

**Foraging Triggers and Source Selection in the Health
Information Sensemaking Processes of Medical Laypeople**

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Abstract

When medical laypeople try to understand their health and determine if they need medical attention, it is important that available information helps answer their questions. The aim of this research was to test and expand upon the general models of sensemaking and research into health information seeking. This qualitative study used a think-aloud digital search task and semi-structured interviews with 11 participants from a UCL technology masters programme to understand how medical laypeople make sense of health information to answer the question "Am I ill?" and decide if medical care is needed. Thematic analysis was used to analyse the data and two themes were found. First, the four factors of worry, symptom severity, symptom novelty, and symptom duration were found to trigger information foraging. Second, the study identified the components of information gain (authority, trustworthiness, and relevance) and source costs (time, mental, social, and personal) that are used to select sources during information foraging. It was also found that the value of the foraging triggers had an inverse relationship to the perceived source costs. This meant when foraging trigger values increased, source costs were perceived to be lower and thus higher information gain sources were selected.

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Introduction

With the rise of digital technology, the amount and availability of health information is continuously increasing both from formal sources, like medical institutions and professionals, and informal sources, like internet message boards and social media. This increase in digital health information may not only cause "Cyberchondria" (Muse, McManus, Leung, Meghreblian, & Williams, 2012), but also have an impact on the ability for the general population of medical laypeople (those without formal medical training) to find reliable, credible health information that can be used to draw reasonable conclusions regarding their health concerns.

The majority of past research into information foraging and sensemaking, the process in which people seek and understand information, has primarily focused on how professionals understand information within their domain of expertise (Sieck et al., 2007; Pirolli & Card, 2005). These studies describe the processes people use to make sense of information, how various source types can be used to support sensemaking, and how the assessment of information gain and source costs impact source selection (Pirolli & Card, 1999; Russell, Stefik, Pirolli, & Card, 1993; Weick, 1995; Sharma, 2006). They have also been used to create general models used to describe and predict how sensemaking and information foraging occur.

Past research into the sensemaking processes of medical laypeople provides more specific insight that was lacking in the general models. This research has identified motivations for health information seeking (Attfield, Adams, & Blandford, 2006), how people assess the credibility and quality of digital health information sources (Eysenbach & Köhler, 2002; Escoffery et al., 2005), and the processes used by medical laypeople to make sense of complex health information (Genuis, 2012;

Wald, Dube, & Anthony, 2007; McMullan, 2006; Dickerson et al., 2004). Although these studies were able to uncover insights into the health information sensemaking processes of medical laypeople, limitations associated with the studies, like the use of participants with specific medical conditions or the sole use of digital information sources, provide an opportunity to improve our understanding of the health information foraging and sensemaking processes of medical laypeople.

Motivated by testing and expanding upon the findings of past research, the aim of this study is to obtain qualitative data regarding the health information sensemaking process of medical laypeople when they try to answer the question "Am I ill?" and determine if they should seek professional medical attention. Driven by this motivation, three research questions were developed:

1. What technology, methods, and processes do people use to discover and understand health information?
2. How do people select information sources to use during health information foraging and why do they choose these sources?
3. How do people assimilate health information obtained from digital sources and those from non-digital ones?

Using the data obtained from this study, two key themes emerged from the results. First, the study identified four triggers for health information foraging:

1. Worry
2. Symptom Severity
3. Symptom Novelty
4. Symptom Duration

Second, the results from this study identified the source attributes used by participants to determine when to select and switch sources during information foraging. These include the source attributes participants used to assess a source's information gain and those used to determine a source's access costs. The study also found that the value of the foraging triggers had an inverse relationship to the perceived value of the source costs. This meant when foraging trigger values increased, source access costs were perceived to be lower and thus higher information gain sources were selected.

Literature Review

This section presents an overview of literature relevant to this research study. First, a general review of existing sensemaking models will be presented. This will be followed by an overview of research into information foraging and source selection during sensemaking. Last, research into the health information sensemaking and foraging processes of medical laypeople will be reviewed.

Sensemaking

Sensemaking has been defined in past research as a continuous and iterative information process in which people attempt to understand a knowledge area, concept, situation, or problem typically to inform a future action or decision. Many of the sensemaking models created in past research have segregated this process into two or more loops. These looping sensemaking models include the Learning Loop Complex (Russell et al., 1993), the Notional Model of Sensemaking (Pirulli & Card, 2005), and the Data/Frame Theory of Sensemaking (Klein, Moon, & Hoffman, 2006).

The first loop in the sensemaking process has been referred to as the generation loop, the elaboration cycle, and the foraging loop

(Russell et al., 1993; Klein et al., 2006; Pirolli & Card, 2005). The foraging loop includes activities such as seeking out new data, determining what data is relevant, and extracting new information from the data. The second loop in the sensemaking process has been referred to as the data coverage loop, the reframing cycle, and the sensemaking loop (Russell et al., 1993; Klein et al., 2006; Pirolli & Card, 2005). The sensemaking loop involves using the information collected in the foraging loop to adjust or create predictions for the future, develop answers to problems and questions, and to iteratively adjust mental models to best fit the information available. In the Learning Loop Complex created by Russell et al. (1993), a third loop was also included called the representational shift loop. In the representational shift loop, when relevant data is without a place in current representations (or mental models) the representation is expanded upon or a new one is created that better fits the relevant data (Russell et al., 1993).

Alternatively, Weick (1995) created a model not involving loops, but one based on social psychology where interpersonal interactions are leveraged to support sensemaking. Sharma (2006) later created a sensemaking model that attempted to reconcile the Learning Loop Complex created by Russell et al. (1993) and the social sensemaking model created by Weick (1995). This new sensemaking model added interpersonal interactions to the Learning Loop Complex. In the generation loop, interpersonal interactions are used to facilitate the representation of new ideas and the resolution of ambiguities in these representations. In the data coverage loop, interpersonal interactions help add new information that can support or cause shifts in the representations created in the generation loop. Finally, in the representational shift loop, interpersonal interactions like arguing, influencing, and negotiating are used to determine and decide upon new

representations.

These sensemaking theories primarily identified new information as a trigger for initiating the sensemaking process. The Learning Loop Complex (Russell et al., 1993) cites the discovery of information that doesn't fit into existing mental representations as a trigger for sensemaking. Similarly, in the Data/Frame Theory (Klein et al., 2006) sensemaking is triggered by an event involving the occurrence of new data. Besides these data based triggers for sensemaking, Pirolli and Card (2005) also cites external factors, like requests from others, as a trigger for sensemaking activities.

Although these general sensemaking models provide an initial framework for understanding sensemaking, they have limitations when considering their applicability to this study. These limitations centre around the participants used in each of the studies and the knowledge domains in which the studies occurred. The Data/Frame Theory and Notional Model of Sensemaking were derived from studies involving professionals that were experts in their sensemaking area, areas that were outside of the healthcare domain (Sieck et al., 2007; Pirolli & Card, 2005). Participants in the current study were medical laypeople that had no formal healthcare training. These differences in domain and participants may lead to the discovery of different events that trigger sensemaking and the finding that participants use different sensemaking processes when compared to past research.

Based on these models, their limitations, and their differences from the current study, certain questions can be developed that are useful for this research. First, using the theory developed by Sharma (2006), further research is needed to determine how social interactions impact the health information sensemaking process of medical laypeople. Additionally, a broader understanding is needed regarding

how the sensemaking process and its motivations differ between medical laypeople and the expert professionals used in past research.

Information Foraging and Source Selection

Information Foraging Theory (Pirolli & Card, 1999) and the general sensemaking models can be used to form an initial understanding of how people search for, find, and select information sources during sensemaking tasks. Information Foraging Theory describes how sources selected during foraging are ones that maximise information gain per unit cost. The theory also recognises that there is an uncertainty in determining a source's information gain and that this uncertainty requires estimating the information gain of each source based on what the theory refers to as "information scent" (Pirolli & Card, 1999). "Information scent" is defined as the proximal cues (keywords) associated to the source that are used to determine how strongly the source relates to the information need of the searcher (Chi, Pirolli, Chen, & Pitkow, 2001). Information Foraging Theory also includes a "patch" model that is used to predict when people will switch information sources. This is based on an information seeker's continuous assessment of "information scent" (Pirolli & Card, 1999) based on the content of the source. The theory states that people will continuously evaluate the "information scent" of a source until the scent falls below a threshold. Once the information scent falls below this threshold, a person will switch sources and begin the evaluation process again.

When determining the applicability of Information Foraging Theory to this study, there are certain limitations that need considering. First, despite the theory's authors' acknowledgment that there are many types of costs associated to accessing information, the model used

to describe information foraging only included costs associated to time. Second, the authors do not define how information gain is valued and what factors impact this perceived value of information gain. Third, the theory focuses solely on digital information foraging and doesn't include any of the other information sources identified in the sensemaking models. This leads to three implications for this study. The first involves the need to understand what source attributes are used to determine the value of information gain during health information seeking tasks. The second involves determining the source costs that impact health information foraging and then understanding how these costs influence source selection. Third, there is a need to understand how health information foraging may differ from the original models when including non-digital sources in foraging activities.

The Notional Model of Sensemaking (Pirolli & Card, 2005) builds on Information Foraging Theory by providing a more tangible description of the general process of information foraging and source selection. The Foraging Loop in the Notional Model is structured into the three steps of explore, enrich, and exploit. This process involves exploring and monitoring new information, narrowing the set of information to be analysed, and then performing an analysis on the selected information. Similar to the limitations of Information Foraging Theory in describing why sources were chosen, the Notional Model only considers the time costs associated to information operations like scanning source content and executing additional searches. Despite these limitations, the information foraging process described by the Notional Model can be a basis for understanding the foraging processes of medical laypeople and help identify potential differences that may arise between the models and the findings in this study.

Additionally, the social sensemaking model created by Weick

(1995), the Data/Frame Theory of Sensemaking (Klein et al., 2006), and the Notional Model of Sensemaking (Pirolli & Card, 2005) all recognise that people's past experiences, knowledge, and perceptions (called "frames" or "schemas") can have an impact on source selection. The models note that these "frames" can cause people to exclude data that doesn't match their mental models while compatible data is readily included in them. Although Klein et al. (2006) found that this is less of an issue amongst professional experts, this data exclusion can lead to a bias towards existing mental models and can result in inappropriate conclusions at the end of the sensemaking cycle. This past research suggests that participants in the study will leverage past experiences during source selection and information foraging activities.

Outside of the sensemaking models, Choo, Detlor, and Turnbull (1998) identified four types of web searches, but the one most applicable to this study is the "informal" search where individuals seek information to deepen their understanding of a specific issue and determine the need for a future action. The search is described as informal because it involves a limited and unstructured search effort and often leads to "satisficing" in source selection, where sources are selected that are determined to be "good enough" (Soegaard & Dam, 2015). Since "satisficing" may impact how participants in this study search for and choose digital health information, this may cause differences between the findings in this study and those found in the studies with professionals that were used to create the sensemaking models. Finally, in learning theory, the I-LEARN Model (Neuman, 2011), a model that researchers have noted for having similarities to sensemaking and information seeking (Zhang & Soergel, 2014), states that relevance, authority, and timeliness are critical attributes that drive the selection of sources during information seeking. These

attributes expand on those of "information scent" from Information Foraging Theory for determining why sources are selected.

