Variations in trust in Dr Google when experiencing potential breast cancer symptoms: Exploring motivations to seek health information online

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Abstract

How people trust the Internet and seek health information online when experiencing and interpreting potential cancer symptoms is not well understood. We interviewed twenty-seven women who had recently experienced at least one potential breast cancer symptom, and explored their symptom experience, help-seeking strategies, and whether they consulted the internet in relation to their symptoms. We conducted a thematic analysis and constructed a typology of attitudes towards, and experiences of, consulting the internet about the symptoms: i) *confident*; ii) *neutral*; iii) *hesitant*; and iv) *avoidant*. 'Hesitant' and 'avoidant' participants rarely mentioned cancer explicitly, doubted being able to interpret the information found online, and expressed concerns over finding 'scaremongering' information or making incorrect self-diagnosis. The 'avoiders' and the 'hesitant' participants perceived online information-seeking as being inherently risky, partly because online health content is likely to be inaccurate or exaggerated, and partly because the process of lay interpretation is likely to be flawed by lack of medical expertise. The findings suggest that not all women experiencing potential breast cancer symptoms seek health information online spontaneously, or trust the internet as a legitimate source of health information. The women who did engage in online information seeking, particularly those with lower education, felt unsure about how to appraise online health sources to interpret their symptoms.

Keywords Breast cancer; Early diagnosis; Internet; Online information-seeking; Trust

Introduction

The Internet is a widely used source of health information, as search engines and social media platforms offer lay people countless possibilities to locate and engage with information relevant to their health condition (Lee et al., 2014). One of the main reasons people search for health information online is to make sense of current symptoms (McDaid & Park, 2011; Fox & Duggan, 2013; Diviani et al., 2016), with search engines acting as tools for self-diagnosis, e.g. “Dr Google” (Lee et al., 2014). Given the online proliferation of sources of health information, both formal (e.g. governmental, healthcare providers and charities) and informal (e.g. user-generated content, social media), it is becoming increasingly easy for Internet users to find information on symptoms and health conditions and interpret their symptoms in light of it. However, it is not entirely clear to what extent the Internet represents a legitimate, trustworthy, and commonplace source of health information for anyone experiencing unexplained symptoms, and whether accessing health information online can help the public appraise their symptoms, particularly prior to seeking formal medical help. While it is generally assumed that accessing online health sources is routine (Chapple et al., 2012), and that it can make users informed, empowered (Henwood et al., 2003; Santana et al., 2011) and able to make better health choices (McDaid and Park, 2011; Powell & Boden, 2012), the plethora of online information sources – varying in quality and accuracy – can make it difficult for consumers to discriminate the most pertinent and legitimate ones. Furthermore, even if scientifically accurate or trustworthy, not all health information accessed online can be “empowering”, particularly if the online sources provide a negative outlook for one’s health condition (Chapple et al., 2012; Gage & Panagakis, 2012). Thus, although searching the Internet for information may be routine, people may avoid it when experiencing symptoms for fear of coming across unfavourable facts. While online information-seeking has been extensively researched among patients following a diagnosis, e.g. cancer (Castleton et al., 2011; Chapple et al., 2012; Thomson et al., 2012), less is known about how people experiencing emerging symptoms might turn to the Internet for help with understanding their health condition.

Trust in online health information sources

Seeking health information online carries a certain level of risk (Nettleton et al., 2005) with lay consumers and patients being potentially misled, misinformed or deceived through lack of accuracy or authenticity (Chapple et al., 2012; Gage & Panagakis, 2012). Such elements of risk – highly recognizable in the online environment and particularly in the post-truth era (O. O'Neill, 2017) – are likely to engender considerations of trust as consumers need to assess the credibility of online health information sources as they engage with them (Sillence et al., 2007; Yi et al., 2013; Sbaffi & Rowley, 2017; Chu et al., 2017). Seeking and appraising health information online also entails the risk of finding information that carries negative implications for one's health, e.g. realizing that one's symptoms may be indicative of cancer. This makes seeking health information online, or seeing the doctor, equivalent to embarking on a risky course (Luhmann, 1990), with consumers having to face potentially distressing information and difficult choices (Chapple et al., 2012).

Deciding not to trust the health information found online can function as a strategy of risk avoidance and a way to deal with negative emotions (e.g. fear about a potential cancer diagnosis) but this can limit consumers' options. As Luhmann (1990) notes, lack of trust reduces the possibility for rational action such as taking early medication, or, in our context, seeking further information or medical help. Theorists have variously defined trust as a 'leap' towards favourable expectation regarding other people's actions and intentions (Möllering, 2001), a means of overcoming the absence of evidence, a confident expectation of another's behaviour, a consequence of being vulnerable and thus constrained to place faith in another, or an asymmetry of dependence on another (Barbalet, 2009). In the present context, consumers seeking health information online may be in a vulnerable state, e.g. concerned about ongoing symptoms or lacking medical expertise, and thus compelled to place trust in the information sources they come across. Importantly, trust is underpinned by two related feelings of confidence: confidence in another's future actions, and confidence in one's own judgment of the other (Barbalet, 2009). Thus, lay people need to be confident in their own judgment of the online sources' accuracy and relevance if they are to trust the health information gathered online.

In the context of online health information, trust and associated concepts of credibility and reliability have been researched to explore consumer confidence in online information sources and antecedents of engagement in information-seeking (Sbaffi & Rowley, 2017). The notion of web credibility is largely grounded in the more traditional concept of source credibility in interpersonal communication, whereby credibility is defined as the sources' ability to instil confidence in their message, with trustworthiness and expertise as key dimensions (Choi & Stvilia, 2015; Metzger & Flanagin, 2015). Trustworthiness involves making judgments about the truth claims, expertise, and commitment of an individual, institution, or organization, and to be trustworthy means to be perceived as honest, competent, and reliable (O. O'Neill, 2018). Yet, judgments of trustworthiness can be difficult in the era of Internet-mediated communication, social media and user-generated content as traditional ways of assessing honesty and competence are disrupted by the complexity of digital technology and the varied nature of information sources (O. O'Neill, 2017; 2018).

