# **Cyberchondria in Relation to Uncertainty and Risk Perception**

# **BACHELOR THESIS**

# K.L. Schulte

Faculty of Behavioral Sciences, Bachelor Psychology of Conflict, Risk and Safety University of Twente, Enschede, the Netherlands

# **Examination Committee**

J.M. Gutteling

P.W. de Vries

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#### Abstract (English)

Due to consumers' increased access to information via the internet, online self-diagnosis of health conditions has proliferated (Avery et al., 2012). The Internet makes it much easier for many people to seek health information themselves, become more exposed to a wider array of health information, and become more involved in their own healthcare (Cline & Haynes, 2001; Rice & Katz, 2001). Nevertheless studies have shown that the use of the Internet as a diagnostic methodology can lead to consumers misdiagnosing themselves and adopting treatments that are inappropriate, wasting money and unnecessarily worrying about illnesses that they do not have (Bupa, 2011 in Robertson et al., 2014). They persist in high levels of anxiety, rather than seeking advice from a qualified health care professional (Bupa, 2011 in Robertson et al., 2014). This makes the web a potentially dangerous and expensive place for health information seekers (White & Horvitz, 2009).

Thus, increased consumer access to self-diagnosis tools creates a double-edged sword for consumer well-being (White & Horvitz, 2009). The purpose of this study is to solve this dilemma or respectively enhance the conditions for both, consumers and medical professionals by analyzing information seeking behavior.

In this research, the main focus was put on uncertainty, measured by the construct information sufficiency. Therefore, the correlation between information sufficiency and information seeking frequency, risk perception and the probability of making wrong selfdiagnoses were examined by means of an online survey.

The results showed that there is a significant correlation between information sufficiency and the probability of making wrong self-diagnoses. The remaining results showed no significant correlations.

However, the research revealed some practical implementations. It showed that nearly everyone at least once used the Internet in order to look up medical information and that most people are lacking the ability to properly handle those pieces of information. Finally, this study provides a sufficient basis for further research on this topic. It clearly underlines the importance of focusing on the adjustment of 'the doctor in the mouse' and taking this phenomenon seriously.

#### Abstract (Dutch)

Door de toegenomen toegang van consumenten tot informatie via het internet, heeft het fenomeen zelfdiagnose ongemeen aan populariteit gewonnen (Avery et al., 2012). Het internet maakt het veel gemakkelijker voor veel mensen om zelfstandig informatie over gezondheid op te zoeken en om meer betrokken te voelen bij hun eigen gezondheidszorg (Cline & Haynes, 2001; Rice & Katz, 2001). Toch hebben studies aangetoond dat het gebruik van het internet als een diagnostische methode kan leiden tot consumenten die zichzelf misdiagnosticeren, behandelingen die niet geschikt zijn, het verspillen van geld of het onnodig zorgen over ziektes die er niet zijn (Bupa, 2011 in Robertson et al., 2014). Mensen volharden op hoge niveaus van angst, in plaats van naar advies van een gekwalificeerde zorgverlener te vragen (Bupa, 2011 in Robertson et al., 2014). Dit maakt het web een potentieel gevaarlijke en dure plaats voor informatie zoekers (White & Horvitz, 2009).

Dus, een vergroot toegang voor consumenten tot zelfdiagnose instrumenten creëert een tweesnijdend zwaard voor het welzijn van de consumenten (White & Horvitz, 2009). Het doel van deze studie is dit dilemma respectievelijk op te lossen en de voorwaarden voor zowel consumenten als medische professionals te verhogen door het analyseren van zoekgedrag.

In dit onderzoek werd de nadruk gelegd op onzekerheid, gemeten door het construct information sufficiency. Daarom wordt de correlatie tussen information sufficiency en information seeking frequency, risicoperceptie en de kans op het maken van foute zelfdiagnoses onderzocht door middel van een online enquête.

De resultaten toonden aan dat er een significante correlatie bestaat tussen information sufficiency en de kans op het maken van verkeerde zelfdiagnose. De overige resultaten toonden geen significante correlaties.

