who can you trust? Credibility ASSESSMENT In online health forums

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Abstract

As the cost of health care rises governments everywhere are examining how on-line services can replace or augment face-to-face services. Consequently, many health bodies are establishing on-line health forums where patients can share ideas with, or solicit information from, both other patients and health professionals. In the wake of this trend, many on-line forums have arisen which do not have the imprimatur of official government services but are run and managed by private individuals sharing experiences outside of the patient-clinician channel. This phenomenon creates risks and challenges for users who need to evaluate the credibility of unknown and often anonymous contributors to these forums. This paper examines how users assess the credibility of the information in these forums. Five criteria were discovered in the first stage of the work. We then quantitatively tested the relationship between those criteria based on two types of information. Our analysis shows that different criteria are used by participants in online health forums for scientific information and experiential information. We used these novel findings to develop a model for how information credibility is assessed in online health forums. These findings provide important lessons for health promotion bodies considering how to encourage the sharing of valuable health information on-line as well as guidelines for improved tools for health self-management.

*Keywords: Online Community; Online Health Forums; eHealth; Information Credibility, User-Generated Content; Experiential Experts*Introduction

The Internet is changing the way that people receive medical information, from the traditional doctor-patient model to one where patients supplement or even replace that interaction with a search for information and advice on the Internet.

People appear to be attracted to the anonymous and convenient information seeking that is possible via the Internet. However, unlike in face-to-face consultations with a doctor, there is no guarantee that the information and advice is objective, truthful, or up-to-date, and there is no follow-up to ensure that any information provided is used appropriately.

Information obtained from government or institutional sources typically does describe best practice, and published studies indicate that they are generally perceived to provide information that is highly credible, accurate, current, and complete [[1](#_ENREF_1), [2](#_ENREF_2)]. However, research into health promotion by government agencies suggest that there are no clear policies and often no clear evidence-base around what is promoted on such sites [[3](#_ENREF_3)]. Thus, despite some positive attributes, the information from these sites is not always ideal: it is frequently jargon-laden, difficult to comprehend, difficult to incorporate into treatment plans, and its inclusion not fully justified. Political ideologies and the values of individuals running such sites can also effect the type of information published [[3](#_ENREF_3)].

Thus, many people also seek advice from social media sites, including social networking sites, blogs, and wikis. This type of interaction has been often treated with suspicion by medical professionals because the interactions are typically between patients with no medical training, and there are no formal mechanisms to ensure that advice is accurate, up-to-date, or even truthful.

This suspicion, however, may not be warranted. Some research indicates that social media sites are not a substitute for high quality information, but rather complement those sites by providing emotional support and information about the lived experience of a condition (experiential information) from other patients. However, very few studies have been conducted into this type of behaviour, so it is currently unclear how patients evaluate social media sites. This is even though previous research has identified the potential danger of incorrect information being put into the public domain and the difficulties in assessing the credibility of such information [[4](#_ENREF_4)].

Online health forums (OHFs) have been chosen for this research, from among all user-centric social media applications. Firstly, OHFs highlight text-based content and are also the most popular tool adopted [[5](#_ENREF_5)]. In contrast to blogs, OHFs centralise users in one place and better maintain users’ anonymity. As opposed to wikis, OHFs enable social interaction and influence between users. To maintain the communication dynamics between users and assess online health information produced by anonymous users, we exclude those OHFs that are explicitly involved with and moderated by medical professionals such as general medical practitioners, specialists, and registered nurses which tend to be more like Q and A and lack emotional exchange. By removing a central authority and medical professionals, we can better answer the research questions:

*What types of information are generated by* OHF’s? *How do people assess health information generated by other anonymous end-users in OHFs? Do people use different criteria to assess different types of information?*

The remainder of this paper is structured as follows: we start with a review of the key concepts and theories that guide our exploration, and then describe the methodology used to execute this research. We then present the emerging results from two studies, and finally discuss the insights and implications of our findings. We show that fears that online forums provide high risk and under-validated information are generally unfounded. Instead, online health forums appear to be a useful complement to institutional sites, and indeed provide a vital service that has to date been largely ignored by policy makers.

## What Information Do Health Consumers Want?

There has been significant work done on what type of information health consumers require [[6](#_ENREF_6)]. This work suggests that people want information falling under the following categories: Disease entity information (what is the disease?) [[7](#_ENREF_7)]; Time information (how does it progress?); Self-information (why me?); Self-disease (what will happen) [[8](#_ENREF_8)]; Self-disease-time (how will my condition change? )[[6](#_ENREF_6)]. However research suggests that many doctors are unable to satisfy these information needs, either because of a lack of information or a lack of empathy, or just reasons of time and efficiency [[9](#_ENREF_9)]. “Mutual acceptance, more emotional care, empathy”..[[9,p.4](#_ENREF_9)] are some of the areas where patients feel the face-to-face provision of health information could be improved, and are cited as reasons for the increased use of On-line Health Forums as a way of satisfy patient needs, not just for different or greater information but for a different style of information communication [[10](#_ENREF_10)].

## Online Health Forums

Online Health Forums (OHFs) have evolved as a strong Internet presence in the area of both physical and mental health. These may be unstructured discussion groups or may be led by an individual, usually a non-professional, who shares the problem that the group addresses [[11](#_ENREF_11)]. The prerequisite of the shared medical condition sets OHFs apart from other online communities. The usefulness of the support provided by these groups has been attested to in studies of eating disorders [[12](#_ENREF_12)] and depression [[13](#_ENREF_13)]. They have been found to allow patients to form supportive bonds with other people [[11](#_ENREF_11)] and have been reported as being helpful by many users [[14](#_ENREF_14)] particularly in providing the sort of information that health consumers want, as discussed in the previous section. Factors working against use have often been technological, such as error prone designs, rather than related to the benefits derived from participation [[15](#_ENREF_15)].

What drives people to OHFs is the possession of a sense of alienation, feelings of isolation, anxiety about treatment and misconceptions and misinformation [[16](#_ENREF_16)]. Emotional distress from a medical condition can be alleviated by satisfying informational needs [[17](#_ENREF_17)], gaining emotional support [[18](#_ENREF_18)] and engaging social comparison [[19](#_ENREF_19)]. Thus, informational and emotional supports are appreciated and positively received by OHF users [[20](#_ENREF_20), [21](#_ENREF_21)].