Motivations for Health Information Seeking

The general sensemaking models attribute the occurrence of new information as a motivation for sensemaking and information foraging. To address the generality of these past models, research within the health domain has focused on studying the motivations of medical laypeople seeking health information and have found more specific details regarding what factors drive health information seeking in this context. Research conducted by Attfield et al. (2006) identified six motivating factors for seeking health information. These factors were segmented into health information seeking motivations in anticipation of a clinical encounter and those following a clinical encounter. The motivations for health information seeking prior to a clinical encounter were identified as:

1. *Am I ill?* This motivation involves understanding experienced symptoms and determining if medical attention is required. The end goal of information seeking driven by this motivation is to find an explanation or diagnosis for the symptoms.
2. *Who can help me?* This motivation arose out of individuals trying to identify the best specialist to treat their medical conditions, including those specialists that may not have been initially recommended by their General Practitioner(GP).
3. *How can I prepare?* Prior to a clinical encounter, individuals reported wanting to be prepared with medical knowledge regarding their health condition. This was so they could support the diagnosis of their medical practitioner and ask better, more

informed questions. Other perceived benefits derived from this motivation were reduced consultation times and a better relationship with their doctor.

The motivations for health information seeking following a clinical encounter were identified as:

1. *Is the diagnosis right?* This motivation led to individuals seeking health information to verify the diagnosis obtained from their doctor.
2. *Is the treatment appropriate?* This information seeking motivation led individuals to verify that their recommended treatment was appropriate given their diagnosis. This also led individuals to explore other, possibly more beneficial, types of treatments for their condition.
3. *How do I manage my treatment?* Once a proper treatment had been obtained and accepted by the individual, many were motivated to seek information regarding how to best manage their treatment. This included learning about their medications, their possible side-effects, and how to administer them properly.

This study also found that a patient's confidence in their medical practitioner's judgement was an underlying factor impacting each of these motivations. The varying levels of confidence were caused by the medical practitioner's perceived lack of concern regarding holistic healthcare and the potential for resource constraints to impact the tests and treatments that are offered to a patient.

Although this study was limited to 16 participants, similar motivations for health information seeking have been found in other research (Genuis, 2012; Wald et al., 2007; McMullan, 2006; Eysenbach & Köhler, 2002). For example, literature reviews conducted by Wald et

al. (2007) and McMullan (2006) also found that people searched for information to make more informed health decisions, especially around sensitive medical topics that are often troubling for people to talk about. They similarly found motivations to augment physician provided information in order to be more involved in decision making regarding their treatment and care. Finally, they also found health information seeking behaviour for the purpose of determining whether or not to seek medical attention.

In a qualitative study involving health information sensemaking conducted with women seeking information regarding menopause management, Genuis (2012) found five motivations for health information seeking. These motivations were similar to those identified by Attfield et al. (2006). These motivations were:

1. To prepare for encounters with health professionals
2. To evaluate, confirm, and/or supplement previously acquired health information
3. To normalise the experience
4. To understand the physical embodiment of this life transition
5. To prepare for potential future information needs

Due to the similarity in findings across various health information seeking studies, these motivations for health information seeking form a solid basis for the research conducted in this study, but also opens up the possibility for additional research to determine if there are underlying triggers within each motivation that can impact this drive for health information seeking amongst medical laypeople.

The Health Information Sensemaking Process of Medical Laypeople

Research into health information seeking and sensemaking have identified that people use different strategies for searching and making sense of both digital and non-digital health information. The interview study conducted by Genuis (2012) found that participants seeking menopause management information used both formal (e.g. academic research and conversations with medical professionals) and informal (e.g. interpersonal relationships and general media) information sources. Participants sought information across complementary sources, both online and offline, in order to form an understanding of their medical condition. A participant's interpersonal relationships proved to be a highly important source for the acquisition of information and important to the development of an understanding of their medical condition. Genuis (2012) also found that participants used different strategies to make sense of the totality of information available to them. Genuis (2012) described how two different "postures" (described as a stance, or attitude) were used to form an understanding of the information. An "Analytical" posture was used by some participants that involved making logical connections between different information sources and justifying information use based on considerations of all available information. Alternatively, some participants used an "Experiential" posture which led them to make decisions based on intuition instead of the logical analysis of information.

Additionally, the literature studies of McMullan (2006) and Wald et al. (2007) identified that health information accessed by patients prior to visiting a doctor can have both positive and negative impacts on their discussions with a medical practitioner and on what information to include in forming an understanding of their health.

Although this was found to be true in a number of studies, the opposite was found in a study conducted by Escoffery et al. (2005). This study, a survey of hundreds of undergraduate students at two academic institutions, found the majority of students did not discuss health information that was found online with their doctor.

Finally, in an interview study conducted with patients in three urban care clinics in the United States, researchers found that technology expertise had a significant impact on the processes used by patients to find health information online (Dickerson et al., 2004). Patients with low technology skills were found to use a social search process that relied on others to perform their internet searches for health information.

Overall, these studies indicate people use different searching and sensemaking strategies based on personal characteristics and preferences, but fail to answer what factors influence the use of these strategies when seeking, selecting, and making sense of health information. The study conducted by Dickerson et al. (2004) highlights the importance of technology expertise on the selection of search strategies and shows that this expertise should be considered when selecting participants for future studies into the sensemaking processes of medical laypeople.

Assessment of Digital Health Information by Health Information Seekers

Information Foraging Theory and the general sensemaking models describe how critical the assessment of information gain is to source selection during information foraging tasks. Within the health domain, past research into how medical laypeople assess digital health information quality and credibility can provide an initial perspective

into how source information gain is assigned to a health information source. A qualitative study conducted by Eysenbach and Köhler (2002) consisting of focus groups, a think aloud laboratory study, and semi-structured interviews was conducted to understand how people search for and appraise health information. Those interviewed were healthy individuals that had previously used the internet to search for health information. The study found various attributes that can impact a person's perception of health information credibility. These attributes are:

1. Authority of the source
2. Layout and appearance
3. Advertising
4. Readability
5. Outbound links
6. Picture of the site owner
7. Email
8. Credentials and qualifications
9. Updating of content
10. Quality seal and third party endorsements

Another study conducted by Escoffery et al. (2005) identified similar criteria for assessing health information. This included accuracy, currency, clarity, and ease of understanding of the health content. Additionally, Genuis (2012) found that information consistency across both formal and informal sources, called "*parallel information*", was used as a heuristic to judge the quality, accuracy, and credibility of new

information obtained during the sensemaking process. Finding the same information across a wide variety of sources, even amongst the traditionally less credible ones, proved to be sufficient to form the perception of credibility for the participants of the study.

Although Eysenbach and Köhler (2002) identified a number of criteria that impact credibility, a contradiction was found in their study between participant statements obtained during focus groups and their actual search behaviour in the think aloud study. Participants in the focus groups stated that they placed an emphasis on understanding the organisation, group, or individual that created the digital health information, but investigations into the health information source only occurred about 20 percent of the time during the search task. This discrepancy may be a result of the fact that interviews rely on memory and memory can be fallible when describing a task or when self-reporting facts (Blandford, 2013). Alternatively, the discrepancy may be a result of the artificiality of the health information seeking task in this study. The lack of source and quality assurance during health information seeking shown by the participants may lead to one of the negatives of health information seeking identified by Wald et al. (2007) which is patient misinformation due to poor quality sources.

The research into the assessment of digital health information quality and credibility still leaves gaps in the understanding of source assessment during the sensemaking cycle. The general sensemaking models and other health sensemaking research indicate the use of non-digital source types, like interpersonal relationships, that have not been included in this research. This presents questions regarding how the assessment of credibility is assigned to different source types, how this assessment relates to the determination of information gain during information foraging, and how this assessment impacts source selection.

Additionally, the contradiction identified between participant statements and actions in the study conducted by Eysenbach and Köhler (2002) supports the use of multiple research methods in the current study to ensure that any discrepancies between participant statements and actions are identified.

Method

For this research approved by the UCLIC Research Ethics Committee as Project ID Number: UCLIC/1213/015, a study was designed to answer the following research questions:

1. What technology, methods, and processes do people use to discover and understand health information?
2. How do people select information sources to use during health information foraging and why do they choose these sources?
3. How do people assimilate health information obtained from digital sources and those from non-digital ones?

To answer these questions, 11 participants were recruited to take part in a semi-structured interview and perform a think-aloud digital health information search task based on the health information seeking motivation of "Am I ill?" identified by Attfield et al. (2006). The goal of the semi-structured interview was to understand people's past experiences with health information sensemaking processes, to determine the digital and non-digital sources that the participants have used to complete these tasks, and to understand how information is prioritised and assimilated from various sources. The digital health information search task was used so the researcher could observe participants' digital search processes and to avoid the issue of memory fallibility noted by Blandford (2013) that occurs when participants

describe a task or self-report facts during interviews. Since recruiting ill participants was not ethically possible, the search task was based on an artificial scenario where users had to imagine themselves feeling ill and then perform a digital search. The search task was used to understand how participants search the internet for health information and how they select digital information sources. Participant interviews and recorded search actions were then analysed using thematic data analysis to identify research themes across participants.

Participants

Eleven participants were recruited using convenience sampling from the student population of a UCL technology masters programme. These participants were not actively screened for specific illnesses or medical conditions. All participants could read, write, and speak English proficiently and were comfortable using computer technology as demonstrated by their admission into a technology masters programme at UCL. To ensure the relevance of the digital health information task for the individuals involved in the study, all participants had reported on a single question recruitment questionnaire that they had used the internet within the past year to search for health information. The participants had a range of nationalities from regions including Asia, Europe, the Middle East, and South America. All participants were over the age of 18 and most were between the ages of 18 and 34. The majority of participants had been living in the UK between 0 and 5 years. Participant demographic information is specified in the table below:

Participant	Gender	Age	Home Region	Time in the UK
1	F	18-24	Asia	< 1 year
2	M	Not Provided	Not Provided	Not Provided
3	F	18-24	Asia	3 - 5 years
4	M	35-44	European Union	> 5 years
5	M	18-24	Asia	3 - 5 years
6	F	25-34	South America	3 - 5 years
7	F	18-24	European Union	> 5 years
8	M	25-34	Middle East	< 1 year
9	M	25-34	Asia	< 1 year
10	M	25-34	Asia	1 - 3 years
11	F	Not Provided	Asia	< 1 year

Participants were remunerated with either £10 or through reciprocal participation in their research study.

Apparatus and Materials

The study was held in various private rooms on the UCL campus. Rooms were chosen based on availability and the room's ability to limit outside distractions. The researcher's 11" Macbook Air was used as the computer in this study. A separate user profile was created on the computer to ensure privacy and separation of data from the laptop owner's data. Before each session all data stored in the browser (e.g. cookies, search and browsing history) was deleted to ensure that this did not impact the user's task. The screen and video recording software Silverback 2.0 was installed on the computer and used to record the session. The researcher's iPhone was also used as a backup recording device in case of issues with the Silverback recording. Both recording devices were set up prior to the participant's arrival so recording could

be initiated in as few steps as possible in order to limit disruptions to the interview and search task. To support a variety of participant browser preferences, the latest versions of the browsers Safari, Chrome, and Firefox were installed on the computer.

To provide a better sense of context for the health information task (Preece, Sharp, & Rogers, 2015), a richly detailed scenario was created that had the user imagine they were ill. This scenario was set at night and involved having trouble sleeping due to symptoms that slowly progressed until the morning. Since the goal of the scenario was to understand how people search for health information and not to assess the ability of the individual to find a correct diagnosis, the symptoms that were used were mixed from various illnesses to ensure that there was not a specific correct answer to their information seeking. Leveraging aspects of the Data/Frame Theory of Sensemaking (Klein, Phillips, Rall, & Peluso, 2007) that state past experiences can influence people's existing mental models and new experiences can cause them to change, the symptoms chosen for this scenario were a mix of uncommon symptoms and symptoms associated with common illnesses, like the common cold and influenza, that were likely to have been experienced by participants in the past. The symptoms associated with the common cold and influenza (Mayo Clinic, 2013, 2014) that were included in the scenario were:

1. Runny Nose
2. Congestion and Sinus Pressure
3. Cough
4. Fever of 38 C (100.4 F)
5. Headache

6. Fatigue

The less common symptoms that were included in the scenario were:

1. Excessive night sweating
2. Dizziness
3. Tingling sensations in the left hand and right face
4. Itchy neck rash

A photograph of the rash was included with the scenario to provide additional context for the user. In the written scenario, which can be found in Appendix A, the use of the proper name of symptoms was avoided when possible to prevent participants from using the exact wording from the scenario text in their digital searches. Instead, longer descriptions were used to describe the symptoms.

