

# Gauging the Patient-Centered Potential of Online Health Seeking

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## ABSTRACT

Online Health Seeking (OHS) is the process by which people find, share and consume online health and wellness information. OHS is widespread, widely studied and often presented as a concerning new trend. We suggest OHS is a natural fit with patient-centered care, representing an opportunity to improve patient provider relationships and patient satisfaction. Over two years we conducted a series of investigations of OHS at a local clinic where OHS plays an important role in care. Through focus groups, shadowing and interviewing we explore how this clinic's health professional advisors and their clients interact around OHS. We also use a set of repeated surveys to investigate the link between components of OHS and concepts like Patient-Centered Care (PCC) and the Multidimensional Health Locus of Control (MHLC). In this paper we present the results of our studies, which describe a clinic that emphasizes OHS and show encouraging links between OHS, PCC and the MHLC. Working to unpack these results, we discuss how OHS could be better operationalized as a tool for improving care and conclude with suggestions for patient-centered OHS interventions.

## Categories and Subject Descriptors

H.5.m. Information interfaces and presentation (e.g., HCI); Miscellaneous.

## General Terms

Measurement, Performance, Design, Human Factors, Verification.

## Keywords

Online Health Seeking, Patient Centered Care, Mixed Methods

## 1. INTRODUCTION

Online Health Seeking (OHS), the process through which people find, consume and share health and wellness information online, is both impactful and prevalent. As Internet access and use has grown, so too has OHS. 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 [12]. Not only is OHS widespread, it has a real impact: 60% of respondents to a 2009 poll reported that information they found online affected a treatment decision [11]. The same poll also found that a

significant portion of OHS, even a majority, is done on behalf of others.

We suggest viewing OHS as an opportunity to improve the healthcare experience rather than a concerning trend to be 'navigated and mitigated'. In particular, OHS seems a good match to the components of patient-centered care (PCC). PCC, cited by the Institute of Medicine as a goal for future health care, emphasizes patient leadership and a holistic understanding of the patient [3]. 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. These studies are often direct and descriptive, offering encouraging data on OHS's positive potential. However, few studies offer detailed examples of how OHS can be incorporated into care. Studying the connections between OHS's different components, and those of generalizable constructs like PCC, is the next step to understanding OHS's potential to improve care.

We have undertaken a multi-year investigation of OHS in-situ at the Emory Predictive Health Institute (EPHI), a relatively unique patient-centered clinic. In this investigation we drew across a spectrum of methods to understand the role OHS plays at EPHI, including how the clinic's advisors use OHS to connect with their clients. In this paper we discuss the results of some of these probes, including focus groups, interviews, and consultation shadowing with clients and advisors. We also report our work to study the relationship between OHS, PCC and the Multidimensional Health Locus of Control (MHLC) [26] via a set of repeated surveys, finding positive correlations between aspects of OHS and these constructs.

By connecting to well-known concepts like PCC and the MHLC, our work begins to unpack the positive effects of OHS noted by other researchers. OHS has a strong presence at our field site, playing a key role for both health advisors and clients. We offer a detailed analysis of how the EPHI's health professionals approach and manage OHS with their clients. Our paper concludes by synthesizing results across our research activities to offer design suggestions for interventions focused on improving care via OHS.

## 2. RELATED WORK

Because of its technical nature and widespread impact, researchers in both the medical and informatics communities have studied health seeker characteristics, habits and relationships.

### 2.1 Non-Professional Health Seekers

Many large-n surveys have been used to collect basic information on OHS, such as correlated demographics and prevalence. National polls in the United States by the Harris and Pew

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organizations provide evidence that the majority of Americans are online, and that seeking health information is amongst the most popular online activities [12,24]. 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 [2]. 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 ‘adigitals’ with a mostly negative reaction to the Internet [8]. Still, the majority in each of these diverse ‘Internet Cultures’ were online health seekers. Both Andreassen *et al.* and Fox found OHS positively correlated with youth, female gender and education level [2,12]. 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.

