome with specialists this way	I'd feel more assured	
Under 18	Female	No	Yes	Hypogondtropic Hypogondism and Kallmann Syndrome	3/18/2020	3-5 years	3-5 years	A few times a week	A few hours	Symptom checker website	5	To find out more about a condition	Mostly	nervous	it's very emotional	your still emotional but then your okay	4	3	4	4	4	4	na not going to read this	na not going to read this	na. not going to read these	getting diagnosed early is usually the best way to start your journey. the longer you wait the more you have to play catch up. don't be discouraged when your doctors don't find answers. you know your body best. advocate for yourself and find your diagnosis
31-45	Female	Yes	Yes	Ehlers Danlos	09/10/2019	Over 7 years	Over 7 years	A few times a week	A few hours	Blog or Chatroom	5	To find out more about a condition	Not at all	Patients have the answer. They are the experts.	See above. Validation. Empathy from others.	The only option	1	1	1	1	5	1	Not helpful. Could be anything.	Not helpful	Not helpful	We look on the internet to speak to fellow patients as doctors don't have time or understand. They often dismiss rare disease as psychological in nature.
31-45	Prefer not to say	Yes	Yes	Early onset cerebellar ataxia	7/16/2014	Over 7 years	Over 7 years	Every day	Several hours	International facebook ataxia groups	3	To find out more about a condition	Yes	I was hopeless	Frustration	Frustration	3	3	3	3	3	3	Nice	Nice	Ok	
46-60	Female	Yes	Yes	King Denborough Syndrome and Central Core Disease	4/14/2016	Over 7 years	Over 7 years	A few times a week	About an hour	Search Engine	3	To find a diagnosis or research your symptoms	Mostly	Looking for answers to as why I am so ill	Frustrating	Confused	3	3	3	3	2	5	Unsure	Unsure	Probably in my case is rare	
31-45	Female	Yes	Yes	Primary Immunodeficiency	03/02/2020	Less than 6 months	Over 7 years	Less than once a month	About 15-30 minutes	Medscape	2	To find out more about a condition	Somewhat	Once I had a diagnosis, not hard to find info	Didn't you just add "whilst" to the above stated question?	I feel better after finding info on my disease. Aka: pt education	2	2	1	1	1	2	I am a nurse. I don't use online info to find a diagnosis. I use info to learn more about the dx. Not having a dx is beyond frustrating and very crazy making. It's not the searching that makes you crazy. It's the docs that treat you crazy. If they don't have an answer you must be crazy. I also have MDS and a TET-2 disorder . I have been ill all of my adult like with very few answers. Yet, if MDs cant find what's wrong, blind google searches aren't going to help. Why is it that only the pt has scientific curiosity? Why is it that the unknown is no longer searched? Sometimes it's a fucking ZEBRA!!!	If you are going to diagnose yourself this might be helpful	See above answer	You missed The real question. Why don't docs believe pts? Why do you (psychology dissertation??) feel that if one searches the internet frequently she/he must be mentally ill? Maybe this is the ideal that is most harmful
46-60	Female	Yes	No					A few times a week	A few hours	PubMed	3	To find a diagnosis or research your symptoms	Yes	I feel desperate as I feel very sick and doctors are refusing to diagnose me	Not very helpful	Desperation	5	5	5	5	5	5	It's not helpful and only has an algorithm to find common diseases	Not helpful	A bit better - but far from perfect	I am a medical education Writer - but these websites are usually written by non-specialists or young graduates

Age	Gender	Q1	Q2		Date			Frequency	Duration	Source	Rating	Reason	Accuracy	Response A	Response B	Response C	R1	R2	R3	R4	R5	R6	Comment 1	Comment 2	Comment 3	Comment 4
26-30	Female	No	No					About once a week	About 15-30 minutes	Search Engine	4	To find out more about a condition	Somewhat	I research bearing in mind that results may not be accurate	I research bearing in mind that results may not be accurate	Know a little more than I did previously	4	2	3	2	2	3	Not any different	Not any different	Not any different. Sorry	
31-45	Male	Yes	No					A few times a week	Less than 15 minutes	Search Engine	3	To seek reassurance	Somewhat	I usualy feel a bit of anxiety	It's usually to look up symptoms and make sure its nothing serious, problem is that often same symptons are associated with very different reasons that span from serious to not	that I have searched for multiple conditions associated with those symptoms, I end up going for good sense but sometimes comon issue are easily solved.	2	3	5	5	1	5	I prefer this a lot more, you can easily exclude yourself by falling into excessive anxiety and thinking you have something extreme (often not the case).	this can help understand how often a sympton is possible, its a lot more intuitive than a general "most cases" or "unlikely"	I would most likely prefer this to other solutions as it has both views that make it a lot better that what is currently offered	I really like this approach it definitely solves a lot of current issues that occur when looking up this kind of information. Usualy people are worried, even if common sense avoids sharind axiety and we rationally exclude certain illnesses it's still something that is there in the back of your mind.
