EXPLORING ONLINE HEALTH SEEKING'S POTENTIAL VIA SOCIAL SEARCH

A Thesis
Presented to
The Academic Faculty

by

Matthew N. Bonner

In Partial Fulfillment
of the Requirements for the Degree
Doctor of Philosophy in the
School of Interactive Computing

Georgia Institute of Technology
August 2014

Copyright © 2014 by Matthew N. Bonner

EXPLORING ONLINE HEALTH SEEKING'S POTENTIAL VIA SOCIAL SEARCH

Approved by:

Dr. Elizabeth D. Mynatt, Advisor
School of Interactive Computing
Georgia Institute of Technology

Dr. Mark Braunstein, MD
School of Interactive Computing
Georgia Institute of Technology

Dr. Eric Gilbert
School of Interactive Computing
Georgia Institute of Technology

Dr. Rebecca E. Grinter
School of Interactive Computing
Georgia Institute of Technology

Dr. Meredith Ringel Morris
neXus Research Group
Microsoft Research

Date Approved: 15 May 2014

Dedicated to my family, friends and most of all my wife, Heather.

ACKNOWLEDGEMENTS

First and foremost, I am grateful to my wife Heather Muñoz. Heather, your determination sets an example for me every day. You were confident in me even when I wasn't confident in myself. I would not be here without your help. Wherever we travel next, I know you will make it spectacular. Thank you for your uncommon love, patience and support. No one else compares. I love you.

I am also grateful to my parents, Kelley and Mark Bonner. Mom, Dad, your advice and love has always been a foundation for me. I know that I can rely on you in any situation. You give me the courage to face an uncertain world. I love you.

My advisor Beth Mynatt guided me through all the twists and turns of my increasingly messy research. Beth, it often feels like you operate on a higher level than the rest of us. You have an uncanny ability to untangle and focus any kind of research problem. However confused or difficult my situation became, I could always count on my next meeting with you to point me in the right direction. Thank you for your unflinching support, incisive advice and dry humor.

I owe a great debt to the faculty members who have advised me during my graduate career. Thank you to my committee members: Mark Braunstein, Eric Gilbert, Beki Grinter and Merrie Ringel Morris. It was both humbling and illuminating to receive so much of your time, and I am profoundly grateful. My thanks also go out to the faculty members who advised and worked with me in my early days: Gregory Abowd, Keith Edwards and my first advisor Blair MacIntyre. Rather than reining me in or writing me off, you gave me freedom to explore in a nurturing environment. Thank you for helping me find my place.

The Human-Centered Computing (HCC) program's incredible faculty are paired

with equally inspiring students. Thank you fellow HCC-ers for your thoughts, criticism and examples. Carrie Bruce, who helped guide me through my first teaching experience, deserves special mention. So too do Yee Chieh Chew and Andrew Miller, my fellow cohort of 2008 survivors. I also feel privileged to be an alum of the Everyday Computing Lab. Andrew Miller, Jessica Pater, Maia Jacobs, Eugene Medynskiy, Jiten Chabra, James Clawson, Andrea Grimes-Parker and Catherine Grevet: you provided just the right blend of wisdom and insanity. And puns.

Sahithya Baskaran and Megha Sandesh provided invaluable development help to create Snack and also worked as qualitative coders. Beyond these contributions, Sahithya and Megha were invaluable sources of ideas and advice during Snack's creation. I could not have built this without you!

Thanks also to the friends and family from Georgia Tech and beyond not yet mentioned, who supported me throughout my studies. In alphabetical order: my brother Will Bonner, Jeremy Brudvik, Nathan Calverley, Arya Irani, Liam MacDermed, Karthik Raveendran, Jon Scholz and Jacob Schonberg. Thank you for sharing the experience with me!

I also acknowledge my collaborators at the Emory Predictive Health Institute (EPHI). To EPHI's current and former directors, doctors Greg Martin and Ken Brigham: thank you for your guidance, open-mindedness and support in my work and beyond. To Lynn Cunningham and Jennifer Vasquez: I am grateful for your suggestions and your help navigating EPHI and Emory. Finally, thank you to EPHI's Health Partners, who shared their limited time and allowed me into their practice, especially Jamie Hamblin, Chesley Large, Theresa O'Hern and Darren Triplett. I owe you my degree.

Finally, I am grateful to Google for funding my work. Thank you for giving me the means to pursue my own research program!

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

SUMMARY

Online Health Seeking (OHS) is widespread and widely studied, but its ideal fit in healthcare is still unclear. OHS is seemingly emblematic of patient self-interest and control and is an intuitive fit with the tenets of patient-centered care (PCC). Researchers have made only a few attempts to evidence or leverage this connection, focusing instead on describing the figures and typical characteristics of OHS. Finding, consuming and sharing online health and wellness information is one of the common online activities, and consumers are generally satisfied with their results despite using simple and error-prone search strategies. Physicians are interested in their patients' OHS, but for a variety of constraints including time, compensation and traditional roles in medicine, most patient OHS goes unshared with doctors. Healthcare facilitators, a relatively new class of health professional that works to bridge the gap between their client's health and personal life, may be an ideal partner for patients in OHS. In this dissertation I share my investigation of the OHS-PCC connection, presenting a case study of a type of healthcare facilitator that has embraced OHS.

By studying OHS, I was also able to contribute to the collaborative information seeking (CIS) community. CIS theory and social search tools have pointed to social factors that can influence the entire process of information seeking. In this dissertation I argue that nearly any social search design can be seen as situated or embedded in a unique socio-environmental context. I suggest that social search tools can be used as probes to understand the environment, and that interactions with a search tool can illustrate phenomena far beyond direct search motivations and goals. I also hypothesize that social search field studies can produce changes in their environment, producing changes in user relationships outside of the experimental search system. My

study of OHS is an opportunity to test these hypotheses by creating a collaborative search tool that seeks to use OHS as a tool to improve patient-provider relationships.

In this dissertation I present the results of a series of field studies at a local clinic that centers on a unique form of health facilitator. Drawing on several formative investigations and related work I synthesize design guidelines for a collaborative OHS tool and describe Snack, a collaborative search tool for OHS customized to my field site. I also present results from Snack's field study and an analysis of email messages between advisors and clients at the clinic. My results show that these health facilitators embraced OHS as a tool to guide and connect with their clients, but fell from this practice after a change at their clinic. After analyzing these results I discuss what makes health facilitators good OHS partners and cover implications for future OHS-based interventions. I also report the positive connections I found between OHS and other quality of care indicators like patient-centered care and the Multidimensional Health Locus of Control. Finally, I consider social search's utility as a probe and intervention in light of my results.

CHAPTER I

INTRODUCTION

Healthcare, with its recent political emphasis, universal relevance and increasing reliance on technology, has grown into a primary topic within the Human-Computer Interaction (HCI) community. Many HCI researchers have used technology to empower the everyday health consumer by making the opaque health system more accessible, exposing new information, motivating healthy choices and more. Technical interventions have been used to help manage chronic illness like asthma and diabetes [111, 112, 60], and to assist the elderly with independent living [86]. Numerous projects have studied exercise-encouraging apps based on pedometers [67, 57, 101]. Other researchers have worked to help individuals track and respond to their health [65], mirroring the recent explosion in personal health devices like the FitBit and Nike Fuel Band. In my own prior work I studied how activities, including a specially developed mobile system, shape interactions between children and Child Life Specialists in a major pediatric hospital [14].

All of these projects connect to the principal of 'Patient-Centered Care' (PCC). PCC, cited by the Institute of Medicine as a goal for future health care [8], suggests care should be tailored to individual patients. A patient-centered care plan fits into the patient's life, and holistically considers patient needs, goals and pressures beyond any one medical goal. PCC also prescribes 'continuous healing relationships' between patients and their care team, in which patients make informed decisions with the ongoing guidance and support of health professionals. Though not all HCI researchers use the medical phrase PCC, the concept is readily identifiable in each project that emphasizes the agency and expertise of ordinary people in managing their own health.

This dissertation explores PCC in an area that has received limited attention from the HCI community despite its informatics roots: Online Health Seeking.

Online Health Seeking (OHS), the process through which people find, consume and share health and wellness information online is both widespread and impactful. As Internet use in the United States grows, OHS has remained a common component of online activity. Similar Pew polls in 2010 and 2012 found Internet use amongst U.S. adults increased from 74% to 81% [34]. In the 2010 poll 59% of adults reported searching for online health information, while in the 2012 poll the same proportion reported searching within the past year. A 2011 Harris Poll reports a similar percentage of adults (60%) searched for health in the past month [97]. OHS also has serious consequences. 60% of respondents to a 2009 poll reported that information they found online affected a treatment decision [35]. Searchers use their results to diagnose themselves and others, to decide if they need to visit a health professional, and more [34]. To summarize, for years the majority of U.S. adults have been online health seekers, and that OHS can have serious effects.

OHS is an intuitive match with HCI's traditional interest in patient-empowerment. Health seekers are demonstrably interested in the care of themselves and others, and take the initiative to find relevant information. Medical and informatics researchers have investigated OHS in detail, covering searcher strategies and motivations as well as effects on patient-provider relationships. Prior work has also uncovered pain-points within OHS, including the variable quality of both online information and health-seeker search skills [100, 31]. In a 2013 study, health seekers found the physician-indicated correct answer only around half of the time [105]. Despite these issues the vast majority of health seekers seem satisfied with their results [97], and a significant number of results aren't shared with a health professional [23, 40, 76, 96, 97]. A wealth of prior work has described OHS and attendant problems, but few studies explore how OHS could benefit health seekers or be incorporated into care. The

stage is thus set for work that investigates OHS's positive potential, including its utility as a patient-centered intervention in the HCI tradition.

OHS is a natural candidate for a social search based intervention. Social search tools, technologies that leverage 'human horsepower' to assist information seeking, are of interest to researchers and industry alike. Companies like Google and Microsoft are trying to include social network data in their search engines, while social networking sites themselves try to ramp up their search capabilities, as Facebook has with Graph Search. Next-gen Q&A sites like Quora and StackExchange are another example of social search's increasing importance. A social search tool for OHS could be used to connect patients and providers, addressing known OHS issues while also creating an opportunity for patients to contribute to their care and take leadership.

By studying and intervening in OHS, my research has also been able to push at the boundaries of social search. Any social search tool is surrounded by a particular social and environmental context. Other researchers have discussed this context's impact on social search to some degree, but in my research context takes on primary importance. Environmental context drove my design of a collaborative search tool via an extended investigation of health professional-client relationships at a specific clinic, emphasizing but not limited to OHS. I also worked to understand my designs use in context, via a field evaluation during a period of upheaval (the clinic's closure). Finally, my systems made an attempt to intervene in the surrounding context of the clinic by using OHS as lever to improve health professional-client relationships. Essentially my dissertation treats social search as a tool that can be customized for specific context, and then used to study and intervene in that context. I call this approach 'Embedded Social Search' to give first-order priority to the network of of relationships and circumstances, search-related and otherwise, that all collaborative search tools are 'embedded' in.

1.1 Research Questions

The above motivation establishes two research threads for my dissertation. The first set of questions revolve around understanding OHS's potential to improve health professional-client relationships. The second set of questions are on the interaction between social search and its 'embedding' context. Because I explore using social search as a probe to investigate a subject or context, in this case OHS at a particular clinic, many of my research activities and findings are relevant to both threads. Along these two threads, I ask the following research questions:

1.1.1 Online Health Seeking's Patient-Centered Potential

RQ-OHS-1: What role does OHS currently play for health advisors and their clients? Existing work has reported on the web-search process of OHS and the attitudes of patients and doctors, including the effects of discussing OHS. Opinions on OHS, use of online resources and reactions to patient OHS vary between doctors, with younger doctors tending to view OHS more favorably [61]. Though the doctor-patient relationship remains a foundation of healthcare, other 'health facilitators' with a variety of training are often involved in helping patients and caregivers manage health. These include Child Life Specialists [14], Cancer Navigators [48] and more. How does this breed of health professional employ OHS? Where does OHS fit in relationships between these health advisors/supporters and their clients?

RQ-OHS-2: Are there connections or correlations between OHS and quality indicators like patient-centered care? Many studies have worked to chronicle and explain OHS, which has been established as a major online activity. Some of these studies have documented both positive and negative effects on patient-provider relationships [76, 40, 106]. Can OHS be systematically related to concepts like PCC? Is OHS worth pursing as a tool for improving patient

agency and holistic care?

RQ-OHS-3: Can OHS be used as tool to create a more patient-centered environment? Work on OHS has been descriptive rather than interventionist. Could a technical system impact OHS activity in a positive way, overcoming some of the challenges identified by existing work? Could OHS activity leveraged to produce positive changes? Projects could study OHS's utility for improving many different aspects of care from adherence to managing a specific health condition. In my dissertation, I focus only on the aspect of patient control and patient-provider relationship satisfaction.

1.1.2 An Embedded Approach to Social Search

RQ-ESS-1: Can social search ground a larger investigation into a specific environment? In social search, a wide variety of social and environmental factors influence the search process. Will studying these search processes illuminate the larger environment? Could social search tools be designed as probes, to fit into and explore specific contexts?

RQ-ESS-2: Can a social search tool be used as an intervention to affect processes besides information seeking? Collaborative information seeking is already a complicated process, influenced by many context-specific factors. Can a social search tool have a targeted effect on those factors in turn? My investigation of this question is closely tied to RQ-OHS-3. My work examines the impact of different social OHS tools on health advisor-client relationships, which exist apart from OHS activity.

1.2 Overview of Dissertation

This dissertation is organized as follows. In Chapter 2, I discuss related work to motivate, guide and contextualize my own experiments. I cover research on OHS,

including interventions and the effect on patient-provider relationships. I also discuss HCI's history of patient-centered interventions. Chapter 2 also includes an overview of collaborative information seeking and social search. I conclude by introducing and defining 'Embedded Social Search'.

Chapter 3 introduces the Emory Predictive Health Institute (EPHI), the field site which hosted my work. In this chapter I discuss the results of three formative studies at EPHI: two different sets of focus groups and a series of shadowing and interviewing. These findings are relevant to RQ-OHS-1 and also informed my following intervention's design.

In Chapter 4, I synthesize a set of design guidelines for an OHS intervention at EPHI. These guidelines are drawn from the literature review and formative work described in the preceding chapters. Next I describe the design of Snack, the system I developed to support a form of OHS conducive to PCC.

Chapter 5 details Snack's field deployment. Health professionals and clients at EPHI used Snack for several months in the summer of 2013. During my deployment, EPHI began a sunsetting process that had a fundamental impact on my deployment. The results of my deployment address OHS's capacity to encourage PCC (RQ-OHS-3), social search's utility as a probe (RQ-ESS-1) and the effects of search on non-search phenomena (RQ-ESS-2).

Coinciding with Snack's field trial, I conducted a series of surveys with EPHI clients. In Chapter 6 I report these results, which illustrate OHS's association with quality indicators like PCC (RQ-OHS2).

Chapter 7 reports my analysis of email messages between EPHI's health professionals and their clients. I was able to access five years of email, the primary mode of communication at EPHI. I used a machine learning approach to analyze this large set of data, including topic modeling and sentiment analysis. These results offer another window into care at the EPHI, and also pertain to RQ-OHS-1.

Chapter 8 reflects on my experiences as a researcher. I first consider the challenge of doing research in a changing environment and the use of interventions as environmental probes. I then discuss my interviewing methodology.

In this chapter, I reflect on some of the research methodologies and data-gathering techniques I used in my work with EPHI. I begin by discussing change and treating interventions as probes of an environment. Then, I discuss my experiences interviewing and observing my participants in private settings.

Finally, Chapter 9 brings my dissertation to a close by revisiting each of my research questions and summarizing my findings. I end with brief reflections on the implications for future work connected to OHS or social search.

1.3 Contributions

My work contributes to the healthcare community by assessing and attempting to harness the power of OHS to improve care. I also give an in-depth look at one form of health facilitator-client pairing by working with EPHI's advisors and clients. My work also contributes to the HCI community by investigating 'Embedded Social Search', which emphasizes social search's interactions with the larger non-search environment. ESS positions social search as a technological probe to study and intervene in specific contexts that are not necessarily limited to search processes and stakeholders alone. This dissertation presents the following specific contributions:

1. A series of field studies that reveal and unpack advisor-client relationships at the EPHI. EPHI's exact model is unique, but related health facilitators are a growing part of the larger healthcare system and my work with EPHI serves as a case study.

    (a) Within these studies, an exploration of OHS's role in the advisor-client relationship.

2. Design guidelines for OHS interventions that link health facilitators and clients, synthesized from my case studies.

3. A design overview of Snack, a collaborative search tool for OHS at the EPHI. Snack encompasses several designs, and was intended to encourage patient leadership and control.

4. A longitudinal deployment of Snack at EPHI exploring the capacity of social search to affect non-search factors by testing OHS as an intervention encouraging patient-centered care.

    (a) As EPHI underwent significant downsizing during my deployment, this field study also contributes a view of health facilitator-client relationships during change and stress.

5. A 3-pronged set of surveys given during my system's deployment. Links were found between OHS and two quality of care metrics, PCC and the Multidimensional Health Locus of Control.

6. Analysis of an email message corpus between EPHI's providers and their clients. This investigation is separate from my fieldwork but contributes to the same case study of EPHI's advisors as healthcare facilitators.

CHAPTER II

RELATED WORK AND EMBEDDED SOCIAL SEARCH

In this chapter I discuss related work by other researchers that motivates and informs my own investigations. I first summarize research on OHS, beginning with statistics and characteristics of health seekers. I then cover several OHS-based interventions and outline the opportunities I see in OHS. In the next section I begin to unpack the phrase 'patient-centered care' and briefly touch on the long history of patient-empowerment in HCI research. Finally, in the last section I discuss information seeking, moving from theory on to a variety of experimental social search studies. To conclude I introduce and define 'Embedded Social Search', an approach to social search research that builds on and compliments existing work and theory.

2.1 Online Health Seeking

2.1.1 Non-Professional Health Seekers

Many large-n surveys have been used to collect basic information on OHS by non-health professionals, such as correlated demographics and overall prevalence. National polls in the United States by the Harris and Pew organizations provide evidence that the majority of Americans are online, and that seeking health information is amongst the most popular online activities [33, 96]. In particular, a 2011 poll by Fox at the Pew Internet and American Life project found that hundreds of millions of people in the United States alone (the majority of US adults) use the Internet to search for health information of all types: to track their diet, compare doctors or insurance, or even to self-diagnose. Outside of the USA, a 2007 seven-country survey in Europe found that 71% of Internet users (a majority of Internet users in each surveyed country) had sought health information [4]. More recently, the 2013 Oxford Internet Survey

split Internet users in the UK (78% of adult Britons) into 5 'cultural' groups, from 'e-mersive' digital natives to 'a-digitals' with a mostly negative reaction to the Internet [26]. Still, the majority in each of these diverse 'Internet Cultures' were online health seekers. Both Fox and Andreassen et al. found OHS positively correlated with youth, female gender and education level [33, 4]. Fox also noted a correlation with income. Andreassen et al. did not explicitly measure income, but noted correlations with related factors like career and education level.

Not only is OHS widespread, it has a real impact: 60% of respondents to a 2009 poll reported that information the found online affected a treatment decision [35]. The same poll also found that a significant portion of OHS, even a majority, is done on behalf of others. A 2005 survey indicated medical professionals and the Internet are the preferred sources of cancer information, but health seekers report turning to the Internet first far more often (10.9% vs. 48.6%) [43]. Similarly, in a 2007 survey respondents listed health professionals as their first choice for information (followed by the Internet), but when asked which source they had last tapped, the Internet led health professionals (34.5% vs 19.4%) [62]. While it does not seem like the Internet is completely replacing health professionals as an information source, online information has clearly become a primary resource on its own.

Researchers have also investigated how non-professionals actually participate in OHS. This work is generally formative, either concluding with straightforward design guidelines or remaining completely descriptive. Some of these studies observed and interviewed small groups of health seekers, independently noting similar characteristics among a diverse set of health seekers [31, 90, 100]. Users preferred using general search engines to specific medical sites or tools and were quick to reject sites, especially based on site presentation, design, and ease of use. In Toms et al. and Eysenbach & Kohler, searchers used extremely simple queries [100, 31]; in the case of Toms et al. search engines automatically excluded so many terms as common 'stop words'

that only a single query per term was used on average [100]. Peterson et al. also reported users tended towards simple search strategies and had misunderstandings about search engine function [79].

Logging of queries or browsing activity seems key to understanding OHS. Given the sporadic nature of OHS, logging allows researchers to capture OHS whenever it occurs, and to monitor searches over a long period of time. Eysenbach & Kohler also noted that while users mentioned their concern over information sources during interviews, none actually visited 'about us' type pages on the sites they selected, and few were able to recall where they had retrieved information [31]. This dissonance suggests, as Peterson *et al.* mention, that user logging or observation are key to accurately understanding user searches. Accordingly, logging was included as part of my experiments.

Many other studies have used observation or logs to describe or model OHS behavior. White and Horvitz found that some types of OHS proceed in a 'bursty' fashion [106]. Their study examined logged queries related to medical symptoms from thousands of subjects, finding that the large majority of queries related to any one symptom take place within two weeks of each other. This study also found that the majority of searchers had used the order of results in a search engine as a way to determine the likelihood of a diagnosis. Two other log-based studies emphasize the importance of searcher hypotheses to OHS, noting that diagnostic searches tend to begin with symptoms and seek a disease hypothesis, or begin with a hypothesis and seek verification [20, 51]. Another third log-based study by White showed that personal biases can affect health search results [105]. White found searchers favored information that confirmed their hypotheses, and also found searchers (as well as search engines!) tend toward results with a positive perspective. Participants in White's study found the (physician-indicated) correct answer only about 50% of the time. Health seekers' domain-specific knowledge can also affect their search process

and results. In an observation-based study, Bhavnani compared health professionals and expert shoppers as they each carried out web searchers on health and shopping. Bhavnani observed that within their respective domains of expertise, the experts have a concretely sequenced set of goals [9]. When searching outside this comfort zone, experts lost this sequencing and resorted to general search engines and bouncing amongst sites.

Taken as a whole, research on non-professional health seekers gives some cause for concern. OHS is extremely widespread and has a noteworthy impact on searchers. The large majority of searchers seem confident in online information's utility, as well as their own ability to find online resources. However, non-expert searchers tend towards simple strategies and often fail to find the correct answer. Furthermore, a great deal of OHS goes unshared with a health professional, as I will discuss in the following section.

2.1.2 OHS and Health Professionals

Other studies have evaluated OHS and Internet use among health professionals, especially doctors. Masters conducted a literature review of studies that asked why physicians did or did not use the Internet [61]. Mirroring non-professionals, Internet use amongst physicians is increasingly common, and younger doctors were often more likely to report Internet use. Typical physician OHS is reviewing medical journals and databases, a contrast to consumer OHS via general searches. Despite this, a low but growing portion of physicians used email to communicate with patients, citing issues like workload, legal and privacy concerns, and the fact that it can be difficult to reimburse or bill time spent on email. The vast majority of physicians (89%) found it 'interesting' when patients shared OHS, but far fewer doctors carried out OHS for patients (44%) or referred patients to web resources (20%).

OHS can involve both patients and providers, and many studies have explored the

impact of OHS on patient-provider relationships. The proportion of health seekers who share their searches with providers varies widely across studies, suggesting that while many discuss OHS with providers, many do not [23, 96, 76, 107]. Some patients fear sharing their OHS with a doctor could be seen as challenging their provider's expertise or role, and a few have experienced negative reactions [15, 40, 42]. This fear seems justified, as physicians feel a patient who uses OHS to challenge their expertise, insisting on a particular diagnosis or treatment, has a negative impact on care [76, 93]. Some patients use 'face-saving strategies' for discussing OHS with providers, such as not mentioning the information under discussion is the product of OHS [17]. Positive reactions seem to be more common however, and patients generally feel discussing OHS improves their relationship with their provider [76, 40]. Patients who did consult a provider were "reassured that their worries were not justified" nearly 75% of the time [106], which meshes well with physicians' feelings that OHS can lead to unfounded fears [3]. Most physicians consider OHS to be helpful to patients [76, 83, 93], if perhaps creating more work for physicians themselves [3, 83].

2.1.3 OHS Interventions

Though the literature on OHS is typically descriptive in nature, there are also examples of interventionist studies. Recall that Toms *et al.* found consumer health queries were frequently ineffective and largely composted of stop-words [100]. Many interventions involve reformulating or interpreting user queries, either with existing search engines or with a new purpose-built product. Plovnick & Zeng *et al.* reformulated consumer queries on Google and MedlinePlus, replacing words with related terminology from the Unified Medical Language System (UMLS) [82, 113]. Reformulated queries were somewhat more successful (1 or more relevant documents in the top 10 of results), but there was no difference in user satisfaction. Can & Baykal created MedicoPort, which also reformulates queries based on the UMLS [18]. MedicoPort uses

its own web crawler to index pages relevant to the overall UMLS hierarchy. Can & Baykal claim that focus groups found MedicoPort to be more effective than Google, but are somewhat vague in their reporting. A final reformulation-based system is iMed, which uses a questionnaire to help users create multiple queries and organizes results (sourced only from certain high-quality sites) using the Medical Subject Headings (MeSH) system [58]. In a limited evaluation based on hypothetical 'diagnosis based on symptoms' scenarios, users found iMed to be faster and more successful than commercial search engines like Google Health, though only 30% of searches ended in success (*i.e.*, the correct diagnosis).

Another intervention, Information RX (IRX), is intended to increase OHS rather than replace existing search tools. IRX is an ongoing project of the American College of Physicians Foundation and the U. S. National Library of Medicine which began in 2002, and is still available today (http://informationrx.org/). IRX offers paper 'information prescription pads' to health professionals, allowing them to prescribe information just as they prescribe a drug. These prescriptions are intended to be 'filled' by visiting MedlinePlus.gov. The first study of IRX (2003) had limited success recruiting physicians, as only 20% of eligible providers in the targeted states of Iowa and Georgia participated [88]. However amongst physicians who did participate, significant portions felt referring patients to MedlinePlus could increase their self-efficacy (54%) and improve patient-provider communication (42%). Patients also had largely positive responses to IRX, feeling it helped them make better health decisions (93%) and that their doctor's recommendation made them more likely to try (74%) and trust (84%). A later study made an extensive effort to integrate IRX into a particular teaching hospital, offering classes on IRX for providers and distributing IRX materials throughout the clinic [16]. The intervention was successful in convincing participating doctors that recommending online information to patients was

useful, but even with the outreach efforts the study had some trouble driving physician participation. Physicians were concerned about patient literacy, but the most prominent barrier was the physician's lack of time during consultations. Elsewhere, a 2009 survey in Georgia found only 2 of 46 physicians and 46 of 105 medical librarians had even heard of IRX, and use appeared very limited [66]

Though researchers have been creating OHS-interventions for over a decade, significant gaps remain for new projects to fill. As described in the previous section, problems like incorrect search results have not gone away. Many interventions have focused only on the patient/consumer, without considering the effects on patient-provider relationships (or trying to leverage health professionals). Projects have also typically relied on hypothetical evaluations or post-hoc investigations of logs, which make it challenging to investigate the social components of OHS in detail. IRX makes an admirable attempt to involve both sides of the patient-provider dyad and has been deployed *in situ* at a number of hospitals/clinics. However, IRX has faced issues with adoption by time-pressed doctors, and as an especially simple intervention is limited in its ability to address OHS challenges like ineffective queries. OHS is a complicated process —these existing interventions are valuable contributions, but space remains for new designs, especially those centered on patient-provider relations. A project that significantly incorporates providers and their clients, directly addresses some of the challenges of OHS and is tested *in situ* would be a valuable contribution to the existing stable of OHS interventions.

2.1.4 Discussion: Framing OHS as an Opportunity

Diverse sets of researchers have long recognized OHS as a common activity with a significant impact on health seeker's care decisions and patient-provider relationships. However, prior work has been mostly descriptive, covering how health seekers search, or how they feel sharing OHS has affected their relationship with a provider. Studies

have noted positive effects on patient-provider relationships from sharing OHS, but offer few concrete strategies or examples for encouraging these encounters. Interventions have typically focused on only one side of the patient-provider relationship, and have rarely been evaluated in the field. IRX is a notable exception to both of these traits, and IRX's suggestions about OHS and patient-self efficacy are inspiring to my own work.

In this dissertation, I explore OHS as a positive, reciprocal connection between patients and providers, rather than as a potentially dangerous patient activity for providers to monitor or an individual task to be handled in isolation. Health seekers are demonstrably interested in the care of themselves and others, and take the initiative to find relevant information. Acknowledging and nurturing this interest, not to mention using OHS as an avenue to develop holistic understanding of a patient's interests, seems aligned with the goals of patient-centered care. However, few interventions have taken this integrative approach to OHS. IRX is rare for its view of OHS in terms of potentials instead of problems, but its basic design represents only a first step towards understanding these potentials. IRX has also struggled to engage with busy doctors, so I investigate other health professionals as OHS partners for patients. By deploying my system over time at a real clinic, I attempt to investigate the effects on real patient-provider relationships as opposed to success rates on hypothetical searches.

2.2 Patient-Centered Care

PCC's simple name belies a somewhat complicated construct. PCC was cited over a decade ago in the Institute of Medicine's landmark '*Crossing the Quality Chasm*' report as a goal for future health care. PCC emphasizes patient leadership and a holistic understanding of the patient [22, 8]. A PCC care model incorporates participatory 'continuous healing relationships' between patients and providers that extend

beyond consultations, and may be contrasted with 'clinically focused' models featuring expert caregivers and passive care receivers. Since the IOM's report, authors have worked to develop a consistent definition and means of measuring PCC [95, 28]. Because circumstances vary so significantly between specific clinics and patient-provider pairs, it is difficult to move from generalities like 'holistic relationships' to specific metrics with which to measure PCC in any context. Robinson *et al.* describe PCC descriptors for both clinical and patient actors, and suggest interviewing and numeric scales to measure PCC via these descriptors [85]. In my dissertation, I develop specific questions based on these descriptors that are suited to OHS and the particular clinic used as my field site. I describe the development of my PCC survey in more detail in Chapter 6. Because PCC emphasizes shared control of care, I also utilized the Multidimensional Health Locus of Control instrument [103].

2.2.1 HCI and PCC

The HCI community has had a longstanding interest patient empowerment. Though these projects have not always referred to 'PCC', they generally aim to give patients more control over their care, and elevate the value of patients' 'everyday expertise'. For example, Bickmore *et al.* developed an agent to explain discharge information to patients, taking less time from pressed nurses and (hopefully) helping patients prepare to integrate their new medical regimes with their regular life [10]. Mamykina *et al.* created MAHI to help diabetic individuals track and learn to manage their condition [60], while Medynskiy & Mynatt developed Salud! as a motivational tool to help users track their weight over time [65].

Other projects have studied patient agency, investigating who controls medical counters and looking for opportunities to place control in the hands of patients. Unruh *et al.* found typical clinic environments inhibited the ability of patients to interact with their physicians in a collaborative way, encouraging passive encounters [102].

Their study suggested a re-imagined exam room, with a more egalitarian physical layout and collaborative technologies like large screens, could support more patient-driven encounters. My own prior work investigated the relationship between Child Life Specialists (CLS) and children at a local hospital [14]. I found that CLS-child encounters were activity-based, and that the type of activity chosen could affect the nature of the interaction. By selecting activities that allowed simultaneous input —like painting instead of a single-player video game —CLS could encourage children to take a more active role in encounters.

These studies are just a small sample of patient-focused work within HCI. Though these projects are varied, they have many common features that my own work takes on as well. Many of these systems counted both patients and health professionals as their users, and sought to make the connection an empowering one for patients. My own work in this dissertation also encompasses both professional and amateur users, and seeks to place patients in a leading role. HCI researchers also typically emphasize fieldwork to study health care, and combine data from several methods when investigating a site or conducting an intervention. I used a variety of methods, from interviewing and observation to surveys and experience sampling, to answer my research questions. All of these activities were conducted at a local clinic, introduced in the next chapter.

2.3 (Collaborative) Information Seeking

Collaborative search is a type of Collaborative Information Seeking (CIS), which is itself a subset of Information Seeking (IS). IS theories traditionally emphasize the individual [27, 55]. Pirolli & Card's Information Foraging (IF) has been another influential theory [81]. IF describes an individual searcher that creates an internal schema to categorize and organize both their search and the information they find. In IF, the searcher continually re-evaluates their available information sources and

decides how to budget their limited search resources. CIS theories are a response to antecedent IS theories like these. CIS theories expand on IS by adding a social component, attempting to explain how other humans can influence an information seeker.

Collaborative theories have abounded in the past decade, reflecting a community that is still working to model the social world's impact on search. Some researchers have studied traditional models in collaborative situations, finding the match to be imperfect and emphasizing the potentially social nature of seemingly individual tasks [39, 47]. For example, Hyldegård examined a traditional IS theory (Kuhlthau's Information Search Process or ISP [47]) in a group search task - students working on a project [47]. These would seem to be very similar searchers, but students each had their own values for information sources and "...divergence in motivations and ambitions between group members had contributed to negative feelings such as frustration and disappointment." Hyldegård found ISP incomplete, and in need of a social extension that could "... address also the impact of contextual and social factors, such as the work task and socio-psychological intragroup issues."

Other researchers have created models that are social from the start. Reddy & Jansen studied collaborative information behavior in two hospital units, where a diverse team meets information needs together [84]. They describe a two-dimensional model of 'Information Behavior' which favors a gradual approach instead of stark classifications. On one dimension, behavior varies from searching (tactical) to seeking (strategic). On the second dimension, behavior varies from individual to collaborative. At the hospital, Reddy & Jensen found that more complicated searches tend to become collaborative. Another model, by Evans & Chi, highlights where social factors can impact a web search [29]. Their model grew from a survey of web searchers, which found social impacts before search (such as a request from a client), during search (such as asking a friend to help refine a search) and after a search (such

as sharing results). In other words, social connections can completely surround the search process!

Collaborative search processes can have social inputs and outputs even outside the act of searching, and thus must consider human relationships outside of information seeking. Highlighting relationships in this way is a call for caution: misunderstanding how a searcher connects with their peers (or their boss) could scuttle a system. However, this highlighting also exposes an opportunity: search tools could directly or indirectly affect human relationships. To understand or even harness collaborative search as a tool to shape human connections, we need to understand the social environment our search tools interact with. This contextual shaping and understanding is the point of 'Embedded Social Search' (ESS), which gives first order priority to the environment tools are embedded in.

2.3.1 Social and Collaborative Search

As researchers have sought to understand social impacts on information seeking, other projects have created or studied search tools expressly designed for social data and collaborative use. These projects represent a broad research area and it can been difficult to identify a clear taxonomy that describes types of social search and types of social search tools. Consider as evidence the preponderance of papers seeking to define social or collaborative search.

1. In the March 2009 edition of the IEEE Computer journal, Ed Chi suggests social search be split into two categories [21]. In "Social Answering" systems, an individual or social network directly responds to a user's query. In "Social Feedback" systems, social data is gathered implicitly (e.g., logging of users) or explicitly (e.g., tagging by users) and used to rank or highlight search results.

2. In the very same journal issue, Golovchinsky *et al.* offer their own taxonomy for collaboration in search which relies on 4 dimensions: intent (do users explicitly

or implicitly collaborate?), mediation (do any underlying algorithms recognize multiple users?), concurrency and location [36].

3. McNally *et al.* use a Venn Diagram to illustrate a continuum of social search, moving from individual "Queries and Searching" towards social "Sharing and Communities" [64]. McNally *et al.* also discuss "implicit collaboration", represented by a user that leaves a social trace like a tag that later impacts another user.

4. Morris and Horvitz describe "passive collaboration", represented by logging and data mining which automatically adjusts search results or rankings [70]. This concept is contrasted with systems that tightly couple users, allowing direct communication and teamwork, including across time or distance.

5. In later work Morris and Teevan position collaborative search, in which users share an information need and are part of an explicit group, as a subset of social search [73]. A social search tool may be 'implicitly social' rather than collaborative. An implicitly social tool may have a social data source, such as search engine for Twitter, but does not create groups or teams of searchers who actively cooperate and interact on searches.