A prepared list of semi-structured interview questions was created to support the interview process. The full list of questions created can be found in Appendix D and included the following:

1. Describe what condition(s) you think may be causing the symptoms and why.
2. Would you seek consultation from a medical professional based on these symptoms and why?
3. What information were you looking for when searching the internet?
4. During your search, what led you to investigate the sources that you did?
 - (a) What qualities were you looking for in each source?
5. How did this task impact your knowledge of these symptoms?

6. Can you remember any other ways you've found health information in the past?
 - (a) If yes, can you describe the situation?

7. Have you ever asked someone else what they thought of your symptoms when you were ill?
 - (a) If yes, can you describe the situation and the kind of information you received from them?
 - (b) Describe how you decided to include the information from them in your thoughts about your symptoms?
 - (c) Was this person a medical professional?

8. Have you used non-digital health information resources in the past?
 - (a) If yes, can you describe a past situation when you used these resources and how you used them?

After the interviews, the software NVivo was used to thematically code the transcribed interview text and recorded search actions in order to identify themes and trends across participants.

Procedure

Upon arrival to the study location, the informed consent document and the study details were reviewed with the participant and consent was obtained. The researcher then opened the laptop and the recording devices were turned on. The participant was then given the written scenario and rash photograph and instructed to imagine that they were experiencing what was described in the scenario. The participants were then asked to describe what they thought the symptoms were and why, if they would seek consultation with a medical

professional, and what their next steps would be in the morning after experiencing these symptoms. The participant was instructed to think aloud while searching digital resources to try to improve their understanding of the symptoms and their possible causes. Participants were allocated 15 minutes to complete this task and this was tracked by the researcher. This time limit is three times longer than the average time of digital health information seeking found by Eysenbach and Köhler (2002) and was used in order to allow for variations in health information seeking behaviour. Participants were not notified of their time limit so that this limitation did not impact their search process.

During the task, the observer made notes of how the participant searched for health information and what tools and websites they used. Interesting statements made by the participant during the think aloud were also included in the research notes. Once the 15 minutes was completed or the participant felt they were finished with the task, a semi-structured interview lasting between 35 and 45 minutes was conducted using the questions described in the Apparatus and Materials section. The goal of this interview was to understand why the participant chose certain tools and methods to complete the task, to understand the participant's past experiences with health information sensemaking, and to understand what other non-digital resources, including social relationships, they have used in the past to support their sensemaking process. Due to ethical concerns, participants were discouraged from discussing specifics regarding past ailments, but were encouraged to talk about their experiences generally.

The researcher's interview notes and data from the screen, video, and voice recordings were compiled and transcribed after the interviews. These notes were uploaded into NVivo and then coded using thematic analysis to identify themes, patterns, and trends across

each of the interviews and search tasks.

Results

This section presents the findings from this study and is based on data from 11 semi-structured interviews and health information search tasks. The results were intended to answer the initial research questions of:

1. What technology, methods, and processes do people use to discover and understand health information?
2. How do people select information sources to use during health information foraging and why do they choose these sources?
3. How do people assimilate health information obtained from digital sources and those from non-digital ones?

Based on the data obtained in this study, two key themes emerged. The first theme covers the factors that trigger information foraging. The second theme covers the criteria and process medical laypeople use to select and switch information sources during health information sensemaking tasks.

Four Triggers for Health Information Foraging

Based on data from this study, four factors were found to trigger health information foraging when answering the question "Am I ill?".

These triggers are:

1. Symptom Novelty
2. Symptom Severity
3. Symptom Duration
4. Worry

Each of these triggers will be discussed in the following sections.

Symptom Novelty. The novelty of the experienced symptoms was found to be one factor that triggered information foraging actions. Symptom novelty was found to include three different experiences of symptoms. The first type of symptom novelty was the result of a completely unknown symptom that hadn't previously been experienced. For example, Participant 5 described encountering unfamiliar symptoms as a reason to go to the doctor:

Interviewer: Based on these symptoms would you go see a doctor?

"I think I would, yes. If it was something I've experienced before [...] I'd probably just go to the pharmacy and grab some pills, but if there's something new there that I feel is a step up from a regular illness then I would go see a doctor."

The second type of symptom novelty was the presence of familiar symptoms that occur somewhat differently than in past experiences. Participant 7 discussed a story regarding her partner and how he experienced familiar symptoms with a novel change and how that resulted in his decision to go to the A&E:

"My boyfriend just went to the A&E on Friday and he gets these stomach aches quite a lot and they've always been kind of mysterious because it's a very localised pain and they're not quite sure what it is, but then it just goes away. But then on Friday the same thing happened, but it was accompanied by the pain moving around, which was very odd. So because of that new sort of symptom he was like 'Okay, I'm not just going to wait this out. I'm going to go to hospital'."

The last type of symptom novelty can be described as a combination of symptoms that may have been experienced before, but not together at one time. When explaining why they might see a doctor for the symptoms described in the task scenario Participant 8 said:

"It's the combination of everything coinciding with each other that would make me worried."

For Participant 2, novelty was an important factor for seeking health information for both them and their daughter. Participant 2 also acknowledged that the novelty of their daughter's experiences drives more information seeking than their own because each experience with their daughter was new while they could rely on their own past experience for their symptoms.

"Yeah, for me I have more than 25 years of past experiences, I know how I suffer with conditions so I know when I have a cold or whatever, and I know when something really different happens so I just go to the doctor. Since I don't know my daughter's conditions, since I haven't seen them before, I was required to ask [...] because I don't know how to react to a new situation."

Symptom Severity. The perceived severity (or seriousness) of symptoms was also found to impact decisions to start seeking health information. Participant 4 described how the intrinsic feeling of symptom severity would drive their decision to call a GP:

"This does sound pretty bad [...] in this situation I would phone the GP first."

Interviewer: Has there been an occasion where you wouldn't phone the GP first?

"When the symptoms are milder."

Participant 6 also used severity to determine when to reach out to family members for health information:

"I trust my mom so I usually talk to her when its severe."

Participant 8 described how the symptoms that had the potential for seriousness resulted in their choice to see a doctor:

"The tingling sensation [...] would make me stand up here because those

are often times signs of things that have nothing to do with a cold and could actually be pretty serious."

Interviewer: So it's the potential seriousness that would get you to go?
"Yeah."

Symptom Duration. Symptom duration was also found to trigger information foraging. Some participants reported waiting to see if symptoms lasted and using home remedies to treat the symptoms during that time. If symptoms were found to be improving (if their severity was reducing) the duration of the symptoms did not become a trigger for information search. If no improvement in severity occurred during that time the next step would be to obtain more information on their symptoms by exploring various information sources. Participant 9 described waiting a day before deciding to go to the doctor:

"What I would do is I would give it a day's rest before I made any conclusion, so drink plenty of water and relax. It could be anything, so if it doesn't decrease in a day then I would definitely go to the doctor."

Participant 9 later described using symptom duration and improvement over time as a measure to determine if medical attention was needed:

"So if I can rate on a scale of how I am feeling and rate it a terrible, 100/10, today and tomorrow I rate it a 90/10 then its better. If it's a fever kind of thing and it doesn't go away for 4 or 5 days then I would seek medical attention since its clear its not getting better."

Participant 5 also described waiting a day before taking any action like seeing a medical professional or searching online:

"So I try to think if its going to get bad and if I do think so then I'll still usually wait a day before I do anything."

Participant 10 described how they would use symptom duration to drive their next steps after finding no relevant information during

the digital search task:

"At first I would try to wait it off, and if it didn't go away in a few hours I would definitely consult a doctor."

Worry. During the study 10 out of 11 participants explicitly mentioned worry in their descriptions of why they would seek health information from both digital and non-digital sources. For example, Participant 10 described worrying about the combination of symptoms experienced as a reason why they chose to search for health information instead of just taking medication:

"Both of these things combined would get me worried about it. If it was just the fever and stuff without the rash then I would probably take [...] a fever medicine."

Similarly, Participant 5 used worry as way to decide if they should purchase medicine at the pharmacy or to search for additional information about their symptoms online:

"I would probably wait again for the next opportunity to go out to find something, or if I'm really worried I would start looking online to try to find out what it is."

Participant 7 stated that some symptoms from the task scenario made them worry and described how that influenced their decision to see their doctor:

"I would definitely be worried about an unusual sensation and pins and needles so I wouldn't go to the office that day or anything. I would try to make it a priority to see a doctor."

Source Selection in Health Information Sensemaking

The results from this study showed that the sources selected during health information seeking were determined by an internal calculation that identified which source had the highest information

gain per unit cost or "information return". This return was calculated by determining the expected information gain of a source (or category of sources) and adjusting this value based on the costs of accessing that information. The information gain and source costs were also impacted by the questions an individual intended to answer during the information seeking task and the information foraging triggers that initially led to health information seeking.

Source Categories. Before introducing how information gain and cost are determined, it is important to first define the three source categories identified in this study. These three categories are:

1. Digital Information
2. Social Information
3. Non-Digital Information

Digital information represents information obtained from the use of a computing device without any social interactions. Social information encompasses the information obtained from interactions with other human beings. These interactions could be in person, over the phone, or via the internet. Finally, non-digital information is used to describe information obtained from non-digital and non-social sources like books, pamphlets, boxes of medicine, and medicine information sheets.

Perceived Information Gain. The perceived information gain of a source can be defined as the expected ability of that source to provide information that will help answer one or more of the information seeker's health questions. When seeking health information, participants were looking for sources that could answer the questions that drove their information seeking actions. During the

study, the participants were found to have the following questions when performing a task inspired by the motivation of determining "Am I ill?":

1. Am I ill and what illness(es) may I have?
2. Is what I'm experiencing severe/serious?
3. Have I experienced anything like this before?
4. Can I treat myself at home and, if so, what are the available treatments?
5. Should I see a doctor and when?

For example, Participant 8 described assessing seriousness and determining if they should see a doctor as reasons for information seeking:

"The only thing I'm thinking about in this situation and I'm searching for information online, is this serious or do I have to go to the hospital or something."

Participant 10 described they would seek information to determine if they should see a doctor:

"I would probably look it up on the internet first or I would call my mom and...and if someone said go see a doctor I would probably do that."

Participant 7 cited determining what condition they may have as a reason for searching for information:

"Yeah, I mean, the first step is to figure out yourself to get some range of options of what it could be."

Participant 3 cited searching for home treatments as a reason for contacting a family member:

"Sometimes I call her [mom] for example if I have a blocked nose and I would call her about what to take to get better."

Participant 9 used a family member to figure out if they've previously experienced similar symptoms:

"So mostly because I kind of forget what I had previously [...] And my mom kind of knows what went wrong [...] and I'll call her and she'll say oh you'll be fine in two days, and its like I've been through this so its no big deal. So it's like a reassurance memory kind of activity."

The assessment of information gain, the expected ability to provide answers to health questions like these, is impacted by various attributes of a source of information. These attributes and their impact on the assessment of perceived information gain were found to vary across participants. The assessment of these source attributes also changed over time as more information was gathered and more experiences with a source occurred. The following attributes for evaluating a source's information gain were found to be common amongst many participants:

1. Authority of Source
2. Trustworthiness of Source
3. Relevance of Information Provided by the Source

Authority of Source. One of the most prominent attributes when determining a source's perceived information gain was the source's authority in the field of medicine. For human sources, this was generally determined by their education and qualifications in medicine or pharmacy. For organisations and internet sites, this was determined by their reputation as an authority in the medical field. For example, when discussing with Participant 10 regarding the people they would seek health information from, they mentioned they would contact an uncle who had a medical specialty in the symptoms they experienced: *"Just thinking back a few years ago, I busted a tendon in my left ankle*

and my uncle is a radiologist and I showed him my MRI scans just to get his opinion."