In the online environment, credibility is also conferred by aspects unique to the Internet, e.g. webpage design, ease of navigation, institutional logos, hyperlinks to other sites, scientific writing style, or citation of medical sources (Eysenbach & Köhler, 2002; Choi & Stvilia, 2015; Mendes et al., 2017). Such 'surface credibility cues' (Machackova & Smahel, 2018) are likely to influence trust in online health sources beyond their actual content or authorship. However, trust in online sources is not only a matter of information source characteristics because credibility is ultimately a subjective perception (Metzger & Flanagin, 2015). Trust in online sources depends on user characteristic, too, such as education level, experience of looking up symptoms online, or confidence in navigating the Internet for health information (Ha & Lee, 2011).

Given that trust is also a matter of confidence in one's own judgment of the other (Barbalet, 2009) and that obtaining health information online places the onus on lay consumers to establish the sources’ accuracy and reliability, self-confidence in being able to do so might influence trust over and above source characteristics. But not all consumers may feel able to appraise online health information for its legitimacy and reliability (Lee et al., 2014), or willing to take on the responsibility to establish the credibility of online sources (Henwood et al., 2003). Equally, the users’ motivations and goals when engaging in information-seeking also drive their willingness to place trust in the information gathered online (Metzger & Flanagin, 2015). Therefore, trust in online health information-seeking is a highly subjective process, underpinned by motivation to believe and confidence in one’s own ability to discriminate between credible and misleading sources. Indeed, when accounting for the strategies that help them discern reliable health information sources online, consumers allude to having common-sense and as being cautious, sensible, users of the Internet (Nettleton et al., 2005).

Education and the digital divide

Not all consumers engage in health information-seeking online, and not all consumers benefit from the wealth of health information available on the Internet. Lower education levels have been associated with lower engagement in health information-seeking (e.g. Cotten & Gupta, 2004; Mayer et al., 2007; Kontos et al., 2014), including cancer-related information (Ramanadhan & Viswanath, 2006; Castleton et al., 2011; Thomson et al., 2012; Lee et al., 2012; Vrinten et al., 2017a). These differences in engagement with online health information have often been attributed to the ‘digital divide’ (Wyatt et al., 2005; McCloud et al., 2016), i.e., disparities in computer access and usage between lower and higher socioeconomic groups. The differences in online health information-seeking have also been explained in terms of disparities in e-health literacy (Viswanath et al., 2007; Diviani et al., 2015), which is defined as “the ability to seek, find, understand, and appraise health information from electronic sources and apply the knowledge gained to addressing or solving a health problem” (Norman & Skinner, 2006: e9). Education level has been found to be associated not only with seeking health information online but also with trust in online health information sources, as people with higher levels of education are more trusting than people with lower levels of education (e.g. Hesse et al., 2005; Kreps & Neuhauser, 2010). In the area of cancer, for example, cancer patients with higher education have been found to be more likely to trust health information found on the Internet than patients with lower education (Lussiez et al., 2017).

Cancer and online information-seeking

Cancer is one of the most searched for health topics online, with breast, bowel, and lung cancer being the most frequent searches, both in the UK and in other English-speaking countries (Foroughi et al., 2016). The high search volume on the Internet around these types of cancer arguably reflects public interest in the topic, but it is also in line with their high incidence; for example, in the UK in 2015, breast, prostate, lung and bowel cancers combined accounted for over half (53%) of all new cancer cases recorded nationwide (Cancer Research UK, 2018). Cancer patients consult the Internet to appraise their potential cancer symptoms before seeing the family doctor (McLeod et al., 2017) or the oncologist (Castleton et al., 2011), or after being diagnosed with cancer (O’Mahoney et al., 2011; Chapple et al., 2012). Seeking information online can crystalize people’s concerns that their symptoms may be serious and that they warrant medical attention. For instance, among patients subsequently diagnosed with colorectal cancer, some reported that seeking information online made them suspect that their symptoms might be cancer before receiving a formal diagnosis (Thomson et al., 2012).

As regards breast cancer, previous research has documented educational differences in how women make sense of breast cancer symptoms and seek help (Marcu et al., 2017), showing that women with lower educational backgrounds are less likely to feel confident seeking medical attention than women with higher education. However, these studies have not focused on how online information is accessed and interpreted by women with symptoms indicative of breast cancer. In the present paper we explored the extent to which women consulted the Internet about breast health information in an educationally diverse group of women recently experiencing breast changes.

Methodology

Design

This study was part of our wider qualitative study about how women with different educational backgrounds appraise their breast changes and seek medical help (reference withheld for blind peer review). The findings presented in this paper constitute secondary data analysis, with a new research focus on the extent to which online information-seeking is a common-sense response to breast changes suggestive of breast cancer. The qualitative approach (individual semi-structured interviews) which we adopted allowed flexibility in the exploration of women's interpretation of breast symptoms, their motivations for seeking (or not) relevant health information on the Internet, and their assessment of the information found online. The diverse nature of the original sample allowed us to be alert to potential educational differences.

Participants and recruitment

With the help of a market research company, SAROS Ltd., we recruited a sample of women who had experienced breast symptoms in the six months prior to the interview, without having a diagnosis for breast cancer. The inclusion criteria were age 47 or older, and breast changes in the previous six months (e.g. lump in armpit, nipple discharge) as indicated by a screening questionnaire adapted from the Breast Cancer Awareness Measure (Linsell et al., 2010). We excluded women younger than 47 because among this age group breast changes are less likely to be symptoms of breast cancer than among women aged 47 or older. This exclusion criterion was in line with the extension of the breast screening programme to women aged 47 to 73 years old, as has recently being trialled in some parts of England (Health & Social Care Information Centre, 2015). We also excluded women with a previous or current diagnosis of breast cancer from the study because we wanted to explore strategies of information-seeking and sense-making in the absence of a cancer diagnosis.

We identified participants through quota sampling according to educational status (lower vs. higher). We categorised the women with no formal qualifications or with just two Ordinary-Levels (national school exams sat at 16 years of age – referred to as O-levels until 1988, now GCSEs) as 'lower education'. We categorized the women with qualifications at and above two O-Levels (e.g. Ordinary National Certificate (awarded by the Business and Technology Education Council, BTEC), Advanced Levels (A-Levels), university degree) as 'higher education'. Within each education group we ensured an equal spread of women who had or had not seen the General Practitioner (GP) for their breast symptoms.