I have found it useful to view social search tools on a continuum, from 'passive' to 'active'. Most of the taxonomies seem to describe two sorts of tool, which I call passive and active social search. Passive tools frequently include implicit grouping and large numbers of anonymous users. Indirect cooperation, indirect communication and general search goals characterize passive tool use. Users typically share identical roles and capabilities. Active tools on the other hand tend to employ explicit user groups, known identities and small numbers of users. Direct communication, direct collaboration and specific shared search goals are hallmarks of active tools.

In this dissertation I focus on active social search (also called collaborative search). In this section I discuss passive and active social search in general, then cover search via Social Networks and Question and Answer tools in more detail.

2.3.1.1 Passive Social Search

Passive social search tools take many forms and leverage a diverse set of data, but tend to share certain key characteristics. Without direct collaboration or explicitly shared goals to connect users, search groups are made implicitly. Grouping users with similar search queries is a common approach [5, 49, 56, 91]. Social bookmarking services like del.icio.us have also been used to create implicit groups of users, assuming that multiple users of a given tag may share interests [7, 109]. Each of these systems relies on large-scale user bases and anonymous users. Smyth *et al.*'s I-SPY and Jones *et al.* both worked from databases with thousands of queries [91, 49], while Bao *et al.* and Yanbe *et al.* drew from an overall corpus with hundreds of thousands of annotations [7, 109]. Any additional user tags or queries would simply be added to the dataset, and when a user sees their search results modified, they have little to no idea who made the queries or tags leading to that modification.

This is not to say that all passive search tools share all these characteristics. Govaerts *et al.* used explicit social networks via the OpenSocial API to group users, while researchers at IBM used both explicit social links and implicit means like co-use of a tag to group users [37, 19]. In both systems, however, browsing data from the grouped users is pooled and used anonymously to adjust or highlight search results. In all of these tools, users are not guaranteed to share exact search goals, and can communicate only indirectly by taking some action (tagging, viewing a page, making a query) that could potentially impact a future searcher.

2.3.1.2 Active/Collaborative Social Search

The social search community also evaluates tools for direct collaboration among smaller, known groups - what I term **active social search**. These systems would also fall under Morris and Teevan's definition of **collaborative search**. For example, CoSense by Paul & Morris was evaluated with groups of 3 members planning a trip [78]. SearchTogether was studied with pairs of users with pre-existing relationships (romantic partners, friends or relatives), who were instructed to search on any topic of mutual interest [70]. Finally WeSearch, a table-top system, was evaluated with groups of 4 who again had pre-existing relationships and were instructed to address 'typical mutual information needs for their team' [71]. Analysis frequently returns to the same topics and challenges, including the division of labor among group members, managing awareness to avoid redundancy, and allowing searches to persist between multiple sessions.

Other systems straddle the line between passive and active/collaborative social search. An example is Heystaks, a tool that allows users to self-select into groups around particular topics, finding and sharing results [92]. Heystaks allows users to create shared searches, or 'staks'. Users can join public staks, tagging and adding pages to staks, and can directly invite friends to a stak. Many of the active social search hallmarks are present: known users, direct communication, and small groups for example. However, once a stak is joined the tool becomes more passive and tagging-like. User contributions (tags) aren't publicly noted, and the system adjusts search results based on the aggregate pool of data in each stak.

2.3.1.3 Social Search, Social Context

Across these projects, there is a focus on the search task itself: avoiding redundant work, improving a list of results, and so on. Many of these projects also touch on the importance of social context. For example, Smyth et al. found their Heystaks system

contained a dichotomy of 'producers' and 'consumers' [92]. With CoSense, Paul and Morris described participants who appraised one another's search skills [78]. Why does the Heystaks dichotomy exist, and do inter-user evaluations in CoSense impact later teamwork? ESS is meant as an approach to answer questions like these by looking at search's interaction with surrounding social context. In this way, I see ESS as motivated by and complimentary to prior social search work, rather than as a replacement or indictment.

2.3.2 Search via Social Networking Services

Most recently, a number of studies have focused on information seeking via Social Networking Services (SNS). Perhaps because these projects begin with social networks, they often consider searcher relationships beyond information seeking. Yang *et al.* found cultural differences among countries in the type of questions users posted to social networking sites, as well as the asker's motivation for using their social network [110]. For example, their work suggested a preference for social network Q&A in India and China could be related to traditional 'collectivist' values. Other researchers directly compare SNS-search with web search. Teevan *et al.* compared Twitter queries with web search engines, finding a number of syntactic differences. Twitter searches were also more frequent than web queries, serving as a way of monitoring current events, trends and user-related information. In another comparison study, Evans *et al.* conducted an experiment contrasting two groups working on the same search challenges: a traditional web search group (search engines, Wikipedia and so on but no SNS services) and a social group (SNS and talking to friends, but no 'regular' search tools) [30]. In the social group users chose who to ask based on perceived knowledge and expertise as well as factors like current accessibility and the social cost of asking. This last observation is interesting: it's not enough to know an expert on a topic. An SNS search (e.g., collaboration) must also fit the relationship

between users, and search can have effects (ex: creating an obligation to answer, to return the favor) on relationships.

Other projects have looked to build on existing social networking services. Hecht *et al.* developed 'SearchBuddies'; agents that would interject search results or mention relevant friends in a user's Facebook feed when the user appeared to post a question [41]. The question-poster's relationships affected their interaction with the SearchBuddy: users did not appreciate it when the agent mentioned peripheral acquaintances, or linked friends who had recently had a falling out. Hecht *et al.* also suggested that SearchBuddies could guide conversations, making them more informative or more social.

These studies show that human relationships, from a macro-societal level down to individual friendships, affect how users perceive and interact with search tools. They also suggest collaborative tools, like SearchBuddies, can frame their users interactions around information seeking. Hecht *et al.* even describe their prototype as a 'socially embedded search engine'. By talking about Embedded Social Search I mean to highlight that any collaborative search tool, not just one designed within a social networking service, is situated in a cultural and individual web of relationships. Understanding how the users relate to one another inside and outside the system, and how the system mediates their self and peer conceptions over time, is relevant to any type of social search.

2.3.3 Q & A Tools

Question and Answer services (Q & A) have a long history of working to match information seeking needs with social structures. For example, Answer Garden was a seminal Q & A system from the early 90's that was initially conceived as an alternative or supplement to manuals and documentation[1]. Answer Garden connected ordinary 'users' with experts, storing expert responses to augment organizational memory. A

second version of Answer Garden made a number of changes, but one telling point was an emphasis on 'context' [2]. Ackerman *et al.* found experts wrote better answers when they had a more holistic understanding of the question and (especially) its asker. Answer Garden 2 sought to connect question-askers to nearby experts who could leverage their knowledge of the asker's skills, issues and motivations in their answer.

Stack Overflow (SO) is a modern Q & A system, a web community for programmers to exchange knowledge. Mamykina *et al.* studied SO and found it to be very successful, with 90% of questions receiving answers [59]. Their paper's discussion makes a blunt point: "Design matters, community organization matters more". In the opinion of Mamykina *et al.*, the most important factor in SO's success was its founders' esteemed position in the programming community and ongoing involvement with the site. The founders' prestige lured in both askers and answerers and encouraged skeptics to try the site, even as it was under development. The researchers report that some users even view their public activity on SO as a valuable part of their professional resume. Mamykina *et al.*'s work with SO is an example of social search's embeddeness. Studying SO's system of badges and achievements or the frequency of questions versus answers is only one part of understanding how and why SO functions. By taking a broader approach, Mamykina *et al.* were able to show that SO's success in part flowed from its founder's social capital, and that users have complex motivations for answering a particular question.

Quora is a general Q & A website with a vote up/vote down system similar to SO, but without SO's focus on programming topics. On Quora questions are organized under topics like 'electric cars', 'healthy eating' or 'college basketball' - any topic is fair game. Wang *et al.* describe Quora in terms of three graphs: one linking users to topics, one linking related questions, and one connecting users to one another [104]. Unlike SO, on Quora users may 'follow' or subscribe to one another. Gang *et al.*

found that 'super users' with many followers tended to end up with the highest-voted answers. Super users also get more answers to their own questions. In another study, Paul *et al.* discuss how Quora users evaluate whether an answer is authoritative. A primary factor is the answerer's reputation, since Quora requires real names [77]. Paul *et al.* discuss several other fascinating effects of Quora's real-identity decision. Quora users will follow others and answer questions as a means of networking and building their reputation. Voting on an answer can also serve as a social signal, as users support their friends or associate with a 'super-user'. As with SO, the collaborative information seeking process interacts heavily with user relationships.

That last Q & A tool I will discuss is another commercial system, Aardvark. Aardvark was a tool that helped users ask one another questions in system-mediated chats [45]. Aardvark automatically found good matches to answer queries using metrics like user-entered expertise, friend-endorsed expertise, politeness and message length. Recall from Evans *et al.*'s comparison of SNS question-asking and web search that finding the correct and *appropriate* person to answer a query depended on more than just expertise [30]. Also, as just discussed, SO and Quora elevate users and answers based on social capital as well as correctness. Aardvark's multi-faceted way of calculating connectedness is an example of a search tool that begins to model user relationships beyond search. Aardvark turns this a fuller picture of searchers back towards information seeking, looking to improve the search experience. In the next section, I ask whether social search tools could extend their reach beyond the search process.

2.4 Discussion: Introducing Embedded Social Search

I use the phrase Embedded Social Search (ESS) to emphasize the critical importance of socio-environmental context for social search. Collaborative information seeking models have expanded to the point that there are social potentials before, during

and after a search. Inward-facing models that consider only the search process itself minimize the social context all collaborative searches are embedded in - a rich data source that could explain searcher interactions and motivations and guide system designs. They also miss the potential to use social search as a probe to modify or simply understand the users and relationships they link.

ESS emphasizes the socio-professional context or environment all social search tools are embedded in. The environment can be relevant from a macro level (e.g. 'the healthcare system') on down to the micro level (e.g., specific patient-provider relationships at a particular clinic). ESS says that environmental features, even ones that seem remote from information seeking, can be important for social search. These features can inform a design and affect its use. Through their interaction with a search tool, users can reveal or illustrate environmental features, including their change over time. Finally, ESS suggests that social search tools can produce changes in their environment. In summary, ESS encourages researchers to consider how social search can be guided and affected by the environment, how the larger environment can reveal itself through search processes, and how search tools can impact the environment.

With ESS, I intend to expand the lens we use to evaluate social search tools. I discussed several exemplary social search systems earlier in this related works section like CoSense and Heystaks, which focus on how users navigate an experimental social search tool. ESS suggests complimentary investigations, asking how the new search system redefines relationships on a team, or what social processes the system has exposed. Social search researchers are stepping into this area as they study social networking services. Studies of Q & A tools have also shown that there is a complex, interactive relationship between collaborative information seeking and social context. Remember for example the critical role of the SO founders' social capital, or Aardvark's multi-leveled way of calculating connectedness. I suggest questions like 'how

does system use vary between cultures?' or 'who are searchers comfortable collaborating with, and how could our tool shape their interaction?' are just as relevant for tools like CoSense as they are for studies of Facebook, Twitter or Quora. Questions of this nature require grappling with the social context tools are embedded in, meaning more longitudinal deployments, more field work and more ethnographically-inspired methods.

At this stage, ESS is not a theory or a new kind of social search system - rather, ESS is a point ABOUT theories, and a point about HOW we create and evaluate a collaborative search tool. In "Where the Action Is", Paul Dourish says that "Embodied interaction is interaction with computer systems that occupy our world, a world of physical and social reality, and that exploit this fact with how they interact with us" [24]. ESS makes a similar point with a narrower scope: social search is always embedded in a network of evolving human and environmental connections, and this should affect how researchers design and evaluate social search.

My ESS-related research questions focus on the relationship between search and social context. **RQ-ESS-1** looks at the effects of the environment on search, asking how a search tool can be tailored to a specific, local context. With **RQ-ESS-1**, I also ask if collaborative search can be used as a probe to understand an environment over time, as changes in user circumstances and relationships are surfaced by search. **RQ-ESS-2** looks at the other side of the equation, asking whether collaborative search can be an avenue for change in an environment. In the following chapters, I describe the development of a collaborative search tool for OHS at a specific clinic, and describe changing relationships as framed by my system (RQ-ESS-1). I also investigate whether any of my designs was able to help create a patient-centered environment (RQ-ESS-2).

2.4.1 An ESS Example

A small hypothetical example can illustrate the ESS approach more concisely than my dissertation *in toto*. In this section, imagine we are developing a collaborative search tool for real estate agents and their clients. ESS encourages us to consider the embedding socio-professional environment from a macro to a micro level throughout our project.

The environment can guide our search tool's design and development. With proper formative work, we can mold our tool to fit the *general* real estate agent model. Perhaps real estate searches usually turn on agents finding homes and clients evaluating the results, so our tool creates seeking utilities for agents and evaluating functionality for clients. We could also choose to intentionally confront or upend the environment in some way; perhaps we have reason to believe searches would be more successful (by some metric) if clients also contributed to the search. We could also adapt our design to a *particular* or *localized* context: a real estate agency, a geographic location or so on, that has unique features of some kind. For example, maybe a particular agency uses multiple agents for each customer, while another focuses on renovations and house flippers. Aspects of our design could be tailored to each of these agencies.

In the course of our deployment, interactions with our search tool can reveal the environment. These interactions could help us discover static features, or expose new changes. For example, we may find searches focus on a particular neighborhood and learn this is due to a tax break in that area. We could also discover varying strategies amongst real estate agents or agencies. Even very low-level environmental features could be important for understanding the behavior of specific searchers: we could see one couple struggle to agree on a house, and learn they disagree about living near a set of in-laws. While some of these environmental features may be apparent from analyzing system use alone, discerning other features will require additional research activities to contextualize system use.

Finally, ESS hypothesizes that social search tools can impact their embedding environment. Our users have the goal of finding a house that fits their budget, has a good location and satisfies various other requirements. Assume that we as researchers have an ulterior motive: encouraging them to select a 'green' eco-friendly house. Perhaps our tool gives homes a 'green rating' which guides eco-conscious buyers. Perhaps we learn that our set of home buyers is *not* eco-conscious and our tool aims to change this by presenting information about the carbon footprint of each home. We could also look to make real estate agents prefer selling green homes: perhaps by creating more eco-friendly agents, perhaps by highlighting that green homes have higher margins. Our project may even find it worthwhile to connect home seekers with eco-conscious friends. If these relationships are strong enough (or we can create and strengthen them), home seekers may be pressured or persuaded into a green home.

I used a collaborative search tool as my example to match the system I developed with EPHI, but ESS could also apply to passive social search. Consider the tagging systems discussed by Bao *et al.* and Yanbe *et al.*, which adjust search results based on queries or tags from 'similar' users [7, 109]. Are there other factors beside search queries —environmental features like demographics, for example —that could be used to group similar users? ESS is also relevant to systems combining active and passive components like Morris *et al's.* 'groupization', which effectively brings similar-query-adjusted search results to smaller collaborative groups [74]. The environment could affect our groupization-based social search tool: perhaps one searcher is more experienced and their results should make a larger contribution to the results-adjustment. Our tool could impact the environment: perchance a team at work has unequal power relationships, but per our groupization algorithm everyone contributes equally. Finally, the environment may reveal itself in our tool's use. Maybe a search tool offers groupization and non-groupization tools to middle school students, and

the groupization results are abandoned when sets of friends have a fight. This in turn could feed back into a redesigned tool allowing re-grouping on the fly.

These hypothetical findings and design decisions are meant to illustrate several tenets of ESS. First, ESS-driven findings may or may not be closely related to actual information seeking or search. Second, findings may or may not be related to social factors like human relationships. Third, it is critical to consider the socio-professional environment throughout a social search research project.

2.4.2 Roles and Asymmetry in Search

Asymmetry, an unusual characteristic for collaborative search tools, is important for my work. In contrast to symmetric designs where all users share the same capabilities, asymmetric tools creates different classes of users [73]. Asymmetry is a novel topic for collaborative search researchers, and there aren't a great deal of examples available. Pickens *et al.* provide a clear-cut instance of asymmetry, describing a system in which a 'prospector' gathers new information resources and a 'miner' does in-depth exploration [80]. This system creates entirely different classes of users (not just different capabilities shared by all users) that govern collaboration.

An ESS-approach to understanding and designing a collaborative search tool, especially for OHS, will likely emphasize asymmetry. When introducing ESS, I stressed the need to understand interactions between system roles and socio-professional relationships. In a heterogenous environment (like health) asymmetry may be necessary for a search tool to properly support a diverse set of users. As Morris & Morris have noted, a collaborative search tool looking to connect different roles in healthcare will almost unavoidably be asymmetric [72]. A doctor and patient may have different backgrounds, expertise, motivations, goals and subgoals even when they both intend to safeguard the patient's health. Huge differences are possible even within broad categories like provider and patient. These differences logically lead to asymmetry;

an added complexity and new research direction.

Interplay between social and system roles has long been a core topic in the Computer-Supported Collaborative Work (CSCW) community. Users may negotiate roles, but roles may also be embedded in a system [50]. Distribution of labor may also reflect the balance of power between collaborators. Kling discusses "c-words" like cooperation, coercion and control to remind us that collaborative systems can serve to connect partners, but can also act as means of encoding and enforcing chosen modes of work [54]. Consider the following health-related example. Bjørn & Balka describe a carefully designed system for triaging that nonetheless failed in practice [11]. It seems the system was designed by doctors, encoding beliefs about how triage should proceed: objectively, standardized, and largely context free. This structure did not match with the actual work practices of triaging nurses, and the resulting complaints and slowdowns led to the end of what was once a mandatory system.

Asymmetry is a likely design characteristic that should be handled with care. A divergent design could help different sets of users connect in a natural way. However, any design's vision for user roles and relationships represents a statement about how the users 'should' view one another. What seems like an actual or even ideal relationship from one role's point of view may be challenging or even abusive for other collaborators. A mismatched design could also be abandoned by users as in Bjørn & Balka's example. My work must carefully consider which viewpoints it embeds, especially in an environment like health where there are stark divides and strongly held opinions about the appropriate relationships among actors.

CHAPTER III

UNDERSTANDING OHS AT THE EPHI

In this chapter I introduce the Emory Predictive Health Institute (EPHI), the field site for all of the work presented in this dissertation. I also discuss a series of formative studies at the EPHI including focus groups, shadowing and interviewing with the two primary roles at EPHI; health professional advisors and their clients. I found EPHI to be a complex environment where advisors strive to connect with, support and empower their clients, and where online resources play an important role.

This work helps answer **RQ-OHS-1**, which asks how non-traditional healthcare facilitators employ OHS in their work. It also sets the stage for my following studies, guiding the design of my intervention and helping me understand its results.

3.1 Field Site: The Emory Predictive Health Institute

All of the research activities I discuss in this document have been in collaboration with the EPHI (also "the center"). The EPHI is a joint research project between Emory and Georgia Tech, homed at and led by Emory. The EPHI runs a unique system of 'predictive' health assessments, creating an ongoing medical history of participants which is made available to researchers. Until August 2013, the EPHI conducted these assessments and patient visits at the Center for Health Discovery and Well Being (CHDWB) [1]. At the CHDWB, EPHI participants worked with a 'Health Partner' to conduct their assessment, amongst other activities. For simplicity, I refer only to the EPHI rather than making a distinction between 'the EPHI' and 'the CHDWB'. I will

[1]The effects of this change on my study and my results will be discussed at length throughout my dissertation. The EPHI still conducts assessments. However, no Health Partners or any other assistance/support is offered to clients

also refer to EPHI Health Partners as 'advisors' and EPHI Participants as 'clients', as this captures the nature of their relationship better than terms like patient or provider.

Every 6 months to a year, EPHI clients undergo an extensive array of medical tests called 'the assessment'. These tests include blood work, bone, muscle and artery scans, psychological surveys and more. Clients go over their thick binder of results with their personal health advisor following each assessment. Advisors help their clients establish an action plan in response to their results, and manage their health through follow-ups (from weekly to monthly at the client's choice) over email and phone. Advisors come from a variety of health-related backgrounds including dietitians and personal trainers, but are not medical doctors or nurses and are prohibited from giving prescriptive advice or medical treatment.

While EPHI's particular system of assessments is unique, their emphasis on patient-centered, participatory care is not. The Institute of Medicine has identified PCC as a core goal for the future of the health system, and patient-centered units are in various stages of deployment across the United States [2].

3.1.1 EPHI Demographics

EPHI operates as a research center serving 763 clients (of which 465 are 'active' or engaged with a health advisor), mostly employees of the university that houses the center. Some clients are health professionals or administrators. Clients are 34.1% male, with an average age of 52.4. The center's racial makeup is 70.5% white, 22.4% African American and 4.7% Asian. Clients have a high average income, with 85.5% making at least $75k per year. Education levels are also high: 56% have attended graduate school. Outside of this group a further 39.5% of clients have at least one year of college, meaning a total of 95.5% have at least attended college.

[2] http://www.ipfcc.org/profiles/index.html

As covered in my Related Work section, some of these characteristics (female gender, income) are correlated with OHS, while others (middle age) are less so. Given that OHS has dramatically increased alongside Internet use and given the massive number of health seekers overall, I feel the EPHI is still a useful sample despite its skew towards highly educated and wealthy clients. Still, other health seekers with fewer socio-economic resources may face barriers not encountered by most EPHI clients, and further work with these groups would be valuable.

3.2 Formative Work: Understanding OHS at EPHI

I conducted a series of formative studies at the EPHI to investigate how clients and advisors work with one another, especially around OHS. Besides using EPHI's advisors as an example datapoint for **RQ-OHS-1**, the material I discuss in this section is foundational to my system's design.

3.2.1 Methodology

I conducted three formative studies: a focus group with the center's advisors, shadowing of 6 advisor - client consultations at the center, and two focus groups with clients. By talking to both EPHI advisors and clients and observing them in action, I have developed a more nuanced understanding of the center than a single interview or tour could provide. The themes and details covered here are contrasted with existing research on OHS and patient-provider communication.

I report and discuss the results of each formative study one at a time. I then conclude the chapter with a discussion considering results from all three studies.

3.2.2 EPHI Advisor Focus Group

Six EPHI advisors participated in a focus group on the role online health resources play in their work. This group encompassed all but one of EPHI's advisors, who had just joined the center and not yet begun working with clients.

EPHI's advisors are heavy online health seekers. All of the advisors were regular health seekers, and all reported sending online resources to their clients. Advisors valued OHS as an up-to-date resource for their clients, as a motivational tool, and even said that online information can be "more reputable" than offline information. As with the typical health seeker described in the OHS literature, advisors frequently used general search tools like Google to find the information they share. However, advisors also seemed to rely more on key go-to sites, using general searches to locate these health aggregators for the first time. Go-to resources included technical sites like PubMed and the American College of Sports Medicine, news media like the New York Times and Dr. Oz's website, and less concretely defined "health blogs".

Advisor OHS also seems especially social. Clients drove most advisor OHS, with advisors looking for new pieces of information to answer client questions or to include in their between-consultation email follow-ups. Advisors were very interested in learning from each other and from clients, looking to apply information from one participant to others. In my other formative studies, I observed several instances of advisors acting as intermediaries to connect clients, helping one client indirectly guide another. Advisors had also created an ad-hoc sharing tool using a networked file system with simple public and private folders for each advisor. Not surprisingly, advisors found the existing system disorganized and prone to redundancy. Some advisors had attempted to standardize or order the system, with unsatisfactory results. Clearly the advisors see room for improvement, and an OHS system specifically aimed at advisor-advisor sharing could address these sore points.

EPHI advisors encourage client OHS by sharing their own health seeking, but do not categorically approve of all client OHS. While advisors estimate that only half of their clients share their OHS with them, they assume nearly every client is engaged in OHS. The assumption seems valid given the survey results discussed in my related work section, given that every participant in my client focus groups

reported performing OHS. Advisors also doubted that most clients 'knew where to look' during OHS, which is congruent with the simple search characteristics reported in OHS literature and in the client focus groups. Advisors described client OHS as interesting, tailored and alternative, an apparent good fit with a center emphasizing customized care. During consultation shadowing, I observed clients sharing OHS related to unorthodox treatments, while in focus groups clients valued OHS as a source of alternative viewpoints and second opinions. Advisors also described "ridiculous" client OHS, and the delicate process of guiding 'wayward' clients would come up in my other formative work. Advisors monitored client responses to test results, looking for confusion or misconceptions and in particular relied on client to ask questions. The results of my shadowing study particularly note the client-led nature of consultations.

3.2.3 Consultation Shadowing

I observed 6 private advisor-client consultations to gather information on this primary interaction point between clients and their advisors and Predictive Health as a whole. I shadowed 6 consultations with 4 different advisors (2 advisors were observed twice). In addition to observational notes, each shadowing concluded with separate, brief unstructured interviews for the advisor and the client. Unfortunately, the clients felt that audio or visual recording was likely to discourage participation (2 clients turned down shadowing even with no recording), so my analysis centers on my field notes (9059 words total).

An inductive analysis of my field notes was conducted with 3 independent coders (myself and two others). Each coder independently reviewed my field notes, generating and assigning pieces of text to hierarchical thematic codes [99]. We then collaboratively grouped, split and merged our 63 thematic codes until reaching the 6 highest level themes presented here. I refer to subjects using the shorthand such as 'C3' and 'A2', for client 3 and advisor 2 respectively.

Theme: Binder Roles

The binder of assessment results was a dominant presence in all 6 consultations. The binder serves as an agenda or guide for the consultation, governing the order results will be discussed in and suggesting when the consultation should shift to adjusting the health action plan. In all pairs, the binder sat open between the two actors, accessible to both. Four of the clients immediately began with the first set of results in the binder, while C's 3 and 4 had significant conversations before opening the binder. Only C3 flipped further into the binder, briefly discussing the cholesterol section in connection with his conversation before returning to the start. Aside from this brief jump, all pairs proceeded through test results in the binder's order. Though pairs can and do discuss other topics, tangents always eventually return to the binder. As expected, the binder and its test results also serve to motivate in-depth discussion. The Dexa bone density and body scans, which include stark images of the client's body, were particularly motivating for clients 1, 4 and 5.

As a physical and a digital artifact, the binder has several important roles aside from 'agenda'. Firstly, the binder can be incorrect, incomplete or out of date (3 pairs), and both advisors and clients may add notes (4 pairs). A4 in particular used the binder to draw diagrams explaining the meaning of a vascular stiffness test. Interestingly for an artifact that was once so central, the binder seems to be quickly discarded after the consultation. All clients described 'throwing their binder on the shelf' (C5 confessed that, as a paperless fan, he was likely to 'chuck' his), with C1 and C6 stating they might review the binder on occasion, to show the graphical Dexa scans to a friend or for motivation, respectively. C's 3-5 all mentioned an interest in sharing all or part of their binder with a physician, but had not done so in the past. C4 in particular stated:

> C4: *"I wish I could believe that any doctor would sit down and read this with me."*

Theme: EPHI Advisor Roles

EPHI Advisors carry out a variety of tasks, many of which are connected to their central responsibility to customize and adapt the consultation to the client. Advisors 1, 3 and 4 all marked up the binder, adding notes or diagrams for the client. While reviewing results, advisors solicited questions and 'sanity checks' of results from clients. Advisors guide and clarify client interpretation of the binder, stating whether test results were good or out of range. Advisors commonly address confusion due to the scaling of results (which fluctuate from test to test) or unclear comparator population of a test (pairs 1-4).

Advisors also take on the role of therapist. As therapists, EPHI Advisors strive to understand client motivations and pressures, to promote healthy thinking, and to validate client struggles. For example, C6 suffers from high blood pressure. Throughout the consultation, A4 gradually discovered C6's cognitive dissonance between diet (many favorite high sodium foods) and long standing health goals (cut sodium). By responding to C6's questions about what foods were highest in sodium and easiest to cut, A4 worked to create goals that could work for C6. In another example, C4 (who struggles with depression) found his body mass index (BMI) target daunting. A3 used the client's past weight loss and a standard BMI chart to persuade the client that not only was the goal healthy, it was realistic for him.

Connected to the role of therapist is the role of confidant. Advisors and clients build a relationship over time, establishing a rapport, trust, and understanding that helps advisors in their other roles. C3 in particular mentioned that the relationship he had developed with A3 made him more likely to pay attention to her email communications. At the consultation, the confidant role frequently involves listening to client storytelling that may or may not be connected to a test result or action plan goal. Some of these are light stories, such as the nearly retired C1's reminisces about past jobs, while others focus on shared experiences like bicycle racing that also appear

in the client's action plan (pair 6). Others are deeply personal: C4 discussed seeking a counselor specializing in LGBTQ issues to address his emotional health.

Finally, EPHI Advisors take on roles that explicitly reach outside the consultation. All 4 advisors took notes to guide their future interactions with the client. A1 noted that C1, whose father died with Alzheimer's, was concerned with his memory test results but reluctant to take action and monitor his memory or to discuss his anxiety. A1 planned to broach the topic again in the future. A4 mentioned that he also looks to apply insights from one client to his interactions with others. Advisors also refer clients to doctors (all but C2). In some cases, this is due to warning signs in a test result, such as in part of C6's blood work or C5's bone density. Frequently this was due to clients seeking a 'doctor's orders' style recommendation or detailed questions about a test result or meaning. C4 expressed some frustration with the limits of the advisors' medical knowledge, and recognized that he'd need a doctor to answer some of his questions. A4 noted a legal reason for this: since the EPHI Advisors are not licensed physicians, they cannot treat, prescribe or diagnose. Lastly, advisors are involved in info tracking and accountability for their clients. A1 felt that the clients who track their health data, such as weight measurements or calorie intake, were the most successful at achieving their goals. C2 and C3 both shared electronic tracking tools (MyNetDiary and TapAndTrack) they used as part of their action plan, while A3 recommended MyNetDiary to C4. C1 said he would begin keeping a log in case A1 wanted to see it, while C2 specifically asked A2 to hold her accountable: just by viewing this tracking information, advisors help keep clients mindful of their goals.

Theme: Client Roles

While the binder creates a general 'roadmap' of the consultation, clients tend to guide conversation depth. This role is readily apparent in how advisors and clients discuss test results. At all shadowed consultations, most in-range results were quickly passed over: the EPHI Advisor announces a positive or neutral test result and the client

acknowledges. C3 described consultations as *"semi-satisfying"*; because he didn't fully understand many of the tests, he was only interested in whether he was in or out of normal ranges, feeling further detail was not meaningful to him. Even C5, a medical doctor who was familiar with some of the tests, stated that he was primarily interested in values that were out of range or already known problems for him. Finally, in his post- consultation interview, A4 said:

A4: *"Really what's motivating for people is anything that's out of range."*

All of the clients seemed to have a similar focus on existing concerns, and looked to deepen discussion when reaching tests or sections connected to their concerns. In some cases, these existing concerns are known health issues. For example, C2 has a history of high cholesterol, and drove a deeper discussion on cholesterol and home remedies after reaching the cholesterol section, despite having an improved score. At other times, clients may simply be focusing on 'buzz worthy' or 'commonly known' markers. This seems to be the case with C3's focus on vitamin D, or for C4's interest in markers like body fat and cholesterol.

C3: *"they're' finding this is a marker for a lot of things."*

C4: *"[they are] standard things that people talk about."*

Like their EPHI Advisors, clients engage in several activities that connect the consultation with post-consultation life. Two clients took notes on items like action plan goals and questions for their doctor (C4), or out of range values *"I need to change"* (C2). Clients are also always responsible for selecting the goals and specific actions they carry out of the consultation in their action plan. While the advisor can provide context by listing previous goals or mentioning something the client said during the consultation, it is the client who has final say. C1 for instance initiated discussions about his memory test results, revealing a *"fear factor"* was present due to his father suffering from Alzheimer's. When A1 suggested creating some action

plan steps based around memory, C1 abruptly changed the subject, and conversation quickly moved to the next test result. In the post consultation interview, C1 described the advisor-client relationship as a *"balance"* in which *"the client finds the answer."* A4 similarly said:

> A4: *"they should be the ones setting those goals, because they're the ones that actually have to do it."*

Even when the advisor has a great deal of expertise on the goal in question, as when A4 and C5 discussed bike racing, clients take the lead. Finally, clients spend a great deal of time acting as storytellers; these stories usually involve life experiences outside the consultation.

Client Roles Sub-Theme: Storytelling

Storytelling plays an important role in the consultations, and it seems to serve a variety of purposes. As mentioned above, it is almost always the client who is the storyteller, while the advisor occasionally chimes in with a brief, similar experience. These stories build a personal connection between advisor and client. In all of these stories, long and short, on and off topic, the clients share personal details about their day-to-day life. Often stories begin from the consultation; such as C5 expanding his action plan goals into a detailed discussion of different races. Other stories are more off topic, such as C1's reminiscing about old jobs and home repairs. C3 expressed how important the *"personal relationship"* he had with A2 is to him, and mentioned it made him more inclined to review any information she sent him. EPHI Advisors also recognize the importance of this rapport. A2 mentioned that clients would sometimes switch advisors if they did not *"click"*. Also, a departing advisor helped guide her clients to other advisors with a good 'fit'. A4 said this was far more effective than cases where they had no such input (e.g. when a different advisor abruptly departed). More concretely, rapport-building stories provide context and personal knowledge that advisors use to recognize client concerns or goals.

Clients also tell stories seeking advice or validation. Two clients (C2 and C6) shared personal online research, both about alternative remedies for high cholesterol. Both sought validation of their choice. C6 mentioned in his interview having already viewed numerous pieces of information before selecting a remedy that was 'the least BS' and 'the most fact-based'. Meanwhile C2 repeated her search during the consultation, citing a reputable site and sharing an anecdote about her brother's positive experience with the remedy. Other times, validation and advice blur together. This was the case when C1 discussed his (perhaps unhealthy) weight goal, personal body image and conversations with his wife. C1 went back and forth with A1 to come up with a plan to lose weight in one area without reaching an unhealthily low overall weight. Sometimes validation seeking can lead to an impasse, and advisors will sometimes avoid addressing a client assertion they cannot validate. This was the case when A3 did not respond to C4's suggestion that the survey scores were 'subjective' and not useful. After discussing some of C6's misconceptions about his diet, A4 said in a post consultation interview:

> A4: *"people have preconceptions, and a lot of times, they're not looking for information, they're looking for affirmation."*

Theme: Questions Advisor to Client, Client to Advisor

During consultations, advisors ask clients several types of question, each with a distinct objective. Clarification questions may be the simplest form: advisors ask for greater detail to a client statement or for details on a test result, such as A3 asking C4 who he considered family for the purposes of a social wellness survey. All but one of the consultations began with a review of recent medical history with advisors asking whether clients had begun any new treatments; this can also be considered clarification. Prompting or rhetorical questions are also common. Advisors frequently asked clients if their results seemed accurate or if they had any questions. A1 described

these questions as a general tool to probe for a response from a quiet client, looking for 'anything to work with'. These questions also seem to serve as landmarks between different sections of the binder. Advisors also use prompting questions to help clients create their action plan, asking which goals they'd like to adjust or how they plan to achieve a specific goal.

Clients also use unique question types during the consultation. Clients commonly ask for advice, often related to an out-of-range test result or health goal. C1 asked how he could lose weight in a specific area, after he reached his weight goal but he was still unsatisfied with his appearance. C6, whose consultation focused on high blood pressure and a high sodium diet, described his diet and asked A4 what high-impact foods he could cut out. When a client wants an explicit directive, they will be referred to a doctor as A2 said after listing some dietary supplements for C2:

> A2: *"I can't suggest you take a supplement [you have to talk about it with your doctor]."*

Other questions are clarifying, asking for example what population the client's scores are compared with (C3), how a test works (C6), or how to interpret a score's scaling (C1 and C4). Finally, clients ask for medical details explaining why a score has shifted, or whether an out of range score is cause for concern. These questions frequently lead the EPHI Advisor to refer their client to a doctor; this was the case when C2 asked A2 whether some new medication could be impacting test results, and when C4 asked A3 for an analysis of how certain results (such as his diet survey) could be affecting others (such as his blood work).