26-30	Female	No	No					Less than once a month	About an hour	Search Engine, Blog or Chatroom	3	To find out more about a condition	Mostly	insecurity, uncertainty and curiosity	insecurity and uncertainty	confused, sometimes satisfied	4	3	3	1	4	1	no	no	maybe	
26-30	Female	Yes	Yes	Not applicable	09/08/2020	6 - 12 months	6 - 12 months	About once a week	A few hours	Symptom checker website	4	To seek reassurance	Mostly	No	No	No	4	2	4	4	4	3	2nd	Yes	Yes	
18-25	Male	No	No					Once a month	About 15-30 minutes	Search Engine	3	To find out more about a condition	Mostly	Mixed - hard to find adequat information regarding a specific problem	See above	Depends on the findings	4	5	5	5	3	3	Seems more professional	Would rather trust a doc	-	
26-30	Female	No	No					Never	Less than 15 minutes	Search Engine	2	To find out more about a condition	Somewhat	I try to find information	mostly its not applicable to me	often not better but also not worse than before. usually researching online is pointless	3	1	3	3	4	3	seems credible	very helpful	very helpful	
18-25	Female	No	No					A few times a month	About 15-30 minutes	Search Engine, Symptom checker website	3	To find out more about a condition	Mostly	Concerned	Sceptical of information	Either reassured or more panicked	3	2	5	4	5	5	Gives you some reassurance of lack of severity	Reassured but also questioning whether it's accurate	Much less intimidating	
18-25	Female	No	No					A few times a month	Less than 15 minutes	Symptom checker website	5	To get a second opinion	Not at all	Wanting to know what could be wrong	Interested in finding a solution	More informed generally	3	3	5	4	4	5	Easier to determine the likelihood of your symptoms than just a long winded list.	Much easier with a visual	Much easier to scroll to more probable options	
18-25	Female	No	No					Less than once a month	About 15-30 minutes	Search Engine, Symptom checker website, NHS site	3	To find out more about a condition	Not at all	Thought is- I need to educate myself on XYZ	Interested, engaged	Either frustrated as I have not found what I wanted or satisfied that I have gained more knowledge	3	3	5	3	3	1	It's clever but I am not always looking for symptoms or health issues I MAY have, I am often expanding my knowledge on conditions friends and family have.	Refer to answer on first image. Although, I can see why this would either reduce fear in people who are searching certain things or increase fear. It should be an optional viewing, in my opinion.	I prefer this to the previous two images, I like that all the information is incorporated.	
18-25	Female	No	No					Less than once a month	Less than 15 minutes	Search Engine	4	To find a diagnosis or research your symptoms	Somewhat	To see if I need to see a GP	To see if I need to see a GP	To see if I need to see a GP	1	4	5	5	5	5	It's very to the point and useful	It gives you the figures to back up the information	I prefer the two images above having them separately	
26-30	Female	Yes	No					About once a week	A few hours	Search Engine	3	To seek reassurance	Mostly	Usually a mixture of concern and anxiety relation to the disorder/health issue.	Mostly just seeking reassurance from shared experiences, to quell any anxiety relating to the issue. I use it as a coping mechanism.	Sometimes I leave feeling relieved, if I have read something useful or which I can empathise with. Other times i am left feeling more confused and concerned than I was before I began my deep dive into online writings on my health problems.	4	4	4	5	5	5	It's quite text heavy. I would browse the reading but probably go elsewhere to seek my answers.	It looks a lot more concise and having all of the options in front of me I could pick and choose which I want to look into more - especially as they are more tailored to what may or may not be useful with the percentages.	I like this option less, it's text heavy and blocked in a way that I would probably go to another site to look for something less overwhelming.	