We recruited a non-clinical sample of 27 women across the UK, mean age = 54.48, age range = 47 to 67. Based on education levels, we categorised 14 as lower education (LE), and 13 as higher education (HE). Half of the participants (*n* = 14) had not sought medical help for their breast changes, while the other half had (*n* = 13), without receiving a breast cancer diagnosis. The most commonly reported symptom at the point of recruitment was pain in the breast or armpit, either on its own (*n* = 15) or with other symptoms, see full details on the participants' demographics and symptoms in Table 1.

INSERT TABLE 1 HERE

Ethical approval

The study received ethics approval from the University of Surrey Ethics Committee (Reference: UEC/2015/013/FHMS). The participants were emailed or handed out an information sheet and consent form that outlined the benefits and risks of taking part and provided detailed information on data protection and confidentiality. We fully debriefed the participants at the end of the interview.

Data collection

The participants were interviewed in April-May 2015, either by telephone or face-to-face, and compensated with £30 for their time. We did not mention breast cancer during the course of the interview so as not to influence participants' interpretation of their breast changes, nor their accounts about what information they sought online and how they appraised it. We asked the participants to describe their breast changes, thoughts and feelings about them, and how they had dealt with them, e.g. seeing the doctor, talking to friends or family, or seeking health information online. If they had sought information online, we asked them to elaborate on the information found, e.g. whether useful or not. If the participants had not sought information online, we probed them to explain why not, or if they intended to do so in the future.

Analytic approach

For the purpose of the present paper we analysed the data using inductive thematic analysis (Joffe & Yardley, 2004), focusing only on the participants' accounts of whether or not they had sought information about their symptoms and whether this enabled them to interpret their symptoms and seek formal medical help. First, we examined the manifest content of the data, and divided the participants into *seekers* vs. *non-seekers* on the basis of their responses as to whether or not they had searched for information online about their breast changes.

Second, we attended to the latent content of the data by examining more closely the participants' responses as to why they had searched for – or avoided seeking – information online and whether they had found the information useful. These included reasoning around seeking health information online (e.g. fear of cancer information) and evaluations of the information-seeking process (e.g. as providing useful answers or not). In line with previous research (Nettleton et al., 2005; Chapple et al., 2012), we were interested in how the participants accounted for their motivations to consult – or not – online health sources, and whether using the Internet was constructed as a commonplace strategy when making sense of symptoms. Thus, we analysed the responses according to how the participants justified their information-seeking approach, and created a nuanced typology of information-seeking profiles beyond a simple division into seekers and avoiders. The accounts of using online health information were relatively short, so we used Microsoft Excel to assign participants to rows, and indexed profiles of information seeking in columns.

Findings

We constructed four profiles summarizing different attitudes and behaviours pertaining to looking up symptoms online and seeking health information: *confident*, *neutral*, *hesitant*, and *avoidant*. Next to each quote we include the participant's ID, age, education status ('LE' representing lower education level and 'HE', higher education level), and highlight where educational differences were apparent. The most frequent symptom was breast pain – where different, we describe the symptom next to the participant's demographic information.

Confident about looking for information online

A number of participants looked up information online about their breast changes, and used it to interpret and act upon their symptoms. We termed these participants 'confident' because their responses suggested that seeking information online about breast symptoms was unproblematic and, contrary to other participants such as 'avoiders' and 'hesitant', they did not express a lack of trust in either the Internet or in their own ability to appraise the information found online. Although the 'confident' participants did not explicitly express trust in the information found, it was noteworthy that none of them viewed the process of looking up health information online as being problematic. For example, P10 arranged to see her GP on the basis of the information she found:

> *I did a lot of research online. When they say that if you find a lump it can be cancerous, because that's the first thing you think of, but then I looked at it for the ones that are under the armpit, unless you don't find out the information you don't know what it is. I put "women's health" and then I put down "a lump under the armpit", "what is cancerous?". I wanted to find out, what can cause these symptoms? Then I thought, 'Getting worried is not going to help me. I need to see the doctor'.* (P10, 47, LE)

Although some participants could not accurately remember what they had searched for and found online, their responses indicated that they used the Internet routinely for health information:

> *I do do things like that, and I don't know whether I did for this, but I'm very renowned for researching and googling everything. But if it was something more serious, I might not feel anything at all apart from actually feeling lumps I probably wouldn't get pain. So I don't know whether I googled it or not, I could have done because I do google a lot.* (P28, 47, LE, pain in breast)

In some instances, participants looked for information online after seeing the GP, supplementing the information received from the GP and providing practical ideas about how to monitor and manage symptoms:

> *I did a bit of research before I went to the doctor's, because I think everybody does now, don't they, now we've got Google. The doctor said, "Your body is changing, and this could be just one of the associated symptoms", then you start looking yourself and do a bit more… There was one on Mumsnet which was quite good, because it was obviously pains in breast but no lumps, and Patient.co.uk. It says about keeping the diary, which where I got the idea from. It mentions some women have breast tissue which is more sensitive than usual to hormonal changes every month. And that's what I've deduced is causing mine*. (P18, 48, HE-SES)

The participant implies here that a popular site like Mumsnet is a trustworthy source, its credibility being conferred by the large volume of users. In the ‘confident’ profile, using the Internet for health information seemed to be a commonplace, everyday activity, and, in this particular instance, an obvious strategy for making sense of current symptoms (cf. Chapple et al., 2012).