Theme: Information Sharing

The consultation's most obvious purpose is information sharing, and EPHI Advisors share information in several ways. Advisors use the binder as a script to present test results to clients, prompting further interaction. When a client asks for advice on

adjusting a score or meeting a goal, advisors offer alternative solutions and information resources. For example, C2 asked what she could do about her high cholesterol, and A2 listed several different diets. As a second example, C1 said he had trouble meeting his cardiovascular exercise goals in part because he didn't share his wife's enthusiasm for jazzercise; A1 suggested yoga as a compromise. Advisors also share medical details, explaining how a test works (ex: A4 explaining the vascular stiffness test to C5 & C6) or why it might be important. Medical details are also shared as context to help a client evaluate their score. Finally, advisors share medical details as a means of encouraging healthy, realistic goal setting and beliefs, 'arguing' in a non-confrontational way. When C1 described his desire to drop his weight to what may have been an unhealthy level, A1 used BMI data to suggest C1 was already at a good weight. At the other end of the spectrum, A3 used BMI data and C4's past progress to encourage C4 to continue setting healthy weight goals. In the interview, A4 said that he would send alternative information resources, rather than directly disagreeing with a client's strongly held belief or goal.

I have already covered or mentioned much of the information shared by clients. This includes personal details and stories that build rapport with the EPHI Advisor, while also providing context to help the advisor understand the client's test results and concerns. Especially at the start of the consultation, clients share an updated medical history, listing things like new treatments or medications, which may impact test results. Clients also share their progress towards their health goals, which sets up pairs to update the client's action plan. Some clients (C2 and C3) use online tracking tools to monitor their progress, and these tools are often included in action plans (C1, C4). Finally, clients share wellness information and tools they have discovered. C1 recommended several spirituality books to A1, C2 & 3 showed off their tracking tools in-session, and C2 & 5 both discussed alternative treatments they found online. As mentioned in the storytelling theme, clients seem to share resources they have found

for validation as often as for advice.

Theme: Technology Use During and Between Consultations

Several technological systems were observed during consultations. Information visualizations, printed in the binder, had noticeable effects on the consultation. Clients were quick to notice outlier summary bars that were empty or low, and frequently struggled with the varying scaling between bars (C1, 3, 4). C1 and C4 even expressed feeling pressure to 'score near the top' when confronted with low bars. As previously mentioned, C1, 4 and 5 were especially interested in the Dexa scan's visualization, and A4 felt the visualization was motivating to many clients. It seems that aside from these static information visualizations, clients are responsible for in-consultation technology use. The primary examples are C2 and C3 demonstrating their food-tracking systems, C2 taking notes on her iPad, and C2 demonstrating her online search for cholesterol remedies. Finally, though most action plans were updated in a paper format, A3 and C4 used a computer to update the action plan. Interestingly, this same 'free' computer sat unused for the rest of that consultation, and for all other consultations.

Some advisor-client roles reach outside the consultation, and technology plays an especially key role between sessions. Firstly, at the conclusion of each consultation, advisors asked clients to select a 'follow-up frequency'. Advisors contact their clients via email at this frequency, and continue to play their various roles, such as helping a client stay accountable to their goals (A2-P2) or sharing information resources like dietary information (A4-C6). This communication can be two-way, as evidenced by C3 asking A2 if she read an article he had sent her. This communication highlights a second type of between-sessions technology use: online health seeking. C2, C6 and A4 all explicitly mentioned searching for online health and wellness information. Online self- tracking tools, which had a presence in half of the consultations (C2, 3, 4), are also used between sessions. Finally, we note that the few clients use the EPHI

electronic portal, which offers a PDF version of their binder. Half of the clients were unaware of this resource's existence (C1, 2, 6), and none used it. Given how quickly the physical binder is discarded, this may not be a surprise.

3.2.4 EPHI Client Focus Groups

I also conducted two focus groups with clients: a small group of 3 and a larger group of 11. The set of codes below are based on the results of the advisor focus group, consultation shadowing and a review of related work on OHS. Recordings of the focus groups were transcribed and deductively coded by myself and 2 other coders. Each coder individually assigned sections of transcript to the below codes until they felt they had exhausted all significant portions of the transcript. We then met to identify and harmonize discrepancies between coders. Results of all three groups were combined, allowing us to compare and contrast advisor and client OHS.

Coding results and quotes from the focus groups are covered below. Participants are coded as "C1 = Subject 1", and clients 1-3 were in the smaller group. The symbols "S=unknown subject" and "M=multiple subjects" are used when necessary, which was only in the larger group.

Code 1: *Confirmation*

Confirmation seeking or confirmation bias has effects across the OHS spectrum, from searching to sharing to acting on information. Previous studies have suggested confirmation bias may lead to selective searching [51, 105]. Validation seeking behavior was also seen during consultation shadowing, and Health Partners discussed different strategies for working with a confirmation-seeking participant.

Confirmation seeking and health beliefs came up in both focus groups, and were discussed at some length in the larger group. Several participants referred back to C12's statement:

> C12: *"Well your beliefs highly influence the news you're gonna read, and the way you're gonna assimilate your information as well. If it validates*

some of your beliefs then you're more likely... it's just human nature, you're more likely to take it as expert."

For example, C7 agreed with C12:

C7: *"I think it's partially what she [C12] said, uh, a lot of it goes.. I really believe in holistic health first, and then you go to the doctor, so, if there's a holistic.. a holistic um.. option, I take that first. I say oh you know, I'll try that first... unless it's something more serious or.. or whatever, I think it really goes to your beliefs."*

These quotes suggest that tightly held beliefs could highlight complimentary information and treatment options. However when C10 told an anecdote about researching the HPV vaccine, information that conflicted with C10's beliefs (that the HPV vaccine was mainly for children) led to more research, not less:

C10: *"My daughter is 10, and almost 11, so we're thinking, HPV vaccine, should I, shouldn't I, the controversy... and I did a little research on it and it said of course you should... but even adult women should have the HPV vaccine. And I said, 'hmm, that doesn't make sense'. Well, when I looked deeper into that study it was sponsored by, um, the pharmaceutical manufacturer."*

Similarly, it seems participant beliefs can encourage acceptance of confirmatory physician guidance, or perhaps dissent if there is a mismatch. While C7 was motivated to share information that matched her doctor's opinion, C8 described using his research to prod his doctor's diagnosis:

C7: *"...if I'm coming in and seeing the doc and he's saying... you know I think we oughta hold off on starting this, and let's just see how this goes... If I've read online that yeah, there's these side-effects of... of starting... a new drug, and I'm a little bit reticent to start a new drug anyway, and if he says.. uh, let's hold off on it... I'm going 'yeah, I read online that'.. yeah, I don't wanna lose my hair..."*

C8: *"...if I'm taking the trouble to go to a doctor because I think x y and z, I've probably already looked up x, y and z, but I wouldn't tell them that, initially.. I would just say, "hey, I've got whatever this is.. what do you think it is?". Now, depending on what their answer back to me is, that would be the time I would say.. 'well, are you sure?' You know, could it be this, this or that? You know, because I have.. done some independent research."*

Finally, the smaller group described the large impact their beliefs have on their health decisions. As the group lamented the high variability in current 'health best practices', C2 gave her approach to female hormone supplements:

> C2: *"I just keep takin' em until it changes back in my direction."*

Similarly, C1 felt disconfirming advice from her doctor has a limited impact:

> C1: *"Well, I can get her opinion, but I'm gonna do what I want anyway."*

Code 2: *Supplement*

Clients view OHS and medical professionals (including EPHI Advisors) as supplementary and complimentary to each other. Related work has found that patients consider medical professionals the 'ideal' information source, despite turning to online sources with more frequency [43, 33]. This conversation snippet from C5, C6 and an unknown subject seems to illustrate this perfectly:

> C5: *"I would think that the other [offline] sources are probably more trusted.."*
> S: *"mm-hmm."*
> C5: *"or we feel like they're more trusted."*
> C6: *".. time consuming, but more trusted."*

For many clients (6 or more), OHS is a means of preparing for or following up on a consultation with a medical professional. This included reviewing new subscriptions and diagnoses from a doctor. It also included a degree of self-diagnosis, a subject of some trepidation for medical professionals [3, 72].

> C1: *" Just a better understanding.. of.. like, a new prescription, um, the symptoms... and... when I go to my doctor, I can ask, you know, be a little more informed, dialogue a little better"*

> C4: *"I look up stuff to see if maybe I need to call.. should I call a doctor."*
> S: *"Yeah I would say.. preliminary."*
> M: *"mm-hmm."*
> C5: *"Help with familiarity."*

Online resources were also widely valued as a source of alternative views and treatments (5 or more clients). C8 held up health professionals as a counterexample, an information source offering fewer viewpoints.

> C7: *"You do get different perspectives, I.. you know, I look up one thing and I end up with holistic health options, and.... you know, different specialist options..."*
>
> ---
>
> C8: *"[OHS is] options, it's um..... you know, in other words, that, they may have a cancer... you have an option of surgery, you know, you have an option of radiation, you have all these options of... it's a very good way to explore it. You go to a doctor and he's a specialist in... the radiation specialist, he's gonna suggest radiation..."* S: *"mm-hmm."* C8: *"... for prostate cancer or something. Another doctor may be up on the latest robotic surgery or something."*
>
> ---
>
> C8: *"I think it's important to uh, if you go to your doctor and they're suggesting surgery, that they're also suggesting other things that maybe you can do, before that becomes your last resort, hopefully, you know, your last resort... I don't like when doctors say.. ok well this.. that's it, that's all you can do.."*

Finally, the issue of scaling and contextualizing personal scores or symptoms, a common feature of my consultation shadowing, also appeared in the smaller focus group. C1 has looked to her doctor to help contextualize her OHS:

> C1: *"I mean I'll listen... you know. Sometimes you wonder, you're looking into stuff deeper than what it really is, and I just, my biggest thing is, 'normal'. What is considered normal on our scale from 1-10? To me, normal is like 5.. 4,5,6, that's in the middle. If I'm a normal.. '2', well I'm really on the low end, so how do I get to the normal in the middle? and it's stuff that I throw at her."*

Code 3: *Social*

Many social pressures directly and indirectly influence OHS. Nearly all participants (10) cited some type of social influence. Surveys suggest that a significant portion or even a majority of OHS is done on behalf of others (Fox 2011, Fox & Jones 2009).

Participants described numerous searches that were socially inspired. Family members figure prominently here, and even when participants are not actively searching on behalf of a relative, they seem to be on the lookout.

> C10: *"I look up parks, and uh.. I have 2 little kids... [unintelligible], and we're always looking for... walking trails."*
>
> ---
>
> C6: *"My dad is on blood thinners, so if I see something related to blood thinners or ¡drug name¿ or whatever, then I tend to.. forward those stories to him, just for his essay."*

Family members can also motivate self-interested OHS. C11's family history is a key motivator for her on and offline health seeking.

> C11: *"I think it's intensely personal, to be honest, and at the end of the day, you know.. there's a mammogram, no mammogram blah blah blah... well, I have a family history, I mean 3 aunts.."*

Clients also share their OHS with broader group of friends and people having similar health experiences. A 2011 Pew Poll emphasized the increasing rate at which people view online commentary (34% of Internet users), but found that few post their own information or questions (6%) [33]. Caretakers and those with chronic disease were more likely to view this information and to post their own. In some respects, the focus groups mirrored these findings closely. Only two clients mentioned participating in this type of sharing, and one of them (C2) suffers from a chronic disease. However, among all groups, only C2 mentioned using message boards or forums as an information source.

> C12: *"You know it'd be nice to be able to, you know, share that with people... it's like this could be good for you, it's been good for me, and... but it's all very subjective, but you know, it might help me share with people.*
>
> ---
>
> C2: *that's about it... actually, I share with a support group for juvenile diabetes, too. If I find articles that I feel are particularly important for Type 1.*

Interestingly, only two clients mentioned being asked to "check on" something by a friend or family member. These were C3 (a retired MD) and C5 (whose job involves creating health information releases), participants who are public authorities on health information. For the focus group participants, it seems the majority of socially motivated OHS, and of OHS sharing, is done at the initiative of the searcher/sharer.

Code 4: *Burst*

As mentioned previously, work by White & Horvitz suggested that some types of OHS proceeds in a 'bursty' fashion [106]. White & Horvitz logged queries related to medical symptoms from thousands of subjects, and found the large majority of queries related to any one symptom took place within two weeks. Participant responses suggest that their overall focus on their health, as well as on online health seeking, can wax and wane. A variety of motivators were observed.

Personal health revelations, particularly the EPHI consultation and action plan, seem to provide potent motivation for participants to act on their health through online searching or otherwise. C11 and C2 described the impact of their last consultations:

> C11: *"I lost a lot of weight, but I was surprised, I also lost a lot of lean muscle mass, so... that was um... that actually... spurred me to look at ways I could stop that."*
>
> ---
>
> C2: *"I felt very determined after my last visit."*
> R: *"Determined to... follow up with your action plan, or to... make an adjustment?"*
> C2: *"To make that picture [referring to dexa scans] look a little different, six months from now. That was horrifying. Wasn't that the worst?"*
> C1: *"yeah."*

In spite of this motivation, participants did not necessarily maintain their focus. Both C1 and C6 expressed difficulties keeping up with their goal of using a tracker, with C6 dropping back to a higher-level tracking approach after the first became a

"part-time job". C2 and C3 both felt a drop-off after an initial period of focus after their consultation.

> C2: *"I thought about it every day, I behaved appropriately for that week."*
> M: *[laughter]*
> C2: *"I did. I only had one glass of wine every night, I was so good."*
>
> ---
>
> C3: *"Oh it stays forefront for a short period of time, but like new year's resolutions, they fade. But they're always there, you know, recommendations.. and periodically you say.. I know I'm not doing everything I should, I should do this... but then something will come up and it'll slip by."*

Events aside from consultations motivated clients to search or focus on their health. Multiple clients agreed with C1, who said she would occasionally search online after hearing an interesting story on NPR. Other clients habitually review health news on sites like MSN (S8), the New York Times (S7) or a diabetes support site (S2). Even these apparently consistent health-seekers seem to have varying levels of interest in their results. C2 for example checks a diabetes lifestyle website "religiously", but tends to remember only key bits of information. It may be that even among participants who do OHS on a regular basis, the impact of search results is irregular.

Social factors can also be a 'bursty' motivation OHS activity, such as C6 noticing and sharing information on blood thinners with his father, or C3 and C5 fielding information requests from others. C1 shared another type of social motivation:

> C1: *"I know this is gonna sound terrible, but when I have to come from.. I'm on the opposite side of, across the way, through the lobby ¡S1 works at the same hospital EPHI is located in¿, and I see people... just.. you know, oxygen tanks.."*
> R: *"you don't want to end up like that?"*
> C1: *"mm-hmm"*
> C2: *"yeah. It is, it's scary."*

Other participants, including C1, C2, C6 and C11, found value in reminders or motivators that re-focused them. EPHI advisors in particular were cited as a resource

to keep participants 'on task'. This is complimentary to the "info tracking and accountability" advisor role seen during my consultation shadowing.

Code 5: *Simple Search and Evaluation Strategies*

In the Related Work section, I covered numerous studies that together suggest the average online health seeker takes a relatively simple approach to finding and evaluating information. This was largely borne out in my focus groups, often when clients described using the same strategies detailed in related work.

Numerous studies noted general search engines as a predominant resource [31, 79, 90, 89, 100]. This was the case in my groups, with all of the smaller group and much of the larger listing Google as their go-to resource. Toms *et al.* went so far as to start all study participants at Google [100]. Peterson *et al.* on the other hand noted that while Google dominates, participants do use other resources. In my groups, Mayo clinic drew a loud response in the larger session, while a few clients mentioned browsing the health sections of news sites (NPR: C4, New York Times: C7, MSN-Health: C8) [79]. Toms *et al.* and Eysenbach *et al.* also emphasized that searchers used short, simple queries [100, 31]. This quote from the smaller group suggests that some clients are aware of the difficulties their simple queries can create:

> C3: *"You'd be surprised what you can find if you just type in 'cramps"'*
> M: *[laughter]*
> C2: *"Leg cramps, too."*
> C3: *"you'll get a host of information... a host of different sites to check out."*

Related work also covered the importance participants place on information sources and site design. In multiple studies by other researchers, participants cited authorship as a key to evaluating pieces information [31, 79, 100]. EPHI clients in agreed, for example C4:

> C4: *"I look at the credentials of the authors.. pay more attention to an*

MD."

The same studies also noted that health seekers tended to place trust in certain reputable sites or sources. This fits with clients citing sources like Mayo Clinic as choices in my focus groups. Consider the following conversation in the larger group:

> C7: *"I was thinking that too.. I can go to the... trust the government one, or ones that have an edu at the end, and I lend a little more... credibility to those than, just.."*
> C6: *"Or the Mayo clinic, like you'll..."*
> C7: *"Yeah or Mayo clinic"*
> C6: *"There's some that we just, I think everybody uses, or has some... basic trust in."*
> C12: *"Yeah you expect that they've done their due diligence, and that you don't have to, for certain..."*
> C6: *"Right."*

Peterson et al. noted that participants don't always agree on ideal information sources, for example pharmaceutical companies. C2, C3 and C7 exemplify this:

> C7: *" ...Well, when I looked deeper into that study it was sponsored by, um, the pharmaceutical manufacturer..."*
> S: *"Heyyyy!"*
> M: *[laughter]*
> C7: *"So... you know, you do have to be very careful and dig deeper... sometimes."*
>
> ---
>
> C2: *"Yes. I recently had that come up, and uh, with a drug that's fairly new, so I just went to the manufacturer's site to check side-effects... of course, they're selling the drug aren't they, the manufacturer?"*
> M: *[laughter]*
> C3: *"If it's from the manufacturer, it's got FDA... they.. they have to review anything that they put out. but if it's not a FDA drug, uh, then..."*
> R: *"Like coconut oil?"*
> C3: *"They can say whatever they want to."*

Researchers have observed site design and content, particularly advertising, can quickly lead to rejection [100, 89]. Two clients in the large focus group illustrated this behavior.

C4: *"The more advertising I see, the less... webMD has gotten so much advertising lately, I sort of just.. S: I was just thinking that..*
C4: *"You know you ask about stomach and then you get 97 antacids..."*
M: *[laughter]*
C4: *"But seriously. I mean and it may be nevertheless correct, but I would like do my own research on it..."*

Interestingly, in the small group C2 seemed to take an opposite approach, reporting that seeing advertisements from 'reputable' companies increased her trust of a given resource.

Finally, the simple search and evaluation strategies described above can be contrasted with those of the EPHI advisors. After clients in the large group discussed where they tended to search, the advisor in attendance offered up his means of searching as a model. The advisor emphasized not only checking author credentials and starting from reputable sites, but a detailed analysis of the study. This included gauging the degree of study claims, methods, number of subjects, and cited works. Further, the advisor suggested viewing each study as a 'grain on a scale', with many studies required to push the scale up or down. Some health seekers do employ a simpler version of this 'scale', noting (if not aggressively seeking) agreement between multiple sources (Toms Latter 2007).

C4: *"Sometimes it's reassuring when WebMD says the same thing as the Mayo clinic.*
R: *"Agreement between sources?"*
C7: *"Or even agreement between... your healthcare provider, or your healthcare professional and..*
C4: *"yeah"*
C7: *"... some other sources that you find... that's reassuring, that's... comforting."*

Code 6: *Trouble Connecting with Doctors*

Related work has shown that patients and their doctors find discussing OHS a challenge, and many of the difficulties cited in previous studies were apparent here. In particular, clients mentioned the touchy issue of challenging or appearing to challenge

a doctor's expertise. C13 had the odd (and somewhat alarming) cause to correct her doctor, showing that even direct challenges can be justified.

> C2: *"They [doctors] feel like... they've been in school, they have the knowledge, and... you shouldn't question them. But, in our day and time now... I just feel like, you need to take your health in your own hands. They do have the schooling and stuff, but it is really ultimately up to you to take care of yourself. You know."*
>
> ———
>
> C13: *"I had an experience that I.. uh my doctor.. [unintelligible].. she prescribed a medication, and I had read about another medication, something that I was taking, and I said..'well won't that interact with this?' and she said, 'well oh yeah! well, I can't give you that!', so..."*
> M: *[laughter]*
> C6: *"Oh yeah?"*
> C8: *"Did you charge her?"*
> M: *[laughter]*

Clients also found it difficult to reach their doctors, or to effectively share or discuss the sheer quantity of information they cover. C6 noted that his doctor would ask him to come in to get a question answered; this may have been related to compensation. These barriers to connecting with physicians through OHS —lack of time and financial disincentives —match with other studies mentioned in my related work chapter. C6 would later say:

> C6: *"I've got a wall with my physician."*

C1 and C2 both had physicians appear reluctant to expend their energy discussing OHS. C3 (a retired MD), responded by echoing workload concerns, as well as the common physician concern that patients will worry over or utilize inappropriate information. These difficulties are reminiscent of clients mentioning how challenging they found it to share their binder with a physician during my consultation shadowing.

> C6: *"I can't call my doctor and sort of.. you know, they're not gonna call me back all the time just with sort of a simple question, like should I be taking this vitamin or not?"*
> S: *"yeah"*

C6: *"they're gonna make me come in"*

C3: *"well... being reasonable, many doctors don't like this because it, uh... they have to spend so much extra time convincing you... "*
M: *[laughter]*
C3: *"that it's not appropriate."*
C2: *"That's very very true."*

C10, C6 and C12 all found that their younger doctors were more receptive to OHS and even expect their patients to participate in OHS. In Masters' literature review, 15 studies found a correlation between youth and Internet use by physicians [61]. Ahmad *et al.* found older doctors more resistant to using the Internet and learning computer skills, as well as to OHS in particular [3].

C6: *"I think younger doctors probably expect you.."*
C10: *"oh, yeah."*
C6: *"... that their patients are doing their homework, and uh.. that old school docs are probably like, 'how dare you.' "*

Code 7: *Ease of Connecting with EPHI Advisors*

While clients had varying degrees of success sharing OHS with their physicians, they found it easy to connect with their EPHI advisors. Every client but C3 reported sharing OHS with their advisor. Relationship building figured prominently during the consultations I shadowed, and this seems to have paid off, especially with respect to OHS. C2, C8, C6 and C12 used their difficulty connecting with doctors as a direct contrast to their bond with their advisor. For example, C2:

C2: *"I sense that my primary care doctor hates it when I go online. I think he absolutely hates it."*
M: *[laughter]*
C2: *"And I don't sense that with [my advisor] at all."*

Other consultation themes came up during focus groups as well. Multiple clients said their advisors referred them to online resources. Tracking and accountability also reappeared: C6 uses an online tracking tool, and relies on his partner to review his

progress and encourage him to continue. Finally, during the previous studies, advisors explained how the information shared by one client could benefit others. During the larger focus group, the facilitating advisor gave a concrete example:

> H: *"Yeah we definitely welcome the art... like I've sent articles that.. [C9's name], you've sent me, to other people.."*
> C9: *"Oh, really?"*
> H: *"Yeah."*
> C9: *"Oh, cool!"*
> H: *"Like the Dr. Oz sugar stuff. So that's very welcome."*

Finally, clients illustrated how their advisors had helped them overcome some of the difficulties they have with OHS. During the consultation shadowing, two clients discussed their OHS, looking for input or validation. C8 asked his advisor for help earlier in the OHS process. Notably, the same client seemed to self-diagnose, and to come to doctor's appointments with very set opinions.

> C8: *"I don't care if it's a nurse.. an extended care provider, any of those. I don't care. Just.. give me what I want, let me go."*

> C8: *"I had a different situation, I had read some research, and I couldn't quite figure out, with all the stuff there, what was sort of... the trusted, or not. So I.. [laughs] passed that assignment on to [EPHI advisor's name]. So it was a little bit interaction there, that I needed some help, to sort of.. after you look at the website and see 100 of these things and can't really figure out.. what's what. Now, if I had known maybe about.. PubMed or those type of things [that were discussed earlier at this focus group], I might have been able to look at those. And, at least come up with a... some information that I felt comfortable with."*

Miscellaneous Of course, not every piece of text fit perfectly into one of the 7 codes. Much of the un-coded text fell into two categories, the first of which being client difficulties with OHS. 'Information overload' has been covered in related OHS literature, and participants in both groups grapple with this:

> C2: *"Sometimes it's too much information..."*
> C1: *"Yes."*
> C2: *"It's hard to sift through and.. and, mmm..."*

C3: *"Sometimes you get two different.. answers."*
C2: *"mm."*

C6: *"Overwhelming."*
M: [broad agreement]
S: *"That's the word."*
S: *"Yeah."*

Clients have trouble contextualizing studies and deciding if they are 'correct' for them. This matches with physician concerns about OHS reported in related work, and also with the EPHI advisor focus group, in which advisors expressed concern with 'ridiculous' client OHS. Clients in both focus groups found it particularly difficult to assess seemingly contradictory studies, especially when best practices seem to fluctuate. Advisors, perhaps thanks to the 'scale' approach mentioned by the facilitating advisor, did not mention similar problems in their focus group.

C1: *"Yeah, you don't know what to believe, what's good at this point down the road is not good."*
C2: *"mm-hmm."*

C10: *"In online you don't know the audience.. they may have been speaking to a trainer, you don't know.."*
C12: *"But it looked like for normal people."*
C10: *"Yeah."*
C12: *"It wasn't real clear at that point.."*

C6: *"Half the time they're telling you that there's been some study that contradicts.."*
M: *[agreement]* C6: *".. what you've been told in the past, like it's ok to eat chocolate..."*
M: *[agreement]*

The second un-coded category is 'inter-client sharing'. In both of the preceding research activities, Advisors explained how they look to re-use information between clients. Information from one client could help another, even if it wasn't of use to the originator. In both of this study's focus groups, I observed concrete examples of clients sharing and benefiting from one another. There is clearly value in client collaboration.

C2: *"I think it would be helpful if there were an online... shared log. [...] And know that someone else is gonna look at that."*
C1: *"Well you know I did do that."*
C2: *"Did you?"*
C1: *"Yeah. Livestrong.com, I was doing..."*

C8: *"Is there a website where you can look up drug interactions?"*
S: *"mm-hmm."*
S: *"mm-hmm!"*
C4: *"Actually, most of the... drug stores.. have pretty good stuff."*
S: *"Yeah, yeah."*

3.3 Discussion: Advisors, Clients and OHS

Besides leading to design guidelines, the results from my formative studies address **RQ-OHS-1**. RQ-OHS-1 asks what role OHS plays for non-traditional healthcare facilitators. EPHI's advisors are just one example of facilitator, and my work with EPHI's advisors and clients is a first step towards answering this question.

For advisors, OHS formed an essential part of their work. Advisors found and shared online resources as a way of checking in with and motivating clients. Online resources were also a tool for nudging clients towards what the advisor viewed as credible or worthwhile information. Especially in response to dubious client beliefs (or resources), advisors would share their own OHS as a low-touch way of pushing back. Advisors felt online resources from clients were very personalized; a valuable insight into the client's thinking regardless of the resource's credibility. Finally, advisors used OHS to share expertise and useful information amongst themselves, but felt they had trouble doing so efficiently.

EPHI's clients seem like typical health seekers in many ways. For example they prefer general search engines, tend to use simple search strategies and their motivation comes and goes. These similarities are encouraging signs for the generalizability of my work at EPHI to other health facilitation settings. Notably, clients felt their EPHI advisors were easier to connect to than their physicians, with some even making

explicit contrasts between their 'accessible advisors' and 'difficult doctors'. Clients also mentioned that their advisors seemed encouraging of and interested in the clients' OHS, again in contrast to some doctors. Despite this connection, only a small part of client OHS was shared with advisors.

OHS's place at EPHI could provide a glimpse into the future of health care. OHS is currently on the periphery of care, an almost universal activity that is only lightly addressed. At EPHI, online resources have become an important tool for health professionals. However, EPHI's model for OHS is unlikely to translate perfectly to the core patient-physician relationship. EPHI advisors' entire duty is to understand and council their clients. The advisors have the time (and job description) to follow up with their clients, and to collect and share OHS, that doctors simply don't have. This increased familiarity, perhaps even their explicit non-physician-ness, is what makes EPHI advisors seem accessible to their clients.

Health care facilitators, like EPHI advisors, seem like an excellent focal point for an OHS intervention. OHS exists in an intermediary zone between health professionals and everyday life as patients reach directly for health information. EPHI's advisors exist in this same intermediary zone: they ideally become friends to their clients, but still have access to and expertise on a wealth of health data and resources. Whether a nurse, a wellness coach or a transplant coordinator, other health facilitators also serve as intermediaries between the health world and the patient's every day life. If other care facilitators also share the characteristics that make EPHI advisors such a fit with OHS —familiarity with clients, accessibility, placement between the professional and personal spheres —they could prove a similar good fit with OHS. More work is needed to evaluate the current state of OHS in other health facilitator-client relationships. Still, my formative work suggests that care facilitators could be the perfect avenue to bring health seekers out of the periphery.

3.4 Discussion: OHS and Motivation

The environment at EPHI also seems primed to motivate OHS. As previously mentioned, other researchers have found OHS to be 'bursty' [106], and in my formative studies client motivation was a recurring theme. Aside from known search motivators like family and friends, EPHI's assessments were widely acknowledged as an inspiration to focus on health. Still, clients struggle with maintaining a constant awareness and drive for health.

EPHI's advisors are the center's key advantage as an OHS intervention site. There an obvious motivational benefit to the regular, extensive health assessments, but advisors could hold even more potential. Like any health seeker, EPHI's clients each have personal, often extremely private reasons for doing OHS. At their best, EPHI's advisors were close partners for their clients who can appreciate when a why a client is health-focused. An intervention may be able to help advisors nurture and leverage these close connections to suggest or share targeted resources that are more motivating to clients. It is unlikely that any intervention could succeed in making OHS a constant activity for most clients. However, between its assessments and advisors EPHI seems to present a strong environment for OHS motivation.

CHAPTER IV

SNACK: A TOOL FOR SOCIAL OHS

4.1 Design Guidelines

In this section, I present design guidelines for an OHS tool at EPHI. These guidelines represent a synthesis of all my formative studies at EPHI with the extensive research literature on OHS. In many cases (for example, OHS's sporadic or 'bursty' nature), my own studies echo the work of other researchers. In other cases (for example, the client-led nature of EPHI interactions), my guidelines are based on new findings that may be context-specific to a degree.

Many of these guidelines are likely to be generalizable to OHS in other contexts. Other patient-centered clinics with health advisor-like roles, or perhaps clinics seeking to become more patient-centered, are particularly good candidates. However, these guidelines should not be naively applied to all future health seeking tools. As I explained when introducing the concept of ESS, the socio-environmental context of a search tool can have large effects on tool use or what kind of design makes sense. In Chapter 5, I go into much greater detail on this subject by analyzing the deployment of an OHS tool based on my guidelines. In the current chapter, I will simply caution other researchers to carefully reassess these guidelines when applying them in a new environment.

4.1.1 OHS is Sporadic, Personal and Broad

My own formative work (and studies by other researchers [106]) has found OHS to be an inconstant phenomenon. While I found that EPHI's advisors frequently retrieved online health resources, typical health seekers (like EPHI's clients) tend to search in fits and starts. Clients were often motivated to search for personal reasons, like a

health event for themselves or a family member. Clients and advisors both favored major search engines to gather a variety of results.

Designs should plan on periodic, perhaps unplanned use. An always-present tool could reside in the periphery during web browsing, ready for action if and when OHS activity begins. Small nudges to carry out OHS —or to highlight the tool when OHS is detected —may be useful. Tools should also recognize that not all resources will be universally appealing, and strive to help users explore based on their own unique interests. Relatedly, OHS systems should work with standard web search engines, and avoid restricting searchers to a particular site or set of resources. Health-centric sites abound, but advisors and clients both still expressed a predilection for generic search. It seems more promising to augment rather than replace these searches.

4.1.2 The Complexity of OHS Sharing

Together, prior related work and my own formative studies paint a complex picture of OHS sharing. Polls have found that significant portions of OHS are not shared with health professionals [23, 76, 96, 97, 40], while other studies report that discussing OHS can have significant positive and negative effects [76, 40, 106, 15, 40, 42]. At EPHI shared OHS seems to represent only a small proportion of total OHS. While it seems nearly all clients engage in OHS, a large portion does not share the results with their EPHI advisor. Even clients who do share give an incomplete picture of their searching; for example C6 from a shadowed consultation sharing only the alternative remedy he felt was 'least like BS'. Clients also share bits of their OHS with a wide audience including friends, family, their EPHI advisors and their doctors. Clients frequently share when looking for explicit judgments on test results or information. Advisors respond to this challenge by sharing alternative resources and referring clients to doctors, but clients expressed difficulties connecting with physicians. Partners also share amongst themselves, but find the process disorganized and prone to redundancy.

Despite the incomplete and challenging nature of sharing, advisors find it useful to share information between clients, and I directly observed clients benefiting from sharing OHS with one another during focus groups.

OHS is simply too complex, idiosyncratic and infrequent for clients to directly collaborate on all searches. Advisors also lack the bandwidth to supervise all client OHS. While it may be a health professional's first instinct to closely monitor or regulate OHS in a system that links them to patients, designs should embrace partial sharing as a way of preserving privacy and allowing the actors to tailor sharing to their personal needs. Therefore, the existing state of partial sharing between advisors and clients at EPHI should be fundamentally supported by my tools, not discouraged. Partial sharing allows for privacy and avoids creating an overwhelming flood of resources. There is also an opportunity to place control with clients by placing them in charge of sharing their own resources.

4.1.3 Communication Channels

At EPHI advisors and clients have two principle communication channels: consultations and email. During consultations, the assessment binder takes a central role as a conversation guide. Follow-up emails frequently refer back to the consultation, as advisors were observed noting test results or action plan goals to reference in future communication. Thus in both of these channels, some piece of the assessment is used to ground communication. Advisors have stated and demonstrated their desire for more communication within these channels, and even look to create new channels by suggesting resources like tracking systems to clients. All of these channels are high effort, requiring an actor to initiate contact.

OHS search tools could be designed to operate within these existing communication channels. Sharing could be email-based, relying on that existing channel. The consultation in particular presents an obvious opportunity for active, synchronous

interaction and as already mentioned could serve as source information for searches. Tools could also use the binder as a means of inserting themselves into advisor-client interaction. During the small client focus group, one client (C3) mentioned not discussing OHS with his advisor because 'it never came up'. An OHS section in the binder would almost certainly change this. Existing communication channels could also serve as 'versioning' tools to organize searches, with each new follow-up email or consultation/binder receiving individual attention.

On the other hand, search tools could also emphasize creating new communication channels. Any sort of in-tool communication, such as messaging or creating persistent access to some shared item, would represent a new channel. Advisors are eager to gain more information and contact from clients, and would likely welcome this approach. Meanwhile, C6 during shadowing and C2 in the small focus group both increased their follow-up contact frequency, while others praised the utility and back-and-forth nature of their follow-ups. Of course not all clients adjusted their follow-up frequency (though none in my formative work decreased it), and advisors mentioned that some clients never respond to follow-ups. This variation suggests that while some clients would be interested in new channels and more communication, others may reject a tool that emphasizes communication outside of email or the consultation.

4.1.4 Client-Led Interactions

EPHI is committed to a patient-centered model, and advisors try to keep clients in the lead. Advisors let clients guide conversation depth during consultations and clients set their action plan's goals. Though advisors were eager for more client communication, follow-ups had a client-set frequency. Finally, rather than directly contradicting clients, advisors relied on sharing alternative information or referring participants to other medical professionals, even if it meant facing repeated questions from their client. While advisors cited legal reasons for not making explicit recommendations,

there may also be practical reasons for the light touch. In both focus groups and during consultations, clients exhibited strongly held health beliefs. Some participants said they would even seek out a new doctor if the mismatch between beliefs and information was too strong, or the conflicting recommendation too absolute.

Designs for OHS at EPHI must emphasize client leadership, keeping them in charge of their own health and reinforcing EPHI's participatory culture. Tools should be designed with client-led interactions, requiring clients to start the interaction or encouraging them to take the initiative. Whenever choices affecting clients are to be made (whether to share a client's search result, when to search, where to search), clients should be make the choice. Any advisor-initiated contact or activities must be carefully considered. Finally, designs should anticipate repeated and rephrased questions from clients, and look to avoid redundant information or work.

4.1.5 Client Motivation

Advisors feel motivated participants are more likely to make healthy changes, follow their health action plans and engage in OHS. However advisors and the clients both recognized that health motivation comes and goes, which likely contributes to the periodic nature of OHS. The EPHI assessment, especially alarming or fluctuating test values, seems to be very compelling. Clients also discussed social connections that inspire OHS, occasionally via direct requests but more often a friend or relative's condition or interests will spark participants to make note of and share information.