18-25	Female	No	No					Once a month	About 15-30 minutes	Search Engine	3	To find out more about a condition	Somewhat	Apprehension about the validity of the site. Usually only trust NHS ones	Interested in the symptoms/ whatever in looking into	Usually a bit more informed about it	3	2	3	1	4	3	Helpful, less anxious	Like that it shows the probability. Can make a more informed decision	Better than seperately	
26-30	Male	No	No					A few times a month	About 30-60 minutes	Search Engine, Blog or Chatroom	4	All of the above	Somewhat	Looking for reasurance	Everything eventually leads to cancer diagnosis, which is intimidating and un realistic	Confused.	4	5	3	2	5	5	Contact GP.	Percentage is weird to comprehend in regards to illness.	Too confusing	
18-25	Female	No	No					Less than once a month	About 30-60 minutes	Search Engine	2	To seek reassurance	Yes	I feel that I have a certain health issue and I hope its not that	This normally makes me more worried that I have that health issue.	I almost always feel down and worried about if I have an issue or not.	3	4	5	5	1	5	I don't know of Mayo clinic so I may be dubious to believe the statment and check this with the NHS website.	I like seeing this as it puts into perspective the likelihood of having this issue and puts me more at ease that its probably not that.	I think this is concise and well laid out and makes it look like a more professional webpage and id be more likely to believe the facts stated.	

Age	Gender	Q1	Q2	Frequency	Duration	Sources	Rating	Purpose	Level	Thoughts before	Thoughts during	Thoughts after	R1	R2	R3	R4	R5	R6	Comment A	Comment B	Comment C	Comment D
18-25	Female	No	No	A few times a month	About 15-30 minutes	Search Engine, Symptom checker website	3	To find out more about a condition	Mostly	Concerned	Sceptical of information	Either reassured or more panicked	3	2	5	4	5	5	Gives you some reassurance of lack of severity	Reassured but also questioning whether it's accurate	Much less intimidating	
31-45	Female	No	No	Every day	About 15-30 minutes	Search Engine, Symptom checker website, Blog or Chatroom	3	To seek reassurance	Mostly	I look for information to avoid a trip to the GP with non-serious concerns.	It's easy to get worried over small concerns, when you read health information on the internet. Basically a sneeze could be deadly. So I take every information with a pinch of salt and look for the most objective/scientific answers.	Sometimes I am annoyed that there is no clear answer and the concern could be diagnosed in so many ways. Sometimes I am reassured that it's a small concern and won't lead to anything serious. Sometimes it makes me anxious and stressed over small concerns, because someone had a major problem from it. Sometimes I find an "over the counter" cure for the concern and I solve the problem with that.	3	2	5	1	5	3	It's helpful.	Percentages don't calm my anxiety... because there is no guarantee I am not in the 1% of anything. For the population the likelihood might be 1%... but for me, if I have the condition, then it's a 100%.	This combined version is a bit better, I guess.	For some conditions, websites tend to list all the symptoms that may accompany that condition, but most of those symptoms are harmless on their own. So I think instead of listing all the symptoms, websites should make symptom groups.
26-30	Male	No	No	A few times a week	Less than 15 minutes	Search Engine, Blog or Chatroom	4	All of above	Somewhat	Always to get initial information for minor things but if it's a more serious thing then double check with gp or go to a&e as info may not be completely accurate	Useful in most cases	Glad I checked and got reassurance	3	2	3	4	2	3	I would check a couple of websites for a stronger chain source	I would again other sources as this may not be that accurate at all	If I felt it very serious then I would call the gp or go to a&e	Looking for health information has been very useful for me in checking symptoms and illnesses for my infant.
18-25	Female	No	No	About once a week	Less than 15 minutes	Search Engine	5	To seek reassurance	Somewhat	Please let my worries not be a serious life-threatening condition.	Often by seeing symptoms of conditions, and treatments I can be reassured about a sensation loss, or a random lump that I've found, which is normally because I've bashed something or that I have a trapped nerve. This calms me.	I may not always find legitimate information, and so have been to the GP with a self-diagnosis, which has been farfetched. However, usually its a feeling again of reassurance, but sometimes you worry about it more and think about it during the day if you have a symptom of a serious illness.	4	4	4	1	5	5	Probably see it as more reliable, as it you choose your symptoms, so you can't then start to create extra symptoms you don't have by seeing a list. This would probably give me more confidence in the potential "diagnoses". I also really like the part where it gives symptoms to lead to something else, that extra information may also help mis-diagnoses.	Again, super useful in not provoking fear in yourself that you have a certain life threatening diseases or illness, just because you bashed your head, and the likelihood is you just need to sit down for a bit.	This is more comprehensive than what was before, and accompanied by the extra information on symptoms would make me more likely to look at this website. May help you to identify different symptoms you didn't realise were symptoms, but again risk of creating symptoms in your head (psychologically).	