Neutral towards online information-seeking

This profile was typified by respondents who had not considered looking up their breast symptoms online. This could have been because the interview was carried out at a time in the symptom appraisal interval where these participants had not yet contemplated the need to seek health information online. Some had “*never really thought to google anything about breast pain*” because it did not worry them enough (P5, 48, LE), while others had simply normalised their breast changes:

> *No. I just feel that [the cyst in the breast] is one of them things, you are either prone to it or you are not. I think that’s just the way it is*. (P21, 48, LE)

Despite not considering consulting the Internet about their breast changes, some women were familiar with using it for different conditions, e.g. Hashimoto's thyroiditis, or bleeding related to hormone-replacement therapy (HRT):

> *I haven’t looked [about breast changes]... I think that tenderness under my arms could be... but I’m not 100% sure, it’s your lymph nodes, or something. That’s what I need to find out. [...] I did a lot of research online for the bleeding and for the HRT, because that was more severe than the [breast] tenderness and the sensitivity. I need to do that next*. (P9, 59, HE)

The experience of mild symptoms in the breasts may have been the main reason why some women had not considered using the Internet for health information. However, the interview process made some participants express intentions to consult the Internet afterwards, thus suggesting that the “neutral” respondents were open to using the Internet for health information. One of the participants, who had not yet considered looking up her symptoms online, portrayed the Internet as overwhelming and confusing people with too much detail on symptoms:

> *I haven’t [sought information] because it didn’t occur to me until I’d spoken [to you]… I thought I’ll go and see my GP, see what he says. But I mean the redness is not… it’s just red. It’s not raised. It’s not bumpy. […] So in my day… you see, you are very blessed because there’s a lot of information out there now and people speak and talk more openly. When I was younger, there wasn’t anything like that. There wasn’t information available. There wasn’t the Internet, there wasn’t people specialising as much. But almost too much information now, because, you know, I could tick off stomach pains, distension, wind* [flatulence]*, fatigue, blah-blah-blah-blah, and mark it against maybe half a dozen illnesses*. (P26, 62, HE, redness of breast skin)

The ‘neutral’ typology thus seems to have been influenced partly by lack of symptom severity, and partly by the relationship of the participant to the Internet. Furthermore, it could be argued that the lack of symptom severity did not trigger feelings of vulnerability, which in turn precluded the need to place trust in, or to evaluate the trustworthiness of, online health information sources.

Hesitant about seeking online information

The ‘hesitant’ profile encapsulates a tension between wanting to know more about one’s symptoms and feeling unsure about one’s ability to interpret the information found online. Some participants looked up their symptoms but felt overwhelmed by the retrieved information and became reluctant to conduct further searches. These participants felt ambivalent about the value of consulting the Internet for health symptoms:

> *I was concerned to get [swelling in breast] checked out because my mother died from breast cancer at my age, 64. I did a little bit of research on the internet. But I tried not to do too much because it can get a bit confusing [with] all the information out there. So I thought I'd better make an appointment with my GP and get it checked out properly*. (P4, 63, HE)

Some 'hesitant' participants, particularly those with lower education, felt *"daunted"* by the information. They expressed preferences for a cursory – rather than thorough – approach to information-seeking, partly because of their fears, partly because of their acknowledged lack of medical expertise:

> *Yes, I looked on the internet. But I try not to read too much into it because everything seems to be daunting, and it doesn't matter what symptoms you have, it always gives you a bleak outlook. You think, what if it is worst-case scenario? I try not to read too much into things like that when I'm looking… I just look for a bit of outline information*. (P27, 47, LE, nipple discharge)

> *I did some googling and found out about Paget's of the breast, and that prompted me to go to the doctor's, because there's a lot of breast cancer in my family*. *It does worry you more because you can read a lot into it, sometimes it doesn't give you peace of mind. So that's why I went to the doctor's as well. It worried me when I did sort of look into NetDoctor and everything. So I thought, no, leave [it]… see what the tablets do and see whether… because I think you can look into things too much and think, oh yes, I have got that, yes I am suffering. So no, I haven't looked at it again.* (P25, 47, LE, nipple discharge)

Given their lack of medical expertise, some participants questioned the appropriateness of looking for information by themselves as this can lead to wrongful interpretations:

> *I looked it up online and that didn't seem to be the symptoms at all for [breast cancer]. I just put 'signs of breast cancer', although I try not to look on the internet because it makes us all doctors and we are not. And then I put in 'redness and soreness round the nipples', 'raised nipples'. And, of course, every website says something different, so I just thought, we are not really doctors, I shouldn't really be doing this. It just worries you. I googled it first and looked at NHS [English National Health Service] websites, and at private breast screening websites. And I thought, it's just not right to do it, because you just have all these visions going round your head.* (P13, 55, LE)

With the exception of P13, all 'hesitant' participants went to see the GP, mostly because they felt that only a healthcare professional could resolve the ambivalence around their symptoms and provide appropriate answers, and they did not trust the Internet, or their interpretation of information they found while searching, to substitute medical help-seeking.

Avoiding online information-seeking

The 'avoidant' profile summarizes the attitudes and behaviours of respondents who avoided seeking information online as a matter of principle. They argued that the information on the Internet is too difficult to navigate and appraise, and that "*you can't take everything as gospel that's written*" (P16, 51, HE, pain in armpit). The 'avoiders' pointed out that one could not describe symptoms accurately enough to get meaningful search results online:

> *If I buy a new washing machine, I'll go online and look at reviews for that, but not when it comes to health, unless it's the NHS Direct. Because I couldn't put in exactly what was wrong, I didn't expect to find anything, so I didn't bother to look*. (P24, 47, LE, sharp pain in breast)

A number of women, particularly those with lower education, shared the 'hesitant' participants' concerns about reading too much into the information found online, and argued that consulting the Internet carried the risk of "*overanalysing your symptoms and convincing yourself that you've got something really bad"* (P14, 58, LE, lump in armpit):

> *No, because I find that when I start looking things up on the computer, I end up self-diagnosing. I'd rather not self-diagnose, because you look on a computer and you think, oh yes, I've got that, that, and that, and then you start to think, I've got cancer*. (P30, 50, LE, pain in breast and armpit)

The 'avoiders', particularly from the lower education group, shared the 'hesitants' information-seekers' concern that they lacked medical knowledge to assess – and filter – potentially untrustworthy information online:

> *I certainly wouldn't trust the information from the computer. […] I think you find out things that are incorrect.* (P30, 50, LE)

Similarly to the 'hesitant' participants, the 'avoiders' argued that it would be unwise to consult the Internet because "*there's so much scaremongering stuff going on there"* which can wrongly make people read "*about the worst possible case scenario"* (P23, 52, HE, swellings in breasts). Participants preferred to "*stay away from Google"* because they would be *"going on somebody else's symptoms and not what the doctor says"* (P24, 47, LE). Contrary to the other participants, the 'avoidant' participants' accounts seemed to be fundamentally underpinned by considerations of the trustworthiness of online information sources and of user-generated content, reminiscent of what other researchers have termed "rhetorics of reliability" (Nettleton et al., 2005). Thus, the information avoiders dismissed from the start the possibility that the Internet could offer useful information about their ongoing symptoms and preferred to maintain a state of uncertainty over their symptoms.