Systems could leverage these motivational factors to encourage and to organize OHS. Out of range test results and action plan goals seem very promising. These could be included in a client's tool as a sort of 'search seed', or in as a reminder and guide for advisors planning a follow-up. Partners could also work with clients to enter these, or even directly help with the first few searches during an assessment. Social motivations could also be incorporated by making it easy for clients to share

results to users outside the tool, or allowing friends and family to join in. Designs could also examine connecting clients with similar information needs or health and life experiences, fostering friendships (and thus social OHS motivation) between clients.

4.1.6 Grouping Opportunities

Finally, my work suggests that there are many opportunities to empower health seekers by grouping them together. The most obvious of these at the EPHI is the advisor-client dyad, which is at the core of all Center activities and which is already connected to OHS. However, the EPHI has many natural groupings of health seekers beyond the advisor-client dyad. In our interviews, some clients expressed interest in connecting with others who shared their goals or interests, and we saw clients spontaneously sharing online resources during focus groups. Clients with similar interests or needs could be matched based on their assessment results or action plan goals, or clients could be connected by their intermediary advisors (for example, if they shared an advisor). Advisors have already created a simple OHS sharing system. New designs could improve on this system by better linking advisors to limit redundancy as they search to answer client questions.

Most of these groupings seem generalizable to any clinic a sufficiently specialized clinic may already be an ideal group without any further divisions. Other social search researchers have suggested grouping searchers by interest [74] even without EPHI's detailed health testing, search histories or even simple questioning could be used to connect health seekers.

4.2 Snack: A Tool for OHS at EPHI

Based on the preceding guidelines I designed Snack, a system for collaborative OHS at EPHI. Besides being simple to refer to, the name 'Snack' derives from OHS's periodic nature and the small, 'snack-sized' resources the system allows users to annotate. Snack's design was refined with iterative feedback from EPHI advisors, as well as a

design workshop where round-robin brainstorming was employed to generate ideas. Snack is intended as a first prototype, and doesn't incorporate every guideline or proposal. These designs were tested in a field deployment at EPHI —I discuss the deployment and its results in later chapters. There are actually two designs for Snack: a basic version and an enhanced version with several added features.

4.2.1 Basic System Design

There are two main components to Snack's basic system; a web app and a browser extension. The web app is visited via a browser like any other web page, the browser extension must be installed on a per-browser, per-machine basis. I used Drupal, a popular open-source Content Management System, to create the web app [1]. The javascript visualization library D3.js was also employed [2]. I used Crossrider[3], a tool for developing cross-platform browser extensions, to develop a browser extension for desktop versions of the Google Chrome, Mozilla Firefox and Internet Explorer browsers. Two Masters students, Sahithya Baskaran and Megha Sandesh, assisted with creating some parts of the web app including the visualizations and site theme.

4.2.1.1 Web App

The web app offers a searchable collection of health resources curated and annotated by the advisors (see Figure 1). A health resource consists of a link, categorizing tags (e.g. 'yoga', 'Atlanta', 'blood pressure' or 'weight management'), and notes from the EPHI advisor. By enforcing this kind of metadata, Snack attempts to address the redundancy issues mentioned by advisors, and to help clients and advisors both discover particularly relevant resources. Users can search resources by tags or by entering a query, or browse using two simple visualizations (see Figure 2).

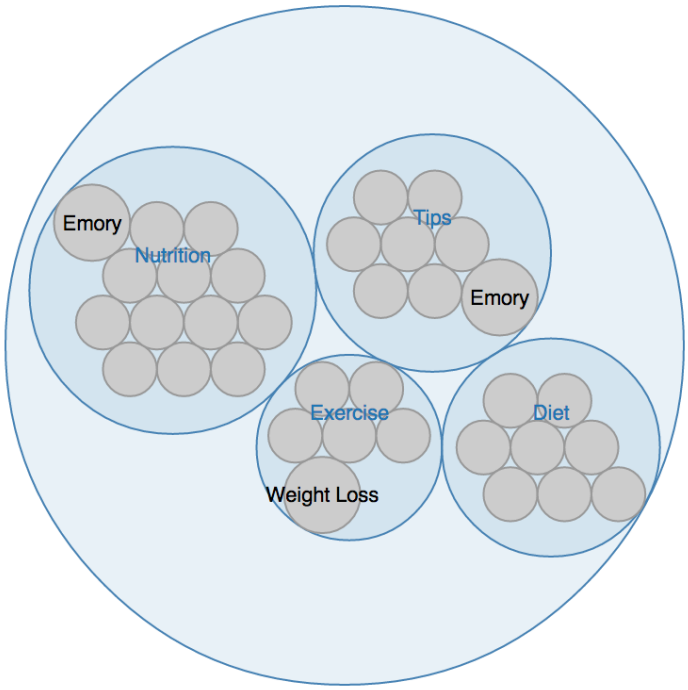
In addition to managing these resources, advisors are able to create unpublished,

[1] https://drupal.org/
[2] http://d3js.org/
[3] www.crossrider.com

Figure 1: Two example public resources saved to Snack by EPHI advisors. All resources are required to have a title, a URL at least one organizing tag and a short description.

private resources that only they can see. These unpublished resources can be shared on a case-by-case basis with the advisor's clients or with another advisor, or they can be published and added to the general collection. This feature was added in response to pilot testing, when several advisors mentioned that some resources were just for personal notes, and that not all resources were appropriate for general consumption.

Finally, the app includes client-to-advisor question asking. Each client's account is linked to their EPHI advisor. Clients may ask their advisor a question about a particular resource on Snack or any online resource. At the client's discretion questions can be made public (meaning all advisors and clients can see the question and any responses), but by default questions are private between the client and their advisor. Public questions were created as a low-impact way of grouping clients as well as combat redundancy. While Snack's questions represent a new communication channel, Snack also piggybacks on existing channel by generating email notifications when questions are asked or answered.



Search Results

Caring for Family, Caring for Self
added by [redacted]
saved url: http://www.nytimes.com/2008/11/18/health/18brod.html
Caregiving, Caregiver Tips Mental Health Nutrition
Good advice on how someone caring for a family member can maintain their own health as well.

Figure 2: In this visualization each circle represents a tag. Smaller circles represent resources with multiple tags (ex: the 'Emory' circle within the larger 'Nutrition' circle is tagged with both Emory and Nutrition). Users can click on each circle to zoom in, progressively filtering their search, which will adjust the list of results present below the search (only one result is shown here to save space). A second, simpler visualization users could select simply created a circle for each tag present in the search results, with circle size tied to the number of results with that tag.

4.2.1.2 Browser extension

While the Drupal web app is the core or repository for Snack, the browser extension is Snack's way of reaching out to health seekers. By syncing with the web app, the browser extension brings the web app's advisor-compiled health resource collection into regular browsing activity. When a user visits a search results page (Google or Microsoft Bing), the extension compares results by URL with the web-app collection. Any items present in the collection are highlighted in the search results page (see Figure 3), giving users quick access to advisor notes. Highlights also serve to remind clients that their advisors are there to answer questions, and have already curated a set of safe and valuable information.

Besides highlights, Snack's extension adds a button to the browser toolbar (see Figure 4). This button changes color to indicate whether the page being viewed in the current browser window is saved as a resource on Snack. Users may also click the button to open a toolpane (see Figure 5) which provides access to advisor notes on the currently displayed page. Users can also ask their advisor a question about the page whether or not the page is stored in Snack as a resource. The toolbar button changes color to indicate when the user is viewing a page that has saved notes (see Figure 4).

The browser extension allows Snack to integrate with the general search engines and sites that typify OHS rather than attempt replacing them, removing a barrier to use that would face a standalone app or site. The extension also avoids restricting clients to a single safe set of information or insinuating that only advisors can find acceptable resources. Clients can browse as they always have, and ask questions on any page they wish. By easing and encouraging question-asking in this way, Snack aims to encourage more client-to-advisor OHS sharing.

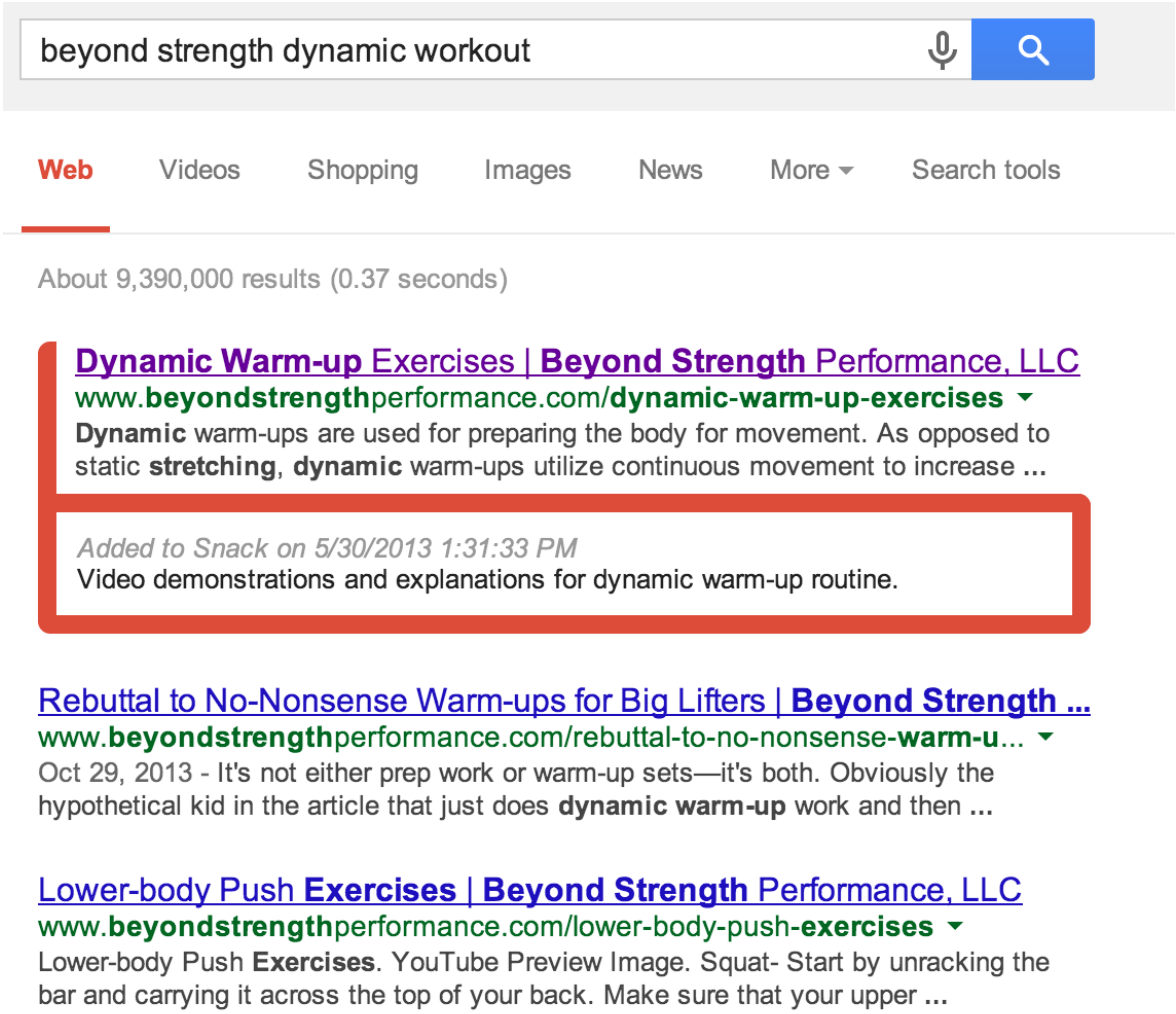


Figure 3: A highlight, created by the Snack browser extension. All public, advisor-saved resources are highlighted in Bing and Google search results, along with the advisor's notes. Search results are matched to resources by URL.

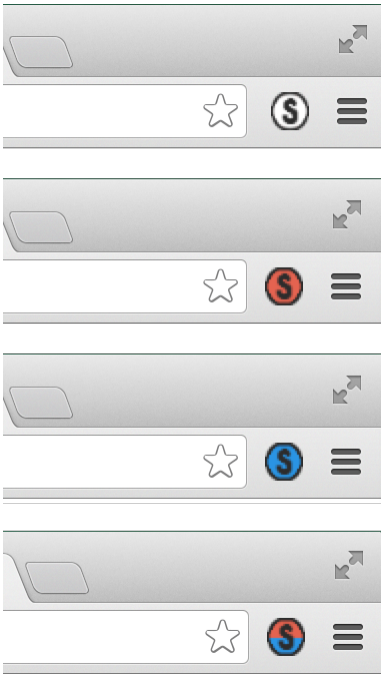


Figure 4: Button added to the user's Internet browser (here, Google Chrome) by Snack. A white background indicates the resource has not been saved to Snack while a red background indicates an EPHI advisor has saved this page (and notes) as a resource. Blue indicates the user has saved their own private notes on this resource (part of the enhanced version of Snack), and a red/blue icon indicates both public (advisor) and private (personal) notes are saved.

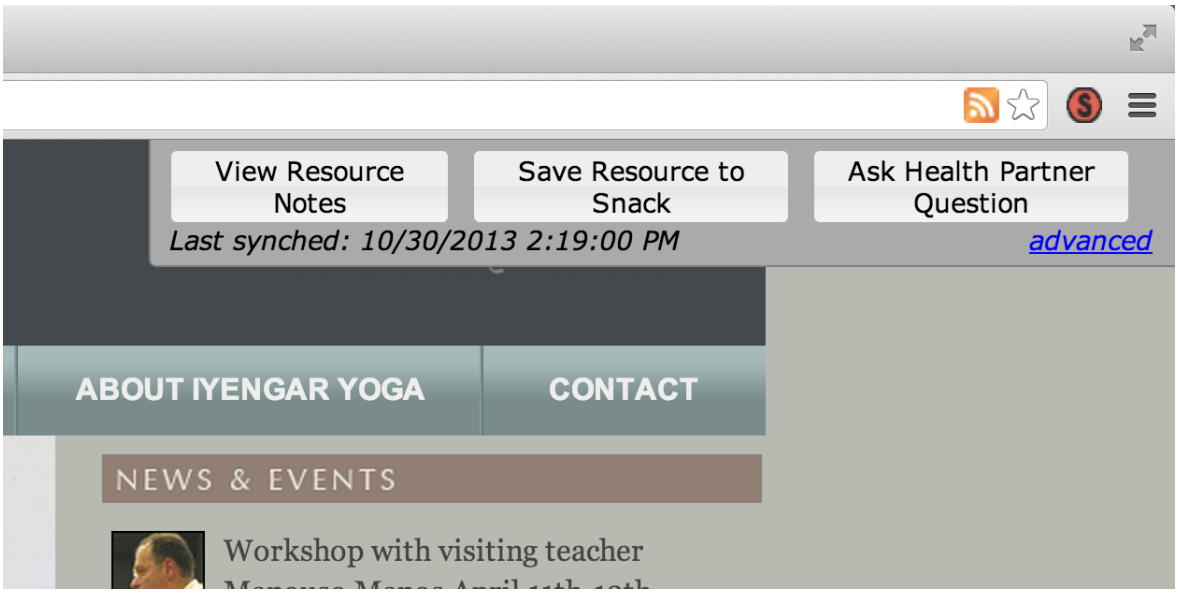


Figure 5: Clicking the 'S' button reveals a toolpane. Note that the S has a red background - an advisor has saved notes on this page. Users can view these notes with the first button. The second button allows EPHI advisors (or clients using the enhanced version of Snack) to save the current page as a resource with notes and tags (see Figure 6). Finally, clients can ask their EPHI advisor ('health partner') a question, which works with a popup that is similar to saving a resource/notes.

4.2.2 Enhanced System Design

I also created an enhanced design, which envisions a slightly different role for clients. Rather than only consuming notes from the health advisors, clients may save their own private notes about any page/resource via the browser extension (see Figure 6). Advisors can also save notes this way rather than working through the web app. These resources and notes are highlighted in the client's own searches via the browser extension, and can also be viewed (again by the client only) en masse at the web app. Clients can choose to share notes with their advisor, again mirroring the client-led approach observed during our consultation shadowing.

A second addition is the 'search challenge', a tool for advisors to encourage OHS and sharing. During the design workshop an advisor suggested assigning optional OHS 'homework' to clients as means of directing and encouraging activity. This suggestion became the search challenge. Via the web app the advisor creates a challenge

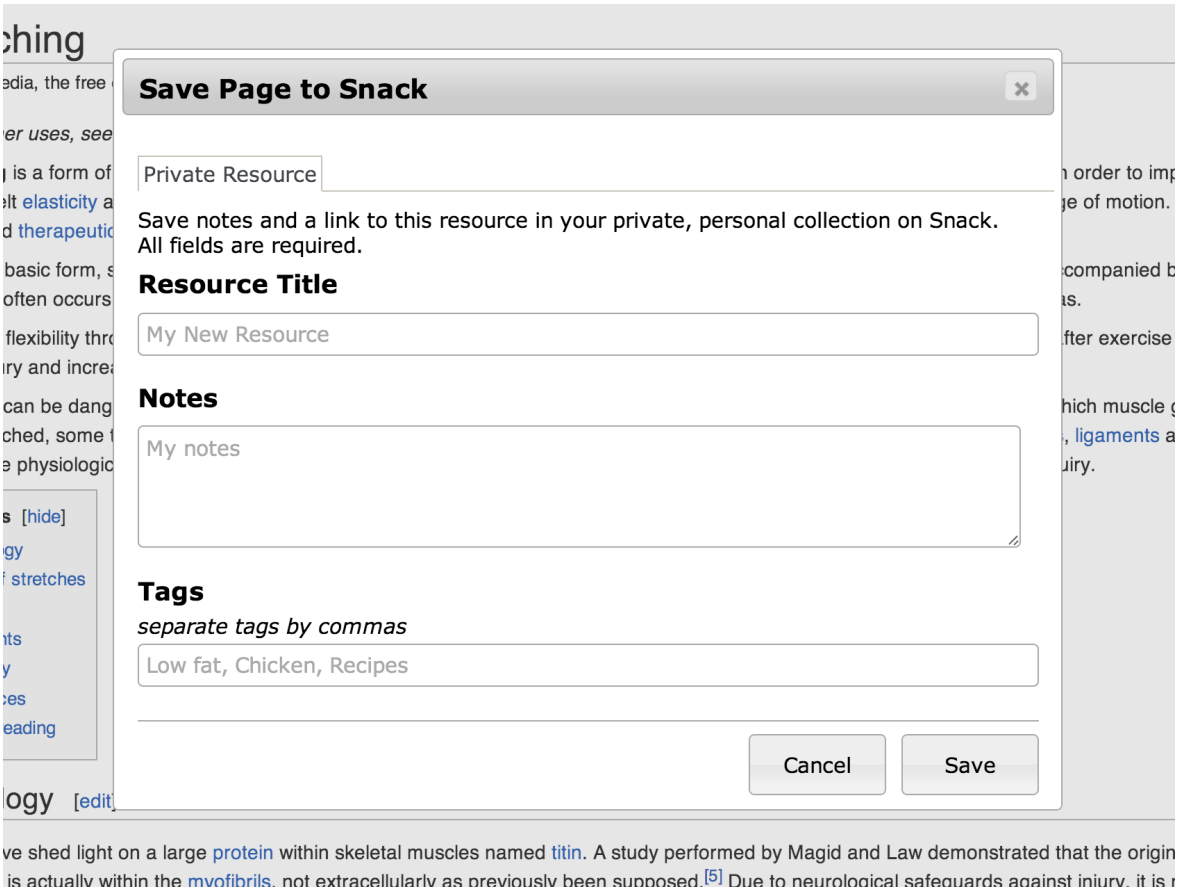


Figure 6: Saving a resource via the Snack browser extension. All fields are required. This pop-up would be seen by clients using the enhanced version of Snack. Their resources are private by default, but they can visit the web app to share with their advisor. Advisors see a slightly modified pop-up that allows them to directly save a resource as public.

for a particular question or topic, such as 'what sites have the best collections of healthy recipes?'. The advisor also attaches an example resources (saved and publicly available on Snack), along with any notes they care to add. This topic is then advertised to clients, asking them to publicly share resources from their private collection that relate to the challenge. Clients can also post public comments on the question, visible to both clients and advisors.

4.2.3 Snack and ESS

ESS suggests that by understanding OHS *in situ* at the EPHI, I can design a search tool that fits EPHI's clients and advisors. Both versions of Snack were designed in response to my formative work and a literature review to fit OHS at EPHI in particular. Snack adjusts generic search results and lives in the browser to fit existing search habits. Rather than including explicit judgments like voting on resources, the systems revolve around sharing, mimicking the advisor strategy of sharing alternatives with clients. To leverage and encourage the close personal relationships I saw between some client-advisor pairs, clients are linked to their advisors with question-asking functionality and 'search challenges'.

ESS also suggests that deploying a search tool can evolve our understanding of searcher relationships, and perhaps impact those relationships. By creating two different versions of the system, I intended to investigate this aspect of ESS. The simpler version of Snack was designed to fit directly into EPHI, casting advisors as consumers of OHS. The enhanced version places clients in a more active role, and offers more tools for advisors to encourage client activity. In my deployment, I monitored whether these differences produced changes in OHS frequency or contact with advisors between experimental groups.

CHAPTER V

AN EMBEDDED APPROACH TO EVALUATING A SOCIAL SEARCH TOOL

To evaluate both versions of Snack, I conducted a field study with the EPHI's advisors and clients. Surveys and semi-structured interviews, experience sampling and web history tracking contributed to my evaluation. My field study took place amid upheaval at the EPHI, concluding with the layoffs of all EPHI advisors and the center's temporary closure.

In this chapter I describe the structure of my field study and report its results. I then discuss **RQ-ESS-1** (evaluating social search as a probe) and what my results mean for ESS. Finally, I begin a discussion (continued in the following chapter) of **RQ-OHS-2** and **RQ-ESS-2**, which ask whether OHS is related to PCC and whether social search tools can serve as interventions, respectively.

5.1 EPHI's Closure and Pilot Study

My field study coincided with EPHI beginning an extended sunsetting process. This closing process began in January 2013, when the EPHI reduced staff from 6 advisors to 3. Clients with assessments scheduled for the fall were moved to earlier dates as possible. These changes placed enormous pressure on advisors by effectively doubling their caseload, creating significant changes during the deployment. By deploying amidst these changes, I was able to use Snack to observe, investigate and evidence the evolution of advisor-client relationships up to EPHI's final closure. I was also able to evaluate the effects on use of Snack in turn, studying the effects of shifting search context on a social search tool.

Prior to my larger field study, EPHI's 3 remaining advisors installed and trailed my tool in a pilot study. This pilot study did not begin until May, well after the EPHI's reduction in staff. As mentioned in the previous chapter, comments from the advisors led to the addition of 'private' resources for advisors. Private resources allowed advisors to create notes for themselves, or to save a resource with the intent of sharing it with only a few clients rather than all.

The pilot study also served as a means of seeding Snack with resources prior to the field study. In my formative work, I found that the EPHI advisors had created an ad-hoc system for sharing useful online resources. Though this system had fallen into disuse by the time of my pilot study, the remaining EPHI advisors still had personal lists of online resources. The advisors shared these lists with me, and I manually entered these resources into their Snack accounts as private resources. Advisors were then able to review and publish those resources they felt comfortable sharing. By the time of the field study, Snack contained 108 annotated online resources.

5.2 Field Study Methodology

My field study of Snack consisted of 42 EPHI clients split between a control group (did not use any system), a group using the basic system, and a group using the enhanced version (with search challenges and the ability for clients to save their own resources). All 3 of the remaining EPHI health advisors participated. Though I initially planned to split the advisors into different study groups, the center's staff reduction made this unworkable as each study group would only have had a single advisor, and contained only that advisor's clients.

The study began in June 2013 with clients joining on a rolling basis, and continued until the center's final closure at the end of August 2013. Knowing the EPHI was nearing its end, one advisor (A3) found new employment and left the EPHI and our study at the end of June. A3's exit interview was thus conducted at the end of June

rather than August. Clients were asked to install the Snack Browser Extension on the computer they typically used for health seeking. A variety of methods were used to gather data during the deployment.

5.2.1 System Use

Traces of system use, like creating resources, responding to search challenges or asking the advisor questions, were captured for inter-group comparisons.

5.2.2 Web History Logs

A separate browser extension was developed to track the web browsing of both clients and advisors. This extension, invisible to the user, captured URL's and timestamps only. To address privacy concerns this data was attached to separate ID numbers, which were not linked either to client/advisor identities at the EPHI or within my study.

5.2.3 Experience Sampling

Experience Sampling Methodology (ESM) presents users with a short (often single question) mini-survey immediately after they take a key action. ESM has been used by other HCI researchers to gather feedback in-the-moment [52]. Snack included an ESM component in its question-asking functionality. When a client asked their advisor a question, Snack opened an optional 1-question survey. This survey asked the user why they had chosen to ask their EPHI advisor a question, and asked what they hoped to learn.

5.2.4 Surveys

Three surveys were given to clients, prior to their enrollment and after the completion of the study. These surveys investigated client attitudes about OHS, how patient-centered they perceived their care at EPHI to be, and how much control the client felt they had over their care. The surveys did not address my system and were taken by

all three study groups. These results are most relevant to RQ-OHS-2 and RQ-OHS-3. I report the results of the surveys and discuss them in detail in the following chapter, leaving this chapter to focus on my system.

5.2.5 Exit Interviews

10 clients (5 from the advanced group, 2 from the control group and 3 from the basic group) and all 3 advisors participated in semi-structured exit interviews. As mentioned, both the advanced and basic versions of Snack saw very limited use. This distribution of interviewees is intentionally focused on the advanced system group, which saw at least some system use. Considering Snack's limited use during the field study, these interviews became a primary means of evaluating both Snack and the social context at EPHI. These interviews covered Snack as well as advisor-client relationships and EPHI's closure, allowing me to synthesize information across these topics.

5.2.6 Recruitment

Though the EPHI served 763 clients, at the time of my study only 465 were considered 'active'. A mass email was sent to these participants, briefly introducing the study and polling for possible times and places to meet with a researcher. I received 139 responses for a 30% response rate, and an eventually enrollment rate (42 clients) of 9%. Clients received two $15 gift cards for participating: one for completing enrollment, and one at the end of the study.

Enrollment required a short meeting with each client. Clients completed their pre-study surveys *before* this meeting and thus before learning any details about Snack. I conducted a number of open enrollment periods, meeting with clients throughout the day, and met with a number of clients individually to fit their schedule. In addition to describing the study and handling consent forms, I gave each client an overview of Snack as appropriate for their study group (basic system, enhanced system, control)

and created a system account for them. I also installed the browser history tracking program and Snack Browser Extension as appropriate. For clients who were unable to bring a computer (ex: primary computer was a desktop), I gave instructions to download these programs.

5.2.6.1 EPHI Advisor Recruitment

EPHI's advisors had already worked with me for over a year during my formative work, and were recruited directly. Each advisor was compensated with $300, split into two payments of $150 at the start and at the conclusion of the field study.

5.3 Field Study Results: System Use and Web Logs

EPHI's closure amongst other factors had a dramatic negative effect on system use. In this section, I report the results my study was able to capture. The utility of most of my data sources is reduced in light of such low system use - it would not be meaningful to make statistical comparisons between groups, for example. As such, my surveys and exit interviews gained primary importance for understanding Snack's (dis)use and what happened at the EPHI. Because of the sparse system use, during the interviews I was able to directly ask clients and advisors about most interactions with Snack. In this section I report the usage statistics for each of Snack's components, and also include quotes and results from the interviews that are especially useful for understanding or contextualizing use of each component. Larger themes from the interviews are covered in greater detail in the next section.

5.3.1 Resources

As mentioned, Snack was seeded with resources the advisors had already collected and saved themselves, launching with 108 annotated online resources. During the study A1 saved 3 resources, roughly once every 2 weeks, and A2 saved only a single resource, mid-study. A3 saved 12 resources throughout June prior to leaving the

center. In her exit interview, A3 mentioned that her schedule had worked out in a way that gave her more time to carry out OHS, while A1 and A2 were pressured to spend their time carrying out assessments before the center's closure. Besides the time spent actually conducting assessments, this pressure required the advisors spend a great deal of time scheduling.

> A3: *"I think with everything going on with the center, I haven't really been doing followups [e.g., assessments at the Center]. So I've been posting more stuff [resources on Snack]. Those two [A1 and A2] have been doing more followups, haven't really been posting stuff. I don't think they're even really looking at resources. [The EPHI's directors] have been pushing for us to get people in."*

A3 was enthusiastic about the system, and said she tried to save resources that gave multiple perspectives, which would seem to mesh with clients who look to OHS in part for a breadth of information (noted in my formative work).

> A3: *"I feel like when you're giving two different perspectives... I'm not trying to force the participants to think one way, but it's more effective."*

Finally, A3 explained in more detail why she kept some resources private. Some of these contained "inappropriate language or swear words". These resources were still valuable information for A3, but she did not want to present them as officially coming from EPHI. She also shied away from publishing resources that were overly specialized, or that clients 'might not take seriously'.

Of the 14 clients in the 'enhanced' group, 4 clients saved a total of 27 resources. Of these 27 resources 4 were shared with the client's advisor, all by the same client in response to a search challenge. Some clients chose to stick with their existing systems for OHS rather than using Snack. For example, C5 used her browser's bookmarks to keep track of health resources. Other clients felt they didn't need Snack because they weren't doing much OHS at the moment. For example, C2 felt she would have used Snack far more the previous year, when she had been diagnosed with cancer.

C3 saved the most resources, 10 in total; for her at least Snack worked as I'd hoped it would for all clients.

> C2: *"I think it would have been great last year [when I received my diagnosis], because I was in the process of doing a lot of learning for myself."*
>
> ---
>
> C3: *"I liked it for being able to keep track of articles and things.. that I found interesting. Without having to bookmark them all, or save the email, or email the link.. it was all in one spot."*

5.3.2 Questions

A single client (in the enhanced group, though question asking functionality was available in both the basic in enhanced versions of Snack) asked their advisor a question via our tool. C4 asked A2 about a TED talk on obesity, including a diet that seemed questionable to C4. In their exit interviews, all three advisors reported that they were getting fewer questions or communications of any kind from their clients. A2 mentioned that some of her clients were unsure if she was even still working at the center.

> A3: *"They know we're closing. [Some clients are probably thinking] 'whats the point of doing the study'."*

5.3.2.1 Experience Sampling

As mentioned, only a single client posed a question using Snack. This made the ESM functionality which triggered on question-asking rather superfluous, as I was able to directly ask both the client (C4) and the advisors about this question.

C4 is a medical professional who is quite sure of her own ability to answer health questions. For most topics, C4 reported that she'd sooner find the answer herself than ask her EPHI advisor. However, she also explained that she especially valued her advisor's expertise on nutrition and diet due to the advisor's training as a dietitian. When she found a questionable diet from a source that otherwise seemed reputable, she turned to A2. A2 acknowledged seeing the question, but unfortunately reported

she simply had no time to view the lengthy video and made no response. For her part, C4 correctly diagnosed the reason for her advisor's failure to answer the question:

> **C4:** *"I was disappointed but I just assumed as they're winding down, they just don't have time to do that sort of thing."*

5.3.3 Site Browsing and Search Highlights

Snack's browsing/searching utility did not seem very compelling to clients. C1 had searched on the site, and went on at some length about her 'visual nature' and desire for a more 'visual, flashy site', but didn't mention Snack's visualizations. C9 visited the site to respond to A2's challenge, but preferred sticking to Google for her health searches, citing a "comfort level". Finally, C7 visited the web app several times, but didn't find any personally relevant content and gave up.

The limited appeal of browsing via the web app was expected, hence the creation of Snack's search result highlight functionality. The browser extension was intended to bring Snack to general search engines, which health seekers are known to prefer. However, the limited addition of new resources by advisors during the study (and the vastness of the web) made it unlikely for searchers to ever encounter a highlight. This quote from C2 captures the issue perfectly, suggesting that the highlight functionality would be worthwhile if a solution to undersaturation could be found:

> C2: *"There was one time when something popped up and it had a highlighted box around it... and I saw the box and was like 'Oh shit! There really is stuff here! This is really cool!' I think because health topics are so diffuse... If you had Snack tell you.. these are vetted resources, from different places (doctors, blogs, elsewhere).. that would be a great resource."*

5.3.4 Search Challenges

The lack of activity from A1 and A2 coupled with A3's departure made it clear that EPHI's situation had changed and no search challenges were likely forthcoming from the advisors. In the interest of testing this system component, I visited the EPHI and asked A1 and A2 to each create a challenge in mid July. A2, a dietitian in

background, asked clients to share their favorite healthy food blogs. A1, a certified fitness instructor, asked for links to short-duration workouts. Each produced a single response. As mentioned A2's challenge resulted in one of A2's clients, C9, finding and sharing 4 online resources. A1's challenge drew a very brief text response from one of A2's clients.

A2 in particular gravitated towards the search challenges during her interview, suggesting she simply lacked the time to use them as EPHI shut down.

> A2: *"I thought the challenges were a great idea, we just quite frankly didn't have the time to do it."*

Three clients mentioned the search challenges in their interviews. C1 said that she had meant to answer a challenge, but didn't get around to it before forgetting. C2 noted the challenges but was busy, and thought the challenges seemed artificial and impersonal. C9 did manage to answer A2's search challenge, sharing multiple resources. Interestingly, C9 had not previously saved any resources to Snack. However, C9 already knew and was excited about several online resources related to A2's challenge. The personal relevancy of the challenge along with a personal connection to A2 triggered C9's response.

> R: *"What motivated you to respond to [A2's] challenge?"*
> C9: *"My relationship with her [A2]... and since I had several blogs that fit, it triggered me to go ahead and share them with her, because I was enthusiastic."*

5.3.5 Web History Logs

The web history tracking component of my study proved problematic. URL history was captured anonymously, containing only an ID, a timestamp and which study group (control, basic, enhanced, advisor) the log was from. Despite this, history tracking was a privacy concern for some participants, with several electing not to participate and one disenrolling from the study shortly after enrolling. An advisor also elected not to participate in the URL-tracking portion of the study.

The tracking data is also inherently incomplete. It was not possible to collect a complete web history for any participant: There was no mobile version of the tracker. To address privacy concerns I only asked clients to install the tracker on their 'primary OHS computer', and explained that they could avoid tracking by using a different browser, a private browsing mode, or another machine. The two advisors participating in tracking installed the tracker only on their primary work machine and browser.

Between the limited number of participants, anonymous and incomplete nature of the logging and infrequent nature of OHS, I do not view my history logs as a contribution and I do not discuss their analysis any further. Logs that could be directly linked to each study participant would be far more interesting - if future work is able to address privacy concerns, non-anonymous logging should be considered. If anonymous logging is necessary, logging at a far greater scale is recommended. Other researchers have carried out log-based studies of OHS at a far greater scale than I could hope to approach at the EPHI [106, 105], giving an excellent example and comparator for future log-based work.

5.4 Field Study Results: Interviews

Exit interviews (10 clients, all 3 advisors) were inductively coded by myself and two other coders. After initial individual coding, we met to merge our 59 codes into thematic clusters, arriving at the following 4 high-level themes.

5.4.1 OHS Characteristics

Every client interview touched on OHS habits and preferences. There was broad confirmation of OHS features noted in my formative work and in related work. Of the 10 clients interviewed, 8 explicitly mentioned their preference for general search engines (C9: *"All things revolve around Google"*). 4 clients mentioned considering a site's aesthetic appearance and organization when deciding if information was valid

and valuable which matches reports from other researchers [31, 89, 100], and 4 acknowledged that they looked for information that matched their expectations [105]. Notably, 6 clients mentioned cross-validating their OHS, looking for agreement from multiple sources.