Desnietaltemin liet het onderzoek een aantal praktische implementaties zien. Het bleek dat bijna iedereen tenminste een keer medische informatie heeft opgezocht en dat de meeste mensen niet over het vermogen beschikken om goed met deze informatie om te kunnen gaan. Tot slot geeft deze studie een voldoende basis voor verder onderzoek over dit onderwerp. Dit onderzoek onderstreept duidelijk het belang van de aanpassing van 'de dokter in de muis' en dat dit fenomeen moet serieus worden aangezien.

#### Introduction

Nowadays, the lay public has more opportunities than ever before in history to take an active role in their own health care (Rains, 2007). The Internet and the World Wide Web have become widely used resources for health information (Cline & Haynes, 2001; Fox & Fallows, 2003; Morahan-Martin, 2004). Actually, per day, more people use the Internet to obtain medical information than visit a health care professional (Fox & Ranie, 2002). In addition, studies have shown that 8 in 10 Americans have at least once searched for health care information online (Pew Internet and American Life Project, 2007).

Due to consumers' increased access to information via the internet, online selfdiagnosis of health conditions has proliferated (Avery et al., 2012). The Internet makes it much easier for many people to seek health information themselves, become more exposed to a wider array of health information, and become more involved in their own healthcare (Cline & Haynes, 2001; Rice & Katz, 2001). Online self-diagnosis refers to consumers engaging with technology by applying their own knowledge and skills to generate medical diagnoses themselves, without the participation of a health care professional (Hu and Haake, 2013). Online self- diagnosing is not only easily accessible, it also offers potential benefits for both consumers and health care professionals, for example cost and time saving, availability of a wide array of information, support for interpersonal interaction and social support, tailored information and anonymity (Finch et al., 2008).

However, the Australian Medical Association has labelled the 'doctor in the mouse' as alarming (News Limited, 2013 in Robertson et al., 2014). Next to a variety of advantages, using the Internet for health and medical information also has a lot of disadvantages (wasting money for unnecessary medication, technical language, unequal access), obstacles (overload, disorganization, complex searching commands and medical language, impermanence), and dangers (lack of peer review, inaccurate or misleading information, risk-promoting messages, online reinforcement of pathologies, addiction) (Cline & Haynes, 2001; Rice & Katz, 2001). And also Benigeri and Pluye (2003) showed that exposing people with no medical training to complex terminology and descriptions of medical conditions may put them at risk of harm from self-diagnosis and self-treatment (Benigeri & Pluye, 2003 in White & Horvitz, 2009). Studies have shown that the use of the internet as a diagnostic methodology can lead to consumers misdiagnosing themselves and adopting treatments that are inappropriate, wasting money and unnecessarily worrying about illnesses that they do not have (Bupa, 2011 in Robertson et al., 2014). They persist in high levels of anxiety, rather than seeking advice from

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a qualified health care professional (Bupa, 2011 in Robertson et al., 2014). For such unfounded escalations of common symptomatology, based on the review of search results and literature on the web, the term *cyberchondria* is used (White & Horvitz, 2009).

Such a risk of cyberchondria makes the web a potentially dangerous and expensive place for health information seekers (White & Horvitz, 2009). Due to that, online selfdiagnosis can negatively influence the consumer health and well-being in itself and furthermore create adverse public health impacts (Robertson, 2014). Thus, increased consumer access to self-diagnosis tools creates a double-edged sword for consumer wellbeing (White & Horvitz, 2009).

The purpose of the study is to solve this dilemma or respectively enhance the conditions for both, consumers and medical professionals. Nevertheless, one cannot detain consumers from seeking medical information on the internet but one can adjust self-diagnosis pages on the internet to preclude consumers' anxiety and uncertainty.

Research has shown that seeking medical information can lead to decreases and/or increases in uncertainty, depending on the content of the information but also on the consumer's appraisal and interpretation of that information (Mishel, 1984). However, searching for medical information on the internet has the potential to lead to greater levels of uncertainty and therefore exacerbate health anxiety (Fergus, 2013). Studies have shown that individuals who score high on uncertainty find ambiguous situations highly distressing (Fergus, 2013). Moreover, the tendency to form catastrophic interpretations of ambiguous health information is mostly related to health anxiety at high levels of uncertainty (Fergus, 2013). Based on these findings, individuals who score high on uncertainty might be expected to experience increased health anxiety as a result of searching for medical information on the Internet (for example cyberchondria) (Fergus, 2013). As such, this study will investigate the following research question: To what extent does uncertainty affect the information search behavior on medical information?