Researchers have also investigated how non-professionals actually participate in OHS. Some of these studies observed and interviewed small groups, independently noting similar characteristics among a diverse set of health seekers [10,22,25]. Users preferred 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. Toms & Latter and Eysenbach & Köhler, both noted searchers used extremely simple queries [10,25]; in the case of Toms & Latter, search engines automatically excluded so many terms as common ‘stop words’ that only a single query per term was used on average. Similarly, Peterson *et al.* reported that Australian health seekers also favored simple search strategies and had misunderstandings about search engine function [19]. Interestingly, Eysenbach & Köhler noted that while health seekers mentioned their concern over information sources and quality, none followed through on professed strategies like viewing disclaimers or about pages, and few were able to recall where they had retrieved information.

Other studies describe OHS behavior based on observations or user search logs. These works emphasize the importance of searcher hypotheses to OHS; noting that diagnostic searches tend begin with symptoms and seek a disease hypothesis, or begin with a hypothesis and seek verification [7,15]. Personal biases can affect health search results. White found searchers favored information that confirmed their hypotheses, and also found searchers (as well as search engines!) tend towards results with a positive perspective [27]. Participants in White’s study found the (physician-indicated) correct answer only ~50% of the time. Health seekers’ domain-specific knowledge can also affect their search process and results. Bhavnani observed that within their domains of expertise, health professionals and expert shoppers have a concretely sequenced set of goals [4]. 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 cause for concern. OHS is extremely widespread, but searchers tend towards simple strategies and often fail to find the correct answer.

## 2.2 Patient OHS and Health Professionals

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 [13,18,24,28]. 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 [5,13,14]. 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 [18,23]. Some patients use ‘face-saving strategies’ for discussing OHS with providers, such as not mentioning the information under discussion is the product of OHS [6]. Positive reactions seem to be more common however, and patients generally feel discussing OHS improves their relationship with their provider [13,18]. Patients who did consult a provider were “reassured that their worries were not justified” nearly 75% of the time [29], which meshes well with physicians’ feelings that OHS can lead to unfounded fears [1]. Most physicians consider OHS to be helpful to patients [18,20,23], if perhaps creating more work for physicians themselves [1,20].

## 2.3 Reframing 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.

In the rest of this paper we explore OHS as a positive, reciprocal connection between patients and providers, rather than as a potentially dangerous patient activity for providers to monitor. In the next section we introduce our field site, a clinic where providers actively share OHS with their clients. We study the role of OHS at this clinic, including health professional strategies for interacting with patients around OHS. We also investigate the link between OHS and higher-level concepts like Patient-Centered Care and the Multidimensional Health Locus of Control, highlighting OHS’s potential to affect these valued measures.

## 3. Methodology

Over a period of almost two years, we conducted a series of investigations into OHS at the EPHI, a patient-centered clinic in downtown Atlanta, Georgia. We first introduce the EPHI, and then describe our methodology.

### 3.1 Field Site: The EPHI

All of our study activities have been in collaboration with EPHI (also, “the center”). Every 6 months to a year, EPHI clients undergo an extensive array of medical tests called ‘the assessment’, including 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. Given this setting, we use ‘advisor’ or ‘health professional’ and ‘client’ instead of ‘patient’ and ‘provider’ to describe the major roles in the center.

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 [30].

### 3.1.1 EPHI Demographics

EPHI operates as a research center serving 763 clients, 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% of clients attended graduate school or beyond, 95.5% have at least one year of college.

As previously mentioned, 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, we are confident our set of participants is a useful sample to generalize from. Still, other health seekers with fewer socio-economic resources may face barriers not covered by our population, and further work with these groups would be valuable.

### 3.2 Focus Groups

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. We also conducted two focus groups with clients: a small group of three and a larger group of eleven. Following our preliminary advisor focus group, we transcribed and deductively coded the two client groups. We discuss the results of all three groups in aggregate to compare and contrast advisor and client OHS.