Clients also described how personal, often acute motivations led to their OHS. C1 was searching to understand her boyfriend's developmentally delayed child, and to inform her decisions about becoming pregnant. C2 and C5 had searched in relation to their cancer. C6 described a scenario that seems typical of client OHS:

> C6: *"It's something like.. one of the kids is sick, or my wife was sick last month with something really weird and esoteric, and so I went straight to google... The doctor knew what it [wife's illness] was, but had only seen it once; I went to google after hearing from doctor."*

All clients discussed or shared at least some of their OHS, though only C3 mentioned sending links to their EPHI advisor. Clients described sharing resources with friends and especially family that were having similar health problems or shared interests, such as trying the same diet. C5, C6 and C7 said they rarely shared OHS with anyone except perhaps their spouse - for these clients, OHS was for their personal understanding only and was neither the interest nor business of others. For example, C5 said:

> C5: *"Normally, it's just for myself. There's nobody to share them with, because it's pertinent just to what I'm going with. Sometimes I'll show them to my husband.. but it's just the two of us that discuss any of it."*

A logical extension of these personal motivations is that health seekers will want specific rather than generic health resources. Given the wide variety of health interests, this made it difficult for Snack (or the advisors) to provide broadly relevant information. C7 in particular mentioned that he didn't see any personally relevant information on Snack, and gave up visiting the site.

5.4.2 Changing Relationships

EPHI's staff reduction and closure led to rapid evolution of the base advisor-client connection, with serious consequences for both types of actor and for my system. For advisors, the closure meant a far heavier caseload and a directive to schedule and complete as many assessments as possible. In my formative work, OHS and client-followups were interconnected and took most of the advisors time. In this new environment, advisors had little time for either. A2 described the effects of EPHI's slow closure:

> A2: *"Initially I tried to keep the same quality of work. It's just impossible with twice as many people... I started doing much more lame, generic followups instead of personal. Eventually I stopped following up with people at all."*

EPHI's staff reduction forced many clients to change advisors, leading them to compare the different relationships. C1 had a negative experience, gradually falling out of touch with her new advisor. C2 on the other hand had positive change, finding her new advisor to be far more communicative than her original advisor.

> C1: *"My relationship with [my previous advisor] was very good. I switched to [A2], who was also good... but then the frequency of contact started to slip [as summer began]. Once we weren't talking every two weeks, I felt myself starting to slip from my goals."*

> C2: *"[my first advisor], she never emailed me, contacted me... I thought it was an odd study. There was a decided difference in my involvement with [A1]. We ended up becoming Facebook friends. I really liked the fact that it made that focus [on my particular health and wellness interests] even more prominent... May of 2012.. the golden years of working with the center! I was telling [A1] about a bike trip... sent her pictures of myself at a restaurant she recommended."*

Other clients, like C4 and C7, had never been particularly attached to their advisor, and didn't seem very affected by EPHI's closure. C4 was a busy medical professional with significant expertise of her own and little time for her advisor. She

felt no change from A2, though A2 self-reported "lame, generic" follow-ups and eventually no follow-ups at all. C7, though not a medical professional, was satisfied with the binder he received at EPHI's assessments and had never looked to connect with his advisor.

> R: *"Has your relationship with [A2] changed?"* C4: *"I don't think so... these past few months, I was so wrapped up with grant deadlines... usually I try really hard to respond to her email and I think there was one or two that I didn't. But I thought she was the same."*
>
> ---
>
> C7: *"...the binder was so straightforward, I didn't need a person there to translate that for me. It was helpful to maybe have someone go, this is what we mean.. but then someone we'd turn to as a coach.. I never saw that as helpful."*

As mentioned when discussing the Question functionality of Snack, all 3 advisors reported receiving fewer and fewer communications from their clients from January (when staff was reduced) on. Interestingly, A1 suggested that reduced client communication could be because some of her clients had progressed beyond needing her. For these clients, the EPHI's goals of self-ownership of health (driven by things like the health action plans) had been realized. On the other hand, A2 felt that much client communication depended on an advisor to start the contact.

> A1: *"A lot of them are at the point where they're their own advisor. Which is the goal of the [EPHI]."*
>
> ---
>
> A2: *"[for some clients] Our whole relationship depended on me being the leader, initiating that contact. Very few people would initiate that on their own. It would happen, but it wasn't the norm."*

These quotes suggest advisor-client relationships go through changes aside from the closure. They also create something of a paradox: the EPHI is looking to empower its clients, but to a certain extent relies on advisors to take charge. This paradox is another instance of the same problem advisor's faced when clients asked for prescriptive advice or judgements on online resources during my formative work.

The center closure was simply another variable, making it difficult to tease apart why any individual client-advisor relationship tailed off during the EPHI's closure.

5.4.3 Support

A key theme was whether advisors could adequately support clients in achieving their health goals. There seem to be 3 requirements for success: familiarity, compatibility and frequency. Clients felt the best supporters were familiar with their motivations and history, compatible with them personally and frequently in touch. C3 felt her personal compatibility with A3 helped them work together, while C7 never formed a familiar connection with their new advisor.

> C3: *"Personalities play a large part in how well you receive your person's suggestions... My first [advisor] was nice, but we had nothing in common... it made it harder for her to relate to me. A3 and I had more in common in terms of background, family, growing up stuff... which makes it easier for me to understand..."*

> C7: *"I was told here is your new person [A2] and she sent me one or two emails. And since I hadn't met her I didn't know what she knew about me... it seemed like she probably sent [those emails] to everyone she works with."*

A1 and A2 echoed C3's point about personalities, and felt they worked best with clients with compatible temperaments. A2 mentioned "similar communication styles", while A1 said:

> A1: *"I know I work better with [clients] that are more like me. Like a guy who was using Fitbit [a commercial, pedometer-based health tracking system] and said 'yeah I love it I can see all the numbers!' And I said, yeah, you're data-driven [like me], that makes sense."*

Frequency of contact, and the familiarity it breeds, also seemed important to clients. For example;

> C8: *"It's hard to say.. ok you've set these goals, I'll see you in a year. If you really want to help me achieve those goals, maybe meet once a month."*

C7: *"I didn't think [my advisors] were the ones to be there supporting me. My wife, my friends in the neighborhood, people I see on a more regular basis... the guy across the street is running, I can say: 'how's that running going?'."*

To adequately support and understand their clients, advisors must develop a personal relationship and knowledge about the client. As the EPHI shut down, there was less and less time to build and maintain these relationships, leading to the disconnects of the previous theme.

When the center shut down, clients who relied on their advisor had to replace this source of support. A1 and C3 suggested some clients had reached a point where they could serve as their own support. Other clients already had replacements lined up, like C2 and C3 who both made friends with nutritionists and trainers. On the other hand, C1 felt herself slipping from her goals as contact with her advisor decreased and wasn't sure yet where to turn. A2 had several clients offer to pay her for continued consultation, but wasn't planning to offer her services in this way. A1 couldn't think of an easy solution for someone like C1 either:

A1: *"Find some kind of support group. That's the only thing I know to tell them."*

5.4.4 System Timing

Snack's deployment right as the EPHI approached its final closure has obvious negative effects on system use. The prior theme of changing relationships was one related consequence. A1 and A2 described their flagging motivation for all things EPHI, including Snack:

A1: *"It's hard to find motivation to even come in to work anymore. All the work you put in... the last 6 years, it's just like 'ok that doesn't matter any more.' And the relationships you established with a lot of people, you're probably not gonna see them again... We weren't motivated to go on there [Snack] anymore."*

A2: *"This question of like.. when do I jump off the boat is hanging in the*

back of everybody's mind. It puts figuring out the next step [finding a new job]... above the priority of our work."

C2 used to enjoy a good relationship with A1, even sharing a diet tracking program with her. Still, C2 ignored her advisor's search challenge on Snack due to the impending closure. A1 saw this resigned attitude in other clients, as well.

C2: *"If the center is closing then, it's not going to go anywhere. Why bother?"*

A1: *"A lot of people are like 'eh center is closing, I'm going to give up'."*

Advisors and clients also reflected on the timing of our deployment beyond the issues created by EHPI's closing. A1, A2 and C10 all wished our system had been around at EPHI's launch, when clients and advisors were still learning how to interact and answer questions.

R: *"Where could Snack fit into an advisor's job?"*
A1: *"Maybe more in the beginning part. That's when we needed a lot of the resources stuff. That was a time when we were trying to find the resources. It would've been helpful to interact with the participants just on that, rather than copy and pasting a note on the portal. In the beginning, when we were learning how to be an [EPHI advisor], and learning the participant's needs."*

A2: *"It would be cool to use it when people first come in. Especially if there were some resources that were particularly pertinent to the resources we have here [at EPHI], or created by the advisors here."*

C10: *"Snack might have been a great resource more at the beginning [of my enrollment at EPHI] when I was more actively seeking resources... Starting [at the EPHI], it felt to me like an enormous opportunity that was unimaginable to have sought out on my own... Having been invited into that felt to me... 'wow, this is a really great opportunity to really understand, to set some goals for myself, really understand what's going on'. I felt like it was a huge opportunity. Therefore, that's a lot of energy too."*

Other clients connected Snack's timing to motivating health events. As mentioned previously, C2 may have found more use for the system a year prior when she was diagnosed with cancer. C7 thought Snack could be integrated into the EPHI assessment

when clients receive their test results.

5.5 Discussion

I divide my discussion section into three parts. I consider RQ-ESS-1 and RQ-ESS-2 in light of my study's results, discussing how future ESS interventions can best use social search to study or impact their surrounding context. I conclude by discussing RQ-OHS-3 and the challenges of intervening in OHS.

5.5.1 Understanding and Intervening via Search

I introduced the term ESS to suggested that holistic study of specific search contexts could aid system design, and that search tools could serve as a lens to study (RQ-ESS-1) or intervene (RQ-ESS-2) in an environment or topic. **RQ-ESS-1** asks whether social search can be designed to fit a particular context or used to investigate an environment. ESS encourages researchers to understand social search *in situ*, motivating my field work at EPHI. My study provides clear examples of the impact of the larger socio-environment on search and the utility of an embedded approach to understanding relationships. However, ESS's suggestion of social-search-as-intervention merits further investigation.

The most obvious and dramatic example of social context affecting Snack and the OHS process in general is EPHI's closure. During my system's development, OHS and client interaction were constant activities. When their caseload increased, advisors were forced to limit follow-up communications with their clients (and attendant OHS), and devote most of their time to carrying out assessments. These changes led the advisors to abandon my system by the midpoint of the study, even when contacted by clients that had posted a question or challenge response. Clients also pulled back from their advisors, both within and without of the system. I envisioned Snack providing another level of contact for advisors and clients, but instead my studies were a snapshot of frayed ends and relationships near their conclusion.

ESS's emphasis on field evaluations let my study serve as a window into the relationships of our searchers. I found participants engaged or disengaged with Snack based on the bond with their advisor, which depends on many factors. Some clients felt simple contact frequency affected relationship strength. Familiarity and compatible personalities were important, as clients sought support from people who could appreciate the nuanced, idiosyncratic and changing narratives that motivate OHS. Personal expertise had an impact, as clients valued an advisor with a background in their pet topics. At first glance, some of these factors would seem to have little direct connection to the information seeking activity of OHS. Still, each had an effect on the ability of Snack (or an EPHI advisor) to impact client health seeking and attitudes. These motivations and connections, and especially their change over time, would be difficult or impossible to observe in a shorter or more controlled study.

With **RQ-ESS-2**, I asked whether search tools could frame or impact searcher relationships. Not surprisingly given the low use of my system, I found few examples of this in my field study despite my designs' attempts to encourage different styles of interactions. Search challenges and question-posting had some very limited success in prompting activity and a few clients saved resources, but no major differences were apparent between my three study groups. My designs were developed in and for a context (the EPHI in normal operation) that no longer existed during the field study. As a result, my designs no longer fit the embedding socio-environmental context, driving disuse and torpedoing any chance for Snack to have a measurable impact on advisor-client relationships. The final days of EPHI were likely an ill-fit for any kind of search-based intervention. The result is effectively further evidence for the larger environment's impact on social search tools, but leaves open the question of how well those tools can impact their environment in turn.

5.5.2 It's a mESS: Designing for Complexity and Change

In my study, simply connecting searchers was not sufficient for creating collaboration. For clients, choosing whether to interact with my app was an idiosyncratic affair influenced by each participant's personal history and relationship with their advisor, all in flux over time. Consider this quote from C5, who was battling cancer:

> C5: *"I had a diabetic dog, and it was a 24 hour thing... [My advisor] said you need to get YOURSELF in shape before you take care of your dog. And I said 'I HAVE to take care of my dog or he's going to die, I don't have a choice.' And I got a little bit irritated... my husband and I, we literally changed our lives [for the dog]."*

This typifies how difficult it is to answer the question 'Is my advisor worth engaging with?' Answering is complicated because in truth, this one question can stand for many others. Does my advisor know me? Are they an expert on my topic? Am I even concerned about my health right now? Factors that seem completely disconnected from personal health, like a diabetic dog, can have an important effect on client engagement. Clients continually weigh their answers to questions like these when deciding whether to reach out to or pull back from their advisors, including via my experimental system.

Researchers that take an ESS approach to developing and evaluating search tools need to prepare for messy, complex and *changing* search environments. Though Snack was carefully modeled to fit the EPHI's complex original context, my design failed to anticipate change in searcher relationships beyond the positive interventions I hoped to achieve. Not all ESS projects are likely to encounter such extreme changes in their environment mid-study —EPHI's closure virtually eliminated the search context I studied in my formative work. Still, advisor discussion about clients 'becoming their own advisor' suggests that relationships were always evolving at the EPHI, perhaps just at a slower pace than during the closure. In a longitudinal social search field study (e.g., an ESS study), researchers must expect searcher relationships to evolve.

A proper response could entail creating a more adaptive system, or re-imagining the system mid-study. Even in EPHI's extraordinary situation, Snack could have been more flexible. As clients replaced their advisors with new experts, my designs could have expanded to encompass these new connections. My tools could also have helped clients without ready replacements connect to these experts. Ensuring designs continue to conform to a varying search context will allow researchers to continue studying an environment (RQ-ESS-1) and improve the chance of an intervention succeeding (RQ-ESS-2).

5.5.3 Intervening in OHS

My research question **RQ-OHS-3** asks whether OHS could be targeted by an intervention and used to promote a patient-centered environment. OHS proved a challenging topic for fieldwork, and a difficult target for an experimental system. Some of the challenge stems from OHS's periodic nature, which would argue for an extremely longitudinal approach. For example, C10 mentioned that they would have found our system more useful when they first enrolled at EPHI, C2 similarly felt she could have used the system when she received a serious diagnosis one year prior. EPHI's closure unfortunately truncated my study; a longer duration would likely have spanned more motivating health events and captured more client OHS. A super-longitudinal system would have to confront its visibility - when their OHS motivation finally arrives, will clients even remember the system exists? Involving valued social connections like EPHI's advisors, or connecting to known motivating events like EPHI's assessments (or more generally, doctors visits), seem like prudent design directions for future OHS interventions.

Another barrier to Snack stemmed from the limited pool of advisors and resources available during my study. Clients wanted highly specific information, and some clients pulled away from Snack (and from their advisors) when they perceived these

resources to be overly generic. Within my system, I described how some clients ignored search challenges that weren't appropriately aligned to their unique interests or found the resources on Snack to be irrelevant. A larger, more varied group of advisors (as had previously existed at the center) may have assuaged this problem simply by increasing breadth of experience amongst advisors and (presumably) the range of information added to Snack. The greatest benefit from working with a full compliment of advisors would likely be the increased time each advisor could spend per-client. Across my studies, I encountered clients who felt closely connected to their advisors. This kind of connection was conducive to OHS sharing on either side of the relationship. These ideal examples, which were more apparent in my formative work during EPHI's regular operation, are a contrast with the 'generic' efforts advisors were driven to under the duress of EPHI's closure. Clients and advisors alike expressed ambivalence towards these resources and contacts.

During EPHI's overloaded final days, advisors lost many of the advantages that made them seem such a good fit for an OHS intervention. Optimal advisor-client relationships require frequency, familiarity and time to build and maintain. In exit interviews, C7 and C8 both stressed the importance of frequent contact for creating a supportive relationship, and C1 described falling away from her goals as advisor contact decreased. During focus groups in my formative work (Chapter 3), clients mentioned how accessible their advisors were... but by the time of my study, advisors were driven to ignore direct client contact. As advisor-client relationships lost these advantages of accessibility, familiarity and frequency, they began to face some of the same problems cited by doctors in Masters' review of physician Internet use [61]. Workload and time pressure, the most frequently cited barrier to physician-patient email, became the primary barrier between advisors and clients. The EPHI directors' instructions to focus on carrying out as many assessments (e.g., office visits) as possible can be analogized to the compensation issues faced by doctors. Sadly for

my system, by the summer of 2013 EPHI's advisors had been overloaded and stripped of many of their strengths.

Alternative approaches could be used to support advisor-client familiarity, both in response to time pressure and as a supplement in an ideal environment. Functionality to elicit health-seeker interests, or intuit them automatically, could help advisors connect with clients by posting relevant and thus interesting challenges or resources. For example, Snack could have automatically aggregated client searches, and report common topics to the advisors. This functionality will be challenging to create however, as it must balance creating familiarity with respecting privacy. An intervention that is too invasive will repel clients, while too little information could miss individual health concern drivers. The EPHI's old model provided for informal encounters between advisors and clients, building the rapport and personal knowledge needed for a successful OHS intervention. Unfortunately, I was unable to evaluate Snack in this environment. Still, a successful OHS intervention will likely depend on how a clinic structures its social interactions as much as it depends on any technical implementation.

Snack's designs emphasized client leadership to mimic EPHI's culture, potentially at the cost of better prodding clients to take OHS action or contact their advisors. At EPHI I saw advisors engage in delicate, almost paradoxical relationships with their clients. Advisors had to weigh their own knowledge against client beliefs and preferences, and also had to prod clients to act on their health while simultaneously trying to build client self-initiative. Search challenges provoked at least a few responses even given the strained state of advisor-client connections during the center's closure. However, it is unlikely that any single design can strike the perfect balance between health professional and patient initiative, even in a single environment like the EPHI. Rather, OHS interventions should consider supporting multiple OHS motivators/instigators, including outlets for both health professionals and their clients

to drive interaction. Designs should also strive to help health professionals evaluate whether and when their clients need a push of some sort. Functionality for familiarity as just described could be an effective indicator.

To summarize and return to **RQ-OHS-3**, OHS is a challenging target for interventions. Health seekers have personal motivations for their searches, but throughly revealing these motivations (to avoid offering only generic information) requires serious time on the part of health professionals and risks violating user privacy. An OHS intervention that looks to empower patients will also need to find the right balance between patient initiative and professional authority and motivation. On top of this, the periodic nature of OHS makes it difficult to study the impact of an intervention.

Though my OHS intervention had a limited impact, I was still able to gather higher-level data on OHS's association with PCC. This association encourages the continued investigation of OHS even given the difficulties my system faced. In the next chapter, I discuss **RQ-OHS-2** and the pattern of positive association I observed between OHS and empowered patients.

CHAPTER VI

OHS AND PCC

In this chapter, I describe the results of 3 surveys given to the clients who participated in the deployment of Snack described in the previous chapter. These surveys were given at the start and end of each client's enrollment. I developed two of the surveys myself: one to measure attitudes about online health information and one to gauge patient-centered care. The third survey is the classic Multidimensional Health Locus of Control survey. I begin by describing the surveys, then report their results and analyze correlations between the surveys. I then discuss implications, especially for research question RQ-OHS-2 (OHS's correlation with other measures) and RQ-OHS-3 (OHS's suitability as an intervention).

6.1 Surveys

Clients also responded to a set of 3 surveys composed mostly of 7-item Likert scales, with a few yes or no questions [1]. Two surveys, the Health Information Attitudes (HIA) and Patient-Centered Care surveys, are new instruments I created for my studies. The third of these surveys was the Multidimensional Health Locus of Control (MHLC), a widely used instrument [103].

6.1.1 Patient-Centered Care Survey

As discussed in the related work section, physicians are still debating how to create measurable metrics for the abstract concept of PCC. There is no generalized instrument available to measure PCC, and due to PCC's context-sensitive nature it may not be possible to create one. Robinson *et al.* broke down two aspects of

[1] see Appendix A for complete reproductions of these surveys

PCC, patient involvement and individualized care, from four different perspectives: public policy, economic, clinical and patient [85]. Epstein *et al.* focused on patient-provider communication, listing the following 4 components of PCC: uncovering and understanding patient needs, individualized understanding of each patient, reaching a shared comprehension of the patient's care, and sharing control and responsibility with the patient [28]. In consultation with the EPHI's advisors, Epstein *et al.'s* 4 descriptors adapted to the EPHI's context as follows:

1. *Eliciting:* The advisor knows what the client is worried about, what the client expects, what they want, and what they need in their health experience, especially at the EPHI.

2. *Holistic:* The advisor knows and cares for each client as a person. They are familiar and concerned with the different social and professional pressures on the client's life and thus their health.

3. *Shared Understanding:* Clients and advisors work together to interpret test results (what do they mean, which are important), and create a common understanding of how to address them.

4. *Shared Decisions:* The client feels they have an impact on the focus of their action plan: which actions to take, what goals to set.

12 7-item Likert scales were created to evaluate the patient-centeredness of a client's care at the EPHI (see Appendix A). Following the example of the MHLC survey (discussed below), I sum these responses into a single 'PCCScore' value.

6.1.2 Multidimensional Health Locus of Control Survey

Given the somewhat murky nature of measuring PCC, I searched for related concepts that could be more easily measured. Because PCC emphasizes patient control of care,

the well-known and widely validated MHLC survey seems like an excellent fit [103]. The MHLC measures how much the taker feels different dimensions control their health: themselves (the 'internal' dimension), chance, and powerful others. A high internal locus of control is a logical match with an empowered, active patient that feels in charge of their care process. Other researchers studying patient control over health have emphasized the importance of an internal locus of control for patient management of chronic conditions like diabetes, finding that an internal locus of control is associated with better adherence and self-management [108, 69], and MHLC is not new to HCI researchers [60].

The MHLC can be given using either Form A, Form B or Form C. Form A was used in my work - the MHLC creators feel forms A & B are equivalent, while form C is intended for studying people with a specific pre-existing medical condition.

6.1.3 Health Information Attitudes Survey

Finally, I created the HIA survey to investigate client use and attitudes towards online health resources. The HIA survey contains 30 items. A few of the questions involve the EPHI advisor (ex: 'My EPHI advisor gives me useful only resources') and are thus EPHI-centric, but many are generically applicable (ex: 'I've made good use of an online health resource').

6.2 Methodology

All three surveys were given to the 42 participating EPHI clients online, sequentially (HIA, PCC, MHLC). Surveys were taken twice over a period of two months. All survey responses were examined for significant differences between study groups (basic Snack, enhanced and control) using ANCOVA's with pre-test scores as the covariate. No significant differences were found, and to avoid confusion with other results I do not list the results in this document. The lack of differentiation between groups is to be expected given the periodic nature of OHS (even if a searcher used Snack for all

searches, more than a few interactions were unlikely in the study's duration) and the effects of EPHI's closure discussed in the previous chapter. It seems there was little chance for either of my systems to produce an impact measurable by my surveys. The lack of significant differences between my three study groups encourages merging this groups; all further analysis makes no distinction between study groups.

In the rest of this chapter, I discuss the descriptive results of my surveys as well as correlations between the 3 surveys to investigate the relationship between OHS, PCC and MHLC. All analysis uses the mean of each client's 2 scores for each question/value. 4 participants failed to complete part or all of a survey; this data was dropped, meaning n = 38 for all survey analysis.

6.3 Survey Results: Descriptive Statistics

In this section I present an overview of each survey's results in isolation. As mentioned, n = 38 for all surveys and the average of each client's two scores is used for all analysis. Unless otherwise noted, all questions were in the form of 7-item Likert scales, with 1 corresponding to 'Strongly Disagree', 4 corresponding to 'Neutral' and 7 to 'Strongly Agree'.

6.3.1 HIA Survey

The HIA survey found that EPHI clients discuss online resources most with their friends and family, followed by their EPHI advisor and then doctors and other health professionals. The reported differences in frequency for discussing OHS between EPHI advisors and doctors(t = 2.857, p = 0.007), other health professionals (t = 3.4645, p = 0.001) and friends/family (t= 6.53, p <0.000) were all significant in paired t-tests.

Clients had generally positive values for OHS (Question 8 and subquestions) and felt their OHS was interesting to their EPHI advisors (question 18). However, clients were more ambivalent about the utility of discussing OHS with their advisors (question 10) and the quality of advisor-provided resources (question 16).

Table 1: HIA survey results, table 1 of 2 n = 38, average of pre and post test used for all calculations. Question 7 was a Yes/No question, with 'Yes' scored as 1 and 'No' scored as 0.

Question	Avg	SD
1. How often do you access the Internet?	5.987	0.081
2. How often do you search online for health or wellness information?	3.724	0.928
3. How often do you discuss online health resources with your EPHI Advisor?	2.013	0.652
4. How often do you discuss online health resources with your Doctor?	1.684	0.471
5. How often do you discuss online health resources with your other health professionals?	1.579	0.703
6. How often do you discuss online health resources with your friends and family?	3.189	1.023
7. Have you ever made a health decision based on information you found online?	0.885	0.268
8. Online health information is useful or good for...		
8A. ...deciding ('diagnosing') how I am sick or hurt.	4.542	1.354
8B. ...getting more details about my health concerns.	6.095	1.073
8C. ...helping others with their health	5.319	0.942
8D. ...deciding if I need to talk to a health professional.	5.270	1.205
8E. ...explaining my concerns to a health professional.	5.014	1.239
8F. ...explaining my health or concerns to friends and family.	5.068	1.179
8G. ...comparing treatment options.	5.861	0.907
8H. ...comparing health professionals understanding the health concerns of others.	5.129	1.165
8I. ...understanding the health concerns of others.	5.716	0.870

Table 2: HIA survey results, table 2 of 2 n = 38, average of pre and post test used for all calculations.

Question	Avg	SD
9. I can usually find useful online health information myself	6.176	0.827
10. Discussing online health information with my EPHI Advisor improved our relationship	4.041	1.216
11. Online health information is NOT very interesting to me	2.473	1.389
12. When I look for online health information, what I find is just for me	3.743	1.388
13. Health professionals are the only good source of health information	2.797	1.367
14. I'm confident I can tell if a piece of online health information is relevant and good quality	4.851	1.290
15. Looking for online health resources myself does more harm than good	2.569	1.036
16. My EPHI advisor gives me useful online health resources	4.459	1.233
17. You can't trust online health information	2.608	1.068
18. My EPHI advisor is NOT interested in the online resources I find	2.581	1.140
19. I've made good use of an online health resource	5.365	1.122
20. The online health information I find could be useful to others	5.365	0.822
21. Online health resources have affected some of my health decisions	5.216	1.017
22. I need help deciding how 'good' the health information I find online is	3.446	1.383

6.3.2 PCC Survey

Table 3 lists the results of the PCC survey. Scores trended towards the positive or 'agree' end of the scale. The strongest ratings were for questions 6 and 7, which related to the client's personal control over their EPHI action plan and their understanding of health. These items also had the lowest standard deviation. On the other hand, items 4 and 9 had both the lowest average scores (though still above neutral) and the highest standard deviation. These questions asked how the client's advisor understood them as well as how close the relationship between advisor and client was. These lower scores and variance are to be expected giving the varying relationships clients expressed during exit interviews (discussed in chapter 5). This could also be an indication of changes at EPHI - several clients mentioned being unsure how to answer these questions given that they had recently changed advisors. Clients were instructed to answer for their current EPHI advisor as of survey time.

For my PCC survey Cronbach's $\alpha = 0.952$, indicating the items from my PCC survey were highly associated with one another. To simplify subsequent analysis I create a 'PCCScore' value for each client by summing their responses to each question - this is the value in the 'Total' column in table 3.

Table 3: PCC survey results. n = 38, average of pre and post test used for all calculations.

Question	Avg	SD
1. My EPHI Advisor makes sure I understand the test results from my assessment that are most important to me.	6.014	1.199
2. My Health Action Plan addresses the health issues I feel are most important for me.	5.947	1.038
3. When I email or talk with my Partner, we cover my main concerns.	5.474	1.299
4. My EPHI Advisor understands and cares about both my personal and my professional life.	5.408	1.428
5. I am comfortable asking my EPHI Advisor questions about my test results, action plan and health in general.	5.908	1.229
6. I am in charge of my Health Action Plan's parts and goals.	6.382	0.834
7. I know which parts of my health I most need to work on.	6.474	0.779
8. My EPHI Advisor knows how I feel about my health. They understand which parts I'm worried about, and what I feel good about.	5.658	1.053
9. I feel like I have a personal relationship with my EPHI Advisor.	4.921	1.671
10. The steps and goals in my Health Action Plan are the best way for me to improve my health.	5.566	1.079
11. My EPHI Advisor recognizes and respects my contributions to my health.	5.842	0.973
12. My EPHI Advisor understands how my job or family life impacts my health.	5.500	1.145
TOTAL 'PCC Score'	**68.934**	**11.548**

6.3.3 MHLC Survey

Table 4 lists the MHLC's results. Scores on the internal dimension were notably higher than external scores (Chance and Powerful Others). These differences were significant as measured by paired t-tests (Internal:Chance $t = 13.616$, p <0.000; Internal:Others $t = 14.202$, p <0.000). There was no significant difference between average scores the two external dimensions (Chance:Others $t = 0.777$, p $= 0.440$). This suggests that the EPHI's clients in my study felt they had more control over their own health than chance events and luck or other people.

Table 4: MHLC (Form A) survey results. n = 38, average of pre and post test used for all calculations.

MHLC Dimension	Avg	SD
Internal	31.158	4.413
Chance (External)	16.434	4.996
Powerful Others (External)	17.250	4.119

6.4 Survey Results: Correlations

In this section I report the correlations between each of my HIA survey's questions and the summative 'PCCScore' value calculated for each client on my PCC survey. I then correlate each HIA question with the 3 dimensions of the MHLC.

6.4.1 HIA & PCCScore

This section reports correlations between the HIA survey investigating client attitudes/practices around OHS and the PCCScore measured by my PCC survey. I report p-values adjusted for multiple comparisons as well as unadjusted p-values. Results are split across 3 tables to create a more manageable presentation.

Table 5: HIA question correlations with PCCScore, table 1 of 3. n = 38. Correlations with PCCScore are Pearson's r. Adj. p values calculated Bejamini-Hochberg adjustment for multiple comparisons. Unadjusted pvalues <= 0.1 are *italicized*, adjusted p-values >= 0.1 are **bolded**.

How often do you...	**r(PCC)**	**p**	**adj. p**
1. access the Internet?	0.598	*0.000*	**0.002**
2. search online for health or wellness information?	0.160	0.338	0.539
How often do you discuss online health resources with...			
3. your EPHI Advisor?	0.691	*0.000*	**0.000**
4. your Doctor?	0.359	*0.027*	0.154
5. your other health professionals?	0.248	0.133	0.346
6. your friends and family?	-0.109	0.520	0.692

Table 6: HIA question correlations with PCCScore, table 2 of 3. n = 38. Correlations with PCCScore are Pearson's r. Adj. p values calculated Bejamini-Hochberg adjustment for multiple comparisons. Unadjusted pvalues <= 0.1 are *italicized*, adjusted p-values >= 0.1 are **bolded**.

8. Online health information is useful or good for...	**r(PCC)**	**p**	**adj. p**
8A deciding ('diagnosing') how I am sick or hurt	0.206	0.228	0.456
8B getting more details about my health concerns	0.372	*0.024*	0.149
8C helping others with their health	0.123	0.475	0.666
8D deciding if I need to talk to a health professional	0.302	*0.069*	0.245
8E explaining my concerns to a health professional 0.253	0.137	0.346	
8F explaining my health or concerns to friends and family	0.348	*0.035*	0.178
8G comparing treatment options	0.174	0.309	0.531
8H comparing health professionals understanding the health concerns of others	0.110	0.529	0.692
8I understanding the health concerns of others	0.246	0.141	0.346

Table 7: HIA question correlations with PCCScore, table 3 of 3. n = 38. Correlations with PCCScore are Pearson's r. Adj. p values calculated Bejamini-Hochberg adjustment for multiple comparisons. Unadjusted pvalues <= 0.1 are *italicized*, adjusted p-values >= 0.1 are **bolded**.

HIA Question	r(PCC)	p	adj. p
9. I can usually find useful online health information myself	0.309	*0.062*	0.241
10. Discussing online health information with my EPHI Advisor improved our relationship	0.631	*0.000*	**0.001**
11. Online health information is NOT very interesting to me	-0.575	*0.000*	**0.004**
12. When I look for online health information, what I find is just for me	0.189	0.263	0.501
13. Health professionals are the only good source of health information	-0.491	*0.002*	**0.032**
14. I'm confident I can tell if a piece of online health information is relevant and good quality	0.354	*0.032*	0.173
15. Looking for online health resources myself does more harm than good	-0.335	*0.046*	0.190
16. My EPHI advisor gives me useful online health resources	0.679	*0.000*	**0.000**
17. You can't trust online health information	-0.252	0.132	0.346
18. My EPHI advisor is NOT interested in the online resources I find	-0.583	*0.000*	**0.004**
19. I've made good use of an online health resource	0.161	0.341	0.539
20. The online health information I find could be useful to others	0.129	0.446	0.645
21. Online health resources have affected some of my health decisions	0.110	0.516	0.692
22. I need help deciding how 'good' the health information I find online is	-0.123	0.468	0.666

As described in the methodology section, the HIA survey analyzes the value EPHI clients assign to online health resources. Meanwhile, I created the PCC survey to measure the degree to which clients feel their care at EPHI is personalized, holistic and self-directed. A strong pattern of correlations was observed between items on the HIA survey and the summative PCCScore.

These results suggest a positive association between OHS and PCCScore —in other words, people with good experiences around and value for OHS were more likely to give their care at EPHI a higher patient-centeredness rating. Clients with high PCCScores were also more likely to be confident in their ability to find and evaluate online health resources.

6.4.2 HIA & MHLC

In this section, I report correlations between the MHLC PCCScore surveys. The MHLC produces scores on three dimensions of Chance (MHLC-CHA), Internal (MHLC-INT) and Powerful Others (MHLC-OTH). Cronbach's α for each dimension were as follows: MHLC-INT $\alpha = 0.794$, MHLC-CHA $\alpha = 0.787$, MHLC-OTH $\alpha = 0.611$ Within the dimensions themselves, MHLC-CHA negatively correlated with the MHLC-INT dimension, and positively correlated with the MHLC-OTH dimension ($r = -0.377$, $p = 0.020$; $r = 0.407$, $p = 0.011$). MHLC-INT and MHLC-OTH were not significantly correlated.

These results are split across 2 tables. So that results for all 3 MHLC dimensions may be placed side-by-side, questions from the HIA survey are coded by number rather than reproduced. Please see Appendix A to view the HIA survey, or reference the preceding HIA-PCC tables.

Table 8: HIA survey correlations with scores on MHLC dimensions, table 1 of 2. See Appendix A for HIA survey to see question text. n = 38. Correlations with MHLC dimensions are Pearson's r. Adj. p values calculated Bejamini-Hochberg adjustment for multiple comparisons. Unadjusted pvalues <= 0.1 are *italicized*, adjusted p-values >= 0.1 are **bolded**.

	MHLC-INT			**MHLC-CHA**			**MHLC-OTH**		
HIA Question	r	p	adj. p	r	p	adj. p	r	p	adj. p
HIA1	0.232	0.160	0.375	-0.119	0.477	0.666	-0.010	0.952	0.968
HIA2	0.163	0.329	0.539	-0.387	*0.016*	0.108	-0.277	*0.093*	0.306
HIA3	0.002	0.992	0.992	-0.209	0.208	0.430	-0.147	0.378	0.582
HIA4	0.015	0.929	0.962	-0.098	0.558	0.714	-0.031	0.852	0.921
HIA5	0.170	0.307	0.531	-0.264	0.109	0.327	0.110	0.512	0.692
HIA6	-0.234	0.163	0.375	-0.265	0.113	0.332	-0.226	0.178	0.396
HIA7	0.299	*0.069*	0.245	-0.221	0.183	0.398	-0.051	0.759	0.876
HIA8-A	0.320	*0.057*	0.228	-0.436	*0.008*	**0.063**	-0.003	0.984	0.992
HIA8-B	0.232	0.167	0.377	-0.474	*0.003*	**0.040**	-0.069	0.684	0.813
HIA8-C	0.438	*0.008*	**0.063**	-0.279	*0.099*	0.306	0.026	0.879	0.929
HIA8-D	0.432	*0.008*	**0.063**	-0.470	*0.003*	**0.040**	-0.039	0.819	0.909
HIA8-E	0.310	*0.066*	0.245	-0.224	0.188	0.398	0.097	0.574	0.718
HIA8-F	0.247	0.141	0.346	-0.347	*0.036*	0.178	-0.015	0.930	0.962
HIA8-G	0.027	0.875	0.929	-0.468	*0.004*	**0.044**	0.040	0.815	0.909
HIA8-H	0.195	0.261	0.501	-0.349	*0.040*	0.178	-0.155	0.374	0.582
HIA8-I	0.221	0.189	0.398	-0.038	0.825	0.909	0.062	0.714	0.832

Table 9: HIA survey correlations with scores on MHLC dimensions, table 2 of 2. n = 38. Correlations with MHLC dimensions are Pearson's r. Adj. p values calculated Bejamini-Hochberg adjustment for multiple comparisons. Unadjusted pvalues <= 0.1 are *italicized*, adjusted p-values >= 0.1 are **bolded**.