OHFs, like other user-centric platforms, place end-users under the spotlight. While medical professionals derive their knowledge from the experience of the majority of patients, patients obtain medical knowledge from living with their medical conditions every day. Thus, patients can articulate not only the location, intensity and duration of sensations, but also how they perceive the experience, what they think and why they behave in particular ways [[22](#_ENREF_22), [23](#_ENREF_23)]. The narrative, personal, discursive and experiential nature of patients’ knowledge challenges the existing credibility criteria used to assess more standard, objective, factual scientific knowledge given by medical professionals. The criteria are particularly tested by the fact that the “wisdom of crowds” can be less accurate than information produced by experts [[24](#_ENREF_24)].

## How Do Users Assess On-line Information?

Consider the following case study:

“Little Charly Johns was a trouper.

She was only six years old and had cancer - but she fought it with determination. She was in and out of hospital as the disease advanced and retreated.

It was tough too for her mother Anna. She joined the Macmillan online cancer forum.

There she found support and help from people who knew exactly what she was going through.

For two years, Anna kept them updated on Charly's progress.

"On the whole she is doing great," she wrote. "She is happy, lively, giggly and very easily excitable. She is always the first to laugh at anything and the last to stop. Nobody could look at Charly now and have any idea of the things she has endured these past 14 months."

But in November last year, Charly lost her fight for life. On the Macmillan forum there was an outpouring of grief. People wrote poems in Charly's memory. They painted their fingernails pink in accordance with her last wishes - even men.

But it was all a lie. Charly did not exist. Neither did Anna.” (BBC News Magazine, *The Cruelest of Internet Hoaxes,* 1 June, 2012).

This case study highlights why being able to assess the credibility of information contained in Online Health Forums is crucial to users. In the OHF context users are concerned about two things: the quality of information and the credibility of the information source, as the consequence of using the information shared in these forums is significant. Patients risk not just believing incorrect treatment advice, but also the sort of emotional exploitation we see in the case study outlined above.

The perceived quality of information is closely related to how credible [[25](#_ENREF_25)] or believable we regard it to be and in fact some researchers regard credibility as a subset of quality [[26](#_ENREF_26)]. Information quality is judged by completeness, accuracy, usefulness and timeliness [[25](#_ENREF_25), [27](#_ENREF_27), [28](#_ENREF_28)], some of which may be more or less difficult to judge in the online context.

Credibility is a complex factor, with research commonly partitioning the concept into multiple components such as information credibility, source credibility, media credibility and web credibility. Information credibility can be evaluated based on information itself, heuristic cues and interaction [[25](#_ENREF_25)]. As one heuristic cue, the credibility of the source of the information can be used to signal information credibility, because a credible source is more likely to produce credible information [[29](#_ENREF_29)]. Cognitive authority, similar to source credibility, specifies a person as a credible source [[30](#_ENREF_30)].

There are two aspects to source credibility: trustworthiness (an information provider’s intention to tell the truth or give unbiased information) and expertise (an information provider’s ability and/or qualification to know the truth of a topic) [[31](#_ENREF_31)]. Source credibility can be judged through surface credibility (simple inspection of superficial features), presumed credibility (stereotyping), reputed credibility (source label such as doctor or professor), and experienced credibility (direct experience with a source over time) [[32](#_ENREF_32)]. Because the environment of the user-led on-line health forum is anonymous and does not involve professionals, only the first of these, surface credibility, can be realistically assessed - which is part of the difficulty of assessing credibility in this context.

Assessing credibility is impacted by the general factors that affect all aspects of information assimilation. Any assessment of information on the Internet is governed by many factors such as age and gender [[33](#_ENREF_33)] or personal attributes and cognitive style [[34](#_ENREF_34)]. In addition, in any cognitive task users tend to utilise the least cognitive effort by taking shortcuts and processing a small amount of information for decision making [[35](#_ENREF_35)]. Prominence-interpretation theory, for example, argues that prominent aspects of a website dominate the evaluation process [[36](#_ENREF_36)]. The limited capacity model of message processing [[37](#_ENREF_37)] reinforces this view, proposing that limited cognitive capacity forces people to select only salient characteristics to encode, store and retrieve messages, particularly in situations where people feel overwhelmed. In these situations, people tend to seek mental shortcuts such as heuristic cues (stereotypes and categories) to minimise the amount of time and cognitive effort needed to process a message [[38](#_ENREF_38)]. Empirical studies provide some support for these theories: for example, although information consumers may report that they verify all online information, in practice, verification methods that minimise time and cognitive effort tend to be used [[39](#_ENREF_39)]. Heuristic cues used as part of this process include lists of links, the design of the site, how information is organised, brand names, street addresses and the length of a message [[40-42](#_ENREF_40)]

This position has been challenged by dual-process theories, suggesting that people can be motivated to exert cognitive effort. The heuristic-systematic model (HSM) [[43](#_ENREF_43)] and the Elaboration Likelihood Model (ELM) [[44](#_ENREF_44)] assert that when individuals’ motivation and ability to process are high, they are inclined to scrutinise carefully all relevant information stemming from the source, message, context, and themselves (e.g. emotions) in an attempt to make an accurate judgment (referred to as the systematic or central route). When either motivation (e.g., personal relevance) or ability to process is low (e.g., insufficient information or knowledge), attitudes can be changed by relatively low-effort processes (referred to as the heuristic or peripheral route). In the health domain, the higher stakes of following the wrong advice and disclosing to the wrong people can motivate users to use more cognitively demanding analytic processes. Nonetheless, without years of systematic medical training, people may not know when to be sceptical and may be more inclined to believe misinformation [[45](#_ENREF_45)].

Theories of cognition, such as the above, only explain part of the process with regard to how information is selected and assimilated when both quality and credibility is important. They do not explain how information credibility is assessed when users seek satisfactory solutions in specific contexts. This research addresses this question.