Discussion

In this study we explored whether women experiencing potential breast cancer symptoms sought health information online as a routine response to health changes, and whether this contributed to symptom appraisal. We also examined whether patterns of online information-seeking might be linked to education attainment level. Our qualitative interview data captured motivations for seeking or avoiding breast-relevant information online, interpretations of the information found, and evaluations of its usefulness, which enabled us to create four profiles of information-seeking: *confident*, *neutral*, *hesitant*, and *avoidant*. Creating typologies of information-seeking behaviour can help researchers understand better the needs, abilities, and motivations of consumers of online health information (cf. Macias et al., 2017). The profiles we created for our participants reflected diverse information needs, different levels of confidence in seeking and appraising online health information, and different attitudes towards the value of the Internet in helping women make sense of cancer-suggestive breast changes. These profiles reflect our participants' online information-seeking (or avoidance) about ongoing breast changes, and may not necessarily represent their information-seeking strategies in relation to other symptoms or illness, nor do they represent a static typology of Internet users in general. We will discuss these profiles in turn, and while we cannot infer the antecedents and consequences of online cancer information-seeking, we will discuss the potential value of the Internet for earlier diagnosis of breast cancer.

Firstly, the 'confident' profile shows that some women can confidently navigate the Internet to locate and evaluate health information, and that they implicitly see the Internet as a legitimate and trustworthy resource for health information and self-management of symptoms. Five out of the seven participants who looked for information online went on to see the GP. We cannot ascertain a causal relationship, yet it could be argued that the nature of the symptoms may have motivated the 'confidence' to both seek information online and to see the GP, or that information-seeking is part of a general positive attitude towards help-seeking. Similar qualitative studies about women's use of the Internet for breast cancer-related information have found that women who sought help promptly also acquired information from websites about their symptoms (O'Mahony et al., 2011). It could be argued that in the case of the ‘confident’ participants trust was a ‘forced option’ (cf. Barbalet, 2009), as the participants sought medical help not necessarily because they had acquired relevant information online, but because they had no option but to trust the healthcare system.

Secondly, the profile of being ‘neutral’ about looking up one’s symptoms online suggests that some women experiencing breast changes may not necessarily feel motivated to look up information about symptoms online, or consider the Internet as a credible or trustworthy source of health information. The mild nature and/or familiarity of the participants’ symptoms underpinned the ‘neutral’ profile, where there was little need for more information or, in some cases, medical help. The participants who did not consider consulting the Internet about their symptoms did not explicitly voice the reasons for their indifference – it may well be that for some people seeking health information on the Internet is not necessarily a mundane, everyday activity. This suggest that another type of “digital divide” may exist, that between people who routinely engage with online health sources when experiencing symptoms, and those who do not (cf. ‘non-engagers’, B. O’Neill, 2017). As other researchers have observed, we should not dichotomize people as information-seekers vs. non-seekers, but interpret online information-seeking as context- and symptom-dependent (Gage & Panagakis, 2012), with people seeking information for some health conditions but not others.

The profiles of ‘hesitant’ and ‘avoidant’ show more complexity than those of ‘confident’ and ‘neutral’, both in terms of trust judgments, information appraisal and help-seeking intentions. The ‘hesitant’ information-seekers’ accounts suggest that online content can cause information overload, where they feel unable to appraise the quality, trustworthiness and content of the information found online, as previous research has suggested (Lee et al., 2014; Nelissen et al., 2015; Santer et al., 2015; Chu et al., 2017). Those with low e-health literacy may find it particularly challenging to navigate the high volume of health information online and apply it to their own symptoms, and thus may be more prone to “filter failure” (Klerings et al., 2015). The ‘hesitant’ participants' accounts also suggest that they sought to come across as "sensible users" of the Internet (Nettleton et al., 2005), acknowledging the limits of their medical knowledge and emphasising how they tried not to seek too much information or read too much into it. Furthermore, the ambivalence in the 'hesitants' information-seeking strategies also shows that there can be a blurred boundary between information-seeking and information-avoidance, and confers support to the view that information-avoidance is a multi-faceted phenomenon and not necessarily the opposite of information-seeking (Case et al., 2005; Gaspar et al., 2016).

The 'avoidant' profile shows that some people can hold negative beliefs about the value and credibility of the Internet in providing health information. The 'avoiders' perceived the health information available on the Internet as predominantly giving a bleak outlook for health conditions and worried about posing risks to their own health through wrong self-diagnosis. The avoidant attitudes to online information-seeking can equally be interpreted as fear of cancer (e.g. Vrinten et al., 2017b), and resonate with research on the relationship between cancer fear and cancer information avoidance (Miles et al., 2008; Persoskie et al., 2014; Nelissen et al., 2015; Emanuel et al., 2015; Vrinten et al., 2017a). In our study, the majority of the 'avoiders' did not go to see the family doctor, suggesting a link between lack of trust in health information sources and fear of a potential cancer diagnosis. This link was compounded by the use of euphemisms such as *"something really bad"* (P14, 58, LE) or *"the worst possible case scenario"* (P23, 52, HE) to describe the potential diagnosis. In contrast, the 'confident' and 'hesitant' information seekers mentioned breast cancer more explicitly as the reason for looking up information online. This suggests that fear of cancer can motivate some people to engage in information-seeking, while for others it may act as a deterrent (Nelissen et al., 2015; Vrinten et al., 2017b).

The information-avoiders' concerns about the accuracy of online information and their fears about coming across unfavourable information bears resemblance to parents' reasons for avoiding seeking cancer information online in relation to their children's cancer (Gage & Panagakis, 2012).

The ‘avoiders’ reasoning about the lack of credibility and legitimacy of the Internet in providing accurate health information also reflects a well-founded concern about the inability of online medical sources to provide personally-relevant answers on cancer (cf. Chu et al., 2017), particularly when cancer outcomes can vary widely according to type of cancer and stage of diagnosis.