### 3.3 Consultation Shadowing and Interviews

Following their health assessment at EPHI, clients meet with their advisor for a consultation. There, the pair goes over the client's assessment results and at the client's discretion creates a 'health action plan' in response. We shadowed 6 advisor-client consultations (shadowing 2 advisors twice). The client and advisor were interviewed separately after each shadowed consultation. One author inductively coded the resulting field notes with assistance from two colleagues as external coders.

### 3.4 Additional Client Interviews

To supplement the studies listed above, we conducted individual interviews with 9 EPHI clients, visiting them outside of the EPHI. These interviews were again transcribed and inductively coded by one author and two colleagues.

### 3.5 Surveys: HIA, PCC and MHLC

Clients also responded to a set of 3 surveys composed of 7-item Likert scales. The Health Information Attitudes (HIA) and Patient-Centered Care (PCC) surveys are new instruments we created for our studies; they are available online<sup>1</sup> for re-use or adaptation. Our HIA survey contains 30 items, asking clients to rate their use and values of online health resources. The PCC survey contains 12 items based on efforts by other groups to describe and measure PCC [9,21]. These items measure patient-centered care at EPHI by summing into a single 'PCCScore' that measures how holistic, participatory and self-driven each client rates their care. Because PCC emphasizes patient control of care, we also employed Form A of the widely used Multidimensional Health Locus of Control (MHLC) [26]. The MHLC measures how much the taker feels different dimensions control their health: themselves (the 'internal' dimension), chance, and powerful

others. 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 [16].

These surveys were given to 42 EPHI clients online, sequentially (HIA, PCC, MHLC). 4 participants failed to complete part or all of a survey; this data was dropped, meaning  $n = 38$  for all survey analysis. Surveys were taken twice over a period of two months; all analysis uses the mean of these two scores. We look at correlations between these 3 surveys to investigate the relationship between OHS, patient-centered care and MHLC.

## 4. UNDERSTANDING OHS AT EPHI

Our focus groups, interviewing and shadowing helped us understand how EPHI's clients and advisors undertake OHS, as well as how they engage one another around OHS. Many of our observations support prior work, while others offer a contrast. In this section we highlight the important role OHS plays at EPHI as a connector between advisors and clients, and compare advisor and client approaches to OHS.

For quotes, 'I' indicates a quote from an interview and 'FG' a focus group, e.g. 'FG-C1' quotes client 1 in a focus group.

### 4.1 The Where and When of OHS

EPHI clients are overwhelmingly health seekers; across all our research activities, each participant mentioned taking part in OHS. In line with existing studies, participants in our focus groups emphasized their preference for general search engines [10,22]. Interviewees expressed similar habits - though 7 of 9 had a few favored sites, OHS typically begins with a search engine. I-C1 explained why she heads to Yahoo search first:

I-C1 "I kind of want to see what all is out there".

Though all participant clients were health seekers, OHS was not a constant activity. Clients suggested they search more periodically, when inspired by things like their EPHI assessment or an interesting news story. Client focus group participants felt their overall health focus waxed and waned, fitting with White and Horvitz's observation of 'bursty' OHS behavior [29]. One client described the effect of creating a health action plan with her EPHI advisor:

FG-C3: "Oh it stays forefront for a short period of time, but like New Year's resolutions, they fade... periodically you say... I should do this. But then something will come up."

In contrast with their clients, advisors were both heavy and frequent health seekers. Advisors value OHS as an up-to-date resource for their clients (all EPHI advisors shared OHS results with clients), as a motivational tool, and even said that online information can be "more reputable" than offline information. In our focus groups advisors reported frequent OHS using general search engines as well as go-to sites including technical sites like PubMed, news media like the New York Times, and less concretely-defined 'health blogs'.

Advisors did not evince a markedly different search process than did their clients. Though advisors placed somewhat more emphasis on go-to sites than their clients, search engines remained key. This is seemingly at odds with Bhavnani's observation of domain experts, including health professionals, using a more regimented search process and bypassing general search engines

<sup>1</sup> <http://ow.ly/uB6dJ>

when searching within their area of expertise [4]. It is unclear exactly what expertise or background Bhavnani's participants had beyond working in a medical library. It seems likely that 'health professional' is not a sufficiently nuanced definition to capture the effects of expertise on OHS.