# Research Design & Methods

The research design contains two phases of investigation. The first phase was conducted to understand what criteria are used in evaluating user-generated health content and reveal the criteria applied by OHF users. Because credibility assessment of user-generated content in OHFs is barely explored and the traditional strategies may not be suitable, it is crucial to understand the phenomenon within a rich social context. The second phase was conducted to validate the findings from Study 1, and to explore the strategies used to assess different types of information. The research design highlights the purposes and strengths of the two studies, by first identifying a set of possible factors contributing to users’ judgments and then testing the strength of the relationships between these factors [[46](#_ENREF_46)].

## Study 1: Qualitative Exploration

### **Data Collection & Analysis**

The theoretical population is defined as every user of all computer-mediated asynchronous message boards, focusing on any physical condition caused by illness, injury, pain or discomfort. Simultaneously, we exclude any mental disorders and spiritual beliefs. Moreover, to eliminate potential confounding factors, we restrict the sampling population to users who have resided in Australia for at least two years. A purposive sampling approach was chosen to maximise the diversity in the sample [[47](#_ENREF_47)], with regard to medical conditions, user’s experience with forums, gender and age mix, education levels, purposes and roles (patient or care giver). The snowballing technique was employed to increase the chance to reach appropriate potential participants, by asking participants to recommend future interview candidates. Participants were recruited from an Australian university and a number of Australia-based OHFs. Recruiting from a university increased the chance of attracting lurkers (i.e., user who only consumer information without contributing), who are also important as part of the theoretical population.

Table 1 lists the medical conditions appearing among the interview participants. Each condition is decomposed based on the illness representation of the Common Sense Model (CSM) [[48](#_ENREF_48)]. The classification of each medical condition is based on the perception of interview participants. It is appropriate as CSM aims to explain how people make sense of and respond to health threats and illness [[48](#_ENREF_48)].

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | Chronic  | Temporary | Manageable | Curable | Stigmatised | Not-Embarrassing | High Impact | Low Impact |
| Diabetes | X |  | X |  |  | X | X |  |
| High Blood Pressure | X |  | X |  |  | X |  | X |
| Pregnancy |  | X |  | X |  | X |  | X |
| Eosinophilic oEsophagitis | X | X | X |  |  | X | X |  |
| Lung Cancer | X |  | X |  | X |  | X |  |
| Spinal Injury | X |  | X |  |  | X | X |  |
| Addison’s Disease | X |  | X |  |  | X | X |  |
| Chronic Fatigue Syndrome | X |  | X |  | X |  | X |  |
| Degenerative Disc | X |  | X |  |  | X | X |  |
| Endometriosis | X |  | X |  |  | X | X |  |
| Fibromyalgia | X |  | X |  |  | X | X |  |
| Minor Ailments\* |  | X |  | X | X | X |  | X |
| \*Here “minor ailments” is used to represent medical conditions that non-regular forum users have. Non-regular forum users usually locate a forum by googling and only visit OHFs when symptoms emerge or medical attention is needed. Their short-term visit will be terminated when they are cured. Some non-regular users in the sample did not have the intention to disclose their exact medical conditions and based on their reported experience with OHFs, it is reasonable to estimate that their ailments can be either stigmatised or not embarrassing. |

*Table 1 Medical Conditions Appeared among Interview Participants*

Guided by the research questions and sensitising concepts derived from our literature review, participants were asked questions such as “What indicators tell you that the information is trustworthy” and “What factors help you determine the quality of the information in a posting”. Interview questions were pre-tested on two PhD students with expertise in health informatics and health education, and on two students who are regular OHF visitors. Based on their responses, the wording of questions, illustrative examples and the order of questions were refined.

In total, the primary investigator conducted one-to-one semi-structured interviews with 16 participants, who represent different medical conditions, length of using forums (from 3 months to over 3 years), genders, ages (from 18 to over 60), education levels (from high school to Master’s degree), roles (patient or care giver) and purposes. The length of interview ranged from 20 minutes to 1.5 hours. In the interview method we used some retrospective analysis was required (eg. invoking memories of postings), as opposed to direct observation, but we feel that the length and number of interviews conducted minimised the limitations of this approach. This is in common with much qualitative research [[49](#_ENREF_49)] .

Table 2, below, sets out the demographic information for the study sample in detail.

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
| ID\* | Gender | Age | Education | Patient / Caregiver | Experience with OHF | Medical Conditions | Duration |
| A1 | m | 40-50 | Bachelor | Patient | 1-3 years | Lung cancer survivor | 25:16 |
| A2 | f | 40-50 | Master | Care giver | 1-3 years | Husband: lung cancer survivor | 39:27 |
| A3 | f | 60+ | Bachelor | Patient | 3 years + | Lung cancer survivor | 48:55 |
| A4 | f | 25-30 | Bachelor | Patient | 1-3 months | Eosinophilic oesophagitis | 17:14 |
| A5 | f | 60+ | High school | Patient | 3 years + | Spinal injury | 64:44 |
| A6 | f | <25 | Bachelor | Patient | 3 years + | Minor temporary Ailments | 46:10 |
| A7 | m | < 25 | Bachelor | Patient | 3-6 months | Minor temporary Ailments | 37:17 |
| A8 | m | 30-40 | Master | Patient, care giver | 1-3 years | Self: Minor temporary AilmentsMom: diabetes, high blood pressure | 32:57 |
| A9 | f | <25 | Bachelor | Patient | 6 months - 1 year | Minor temporary Ailments | 20:26 |
| A10 | f | 60+ | Bachelor | Patient | 3 years + | Chronic fatigue syndrome | 61:37 |
| A11 | f | 60+ | Bachelor | Patient | 3 years + | Addison's disease | 75:06 |
| A12 | m | 60+ | High school | Patient | 6 months - 1 year | Lung cancer (12months) | 52:08 |
| A13 | f | 30-40 | Bachelor | Self (was pregnant)  | 3 years + | Past pregnancy | 44:22 |
| A14 | f | 50-60 | High school | Patient | 3 years + | Degenerative disc | 83:37 |
| A15 | f | 30-40 | Bachelor | Self  | 3-6 months | Pregnancy | 45:38 |
| A16 | f | 30-40 | Bachelor | Patient | 3 years + | Endometriosis, fibromyalgia | 58:47 |