Participant 10 also described the reputation of an institution's authority, specifically the Mayo Clinic and the NHS, as important when selecting digital sources:

"I don't know enough about health information that I can dispute something, like I can't read something and know that its definitely wrong. I don't have enough knowledge to do that. So I would rather trust the source than to look around on yahoo answers."

To a lesser degree, authority was determined by a person having past experiences that are similar to the ones that are currently being experienced by the individual. This was found to be true in cases where others had past experiences with similar symptoms and in parenting. For example, Participant 2 reached out to their uncle when trying to understand their daughter's symptoms:

"I think when you have kids and they're really small, I think you tend to ask more of other parents. I remember when my daughter was a few months old and she got a fever, I asked my uncle what do you think about this condition [...] and I guess sometimes kids have a fever one day and then the next everything is cool."

Participant 2 later described how they valued having a medical professional that also had the experience of being parent in treating their daughter:

"I think [...] its an emotional link between the professional aspect and the mother aspect. If they're well balanced its really really nice. I'm just guessing but its just an emotional feeling that I'll get that she won't give my daughter a too strong medicine or something."

Participant 3 also used acquaintances' past experiences as a way to understand the seriousness of their condition:

"I tend to ask them if something is serious and they might have had similar symptoms before."

Although past experiences were used as a sign of authority for some participants, others did not value it. Participant 5 described when they would consider others' past experiences and when they wouldn't:

"I mean, I can hear from friends when they're ill with anything, but because I don't see it with my own eye's I'm not sure if its right or not, but with my family when I'm at home, I can see what they're dealing with, so it's a lot easier for me to relate their experiences."

When evaluating information sources, a person's weighting of the importance of authority was found to change over time with the addition of new experiences and information. For example, Participant 6 described an experience with their GP that caused them to place less value on their expertise and to rely on alternative sources:

"It just worries me sometimes when you go to the GP and you just sit there and you tell them how you're feeling and they will grab a book and check your symptoms from a book and its like 'wow, did you go to med school or not' because you can just give me that book and I can do this from home."

In digital search, Participant 5 also experienced changes in the priority of authority when trying to find health information. They would start with authoritative sites, but if no progress in their information seeking was made, they would move to less authoritative ones:

"There have been times I've gone through all of those [authoritative sites] and haven't really gotten much progress in which case I would end up clicking something like a site where it's a person just on a forum asking questions outright. And the reason why I would click into those is that you can kind of relate to the person that's asking the questions"

since its probably a person that has done a little searching themselves and has no idea what it is, so they need to ask somebody and their knowledge of how to ask this question is probably as good as mine."

When authority wasn't available during digital search, Participant 5 used similar information, or "parallel information", across multiple sources as a substitute for medical authority:

"Because I'm not asking a specialist I want to get multiple sources that tell me the same thing so that I can get more assurance that I can do the right thing."

Similar to the other information gain attributes, the importance that participants assigned to authority varied across individuals. Some regarded authority to be one of the most important attributes of information gain. For example, Participant 7 said the following about obtaining health information from relationships that did not have authority because a lack of medical training:

"I wouldn't trust their opinion as medical advice."

Participant 7 also described how they would listen to the opinion of a friend who did have medical training:

"I have asked a friend of mine who has just finished her medical school studies and like I did literally just call her up and explain exactly what my symptoms were as if I were talking to a doctor and I did trust her opinion."

Participant 11 described how a high level of authority can overcome a lack of relevance:

"So that's why I chose the NHS first, even though the page isn't necessarily what I want, but maybe in this website I can find something I need."

Alternatively, other participants placed more value on other information gain attributes, like relevance, during source selection. For

example, during the search task Participants 1 and 2 selected sites from unknown institutions that they did not know the authority of because they perceived the content on their sites to be most relevant to their search.

Trustworthiness. Perceived trustworthiness proved to be an important attribute when selecting sources as well. The authority of the source had an impact on trustworthiness, but other characteristics were also found to have an impact on the perception of trust. These characteristics included the closeness a person felt to the source, positive past experiences with a brand or individual, and knowledge of a trustworthy reputation. Exclusively for digital sources, the use of sales and advertising was found to be detrimental to trust. Participant 2 discussed how closeness with a source supports trust and how sales and advertising negatively impacts it:

"I think if my daughter's doctor or my doctor puts some information on, for example, on my allergy of the skin, probably I will trust more of that source because I know that source, but if I'm looking at general information on the internet, I don't know who's the source of that and I don't know if its some specific research backing that information or specific institution...or if it's a pharmaceutical company trying to sell me some extra pills or the more expensive ones."

Participant 6 also discussed closeness and past experiences with their medical professional as impacting their trustworthiness:

"In [South America] usually you go see the same doctor always and they know your history, they know you by name, they know your mom, they know your sister and they know everybody because you go to the same doctor with the whole family and here they're like 'Remind me of your name' and that kind of pisses me off. So sometimes I'd rather search online and if I think its something I should be worried about I'll call my

doctor in [South America] [...] because I just couldn't get a way to trust properly GPs here."

Positive past experiences with a specific brand or individual, like the NHS, was found to impact trust and the selection of sources.

Participant 3 described their use and positive past experience with the NHS symptom checker as a reason for using it:

"I know NHS has a symptom checker [...] and I use it several times. I think it's quite accurate. And sometimes the information on that checker is really helpful."

Participant 4 described Wikipedia as a potential source from their search results because of their past experience with the site and perception of the website's reputation:

"I know Wikipedia and their reputation, I would probably have a look at Wikipedia."

Participant 5 mentioned how an institution's professional reputation would impact trust and drive the selection of sources during digital search:

"Usually I'll be looking for something that looks a bit more professional so either medical centers or research centers, that's something I'd look into a bit more and trust a bit more."

Specifically for digital sources, some participants felt that the use of sales and advertising negatively impacted a site's trustworthiness since it gave the perception of having an ulterior motive to providing the information. Participant 2 described how sites with ads hindered trust and domain names with .org gave a better sense of trust:

".org makes you think they won't ask for money, but you really don't know how the call to actions at the final get...they give me references, they don't try to sell me anything, there's no ad banner."

Interviewer: So those ads take away from your trust?

"Yeah. "

Participant 8 and 9 described discomfort with the Boots and WebMD partnership since there seemed to be a conflict of interest caused by advertisements. Participant 8 said:

"Whatever legally they can advertise and sell which wouldn't aid my situation would make them richer is something that I kind of feel is the moral conflict of interest in the situation. That's why I kind of felt really bad about that."

Participant 9 said:

"The second result is Boots and I wouldn't use it because I don't trust them. I mean I go there if I need to buy something, but not if I need health information because they might...my instinct is that they would always have an ulterior motive in giving me that information."

Trust was also found to change over time as participants accumulated positive and negative experiences with an information source. For example, Participant 2 described how they once relied on their family for health information, but now rely solely on their personal doctor:

"I know when I was younger I would ask them more and give them a list of symptoms to try to get an answer, but getting older, say at 25 and over, I just don't trust them, I know the final answer will be check with the real doctor and I think that's the proper thing to do."

Similar to authority, the importance of trustworthiness during source selection varied across participants with some placing a lot of weight on this attribute and others barely considering it. For example, one of the participants, Participant 7, didn't consider trustworthiness in source selection:

"When I look for medical information like this [...] I wouldn't be concerned at all whether that particular site is known to be trustworthy"

or not."

Relevance. Finally, relevance also played an important role when selecting sources. Across all source categories, the use of past experiences and knowledge were important for assessing relevance. Additionally, during digital search, participants determined relevance by matching their symptoms with search result titles and descriptions as well as the contents of web pages. For example, Participant 6 used a combination of past experience and the keywords in the title and description of the search results to determine the relevance of a link:

"I clicked on the first ones and I basically ignored the ones that said hay fever or allergic reaction because I know its not that since I have that a lot so I would never have tingling sensation on my face if I have an allergy."

Participant 5 determined a source's relevance by matching their symptoms with those in the titles and descriptions of the Google search results:

"If I look through here, mostly its looking at the titles and looking at the descriptions so if I can see some of the symptoms I have in the description that I have, that helps, and also in the title."

Participant 7 used titles and descriptions to determine if their search query was returning relevant results:

"I think maybe I'm using the titles, without clicking on any of them and scanning them. It's a good way for me to figure out if my search term was good or not so for example, many of them were mentioning body parts that I'm not concerned about [...] so I know now that I have to specify that it's on the neck."

When searching web pages most participants first tried matching their symptoms with those listed on the web page. If the page was assessed as relevant based on this symptom matching, the participant

continued to scan the page looking for other information such as treatments and when to seek medical attention. If participants determined the source was not relevant, they would switch to another source. Participant 5 described trying to match their symptoms when scanning a web page:

"So I'd be looking at 'do my symptoms match' and then I'd look at what I can do."

Participant 6 also mentioned matching symptoms during their web page search:

"I'm looking for the diseases and I'm looking for my specific symptoms and trying to understand if my symptoms will show there or at least most of them."

Additionally, Participant 9 performed symptom matching to determine the relevance of their search results:

"There are some names of illnesses and some symptoms down there, so I'm trying to match the symptoms with these to see if there is something similar."

Participants also used image comparison to determine the relevance of digital information sources. Participants would compare their physical symptoms with pictures that were found online.

Participant 5 used photos on websites to match the image of the rash from the task scenario:

"I'm looking for photos to help me with the rash."

During the digital search task, Participant 9 switched to Google Image search to assess the rash and the relevance of the source:

"Another thing I actually do is look at pictures and see what closely resembles it."

Participant 1 also used photos on a website to help assess relevance:

"It showed some symptoms similar to the scenario, also it says you'll have a rash similar to sunburn, and the picture of the rash looked quite similar to this."

For digital information sources, web pages that were organized into clear sections and used understandable language helped in the assessment of relevance. Use of language and the inability to find information due to poor organisation caused some participants to switch sources. Participant 4 noted positive experiences with the NHS in these areas:

"The website is very good and I used it quite a lot. I've found the language to be good, the pages are well structured, its quite easy just to scan them."

Participant 2 had a negative experience due to the use of difficult to understand language and this led them to search for information in other sources:

"Reading this... this official NHS [website], but the language is really cryptic and really specific like in medical terms, and I don't know what some of this means."

Although not specified as a means to determine relevance during participant interviews, the order of which the search results appeared had an impact on the perceived relevance of a source. None of the participants clicked into the second page of the Google search results, with most participants using the top 5 or 6 links in their search results.

Outside of digital information, relevance in social information was characterised by the source having similar past experiences or the appropriate specialist education. Relevance in non-digital sources was determined by scanning medicine information sheets. Participant 7 described their use of medicine at home to determine their medical condition and its correct treatment:

"I have loads of medicine at home and so a lot of the times you have a condition or something and let's say I should probably take something for my stomach and you're confronted by 5 different things and I'll just browse through and see which one fits the best and that will also tell what condition I have at that moment."

Of the three source attributes identified that impact perceived information gain, relevance was the most dynamic in its ability to have its assessed value change over a short period of time. This was especially prevalent during digital information searching where the quick assessment of relevance was used to select and switch sources.