18-25	Female	No	No	About once a week	About 30-60 minutes	Search Engine, Symptom checker website, Blog or Chatroom	3	To seek reassurance	Somewhat	I am often nervous but even more eager to find an answer.	I feel good when I learn about what is happening to me. On the flip side, it can make me feel even more anxious about what is happening to me.	Usually reassured and content that I have learned something about my body.	4	3	4	1	4	4	I would feel much more informed and less stressed jumping to conclusion from information that does not present the whole picture.	I would find this helpful and I am much more likely to read it if it then was followed up by explanations of each condition.	I am very likely to use this format over other websites, but if I don't know about it from an advertisement etc, I'd never know what I am missing out on. This looks great!	
46-60	Female	No	No	Less than once a month	Less than 15 minutes	Search Engine	5	To find out more about a condition	Mostly	Take it with a pinch of salt	Take it with a pinch of salt	Take it with a pinch of salt	2	3	3	1	1	3	.	.	.	.
18-25	Female	No	No	Less than once a month	Less than 15 minutes	Search Engine	4	To find a diagnosis or research your symptoms	Somewhat	To see if I need to see a GP	To see if I need to see a GP	To see if I need to see a GP	1	4	5	5	5	5	It's very to the point and useful	It gives you the figures to back up the information	I prefer the two images above having them separately	
31-45	Female	No..?	No..!	A few times a month	About 15-30 minutes	Search Engine	4	To seek reassurance	Somewhat	Before searching, my thoughts are very analytical, I know I'll be looking for a variety of reliable sources from websites that have positive feedback in order to compare the information	While I am looking I am usually very anxious and stressed, depending on how urgently I need an answer for my problem.	Once I've found the information that I was looking for, I am usually relieved, and also I have very analytical thoughts in order to decide the next steps to take.	3	3	4	2	4	4	I would considerate as reliable, and probably I would need to do less search in other websites to validate this information	Yes, I would appreciate this extra information, it's very useful information	Yes, its useful but how are these percentages calculated? I would like some explanation.. based on the population of a specific country, or city..?	Thank you for asking me to be part of your research, best of luck! :)

Age	Gender							Frequency	Time Spent	Source	Rating	Purpose	Trust	Reaction A	Reaction B	Reaction C	N1	N2	N3	N4	N5	N6	Comment A	Comment B	Comment C	
18-25	Female	No	No					A few times a month	Less than 15 minutes	Search Engine	2	To seek reassurance	Yes	I'm normally anxious and looking for reassurance or ways I can deal with my symptoms without having to go to the doctor.	See above	Normally don't feel much better	4	3	4	4	4	4	That looks good - though it looks like it probably doesn't translate well onto a mobile screen which is where I do most searches	Could potentially ease my anxiety	Good combination	Needs to be mobile friendly
18-25	Female	No	No					Never	Less than 15 minutes	I ring family or the doctors	1	To find out more about a condition	Mostly	Intrigued	Overdramatic	will probably not work for me	1	1	5	5	3	3	I would be even more confused	makes more sense	Not much help	
18-25	Female	No	No					Less than once a month	About 30-60 minutes	Search Engine, Symptom checker website, Blog or Chatroom	4	To find a diagnosis or research your symptoms	Somewhat	Ciritically examining the content, bein aware that most of it might not be a reliable source.	comparing the information to my own situation	evaluation the usefulness of the information	5	3	4	3	5	4	it gives good reasons and clear information	the percentages provide clear information about likelihood and are easy to understand. good estimate	i think it would be best to have the second option and then be able to klick on it to get the detailed information shown in the first window	
18-25	Male	Yes	No					Less than once a month	About an hour	Search Engine	4	To find out more about a condition	Mostly	worry	doubt	calm	4	1	4	1	1	3	id take this more seriously as it has clear symptoms for health problems as well as things that will discredit worry that you have a paticular health problem	helps you quickly identify likely problems, more likely to skim	id spend less time second guessing symptoms as you can see likelihood percentage as well	
18-25	Male	Yes	No					Once a month	About 15-30 minutes	Search Engine	3	To find a diagnosis or research your symptoms	Mostly	hoping that it's nothing serious	hoping that its nothing serious	I shouldn't do that again	4	2	4	5	5	5	I wouldn't	look at the most likely first	best option, look at the most frequent first	
31-45	Female	Yes	Yes	.	09/12/2000	Less than 6 months	1 - 2 years	Once a month	About an hour	Search Engine	4	To seek reassurance	Mostly	.	.	.	3	4	3	3	4	4	.	.	.	.