*Table 2: Demographic Information of Interview Participants*

The interviews were conducted over Skype and recorded using MP3 Skype Recorder. Transcription and coding were conducted shortly after an interview was finished. Recruiting was stopped when theoretical saturation was reached and most of the categories and properties remained unchanged when a new transcript was introduced. It is recommended to have 12 to 20 interviews when intending to achieve maximum variation [[50](#_ENREF_50), [51](#_ENREF_51)]. During the open coding, both the number and the names of codes did not change significantly after coding the first 14 transcripts, which indicated data saturation. Data were coded using open, axial and selective coding [[52](#_ENREF_52)]. The iterative coding process is facilitated by computer software. The same set of data has been coded twice by the primary investigator using different software one month apart: Excel and NVivo 8. The two coding processes generated nearly the same categories and similar properties. The codes were further affirmed by additional investigators, both individually and in team meetings to resolve differences of opinion regarding the meaning of each data point analysed. This multiple-assessor process ensured inter-rater agreement and sufficient depth of analysis.

### **Study 1 Sampling limitation**

It is possible that gender affects trust formation and that our sample may have been affected by the dominance of female members. There is evidence that men interacting in male-dominated OHFs (e.g., prostate cancer) are more likely to seek information, while women in female-dominated OHFs (e.g., breast cancer) tend to seek social and emotional support [[53-55](#_ENREF_53)]. However, these search patterns seem not to be apparent in mixed-sex OHFs [[56](#_ENREF_56)], raising the question of whether it is biology or environment that is actually responsible. The framework reported here is developed using a sample of 12 females and 4 males from mixed-sex OHFs. The gender influence on the framework may not be significant but it is still worth exploring in future research whether different genders can progress in the framework differently.

### **Research Findings: Study 1**

Research Question 1

The first research question asked “What types of information are generated by OHF’s”? As discussed in the theoretical background, both emotional and informational support emerged from the data as important factors and provided a context for information. Emotional support can help users cope with emotional distress caused by their medical related situation. A chronic fatigue syndrome patient mentioned the reason for using OHFs: “*Loneliness basically. I started to use it mainly because I want to find someone who has the same illness. It’s isolating when you have a medical condition that is not well-understood by the outside. So isolation I suppose. Like to talk to someone who believes you, understands and recognises my illness* (p1)*…… outside world doesn’t recognise this illness and we get deflected a lot from doctors and from the general community*” (p2, A13)[[1]](#footnote-2).

Furthermore, three types of informational support are uncovered. **Experiential information** stems from the first-hand experience with a condition or situation. For example, “*The problem of using drug B is you got no way of gauging it. [There is] no way to accurately measure the dose for the steroid you are given. So a few years back somebody discovered it about drug B and they were writing to stop taking drug B. I reduced my own drug B intake from time to time and only use it as buffer*” (p3, A12). Because everybody experiences the same illness differently (e.g., reacts to the same treatment or medication with a variety of symptoms and degrees), experiential information varies greatly, as stated by one participant: “*You might find that most of the people who regularly attend the support group are on Tarceva. Everybody seems to be affected differently by it. It seems to be beneficial to some people but simple things like I have a problem that my eyelashes keep on growing. They don’t fall out. At the very end they touch my glasses and I can’t see. Nobody else has that problem. There is an old lady there, she actually passed away, she was on Tarceva [but] she lost all her hair. That only happens with chemotherapy*” (p7, A11).

Similarly, the Charly Johns story, related earlier, is an emotive story likely to engage the experiential system. However, as personal experience varies, there is no clear standard to indicate what is credible.

**Scientific information** refers to facts directly related to diseases and explains the underlying scientific mechanisms and research (e.g., medication, treatment, studies, explanation, etc.). It is usually shown in the form of referrals to other websites or citing information from external media (e.g., the Internet, books, journal, etc.). The forum is utilised as an information filter, as one said “*You often put in the forum that ‘I heard about this [new cancer drug]. Did anybody hear about it?’ You get a lot of information. If you look up on the Internet, you just get very critical. You don’t know all the information that if anyone ever tried it*” (p3, A8).

**Non-medical factual information** (in a narrow sense) pertains to facts that are indirectly related to the disease but help people cope with other aspects of daily life (including insurance policy, hospital policy, and government financial aid). For example, “*I posted on the managing money section, and I asked suggestion about what other people think…… I do look for information a bit. A lot of reasons I’m on is payment, at the point of my life*” (p4, A5,).

Although both scientific information and non-medical factual information are objective and factual, scientific information may contain competing theories which lead to different explanations, as one pointed out: “*Even those specialists and PhDs, they have various opinions on what the right answer is. So I cannot actually judge what is right. People don’t really have the same opinions really. Sometimes some studies say this and the others have different opinions*” (p5, A10). Therefore, compared with non-medial factual information that has standard answers from authorities (e.g., governments, insurance companies, hospitals), it is more difficult but valuable to study the assessment criteria of credibility of experiential and scientific information, which are the focus of the rest of the paper.

Research Questions 2 and 3

The second and third research questions ask how people assess these different types of information and if they use different criteria to assess different types of information. Figure 1 depicts the factors that affect assessment of the credibility of experiential and scientific information. Both types require argument quality, verification and literacy competence. Reference credibility specifically pertains to scientific information and crowd consensus is especially used to assess experiential information.



Figure 1 Assessment Criteria of Perceived Information Credibility

**Argument quality** refers to a logical soundness based on common sense. Logical soundness is repeatedly mentioned by interview participants, using phrases like “*it makes sense*”, “*reasonable*”, “*logical*” and “*they know what they are talking about*”, to describe credible information. It is the result of cognitive effort in assessing argument strength, as one stated that “*if there is only one person answered, I’ll be reading his post and based on my experience that he’s a rational person and what he said make sense, I’ll try* (p8, A13).

**Verification** is another cognitively demanding activity. It can be accomplished by confirming with external sources (e.g., websites, books, academic journals, etc.) or internal sources (e.g., self knowledge). A participant elaborated on external verification: “*If the advice is like if you hurt your foot you should put a cold pad and someone else said if you hurt your foot you should use a hot pad. I’ll actually go get journal articles and search the nature of the injury and whether a hot pad is better or a cold one is better in control trials and based on that*” (p7, A2). Self knowledge can be gained through studying and researching as well as experiencing the medical condition on a daily basis, as one said: “*[To judge what others said,] I suppose it’s based on my own personal experience of the illness. I do research and get medical status and I belong to some medical association. I’m constantly reading up about my illness. So it’s based on that*” (p2, A12).