## 4.2 Social Connections

In their focus group, advisors revealed social motivations for much of their OHS. Clients drive most advisor searches, and advisors scour the web for resources to answer questions or to include in their between-consultation email follow-ups. Advisors also try to learn from one another and their clients, reusing resources when possible. During our shadowing we observed advisors reusing resources between clients, helping one client indirectly guide another.

Social ties are also key in client OHS. 10 of 11 participants in our client focus groups reported social OHS motivations. These motivations included searching based on family history and for an ill friend or family member. Advisors assumed most clients were online health seekers, but assumed clients shared few OHS results with their advisors or other health professionals. Clients confirmed this in their focus group. Other studies have also found much OHS is unshared with health professionals [24].

When it does occur, client-advisor OHS sharing is a complicated process. Advisors described participant OHS as interesting, tailored and alternative, an apparent good fit for a center emphasizing customized care. However, advisors also described "ridiculous" client OHS results that they felt were useless or even dangerous. Clients meanwhile have tightly held beliefs about their healthcare, often rejecting non-conforming online resources and even professional advice.

**FG-C1:** *"Well, I can get [my doctor's] opinion, but I'm going to do what I want anyway."*

This observation implies that simply rejecting 'ridiculous' information is an ineffective strategy. During our shadowing we saw advisors respond to questionable client OHS by offering alternative information rather than directly disagreeing.

## 4.3 Advising versus Prescribing: Gently Guiding Clients

EPHI clients ask their advisors questions based on their beliefs, and often ask for feedback on connected OHS. While shadowing consultations, we saw that advisors must walk a narrow line between advising their client and prescribing concrete actions. Advisors always seek to put control in their clients' hands. Clients control conversation depth by choosing when to ask questions (almost always about test results that are out of range), and clients set their action plan's goals. However, clients frequently seek absolute directives from their advisor, asking questions like 'should I take this supplement I've read about online'. Confronted with questions like these, advisors avoid explicit judgments. Instead they will offer up additional or alternative information and resources, attempting to gently guide their clients. Sometimes, advisors have no choice but to limit the discussion or refer clients to their doctors.

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

## 4.4 (Online) Health is Personal

In our interviews, clients connected their OHS to deeply personal stories and motivations. This included searching for answers to a personal or a family member's health problem and reacting to an acute health event. Some participants connected OHS to their personal responsibility for control over their health

Explaining why they search online, clients revealed struggles with cancer, weight, chronically ill children and spousal surgery. I-C1's interest in online resources stemmed from her family history and her private desire to become pregnant:

**I-C1:** *"My parents died of disease that may have been preventable. They were both very young, 50 and 51... The fact that I want to have a child, I need to be very cognizant of my health, and to be around as long as I can be."*

These intense, personal motivations were often connected to acute or semi-acute events. Family often provides this acute motivation (5 clients of 9 interviewed): for example, I-C6 researched his wife's sudden illness, and I-C8 read up on her son's baseball injury. However, clients do not always share what they find, instead using results to understand another's health issues. The EPHI assessment itself motivated I-C3 and I-C7 to search for weight loss resources.

Clients wanted detailed information to match their unique, personal search motivation. For example, I-C1 and I-C8 were dissatisfied by the depth of information on WebMD and continued searching. I-C7 ignored 'generic' resources from his EPHI advisor that did not seem sufficiently tailored to his needs. In contrast, I-C6 was focused on her diet and especially valued expertise and resources from her advisor, a registered dietitian. The detailed, personal history that motivates client OHS means it will be difficult for any single resource or even group of resources, whether an online site or a full-time health advisor, to completely satisfy all health seekers.

Lastly, three participants connected OHS to their personal control over their health. I-C4 *"would feel so stupid"* if she went to her doctor before checking for easy solutions to her a health problem. On the other hand, two clients skipped OHS when they felt a health issue was out of their control:

**I-C3:** *"It's not so much that the allergy medicine is amazingly effective, I just assume I don't have much control over... [the causes of my allergies]."*

In the next section, we will explore the link between OHS and perceived control in more detail.