Perceived Cost. Perceived costs detracted from the perceived information gain of each source and were associated to negative aspects of accessing a source. The three types of costs identified in this study were:

1. Time Costs
2. Mental Costs
3. Social and Personal Costs

Time Costs. Time cost is the time needed to access a source. This includes the time required to travel to the source, time to search for information, and waiting times. These time costs became especially apparent in the study when participants from other countries described differences between their home country's health systems and those in the UK. Participant 5 described how their information seeking process differs between their home country and the UK:

"I still search online and I do it in the same manner, but I probably do it less because I know I can go to the doctor a lot easier over there. And I guess distance is also involved because where I live I've got a doctor 5 minutes away from me. Where I am here I would have to travel 30 to

40 minutes before I get to a GP and then adding on the wait time I'd rather not do that. So I'm more motivated to look up how to do it here than when I'm back home."

Participant 5 also went into detail about how waiting impacted their decision to see a doctor:

"I find it easier to make appointments over there than over here. The past few years when I phoned into the GP and asked for an appointment they told me you can either walk in and risk not getting an appointment which I've done that before, where I walked in and waited 3 hours, which is not ideal [...] I don't want to wait that long to see the doctor when I'm ill."

Participant 1 mentioned time to see a doctor as a reason to seek information elsewhere:

"In [Asia] its more convenient. You can see a doctor when you want, but here if its not that severe you might just search the internet before seeing them since it might be a long time before you see them."

Participant 3 also mentioned the wait time to see a doctor as a reason to explore other sources:

"Here in UK it's gonna be a long wait and if I've got a lot of work to do, first of all I would go to Boots and see a pharmacist and ask them about the symptoms and what I should do. If they can just get me some medicine for the relief of these symptoms then I probably could wait until I get to see the doctor."

Mental Costs. Mental costs involve those actions that are needed to access information that take mental or cognitive effort. This was most prominent in the digital information search when an information source wasn't able to limit potential conditions based on the symptoms provided. This required the participant to exert mental effort to scan multiple pages or long lists of information and store

relevant information in memory. Participant 5 discussed the ability to limit potential conditions as impacting the return they'd get from doing a digital search:

"In my mind I'd feel that it's a lot more difficult and probably the return you get from it is not great since there are so many conditions it can be."

Participant 6 had the following reaction after opening a web page that listed many results of potential illnesses:

"Oh my god this one has so much [referring to the large number of conditions listed on the page] I would seriously run to the doctor...The options here are so different from each other that it got me really confused."

Participant 6 also cited the ability to limit options as a reason to start using a symptom checker tool instead of a simple Google search:

"When its more complicated, and I can't get everything I need off of Google or when I click in a bunch of links and its nothing like that, so I would try the symptom checker then."

Personal and Social Costs. Personal and social costs were found to be closely related in participant interviews. Social costs are the negative social impacts that requesting or accessing information might have. Personal costs are those costs that oppose personal preferences. For example, hypochondriac perception or the thought that others might feel that they are overreacting to symptoms proved to be deterrents from discussing health information with other people or even visiting a doctor. Participant 6 avoided calling their mother to prevent social costs from occurring:

"My mom knows I have this doctor fixation thingy, she calls me a hypochondriac. So I usually avoid calling."

Participant 8 didn't want to be seen by others as overreacting to

their symptoms and also had a personal preference to not visit a doctor or hospital. This would prevent them from seeking professional medical attention:

"Even if there's a chance this might be serious I don't really want to go to A&E because I might seem that I'm making too much of it and I just can't stand hospitals in general."

Participant 8 later described their process for determining what to do when they're ill and how their hatred of hospitals impacted it:

"My first thought would be like a filter question. Is this bad enough to go to A&E. My default would always be to 'no' because I absolutely hate hospitals."

Social costs also included the impact of accessing information on the feelings of others. Participant 6 mentioned that they did not want to call their mother to ask about symptoms if they thought it would make her worry and would only call her about non-serious symptoms:

"I don't want to make her worry. Like if it's a small problem that will probably go away sometimes I call her, for example, if I have a blocked nose and I would call her about what to take to get better, but that's not a big deal so she wouldn't worry about it too much."

Foraging Triggers in Source Selection. Besides the source attributes that affect perceived information gain and source costs, the health information seeking triggers (worry and the three symptom factors) were also found to impact source selection, specifically on how the total cost of a source is assessed. In determining cost, increased levels of the information foraging triggers resulted in a lower assessment of the source costs. For example, Participant 8 described how the foraging triggers played a role throughout their information search. First, they described how the novelty of their symptom combination caused them to initiate their digital search and then how they would

stop searching if they found the symptoms weren't serious. They later mentioned how changes in the duration of their symptoms would impact their future information seeking actions:

"All the symptoms described here are something that has happened to me at one point or another and I don't deem them to be serious. So, its like I said before the only thing that bothers me about it is everything happening at the same time. [...] The only thing I'm thinking about in this situation when I'm searching for information online, is this serious or do I have to go to the hospital or something. And if the answer is no, then I'll just go 'Ok fine, I'm sick, I'll just wait and see if it improves, and if not then I always know I can go to my GP.'"

Participant 6 described how severity impacts their perception of the social costs associated to calling family members for information:

"I usually avoid calling my mom unless I'm really bad."

Participant 4, after describing how severity resulted in them being more likely to contact a medical professional, described how less severe symptoms led them to use the internet as a first step in their information seeking process. After using the digital search, they described that if their worry or perception of symptom severity increased, they would seek advice from a medical professional:

Interviewer: Has there been an occasion where you wouldn't phone the GP first?

"When the symptoms are milder, but there are other things I've had problems with, like general sleeplessness or stress, or things like that where I would consult internet research first to assess if its an issue that I should really feel like I should go to my GP about. Sometimes reading things kind of helps you make that decision. You read something that consoles you slightly or worries you slightly."

Participant 7 stated that if something was more serious they

would be more comfortable calling a doctor, ignoring the costs of doing so when compared to the lower cost of searching digital information:

"If it was something really serious, I would feel more comfortable contacting the doctor directly and straight away so I wouldn't have time to do a Google search."

Discussion

The results from the research uncovered two themes. First, the study identified four health information foraging triggers associated to the health information seeking motivation of "Am I Ill?" (Attfield et al., 2006). These triggers are:

1. Worry
2. Symptom Severity
3. Symptom Novelty
4. Symptom Duration

Second, the study found the attributes used to determine a source's information gain and costs and how the foraging triggers impact the assessment of these source costs.

Triggering the Information Foraging Process

The study found that health information seeking is triggered when the experienced levels of the information foraging triggers rise above a person's search threshold. If this threshold is not met, no information seeking is triggered. When the threshold is surpassed, information seeking begins. The general sensemaking models cite the discovery of new information as the trigger for sensemaking and foraging processes (Russell et al., 1993; Klein et al., 2006). The foraging trigger of symptom novelty is the most consistent with the new

information trigger identified in the general models, but nothing in these models highlight anything similar to the other foraging triggers found in this study. This may be a result of this study's focus on the health domain and the specific health information seeking motivation of "Am I ill?" (Attfield et al., 2006), but the concept of factors besides new information triggering information foraging is not unique to this study. In addition to citing new information as a foraging trigger, the Notional Model (Pirolli & Card, 2005) also found that external factors can lead to sensemaking and information foraging. This may indicate that sensemaking within specific domains can have contextual factors that trigger foraging processes.

The Assessment of Information Gain and Costs

Information Foraging Theory describes the reason for selecting sources as an attempt to maximise information gain per unit cost (Pirolli & Card, 1999). The theory also notes there is uncertainty in determining source information gain, so information scent is critical in determining the perceived information gain of a source. The findings from this study were similar, but were able to provide more detail into how a source's information gain was assessed during health information seeking tasks. The study was also able to uncover multiple types of costs, other than time, that impact source selection.

The study found that the perceived value of information gain is determined by assessing the authority, trustworthiness, and relevance of the source. The components that influenced the assessment of authority included the source's education and qualifications, having an authoritative reputation, and a source having past experiences similar to what was being experienced by the information seeker. Various components had an influence on the assessment of a source's

trustworthiness. These included the health information seeker's closeness with the source, the seeker having positive past experiences with the source, and the seeker having knowledge of a source's positive reputation. Specifically for digital sources, the use of sales and advertising on the site was found to be detrimental to trustworthiness. Finally, the assessment of relevance was largely influenced by the seeker's past experience and knowledge. For digital sources, matching symptoms in the title and description of search results and in the contents of a web page proved to be important in determining relevance.

The criteria identified for assessing information gain share many similarities to the source evaluation criteria described in the I-LEARN model (Neuman, 2011) and the quality and credibility criteria found in the study conducted by Eysenbach and Köhler (2002). Despite being similar, those studies also found source attributes, like timeliness, that were not discovered in this study. This may be a result of the different research methods used, the comparatively small number of participants in this study, or simply a difference in search preferences between participants in this study and those used in others. The limitation of the assessment criteria found in these other studies was that they were exclusive to digital information sources, while this study found criteria that were applicable across multiple source categories including those from non-digital and social sources. Additionally, the results of this study found that the assessment of information gain and the weight assigned to each attribute varied between individuals and was shaped by past experiences with a source. This impact of past experience on source selection is consistent with the findings of the general sensemaking models that state that source selection is impacted by "frames" or "schemas" created by past experiences (Klein et al., 2006; Pirolli & Card, 2005).

According to Information Foraging Theory (Pirolli & Card, 1999) and the Notional Model (Pirolli & Card, 2005) the costs associated to a source also contribute to source selection. In these models, only time costs were considered relevant to source selection. The findings of this study also point to the importance of time costs in determining source selection, but also found other costs that had an impact on the selection of sources during health information seeking. These other costs included social, personal and mental costs. Similar to the assessment of information gain, the valuation of these costs varied between individuals and the individual's context. These contextual elements impacting source selection include physical location and who is around the seeker when health information foraging is triggered.

Foraging Trigger Impact on Source Selection

Another difference found between this study and past research into sensemaking and information foraging (Pirolli & Card, 1999, 2005) is how different factors, specifically the experienced levels of the information foraging triggers, can impact the assessment of cost. As the experienced levels of the different foraging triggers increased, the valuation of costs associated to all sources decreased. This indicated that as the experienced levels of the foraging triggers increased, participants were more likely to seek higher information gain sources since they became less concerned about their associated costs. Although it intuitively makes sense that people will seek out higher value sources, like doctors, when they are more worried or their symptoms are more severe, the recognition that factors other than source attributes can impact source selection is lacking in the general models of sensemaking and information foraging.

Changes in the Value of Gain, Cost, and the Foraging Triggers Over Time

Similar to the "patch" model in Information Foraging Theory that has been used to predict when source switching will occur based on "information scent" (Pirolli & Card, 1999), participants in this study spent time continuously re-evaluating their assessed values of information gain, costs, and the foraging triggers. Also like Information Foraging Theory and the other sensemaking models, the evaluation of these values changed over time as new information was gathered and mental representations, "frames", or "schemas" were changed to fit this new data (Russell et al., 1993; Klein et al., 2006; Pirolli & Card, 2005). In this study, as predicted by the past models, these changes in valuation over time led participants to switch information sources. These changes happened both over a short period of time, like during digital information search, and over longer periods of time after numerous experiences with an information source had occurred. These changes in assessed value of gain, costs, and the foraging triggers is ultimately what drove source switching in this study as sources were continuously re-evaluated to determine their perceived information return when compared to other sources.

Use of Social Sources During Information Foraging

The use of social sources in the sensemaking process was introduced by Weick (1995) and then synthesised with the Learning Loop Complex by Sharma (2006), but was not included in the original models of Information Foraging Theory (Pirolli & Card, 1999). In this study, social information sources were one of the predominant source categories involved in health information seeking with all participants using social interactions with doctors, pharmacists, family members,

and friends to help them complete their information seeking tasks. The inclusion of social interactions did differ slightly from the findings of Genuis (2012) where participants placed a high value on information from interpersonal relationships, even those that lacked medical training. Most participants in this study placed little value on interpersonal relationships unless they had a medical education and background. This difference in the use of social sources between this study and the study conducted by Genuis (2012) could be a result of its focus on a different health information seeking motivation (How do I manage my treatment?) and its use of participants with a specific medical condition (menopause).