**Contributor’s literacy competence** is the most frequently mentioned heuristic cue (13 out of 16 participants), forming a first impression of information. The way a message is written can imply the quality of the message. One participant explained: “*[The information and advice in OHFs] are particularly trustworthy because some of the postings are extremely well-written, seen like medical literature and put into the words that the rest of us can understand*” (p1, A13). Another stated: “*If in the title and preview, the information is punctuated poorly or wrongly capitalised, then the quality is poor*” (p2, A2). However, one pain sufferer does not respond to this cue: “*It doesn’t matter if people can’t spell or their grammar is incorrect, they still suffer pain. If they are not articulate on what happened, if it’s very basic, I’m very thankful they gave me their opinion and told me how it affects them. So they genuinely care. No, I don’t put much emphasis on how information on the forum comes to me, like grammar. I don’t take too much notice on that*” (p7, A15). This indicates that while a contributor’s literacy competence is a widely applied shortcut, users also recognise the impact of physical and mental exhaustion on patients and can be more forgiving.

**Reference credibility** is a criterion relevant to scientific information. As scientific information is provided as referrals, reference credibility pertains to the credibility of cited external sources, similar to source credibility in literature. It is a strong cue to infer the credibility of scientific information, assuming that a credible source is more likely to produce credible information. As a result, the provision of an external reference in the text is strongly desired: “*I need to see some evidence for the suggestion and what proof of research or study might be done and I’ll count and analyse it in great detail*” (p4, A13). To assess the credibility of a reference, the patient who used to be a librarian described a strategy: “*If the research only involved ten people, I wouldn’t bother to try it out; if it took 500 and 500 state trials, it would probably be worthy trying. I’ll be looking for evidence and also the quality of trials, which is really important in medical literature. Look at the quality of the research. You have to say that it has been done on how many people, like 500 or 5000, and also have to look at the dropout rate because a lot of them may drop out. If the dropout rate is very high, then you have to think about why people drop out, is it because what they’ve been asked for is not possible*” (p4, A13). Another strategy is also discussed: “*I suppose depending what websites it comes from, if it’s reputable, whether it’s government, university websites, if it’s research based, those are pretty trustworthy. You’ve got other websites either business or people put information out there. You don’t know if they’re trustworthy. Business obvious tries to promote products so they’re biased*” (p3, A16).

**Crowd consensus** is adopted to assess experiential information. Because experiential information is subjective, personal and lack of objective standards, crowd consensus provides a group opinion regarding the validity of an experiential statement. One explained how it works: “*The one way you can get some sort of ideas is to get all your info, line them up and see how much they’re the same. The majority is the same and you get them from different sources, then you can pretty well say that they live with pretty much the same side-effects. So you get a pretty good idea how it’s going to react to you*” (p7, A15). The social influence on adopting behaviour is obvious: “*If the crowds really really like something, yes I would try. If 60 people say it’s good, I’ll give it a go. But if only one person mentions it, I’ll do some research. If I can’t find anyone else who thinks it’s good, I may be less likely to try*” (p9, A8).

Study 1 enriches our understanding of how users assess the credibility of user-generated health content by revealing the criteria used to evaluate the credibility of scientific information and experiential information. Though cognitive authority was mentioned by experienced OHF users who have repeated interaction with a contributor, we excluded it because we intended to form a uniform model suitable for all OHF users and cognitive authority is missing among inexperienced user. Interestingly, other criteria mentioned in the literature review such as completeness and length is not prominent. Completeness is not necessary because users can learn one’s experience through discourse and the appropriateness of details enclosed in a message varies among situations. Also, the preferred length varies. When describing experience, users prefer some details without undue elaboration. When showing emotional support, a very short message can fail to convey compassion and sincerity without illustrating any shared experience. Moreover, though details are important for communication, some participants could not read long postings due to cognitive function decline or physical discomfort.

## Study 2: Quantitative Validation

Study 1 generates a set of criteria used by OHF users to assess user-generated health information. However, it did not specify whether they work uniformly, or whether there is any preference for a criterion when evaluating different types of information. Moreover, as a common limitation of qualitative studies, lack of generalisability and the nature of subjective interpretation are often mentioned. To address those concerns, a quantitative study was conducted using an online sampling tool and structural equation modelling to test two general hypotheses (as in Figure 1): 1) Argument quality (ARQ), verification (VER), contributor’s literacy competence (LIC), and reference credibility (REC) positively contribute to perceived credibility of scientific information respectively; 2) Argument quality, verification, contributor’s literacy competence, and crowd consensus (CRC) positively contribute to perceived credibility of experiential information respectively. This study provides further data to answer research questions 2 and 3.

### **Subjects & Procedures**

Participants were recruited using Amazon’s Mechanical Turk (MTruk), which is recognised as an inexpensive way to collect high quality representative data, compared with traditional methods [[57](#_ENREF_57), [58](#_ENREF_58)]. 159 online forums users living in the United States were self-selected and completed a 10-minute online survey on their perceptions of the posting they have the best memory of during their last visit to an OHF. While 15 of them left out demographic questions, the average age is 32 with a standard deviation of 11.8. 44.7% of participants are female and 54.1% have a Bachelor’s degree or a more advanced degree. The demographic pattern is consistent with previous studies on online health information seeking [[59](#_ENREF_59), [60](#_ENREF_60)]. The items used in the on-line survey and their factor loadings can be found in Appendix 1.