## 5. LINKING PATIENT CENTERED CARE, ONLINE HEALTH SEEKING AND THE MHLC

Prior work investigating OHS has focused on first-order descriptions and basic ratings. In this section, we build on this work by investigating OHS components' links with two higher-level concepts; Patient-Centered Care and the Multidimensional Health Locus of Control. Understanding these links better illustrates OHS's potential as an avenue to improved care, and also identifies first steps or strategies to employ OHS in this way. All p-values reported in this section are unadjusted.

## 5.1 Health Information Attitudes and Patient Centered Care

As described in the methodology section, we created the Health Information Attitudes (HIA) survey to analyze the value EPHI clients assign to online health resources. Meanwhile, we 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 (Pearson's  $r$ ) was observed between items on our HIA survey and Patient Centered Care scores (PCCScore, created by summing PCC survey items, Cronbach's  $\alpha = 0.952$ ).

Table 1 lists these correlations. Amongst these significant results there is a uniform positive association between PCCScore and favorable OHS values and experiences. Discussing online resources seems to be a key associate of PCC. Positive discussions with doctors or advisors trended up with PCCScore; discussion with or receiving resources from the advisor was correlated especially strongly. The strongest negative PCCScore correlations were with perceived disinterest from advisors in personal OHS, and with personal disinterest in online resources. Interestingly, self-reported frequency of online health searching was not significantly correlated. ( $r = 0.160, p = 0.338$ ).

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

## 5.2 Multidimensional Health Locus of Control (MHLC) and Correlates

We use Pearson's  $r$  to examine the relationship between scores on our HIA and PCC surveys and the three MHLC dimensions of Chance (MHLC-CHA), Internal (MHLC-INT) and Powerful Others (MHLC-OTH). 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. Cronbach's alpha for each dimension were as follows: MHLC-INT  $\alpha = 0.794$ , MHLC-CHA  $\alpha = 0.787$ , MHLC-OTH  $\alpha = 0.611$ .

HIA Question	Correlation with PCCScore	
	$r$	$p =$
How often do you discuss online health resources with your advisor?	0.691	0.000
How often do you discuss online health resources with your doctor?	0.359	0.027
I can usually find useful online health information myself	0.309	0.062
Online health information is not very interesting to me	-0.575	0.000
Health professionals are the only source of good health information	-0.491	0.002
I'm confident I can tell if online health information is relevant and good.	0.354	0.032
Looking for online health resources myself does more harm than good.	-0.335	0.046
My advisor gives me useful online health resources.	0.679	0.000
My advisor is NOT interested in the online resources I find.	-0.583	0.000
Online health information is useful or good for getting more details about my health concerns	0.372	0.024
Online health information is useful or good for deciding if I need to talk to a health professional	0.302	0.069
Online health information is useful or good for explaining my health or concerns to friends and family	0.348	0.035

**Table 1: Significant Pearson correlations of Health Information Attitude (HIA) survey items with PCCScore. Items with non-significant correlations are omitted. N = 38.**

Question: "Online Health Information is useful or good for.."	Correlation with MHLC-INT		Correlation with MHLC-CHA	
	Pearson's $r$	$p =$	Pearson's $r$	$p =$
... deciding ("diagnosing") how I am sick or hurt	<b>0.320</b>	<b>0.06</b>	<b>-0.440</b>	<b>0.008</b>
... getting more details about my health concerns	0.232	0.167	<b>-0.474</b>	<b>0.003</b>
... helping others with their health	<b>0.438</b>	<b>0.008</b>	<b>-0.279</b>	<b>0.099</b>
... deciding if I need to talk to a health professional	<b>0.432</b>	<b>0.008</b>	<b>-0.470</b>	<b>0.003</b>
... explaining my concerns to a health professional	<b>0.310</b>	<b>0.066</b>	-0.224	0.188
... explaining my health or concerns to friends and family	0.247	0.141	<b>-0.347</b>	<b>0.036</b>
... comparing treatment options	0.027	0.875	<b>-0.468</b>	<b>0.004</b>