Hesitance among our participants, particularly those with lower education level, to access health information online (the ‘avoiders’) or to evaluate it and seek further (the ‘hesitants’) denotes lack of trust in the online medical information. This is a common concern among the public and a barrier to Internet lay use for health purposes (e.g. Lee et al., 2014; Chu et al., 2017; Sbaffi & Rowley, 2017). Lack of trust in online health information is a potential limit to how much it can engender informed (Henwood et al., 2003) or empower patients (Santana et al., 2011), or reduce the ‘digital divide’ linked to educational attainment or socioeconomic status (e.g. Wyatt et al., 2005). At the same time, the ‘hesitants’ and the ‘avoiders’’ legitimate concerns about incorrect interpretation and over-diagnosis reflect lack of trust (or of self-confidence) in their own ability to judge the medical information accessed online. This ties in with Barbalet’s (2009) view that there is double confidence within trust, as an individual needs to have confidence in other’s future actions but also in their own judgment of the other. Such lack of confidence was explicit in some participants’ claim that ‘we are not doctors’, where the cliché ‘I’m not a doctor’ (see also Marcu et al., 2017) functioned as an admission of lack of expertise and as a justification for stopping (or not initiating) health information-seeking online.

We found subtle educational differences in attitudes and behaviour regarding online information-seeking among our sample, these being more pronounced in the hesitant and avoider profiles. Women with lower education were somewhat more likely to fit these profiles and to express less confidence in seeking and appraising online health information. These results support existing research on the relationship between education level and cancer information-seeking (Ramanadhan & Viswanath, 2006; Castleton et al., 2011; Thomson et al., 2012; Lee et al., 2012;

Vrinten et al., 2017a; Chu et al., 2017). While we did not measure e-health literacy in the present study, our findings suggest that lower e-health literacy and lower ability to discern credible information may be a reason for lower confidence in navigating the Internet and lower trust in the health information found online (cf. Kreps & Neuhauser, 2010; Lee et al., 2012). However, further research is required to clarify the relationship between education level and online information seeking, because our study was limited to a secondary data analysis and we therefore could not exhaustively explore all potentially relevant dimensions (e.g. subtleties in layers of trust, e.g. person vs. system). Furthermore, we used O-Levels to categorise women into lower or higher education level groups. However, there are a number of other ways that women could have been categorised (i.e. with a different education 'cut-off' point) and this should be recognised in future research exploring educational differences in online health information-seeking.

As to the strengths and weakness of this study: first, we examined reported *behaviour*, rather than *intentions*, pertaining to online health information seeking about breast changes, even if some of these behaviours consisted of hesitancy or avoidance. This provided a more accurate measure of information-seeking and insight into the actions that followed it (e.g. seeing the GP, keeping a diary to monitor symptoms). Second, the participants consulted the Internet in a natural setting, not influenced by the researchers' presence or by social desirability. Furthermore, the participants sought information about ongoing or recent symptoms, rather than anticipated or fictitious ones, thus conferring the findings greater ecological validity.

There are also a number of limitations to this study. We did not specifically design the study to examine engagement with the Internet prior to a medical consultation, nor did we recruit the participants according to their engagement in health information-seeking online. However, conducting a secondary analysis of qualitative data can be a pragmatic and cost-effective means to gain novel insights from rich and comprehensive datasets (Ziebland & Hunt, 2014). Also, studying a phenomenon in qualitative data (in our case, trust in online health information) which we did not directly ask about can nonetheless be helpful as it can lead to fewer artefacts in the participants' responses. In addition, the participants' recollection of the search terms used or the information found online was not always detailed enough to infer its role in symptom appraisal or in motivations to seek help. In some cases, the participants could not recall these details because they had searched for information online considerable time prior to the present study. Health information-seeking did not always take place *before* the seeing the GP, and thus causal links between information-seeking and early symptomatic presentation cannot be inferred. Finally, we only included women for whom symptoms turned out not to be cancer, and it would be interesting to explore whether our typology would be impacted by including women with a breast cancer diagnosis.

Conclusion

Our present findings suggest that, apart from considerations of severity of own symptoms, health information-seeking on the Internet is underpinned by considerations of trust in online sources and risk perceptions from information overload and incorrect self-diagnosis. Despite NHS (National Health Service) websites and cancer websites investing significant resources to provide accurate information to the public about cancer symptoms in a way that minimizes alarm, fears about cancer information and distrust in the Internet persist, reducing the chances of relevant cancer information reaching those who might benefit from it most. Healthcare professionals should invest greater efforts to educate their patients about trustworthy online health resources and to promote endorsed health websites. This could make patients more confident about which Internet sources to consult in the event of symptoms, although another step is needed to ensure women have trust in themselves to be able to adequately interpret the information. In light of the present results, we would posit that 'Dr Google' is not so much a *source* or a *channel* of health information, but rather a *process* of seeking and processing health information online, whereby trust in online sources and in one's own ability to appraise the information play a crucial role.

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References

Barbalet, J. (2009). A characterization of trust, and its consequences. *Theory and society, 38*(4), 367-382. Cancer Research UK. Cancer Statistics for the UK. [Last accessed: 1/02/2018]. [Available from: http://www.cancerresearchuk.org/health-professional/cancer-statistics.]

Case D.O., Andrews, J.E., Johnson, J.D., & Allard, S.L. (2005). Avoiding versus Seeking: The Relationship of Information Seeking to Avoidance, Blunting, Coping, Dissonance, and Related Concepts. *Journal of the Medical Library Association, 93*, 353–362.

Castleton, K., Fong, T., Wang-Gillam, A., Waqar, M. A., Jeffe, D. B., Kehlenbrink, L., . . . Govindan, R. (2011). A survey of Internet utilization among patients with cancer. *Supportive Care in Cancer, 19*(8), 1183-1190.

Chapple, A., Evans, J., & Ziebland, S. (2012). An Alarming Prognosis: How People Affected by Pancreatic Cancer Use (and Avoid) Internet Information. *Policy & Internet, 4*(2), 1-20.

Choi, W., & Stvilia, B. (2015). Web credibility assessment: Conceptualization, operationalization, variability, and models. *Journal of the Association for Information Science and Technology, 66*(12), 2399-2414.

Chu, T. W. J., Wang, P. M., Shen, C., Viswanath, K., Lam, H. T., & Chan, C. S. S. (2017). How, When and Why People Seek Health Information Online: Qualitative Study in Hong Kong. *Interactive Journal of Medical Research, 6*(2), e24.