31-45	Female	No	No					Once a month	About 15-30 minutes	Search Engine, Academic Journal	5	To find out more about a condition	Not at all	Interested and curious	Engaged and absorbed	Satisfied	5	5	3	3	1	3	I would likely feel less confused and less likely to continue searching for answers.	Same as above	Same as above	
18-25	Female	No	No					A few times a month	About an hour	Search Engine	3	To find a diagnosis or research your symptoms	Yes	Curious... wondering why I have a certain symptom	It's hard to find useful information	Sometimes more clarity	4	2	5	5	4	3	It is useful to have more information, but you don't know how likely each of the symptoms are	This is kinda useful, I would probably click on the options with the highest likelihood first before the other ones	Not as useful as you can't see as much on the list	
18-25	Male	No	No					Once a month	About 15-30 minutes	Search Engine	4	To find out more about a condition	Somewhat	Interested	Engaged	Either reassured or nervous	3	2	5	2	5	4	I would respond more positively. I would judge the presented information as more trustworthy as I would gain a more holistic insight.	I'd react positively to this presentation but would like to gain more insight into how this output is calculated.	Great! If this design was implemented, I'd use this site as my primary information source.	
18-25	Male	No	No					Less than once a month	Less than 15 minutes	Search Engine	5	To find out more about a condition	Not at all	Curious	Curious	Satisfied	4	1	4	4	4	5	More trusting but quizzical	Accurate	More trusting and satisfied	
18-25	Female	No	No					Once a month	About 30-60 minutes	Search Engine, Symptom checker website, Blog or Chatroom	4	To seek reassurance	Not at all	Worried, wanting an answer fast, hoping for the best	Calmer if I can find an answer but more worried if it's negative or confusing	Sometimes reassured sometimes more worried	3	3	5	5	5	5	Confused as it could be any some are ok some are bad. Get more worried then	Much better the percentage chance can settle you if it's nothing serious and alert you to check if it isnt	Last one is better	
18-25	Male	No	No					Less than once a month	Less than 15 minutes	Search Engine	5	To find out more about a condition	Not at all	Curious	Curious	Satisfied	4	1	4	4	4	5	More trusting but quizzical	Accurate	More trusting and satisfied	
31-45	Male	No	No					Less than once a month	Less than 15 minutes	Search Engine	3	To find a diagnosis or research your symptoms	Somewhat	Do I have to go to a doctor or can I diagnose myself and sort it out.	Impartial	Apply knowledge	3	2	5	2	3	4	Checking the reputation of the site	More clear as long as it's accurate.	Prefer other option	
26-30	Female	No	No					Less than once a month	Less than 15 minutes	Search Engine	4	To find out more about a condition	Not at all	I just want to know what the disease is, sometime I'm nervous if it is related to a family member but mostly not	I'm anxious to know what they have and how it could be cured or what could be done	It sometimes bothers my mind but not overly long	3	3	4		1	5	It seems quite legit to me, if I had to select my symptoms and the program would tell me what it could possibly be	I think that is quite good to know because sometimes I could be everything, so the percentage would help to sort through all the possibilities	I think I like the above the design more, to have a good overview of the diseases and the possibilities and I'd like to know more about the illness I would look into it	
26-30	Female	No	No					Less than once a month	About 30-60 minutes	Search Engine, Symptom checker website	2	To find out more about a condition	Somewhat	I'm sceptical sometimes because some things online may not be factually correct depending on the source.	I try to keep an open mind and don't just stick to what the first website says.	It varies, sometimes I am more confused other times I feel like my questions have been answered.	4	5	5	4	3	4	This isn't a bad way but I would want a bit more information.	Having a numerical figure to measure the likelihood assures me more that the information is reliable.	Again I would feel a lot more assured.	
18-25	Female	Yes	No					Once a month	Less than 15 minutes	Search Engine, Symptom checker website, Blog or Chatroom	4	To find a diagnosis or research your symptoms	Somewhat	I am curious to learn more about a disease	I find it difficult to filter all the information available online concerning health	I am sometimes more confused than before	4	3	4	4	4	4	I like that the symptoms are listed	I like that the likelihood is given in percentages	I like that the symptoms are listed	
18-25	Female	Yes	No					Once a month	Less than 15 minutes	Search Engine, Symptom checker website, Blog or Chatroom	4	To find a diagnosis or research your symptoms	Somewhat	I am curious to learn more about a disease	I find it difficult to filter all the information available online concerning health	I am sometimes more confused than before	4	3	4	4	3	4	I like that the symptoms are listed	I like that the likelihood is given in percentages	I like that the symptoms are listed	

Age	Gender	Q1	Q2	Condition	Date	Duration A	Duration B	Frequency	Time spent	Source	Rating	Purpose	Trust	Feeling 1	Feeling 2	Feeling 3	R1	R2	R3	R4	R5	R6	Comment 1	Comment 2	Comment 3	Comment 4
31-45	Male	No	No					Less than once a month	Less than 15 minutes	Search Engine	4	To find a diagnosis or research your symptoms	Not at all	Plenty advice online	Hope it's not too expensive	Hopefully information gathered!	5	3	3	3	3	3	It's ok! Wordy	Percentages can help	Maybe a graph?	Thanks
18-25	Male	Yes	No					Less than once a month	About 15-30 minutes	Search Engine	3	To find a diagnosis or research your symptoms	Mostly	Concern about something I dont recognise	Vague reassurance its nothing clear, determination to go see a doctor if it continues.	Mostly the same	3	4	4	2	3	4	Well, as its provides a more nuanced suggestion.	Fairly well, would help with better assurance but i would doubt my prior assesment of symptoms.	Very well, combines good bits of both.	