#### Sample Size Sufficiency

Chin and Newsted [[61](#_ENREF_61)] recommended that the minimum sample size should be either ten times of the largest number of formative indicators or ten times of the largest number of Independent Variables influencing a Dependent Variable, whichever is greater. Based on Table 3, the information credibility assessment model (n=159) satisfies the Ten Times rule of thumb. Thus, the sample size is sufficient for model testing.

|  |  |
| --- | --- |
| Construct | Indicator |
| Argument quality (ARQ) | ARQ1, ARQ2, ARQ10 |
| Verification (VER) | VER1, VER2, VER3 |
| Contributor’s literary competence | LIC1, LIC2, LIC3, LIC9 |
| Reference credibility (REC) | REC1, REC2, REC5,REC7,REC9 |
| Crowd consensus (CRC) | CRC1, CRC2, CRC3, CRC4 |

Table 3: Indicators and Constructs

#### Sampling Limitations

There may be some limitations in the sampling method for study two that require noting. Due to the sensitive nature of the research it was not possible to initiate direct contact with patients in online health forums and conduct probability or random sampling. The sample may have a smaller variance and not be fully representative of the population, because only those who read the recruiting invitation and decided to participate are included in the sample. Users who did not visit those forums during those 4 weeks did not have an equal chance of reading the recruiting invitation and participating.

Some remedies were applied to alleviate the limitation:

* Data was collected from both online health forums and universities to increase the representativeness of non-regular users;
* Permission and support from the forum administration was obtained to increase legitimacy so that users would be more likely to click through and read the recruiting invitation;
* whenever possible, the invitation was included in a monthly newsletter distributed by the administration to all registered users of a forum, or was promoted as a “sticky” posting, which permanently resides at the top of a forum;
* each initial posting (the recruiting invitation) had two subsequent postings posted at the beginning of the second and the third week, to bump up the thread to the top and to update the progress of the study;
* the survey was open for 4 weeks, prolonging the exposure of the study.

### **Measures**

All measures were adapted from existing literature and all items were measured using a seven point Likert scale with anchors from strongly disagree to strongly agree. Following Podsakoff et al.’s [[62](#_ENREF_62)] remedies for common method bias, the measures of dependent variable and independent variables are drawn from different sources, and temporal separation is created between them. Perceived information credibility was measured using Hilligoss et al. [[25](#_ENREF_25)] and Rains et al.’s [[63](#_ENREF_63)] items, while measures of dependent variables were chosen from a number of studies [[31](#_ENREF_31), [64-69](#_ENREF_64)]. A pre-test on a sample of 104 OHF users using the same recruiting and analysing procedures were conducted to ensure the reliability and validity of the instrument. As a result, items of verification were reworded and adjusted to better fit the context based on the results of Study 1 and the pre-test. Each construct has three to five items and in total we have 23 items.

### **Measurement Model and Validity Analysis**

The measurement model was analysed using Partial Least Squares (PLS) software package Smart PLS 2.0. Its tolerance for small sample sizes and purpose of prediction suits our needs. Due to the nature of the phenomenon, not every participant encountered both types of information in the last visit. Participants whose most memorable message contains only scientific information did not answer questions on crowd consensus, and same with experiential information on reference credibility. Hence, there are missing data values in the sample. Though PLS can handle missing data through case wise or mean replacement, the adequacy of its ability is seriously questioned recently [[70](#_ENREF_70)]. Thus, we split the sample into two: Sample 1 for scientific information with 140 cases, and Sample 2 for experiential information with 128 cases.

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Variables** | **Mean** | **St.D** | **Cronbach’s Alpha** | **ARQ** | **VER** | **LIC** | **REC** | **INC** |
| **ARQ** | 4.7288 | 1.3633 | 0.8102 | **0.9001** |  |  |  |  |
| **VER** | 4.8226 | 1.3237 | 0.7807 | 0.7226 | **0.8836** |  |  |  |
| **LIC** | 4.8365 | 1.4379 | 0.8208 | 0.6839 | 0.6873 | **0.9099** |  |  |
| **REC** | 4.4239 | 1.3389 | 0.7978 | 0.6258 | 0.6547 | 0.5058 | **0.8932** |  |
| **INC** | 4.9638 | 1.4333 | 0.8459 | 0.7340 | 0.8021 | 0.6907 | 0.6910 | **0.9197** |
|  |  |  | AVE | 0.8102 | 0.7807 | 0.8208 | 0.7978 | 0.8459 |

Note: The diagonal is the square root of the average variance extracted (AVE).

Table 2. Correlation of Latent variables (Scientific information sample; n=140)

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Variables** | **Mean** | **St.D** | **Cronbach’s Alpha** | **ARQ** | **VER** | **LIC** | **CRC** | **INC** |
| **ARQ** | 4.8706 | 1.2903 | 0.8133 | **0.9018** |  |  |  |  |
| **VER** | 4.9914 | 1.2256 | 0.7507 | 0.6475 | **0.8664** |  |  |  |
| **LIC** | 4.9402 | 1.4026 | 0.8355 | 0.5013 | 0.5594 | **0.9141** |  |  |
| **CRC** | 4.8404 | 1.2951 | 0.8744 | 0.5421 | 0.7323 | 0.4926 | **0.9351** |  |
| **INC** | 5.0753 | 1.3064 | 0.8132 | 0.6526 | 0.7733 | 0.6238 | 0.7110 | **0.9018** |
|  |  |  | AVE | 0.8133 | 0.7507 | 0.8355 | 0.8744 | 0.8132 |

Note: The diagonal is the square root of the average variance extracted (AVE).

Table 3. Correlation of Latent variables (Experiential information sample; n=128)

PLS analysis was performed on both samples. Table 2 and 3 demonstrate strong reliability and validity of the measures. All Cronbach’s Alpha scores fall between 0.75 and 0.85, which satisfies Nunnally’s [[71](#_ENREF_71)] recommendation of 0.7. Moreover, all items have loadings over 0.8, except one item of verification, which is 0.7814 in Sample 1 and 0.6967 in Sample 2, with 0.2 differences from all cross-loadings in both samples. Overall, the instrument satisfies the general agreed cut-off point of 0.7 for loading on a factor [[72](#_ENREF_72)]. To analyse the factorial validity, all items load with a significant t-value on its latent construct. The minimum t-value of loadings is 11.842 in Sample 1 and 8.897 in Sample 2. A further support of convergent validity is that the average variance extracted (AVE) of constructs exceeds 0.5 [[73](#_ENREF_73)]. Moreover, discriminant validity is demonstrated with low cross-loadings (0.2 differences from the loading on a factor) and reinforced by meeting the Fornell-Larcker Criterion (the square root of the AVE should be higher than the correlations between the latent variable and all other latent variables). The diagonal in both tables is the square root of AVE, which is higher than any values in its row and column. Based on the above tests, we conclude that the measurement model is reliable and valid. Next, we test the structural model.