	MHLC-INT			**MHLC-CHA**			**MHLC-OTH**		
HIA Question	r	p	adj. p	r	p	adj. p	r	p	adj. p
HIA9	0.099	0.559	0.714	-0.242	0.149	0.358	-0.179	0.290	0.526
HIA10	0.178	0.293	0.526	-0.175	0.301	0.531	-0.065	0.703	0.827
HIA11	-0.139	0.412	0.612	0.339	*0.040*	0.178	0.146	0.388	0.590
HIA12	0.489	*0.002*	**0.032**	-0.456	*0.005*	**0.046**	-0.070	0.683	0.813
HIA13	-0.247	0.141	0.346	0.398	*0.015*	0.104	0.364	*0.027*	0.154
HIA14	0.092	0.587	0.727	-0.201	0.233	0.458	0.025	0.883	0.929
HIA15	-0.043	0.804	0.909	0.208	0.224	0.455	0.172	0.315	0.532
HIA16	0.096	0.571	0.718	-0.010	0.951	0.968	-0.034	0.840	0.917
HIA17	-0.137	0.418	0.612	0.339	*0.040*	0.178	0.275	*0.099*	0.306
HIA18	0.139	0.413	0.612	0.084	0.623	0.755	0.090	0.595	0.728
HIA19	0.161	0.342	0.539	-0.177	0.294	0.526	-0.163	0.334	0.539
HIA20	0.257	0.124	0.346	-0.256	0.127	0.346	-0.106	0.530	0.692
HIA21	0.285	*0.087*	0.299	-0.412	*0.011*	**0.084**	-0.337	*0.041*	0.178
HIA22	-0.111	0.515	0.692	0.277	*0.097*	0.306	0.049	0.774	0.884

6.4.3 PCC & MHLC

Since the MHLC and PCC surveys were both partially targeted at evaluating each client's view of care at EPHI, I also investigated MHLC & PCCScore's relation to one another. Correlations between MHLC dimensions and PCCScore were less sweeping than with the HIA survey. MHLC-INT was positively correlated with PCC score and MHLC-CHA was negatively correlated, but these effects did not reach statistical significance. MHLC-OTH showed little correlation.

When the PCCScore is decomposed into individual questions, significant positive connections with MHLC-INT emerge for a few items. These include comfort asking their advisor a question ($r = 0.345$, $p = 0.034$) and feeling in charge of their health action plan ($r = 0.468$, $p = 0.003$). MHLC-CHA meanwhile is negatively correlated with feeling in charge of the action plan ($r = 0.424$, $p = 0.008$). MHLC-OTH remained an insignificant correlate.

6.5 Discussion

First, I discuss my research question **RQ-OHS-2**, which asks whether OHS is related to PCC or other desirable indicators of care quality and patient empowerment. Second, I consider the relationship between MHLC and my PCCScore metric. Finally, I consider what my survey results mean for related research questions **RQ-OHS-3** (OHS-as-intervention) and **RQ-ESS-2** (social-search-as-intervention).

6.5.1 OHS's Patient-Centered Potential

Relevant to **RQ-OHS-2**, I found evidence suggesting OHS is related desirable health metrics like PCC. Multiple strong correlations between my PCCScore metric and positive OHS experiences (refer back to Tables 5, 6, and 7) are an encouraging sign for OHS's potential. Desirable higher internal MHLC scores were also associated with positive OHS values (refer back to Table 8 and 9), while less-desirable external

scores (particularly on the MHLC Chance dimension) were negatively correlated. I also saw connections between OHS and MHLC in my interviews (discussed in the previous chapter), such as C1's description of searching as part of their personal health responsibility given their desire to have children.

Further work is needed to completely understand OHS's relationship to patient sentiments about their care and health. OHS's sporadic nature makes it challenging to study the causality of the OHS-PCC-MHLC relationship, which was exacerbated by EPHI's closure. Future work should consider taking an extremely longitudinal approach of many months or even years. Still, the sheer number of positive associations with OHS observed in my surveys encourages further investigation.

Going forward, it will also be important to assess OHS in other healthcare settings. EPHI was on the leading edge of healthcare delivery, emphasizing proactive, participatory care. As more healthcare providers adopt these approaches, my results can guide the structuring of similar advisor-client relationships relative to OHS. The EPHI's mostly high socio-economic status clients are particularly likely to be online health seekers. In other settings with different demographics, clients may be dissuaded from OHS by a perceived lack of options or expertise. My results can serve as a comparator to these other settings. Even as OHS and Internet use continue to increase, researchers must be cognizant of a potential 'digital divide'.

6.5.2 MHLC vs PCC

Comparing MHLC-OHS and PCCScore-OHS correlations reveals interesting differences. PCCScore was strongly associated with positive OHS experiences like discussing resources with an advisor or doctor, or receiving resources. MHLC correlated instead with OHS values; with viewing online health information as useful for different tasks. It is straightforward to imagine a self-actualized, high MHLC-INT patient

is more likely to value online resources they find themselves. Why however was discussing these resources associated with PCCScore, but not MHLC-INT?

MHLC is tightly focused on falling ill, recovering, and who is 'in charge' of these processes. There is little within the MHLC that directly measures aspects of patient-centered care like whether health professionals have a holistic understanding of the patient's life. In contrast, PCCScore includes items measuring health professionals' familiarity with the patient's life and health concerns. This distinction seems to explain the correlation between PCCScore and discussing resources, as well as the absence of a similar link with internal MHLC. In this light, perhaps it is not surprising that MHLC and PCCScore were only lightly correlated they may be measuring different, complimentary but partially independent components of care. It is difficult to completely encapsulate a concept as broad and context-sensitive as patient-centeredness. I thus recommend researchers interested in patient-centered care combine a custom measure with other instruments as I have done with PCCScore, the MHLC scale and interviews.

6.5.3 OHS as an Intervention

Though my system was not successful in creating measurable responses, the correlations between OHS and other metrics like MHLC and PCC are motivation to continue exploring OHS as an intervention (**RQ-OHS-3**). In this section, I discuss how a future OHS-based intervention could learn from my own experiment.

An intervention may be able to increase user motivation for OHS. At EPHI, clients search sporadically, often when inspired by a health-related event like the EPHI assessment or a family member's health need. Designs should try to drive engagement by connecting to common sources of motivation like family and novel test results. Clients also described searching after reading or listening to a personally interesting resource. An application could try to help advisors use their familiarity

with clients to share relevant resources to motivate OHS.

Though there are plausible approaches, simply encouraging more online searching is likely not the best approach. While increasing the frequency of OHS may appear to be low-hanging fruit, in practice this is not the case. We have seen that personal OHS is not for most a daily routine; rather it is 'bursty', stemming from important health experiences. In our interviews, we saw examples like a new cancer diagnosis or an EPHI assessment: while an intervention may be able to create a unique health experience to provoke OHS, it will be difficult to 'keep it up' and continually re-motivate searches. Participants will eventually sate their information needs, or the intervention's health experience risks becoming routine and less motivating, as with EPHI's assessments. If EPHI's extensive testing and scanning devices can become old hat, continually motivating more OHS seems daunting.

Interestingly, self-reported frequency of OHS was not significantly correlated with either PCCScore internal MHLC scores, but was significantly negatively correlated with external MHLC scores. Rather than search frequency, valuing online resources (for MHLC-INT) and interacting around those resources (for PCCScore) are the best predictors. This seems to be an encouraging sign, since OHS frequency is likely difficult to affect.

Rather than focusing on OHS frequency, future work should consider OHS quality, including the quality of interactions around online resources. PCCScore was strongly correlated with discussing online health resources with doctors and advisors, and with receiving resources from advisors. Encouraging these conversations and exchanges and ensuring that they are positive fits the model of a participatory, patient-centered environment and could have a salutatory effect on measures of PCC. Desirable internal-MHLC scores were also associated with valuing online resources. An intervention could improve perceived resource quality: our interviews suggest ensuring resources are personally relevant and detailed could be effective. Creating

more positive exchanges around OHS with health professionals could also have the side effect of making those online resources seem more useful.

CHAPTER VII

ANALYSIS OF ADVISOR-CLIENT EMAIL COMMUNICATION

In this chapter, I present my initial analysis of client-advisor email communications. I was able to access and analyze a historical record of emails between all advisor and clients, not just those in my survey and system deployments. Along with basic analysis of message frequency and length, I use topic modeling and sentiment analysis to evaluate this dataset. My results are a valuable window into a healthcare facilitator-client relationship, including but not limited to OHS (**RQ-OHS-1**).

7.1 Dataset

The source my dataset is the EPHI's 'patient portal'. This is a website maintained by the EPHI to store all client data, which is made accessible to clients through a web interface. EPHI advisors are also required to log all communications with their clients in this portal. I was granted access to the portal, and scraped these communication logs. Log data was initially extremely noisy. Advisors uploaded their communications via a webform with a single blank textbox, which led to an extreme lack of consistency. While some advisors uploaded each email individually, others uploaded in bulk. Some advisors included some type of email header or exported from an email client, others included just the message itself, and others switched between multiple styles. Advisors also included notes-to-self, notes on phone calls with clients, messages to others about the client (ex: to the client's primary physician) and messages forwarded by the client.

Through an extremely labor-intensive process, I pruned and standardized this dataset to contain only direct messages between advisors and clients. Via manual

examination, I identified a number of email headers that appeared in front of many logs. I also recognized log beginnings based on common salutations like 'Hey [Name]' or 'Good morning,'. When dates could not be concretely determined, ranges were inferred by the date of upload (e.g., a log's possible dates range from the date of the preceding log to the date of the following log). I also compiled a set of email signatures (to remove) and names or aliases (to remove and to recognize who messages were to/from) for each advisor and client. Finally, I used Python's support for regular expressions to process the dataset.

The result of my processing is a set of 49,131 messages; 16,819 from clients to advisors and 32,312 from advisors to clients. I randomly sampled and manually examined 5% of this dataset to confirm it was correctly labeled. The dataset includes messages from 463 clients and all 10 advisors that ever worked at EPHI - two clients of EPHI's 465 total 'active' participants had no recognizable messages logged. These messages span over 5 years, from the first messages between advisors and clients (July 2008) to the last month of the center's operation (August 2013).

While this is a rich dataset, there are significant limitations to be aware of. Most importantly, my logs do not represent a complete record of advisor-client communication. Phone calls and in person conversations are not covered here, nor could all emails be automatically recognized in the raw data scraped from EPHI's portal. Advisors likely failed to log some emails. Less consequentially, despite my sampling it is likely some messages were incorrectly classified in some way. For these reasons, I treat the logs in aggregate, rather than attempting to make comparisons between clients. Bulk collection and analysis of other advisor-client communications was not possible, but Chapter 3 gives a glimpse of EPHI consultations via my shadowing. Even with these limitations, advisors reported email was by far their primary means of communicating with clients aside from in-person assessments. The dataset contains tens of thousands of logs, and likely represents the majority of advisor-client emails.

7.2 Topic Modeling

Topic Modeling is a mixture of machine learning and natural language processing. Generally, an algorithm is trained on a corpus of documents to create a statistical model that describes a set of 'topics'. A topic is a group of related, frequently co-occurring words which presumably represent a common theme, idea or subject. Individual documents can be labeled with topics based on the words they contain, or documents can be described in proportions (e.g., 10% topic A, 30% topic B, 60% topic C). It is generally up to the researcher to label the topics themselves and decide their significance.

In this section of the paper I use Latent Dirichlet Analysis (LDA)[12][1], a popular form of topic modeling, to investigate advisor-client messages. LDA uses a 'bag of words' approach, meaning the order of words in each document (e.g., an individual email/message in my corpus) does not matter. Words may appear in multiple topics. Within topics words are weighted by a multinomial distribution, meaning that when randomly selecting a word from a topic some words are more likely than others. LDA begins by making assumptions about how documents in a corpus are created given a set of words organized into a pre-set number of topics. Given these rules for creating documents from topics and an observed corpus of documents, LDA works backwards to create a model (e.g. set of topics) that is likely to have created to observed set of documents.

While machine learning researchers are still working to modify and extend LDA, the approach has become a popular off-the-shelf tool for other researchers to investigate text data. LDA has been applied to Twitter [98] and to the Enron corpus of emails [25] amongst others. I used MALLET, an open-source machine learning toolkit which includes LDA functionality using a Gibbs sampling approach, to build a series

[1] for a lighter introduction to LDA, see Edwin Chen's blog post at http://blog.echen.me/2011/08/22/introduction-to-latent-dirichlet-allocation/

of topic models for my dataset [63]. Prior to running MALLET, several modifications were made to my full dataset. A list of common stop words was excluded, and I used regular expressions to replace groups of words referring to dates and times (ex: December 5th, 9:00 am) with tokens like 'timeOfDayToken'. Messages were also split into two groups: those sent by advisors and those sent by clients. I generated topics for each group separately.

Setting the number of topics can greatly influence the results of LDA. Taking an exploratory approach I created models of 10, 20, 50 and 100 topics, ultimately selecting the set of 50 as the best fit. Topics in the 10 and 20 model sets tended to be too generic to label, while the 100-topic model was unwieldy and prone to topics that fit only a few individuals. For all models, I ran 2000 iterations with an α of 50/T (T = num topics). MALLET labels topics sequentially (so, from 0-49 for a 50 topic model) and I use these numbers as shorthand to identify topics. This number does NOT represent the size or priority of a topic. In this section I use the number of documents a topic appears in as a measure of size/frequency. Tables 10 and 11 list 10 examples of advisor and client topics respectively.

Though I removed advisor and client names and aliases from my message set, a few of the smaller topics still included proper names in their top terms. In some cases these were friends, family and significant others. In other cases these names appear to refer to public figures like doctors and authors. When I found a proper name in a topic's top terms, I manually investigated whether it was a personal relationship or a public figure. Personal relations were removed from top term lists, public figures were left in.

Table 10: Selected LDA Topics - Advisors. Selected examples of advisor topics, see Appendix B for full list (of 50). Documents is the number of messages containing text from this topic. Italicized *example terms* are selected from each topic's top 20 words.

#	Advisor Topic Description	Documents
37	Positive Responses	7447
	great good hear like glad time back forward hope enjoy better day news	
27	Weight Management Progress	4482
	weight week pounds goal youre exercise great loss help plan progress lose hope	
4	Action Plan Reminder/Update	3116
	action week steps goals health plan day work continue exercise hope update	
29	Evaluating Action Plan	1506
	goal action main steps optimal vision continue obstacles motivators plan	
49	Scheduling	6079
	appointment visit time good schedule datetoken timetoken send dates available	
1	Sharing a Resource: Exercise	1463
	article great attached health exercise read interesting study book share enjoy	
3	Sharing a Resource: Educational Program	1016
	session heart health presentation disease education attached information	
13	Releasing Assessment Results	3187
	results dr attach lab questions report test pcp blood appointment send review	
7	Preparing for Assessment	1748
	surveys appointment complete timetoken username questionnaires password	
15	Vitamins and Diet	910
	vitamins cholesterol blood density bone levels high diet pressure fat calcium help	

Table 11: Selected LDA Topics - Clients. Selected examples of client topics, see Appendix B for full list (of 50). Documents is the number of messages containing text from this topic. Italicized *example terms* are selected from each topic's top 20 words.

#	Client Topic Description	Documents
14	Health Update: Illness 1	508
	sick cold infection throat week flu fever allergies antibiotics yesterday	
49	Update: Weekend	2700
	weekend great good day nice week fun work weather husband family friends enjoy	
15	Update: Work	478
	work time home day working hours office usually house lot hard lunch	
42	Diet	1958
	eat food day fruits calories less meals veggies sweets good week foods diet intake	
23	Physical Problems	1637
	back pain knee foot better im surgery walking physical doctor shoulder therapy	
20	Share EPHI Results with a Doctor	1771
	results test lab doctor appointment email send blood emory fax office primary	
28	Health Action Plan	2727
	health goal plan exercise action think better good change progress working	
43	Reflecting on Progress 2 (+)	4395
	im ive week good havent trying hope better working try pretty great	
2	Reflecting on Progress 3 (-)	3868
	like dont think time need feel didnt thought guess try never life	
35	Sharing/Responding to Resources	2092
	article great read good information interesting book like forward thought helpful	

7.2.1 Results Overview - Advisors

Again, see Table 10 for an example of advisor topics or see Appendix B for the complete 50-topic list.

For advisors, the top topic by number of documents was 'acknowledgement' or 'positive responses'. Three of the top 4 topics related to generic acknowledgements which seem to be responses to client information/experiences (topics 5, 37, 43). These topics frequently include positive words like *good*, *enjoy*, *great* and *glad*. Scheduling was also common, taking 2 of the top 10 topics (8, 49) and the second most frequent topic overall. Relatedly, four medium to small sized topics (7, 33, 20, 45) concerned preparing for the in-person EPHI assessments. Setting up a visit requires interaction and is a requirement in every advisor-client relationship, so the prevalence of scheduling and visits as topics is to be expected.

Advisors also frequently discussed their client's EPHI Health Action Plan (HAP), with 6 topics (4, 14, 23, 29, 31, 35) related to the HAP. In fact, the aggregate the number of documents containing a HAP topic (13754, 11630 unique documents) is larger than the combined count of scheduling and assessment/visit prep (13095, 11036 unique documents) . Each of these topics blends HAP-centric words like *plan*, *goal*, *action*, *steps* and *progress* with other subjects. Some HAP topics (4, 23, 31) appear to be reminding clients about their HAP or requesting a progress update with words like *check*, *update* or *last* and time periods like *month*. Other HAP topics (14, 29) seem geared to re-evaluating the HAP and creating updated goals. As with the 'acknowledgements' topics, Advisors seem to associate positive words with the HAP - one smaller HAP topic (35) seems to simply be 'positive feelings about the HAP'.

Another key subject for advisors is 'sharing resources'. Like the HAP, there are multiple topics that connect to the overall theme of sharing an informational resource (topics 1, 2, 3, 6, 11, 16, 18, 24, 25, 26, 34, 36, 39, 40, 42, 46). This is a very large number of topics (16), but only two appear in more than 1000 documents and the total

document appearance count (7529, 6866 unique documents) is a little more than half the size of scheduling or the HAP. These topics include resource-indicating words like *story*, *article*, *video*, *information* and *study*, sharing words like *attached*, *thought* and *interested* and positive editorial words like *enjoy*, *hope* and *great*. Along with this base of words, each topic includes subject-specific terms indicating the resource's theme. The larger topics have more generic subjects like articles and books on exercise (topic 1) or educational programs/presentations (topic 3). Smaller topics tend to be more specific: articles on TV time (topic 2), a TED talk on stress (topic 46), a diet-tracking app (topic 34) or MyPlate (the USDA's replacement for the food pyramid, topic 42). These smaller topics still appear in hundreds of messages each, which could indicate these particular resources were used broadly by advisors across multiple clients.

7.2.2 Results Overview - Clients

See Table 11 for an example of client topics or see Appendix B for the complete 50-topic list.

The most common type of topic for clients was 'Reflecting on Progress', with 3 mostly indistinguishable topics in the top 4 receiving this label (topics 2, 34, 43). Each of these topics includes time periods like *days* and *weeks* and personal pronouns like *I* and *I'm*. The topics also include positive words *good* and *better*, negatives like *haven't* and *didn't* and aspirational words like *hope* and *try*. Each of these topics seem to indicate a client reflecting on their progress over a period of time or planning for the future. Scheduling was also a top topic (as with advisors), with 3 topics in the top 10 relating to scheduling (topics 16, 21, 17).

Several other client topics fell into two related categories I call 'Life Update' and 'Health Update'. Life Update topics covered quotidian subjects like work or weekend recreation (Topic 15: *work*, *time*, *hours*, *office*, *hard*; Topic 49: *weekend*, *great*, *weather*, *birthday*, *husband*, *friends*). Topic 5 represents discussions about family

health issues (*mother*, *sister*, *father*, *hospital*, *cancer*, *timeOfDay*). Health Updates seem to be the client's self reports on their own health. The largest of these topics dealt with physical problems (topic 23: *surgery*, *back*, *knee*, *pain*, *therapy*). Other Health Updates covered sleep, illness, surgery and menopause (topics 31, 14, 44 and 36 respectively). Taken together, Life and Health Updates represent clients filling their advisors in on their personal health concerns in the context of their wider life.

Weight management, diet and exercise are three related, common client topic categories. Generic weight management (topic 10, 3209 documents) was the largest single topic not related to scheduling or reflections. Along with words like *weight*, *pounds* and *lost* Topic 10 also counts *diet* and *exercise* among its top terms; both diet and exercise also have a number of their own topics. Diet-related topics (topics 8, 13, 17, 35, 42) range from broad nutrition and eating (topic 8: *eat*, *meal*, *calories*, *food*) to specific 'healthy' foods (topic 13: *salmon*, *broccoli*, *chicken*, *grilled*, *salad*) to parts of the diet (topic 17: drinks). Of 10 exercise-related topics (topics 1, 12, 18, 19, 22, 25, 26, 32, 47, 48), the largest was more generic (topic 25: *training*, *workout*). Others drill down to specific types of exercise including strength training (topic 32), cardio like biking, walking or running (topics 1, 12, 18, 19) and fitness classes (topics 22, 47, 48). Besides exercise-related terms, these topics include timing words like *last*, *week*, *day*, *today*, *minutes* and *hours*. These likely indicate progress reports and planning.

Advisors and clients seem to take a different approach to the HAP. The word 'goal' appears in the top terms list of 4 topics, but other words that were HAP-centric for advisors (progress, action, plan) only appear in one or two topics. Of these few topics, only one (Topic 28, in 2727 messages) seems to be about the HAP. This is still a significant number of documents (16.2% of client messages), but suggests less of an emphasis on the mechanics and terminology of the HAP itself. It may also be the case that topics like 'Reflecting on Progress' and updates on exercise and diet are

in response to an advisor mail about the HAP.

Another difference between advisor and client topics is sharing resources. Advisors clearly devoted a significant portion of email bandwidth to sharing health resources and information with their clients. Client topics had just a single topic (35) that is clearly in response to resource sharing. While this is a larger topic, advisors had a whopping 14 topics related to sharing resources. Client topic 35 likely represents the generic client response to advisor resource sharing. This would also seem to suggest that clients share resources less frequently, though it may also be the case that individual clients shared specialized resources that were not common enough to result in topics of their own.

7.3 Message Lengths and Frequency

To investigate the effects of the EPHI's closing, I next split messages up by date into one of 3 periods. The 'regular period' (RP) spans 1628 days from the earliest advisor message in July 2008 to January 1st, 2013. This represents the center's normal operation. The next period spans 4 months or 120 days from January 2013 through April 2013 representing 'closing period 1' (CP1), after the EPHI's major staff reduction. The center had changed significantly at this point, but had not yet announced its closure. Lastly, 'closing period 2' (CP2) runs 4 months or 123 days through August 2013, up to the center's final closure.

In this part of the analysis I used a new subset of my message dataset. I call this new subset the 'periods' dataset. For this portion of my analysis I first dropped all relationships that did not have at least one client message (6 relationships, meaning n = 457 relationships). Next, I dropped messages with ambiguous dates. Recall that I was unable to generate exact dates for all messages, inferring ranges for these messages instead. I dropped any messages with an inferred date range greater than 2 months. Then, for all messages with a date-range I assigned the middle of this range

Table 12: Periods Dataset - Overview of Messages by Time Period Advisor and client messages for each period were totaled for each of the 463 client-advisor relationships. These totals where then averaged to examine the data in aggregated form, across all advisor-client relationships. Data was scaled to messages-per-month, where 1 month = 4 weeks = 28 days.

Period	Total Msgs, Advisor	Total Msgs, Client	Avg Msgs/Month, Advisor (SD)	Avg Msgs/Month, Client (SD)
RP	27365	14953	1.030 (0.993)	0.567 (0.734)
CP1	2209	1022	1.128 (0.921)	0.522 (0.617)
CP2	1171	503	0.583 (0.614)	0.251 (0.388)

as their exact date. This left me with a set of messages that could be unambiguously divided between the three RP, CP1 and CP2 time periods. This reduced the total number of messages from advisors by 1,525 to a new total of 30,787. Client messages were reduced by 341 to a new total of 16,478.

7.3.1 Message Frequency/Counts

Table 12 provides an overview of this version of my dataset (called the 'Periods Dataset' in contrast to two 'Limited Datasets' I introduce in a moment). From this data we can see that advisors on average sent similar proportions of messages to their clients in periods RP and CP1, but fewer messages during the final CP2 period. Clients followed a similar pattern, but sent roughly half as many messages as their advisors. In each case, the standard deviation is quite high in comparison to the mean. This indicates that some client/advisor relationships saw very few messages, while others saw a very large number. Furthermore in all 3 periods the number of advisor and client messages in any given relationship was strongly correlated (Pearson's r for RP: $r = 0.879$, CP1: $r = 0.783$, CP2: $r = 0.817$, all $p < 0.001$). While this does not reveal whether advisors or clients were driving communication, it does indicate a lack of one-sided relationships with high activity on one side.

Table 13: Limited Dataset - Overview of Messages by Time Period Two limited datasets were constructed, one considering only relationships with at least one message from the client per time period, and an analogous dataset for advisors. This leaves 319 relationships for the advisor dataset and 152 for the client dataset.

Period	Total Msgs, Advisor	Total Msgs, Client	Avg Msgs/Month, Advisor (SD)	Avg Msgs/Month, Client (SD)
RP	19248	6649	1.038 (0.977)	0.752 (0.940)
CP1	1774	577	1.298 (0.964)	0.886 (0.677)
CP2	1082	392	0.772 (0.058)	0.587 (0.407)

7.3.1.1 Analysis with Limited Dataset

The large variances observed above could also be an issue with the the dataset. A relationship that was missing a large number of messages (due to having an unknown date, existing in an uninterpretable form or never being entered into the portal by an advisor) would incorrectly contribute to the large variance. It is not possible to definitively say which relationships truly lacked for messages and which are the product of incomplete data. In an effort to ameliorate this issue, I also report the results of two 'limited' datasets, one for each advisors and clients. These limited datasets are reduced versions of the periods dataset. The limited advisor dataset considers only relationships with at least one advisor message in each time period. The limited client dataset considers only relationships with at least one client message during each period. This leaves 319 relationships and 22104 messages (71.8 % of the full count from the periods dataset) for the limited advisor dataset, 152 relationships and 7618 messages (46.2% of the full count) for the limited client dataset. Table 13 offers an overview of these limited datasets.

Passing a simple sanity check, both limited datasets offer higher message counts per-relationship than the periods dataset, though the difference is small for the advisor RP period. As in the periods dataset, CP2 again has fewer messages than the other periods. The advisor side of relationships again saw the most messages in CP1, then

Table 14: All Datasets - Messages by Time Period Post-Hoc Testing For 'periods' columns, n = 457 (e.g., 457 relationships). For 'limited' data columns, client n = 152 and advisor n = 319. All t-tests are the result of Tukey's HSD.

Period Comparison	Advisor-Periods	Advisor-Limited	Client-Periods	Client-Limited
RP : CP1	-1.962 (p = 0.122)	-4.962 (p <0.001)	1.109 (p = 0.509)	-1.634 (p = 0.233)
RP : CP2	8.488 (p <0.001)	4.478 (p <0.001)	8.444 (p <0.001)	2.056 (p = 0.101)
CP1 : CP2	12.396 (p <0.001)	9.695 (p <0.001)	9.221 (p <0.001)	5.087 (p <0.001)

RP, then CP2. The client limited dataset follows this same order, a departure from the periods dataset where RP had the most client messages. For both advisors and clients, one-way repeated measures ANOVA's suggested the differences between the RP-CP1-CP2 groups were significant for both datasets. For advisors, the periods dataset F = 70.302 and the limited dataset F = 43.495. For clients, the periods dataset F = 48.036 and the limited dataset F = 8.102. For all F-values, p <0.001. Greenhouse-Geisser p-value corrections were needed for all but the advisor-limited dataset, but made no impact given very large F-values. Table 14 reports the result of post-hoc testing with Tukey's HSD.

There were several differences between the limited and periods datasets. On the advisor side, CP1 had a greater relative quantity of messages than RP, but this difference was only significant in the limited dataset. On the client side, the difference between RP and CP2 (RP having a greater relative quantity in both cases) was significant in the periods dataset, but fell just short (p = 0.101) in the limited dataset. Though the client limited dataset flips the relationship between RP and CP1 this difference was not significant in either dataset.

Table 15: Average Message Lengths by Time Period For 'all' columns, n = 457 (e.g., 457 relationships). For 'limited' data columns, client n = 152 and advisor n = 319.

Period	Advisor-Periods (SD)	Advisor-Limited (SD)	Client-Periods (SD)	Client-Limited (SD)
RP	361.752 (162.068)	374.365 (162.833)	218.620 (151.501)	242.511 (140.556)
CP1	292.489 (205.572)	322.307 (203.051)	169.246 (292.489)	282.700 (243.464)
CP2	243.253 (220.630)	324.859 (199.377)	94.247 (180.999)	210.448 (222.491)

7.3.2 Message Lengths

I also examined message length (e.g. character count). As with message frequency in the previous section, the unit of analysis was again advisor-client relationships over three time periods RP, CP1 and CP2. I report results for the periods dataset introduced at the start of this section (all messages that could be dated within 2 months) alongside corresponding results from the 'limited' dataset, considering only relationships with at least one message from during each time period. In the periods data set, advisor and client message lengths were very lightly correlated (Pearson's r for RP: $r = 0.189$ $p < 0.001$, CP1: $r = 0.155$ $p = 0.001$, CP2: $r = 0.110$ $p = 0.018$). It seems advisor and client message lengths are less closely associated than message count.

Table 15 lists the average-per-relationship message lengths for advisors and clients. Two values are reported: one considering all messages, and one ('limited') considering only relationships where there was at least one message in each time period for the given message type (advisor/client). For both the periods and limited datasets and for both advisors and clients, one-way repeated measures ANOVA's indicated a significant difference between groups. For clients, F values were 71.38 (periods) and

Table 16: Average Message Lengths by Time Period Post-Hoc Testing For 'periods' columns, n = 457 (e.g., 457 relationships). For 'limited' data columns, client n = 152 and advisor n = 319. All t-tests are the result of Tukey's HSD.

Period Comparison	Advisor-Periods	Advisor-Limited	Client-Periods	Client-Limited
RP : CP1	6.212 (p <0.001)	3.916 (p <0.001)	4.832 (p <0.001)	-2.220 (p = 0.069)
RP : CP2	10.101 (p <0.001)	3.695 (p <0.001)	13.271 (p <0.001)	1.948 (p = 0.127)
CP1 : CP2	3.742 (p = 0.001)	-0.167 (p = 0.984)	6.417 (p <0.001)	3.053 (p = 0.007)

35.334 (limited). For advisors, F values were 49.448 (periods) and 8.742 (limited). All required a Greenhouse-Geisser correction, but the massive F-values meant p values remained below 0.001. There are clearly stark message length differences between time periods.

Table 16 reports the results of post-hoc t-tests comparing the three time periods. In the periods dataset, both advisors and clients wrote significantly shorter messages moving from RP to CP1 to CP2. The limited dataset has more complicated results. Amongst clients with at least one message in each period (n=152), Messages in CP1 were significantly larger than either RP or CP2. Messages in RP were larger than CP2, but this effect was not significant. On the advisor side, 319 relationships had at least one advisor message in each time period. Messages in RP were larger than in either closing period, while message lengths during the two closing periods appeared equivalent.

7.3.3 Summary

For advisor and clients and in both periods and limited datasets, fewer messages were written in CP2 than other periods, and these messages were shorter. One notable exception is that in the client limited datasets neither message count nor length were

significantly different between RP and CP2. This would seem to indicate that the subset of clients in more regular correspondence with their advisors (represented by the limited dataset) kept closer to their regular messaging habits during CP2 than the bulk of clients. It may also mean that the duration of CP2, when advisors sent their fewest and shortest messages, was not long enough to have a more significant effect on these clients given the less frequent nature of client messaging.

There are other notable differences between the periods and limited datasets comparing RP and CP1. Advisors saw an uptick in number of messages (but not message length) from RP to CP1 in both datasets, though the difference was only significant in the limited set. This may be due to the large number of health advisor switches at the RP:CP1 boundary when EPHI reduced staff. This turnover could have led to a wave of farewell mails from departing advisors and introductory mails from new advisors. Clients did not send a significantly different number of messages from RP to CP1, but in the limited dataset did send significantly longer messages in CP1 than in either other time period. This could also be related to introductory emails, with more committed clients writing more detailed/lengthier farewells and introductions.

7.4 Sentiment Analysis

To study the sentiments of the advisor-client messages, I used the public API available at *www.text-processing.com*[2], which was built using the open-source Python Natural Language Toolkit[3]. The API provides access to a classifier which was trained on datasets from Twitter and movie reviews. Though this is not an ideal training set, other researchers have also used the text-processing.com classifier to provide a first look at sentiments in email messages [68]. The classifier returns 3 scores (each between 0 and 1) for any snippet of text. The first score indicates whether text should be considered polarized or neutral. In a polarized text, the majority of the content

[2]http://text-processing.com/demo/sentiment/
[3]http://www.nltk.org/

Table 17: Sentiment Analysis - Advisors 'Periods' dataset. Percentages are (count of strongly polarized messages during period / total messages in period)

Period	Total Messages	Polarized	Strongly Positive	Strongly Negative
RP	27365	21930	4857 (%17.7)	613 (%2.2)
CP1	2209	1981	490 (%22.2)	35 (%1.6)
CP2	1171	996	225 (%19.2)	16 (%1.4)

Table 18: Sentiment Analysis - Clients 'Periods' dataset. Percentages are (count of strongly polarized messages during period / total messages in period)

Period	Total Messages	Polarized	Strongly Positive	Strongly Negative
RP	14953	11467	1535 (%10.3)	1920 (%12.9)
CP1	1022	786	122 (%11.9)	100 (%9.8)
CP2	503	415	71 (%14.1)	50 (%9.9)

has a positive or negative connotation. The second and third scores indicate the proportion of positive and negative sentiments within polarized text. These scores may each range between 0 and 1, but always sum to 1.

Tables 17 and 18 report sentiment analysis results using the 'periods' dataset (all messages that can be reasonably dated within a 2 month range) across my 3 RP, CP1 and CP2 time periods. Here, I consider any message with a neutrality score below 0.5 to be polarized. I consider a message to be strongly positive or strongly negative if it is both polarized and has a positive/negative score greater than or equal to 0.7.

Across advisors and clients the majority of emails were polarized, but less than half of these messages were strongly polarized. This indicates a large number of emails that contain both positive and negative components. This fits with an image of a typical 'update' email that covers what is going well and what isn't going so well. There is also a very noticeable positive bias with advisors, who wrote over 8 times as many strongly positive messages as strongly negative messages (clients

actually wrote more negative than positive messages). This is a massive difference - as expected, a chi squared test found it to be significant ($\chi^2 = 2287.825$, p <0.001). Across relationships, the ratio of strongly positive to negative messages for advisors vs clients was not strongly correlated.

7.5 Messages and URLs

I also worked to identify messages containing a URL - defined as chunks of text beginning with "http://" or "www.". Table 19 reports the distribution of URLs across the 3 time periods. The total URL counts (inclusive of messages that could not be dated within 2 months) are increased to 4957 for advisors and 347 for clients.