18-25	Female	Yes	Yes	Aquagenic urticaria, bilateral foot drop know caused	09/12/2018	1 - 2 years	1 - 2 years	A few times a week	A few hours	Search Engine	2	Treatment	Yes	Hopeful	Willing to leard	Disappointed	3	2	2	3	2	3	Hard to know that information really things you have	Would not	Trust mayo with my medical conditions	None
46-60	Female	Yes	Yes	MOG	9/17/2018	3-5 years	2-3 years	Every day	About an hour	Blog or Chatroom, Mog community	5	To find out more about a condition	Somewhat	I just need answers	None of the info is understandable	Lost	4	3	4	5	5	5	I have a hard time understanding most of it	Seems like its useful	I think it all just needs to be easier for a non Dr to read	Im constant looking for others with mog that have my symptoms. Like i have hearing loss my dr says not a mog symptom but people who have mog have suffer hearing loss
31-45	Female	Yes	Yes	Hypophosphatasia	8/19/2019	Over 7 years	Over 7 years	A few times a week	Several hours	Search Engine, Research articles	4	To find out more about a condition	Somewhat	I want more information	There is a lot of misinformation out there but research articles are good	It's a lot	5	4	4	4	3	3	The negatives are confusing	Find it interesting but as we have a rare disease, likelihood doesn't always apply	Should order by most likely	
18-25	Female	Yes	No					A few times a month	About an hour	Search Engine	3	To find out more about a condition	Somewhat	I try and make sure I don't use too many sites so I don't get overloaded	Panic, hope, worry, finding new information	Sometimes I wonder if I have done the right thing and this can cause more worry	5	5	5	4	5	3	Maybe talk to my doctors	This may be good so that I can see what things maybe and it may give light to something the doctors have not looked at	This is a good way to start but sometimes it can be a little generic and may confuse some people	
18-25	Female	No	No					Once a month	About 15-30 minutes	Search Engine, Symptom checker website	4	To find a diagnosis or research your symptoms	Mostly	Erster Ansatz	manchmal schwer einzuschätzen	meist beruhigt	2	2	3	3	2	3	-	-	-	
46-60	Female	Yes	Yes	Relapsing Polychondritis	1/17/2015	6 - 12 months	6 - 12 months	A few times a week	About an hour	Search Engine	3	To find out more about a condition	Somewhat	It can't hurt. Sometimes you can find just what you're looking for	I'm amazed at some of the things I find out	I ask people in my support groups for advice	3	3	4	4	4	4	It helps alleviate panic thinking you might have something you actually do not have	It would be more beneficial	I welcome any information and if I am not sure I ask my dr	
31-45	Female	Yes	Yes	Functional Neurological Disorder and Ataxia	3/1/0020	3-5 years	3-5 years	A few times a month	A few hours	Search Engine, Blog or Chatroom	3	To find out more about a condition	Somewhat	It is very overwhelming.	Information is not up to date and sometimes it creates more questions rather than answers.	When looking at the information I get anxious and overwhelmed so I have to stop and take a step back.	5	4	3	3	4	4	It is a little more easier to digest	I think there could be a large percentage that is inaccurate.	Perfect	
18-25	Female	Yes	Yes	Tularemia	6/25/2018	Over 7 years	Over 7 years	Every day	About an hour	Search Engine	3	To find out more about a condition	Mostly	Confused	Determined	Sometimes relieved and sometimes still confused or irritated	5	4	4	3	5	3	Helpful but might not be specific enough	Good	Quite helpful	
18-25	Female	No	No					Once a month	About 30-60 minutes	Blog or Chatroom	2	To find out more about a condition	Mostly	uncertainty	doubt	uncertainty	3	1	4	1	5	5	positiv, because it provides more information	negativ, less visual clarity	the best vof both versions combined in one (percentage and clarity)	
31-45	Female	No	No					A few times a week	About an hour	Search Engine, Blog or Chatroom	2	To find out more about a condition	Mostly	Feeling frustrated doctors can't provide more information on my sons diagnosis	Overwhelmed	Mostly more confused	2	4	5	1	5	4	Information appears easier to read	I would use this website over others	Layout is great	
Under 18	Female	Yes	Yes	Lissencephaly	07/07/2019	1 - 2 years	1 - 2 years	A few times a week	About an hour	Search Engine, Blog or Chatroom	3	To find out more about a condition	Yes	Uncertainty	Is it true	Defeated	5	3	5	5	5	5	I don't use symptom checker	I don't use symptom checker	I don't use symptom checker	