**Table 2: Significant Pearson correlations of MHLC scores (INT and CHA dimensions) with questions from our Health Information Attitudes survey. The MHLC-OTH dimension's correlations were insignificant, generally minor, and are omitted. N = 38.**

### 5.3 MHLC and Health Information Attitudes

Correlating MHLC dimension scores with responses to the HIA survey suggests that participants with higher MHLC-INT scores - those who feel they exert more control over their own health - are more likely to value online health information (see Table 2). MHLC-CHA on the other hand, which measures the perceived influence of chance on health, was negatively correlated with valuing online health information. High MHLC-INT scorers were also more likely to say online health information had affected a treatment decision ( $r = 0.285, p = 0.087$ ), while MHLC-CHA and MHLC-OTH showed strong negative correlations ( $r = -0.412, p = 0.011$  and  $r = -0.337, p = 0.041$  respectively). High MHLC-CHA and MHLC-OTH scorers were also more likely to say that they couldn't trust online health information ( $r = 0.339, p = 0.040$  and  $r = 0.275, p = 0.099$  respectively). Finally, higher MHLC-CHA and MHLC-OTH scores correlated with lower self-reported levels of online health searching ( $r = -0.387, p = 0.016$  and  $r = -0.277, p = 0.092$  respectively).

In aggregate these correlations suggest a positive connection between an internal health locus of control and valuing OHS. Conversely, it seems those with a more external locus of control have less use for OHS.

### 5.4 MHLC and PCCScore

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 some 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. DISCUSSION

We divide our discussion section into two parts. First, we consider the relationship between PCC and MHLC. In our results, there were interesting distinctions between OHS's relationship to each of these measures: we suggest PCC and MHLC are related, but complimentary concepts. Second, we discuss what our results mean for those seeking to harness OHS as a positive force for patient-provider relationships. We emphasize design implications for interventions (technical or otherwise) centered on OHS, which we feel are the logical next step for future work.

### 6.1 PCC vs MHLC

Multiple strong correlations between our PCCScore metric and positive OHS experiences (refer back to Table 1) are an encouraging sign. Higher internal MHLC scores were also associated with positive OHS values (refer back to Table 2), while external scores (particularly on the MHLC 'Chance' dimension) were negatively correlated. We also saw connections between OHS and MHLC in our interviews, such as I-CI's description of searching as part of their personal health responsibility given their desire to have children.

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 components of care. It is difficult to completely encapsulate a concept as broad and context-sensitive as patient-centeredness. We thus recommend researchers interested in patient-centered care combine a custom measure with other instruments as we have done with PCCScore, the MHLC scale and interviews.

### 6.2 Future Work: Designing for OHS

We have framed OHS as a widespread phenomenon with an unexplored potential for supporting patient-centered care. The next step in understanding and harnessing OHS's potential is to incorporate it into a patient-centered intervention. OHS already plays a key part in advisor-client relations at the EPHI. Our work has several implications and suggestions for OHS-based investigation, especially interventions, which we discuss in this section. Apart from technical systems, our suggestions can inform health professionals who interact with patients around OHS.

#### 6.2.1 OHS Frequency vs OHS Quality

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.

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 beyond the self-reported 'monthly' average observed here seems daunting.

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.

### 6.2.2 Sharing and Patient Leadership

We have seen that client OHS is incompletely shared: partial sharing from clients/patients is not a difficulty to overcome, but a logical response to OHS's complexity and periodicity. Clients do not want to share every single resource they find, even if they have a positive relationship with their advisor, and advisors (or a larger cast of health professionals) don't have time to review all 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.