As with sentiment analysis, there is again a massive difference between advisors and clients. Advisors were far more likely to send a message with a URL than clients ($\chi^2 = 1927.553$, p <0.001). For clients, there did not seem to be much change in number of messages with URLs between time periods, but advisors sent a larger chunk of URLs during CP2. This may be due to advisors sending bulk mails to clients which contained URLs.

To connect with my topic modeling, for both advisors and clients I calculated the 10 topics with the highest ratio of URLs within documents that topic appeared in. For advisors, 5 of these topics were in the 'sharing resources' category, while two more (topics 21 and 47) likely could be re-classified as sharing resources. The other topics related to preparing for the EPHI assessment (topics 20 and 45, likely links to

Table 19: Messages Containing URLs Number of messages containing a URL. Percentages based on total number of messages during each period of the 'periods' dataset. 450 relationships (out of 457) contained at least one message with a URL.

Period	Messages with URLs - Advisor	Messages with URLs - Client
RP	4030 (14.7%)	303 (2.0%)
CP1	305 (13.8%)	20 (2.0%)
CP2	218 (18.6%)	9 (1.8%)

complete surveys online) and the EPHI website (topic 28). The far lower number of URLs in client messages makes it less interesting to connect them to topics, but it is at least worth noting that the single client topic on sharing/responding to resources (topic 35) had the highest ratio. Still, this ratio (0.090, meaning 9% of client messages which topic 35 appeared in included a URL) was far below advisor ratios (where the lowest ratio in top 10 was 0.471).

7.6 Discussion

To conclude this chapter, I briefly discuss my analysis.

7.6.1 Information Resources

In previous chapters, I described how advisors used online resources to connect with their clients. Their email records are further testament to this fact. In topic modeling, advisors had 15 of 50 topics fall into a 'sharing resources' category, and frequently sent URLs to their clients. Clients in contrast sent only a few URLs and featured only one topic that seemed to revolve around informational health resources. This is congruent with my other findings suggesting that clients share only a portion of their OHS with their advisors. This also suggests that a health facilitator simply sharing resources with clients is not in itself enough to prompt clients to share back.

The idiosyncratic nature of OHS may also make it difficult to investigate with the aggregate methods I used in this chapter. For example, resources that were specially shared with one or two clients could be subsumed in larger topics related to resource-sharing or otherwise. Topic modeling on a per-relationship basis would be laborious to analyze and likely overkill for relationships with only a few messages. Another approach to investigate OHS in greater detail could be to retrieve and analyze the URLs being passed between advisors and clients.

7.6.2 Client Leadership and Familiarity

As in other chapters, my analysis here suggests that advisors are constantly working to empower their clients. Numerous advisor topics related to the HAP, a tool used by advisors to get clients planning for their own health. Top terms in topics and sentiment analysis both indicated that advisors strongly positive in their messages and very rarely negative, suggesting an effort to create an encouraging atmosphere. It is difficult to gauge how successful these efforts were: only a few client topics were obviously related to the HAP, but more common 'update' client topics could still be related to the action plan. The sheer number of advisor mails compared to client mails fits with feedback from advisors that it was frequently up to them to drive the relationship.

My analysis also indicates email played a role in building familiarity and the advisor-client bond. Numerous client topics relating to 'life updates' and 'health updates' would have helped inform advisors about their clients' lives. Topics like client topic 5 (family illness) and 4 (surgery) show that some clients were comfortable sharing sensitive updates over email. The decrease in messaging during the final closure period (CP2) means this connection point was being squeezed shut.

The rest of my work has evidenced that advisor familiarity and approachability is valued by clients, and in particular is essential for effective OHS. Though per-relationship topic modeling seems like overkill as a research approach, it could be useful as an intervention. Other researchers have used topic modeling to generate summaries about emails [25]. A similar approach could be used to help health facilitators identify subjects that were likely to be sensitive or individual-specific, perhaps to help facilitators catalogue a larger number of clients or to introduce a new facilitator to a client. This information could also be used to target health facilitator OHS or even suggest resources for the facilitator to share.

CHAPTER VIII

REFLECTIONS

In this chapter, I reflect on some of the research methodologies and data-gathering techniques I used in my work with EPHI. I begin by discussing change and treating interventions as probes of an environment. Then, I discuss my experiences interviewing and observing my participants in private settings.

8.1 Changes and Probes

A great deal of HCI research is focused on producing change. I previously discussed researcher's efforts to encourage healthy new behaviors, such as through Chick Clique [101] or StepStream [67]. Fogg attempted to include a wide variety of interventionist research under the label 'Persuasive Technology', defined as "an interactive technology that changes a person's attitudes or behaviors" [32]. Even projects like WeSearch, the experimental tabletop collaborative search system, can be described as an attempt to change the way users search [71]. Each of these projects aims to alter the environment via a technical system.

I suggest along with *producing* changes, researchers should be concerned with *detecting* changes besides those they seek to create. Though EPHI's shutdown is a rather extreme scenario, I found other shifting environmental features —broad features like EPHI's fading novelty and narrow features like individual focus on health —that seemed to play a role in Snack's efficacy. Detecting and understanding changes like these was material to understanding Snack's lackluster performance. An up-to-date picture of the environment could also guide redesigns or even completely distinct interventions.

Technical systems can be used to prod and understand an environment, including

environmental changes. This approach is reminiscent of Hutchinson *et al.'s* technology probes, simple, flexible, and temporary interventions used to gauge technical potential [46]. Hutchinson *et al.* discuss numerous environmental features revealed and characterized through interactions with their probes: idiosyncratic features like the style of a participant's home as well as larger themes like 'families seek playful interactions with one another'. More complicated systems and longer deployments can still function in this capacity —if anything, they increases a project's capacity to detect changes. If a technology probe is like getting a quick temperature reading, a large-scale deployment is akin to installing a thermostat.

A technical intervention should not be deployed in isolation, but rather serve as a grounding point for other research activities, creating a comprehensive program to detect and analyze the environment. Hutchinson *et al.* relied on a broad mix of workshops, interviews and logs to understand their probes relationship to the environment. Yun *et al.*'s asthma technology probes were paired with repeated interviews and sketching activities [112]. My own deployment of Snack included interviews, surveys and logging. A feature or change detected by one method can often be explained or confirmed by another. For example, Snack's use, my exit interviews and my email message analysis all contributed to my understanding of changing advisor-client relationships. Triangulation through mixed methods can unlock otherwise cryptic results, create more rigorous conclusions and correct misconceptions.

8.2 Effective Interviews

Irving Seidman's treatise on interviewing is an invaluable resource for any interviewer [87]. In this section I reflect on which of Seidman's recommendations were highlighted in my work.

I broke with Seidman's suggestion to conduct interviews as a series, which I felt did not match my subject or environment. Seidman suggests running 3 interviews

per participant, spaced apart by several days to a week. The first interview gathers the life history of the interviewee, providing context for later topical (second) and reflection-based (third) interviews. When evaluating Snack I conducted only exit interviews with my participants, compressing the three parts (life history, topical, reflections) into a single interview. I found this format to be an effective 'discount methodology' and question whether multiple interviews would have offered me significantly improved data. An entire 90-minute interview on OHS seems excessive - most clients felt we had exhausted their thoughts on the subject even in my compressed, single interviews. A multi-interview approach may be better suited to topics that are more central to the interviewee. Repeated interviewing could also be a good match for more longitudinal work, as means of detecting changes over time.

Gatekeepers who can give, control or monitor access to participants were absolutely critical in my work. Seidman considers gatekeepers mostly in the context of which authorities the interviewer is socially or legally obligated to consult. In my case, EPHI's advisors served as gatekeepers to EPHI's clients. Seidman wisely cautions researchers to mind any undue influence a gatekeeper could have on participation. When contacting clients I was careful to emphasize that non-participation would have no negative effect on their care at EPHI or with their advisor. Despite this risk, it would have been impossible to conduct my research without working through EPHI's advisors. Like most health care organizations, records and contact information at EPHI are private, and working with gatekeepers like the advisors and the center's directors was a practical necessity. Some clients also mentioned consulting with their EPHI advisor prior to joining one of my research activities. Seidman talks at length about building a relationship with interviewees. For a sensitive subject like health, I suggest that some degree of relationship building is necessary before an interview can even be scheduled. In a sense, my public connection to a trusted

gatekeeper was the first step in building my relationship with each client. My hypothesis is that when studying a sensitive, private topic like health or working with a vulnerable population, working with legitimate gatekeepers from the start is of the utmost importance.

I found the same sort of small, relationship-supporting activities to be key for my shadowing activities as well. As described in Chapter 3, I was present for some intensely personal exchanges between advisors and clients. Consultations took place in a small room, which could have emphasized my intrusion. I feel that extra contact with clients before and after these observations helped humanize myself and clarify my motivations. Again relying on advisors as gatekeepers, I arranged client permission to observe a consultation days or weeks in advance. Clients had the prerogative to cancel my shadowing appointment, though only one chose to do so. I briefly met with clients prior to the consultation, also reminding them that they could ask me to step out temporarily or permanently during the consultation. Finally, conducting an exit interview immediately after gave the clients an opening to reference any part of the observation or ask me a question. Essentially, I was working to build familiarity or rapport with participants in contact beyond the interview itself. This process helped put me at ease as an interloper in a private space. A more targeted investigation would be needed to investigate whether clients felt the same way, but I was pleased that no clients asked me to halt the observation or appeared unsettled in their exit interview.

CHAPTER IX

CONCLUSION

In this final chapter, I revisit my research questions and summarize my work to answer each one. I then reflect on my results overall and consider future research directions suggested by my work in both health and social search.

9.1 Research Questions Revisited

My work in this dissertation revolved around two interconnected themes; Online Health Seeking and Embedded Social Search. By using ESS as a means of studying and intervening in OHS, I was able to investigate both topics simultaneously.

9.1.1 Online Health Seeking

By the time I began my studies at the EPHI, OHS had already been a concern of technologists and especially health researchers for over a decade. Researchers have demonstrated that OHS is a typical activity for large portions of patients and health professionals, and that online resources can have serious effects on searchers. Despite this work it's unclear how exactly OHS should fit into care. My OHS-focused research questions attempt to push this research space forward by investigating OHS's potential to improve healthcare.

RQ-OHS-1: What role does OHS currently play for health facilitators and their clients? Other researchers have described barriers to connecting physicians and their patients through OHS. At the same time non-traditional 'health facilitator' roles that seem more suited to OHS have arisen, such as the EPHI's health advisors. Using EPHI's advisors and clients as an example, RQ-OHS-1 asks how OHS currently fits into this kind of patient-provider relationship.

In Chapter 3, I described the results of a series of a series of formative studies at EPHI including focus groups, shadowing and interviewing. This work helped me to understand the advisor-client relationship as well as OHS's place in that relationship, with the following findings.

1. OHS was a critical, everyday activity for EPHI advisors. Advisors used online resources as a way of reaching out to clients during followups, and also shared resources with one another. Advisors felt client OHS was of variable quality, but could offer insights on individual clients. Advisors also turned to online resources to guide wayward clients towards reputable or 'good' health beliefs.

2. EPHI's clients were for the most part typical health seekers, fitting the profile established by existing OHS research. Clients preferred general search engines and mostly reported using simple search strategies.

3. Many clients felt especially comfortable with their advisors, and some even positively contrasted their advisor with their physicians. Between in-person assessments and remote follow-ups, advisors built up their familiarity and rapport with clients, while making themselves available to contact. This familiarity extended to OHS, which clients seem willing to share with advisors.

In Chapter 5 I described the deployment of Snack, a collaborative search tool for OHS at EPHI. This study coincided with EPHI's closure and highlighted changing advisor-client relationships, including around OHS. This extended study also illustrated the significance of advisor-client familiarity and

1. While OHS has previously been a primary activity for advisors, for most advisors during EPHI's sunsetting process OHS was displaced by scheduling and executing in-person assessments. Advisors had less time to devote to OHS, and less time for client/individual-specific OHS in particular.

2. Individual idiosyncrasy and health concerns played a key role in connecting to advisors, including through OHS. A close bond with an advisor or (especially) recognizing the advisor as an information authority in one of the client's pet topics drove clients to respond to advisor resources and activity. Advisor-shared resources that were perceived as generic or irrelevant had less impact.

RQ-OHS-2: Are there connections or correlations between OHS and quality indicators like patient-centered care? OHS seems intuitively compatible with creating a patient-centered environment. In Chapter 6 I described the results of a series of 3 surveys deployed with EPHI clients. These surveys let me examine the correlations between attitudes about online health seeking, components of patient-centered care and perceived control of health.

1. Positive values and experiences with OHS were associated with higher PCC scores, while some negative OHS values were negatively correlated with PCC. The strongest positive OHS:PCC correlations involved positive OHS experiences with an EPHI advisor, like sharing or discussing OHS.

2. Several significant correlations were observed between the 3 MHLC dimensions and OHS values. All significant correlations between OHS values and a desirable Internal locus of control were positive. All significant correlations between OHS and the less-desirable Chance or Powerful Others loci were negative.

3. The quality of online resources and OHS-related interactions may be more important than their frequency.

Of course, these survey correlations do not show causality. However in aggregate they paint a uniformly positive association between high ratings of OHS, good advisor-client relations and client control of health.

RQ-OHS-3: Can OHS be used as tool to create a more patient-centered environment? Chapter 4 described the design of Snack, an intervention intended to

encourage a patient-centered environment through OHS. Chapter5 covered Snack's evaluation.

1. Timing is absolutely critical for OHS. Health seeking is not usually a continual activity. Instead, it is typically motivated by a new personal, family or friend health concern. Even EPHI's extensive assessments were most motivating when they revealed a previously unknown health problem. If a patient doesn't experience any health events during a study, OHS and any interventions could be minimized.

2. Health seekers are largely satisfied with existing online resources. Furthermore, they have no patience for tools or information they view as generic or restrictive, even when the information comes from a valued source.

3. Health professionals can drive client engagement with an intervention if they share a good relationship with their clients *and* leverage resources that are personally relevant to individual clients. This requires significant effort, knowledge and familiarity on the part of health professionals.

9.1.2 Embedded Social Search

I suggested the term 'embedded social search' to emphasize that social search processes and tools are enmeshed in complicated, changing environment. Existing theories of collaborative information seeking already suggest that social inputs (and thus, human relationships) can affect all phases of a search. Studies of collaborative search tools have also shown that factors that seem only indirectly connected to information seeking needs, like social hierarchies, can change how users interact during searches. My ESS-related research questions ask if researchers can use social search as a springboard to understand and change larger environments.

RQ-ESS-1: Can collaborative search ground a larger investigation into a specific environment? My first ESS research question asks whether social search

tools can drive wider investigations of any given search context. In a field study, collaborative search is immersed in and influenced by the day-to-day life of searchers. Can social search tools thus provide a window into non-search activities?

1. Traditional user-centered design approaches can reveal searcher relationships, styles and motivations in given environment. This can guide a tailored system design that fits existing social relationships. This approach comes with some risk however, as a search tool that is ill-fitting risks being less appealing than generic alternatives. Snack, for example, was designed for a context that no longer existed at the EPHI by the time of its deployment and was largely abandoned.

2. Understanding social search *in situ* requires a multi-pronged investigation. In the case of my studies, examining system logs or browser history traces alone would never have exposed client sentiments about their advisors or explained shifting advisor priorities. Researchers should employ a variety of ethnographic methods to dig into the rich context search tools are embedded in and influenced by during a field study.

3. Social relationships can be a significant factor for collaborative search engagement, and investigating how and why users engage (or disengage) with a system can reveal their perceptions of one another. Researchers can gain broad insights about a class of user, like feeling their advisors no longer had time for them. Idiosyncratic details specific to one searcher or relationship can also be expressed in search system engagement.

RQ-ESS-2: Can a social search tool be used as an intervention to affect processes besides information seeking? While my first ESS research question covers the affect of the world on a social search tool, my second question asks how social search can affect the world. Can social search tools change user relationships beyond search?

My results offer no concrete answer to this question. EPHI's closure created a severe shift in client-advisor ties making Snack a poor fit to begin with. OHS's infrequent nature only exacerbated the problem as components intended to drive engagement, like search challenges, had little effect. Though my studies can't resolve the suitability of social search as an intervention, my work can still guide future social search intervention attempts.

In the field, social search tools must be vigilant for changes in the search context. EPHI's funding issues have nothing to do with client OHS but over time produced sweeping changes at EPHI, including the role of online resources. Especially if the tool is tightly tailored to match a certain model of user relationships and roles, unanticipated shifts in search context can be crippling. Asymmetric search tools that involve users with different settings and backgrounds introduce more opportunities for an environment in flux to impact search, and may be particularly susceptible.

9.2 Reflections and Future Work: OHS

In my work I found a number of encouraging signs for OHS's viability as part of a patient-centered clinic. OHS values were associated with health measures like an internal locus of control and prior to the shutdown process, OHS was a key part of care at EPHI. EPHI seemed like an ideal candidate for an OHS intervention, which makes its closure all the more frustrating. EPHI advisors often had a perfect mix of characteristics: familiarity with what individual clients were interested in, relevant professional knowledge and resources, enough rapport to put clients at ease, and the time (and job description) to put it all together in the form of social OHS.

Though EPHI's advisors are gone, other such healthcare facilitators exist, and these non-traditional roles may be the best bet for future OHS interventions. Just like EPHI's advisors, health facilitators like cancer navigators and child life specialists are working to help clients bridge the gap between the health world and their personal

life. OHS seems like a good match with a health care facilitator's mission of educating and empowering their charges. Perhaps more importantly, health care facilitators may be able to side step some of the issues facing a physician-focused intervention.

Casting an even wider net, other personal health experts like trainers and coaches could be a match for OHS. EPHI clients were particularly interested in resources from advisors whom were a recognized authority on a topic of particular personal interest for the client. Advisors each had a unique background however. While expertise as a personal trainer could be exciting to a weight-lifting client but irrelevant to another. Working with a specialized health expert like a trainer with their regular clients, as opposed to a generalized environment like the EPHI, could avoid this issue and set the stage for a motivating social search tool.

Future studies of OHS should also explore more formal integration with a health system. I received feedback from advisors and clients that Snack would have been most useful when they first joined EPHI or first discovered a health problem. An OHS system that was considered a basic part of treatment would be available at these critical times. Making OHS part of a standard encounter, like embedding online resources into EPHI's assessments, could also encourage OHS discussion and make it clear to patients that the subject was welcome. Finally, personal health records (PHR's) could be a natural landing spot for OHS. PHR's are already an electronic 'home' for patients to take control of their health data. OHS systems could draw on information in the PHR to motivate or guide patient searches or even store and treat OHS as another form of 'patient health information', of interest to patients and doctors alike.

9.3 Reflections and Future Work: ESS

My work shows that search processes and tools can be a grounding point to investigate an environment over time. OHS was just one of many threads between EPHI's

advisors and clients, but explaining OHS activities forced me to reach beyond online resources to both high-level trends like new advisor priorities and low-level trends like individual health events. Deploying Snack put the changes at EPHI into sharp relief and the system served as concrete foil for clients and advisors to explain their current relationships.

Though collaborative search proved excellent means of investigating EPHI and OHS, my designs failed as interventions. My systems had little chance to succeed when the search context they were designed for disappeared from underneath them. It is impossible to say whether Snack would have been more successful in the original EPHI environment - other issues with the design may have arisen in that scenario. However, even if the design was a solid match it may have been difficult to evaluate my intervention's success.

When I selected OHS it seemed an ideal candidate for intervention, but several characteristics made my work a challenge. For one, patient-centered care cannot be measured as readily as something like blood pressure. Researchers write entire papers just trying to nail down the generic definition of PCC. Getting to the level of measurable outcomes requires context-specific planning and instrumentation. I had to carry out a thick investigation with a variety of methods to identify and then monitor PCC's different facets at EPHI, which may not always be generalizable. Besides these measurement issues, OHS is naturally an irregular occurrence for typical health seekers. While EPHI advisors used to be constant health seekers, even if search challenges had been more successful my intervention would have a limited number of chances to impact clients.

Future researchers investigating social search as an intervention should choose their search environment very carefully. An environment with frequent searches would be ideal, giving an intervention ample opportunities to produce a measurable change.

If possible researchers should also select a stable environment, or one where sweeping changes in search context are part of the research plan from the start. More work is also needed to determine whether there is a difference in how passive and active/collaborative social search tools relate to their embedding environment. While Snack included some passive components (like results highlighting), my system clearly falls toward the collaborative end of the social search spectrum. A social search design that skews passive seems likely to place less emphasis on individual user relationships than I observed with Snack, for example.

Despite Snack's struggles, the prospect of using social search as an intervention remains enticing. Collaborative information seeking is becoming ever more omnipresent - here I studied healthcare, but the generic nature of searching via social networks brings CIS nearly to omnipresence. If a social search tool can be shown to change its surrounding environment, such as how users relate to one another when not searching, researchers will have a new avenue for interventions anywhere collaborative search takes place.

APPENDIX A

SURVEYS

A.1 Health Information Attitudes (HIA)

The next few questions ask about '**online health or wellness information**'. This includes everything from diets and exercise to comparing drugs, doctors, insurance or symptoms. Anything directly concerned with health, for you or for others! For example: Looking up low-fat recipes or a gym for your child counts. So does searching for cold remedies or visiting an online forum for depression support.

1. How often do you access the Internet?
   1 – Never
   2 – Rarely: a few times a year
   3 – Sometimes: every month or two
   4 – Frequently: multiple times a month
   5 – Often: multiple times a week
   6 – Very Often: daily or more

2. How often do you search online for health or wellness information?
   1 – Never
   2 – Rarely: a few times a year
   3 – Sometimes: every month or two
   4 – Frequently: multiple times a month
   5 – Often: multiple times a week
   6 – Very Often: daily or more

3. How often do discuss online health resources with your HEALTH PARTNER?
   1 – Never
   2 – Rarely: a few times a year
   3 – Sometimes: every month or two
   4 – Frequently: multiple times a month
   5 – Often: multiple times a week
   6 – Very Often: daily or more

4. How often do discuss online health resources with your DOCTOR?
   1 – Never
   2 – Rarely: a few times a year
   3 – Sometimes: every month or two
   4 – Frequently: multiple times a month
   5 – Often: multiple times a week
   6 – Very Often: daily or more

5. How often do discuss online health resources with your OTHER HEALTH PROFESSIONALS (Examples: Therapist, Counselor, Trainer)?
   1 – Never
   2 – Rarely: a few times a year
   3 – Sometimes: every month or two
   4 – Frequently: multiple times a month
   5 – Often: multiple times a week
   6 – Very Often: daily or more

6. How often do discuss online health resources with your FRIENDS and FAMILY?
   1 – Never
   2 – Rarely: a few times a year
   3 – Sometimes: every month or two
   4 – Frequently: multiple times a month
   5 – Often: multiple times a week
   6 – Very Often: daily or more

7. Have you ever made a health decision based on information you found online?
   a. Yes
   b. No

For the following questions, please indicate how much you agree with each statement by circling a number.

8. Online health information is useful or good for...

	Strongly Disagree			*Neutral*			*Strongly Agree*
A deciding ('diagnosing') how I am sick or hurt	1	2	3	4	5	6	7
B getting more details about my health concerns	1	2	3	4	5	6	7
C helping others with their health	1	2	3	4	5	6	7
D deciding if I need to talk to a health professional	1	2	3	4	5	6	7
E explaining my concerns to a health professional	1	2	3	4	5	6	7
F explaining my health or concerns to friends and family	1	2	3	4	5	6	7
G comparing treatment options	1	2	3	4	5	6	7
H comparing health professionals	1	2	3	4	5	6	7
I understanding the health concerns of others (friends, family)	1	2	3	4	5	6	7

9. I can usually find useful online health information myself.
Strongly Disagree *Neutral* *Strongly Agree*
1 2 3 4 5 6 7

10. Discussing online health information with my Health Partner improved our relationship.
Strongly Disagree *Neutral* *Strongly Agree*
1 2 3 4 5 6 7

11. Online health information is NOT very interesting to me.
Strongly Disagree *Neutral* *Strongly Agree*
1 2 3 4 5 6 7

12. When I look for online health information, what I find is just for me.
Strongly Disagree *Neutral* *Strongly Agree*
1 2 3 4 5 6 7

13. Health professionals are the only source of good health information.
Strongly Disagree *Neutral* *Strongly Agree*
1 2 3 4 5 6 7

14. I'm confident I can tell if a piece of online health information is relevant and good quality.
Strongly Disagree *Neutral* *Strongly Agree*
1 2 3 4 5 6 7

15. Looking for online health resources myself does more harm than good.
Strongly Disagree *Neutral* *Strongly Agree*
1 2 3 4 5 6 7

16. My Health Partner gives me useful online health resources.

Strongly Disagree			*Neutral*			*Strongly Agree*
1	2	3	4	5	6	7

17. You can't trust online health information.

Strongly Disagree			*Neutral*			*Strongly Agree*
1	2	3	4	5	6	7

18. My Health Partner is NOT interested in the online resources I find.

Strongly Disagree			*Neutral*			*Strongly Agree*
1	2	3	4	5	6	7

19. I've made good use of an online health resource.

Strongly Disagree			*Neutral*			*Strongly Agree*
1	2	3	4	5	6	7

20. The online health information I find could be useful to others.

Strongly Disagree			*Neutral*			*Strongly Agree*
1	2	3	4	5	6	7

21. Online health resources have affected some of my health decisions.

Strongly Disagree			*Neutral*			*Strongly Agree*
1	2	3	4	5	6	7

22. I need help deciding how 'good' the health information I find online is.

Strongly Disagree			*Neutral*			*Strongly Agree*
1	2	3	4	5	6	7

A.2 Patient-Centered Care (PCC)

Bonner, M., M. Mynatt, E. D. Gauging the Patient-Centered Potential of Online Health Seeking. In Proceedings of the eighth annual International conference on Pervasive Computing Technologies forHealthcare. Pervasive Health '14. Oldenburg, Germany.

This survey should not be considered broadly validated!

Client Survey - PCC

Instructions: Please indicate how much you agree with each statement by circling a number below.

1. My Health Partner makes sure I understand the test results from my Assessment that are most important to me.

Strongly Disagree			*Neutral*			*Strongly Agree*
1	2	3	4	5	6	7

2. My Health Action Plan addresses the health issues I feel are most important for me.

Strongly Disagree			*Neutral*			*Strongly Agree*
1	2	3	4	5	6	7

3. When I email or talk with my Partner, we cover my main concerns.

Strongly Disagree			*Neutral*			*Strongly Agree*
1	2	3	4	5	6	7

4. My Health Partner understands and cares about both my personal and my professional life.

Strongly Disagree			*Neutral*			*Strongly Agree*
1	2	3	4	5	6	7

5. I am comfortable asking my Health Partner questions about my test results, action plan and health in general.

Strongly Disagree			*Neutral*			*Strongly Agree*
1	2	3	4	5	6	7

6. I am in charge of my Health Action Plan's parts and goals.

Strongly Disagree			*Neutral*			*Strongly Agree*
1	2	3	4	5	6	7

7. I know which parts of my health I most need to work on.

Strongly Disagree			*Neutral*			*Strongly Agree*
1	2	3	4	5	6	7

8. My Health Partner knows how I feel about my health. They understand which parts I'm worried about, and what I feel good about.

Strongly Disagree			*Neutral*			*Strongly Agree*
1	2	3	4	5	6	7

Version Date: 2/21/2013

9. I feel like I have a personal relationship with my Health Partner.

Strongly Disagree			*Neutral*			*Strongly Agree*
1	2	3	4	5	6	7

10. The steps and goals in my Health Action Plan are the best way for me to improve my health.

Strongly Disagree			*Neutral*			*Strongly Agree*
1	2	3	4	5	6	7

11. My Health Partner recognizes and respects my contributions to my health.

Strongly Disagree			*Neutral*			*Strongly Agree*
1	2	3	4	5	6	7

12. My Health Partner understands how my job or family life impacts my health.

Strongly Disagree			*Neutral*			*Strongly Agree*
1	2	3	4	5	6	7

A.3 Multidimensional Health Locus of Control Form A (MHLC)

Adapted from http://www.nursing.vanderbilt.edu/faculty/kwallston/mhlcforma.htm.
Wallston, K.A., Strudler Wallston, B., and DeVellis, R. Development of the Multidimensional Health Locus of Control (MHLC) Scales. *Health Education & Behavior 6*, 1 (1978), 160 –170.

Client Survey - HLC

Instructions: Please indicate how much you agree with each statement by circling a number below.

1. If I get sick, it is my own behavior which determines how soon I get well again.

Strongly Disagree			*Neutral*			*Strongly Agree*
1	2	3	4	5	6	7

2. No matter what I do, if I am going to get sick, I will get sick.

Strongly Disagree			*Neutral*			*Strongly Agree*
1	2	3	4	5	6	7

3. Having regular contact with my physician is the best way for me to avoid illness.

Strongly Disagree			*Neutral*			*Strongly Agree*
1	2	3	4	5	6	7

4. Most things that affect my health happen to me by accident.

Strongly Disagree			*Neutral*			*Strongly Agree*
1	2	3	4	5	6	7

5. Whenever I don't feel well, I should consult a medically trained professional.

Strongly Disagree			*Neutral*			*Strongly Agree*
1	2	3	4	5	6	7

6. I am in control of my health.

Strongly Disagree			*Neutral*			*Strongly Agree*
1	2	3	4	5	6	7

7. My family has a lot to do with my becoming sick or staying healthy.

Strongly Disagree			*Neutral*			*Strongly Agree*
1	2	3	4	5	6	7

8. When I get sick, I am to blame.

Strongly Disagree			*Neutral*			*Strongly Agree*
1	2	3	4	5	6	7

Version Date: 2/21/2013

Adapted from http://www.nursing.vanderbilt.edu/faculty/kwallston/mhlcforma.htm.
Wallston, K.A., Strudler Wallston, B., and DeVellis, R. Development of the Multidimensional Health Locus of Control (MHLC) Scales. *Health Education & Behavior 6*, 1 (1978), 160 –170.

9. Luck plays a big part in determining how soon I will recover from an illness.

Strongly Disagree			*Neutral*			*Strongly Agree*
1	2	3	4	5	6	7

10. Health professionals control my health

Strongly Disagree			*Neutral*			*Strongly Agree*
1	2	3	4	5	6	7

11. My good health is largely a matter of good fortune.

Strongly Disagree			*Neutral*			*Strongly Agree*
1	2	3	4	5	6	7

12. The main thing which affects my health is what I myself do.

Strongly Disagree			*Neutral*			*Strongly Agree*
1	2	3	4	5	6	7

13. If I take care of myself, I can avoid illness.

Strongly Disagree			*Neutral*			*Strongly Agree*
1	2	3	4	5	6	7

14. Whenever I recover from an illness, it's usually because other people (for example, doctors, nurses, family, friends) have been taking good care of me.

Strongly Disagree			*Neutral*			*Strongly Agree*
1	2	3	4	5	6	7

15. No matter what I do, I'm likely to get sick.

Strongly Disagree			*Neutral*			*Strongly Agree*
1	2	3	4	5	6	7

16. If it's meant to be, I will stay healthy.

Strongly Disagree			*Neutral*			*Strongly Agree*
1	2	3	4	5	6	7

17. If I take the right actions, I can stay healthy.

Strongly Disagree			*Neutral*			*Strongly Agree*
1	2	3	4	5	6	7

Adapted from http://www.nursing.vanderbilt.edu/faculty/kwallston/mhlcforma.htm.
Wallston, K.A., Strudler Wallston, B., and DeVellis, R. Development of the Multidimensional Health Locus of Control (MHLC) Scales. *Health Education & Behavior 6*, 1 (1978), 160 –170.

18. Regarding my health, I can only do what my doctor tells me to do.

Strongly Disagree			*Neutral*			*Strongly Agree*
1	2	3	4	5	6	7

Version Date: 2/21/2013

APPENDIX B

TOPIC MODELING

This Appendix contains complete 50-topic lists for advisors and clients, as described in chapter 7. The top 20 words for each topic are also listed.

B.1 Advisor Topics

Table 20: **All LDA Topics - 50 Topic Model Advisors** Italicized *example terms* are the topic's top 20 words.

#	Advisor Topic Description	Documents
0	Checking In: New Year	476
	new year time health things days like think happiness trying article better accomplished happy equation start months try reflect	
1	Sharing Resources: Exercise	1463
	article hope thought great attached week health good exercise read interesting wanted study dr book share enjoy weekend things	
2	Sharing Resources: TV And Health	705
	article time sitting day interesting spend attached hope think thought new tv front york week times reading find health	
3	Sharing Resources: Educational Program	1016
	session heart health presentation disease education hope attached week questions power point last information interested thought cancers weekend genes	

4	Health Action Plan:Reminder/Update	3116
	action week goal steps goals minutes health plan day days work continue exercise times hope update follow wanted time	
5	Giving Tips: Strength Training	1753
	training strength exercise body weight exercises muscle week workout routine workouts fat reps weights intensity cardio good increase mass	
6	Sharing Resources: Sugar And Drinks	555
	information hope questions week great helpful good find sugar attached best types water drinks obvious morning day wanted share	
7	Preparing For Assessment	1748
	surveys appointment complete timeofdaytoken username questions need information questionnaires password dateofmonthtoken water prior hours remember survey visit wanted website	
8	Scheduling	3021
	timeofdaytoken dateofmonthtoken work dates times available appointment schedule time visit hours need hope tues great friday thursday thurs week	
9	Checking In	2014
	hope week day weekend weather great good enjoy nice best thing days last asked happened past youre like today	
10	Acknowledgement	5130
	think like dont im good time help day feel back youre work lot better try stress hear things few	
11	Sharing Resources: Health And Halloween	418
	exercise halloween article like great benefits research keeping questions enjoy weekend completely highlights green tea across feel treats thought	

12	Healthy Diet	2680
	eating eat fruit day food diet fruits foods veggies dinner vegetables fat less lunch breakfast protein snack meals snacks	
13	Releasing Assessment Results	3187
	results dr attached lab questions report health test pcp hope blood appointment assessment good great send visit review follow	
14	Health Action Plan: Reminding ,Changing	1894
	health plan action hope changes week follow hey important things goals last new great confident weekend making area started	
15	Vitamins, Diet And Health	910
	vitamin cholesterol blood density bone foods levels high food diet eating low lower pressure less calcium help good fat	
16	Sharing Resources: Fitness Program	675
	water emory health program exercise like family atlanta day sports walk staff care years background georgia physical meals medicine	
17	Giving Tips: Cardio And Bike Training Tips	1172
	heart rate minutes bike run time questions running test heat minute training information workouts ride weekend stay send workout	
18	Sharing Resources: Exercise, Smoking And Aging	196
	exercise smoking mice foods new dr eat activity article aging living weight gray prematurely physical program least research raw	
19	EPHI Introduction	381
	health center wanted part new page discovery continue participants information week emory years services time dateofmonthtoken change predictive planning	
20	Preparing For Assessment	824
	visit surveys questionnaires appointment treadmill hours login test blood shoes comfortable vascular username completed time testing clothes side bring	

21	Giving Tips: Holiday Health Advice	277
	time healthy stress family fall pumpkin year enjoy alcohol gatherings drink hope season weekend parties enjoying recipes football weather	
22	Health Over Thanks Giving	288
	thanksgiving meal calories day help vegetables sauce overeating healthy food dinner table turkey pie time enjoy salad dish alcohol	
23	Health Action Plan: Reminding, Requesting Update	4313
	good hope day week weekend youre great afternoon like morning enjoy goal month youve start exercise last forward evening	
24	Sharing Resources: BMI	202
	body story obesity bmi percentage fat watching give think reason health minutes new study hear issue rate eating reported	
25	Sharing Resources: Wasink Dieting	101
	eating people wansink bowls plates glasses environment smaller healthier bowl weight popcorn ate large simple percent ounce full eat	
26	Sharing Resources: Healthy Recipes, Sleep	533
	sleep article people week better help great share wanted salads interesting helpful bed questions research reason eat recipes learn	
27	Weight Management Progress	4482
	last weight week pounds time like goal youre exercise mentioned great loss help plan progress lose hope health month	
28	EPHI Website	894
	link surveys center password username portal questionnaires health page side discovery click login tab free feel contact questions message	
29	Evaluating Action Plan	1506
	goal action description main steps like week vision continue optimal work exercise obstacles motivators health plan better time intake	

30	Advisor Introductions	540
	health exercise partner forward certified center wellness opportunity fitness future training personal instructor new coach introduce working university im	
31	Health Action Plan: Reminding, Requesting Update	2603
	weeks health wanted past week goals forward check couple hearing best few things follow month hear hope last update	
32	Running And Races	213
	run race miles ticket book peachtree good road morning share summer email news work send feel update thought free	
33	Preparing For Assessment/Visit	959
	visit health appointment assessments need hours prior treadmill blood update test review plan action shoes timeofdaytoken surveys assessment vascular	
34	Sharing Resources: Diet Tracker App 2	203
	food youre fooducate item feedback app iphone code website tool android grade sugar type called processed calories apps choices	
35	Health Action Plan: Positive Thinking	322
	like success wanted great goal need feel wont number people weeks picture office example progress think dateofmonthtoken achieving day	
36	Sharing Resources: Added Sugars	201
	sugar added sugars oz amount good dr videos yogurt syrup questions day grams intake fruit recommended dannon product high	
37	Positivity, Acknowledgement	7447
	great im good hear like youre sounds glad time back weekend forward work hope enjoy job better day news	
38	Giving Tips: Cupcake Recipe	201
	cupcakes like day baked ingredients break good think home months time friends dye brownie cupcake alone bakery dateofmonthtoken trunk	

39	Sharing Resources: Sugar and Smoothies	288
	foods article eat including frozen sugar lowest plain like attached dont works thought ideas healthful adding packs smoothies restriction	
40	Sharing Resources: Sun Health	169
	skin sun exposure information sunscreen percent summer months rays enter online cancer wanted addition fact cooking hear ignore cancers	
41	Holiday Wishes	1827
	holiday hope thanksgiving holidays year happy great new season best like week part healthy family goals hey forward focus	
42	Sharing Resources: MyPlate	490
	food myplate weight new calories video intake plate day healthy tracking help attached time diet great guidelines nutrition caloric	
43	Positivity, Acknowledgement	5953
	good hey hope great week weekend glad hear work things nice time last back class fun plan hearing better	
44	Giving Tips: Berry Ice Recipe	201
	day berries sugar fresh tip week work good eating vinegar prepare find hope home ice fruit mixture ingredients recipes	
45	Preparing For Assessment	464
	health visit forward prior hours password tests need blood shoes parking deck last log water discovering excited expected questionnaires	
46	Sharing Resources: TED Talk, Stress	403
	great ted talks wanted thought article week short stress video food time thoughts life share hear hope system immune	
47	(?) Sharing Resources	164
	great top survey strengths character book wanted ive week pretty food hope find things mental hear id makes center	

48	Advisor Introductions	484
	health partner center working love good georgia nutrition new discovery wanted great hope time forward hear id started give	
49	Scheduling	6079
	appointment visit time good schedule hope like dateofmonthtoken day timeofday-token week great wanted work year send dates available follow	

B.2 Client Topics

Table 21: **All LDA Topics - 50 Topic Model Clients**

Italicized *example terms* are the topic's top 20 words.