46-60	Female	Yes	Yes	Chronic inflammatory demyelinating polyradiculoneuropathy (CIDP)	12/12/2012	6 - 12 months	6 - 12 months	About once a week	A few hours	Search Engine, Symptom checker website, Blog or Chatroom	3	To find out more about a condition	Somewhat	Info gathering	Sad	Discouraged	5	5	3	3	5	5	It's good	It's good	It's good	

Age	Gender	Q1	Q2	Condition	Date	Duration 1	Duration 2	Frequency	Time Spent	Sources	R	Purpose	Trust	Open 1	Open 2	Open 3						R2	Response 1	Response 2	Response 3	Response 4
26-30	Female	Yes	No					A few times a week	Several hours	Research or Journal Articles	5	To find a diagnosis or research your symptoms	Yes	My thoughts and feelings about looking for health information online are neutral. My family has a rare genetic mutation, and I am a carrier for a rare genetic illness. If I did not do my research, we would have never found a doctor willing to help make sense of my mysterious symptoms.	I am saddened by the fact that I have to look online for health information. We are taught to trust our physicians, but what do you do when they can't help you or are unwilling to help. It's exhausting suffering without an answer so I do my own research.	I feel enlightened because I am doing this for me. I am the type of person that needs an answer to a problem, or I will never move on. There is a reason for my symptoms, and I will find the answer. You find the answer, you can begin the work to solve the problem.	5	5	5	5	1	5	I would view this as a credible source because I know from prior research that they will give the most likely cause and aren't unrealistic about not having a dangerous condition. Even, though we all like to think the worst about our symptoms.	I love it when the website has percentages of the least or most likely because it gives you an idea of what to look for.	Same as the above comments. This is a beneficial tool and allows you to have a great base for further research.	
Under 18	Female	No	No					Once a month	Less than 15 minutes	Search Engine, Symptom checker website, Blog or Chatroom	3	To find a diagnosis or research your symptoms	Mostly	maybe I can find something helpful	I hope I don't find fake news	this wasn't very helpful	4	5	4	5	5	5	it feels more relevant	it is helpful, but it may not help me	it is the best design	
18-25	Female	No	No					A few times a month	About 30-60 minutes	Search Engine	3	To find out more about a condition	Somewhat	I just want to know more about my sons diagnosis. It's very rare.	I just get sad.	I can't stop thinking about it	3	3	3	3	3	4	I'm not sure	Not sure	Not sure	
18-25	Female	No	No					Less than once a month	About 15-30 minutes	Search Engine	4	To find a diagnosis or research your symptoms	Somewhat	nothing special	neutral	reassured	4	4	3	1	4	4	More objective	positive	positive	
18-25	Female	Yes	Yes	Trigeminal neuralgia	12/15/2017	Less than 6 months	6 - 12 months	A few times a month	A few hours	Search Engine, Blog or Chatroom	4	To find out more about a condition	Mostly	Looking for new options or research	Normally see something interesting	Nothing different	4	2	2	2	2	2	I like this	Percentages scare people. From most likely to least likely without number would be nice	Don't like the percentages	
46-60	Female	Yes	Yes	Intracranial hypertension	07/04/2017	6 - 12 months	6 - 12 months	A few times a month	About an hour	Blog or Chatroom, Research articles	3	To find out more about a condition	Somewhat	Wanting to be well informed	More could be done	?	3	2	2	2	4	4	I wouldn't respond differently to this than anything else particularly... While valid this type of information website is too basic for my needs	While valid I wouldn't take this for granted. This seems a little like those doctors who overlook the smaller details for the obvious or easy solutions, and thus isn't always the case with chronic or rare disease... When you hear hoofbeats, it doesn't always mean it's a horse unless you see a horse	I wouldnt. See previous responses	While symptom checkers may have some place, I think they can perpetuate a problem that is seen in the medical work in minimising, dismissing or overlooking health complaints. All symptoms and signs need to be viewed holistically in order to get a complete picture of what is going on for a person, and and *good* website would explain this and why.