Areas for Future Research

The results from this study were able to provide insights into the first two questions posed by the author:

1. What technology, methods, and processes do people use to discover and understand health information?
2. How do people select information sources to use during health information foraging and why do they choose these sources?

Despite providing answers to these questions and adding clarity to the health information sensemaking process of medical laypeople, the final research question (*How do people assimilate health information obtained from digital sources and those from non-digital ones?*) still remains largely unanswered. Additionally, new questions arose out of the research results. These questions can be used to guide future research into this subject matter.

The Information Foraging Triggers. This study identified four different triggers for information foraging, but additional research

is needed to completely understand them and how they impact the sensemaking process. This additional research includes determining how to assess the value of each of the foraging triggers individually and understanding how they relate to and influence one another. For example, some participants felt more worried the more novel or severe their symptoms were. Other participant statements indicated that the perception of symptom severity increased when symptom duration was longer. Determining the value of the triggers and their impact on each other would also require understanding how different values of novelty, duration, severity, and worry trigger information foraging. This leads to questions such as:

1. Would a high value of one trigger overcome low values of others and trigger information foraging?
2. Would middling levels of each trigger initiate information foraging or does foraging only occur when the level of one trigger is high?

Questions like these could all be answered by future research.

Additionally, there may be more foraging triggers in the health domain that were not found in this study so research with a broader range of participants may identify other factors that trigger information foraging.

Other Attributes of Information Gain and Costs. Further research is also needed to better understand the source attributes affecting information gain and costs during source selection. This study was able to find a number of attributes that are associated to information gain, but there may be more that were not found due to the study's limitations including the number of research participants used and the similarities of the participants across various characteristics. When considering the assessment of information gain,

other research had found criteria for evaluating source quality and credibility that were closely related to this study's findings (Eysenbach & Köhler, 2002), but there were also a number of criteria from that past research that were not found in the current study. Additional research is needed to determine if those other criteria influence the assessment of information gain during source selection.

There may also be other costs that impact source selection that were not found in this study and that future research may uncover. For examples, financial costs were mentioned by one participant, but this only influenced their decision of how to travel to their medical practitioner. The lack of mention of financial costs by other participants may have been a result of the population used for this study or influenced by the study taking place in the UK where many health services can be used at little or no cost. Further research may find that financial costs, and other new types of cost, are also included in the assessment of costs during source selection.

Information Foraging Stopping Conditions. This study found that the values assigned to the information foraging triggers change over time as new information is discovered. Some of the interview data from this study also suggested that participants would stop information seeking if the changing value of the foraging triggers fell below their search threshold. There was not enough data to support this conclusively so additional research is needed to conclude that these triggers are also involved in the decision to stop seeking information. If proven to be true, this would thread the foraging triggers throughout the entire information foraging process from triggering foraging, to selecting and switching sources, and through to the decision of when to stop seeking new information.

Source Selection in Other Motivations and Domains.

Since research in this study was focused on a single health information seeking motivation, another area of future research is determining if the findings from this study hold true in the other motivations identified by Attfield et al. (2006). Research with these other motivations may uncover different factors that impact source selection, information foraging, and sensemaking. Future research into worry and other foraging triggers could also be expanded into domains other than health. Further research may identify whether or not the influence of worry and other factors are unique to the health domain, but more research is needed to properly conclude this.

Implications for Design

Numerous implications for the design of health information systems can be concluded from this research. These implications vary from basic design recommendations to complex considerations with potential ethical consequences.

Design and Structure of Health Information Web Pages.

Basic improvements can be made to web pages that can influence the values of information gain and cost associated to source selection. The first is to make sure the web page being designed is optimised to appear high in search engine results and that the title and descriptions are well written. Title, description, and placement in the search results proved to be important factors in determining relevance and impacted the sources that were selected by participants. Concerning the web page itself, designers should ensure the information is presented in a well structured manner and that only language that is easily understood by medical laypeople should be used. Important sections in a well structured page would include a list of symptoms associated to the

condition described, possible home treatments, and a description of when to see the doctor. For symptoms with physical characteristics, designers should use images to support symptom matching. Some web pages during the study were found to display long lists of possible conditions given the symptoms searched by the participant. These long lists were found to have significant time and mental costs due to the need for users to search and analyse each potential condition individually. To reduce the costs associated to searching these long lists, designers should include filters that can help users reduce the number of conditions that need to be analysed.

Emotional Design Using Worry and Trust. Overall, the author would not recommend attempting to adjust health information design to impact the foraging trigger of worry. In this study, increases in worry often resulted in participants visiting a doctor and because of this some may argue that it is actually beneficial to induce a sense of worry so that a person seeks professional medical attention. Besides the ethical problems involved with inducing a negative emotion in users, causing too much worry can damage trust and cause users to no longer visit a site. This was seen in one of the participants of this study where they no longer trusted digital sources because they would provide extreme conditions to all of their queries. This implies that emotional design activities should focus on building trust by providing relevant and accurate information that is created by an authority/expert in health (if the institution behind the site is not already considered to be one). This may involve partnering with a medical expert to provide relevant information, but partnerships that involve sales and advertising should be avoided as this may be interpreted as a conflict of interest and damage trust more than it helps.

Information and Technologies to Support Health

Information Seeking. There is also potential for integrating new technologies and information to support health information seeking across digital sources. One possibility of this is to be able to use contextual information, like the user's location, to better assess symptoms and their potential to be a specific illness, especially when there are cases of disease outbreaks in the local area. This may be useful for improving exploratory search tools like Google or digital symptom checker tools like the ones created by WebMD or the NHS. Additionally, digital platforms that lower the costs of accessing health information from high information gain sources, like medical professionals, can be beneficial in helping users accurately understand their symptoms. Tools like this already exist in Asia and were reviewed positively by one participant in this study.

Limitations

Participants. Although the participants involved in this study represented a diverse set of nationalities and age groups, there are limitations to the generalisations that can be made from the data. All participants were well educated (up to a postgraduate level) and had strong technology skills based on the fact that they were all members of a technology related masters programme at UCL. Members of the general population may not reflect this level of education or technology skill, so further studies would need to be completed to ensure the generalisability of the findings from this study. Technology skill may be an important variable in people's use of technology in health information sensemaking so it cannot be ignored as a potentially impactful factor especially when other research has found that technology skills impact digital search habits (Dickerson et al., 2004).

Continuing this research with a more generalisable population would help validate the research results for a wider audience of technology users. Also, the majority of participants were international students that had lived in the UK for a relatively short time. Although this was beneficial to understanding the costs associated with different location contexts and health systems, it may result in the data not being generalisable to a population consisting of long term residents of a country. Additionally, none of the participants in this study were screened for illnesses or for having a specific medical condition so the impact that these may have on the sensemaking process could not be assessed during this study. Due to time constraints, the study was limited to only 11 participants. Although some conclusions can be made with this number of participants, further research may uncover additional themes, relations, and information that could provide more insight to the data collected during this study.

Task Artificiality. One contributing factor to the artificiality of the digital search task was the time limitation required by the methods utilised. Most theories of sensemaking describe information foraging as a continuous and iterative process that does not have a beginning and end. Due to this limitation, conditions that caused participants to stop searching could not be conclusively determined so further research is required in this area. The health conditions of participants and the context where the search task occurred also contributed to its artificiality. Using physically ill participants would not have been viable for ethical reasons, so participants were required to imagine that they were ill using the task scenario. Although effective for the purpose of the study, the impact of actually being ill on the sensemaking and information foraging process could not be assessed. The digital search task setup which involved a laptop computer excluded the possibility

that some people may use mobile devices to search for health information. Further research may be required to understand how different uses of each device affect the health information sensemaking process. The digital search task was also limiting because it focused solely on the health information seeking motivation of "Am I ill?". Although some of the interviews and search tasks expanded into the other motivations of health information seeking, further research is needed to identify if there are differences between the findings from this study and ones based on the other motivations.

Analysis. Although the researcher attempted to utilise a grounded approach to analysing the data collected in this study, it is recognised that there may have been theoretical bias in the analysis due to knowledge of past research into the field of sensemaking and information foraging. Further research conducted by other researchers should be performed to verify the findings and ensure that this potential bias introduced by the researcher is limited.

Conclusion

The results from this study uncovered two themes regarding the health information sensemaking processes of medical laypeople when they try to answer the question of "Am I ill?" and determine if they should seek medical attention. The first is an understanding of how worry, symptom novelty, symptom severity, and symptom duration can trigger information foraging. Second, the results from this study identified the source attributes used by health information seekers to determine when to select and switch sources during information foraging. These include the source attributes used to assess a source's information gain (authority, trustworthiness, and relevance) and a source's costs (time, mental, social, and personal). It was also found

that factors other than these source attributes can influence source selection and that the perceived values of the foraging triggers has an inverse relationship to the assessment of perceived source costs. This meant when the foraging trigger values increased, source access costs were perceived to be lower and thus higher information gain sources were selected. These findings share many similarities with past research, but expand on the overall understanding of sensemaking and information foraging within the health domain. Despite limitations with the study, some design recommendations for health information systems were identified that can help improve their trustworthiness and relevance and also reduce the costs associated to accessing information from these sources. Further research is needed to better understand how these foraging triggers integrate into source selection and general sensemaking, to expand on the attributes impacting source selection, and to ensure the generalisability of the findings from this study.

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Appendix A

Search Task Scenario

Imagine the following scenario:

You've been having trouble sleeping and have been tossing and turning all night. You feel very warm and you find your pillow is soaking wet because you've been sweating profusely through the night. You feel congested and a substantial amount pressure behind your eyes, nose and cheeks. Your nose keeps running, so you reach over to grab another tissue only to notice you've used the entire box. Since you're feeling warm, you get out of bed to grab a thermometer from the closet so you can check your temperature. As you walk to the bathroom you feel a strong itchy sensation on your neck so you decide to scratch your neck. You walk into the bathroom and turn on the light. You put the digital thermometer in your mouth and wait for a beep and the temperature reading. While waiting you see your neck in the mirror and it looks like the attached picture. You keep scratching it because it continues to be itchy. The thermometer beeps at you indicating that it's ready and you find you have a temperature of 38 C (100.4 F). You put the thermometer away, grab a new box of tissues and walk back to bed. Before heading back to bed, you begin to feel a tingling, pins and needles sensation in your left hand and right side of your face, the same sensation you get when your foot falls asleep. You blow your nose, lie down, and try to get back to sleep. After a restless night you wake in the morning with a throbbing headache and notice none of your symptoms have gone away. You decide to step out of bed, but when you do you get an immediate sense that the room is spinning around you. This spinning sensation lasts for the next 10 minutes.



Appendix B

Information Sheet

Making Sense of Health Information: Information Sheet

You will be given a copy of this information sheet.

Title of Project: Making Sense of Health Information

This study has been approved by the UCL Research Ethics Committee as Project ID Number: UCLIC/1213/015

Name and Contact Details of Investigators: The primary researcher is Benjamin Skowera (benjamin.skowera.14@ucl.ac.uk). This project is supervised by Ann Blandford (a.blandford@ucl.ac.uk).

We would like to invite you to participate in this research project. You should only participate if you want to; choosing not to take part will not disadvantage you in any way. Before you decide whether you want to take part, please read the following information carefully. Ask us if there is anything that is not clear or you would like more information.

Study Details

The purpose of this research is to develop an understanding of how people make sense of digital health information so that this understanding can be used to inform future research and improve health information systems. Although there are many areas to study that involve health information, this research will focus on how people use digital technologies and health information in order to determine if they are ill and need to visit a medical practitioner.

The study will consist of a think aloud health information search task based on a given scenario and an interview involving a discussion of the search task as well as past experiences searching for health information from both digital and non-digital sources.