#### **Theoretical framework**

Based on these considerations, this study looks into the variable uncertainty regarding to medical information seeking which again causes anxiety and uncertainty. Uncertainty is defined as the inability to determine the meaning of illness-related events (Mishel, 1984). It is the cognitive state created when the person cannot adequately structure or categorize an event because of the lack of sufficient cues (Mishel, 1984). Uncertainty occurs in a situation in

which the decision maker is unable to predict outcomes accurately (Mishel, 1984).

Pertaining to this study, the FRIS (Framework for Risk Information Seeking) is used to measure and explain uncertainty. This model contains the variable information sufficiency which equals the construct uncertainty. According to Windschitl and Wells, uncertainty 'exists only in the mind; if a person's knowledge was complete, that person would have no uncertainty' (Windschitl and Wells, 1996, p. 343). Information sufficiency picks up this aspect of complete or incomplete knowledge and is therefore a suitable construct to measure uncertainty.

The variable information insufficiency according to the FRIS consists of a discrepancy between the amount of knowledge held and the amount of knowledge someone perceives as necessary in order to deal with a certain risk. If the discrepancy and the lack of knowledge rise, the only way to lower the discrepancy is to seek for information. According to Atkin (1973), the need for information is a function of extrinsic uncertainty produced by a perceived discrepancy between the individual's current level of certainty regarding important environmental objects and a criterion state he seeks to achieve (Atkin, 1973). If the discrepancy between current knowledge and wanted knowledge is too high, people feel uncertain about that certain topic. In consequence they begin to worry about their health status. In general, an individual who worries is concerned about a future event, is uncertain about the outcome, has negative expectations, and feels anxiety (MacLeod et al., 1991).

According to Shannon and Weaver (1949), the presentation of information reduces uncertainty: the more information a person receives, the lower their uncertainty. Kuhlthau (1993) has also proposed uncertainty as a basic principle for information seeking, drawing upon her research, noting that 'Uncertainty and anxiety can be expected in the early stages of the information search process... Uncertainty due to a lack of understanding, a gap in meaning, or a limited construct initiates the process of information seeking.' (Kuhlthau, 1993). It is usually assumed that, whether one is reading or conversing, one is at least partially engaged in an attempt to reduce uncertainty (Case, 2002).

Finally, people who are more likely to experience uncertainty are more likely to seek information on the Internet. In addition do people also seek information to reduce uncertainty, thus the other way around. Individuals with a higher discrepancy should therefore experience higher levels of uncertainty and in consequence seek information about medical issues more often. On the basis of this knowledge, the following hypothesis can be derived: **H1:** People who score low on information sufficiency more often use the internet for seeking information about medical issues than people who score high on information sufficiency.

#### Wrong Self-Diagnoses

There is little research done regarding making wrong self-diagnoses. The possibility to look up symptoms on the Internet is quite a young one and consequently, the risk of making selfdiagnoses is hardly investigated. As such, it would be interesting to have a closer look at the type of people who make self-diagnoses with the help of medical web pages. There is evidence that the need for information is caused by extrinsic uncertainty which is produced by a discrepancy between already gained knowledge and knowledge one wants to seek (Atkin, 1973). In consequence, people with a big gap between gained and wanted knowledge should therefore be more likely to experience uncertainty about making self-diagnoses competently. As such, people with a higher discrepancy are experiencing a higher need for information. In consequence, they make self-diagnoses on the basis of a perceived lack of knowledge which could result in making wrong-self diagnoses. This relation between information sufficiency and making wrong self-diagnoses is still very vague. For this reason, the following hypothesis and its measurement should shed light on this relation:

**H2:** People with low levels of information sufficiency have a higher chance on making a wrong self-diagnosis than people with high levels of information sufficiency.

#### **Risk Perception**

Perceived risk has been the focus of interest of researchers for several decades. Risk perception is and always was a substantial factor of every living being. The ability to sense and avoid harmful environmental conditions is necessary for the survival of all living organisms (Slovic, 1987). Survival is also aided by an ability to codify and learn from past experience (Slovic, 1987). Humans have an additional capability that allows them to alter their environment as well as respond to it (Slovic, 1987). This capacity creates and reduces risk (Slovic, 1987). Most people rely on intuitive risk judgments when facing a risk which are typically called 'risk perceptions' (Slovic, 1987).