Cotten, S. R., & Gupta, S. S. (2004). Characteristics of online and offline health information seekers and factors that discriminate between them. *Social Science & Medicine, 59*(9), 1795-1806.

Diviani, N., van den Putte, B., Giani, S., & van Weert, J. C. M. (2015). Low Health Literacy and Evaluation of Online Health Information: A Systematic Review of the Literature. *Journal of Medical Internet Research, 17*(5), e112.

Diviani, N., van den Putte, B., Meppelink, C. S., & van Weert, J. C. M. (2016). Exploring the role of health literacy in the evaluation of online health information: Insights from a mixed-methods study. *Patient Education and Counseling, 99*(6), 1017-1025.

Emanuel, A. S., Kiviniemi, M. T., Howell, J. L., Hay, J. L., Waters, E. A., Orom, H., & Shepperd, J. A. (2015). Avoiding cancer risk information. *Social Science & Medicine, 147*, 113-120.

Eysenbach, G., & Köhler, C. (2002). How do consumers search for and appraise health information on the world wide web? Qualitative study using focus groups, usability tests, and in-depth interviews. *BMJ, 324*(7337), 573-577.

Foroughi, F., Lam, A. K., Lim, M. S., Saremi, N., & Ahmadvand, A. (2016). “Googling” for cancer: An infodemiological assessment of online search interests in Australia, Canada, New Zealand, the United Kingdom, and the United States. *JMIR Cancer, 2*(1): e5.

Fox, S., and Duggan, M. (2013). *Health Online 2013*. Washington, DC: Pew Research Center’s Internet & American Life Project.

Gage, E. A., & Panagakis, C. (2012). The devil you know: parents seeking information online for paediatric cancer. *Sociology of Health & Illness, 34*(3), 444-458.

Gaspar, R., Luís, S., Seibt, B., Lima, M. L., Marcu, A., Rutsaert, P., . . . Barnett, J. (2016). Consumers’ avoidance of information on red meat risks: information exposure effects on attitudes and perceived knowledge. *Journal of Risk Research, 19*(4), 533-549.

Ha, S., & Jung Lee, Y. (2011). Determinants of consumer-driven healthcare: Self-confidence in information search, health literacy, and trust in information sources. *International Journal of Pharmaceutical and Healthcare Marketing, 5*(1), 8-24.

Health & Social Care Information Centre. (2015). *Breast Screening Programme, England: Statistics for 2013-14*. London: Health & Social Care Information Centre. Retrieved from: file://homes.surrey.ac.uk/home/bres-scre-prog-eng-2013-14-rep.pdf

Henwood, F., Wyatt, S., Hart, A., & Smith, J. (2003). ‘Ignorance is bliss sometimes’: constraints on the emergence of the ‘informed patient’ in the changing landscapes of health information. *Sociology of Health & Illness, 25*(6), 589-607.

Hesse, B. W., Nelson, D. E., Kreps, G. L., Croyle, R. T., Arora, N. K., Rimer, B. K., & Viswanath, K. (2005). Trust and sources of health information: the impact of the Internet and its implications for health care providers: findings from the first Health Information National Trends Survey. *Archives of internal medicine, 165*(22), 2618-2624.

Joffe, H., & Yardley, L. (2004). Content and thematic analysis. In: D.F. Marks and L. Yardley (Eds.) *Research methods for clinical and health psychology*. London: Sage.

Klerings, I., Weinhandl, A. S., & Thaler, K. J. (2015). Information overload in healthcare: too much of a good thing? *Zeitschrift für Evidenz, Fortbildung und Qualität im Gesundheitswesen, 109*(4), 285-290.

Kontos, E., Blake, D. K., Chou, S. W.-Y., & Prestin, A. (2014). Predictors of eHealth Usage: Insights on The Digital Divide From the Health Information National Trends Survey 2012. *Journal of Medical Internet Research, 16*(7), e172.

Kreps, G. L., & Neuhauser, L. (2010). New directions in eHealth communication: Opportunities and challenges. *Patient Education and Counseling, 78*(3), 329-336.

Lee, C.-j., Ramírez, A. S., Lewis, N., Gray, S. W., & Hornik, R. C. (2012). Looking Beyond the Internet: Examining Socioeconomic Inequalities in Cancer Information Seeking Among Cancer Patients. *Health Communication, 27*(8), 806-817.

Lee, K., Hoti, K., Hughes, D. J., & Emmerton, L. (2014). Dr Google and the Consumer: A Qualitative Study Exploring the Navigational Needs and Online Health Information-Seeking Behaviors of Consumers With Chronic Health Conditions. *Journal of Medical Internet Research, 16*(12), e262.

Linsell, L., Burgess, C., & Ramirez, A. (2008). Breast cancer awareness among older women. *British journal of cancer, 99*(8), 1221.

Linsell, L., Forbes, L. J. L., Burgess, C., Kapari, M., Thurnham, A., & Ramirez, A. J. (2010). Validation of a measurement tool to assess awareness of breast cancer. *European Journal of Cancer, 46*(8), 1374-1381.

Luhmann, N. (1990). Familiarity, confidence, trust: problems and alternatives. In D. Gambetta (Ed.), Trust: making and breaking cooperative relations, pp. 94–107. Oxford: Blackwell.

Lussiez, A. D., Burdick, S., Kodali, S., Rubio, G., Mack, J. A., Lin, J., . . . Reddy, R. M. (2017). Internet Usage Trends in Thoracic Surgery Patients and Their Caregivers. *Journal of Cancer Education, 32*(1), 91-96.

Machackova, H., & Smahel, D. (2018). The perceived importance of credibility cues for the assessment of the trustworthiness of online information by visitors of health-related websites: The role of individual factors. *Telematics and Informatics, 35*(5), 1534-1541.

Macias, W., Lee, M., & Cunningham, N. (2017). Inside the Mind of the Online Health Information Searcher using Think-Aloud Protocol. *Health Communication*, 1-12. doi:10.1080/10410236.2017.1372040

Marcu, A., Black, G., Vedsted, P., Lyratzopoulos, G., & Whitaker, K. L. (2017). Educational differences in responses to breast cancer symptoms: A qualitative comparative study. *British Journal of Health Psychology, 22*(1), 26-41.