It is up to you to decide whether or not to take part. If you

choose not to participate, you won't incur any penalties or lose any benefits to which you might have been entitled. However, if you do decide to take part, you will be given this information sheet to keep and asked to sign a consent form. Even after agreeing to take part, you can still withdraw at any time and without giving a reason.

All data will be collected and stored in accordance with the Data Protection Act 1998 and will only be used for the purposes of this research study.

Appendix C

Informed Consent Form

Making Sense of Health Information: Informed Consent Form

Title of Project: Making Sense of Health Information

This study has been approved by the UCL Research Ethics Committee as Project ID Number: UCLIC/1213/015

Participant's Statement

I agree that I have:

- read the information sheet and/or the project has been explained to me orally;
- had the opportunity to ask questions and discuss the study;
- received satisfactory answers to all my questions or have been advised of an individual to contact for answers to pertinent questions about the research and my rights as a participant and whom to contact in the event of a research-related injury; and
- understood that my participation will be taped/video recorded, and I am aware of, and consent to, any use you intend to make of the recordings after the end of the project.

I understand that I am free to withdraw from the study without penalty if I so wish, and I consent to the processing of my personal information for the purposes of this study only and that it will not be used for any other purpose. I understand that such information will be treated as strictly confidential and handled in accordance with the provisions of the Data Protection Act 1998.

Signed:

Date:

Investigator's Statement

I, Benjamin Skowera, confirm that I have carefully explained the purpose of the study to the participant and outlined any reasonably foreseeable risks or benefits (where applicable).

Signed:

Date:

Appendix D

Interview Field Guide

Setup

1. Book a room with a power source, privacy (limited windows, etc)
2. Send reminder email 24 hours before session
3. Print off Informed Consent form and Field Guide, Receipt form
4. Configure laptop and prep software
 - (a) Turn on Silverback
 - (b) Clear browser history, cache, and cookies of past sessions in Chrome, Firefox, and Safari
5. Grab agreed remuneration and receipt form
6. Arrive 15 minutes before to prep and meet at coordinated spot
 - (a) Open laptop and log into user research profile
 - (b) Start recording with Silverback

Pre-Session

1. Welcome person, thank them for coming, have them sit down in front of computer
2. Review information sheet and informed consent and have them sign it
3. Remind them that information will be recorded using a video and sound recording devices.
4. Review what will be done at the session today

- (a) Today will be split up into two sections. The first will involve a think aloud health information search task based on a given scenario where you'll be saying exactly what's going through your mind while you search. Have you done this before?
- Yes, okay.
 - No. Do a basic google search task
- (b) Once that is complete we'll move on to an interview to discuss the task and some of your past experiences with searching for health information both online and through non-digital sources.
- (c) Remember throughout the interview and task, there are no wrong answers and you're not being tested. I just want to understand the process you go through and the tools you use to make sense of health information.

5. Any questions before we start?

Task

1. Hand them the scenario. Prompt them to let you know if they have any questions. After they've read the scenario ask
 - (a) what illnesses do you think you have?
 - (b) Do you think you need to see a doctor and why?
 - (c) What would be your next steps in a scenario similar to this?
2. During this task you'll be using the internet to search for information on the two questions we just discussed. What illnesses do you think you have and do you think you need to see a doctor and why? You can use whichever browser and internet sites you prefer, just remember to think aloud as you're doing the task.

- During this take notes on tools/ information gathered, key statements
- Prompt them if they forget
- Keep track of time using watch. After 10 minutes ask them to stop
- Ask questions again.

Interview Questions

Questions Regarding Task

- What information were you looking for when searching the internet?
- What qualities were you looking for in each source?
- During your search, what led you to choose to investigate the sources that you did?
- (If a change occurred between the responses on the questionnaire before and after the task) how did this task impact your knowledge of these symptoms?
- What led you to initially believe what illnesses you had and what was wrong with you?

Questions Regarding Other Times that they've used digital Health Information

- Given a situation similar to the scenario in real life, what's usually your first step in trying to figure out what you have?
- Can you remember any other ways you've found health information in the past?
 - If yes, can you describe the situation?

- What kind of health information do you typically consume?

Questions Regarding use of Non-Digital Health Information and Social Relationships

- Have you ever asked someone else what they thought of your symptoms when you were ill?
 - If yes, can you describe the situation and what kind of information did you get from them?
 - Describe how you decided to include the information from them in your thoughts about your symptoms?
 - Was this person a medical professional?
- Have you used non-digital health information resources in the past?
 - If yes, can you describe a past situation when you used these resources and how you used them?

Closing

Have participant sign receipt form and give them their money.

Appendix E

Example Interview Transcript

Note: The interview transcript begins after the participant reviews the task scenario.

Key: P = Participant; I = Interviewer; [] = actions taken during digital search, subtext, or replacement of word/statements that would reduce anonymity.

I: Based on what's happening in this situation what conditions do you think you might have?

P: It sounds like an allergic reaction to something, because my skin is itchy, plus I'm feeling dizzy, and it could be some sort of food poisoning and then I'm not 100% sure since I'd like to know how my stomach is feeling and its not mentioned here.

I: If it's not mentioned you can assume its feeling alright

P: It could be some sort of food poisoning still or some sort of allergic reaction.

I: What are you drawing on to make that conclusion?

P: Especially the itchy skin, but this kind of like the way it could be and the way and that you're completely drained and feeling dizzy and so for some reason I'm ignoring this section where it says the tingling pins and needles sensation on your left hand and right side of your face like when your foot falls asleep, but I'm ignoring that because I've already had a bad night and it could just be a continuation of that. It doesn't necessarily need to have a strong impact from any perspective. That's why I'm ignoring it. The temperature is also kind of consistent, any time you have some sort of allergic reaction or food poisoning your temperature is higher than usual. And that is why I kind of concluded that way.

I: Well based on that would you go see a doctor?

P: It actually depends. What I would do is I would give it a day's rest before I made any conclusion so drink plenty of water and relax. It could be anything, so if it doesn't decrease in a day then I would definitely go to the doctor.

I: So given that situation and you do a day's rest. Is there anything else you would do during that day?

P: Just drink a lot of water, eat very simple food and try relaxing.

I: Now why would you do those?

P: Because I'm assuming it could be something related to the stomach so it could be malnutrition[?] or it could be food poisoning that it needs to clear out of the symptom so drink a lot of water and have simple food doesn't seem to....that your stomach can handle kind of things. I: In similar situations, like this, have you ever used to internet to figure it out?

P: Yes, at this point, in the scenario it describes when I get out of bed at that point I would not search the internet because I'm already feeling extremely bad so I would try to rest it off a bit more before I get better and then at that point I'd be more interested in knowing what is wrong.

I: What kinds of things have you searched on?

P: So basically symptoms. I would search based on symptoms and see if it requires immediate medical attention or not. Most of things I kind of search on are RSI kind of pains that I think might be that and kind of need to avoid it. Especially like aches in pains, would be the biggest categories of search. Usually the tingling sensation, especially in the hands, is like an RSI kind of situation. SO that is would I usually and see if there are exercises that you can do to make it better and other things like that. But generally what happens is you don't bother about it until the point that it is slightly bothering you. And at that point you say "Okay I need to search" and they say that you need to do RSI

exercises often, but what happens is that you kind of forget and just doesn't get figured into a routine so you end searching whenever you feel that it is required.

I: Can you show me how you would search for your symptoms here?

P: [Opens Chrome, types in fever itchy neck dizzy, page loads. Clicks to open the first three links in new tabs] I think all of the are webMD. [opens 4th in new tab as well]. So, I'll definitely go for the first for links. For some reason I avoid Mayo Clinic because I kind of feel there is something iffy about it. [switches over to tab for first link, reads overview and scans illness and symptoms]

I: So what are you looking for on this page?

P: So I'm just seeing and just looking through and finding out what are the possible things [scans illnesses and symptoms. Reads some out loud]. So which could be something that I'm not sure. I would not put sinusitis as a possibility because I don't have a history of that. Hmmm, medication reaction or side effect, which I kind of would ignore since I would not recently having any medications. Possible things are hay fever, viral syndrome [continues reading illnesses on page and scans through the list] I would ignore tuberculosis mumps because its difficult to get that stuff and mostly because I've been vaccinated for that stuff. This is definitely a long list of things, I'm not sure, I was thinking if there was like 10 things that there'd be some way to kind of narrow it down. This actually says everything from cat scratch disease to plague. So, it actually says plague. [continues reading through potential causes and says no to all of them] [reads one condition] Oh its inherited. So I would not be that bothered, because that would not show up overnight. Things that would bother me are the poisoning kind of thing like lead poisoning is one, radiation sickness. I mean these are real possible ways that could happen. But the simple thing that makes the most sense is a

fever. It could just be your sweating a lot and maybe that caused itchiness and your body reacting to that. [switches to next tab and begins scanning the illnesses on that page] I don't know, I think my initial judgement was kind of right because it has something to do with the stomach, or a normal cold, or some sort of allergic reaction. It again depends on the persons, for me catching a fever is reasonably difficult, I wouldn't call it extremely, unless I've been exposed to somebody who has a fever at the point I would not be bothered about it. Food poisoning could be, it may have been something I've eaten that caused something. [looks back over page] and a lot of these things are not single point diseases that happen overnight, but these kind of things are irrelevant because I'm not a kid [scanning over a few of the illnesses] It could be filtered, or if I could filter it out and say like, this is my age, how fast the symptoms appear and it can solve it that way. So probably here is one thing that I can really not think is important is the UTI, and my search function is on itchy neck and with that you would not itch on your neck. [continues to scan page] There's another possible thing is an infection, like you have an ear infection [this was the illness he was looking at on the page. Continues to scan] Yeah, a lot of these things seem to be way too scary. [switches to third tab, scans page, goes back to search results. Switches query using autocomplete to "fever and itchy rash in adults". New search results load, looks at results and changes query to "rash neck" and switches to images.] Another thing I actually do is look at pictures and see what closely resembles it. [scans pictures clicks on one] I think this is the closest. [continues scanning, clicks view page to go to the website where the rash picture was found, switches back to one of the webmd tabs with a list of possible illnesses] Another thing that can happen is what I'd like to do is try to find out what are the immediate things I need to do. Like the normal thing is

drink lots of water, liquids, see if your body functions are kind of normal and which parts are not normal. [opens the webmd symptom checker] Now its saying that I need to...for me, for male, and age 25 -34 [clicks submit and results load. While loading goes back to rash image and the page is actually from someones blog. Scans it briefly] Hmm this is somebody's blog. [looks at a few comments on the blog post] Nahh [switches back to webMD symptom checker] I didn't know boots was doing webMD in the UK. Now it kind of looks like a marketing stunt, which I'm not comfortable with. [navigates through the UK symptom checker boots/webmd version] Alright, clicks on human neck area [page loads slowly, clicks around a bit page but takes awhile]

I: Have you used symptom checkers before?

P: Yeah, but not this version, it's a non-interactive one where you say I've got an itch here, I've got a tingling sensation. So usually most cases it easy to find, I think in this particular scenario the problem is I'm not sure which is the higher priority. So pretty much anytime you're sick you feel like everything is terrible, but there is an interal filter or something that let's you say this is the worst part and then I can concentrate on that and help me figure out what is the root cause. The itchiness is just the end result of something I think hand tingling is also something like that so I which I could not think about. I mean it could be just that I slept wrong. [reclicks on page and it finally loads again. Begins interacting with the tool by searching for symtpoms.] Hmm this doesn't have a search. [finds itching in the list and adds it] Now what else do I have? [zoom out on body in symptom checker] In the left hand so [Hovers over left hand and clicks it, takes it to is right arm] That was interesting. [hovers over arm to see areas] So it doesn't tell me where I feel the tingling feel so I'd select entire arm. [continues searching for symptoms in the tool] What is confusing me here, is those

that are a different color than others. From here a few things look darker. [referring to text color on the list]. Clicks on one symptom and it gives him a warning to see the doctor if it's serious. [continues adding symptoms using the tool] . This is interesting the more I add, its not reducing the number of options, it's just increasing. [adds fever to the list] I don't know [referring to question regarding fever from the symptom checker] there's no I don't know option on here. [scrolls through potential conditions]. I don't know. This made me more confused then when I started off.