31-45	Female	Yes	Yes	Allen Herndon Dudley syndrome or MCT8 def	01/01/2018	3-5 years	5-7 years	Every day	A few hours	Search Engine, International Medical journals and the like	4	To find out more about a condition	Somewhat	Unsure	Unsure	Unsure or open	5	5	5	5	4	5	Possibly	Possibly	Good	Not at this time i will have to think. These are good questions.
46-60	Male	Yes	Yes	Goods Syndrome	07/12/2018	6 - 12 months	6 - 12 months	A few times a month	About an hour	Search Engine	3	To find out more about a condition	Somewhat	Need explanation for medical or scientific terms.	A lot of information is still difficult to understand for me.	Not all questions answered.	3	3	1	4	2	3	Too general?	It's clear.	Rather good.	
26-30	Male	No	No					Less than once a month	About an hour	Search Engine	3	To seek reassurance	Mostly	-	-	-	3	3	4	2	3	2	-	-	-	
31-45	Female	Yes	No					About once a week	About 30-60 minutes	Search Engine, Blog or Chatroom	4	To find out more about a condition	Somewhat	It is easier and quicker than going to the doctor all the time	Interested	Usually ok	4	2	4	2	5	4	I like the evidence on both sides of why you may not have or have the disease	That's nice	Very good	
31-45	Female	Prefer not to say	No					A few times a month	About 30-60 minutes	Search Engine, Symptom checker website, Blog or Chatroom	4	To find out more about a condition	Somewhat	Nervous	Curious	Usually helpful	4	2	4	2	4	4	Helpful	Thats very nice	I like both	
18-25	Female	No	No					Less than once a month	About 15-30 minutes	Symptom checker website	2	To find a diagnosis or research your symptoms	Mostly	Getting first ideas about an illness I think I might have.	It is mostly scary what you read when googeling your symptoms.	I tell myself not to panick after I have read worst case diagnosis.	3	5	5	5	5	4	Definately, this is more refined than other websites.	Yes, it is less scary when seeing the likelihood.	This is the best option.	
26-30	Female	No	No					About once a week	Less than 15 minutes	Search Engine	4	To seek reassurance	Mostly	Nervous Concerning interesting	reassuring	Satisfying	5	4	4	4	4	3	Lots of detail	uncertain	Reliable	

Age	Gender			Condition	Date	Duration	Duration2	Frequency	Time spent	Source	Rating	Reason	Anxiety	Comment 1	Comment 2	Comment 3							Feedback 1	Feedback 2	Feedback 3
31-45	Female	No	No					Less than once a month	Less than 15 minutes	Search Engine	4	To find out more about a condition	Not at all	I find it convenient	Aware that I need to identify a reliable source	Satisfied	4	4	3	2	5	5	This is likely to lead to mis diagnosis.	This is not a bad design although it may well be showing too much information which is likely ton increase anxiety.	Again, I would rather to have to input a bit more information to narrow down the possible diagnosis than to have a wide ranging number of conditions based on a poor ability scale.
31-45	Female	No	No					Less than once a month	Less than 15 minutes	Search Engine	4	To find out more about a condition	Not at all	I find it convenient	Aware that I need to identify a reliable source	Satisfied	4	4	3	2	5	5	This is likely to lead to mis diagnosis.	This is not a bad design although it may well be showing too much information which is likely ton increase anxiety.	Again, I would rather to have to input a bit more information to narrow down the possible diagnosis than to have a wide ranging number of conditions based on a poor ability scale.
46-60	Female	Yes	Yes	Shapiro Syndrome	6/17/2020	Over 7 years	5-7 years	Every day	About an hour	Search Engine	2	To seek reassurance	Not at all	Frustrated at only finding medical facts.	Curiosity & frustration.	Deflation.	4	3	4	2	3	2	Possibly too easy to self-diagnose.	It's possibly easier to follow.	It's possibly easier to follow.
18-25	Female	No	No					Once a month	Less than 15 minutes	Search Engine	3	To find out more about a condition	Not at all	Usually to find out more about a particular condition that I've seen mentioned somewhere. Just out of curiosity	Usually just a learning experience, I don't take ALL the information I read as the truth though	Gained new knowledge	4	2	4	1	5	4	Seems a little more credible since I can explore comorbidities	Seems to be more reassuring, less fear-mongering. Could make educated inference on what I could (realistically) possibly have	Seems to be complementary with each other.
18-25	Female	No	No					Less than once a month	About 15-30 minutes	Symptom checker website	2	To find out more about a condition	Somewhat	not really reliable, should i trust this information?	should i trust this information?	didn't do me any good	3	2	3	1	5	3	seems reliable and credible	don't like it	ok