Psychological research on risk perception originated in empirical studies of probability assessment, utility assessment and decision-making processes (Edwards, 1961). An important development in this area has been the discovery of a set of mental strategies, called heuristics,

that people employ in order to make sense out of an uncertain world (Kahneman et al., 1982). Laboratory research on basic perceptions and cognitions has shown that the anxieties generated by life's gambles cause uncertainty to be denied, risks to be misjudged (sometimes overestimated and sometime underestimated), and judgments of fact to be held with unwarranted confidence (Slovic, 1987). And this is exactly what is happening with the perception of the risk of making self-diagnoses: People's risk perception might lead to uncertainty to be denied, risks of self-diagnoses to be underestimated or overestimated or self-made medical judgments to be held with unwarranted confidence. In consequence risk is perception an important factor that needs to be taken into account when looking at the risk of making self-diagnoses. It is important to get to know to what extent risk perception is influenced in order to be able to evaluate the handling of self-diagnoses on the Internet.

This research aims to investigate to what extent uncertainty influences factors of making self-diagnoses on the Internet. Hence, uncertainty is closely related to risk and part of many theories of behavior (Sjöberg et al., 2004). And also Johnson and Scicchitano (2000) argue that risk perception and uncertainty are distinct concepts when assessing risks (Johnson & Scicchitano, 2000). This research aims to investigate how and whether uncertainty and risk perception correlate.

It is known that a higher risk perception is assumed to reflect higher levels of uncertainty (Ter Huurne, 2008). This approach is taken as a basis for the current study: It is certain that higher levels of risk perception cause higher levels of uncertainty, but do higher levels of uncertainty also cause higher levels of risk perception? Till today, there is no literature to be found that describes this relation. As such, this research will investigate the correlation as a pioneer. Therefore the following research question will be studied:

**RQ1:** People who score low on information sufficiency experience a higher risk perception (regarding medical issues) than people who score high on information sufficiency.

Lower information sufficiency	H1 $\rightarrow$ more often information seeking behavior
	H2 $\rightarrow$ higher chance making wrong self-diagnoses
	RQ1 $\rightarrow$ higher risk perception

Table 1 Overview hypotheses/research question

#### Method

#### Design

To investigate to what extent information sufficiency and risk perception are related to selfmisdiagnoses, an online survey is used. This method is called a questionnaire survey design.

#### **Participants**

In total, 144 participants comprised the initial online survey. Out of 144 participants, 24 did not finish the survey which makes a dropout rate of 16,6%. Out of the 121 participants who finished the survey, 57(47,1%) were male and 64 (52,9%) were female with an average age of 27,9 years (min. 15; max. 60; SD=12,7). 3 respondents had a Dutch nationality, 117 were German and one respondent had an Afghanistan nationality. The researcher used a convenience sample technique for the present study. As such, the participants were approached by the researcher herself by social networks or e-mail.

#### Procedure

All participants received the link that transferred them to the online survey. On the first page, there was the informed consent (see Appendix B). Participants had to agree or disagree with the conditions to start the survey. In case of a disagreement, the survey was ended at this point. When participants agreed with the conditions, the actual survey could be started. All questions were displayed in so called blocks. Thus, participants could not see all questions at once but they were able to see questions that belong to the same construct (e.g. information sufficiency or risk perception). By pressing the next button, they got to the next block. Participants got even the opportunity to go back to a block by pressing the back button. After running through all the blocks, the survey was ended with a termination message where the researcher thanks the participants for taking part in the survey and providing the contact details for further enquiry.

#### **Measures and Manipulations**

In view of the research questions, an online questionnaire in structural form has been designed on the basis of the online program *Qualtrics*. The survey (to be found in Appendix A) comprised twenty-seven items covering different facets: demographic information, information about using the Internet for seeking medical information, information about information sufficiency, information about risk perception, and knowledge testing. Except for the demographic questions, all items were extracted from already existing and validated scales. If necessary, they were adapted to the risk of making self-diagnoses whereby the changes were made as minimal as possible. To facilitate quantification and analysis, only multiple choice questions were used along with rating scales to ensure a response and avoid missing questions.