Mayer, D. K., Terrin, N. C., Kreps, G. L., Menon, U., McCance, K., Parsons, S. K., & Mooney, K. H. (2007). Cancer survivors information seeking behaviors: A comparison of survivors who do and do not seek information about cancer. *Patient Education and Counseling, 65*(3), 342-350.

McCloud, R. F., Okechukwu, C. A., Sorensen, G., & Viswanath, K. (2016). Beyond access: barriers to internet health information seeking among the urban poor. *Journal of the American Medical Informatics Association, 23*(6), 1053-1059.

McDaid, D., & Park, A.L. (2011). *Online health: untangling the web*. London: BUPA.

McLeod, J., Yu, I., & Ingledew, P.-A. (2017). Peering into the Deep: Characterizing the Internet Search Patterns of Patients with Gynecologic Cancers. *Journal of Cancer Education, 32*, 85-90.

Mendes, Á., Abreu, L., Vilar-Correia, M. R., & Borlido-Santos, J. (2017). "That Should Be Left to Doctors, That's What They are There For!"—Exploring the Reflexivity and Trust of Young Adults When Seeking Health Information. *Health Communication, 32*(9), 1076-1081. doi:10.1080/10410236.2016.1199081

Metzger, M. J., & Flanagin, A. J. (2015). Psychological Approaches to Credibility Assessment Online. In S. S. Sundar (Ed.), *The handbook of the psychology of communication technology* (pp. 445-466). Chichester: Wiley-Blackwell.

Miles, A., Voorwinden, S., Chapman, S., & Wardle, J. (2008). Psychologic Predictors of Cancer Information Avoidance among Older Adults: The Role of Cancer Fear and Fatalism. *Cancer Epidemiology Biomarkers &amp; Prevention, 17*(8), 1872-1879.

Möllering, G. (2001). The nature of trust: From Georg Simmel to a theory of expectation, interpretation and suspension. *Sociology, 35*(2), 403-420.

Nelissen, S., Beullens, K., Lemal, M., & Van den Bulck, J. (2015). Fear of cancer is associated with cancer information seeking, scanning and avoiding: a cross-sectional study among cancer diagnosed and non-diagnosed individuals. *Health Information & Libraries Journal, 32*(2), 107-119.

Nettleton, S., Burrows, R., & O'Malley, L. (2005). The mundane realities of the everyday lay use of the internet for health, and their consequences for media convergence. *Sociology of Health & Illness, 27*(7), 972-992.

Norman, D. C., & Skinner, A. H. (2006). eHealth Literacy: Essential Skills for Consumer Health in a Networked World. *Journal of Medical Internet Research, 8*(2), e9.

O'Mahony, M., Hegarty, J., & McCarthy, G. (2011). Women's help seeking behaviour for self discovered breast cancer symptoms. *European Journal of Oncology Nursing, 15*(5), 410-418.

O'Neill, B. (2017). Towards an improved understanding of modern health information ecology. *Social Science & Medicine, 173*, 108-109.

O'Neill, O. (2017). Intelligent Trust in a Digital World. *New Perspectives Quarterly, 34*(4), 27-31.

O'Neill, O. (2018). Linking Trust to Trustworthiness. *International Journal of Philosophical Studies, 26*(2), 293-300.

Persoskie, A., Ferrer, R. A., & Klein, W. M. P. (2014). Association of cancer worry and perceived risk with doctor avoidance: an analysis of information avoidance in a nationally representative US sample. *Journal of Behavioral Medicine, 37*(5), 977-987.

Powell, J. A., & Boden, S. (2012). Greater choice and control? Health policy in England and the online health consumer. *Policy & Internet, 4*(2), 1-23.

Ramanadhan, S., & Viswanath, K. (2006). Health and the Information Nonseeker: A Profile. *Health Communication, 20*(2), 131-139.

Santana, S., Lausen, B., Bujnowska-Fedak, M., Chronaki, C. E., Prokosch, H.-U., & Wynn, R. (2011). Informed citizen and empowered citizen in health: results from an European survey. *BMC Family Practice, 12*(1), 20.

Santer, M., Muller, I., Yardley, L., Burgess, H., Ersser, S. J., Lewis-Jones, S., & Little, P. (2015). 'You don't know which bits to believe': qualitative study exploring carers' experiences of seeking information on the internet about childhood eczema. *BMJ Open, 5*(4), e006339.

Sbaffi, L., & Rowley, J. (2017). Trust and Credibility in Web-Based Health Information: A Review and Agenda for Future Research. *Journal of Medical Internet Research, 19*(6), e218.

Sillence, E., Briggs, P., Harris, P. R., & Fishwick, L. (2007). How do patients evaluate and make use of online health information? *Social Science & Medicine, 64*(9), 1853-1862.

Thomson, M. D., Siminoff, L. A., & Longo, D. R. (2012). Internet Use for Prediagnosis Symptom Appraisal by Colorectal Cancer Patients. *Health Education & Behavior, 39*(5), 583-588.

Viswanath, K., & Kreuter, M. W. (2007). Health disparities, communication inequalities, and eHealth. *American journal of preventive medicine, 32*(5 Suppl), S131-133.

Vrinten, C., Boniface, D., Lo, S. H., Kobayashi, L. C., von Wagner, C., & Waller, J. (2017a). Does psychosocial stress exacerbate avoidant responses to cancer information in those who are afraid of cancer? A population-based survey among older adults in England. *Psychology & Health, in press*. doi:10.1080/08870446.2017.1314475

Vrinten, C., McGregor, L. M., Heinrich, M., von Wagner, C., Waller, J., Wardle, J., & Black, G. B. (2017b). What do people fear about cancer? A systematic review and meta-synthesis of cancer fears in the general population. *Psycho-Oncology, 26*(8), 1070–1079.

Wyatt, S., Henwood, F., Hart, A., & Smith, J. (2005). The digital divide, health information and everyday life. *New Media & Society, 7*(2), 199-218.

Yi, M. Y., Yoon, J. J., Davis, J. M., & Lee, T. (2013). Untangling the antecedents of initial trust in Web-based health information: The roles of argument quality, source expertise, and user perceptions of information quality and risk. *Decision Support Systems, 55*(1), 284-295.

Ziebland, S., & Hunt, K. (2014). Using secondary analysis of qualitative data of patient experiences of health care to inform health services research and policy. *Journal of Health Services Research & Policy*, *19*(3), 177–182.