#	Client Topic	Description	Documents
0	407	Life Update: Work And Changing Jobs	
	emory job new work position stress department management hospital atlanta medical boss person starting interview university phone working fairfax		
1	873	Exercise: Race Training	
	run running half race miles hey training peachtree marathon ran time think road goal mile swim signed runs train		
2	3868	Reflecting On Progress 3	
	like dont think time need feel things didnt good thought guess life better thing give try part never put		
3	815	Alternative Followups (Phone)	
	call email phone message number office cell today mail meeting work received talk home tomorrow called information give reach		
4	493	Vitamins And Supplements	
	vitamin taking supplement daily supplements day iron calcium fish oil vit started pills mg vitamins iu multi cholesterol pill		
5	903	Life Update: Family Illnesses	
	back mother hospital sister daughter surgery old home law last father cancer family dateofmonthtoken mom weeks care dad ago		
6	568	School And Education	
	emory school years classes semester summer college forward university atlanta teaching students ga degree research year class graduation		

7	309	Running
	shoes new running wear bought pair big pretty comfortable disney feet wearing size buy shoe clothes wait foot dont	
8	370	Diet
	sugar diet fat food foods vegan eat think didnt read buy trying baked eggs organic kind intake goods dairy	
9	558	(?) Vacation
	lol good dont today think thing paris red big tomorrow ha yeah tonight bit cheers talk cake food like	
10	3209	Weight Management
	weight pounds lost lbs back lose week think loss last goal exercise down good gained im eating diet plan	
11	260	(?) Chat
	health people ps age info purpose asked smile attached learning parts swimming energy life group ask kind experience	
12	565	Exercise: Biking
	bike ride riding miles weather rode weekend biking saturday mile last silver today didnt rides comet stationary sunday hills	
13	478	Diet
	chicken salad beans cheese made grilled rice oil broccoli olive meat like dinner red last green salmon greens cook	
14	508	Health Update: Illness
	sick cold days infection better throat week flu tomorrow fever allergies stomach feeling virus hoping sinus head antibiotics yesterday	
15	1535	Life Update: Work
	work time home day dont working hours think back down office usually house lot tv need walk hard lunch	

16 2654 Scheduling And Gym

week last today morning day friday gym days yesterday good monday sunday saturday back work night tomorrow thursday didnt

17 710 Diet: Drinks

water drink drinking tea day wine coffee days intake green oz consumption started sweet soda sugar juice glass beer

18 708 Exercise: Cardio Training

minutes rate heart treadmill time run hr monitor min bike minute mph miles gym walk speed elliptical down target

19 1141 Exercise: Biking, Walking

walk walking day miles walked week dog mile times mountain walks days minutes good stone try park weather last

20 1771 Releasing Assessment Results

results dr test lab doctor appointment care email send blood emory visit physical fax pcp work tests office primary

21 2477 Scheduling

timeofdaytoken dateofmonthtoken lets great works work good tuesday time fine best monday thursday sounds available wednesday subject friday ill

22 327 Exercise: Yoga

yoga lbs body fat new room head house move ive moving friends couple wedding weighed duty kitchen workout morning

23 1637 Health Update: Physical Problems

back pain knee weeks foot better im surgery walking physical doctor shoulder left ive pt therapy exercises walk bit

24 379 Driving Directions

road atlanta house building car floor ga parking clifton across left blue room front deck hospital north attached street

25 2505 Exercise: General

week training times exercise gym minutes day weight days cardio goal least walking good strength weights work treadmill workout

26 289 Life Update: Diet, Exercise, Work

bc think like dogs dog track tap yoga stuff yesterday sugar trying love started boss totally taking told

27 6914 Scheduling

appointment dateofmonthtoken work morning need timeofdaytoken time schedule day week available meeting reschedule early friday appt visit afternoon thursday

28 2727 Health Action Plan

health goals goal plan time exercise action think im better work feel need good made change progress working great

29 1165 EPHI Surveys

surveys survey complete completed food password questionnaires visit tomorrow log need send time link finished tried remember site questions

30 1696 Holiday Wishes

year holiday new happy hope thanksgiving holidays great family christmas time good best wonderful day years season part enjoy

31 585 Health Update: Sleep

sleep night bed hours timeofdaytoken better sleeping nights early earlier good morning late asleep dont wake think last working

32 484 Exercise: Strength Training

ups exercises weights push sets leg minutes sit ball pull core body arms squats reps legs arm strength workout

33 1061 Diet

eat fruit eating lunch breakfast protein yogurt snack dinner like foods salad morning cheese fat apple nuts milk day

34 7364 Reflecting On Progress 1

back week work exercise good hope things im time better weeks last busy trying eating few pretty working havent

35 2092 Sharing/Responding To Resources

article great read good information interesting book im think like reading info sending forward love thought link video helpful

36 267 Health Update: Menopause And Wellness

bye hormone trainer food sessions month pilates low menopause doctor dont level weeks day wheat doc journal sleep group

37 183 Heart Disease, Emory Research

heart risk disease women treatment side emory effects long butter research stroke quality system months attack insurance university

38 215 Stress And Wellness

stress fat loss chocolate depression help headaches anxiety energy like body hormone overweight thoughts breathing natural levels high cortisol

39 584 Sports

playing tennis play team game good weekend football games soccer won kind played best year season saturday

40 391 Study Participation

health program center emory study partner university predictive care sciences woodruff discovery support miller group people years participants participate

41 1244 Vacation

back week trip weeks vacation days last travel im summer leaving hope best return couple few home dateofmonthtoken june

42 1958 Diet

eat eating food day fruits calories less meals dont veggies sweets good week foods vegetables diet lot intake fruit

43	4395	Reflecting On Progress 2
	im ive week good havent think trying ill hope day better back days working like time try pretty great	
44	269	Health Update: Surgery
	surgery fingers eye crossed told annual month project cataract wireless insurance evaluation free dog eyes connected strength concerns future	
45	1086	Bloodwork Results
	blood cholesterol high pressure test levels doctor low normal glucose level results months thyroid tests taking last bp meds	
46	1097	Best Wishes
	best good great forward hope school wish meeting hear wishes luck center working health medical congratulations care news dear	
47	489	Exercise: Running And Boot Camps
	im camp boot like ive think weekend body run dont hurt hard saturday last didnt fat fit scrabble	
48	986	Exercise: Fitness Classes And Wii Fit
	class yoga classes zumba dance im workout pilates great wii fitness fun try fit exercise dancing spin like hour	
49	2700	Life Update: Weekends, Friends, Family
	weekend great hope good time day nice week fun work weather husband lot family wonderful friends enjoy birthday long	

REFERENCES

[1] Ackerman, M. S., "Augmenting the organizational memory: A field study of answer garden," in *Proceedings of the 1994 ACM Conference on Computer Supported Cooperative Work*, CSCW '94, (New York, NY, USA), p. 243252, ACM, 1994.

[2] Ackerman, M. S. and McDonald, D. W., "Answer garden 2: Merging organizational memory with collaborative help," in *Proceedings of the 1996 ACM Conference on Computer Supported Cooperative Work*, CSCW '96, (New York, NY, USA), p. 97105, ACM, 1996.

[3] Ahmad, F., Hudak, P. L., Bercovitz, K., Hollenberg, E., and Levinson, W., "Are physicians ready for patients with internet-based health information?," *Journal of Medical Internet Research*, vol. 8, p. e22, Sept. 2006.

[4] Andreassen, H. K., Bujnowska-Fedak, M. M., Chronaki, C. E., Dumitru, R. C., Pudule, I., Santana, S., Voss, H., and Wynn, R., "European citizens' use of e-health services: A study of seven countries," *BMC Public Health*, vol. 7, p. 53, Apr. 2007. PMID: 17425798.

[5] Balfe, E. and Smyth, B., "Case-based collaborative web search," in *Advances in Case-Based Reasoning* (Funk, P. and Gonzlez Calero, P. A., eds.), vol. 3155, pp. 489–503, Berlin, Heidelberg: Springer Berlin Heidelberg, 2004.

[6] Ballegaard, S. A., Hansen, T. R., and Kyng, M., "Healthcare in everyday life: designing healthcare services for daily life," in *Proceeding of the twenty-sixth annual SIGCHI conference on Human factors in computing systems*, (Florence, Italy), pp. 1807–1816, ACM, 2008.

[7] Bao, S., Xue, G., Wu, X., Yu, Y., Fei, B., and Su, Z., "Optimizing web search using social annotations," in *Proceedings of the 16th international conference on World Wide Web*, WWW '07, (New York, NY, USA), p. 501510, ACM, 2007.

[8] Berwick, D. M., "A user's manual for the IOM's 'Quality chasm' report," *Health Aff*, vol. 21, pp. 80–90, May 2002.

[9] Bhavnani, S. K., "Domain-specific search strategies for the effective retrieval of healthcare and shopping information," in *CHI '02 extended abstracts on Human factors in computing systems*, CHI EA '02, (New York, NY, USA), p. 610611, ACM, 2002.

[10] Bickmore, T. W., Pfeifer, L. M., and Jack, B. W., "Taking the time to care," in *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI '09)*, p. 1265, ACM Press, 2009.

[11] Bjrn, P. and Balka, E., "Health care categories have politics too: Unpacking the managerial agendas of electronic triage systems," in *ECSCW 2007*, pp. 371–390, 2007.

[12] Blei, D. M., Ng, A. Y., and Jordan, M. I., "Latent dirichlet allocation," *J. Mach. Learn. Res.*, vol. 3, p. 9931022, Mar. 2003.

[13] Blei, D. M., Ng, A. Y., and Jordan, M. I., "Latent dirichlet allocation," *J. Mach. Learn. Res.*, vol. 3, p. 9931022, Mar. 2003.

[14] Bonner, M., Wang, L., and Mynatt, E., "Activity-based interaction: Designing with child life specialists in a childrens hospital," in *Proceedings of the Thirtieth Annual SIGCHI Conference on Human Factors in Computing Systems*, (Austin, TX), In Press, 2012.

[15] Broom, A., "Virtually he@lthy: The impact of internet use on disease experience and the doctor-patient relationship," *Qual Health Res*, vol. 15, pp. 325–345, Mar. 2005.

[16] Burke, M., Carey, P., Haines, L., Lampson, A. P., and Pond, F., "Implementing the information prescription protocol in a family medicine practice: a case study," *Journal of the Medical Library Association : JMLA*, vol. 98, pp. 228–234, July 2010. PMID: 20648257 PMCID: PMC2901015.

[17] Bylund, C. L., Gueguen, J. A., Sabee, C. M., Imes, R. S., Li, Y., and Sanford, A. A., "Provider-patient dialogue about internet health information: An exploration of strategies to improve the provider-patient relationship," *Patient Education and Counseling*, vol. 66, pp. 346–352, June 2007.

[18] Can, A. B. and Baykal, N., "MedicoPort: a medical search engine for all," *Computer Methods and Programs in Biomedicine*, vol. 86, pp. 73–86, Apr. 2007.

[19] Carmel, D., Zwerdling, N., Guy, I., Ofek-Koifman, S., Har'el, N., Ronen, I., Uziel, E., Yogev, S., and Chernov, S., "Personalized social search based on the user's social network," in *Proceedings of the 18th ACM conference on Information and knowledge management*, CIKM '09, (New York, NY, USA), p. 12271236, ACM, 2009.

[20] Cartright, M.-A., White, R. W., and Horvitz, E., "Intentions and attention in exploratory health search," in *Proceedings of the 34th international ACM SIGIR conference on Research and development in Information*, SIGIR '11, (New York, NY, USA), p. 6574, ACM, 2011.

[21] Chi, E., "Information seeking can be social," *Computer*, vol. 42, pp. 42 –46, Mar. 2009.

[22] Corrigan, J., Donaldson, M., and Kohn, L., eds., *Crossing the quality chasm*. National Academies Press, June 2001.

[23] Diaz, J. A., Griffith, R. A., Ng, J. J., Reinert, S. E., Friedmann, P. D., and Moulton, A. W., "Patients' use of the internet for medical information," *Journal of General Internal Medicine*, vol. 17, pp. 180–185, Mar. 2002.

[24] Dourish, P., *Where the Action Is: The Foundations of Embodied Interaction*. Cambridge, MA: MIT Press, 2001.

[25] Dredze, M., Wallach, H. M., Puller, D., and Pereira, F., "Generating summary keywords for emails using topics," IUI '08, (New York, NY, USA), ACM, 2008.

[26] Dutton, W. H. and Blank, G., "Cultures of the internet: The internet in britain. oxford internet survey 2013.," 2013.

[27] Ellis, D. and Haugan, M., "Modelling the information seeking patterns of engineers and research scientists in an industrial environment," *Journal of Documentation*, vol. 53, pp. 384–403, Jan. 1997.

[28] Epstein, R. M., Franks, P., Fiscella, K., Shields, C. G., Meldrum, S. C., Kravitz, R. L., and Duberstein, P. R., "Measuring patient-centered communication in patient-physician consultations: Theoretical and practical issues," *Social Science & Medicine*, vol. 61, pp. 1516–1528, Oct. 2005.

[29] Evans, B. M. and Chi, E. H., "An elaborated model of social search," *Information Processing & Management*, vol. 46, pp. 656–678, Nov. 2010.

[30] Evans, B. M., Kairam, S., and Pirolli, P., "Do your friends make you smarter?: An analysis of social strategies in online information seeking," *Information Processing & Management*, vol. 46, pp. 679–692, Nov. 2010.

[31] Eysenbach, G. and Köhler, C., "How do consumers search for and appraise health information on the world wide web? qualitative study using focus groups, usability tests, and in-depth interviews," *BMJ*, vol. 324, pp. 573–577, Mar. 2002.

[32] Fogg, B., *Persuasive Technology: Using Computers to Change What We Think and Do (Interactive Technologies)*. Morgan Kaufmann, Dec. 2002.

[33] Fox, S., "The social life of health information, 2011," national survey, Pew Internet & American Life Project, United States, 2011.

[34] Fox, S., "Health online 2013," national survey, Pew Internet & American Life Project, United States, Jan. 2013.

[35] Fox, S. and Jones, S., "The social life of health information," national survey, Pew Internet & American Life Project, United States, June 2009.

[36] Golovchinsky, G., Pickens, J., and Back, M., "A taxonomy of collaboration in online information seeking," *arXiv:0908.0704*, Aug. 2009.

[37] Govaerts, S., El Helou, S., Duval, E., and Gillet, D., "A federated search and social recommendation widget," Mar. 2011.

[38] Grudin, J., "Why CSCW applications fail: problems in the design and evaluationof organizational interfaces," in *Proceedings of the 1988 ACM conference on Computer-supported cooperative work*, (Portland, Oregon, United States), pp. 85–93, ACM, 1988.

[39] Hansen, P. and Jrvelin, K., "Collaborative information retrieval in an information-intensive domain," *Information Processing & Management*, vol. 41, pp. 1101–1119, Sept. 2005.

[40] Hay, M. C., Cadigan, R. J., Khanna, D., Strathmann, C., Lieber, E., Altman, R., McMahon, M., Kokhab, M., and Furst, D. E., "Prepared patients: Internet information seeking by new rheumatology patients," *Arthritis Care & Research*, vol. 59, pp. 575–582, Apr. 2008.

[41] Hecht, B., Teevan, J., Ringel Morris, M., and Liebling, D. J., "SearchBuddies: bringing search engines into the conversation," in *Proceedings of the Sixth International AAAI Conference on Weblogs and Social Media*, (Dublin, Ireland), June 2012.

[42] Henwood, F., Wyatt, S., Hart, A., and Smith, J., "'Ignorance is bliss sometimes': constraints on the emergence of the 'informed patient' in the changing landscapes of health information," *Sociology of Health & Illness*, vol. 25, pp. 589–607, Sept. 2003. PMID: 12919447.

[43] Hesse, B. W., Nelson, D. E., Kreps, G. L., Croyle, R. T., Arora, N. K., Rimer, B. K., and Viswanath, K., "Trust and sources of health information: The impact of the internet and its implications for health care providers: Findings from the first health information national trends survey," *Arch Intern Med*, vol. 165, pp. 2618–2624, Dec. 2005.

[44] Hesse, B. W., Nelson, D. E., Kreps, G. L., Croyle, R. T., Arora, N. K., Rimer, B. K., and Viswanath, K., "Trust and sources of health information: The impact of the internet and its implications for health care providers: Findings from the first health information national trends survey," *Arch Intern Med*, vol. 165, pp. 2618–2624, Dec. 2005.

[45] Horowitz, D. and Kamvar, S. D., "The anatomy of a large-scale social search engine," in *Proceedings of the 19th International Conference on World Wide Web*, WWW '10, (New York, NY, USA), p. 431440, ACM, 2010.

[46] Hutchinson, H., Mackay, W., Westerlund, B., Bederson, B. B., Druin, A., Plaisant, C., Beaudouin-Lafon, M., Conversy, S., Evans,

H., Hansen, H., Roussel, N., and Eiderbck, B., "Technology probes: inspiring design for and with families," in *Proceedings of the SIGCHI conference on Human factors in computing systems*, (Ft. Lauderdale, Florida, USA), pp. 17–24, ACM, 2003.

[47] Hyldegrd, J., "Collaborative information behaviourexploring kuhlthaus information search process model in a group-based educational setting," *Information Processing & Management*, vol. 42, pp. 276–298, Jan. 2006.

[48] Jacobs, M., Clawson, J., and Mynatt, E. D., "My journey compass: A preliminary investigation of a mobile tool for cancer patients.," in *Proceedings of the ACM Conference on Human Factors in Computing Systems (CHI '14).*, (Toronto, Ontario, Canada), ACM, May 2014.

[49] Jones, R., Rey, B., Madani, O., and Greiner, W., "Generating query substitutions," in *Proceedings of the 15th international conference on World Wide Web*, WWW '06, (New York, NY, USA), p. 387396, ACM, 2006.

[50] K., E., "Division of labour and the design of systems for computer support for cooperative work," *Journal of Information Technology*, vol. 11, pp. 39–50, Mar. 1996.

[51] Keselman, A., Browne, A. C., and Kaufman, D. R., "Consumer health information seeking as hypothesis testing," *Journal of the American Medical Informatics Association*, vol. 15, pp. 484–495, July 2008.

[52] Khalil, A. and Connelly, K., "Context-aware telephony: privacy preferences and sharing patterns," in *Proceedings of the 2006 20th anniversary conference on Computer supported cooperative work*, CSCW '06, (New York, NY, USA), p. 469478, ACM, 2006.

[53] Klasnja, P., Hartzler, A. C., Unruh, K. T., and Pratt, W., "Blowing in the wind: Unanchored patient information work during cancer care," in *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI '10)*, (Atlanta, GA), 2010.

[54] Kling, R., "Cooperation, coordination and control in computer-supported work," *Commun. ACM*, vol. 34, no. 12, pp. 83–88, 1991.

[55] Kuhlthau, C. C., "Inside the search process: Information seeking from the user's perspective," *Journal of the American Society for Information Science*, vol. 42, pp. 361–371, June 1991.

[56] Lee, Y.-J., "VisSearch: a collaborative web searching environment," *Computers & Education*, vol. 44, pp. 423–439, May 2005.

[57] Lin, J. J., Mamykina, L., Lindtner, S., Delajoux, G., and Strub, H. B., "FishnSteps: encouraging physical activity with an interactive computer

game," in *UbiComp 2006: Ubiquitous Computing* (Dourish, P. and Friday, A., eds.), no. 4206 in Lecture Notes in Computer Science, pp. 261–278, Springer Berlin Heidelberg, Jan. 2006.

[58] Luo, G., "Design and evaluation of the iMed intelligent medical search engine," in *IEEE 25th International Conference on Data Engineering, 2009. ICDE '09*, pp. 1379–1390, Mar. 2009.

[59] Mamykina, L., Manoim, B., Mittal, M., Hripcsak, G., and Hartmann, B., "Design lessons from the fastest Q&A site in the west," in *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*, CHI '11, (New York, NY, USA), p. 28572866, ACM, 2011.

[60] Mamykina, L., Mynatt, E., Davidson, P., and Greenblatt, D., "MAHI: investigation of social scaffolding for reflective thinking in diabetes management," in *Proceeding of the twenty-sixth annual SIGCHI conference on Human factors in computing systems*, (Florence, Italy), pp. 477–486, ACM, 2008.

[61] Masters, K., "For what purpose and reasons do doctors use the internet: A systematic review," *International Journal of Medical Informatics*, vol. 77, pp. 4–16, Jan. 2008.

[62] Mayer, D. K., Terrin, N. C., Kreps, G. L., Menon, U., McCance, K., Parsons, S. K., and Mooney, K. H., "Cancer survivors information seeking behaviors: A comparison of survivors who do and do not seek information about cancer," *Patient Education and Counseling*, vol. 65, pp. 342–350, Mar. 2007.

[63] McCallum, A. K., "MALLET: a machine learning for language toolkit.," 2002.

[64] McNally, K., O'Mahony, M. P., Coyle, M., Briggs, P., and Smyth, B., "A case study of collaboration and reputation in social web search," *ACM Trans. Intell. Syst. Technol.*, vol. 3, p. 4:14:29, Oct. 2011.

[65] Medynskiy, Y. and Mynatt, E., "Salud!: An open infrastructure for developing and deploying health self-management applications," in *Pervasive Computing Technologies for Healthcare (PervasiveHealth), 2010 4th International Conference on-NO PERMISSIONS*, pp. 1–8, IEEE, Mar. 2010.

[66] Meeks, K., "Information rx: Promotion and utilization by georgia librarians and the georgia american college of physicians," *Journal of Consumer Health On the Internet*, vol. 13, no. 2, pp. 129–134, 2009.

[67] Miller, A. D. and Mynatt, E. D., "StepStream: a school-based pervasive social fitness system for everyday adolescent health," in *Proceedings of the ACM Conference on Human Factors in Computing Systems (CHI '14).*, (Toronto, Ontario, Canada), ACM, May 2014.

[68] Mitra, T. and Gilbert, E., "Analyzing gossip in workplace email," *ACM Newsletter*, 2013.

[69] Morowatisharifabad, M. A., Mahmoodabad, S. S. M., Baghianimoghadam, M. H., and Tonekaboni, N. R., "Relationships between locus of control and adherence to diabetes regimen in a sample of iranians," *International Journal of Diabetes in Developing Countries*, vol. 30, no. 1, pp. 27–32, 2010. PMID: 20431803 PMCID: PMC2859281.

[70] Morris, M. R. and Horvitz, E., "SearchTogether: an interface for collaborative web search," in *Proceedings of the 20th annual ACM symposium on User interface software and technology*, UIST '07, (New York, NY, USA), p. 312, ACM, 2007.

[71] Morris, M. R., Lombardo, J., and Wigdor, D., "WeSearch: supporting collaborative search and sensemaking on a tabletop display," in *Proceedings of the 2010 ACM conference on Computer supported cooperative work*, (Savannah, Georgia, USA), pp. 401–410, ACM, 2010.

[72] Morris, M. R. and Morris, D., "Understanding the potential for collaborative search technologies in clinical settings," in *Proceedings of the 3rd International Workshop on Collaborative Information Retrieval*, CIR '11, (New York, NY, USA), p. 1114, ACM, 2011.

[73] Morris, M. R. and Teevan, J., "Collaborative web search: Who, what, where, when, and why," *Synthesis Lectures on Information Concepts, Retrieval, and Services*, vol. 1, pp. 1–99, Jan. 2010.

[74] Morris, M. R., Teevan, J., and Bush, S., "Enhancing collaborative web search with personalization: groupization, smart splitting, and group hit-highlighting," in *Proceedings of the 2008 ACM conference on Computer supported cooperative work*, CSCW '08, (New York, NY, USA), p. 481484, ACM, 2008.

[75] Morris, M. R., Teevan, J., and Panovich, K., "What do people ask their social networks, and why?: a survey study of status message q&a behavior," in *Proceedings of the 28th international conference on Human factors in computing systems*, CHI '10, (New York, NY, USA), p. 17391748, ACM, 2010.

[76] Murray, E., Lo, B., Pollack, L., Donelan, K., Catania, J., Lee, K., Zapert, K., and Turner, R., "The impact of health information on the internet on health care and the physician-patient relationship: National U.S. survey among 1.050 U.S. physicians," *Journal of Medical Internet Research*, vol. 5, p. e17, Aug. 2003.

[77] Paul, S. A., Hong, L., and Chi, E. H., "Who is authoritative? understanding reputation mechanisms in quora," *ArXiv e-prints*, vol. 1204, p. 3724, Apr. 2012.

[78] Paul, S. A. and Morris, M. R., "CoSense: enhancing sensemaking for collaborative web search," in *Proceedings of the 27th international conference on Human factors in computing systems*, CHI '09, (New York, NY, USA), p. 17711780, ACM, 2009.

[79] Peterson, G., Aslani, P., and Williams, K. A., "How do consumers search for and appraise information on medicines on the internet? a qualitative study using focus groups," *Journal of Medical Internet Research*, vol. 5, Dec. 2003. PMID: 14713661 PMCID: 1550579.

[80] Pickens, J., Golovchinsky, G., Shah, C., Qvarfordt, P., and Back, M., "Algorithmic mediation for collaborative exploratory search," in *Proceedings of the 31st annual international ACM SIGIR conference on Research and development in information retrieval*, SIGIR '08, (New York, NY, USA), p. 315322, ACM, 2008.

[81] Pirolli, P. and Card, S., "Information foraging," *Psychological review*, vol. 106, no. 4, p. 643675, 1999.

[82] Plovnick, R. M. and Zeng, Q. T., "Reformulation of consumer health queries with professional terminology: A pilot study," *Journal of Medical Internet Research*, vol. 6, p. e27, Sept. 2004.

[83] Potts, H. W. W. and Wyatt, J. C., "Survey of doctors' experience of patients using the internet," *Journal of Medical Internet Research*, vol. 4, Mar. 2002. PMID: 11956037 PMCID: 1761928.

[84] Reddy, M. C. and Jansen, B. J., "A model for understanding collaborative information behavior in context: A study of two healthcare teams," *Information Processing & Management*, vol. 44, pp. 256–273, Jan. 2008.

[85] Robinson, J. H., Callister, L. C., Berry, J. A., and Dearing, K. A., "Patientcentered care and adherence: Definitions and applications to improve outcomes," *Journal of the American Academy of Nurse Practitioners*, vol. 20, pp. 600–607, Dec. 2008.

[86] Rowan, J. and Mynatt, E. D., "Digital family portrait field trial: Support for aging in place," in *Proceedings of the SIGCHI conference on Human factors in computing systems*, (Portland, Oregon, USA), pp. 521–530, ACM, 2005.

[87] Seidman, I., *Interviewing as Qualitative Research: A Guide for Researchers in Education and the Social Sciences*. New York: Teachers College Press, 3rd ed ed., 2006.

[88] Siegel, E. R., Logan, R. A., Harnsberger, R. L., Cravedi, K., Krause, J. A., Lyon, B., Hajarian, K., Uhl, J., Ruffin, A., and Lindberg, D. A., "Information rx: Evaluation of a new informatics tool for physicians, patients, and libraries," *Information Services and Use*, vol. 26, pp. 1–10, Jan. 2006.

[89] Sillence, E., Briggs, P., Fishwick, L., and Harris, P., "Trust and mistrust of online health sites," in *Proceedings of the SIGCHI conference on Human factors in computing systems*, CHI '04, (New York, NY, USA), p. 663670, ACM, 2004.

[90] Sillence, E., Briggs, P., Harris, P. R., and Fishwick, L., "How do patients evaluate and make use of online health information?," *Social Science & Medicine*, vol. 64, pp. 1853–1862, May 2007.

[91] Smyth, B., Balfe, E., Boydell, O., Bradley, K., Briggs, P., Coyle, M., and Freyne, J., "A live-user evaluation of collaborative web search," in *Proceedings of the 19th international joint conference on Artificial intelligence*, IJCAI'05, (San Francisco, CA, USA), p. 14191424, Morgan Kaufmann Publishers Inc., 2005.

[92] Smyth, B., Briggs, P., Coyle, M., and OMahony, M., "Google shared. a case-study in social search," in *User Modeling, Adaptation, and Personalization* (Houben, G.-J., McCalla, G., Pianesi, F., and Zancanaro, M., eds.), vol. 5535, pp. 283–294, Berlin, Heidelberg: Springer Berlin Heidelberg, 2009.

[93] Sommerhalder, K., Abraham, A., Zufferey, M. C., Barth, J., and Abel, T., "Internet information and medical consultations: Experiences from patients and physicians perspectives," *Patient Education and Counseling*, vol. 77, pp. 266–271, Nov. 2009.

[94] Stevenson, F., Kerr, C., Murray, E., and Nazareth, I., "Information from the internet and the doctor-patient relationship: the patient perspective - a qualitative study," *BMC Family Practice*, vol. 8, no. 1, p. 47, 2007.

[95] Stewart, M., "Towards a global definition of patient centred care," *BMJ : British Medical Journal*, vol. 322, pp. 444–445, Feb. 2001. PMID: 11222407 PMCID: 1119673.

[96] Taylor, H., "Harris poll: Cyberchondriacs on the rise?," tech. rep., The Harris Poll #95, Aug. 2010.

[97] Taylor, H., "Harris poll: The growing influence and use of health care information obtained online," tech. rep., The Harris Poll #98, Sept. 2011.

[98] Teevan, J., Ramage, D., and Morris, M. R., "#TwitterSearch: a comparison of microblog search and web search," in *Proceedings of the Fourth ACM International Conference on Web Search and Data Mining*, WSDM '11, (New York, NY, USA), p. 3544, ACM, 2011.

[99] Thomas, D. R., "A general inductive approach for analyzing qualitative evaluation data," *American Journal of Evaluation*, vol. 27, pp. 237–246, June 2006.

[100] Toms, E. G. and Latter, C., "How consumers search for health information," *Health Informatics Journal*, vol. 13, no. 3, pp. 223 –235, 2007.

[101] Toscos, T., Faber, A., An, S., and Gandhi, M. P., "Chick clique: Persuasive technology to motivate teenage girls to exercise," in *CHI '06 Extended Abstracts on Human Factors in Computing Systems*, CHI EA '06, (New York, NY, USA), p. 18731878, ACM, 2006.

[102] Unruh, K. T., Skeels, M., Civian-Hartzler, A., and Pratt, W., "Transforming clinic environments into information workspaces for patients," in *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI '10)*, (Atlanta, GA), Apr. 2010.

[103] Wallston, K. A., Strudler Wallston, B., and DeVellis, R., "Development of the multidimensional health locus of control (MHLC) scales," *Health Education & Behavior*, vol. 6, pp. 160 –170, Mar. 1978.

[104] Wang, G., Gill, K., Mohanlal, M., Zheng, H., and Zhao, B. Y., "Wisdom in the social crowd: An analysis of quora," in *Proceedings of the 22Nd International Conference on World Wide Web*, WWW '13, (Republic and Canton of Geneva, Switzerland), p. 13411352, International World Wide Web Conferences Steering Committee, 2013.

[105] White, R., "Beliefs and biases in web search," in *Proceedings of the 36th international ACM SIGIR conference on Research and development in information retrieval*, SIGIR '13, (New York, NY, USA), p. 312, ACM, 2013.

[106] White, R. W. and Horvitz, E., "Cyberchondria: Studies of the escalation of medical concerns in web search," *ACM Transactions on Information Systems (TOIS)*, vol. 27, Nov. 2009.

[107] White, R. W. and Horvitz, E., "Experiences with web search on medical concerns and self diagnosis," *AMIA Annual Symposium Proceedings*, vol. 2009, pp. 696–700, 2009. PMID: 20351943 PMCID: 2815378.

[108] Wooldridge, K. L., Wallston, K. A., Graber, A. L., Brown, A. W., and Davidson, P., "The relationship between health beliefs, adherence, and metabolic control of diabetes," *The Diabetes educator*, vol. 18, pp. 495–500, Dec. 1992. PMID: 1296900.

[109] Yanbe, Y., Jatowt, A., Nakamura, S., and Tanaka, K., "Can social bookmarking enhance search in the web?," in *Proceedings of the 7th ACM/IEEE-CS joint conference on Digital libraries*, JCDL '07, (New York, NY, USA), p. 107116, ACM, 2007.

[110] Yang, J., Morris, M. R., Teevan, J., Adamic, L. A., and Ackerman, M. S., "Culture matters: A survey study of social Q&A behavior," *ICWSM 2011*, July 2011.

[111] Yun, T.-J., Jeong, H. Y., Hill, T. D., Lesnick, B., Brown, R., Abowd, G. D., and Arriaga, R. I., "Using SMS to provide continuous assessment

and improve health outcomes for children with asthma," in *Proceedings of the 2Nd ACM SIGHIT International Health Informatics Symposium*, IHI '12, (New York, NY, USA), p. 621630, ACM, 2012.

[112] Yun, T.-J., Jeong, H. Y., Lee, H. R., Arriaga, R., and Abowd, G., "Assessing asthma management practices through in-home technology probes," in *Pervasive Computing Technologies for Healthcare (PervasiveHealth), 2010 4th International Conference on-NO PERMISSIONS*, pp. 1–9, Mar. 2010.

[113] Zeng, Q. T., Crowell, J., Plovnick, R. M., Kim, E., Ngo, L., and Dibble, E., "Assisting consumer health information retrieval with query recommendations," *Journal of the American Medical Informatics Association*, vol. 13, pp. 80–90, Jan. 2006. PMID: 16221944.