I: Now what makes you say that?

P: It gave me more options than I thought it is. Makes me more far more anxious than I need to be.

I: What do you think of your initial conclusions now after the search? Do you think those are still possibilities?

P: I mean, from a logical perspective yes, but there is definitely lists showing there's something else, so that is one of the reasons why I said its better to take rest with a lot of liquid to see if its subsiding. If it is, very good. Then probably my diagnosis was right, if not, I'll seek medical attention.

I: So if it didn't subside you'd go see a doctor?

P: It depends, so if I can rate on a scale of of how I am feeling and rate it a terrible, 100/10, today and tomorrow I rate it a 90/10 then its better. If it's a fever kind of thing and it doesn't go away for 4 or 5 days then only I would seeking medical attentions since its clear its not getting better.

I: So it's the improvement in your condition that would judge whether or not you go see a doctor?

P: Yeah

I: I have a few questions about what you did during the task. So how

did you go about choosing your search query?

P: So basically what I did was, the reason why I chose these queries was because I kind of prioritized these things. Itchy neck is not something that I would put on a high priority just because it could've been because I was sweating, but it just came in there to see if there was a combination that caused that. It looks just a little like a normal fever to me at this point because fever causes you to sweat a lot, hands getting an itchy neck, and not sleeping properly and hence waking up in a disoriented way. [? Couldn't make out a lot of this structure] It could just be one thing. So that is why the fever came up as the first one, and then itchy neck and dizzy in that order.

I: Now when the results came up you clicked on the first four and opened up new tabs. Is that what you commonly do?

P: Yes, pretty much whatever I do, I google essentially doesn't work for me for the first thing so I go for the first five links. I don't go for the whole pages unless I can't find anything, so if I go beyond five it means that my keywords are very off

I: Now what are you looking for at links that cause you to click at them?

P: What I look at is the domain. So the domain is high priority so that's way, I saw WebMD, it looks respectable but I did not go further and Mayo Clinic I was like no thanks and then it goes into very specific diseases. So what I feel about most of these four links that I clicked kind of are pretty much the same thing, it is just providing different versions of it that have different conditions but are pretty much the same thing.

I: Now you mentioned that you avoid the Mayo Clinic and that their content is kind of iffy. What led you to think that?

P: I'm not sure, it's just something about. I kind of feel that there's some alternate healing thing. I'm not sure they could be good, but for some reason I have a bias against them.

I: You mentioned that you did trust WebMD and that they were reputable. Have you used them before and what made you conclude that?

P: Because webMD's specific disease page could be you know, [going back to the internet to check out the symptom checker] oh this current website is really bad. On the previous website you would just go onto a particular disease information and it will tell you all the things, like the way to manage the disease and preventative mechanisms and all other kinds of things. Its like, really solid information, it just doesn't bullshit around. That's one of the reasons I trust webMD more.

I: When you were going to webMD, and looking at the page with all the illnesses, what were you looking at specifically?

P: Mostly like looking at it as logically at possible. Like it could be the craziest disease of all, but not necessarily when it happens overnight, and not necessarily...it actually doesn't do likelihood based guesswork, so for example malaria, crohn's disease, that is not an overnight disease so it needs to actually gauge that in a better fashion. So what I was doing was going through and if it didn't make sense, throw it out, throw it out, throw it out. Mumps, measles, and whatever that other thing was, no, no, no.

I: So you had past knowledge of those disease and what they were?

P: Yeah something of that sort, my very limited knowledge of these.

I: Was there anything else in the descriptions you were looking at?

P: I was just one to read the titles, but some were like okay I can't even pronounce that

I: When you went to the boots page, you said you weren't comfortable about the marketing aspect of it. What about it made you uncomfortable?

P: When you have some sort of information source, that information

source needs to be pure, it needs to be...I mean it would be okay if on the side it had an ad, but boots and webMD means that it'll push an ad to you, like why don't you buy this at the nearest boots, go and buy it right now. So I'm not quite happy about the prospects of that, that kind of lowered the trust value. And the experience that was not that good.

I: Are there anythings that raise the trust value of sites that you're looking into?

P: Usually, impartial non-aligned identities [maybe entities?]. Unless you're talking about something completely unrelated in core marketing like android kit kat which is alright, but boots and webmd is kind of a relationship that can go wrong for the consumer. So if they're not using the webmd and boots was having a page, I'd be okay with that.

Because, a lot of drug manufacturing companies do have their [couldn't understand]. But I'm okay with that because they're openly acknowledging it, but here it's like an information that's kind of like Wikipedia but but their wrapping this with something else that's kind of tricky situation I think.

I: So I'm just trying to understand this. You used the word purity of the content its coming from one single source as opposed to a couple sources that are different?

P: It could be and no. It could be that these are webMD sources but just a boots co-brand. I would still be uncomfortable with that, even if it's a pure WebMD source. SO for example, instead of calling it Boots WebMD, if it was let's say M&S WebMD I would be okay with it because marks and spencers is not in the business of selling drugs.

I: So there's a business conflict of interest?

P: Yeah. That's the way I feel. I'm not sure if the content is trying to make me buy something, I don't know some sort of testing kit.

Whatever kind of disease testing kit they want to sell. Whatever legally they can advertise and sell which wouldn't aid my situation would make them richer is something that I kind of feel is the moral conflict of interest in the situation. That's why I kind of felt really bad about that.

I: Outside of getting digital information when you're sick, do you ever leverage social relationships or other people to obtain any sort of health information?

P: Yes, my mom.

I: What kind of information do you...how do those conversations go?

P: So mostly because I kind of forget what I had previously, it could be as previous as one year and I kind of forget about it. And my mom kind of knows what went wrong, she has a really good memory, and that helps a lot because once your forget about something like "I've never felt so bad in my life with this fever or with this disease or something like that" and I'll call her and she'll say oh you'll be fine in two days, and its like I've been through this so its no big deal. So it's like a reassurance memory kind of activity.

I: So not a diagnosis and more of knowledge of your own history?

P: Yeah, its like if my history is known and kind of it's like a so. I mean this is very positive(?) To me, so what happens is if I have a disease I would think, for example if this is a week long thing, so middle of the week I'm like "how does it even feel to be normal" I can't even imagine how to breathe normally. So you kind of forget about how that normality is because normal is so far you don't remember about it. The same way when you're feeling well you don't really think about how terrible it was so since that memory is automatically cropped in my mind, that is why mom comes into the picture and she's like "you had this before its not a big deal". Because at that point, in this scenario, if your searching for something and you can't think rationally, uhh I don't

know what to search on that's the way I would approach it.

I: So where in your general process...when do you call your mom?

P: It actually depends on the severity. So usually what I'll do is try to sleep it off and if I can't make any improvement in a day or two that is when I would call my mom. And say I'm feeling this way and she'll be like don't worry about it. Then I'll go 'yeahhhh' this has happened before, and that gives me the confidence to say its alright, its not going to be that bad.

I: does that happen before or after you search the internet?

P: Usually the most common disease I have is fever so not unusually the searches are usually for something that are non fever related for example like the RSI kind of pains which are quite difficult to explain so those are things I would search and to find out other words I can search from.

I: So if you were ill you wouldn't necessarily just go search the internet for it?

P: Not immediately no. The first thing I would do is drink water and sleep.

I: And the next thing you do is reassess the situation about how you're feeling if it improved?

P: And then send out emails about working from home

I: Now do things like work and other commitments impact information sources you'd go to?

P: Umm, usually I would not give it that big of a priority. And personally couldn't explain very well to others what is happening. And work that priority that my last place had was if you're sick don't come in like "I don't want you to make other people sick". If you're sick that's fine. If there's a meeting that needs to be attended you'll get it from home as long as that is taken care of that's fine. So yeah its never

been such situation where that's taken any priority. Well on things like that are like immobile things like exam deadlines. Those are the things where I'd be a little more cautious and the first thing I would do is take some medicine and see if it helps my situation and power through. And again it depends if I'll be able to get an appointment before the time I would need to to help me to do things

I: Does the time it takes to get an appointment how you go about this process?

P: It depends. [At home], if I want to see a doctor now I can see a doctor now. Now means now.

I: And then here it's like?

P: And then here it's like, next year I'll see you bye bye.

I: Because of that are you less likely to search on the internet or call your mom?

P: It depends

I: What is it depending on?

P: It depends on whether it can be handled locally or do I need to go for some assistance

I: How do you determine that?

P: Mostly self evaluation. I think the highest escalation so far I've gone is I call my uncle, he's a doctor, and he's like have this medicine blah blah blah and just go get. And you won't need a prescription (? Or he'll write me a prescription?) That's the highest escalation I've been to. Other than when I was really young I was hospitalised once, and when I broke my hand (?).

I: Now you said you'd call your uncle as a last escalation point. What would lead you to call your uncle?

P: Beyond three days of symptoms that I can't get rid of (or control?).

I: Now would you call your mom before you call your uncle?

P: Yes. Three to four days.

I: So you would call your mom and get your history and reassurance and then if it didn't get better you'd call your uncle?

P: yeah

I: Has he recommended in the past that you go see a doctor...like what kind of things does he recommend?

P: He actually, that's like one of the beautiful things about having a doctor that is local, kind of available, he knows what the diseases going around, he knows the likely things that will happen, and he knows exactly how to treat you even without even seeing you so you don't need someone to physically see you. And he knows how much I exaggerate, very important. "I can't even open my eyes!... yeah I know" [jokingly] "Oh alright, so don't open your eyes, go to the store, and go get this medicine and you'll be fine" [talking as his uncle]

I: Is he here or back [home]?

P: He's (home). There's an uncle here who's also a doctor who will help me out, but his process is "you're not feeling well right? So why don't you rest?" "I rested for four days" "Well why don't you rest again for another four days" And after fifteen days he will think about if he will need to get you any medicines. Because his views are completely different, he doesn't believe in fixing things immediately and he thinks body immunity given plentiful time to react to the situation but my uncle back in India says that 4 or 5 days are enough don't go beyond that and he, my uncle here, would take 10 days before he gets to a situation where you need to get anything, so my first priority is I call my uncle back home. I: So you'd call him first before you'd call your uncle here?

P: Yes, unless it's a situation that is beyond my control

I: So it sounds like you have some medical professionals in the family, is

there anyone else that you ask that isn't a medical professional that you try to get guidance from?

P: Yes, my mom

I: Besides your mom?

P: She is, technically a pharmacologist

I: So she has a medical background as well?

P: She does pharmacology, so I don't know. She knows what to eat and what not to eat.

I: I know you mentioned your own history as being informative, is family history something you consider in these situations?

P: No, not really. So far no

I: Any friends here that you ask for medical advice?

P: I think the last time I involved somebody else, it was my neighbour and I was too sick to get out of bed and asked if he could get medicine

I: So you were looking for help because you were sick and not advice?

P: Exactly, not for medical advice. Because advice everyone has their own contradictory belief of whether this is better or that is better so somebody would say "don't drink any water that is causing you to have more fever" its like crazy amount of beliefs there. [talks about indian arranged marriage to explain how two senior experts of the ceremony would disagree]. So it ends up being a lot of conflicting advice. Same thing with medical advice so if you're not going to a professional you end up getting a lot of advice like that its very conflicting and you do this or you do that.

I: Outside of relationships and digital information, is there any non digital information that you use to help you assess your symptoms or treatment?

P: No, other than instructions of use for medicine.