Beyond sharing, interventions should avoid restrictions and emphasize patient leadership. It is straightforward to imagine an intervention that provides a set of 'safe' resources collected or approved by health professionals. However, patients are online in part to get wider range of opinions. The nuanced OHS motivation expressed by our participants and their hunger for details makes it difficult for pre-selected information to completely satisfy all search needs. Interventions should accept and plan on users leaving these 'walled gardens'. Designing a tool that works with or elaborates a general search engine, the first choice of a typical health seeker (and even some health professionals, as seen with the EPHI's advisors), makes more sense than trying to replace or restrict general searching.

A less restrictive OHS intervention should anticipate that patients will find some suspect resources. Recall White's study that found significant confirmation bias in OHS searches and many incorrect results [27]. Researchers should avoid the temptation to allow health professionals to pass explicit 'up or down' judgments on patient OHS. Recall FG-C1's quote: "Well, I can get [my doctor's] opinion, but I'm going to do what I want anyway." Trying to rein in patient OHS in this fashion will likely lead to disengagement or disuse – especially alarming in the context of an incorrect medical resource! EPHI advisors approached questionable client OHS delicately, avoiding direct contradictions even when they might privately deem a patient's resource to be ridiculous. Rather, EPHI advisors offered alternative resources and information, allowing patients to contextualize and re-interpret their resources. We suggest interventions and health professionals take a similar approach, taking care to respect

patient OHS as a legitimate contribution and interest even in the face of spurious results.

### 6.2.3 Grouping Opportunities

Finally, our work suggests that there are many opportunities to empower health seekers by grouping them together. At EPHI, clients relied on a personal network to support their health goals and information needs. In our interviews, some clients expressed interest in connecting with others who shared their goals or interests. The EPHI has many natural groupings of health seekers beyond the advisor-client dyad, and clients could be matched based on their assessment results or action plan goals. Advisors could be linked 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 [17] – even without EPHI's detailed health testing, search histories or even simple questioning could be used to connect health seekers.

## 7. CONCLUSION

Our work builds on existing studies of OHS, setting the stage for interventions centered on this mainstream phenomenon. We conducted a series of field studies at the EPHI, a patient-centered clinic that strives to empower its clients. At the EPHI, OHS is a crucial part of health professional and client relationships. We found health seekers with characteristics that matched existing studies – such as a preference for general search engines – while diverging on others, such as the similarity between client and advisor search strategies.

OHS's bursty nature makes it challenging to study the causality of the OHS-PCC-MHLC relationship. Still, the sheer number of positive associations with OHS we observed encourage further investigation and intervention. Though our individual research activities were limited in duration, this was balanced against the number of studies and an almost two year period of working with the EPHI. Future work should also consider taking an extremely longitudinal approach of many months or even years.

Through interviews, shadowing and focus groups, we learned just where OHS fits between the EPHI's advisors and clients. The EPHI's advisors are particularly invested in OHS, using online resources to answer client questions and to collaborate with one another. Advisors are careful to acknowledge client OHS, and will share alternative resources rather than reject a client's search results. The examples of EPHI show that OHS can be a productive link even between searchers with varying expertise, such as health professionals and their clients.

Our survey work analyzed the relationship between OHS, Patient-Centered Care and the Multidimensional Health Locus of Control. We found positive links between components of OHS and aspects PCC, such as discussing online resources. OHS and the MLHC were also correlated – it seems that individuals who feel in control of their own health are more likely to value online health resources. These results move beyond simply noting whether OHS is 'satisfying' and connect it to valued, generalizable measures. Further, they identify key areas of OHS to focus future investigations or interventions.

Finally, we concluded by discussing implications for future investigations centered on OHS. At this stage, we feel OHS is well-linked to positive outcomes for patient-provider relationships. The next step to understanding and harnessing

OHS's potential is to develop and evaluate technical and social interventions.

Going forward, it will be important to assess OHS in other healthcare settings. EPHI is on the leading edge of healthcare delivery, emphasizing proactive, participatory care. As more healthcare providers adopt these approaches, our research results can guide the structuring of these 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. As OHS and Internet use continue to increase, researchers must be cognizant of a potential 'digital divide' within OHS. Our results can serve as a comparison to those settings and point to ways to lower the barriers to OHS overall.

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