### **Structural Model Analysis and Results**

Both the PLS Algorithm and Bootstrapping procedure were performed. Since PLS does not provide fitness indices like LISREL or AMOS, results were evaluated based on path coefficients and the R squares that indicate the explained variance by the models.

|  |  |
| --- | --- |
| Sample 1 (Scientific Information) | Sample 2 (Experiential Information) |
| **R2 = 0.733** | ARQ - INC | VER - INC | LIC - INC | REC - INC | **R2 = 0.702** | ARQ - INC | VER - INC | LIC - INC | CRC - INC |
| Coefficient | 0.183\*\* | 0.402\*\*\*\* | 0.176\* | 0.224\*\*\*\* | Coefficient | 0.182\*\* | 0.356\*\*\*\* | 0.212\*\*\* | 0.248\*\* |
| t-value | 2.002 | 3.885 | 1.681 | 2.796 | t-value | 2.084 | 2.753 | 2.448 | 1.988 |

\*p≤0.1, \*\*P≤0.05, \*\*\*P≤0.01, \*\*\*\*P≤0.005

Table 4. Path Analysis Results

As shown in Table 4, all paths in both samples are significant and both models have explained more than 70% of the variance in perceived information credibility. Among all criteria, verification has shown the strongest impact on perceived credibility of both scientific information and experiential information, while argument quality has shown less impact across both samples. To assess scientific information, reference credibility is the second most important criterion, and a contributor’s literacy competence is the least useful and salient factor. On the other hand, to evaluate experiential information, crowd consensus and a contributor’s literacy competence is the second and third most influential criteria.

# Discussion

On-line health information comes in a number of forms and users employ multiple strategies in deciding which information to trust or rely on. While the information supplied on official sites is generally seen as evidenced based and scientific, in fact research shows it often reflects government health policy or the particular values of its authors. Consequently, as we have seen in this research, large numbers of people are turning to often anonymous sources on community health forums where they need to implement strategies to test the credibility of the information they find in them.

This paper provides an understanding onhow people assess health information generated by other anonymous users in OHFs. Employing sequential mixed-method, we conducted a qualitative enquiry to understand what criteria are used by users of OHFs for evaluation, followed by a quantitative validation of the criteria and an exploration on how those criteria are employed in judging the credibility of different information. The findings show that two broad types of information are commonly generated by OHF’s: scientific information and experiential information. These two types of information are assessed using different strategies in OHFs.

What is most important to users is being able to verify the information. This can be done by reference to established evidence in the case of scientific information and through crowd consensus with respect to experiential information. The low coefficients for argument quality suggest that users do not have full confidence in their logical reasoning ability to confirm or refute arguments. This clearly reinforces the vulnerability of users of such sites.

 A contributor’s literacy competence is less important when a message is based on reference to external scientific content. This might support the validity of those cognitive models which hold that users tend to choose verification methods that reduce cognitive effort.

The findings are consistent with previous studies. Toulmin’s model of completeness [[74](#_ENREF_74)] suggests that a logically complete argument contains three elements: claim assertions, evidence (grounds), and authority (warrants and backing). In our context, due to anonymity, authority is difficult to establish and to be recognised by users without repeated interaction with the same contributor. Thus, claim assertions (argument quality) and evidence (verification, reference credibility and crowd consensus) are heavily relied on. Particularly, extreme weight has been placed on evidence by OHF users, which echoes with the advocacy of evidence-based public health practice and self-management [[75](#_ENREF_75), [76](#_ENREF_76)]. Moreover, reference credibility and crowd consensus dovetail with informational influence and the normative influence of Deutsch and Gerrard’s [[77](#_ENREF_77)] dual process theory. People are more likely to depend on objective standards (e.g., scientific mechanisms and explanation) if they are available; when objective standards are absent or obscured (e.g., assessing experiential information), people are inclined to apply social reality testing primarily by detecting shared patterns among subjective and conflicting information [[19](#_ENREF_19)]. This may be why some user at some point was motivated to investigate and uncover the Charly Johns fraud. In addition, to contrast with previous findings on user-centric applications where heuristic cues are largely adopted, users affected by health issues are more motivated to adopt an effortful approach and are less likely to depend on heuristic cues. The low but significant coefficient of the ARQ – INC path also indicates the high knowledge barrier and cognitive consumption faced by OHF users. Hence, when motivation is high but ability is low, users tend to adaptively allocate their efforts to cognition demanding tasks, in order to secure a satisfactory outcome. Finally, a contributor’s literacy competence has been less helpful when assessing scientific information than experiential information. This may be explained by the nature of scientific information, which is cited from external sources. Perceived information credibility is more likely to originate from external sources than from the contributors of postings, thus literary competence becomes a less significant factor.

# Conclusion

This paper makes a unique contribution to an understudied area of research by providing insight into how people assess the credibility of user-developed on-line information in the health context. It helps solve the enigma of how people can have the confidence to move away from traditional sources of medical advice to trust the information provided by strangers.

The results show that a different mix of assessment criteria and preferences on each criterion are employed to evaluate the credibility of scientific information which is supported by searchable sources and experiential information which comes from the writers own lived experience. These findings may have implications for non-medical forums such as investment advice or travel where stakes can be high in terms of possible economic loss and trust is important. The findings of this research can provide enhanced opportunities for self-education and self-management within a theoretically sound interface design.

In a world where health costs are rising and the provision of face- to -face care is a growing public expense the findings are of significant value to those official bodies that are involved in the development of online support for chronic disease management in providing useful guidelines for site development and the inclusion of materials and user inputs that are likely to be seen as originating from credible sources. A greater understanding of the way information is developed and shared on these sites and the value of this information to patients may lead to an increased inclination by doctors and medical professionals to see them as a supportive and valuable resource not influenced by official policy or government endorsed values. With the popularity of such sites offering ubiquitous access to types of information not easily provided by traditional sources, the ability of consumers to develop ways of assessing the credibility of such sites is an important development in facilitating the role of these sites as valuable health education tools.

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Appendix 1: Factor Loadings of Credibility Assessment Model of Experiential Information

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| Code | Item | ARQ | INC | LIC | REC | VER |
|  ARQ1 | The arguments in the posting are convincing. | 0.888  | 0.598  | 0.577  | 0.465  | 0.572  |
| ARQ10 | The arguments in the posting are well-supported. | 0.895  | 0.537  | 0.639  | 0.486  | 0.664  |
|  ARQ2 | The arguments in the posting are strong. | 0.909  | 0.559  | 0.556  | 0.403  | 0.571  |
|  INC3 | I think the message is credible. | 0.609  | 0.887  | 0.508  | 0.593  | 0.586  |
|  INC4 | I think the message is believable. | 0.566  | 0.911  | 0.545  | 0.543  | 0.588  |
|  INC5 | I think the message is trustworthy. | 0.577  | 0.934  | 0.511  | 0.608  | 0.539  |
|  INC7 | I think the message is truthful. | 0.544  | 0.893  | 0.536  | 0.529  | 0.535  |
|  INC9 | I think the message is reliable. | 0.544  | 0.883  | 0.532  | 0.577  | 0.536  |
|  LIC1 | I think that the message demonstrates acceptable grammar. | 0.690  | 0.578  | 0.934  | 0.409  | 0.755  |
|  LIC2 | I think that the message is punctuated properly. | 0.602  | 0.512  | 0.949  | 0.350  | 0.752  |
|  LIC3 | I think the message is capitalised properly. | 0.592  | 0.546  | 0.961  | 0.355  | 0.731  |
|  LIC9 | I think that the message has good spelling. | 0.585  | 0.556  | 0.924  | 0.395  | 0.720  |
|  REC1 | The information in the message is cited from a reputable source. | 0.505  | 0.568  | 0.364  | 0.893  | 0.456  |
|  REC2 | The information in the message is cited from a highly rated source. | 0.472  | 0.552  | 0.371  | 0.925  | 0.437  |
|  REC5 | The information in the message is cited from a reliable source. | 0.466  | 0.597  | 0.361  | 0.929  | 0.402  |
|  REC7 | The information in the message is cited from a well-known source. | 0.422  | 0.556  | 0.348  | 0.899  | 0.370  |
|  REC9 | The information in the message is cited from an informative source. | 0.400  | 0.575  | 0.365  | 0.856  | 0.392  |
|  VER1 | The information in the message is consistent with my experience with the medical condition. | 0.661  | 0.557  | 0.619  | 0.436  | 0.863  |
|  VER2 | What I know about the medical condition verifies the information in the message. | 0.509  | 0.488  | 0.708  | 0.338  | 0.884  |
|  VER3 | What my doctor told me supports the information in the message. | 0.611  | 0.611  | 0.724  | 0.456  | 0.927  |
| VER9\* | There is evidence that the information in the message is confirmed. | 0.593  | 0.533  | 0.750  | 0.383  | 0.886  |
| \*The item was dropped in the structural model analysis due to high cross-loading. |

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| Code | Item | ARQ | CRC | INC | LIC | VER |
| ARQ1 | The arguments in the posting are convincing. | **0.903**  | 0.373  | 0.504  | 0.446  | 0.514  |
| ARQ10 | The arguments in the posting are well-supported. | **0.883**  | 0.378  | 0.485  | 0.543  | 0.622  |
| ARQ2 | The arguments in the posting are strong. | **0.905**  | 0.359  | 0.454  | 0.419  | 0.508  |
| CRC1 | The arguments in the message are consistent with the opinions of the majority on the discussed medical issues. | 0.408  | **0.894**  | 0.551  | 0.305  | 0.457  |
| CRC2 | The arguments in the message are similar to the opinions of the majority on the discussed medical issues. | 0.422  | **0.936**  | 0.546  | 0.325  | 0.495  |
| CRC3 | The arguments in the message are agreed by the opinions of the majority on the discussed medical issues. | 0.312  | **0.910**  | 0.481  | 0.302  | 0.421  |
| CRC4 | The arguments in the message are supported by the opinions of the majority on the discussed medical issues. | 0.361  | **0.925**  | 0.528  | 0.358  | 0.464  |
| INC3 | I think the message is credible. | 0.498  | 0.537  | **0.896**  | 0.439  | 0.467  |
| INC4 | I think the message is believable. | 0.483  | 0.547  | **0.916**  | 0.467  | 0.495  |
| INC5 | I think the message is trustworthy. | 0.490  | 0.542  | **0.940**  | 0.422  | 0.452  |
| INC7 | I think the message is truthful. | 0.506  | 0.507  | **0.916**  | 0.447  | 0.478  |
| INC9 | I think the message is reliable. | 0.459  | 0.479  | **0.870**  | 0.420  | 0.421  |
| LIC1 | I think that the message demonstrates acceptable grammar. | 0.564  | 0.382  | 0.476  | **0.944**  | 0.723  |
| LIC2 | I think that the message is punctuated properly. | 0.495  | 0.312  | 0.439  | **0.973**  | 0.731  |
| LIC3 | I think the message is capitalised properly. | 0.470  | 0.308  | 0.466  | **0.958**  | 0.700  |
| LIC9 | I think that the message has good spelling. | 0.474  | 0.343  | 0.470  | **0.954**  | 0.692  |
| VER1 | The information in the message is consistent with my experience with the medical condition. | 0.672  | 0.502  | 0.497  | 0.474  | **0.821**  |
| VER2 | What I know about the medical condition verifies the information in the message. | 0.422  | 0.387  | 0.368  | 0.678  | **0.870**  |
| VER3 | What my doctor told me supports the information in the message. | 0.509  | 0.466  | 0.456  | 0.713  | **0.920**  |
| VER9\* | There is evidence that the information in the message is confirmed. | 0.487  | 0.373  | 0.434  | 0.747  | **0.871**  |
| \*The item was dropped in the structural model analysis due to high cross-loading. |

1. Quotations from the interview data are listed as the page (P#) of transcript of participant (A#). [↑](#footnote-ref-2)