The demographic background was measured by means of four items regarding age, gender, nationality and level of education. Information sufficiency was measured by four items taken from the article 'How to trust?' (Huurne & Gutteling, 2009). However, the questionnaire originally was about hazardous substances, so the topic was changed into the risk of self-misdiagnoses. Those items were scored by using a five-point Likert-scale ranging from 1 (strongly disagree) to 5 (strongly agree). This scale was rated with an Alpha value of 0,85. In this case, the Alpha value did not get higher if an item was deleted. As such, the scale was taken with all initial items into further analyses.

The information seeking behavior for medical information on the Internet was determined by means of six items. The first item of this category was a dichotomous question were the participant had to state whether he or she at least once used the Internet for seeking medical information. The five remaining items were taken from the ehealth literacy scale and scored using a five-point Likert-scale ranging from 1 (not important at all/ not useful at all/ strongly disagree) to 5 (very important/ very useful / strongly agree).

Furthermore, four items measured the probability of making a wrong self-diagnosis. These items were developed with the help of RightDiagnosis.com which is (according to them) one of the world's leading providers of online medical health information. The site is an independent and an objective source of factual, mainstream health information for both consumers and health professionals. It provides 'a free health-information service to help people understand their health better, offering crucial and factual health information that is otherwise difficult to find' (Rightdiagnosis.com, 2016). Those items consisted of a description of symptoms that were listed under a certain disease. The participant had to make a choice out of eight answers. A number of eight possible answers were taken in order to lower the probability of guessing right. The correct answer was the disease which was related to the symptoms. The other seven options were taken from the list with often made misdiagnoses. In this case, only one answer was the right answer. All other chosen answers were wrong.

And finally, risk perception was assessed on the basis of the perceived riskiness of several events. Therefore, the Domain-Specific Risk-Taking Scale (DOSPERT)- RT Scale

was used (Weber et al., 2002). The original scale includes 50 items about risky behaviors originating from five domains of life (ethical, financial, health/safety, social and recreational risks) using a five-point rating scale from 1 (not risky at all) to 5 (extremely risky). For the purpose of this study, only the eight items about health/safety were taken. The remaining domains were excluded because they were irrelevant regarding the study. This scale was rated with an Alpha score of 0,83. This is quite high and therefore no item was deleted.

#### Results

In the following table (table 2), an overview of the variables is presented in order to give a short overview of the variables' characteristics. Regarding the four variables presented below, there are no striking peculiarities. Standard deviations are below 1, which is within a range of four and five an ordinary value. The scenario results represent knowledge and the other ones display self-evaluation which causes a slight difference in evaluating those item characteristics. The mean of the scenario results is in comparison to the other three means obviously lower. This indicates that on average people tend to give incorrect answers on the scenario. But one has to take the range into account. People could score between 1 and 5 on all three self-evaluation variables and between 0 and 4 on the scenario answers. Consequently, those values cannot be compared with each other without taking the range into account.

	Ν	Minimu m	Maximu m	Mean	Std. Deviation
Information Sufficiency Average	121	1,00	5,00	3,66	,91
Risk Perception Average	121	1,13	5,00	3,63	,73
Actual Knowledge Average	121	1,67	5,00	3,77	,88
Scenario Results	121	,00	4,00	1,22	,95
Valid N (listwise)	121				

Table 2 Descriptive Statistics

In table 3, a short overview of the hypotheses regarding the variables is given in order to have a closer look at the hypotheses:

Table 3 Results

Hypothesis/ Research Question	Variables tested	<b>Significance level</b> (α=0.05, N=121)	Pearson Correlation coefficient	Hypothesis accepted/ rejected
H1: Lower information sufficiency → more often information seeking behavior	Information sufficiency → Frequency of looking up medical information	<i>p</i> =.414	r=.02	Rejected
	Information sufficiency → Ever looked up a symptom	<i>p</i> = .487	r=003	Rejected/ not measurable
H2: Lower information sufficiency → higher chance making wrong self- diagnoses	Information sufficiency → Actual knowledge about making self- diagnoses	<i>p</i> =.001	r=.3	Accepted
	Actual knowledge → Scenario (right answers)	<i>p</i> =.336	r=0.09	Rejected
<b>RQ1</b> : Lower information sufficiency → higher risk perception	Information sufficiency → Risk perception	<i>p</i> =.627	r=.05	Rejected

Contrary to all expectations, hypothesis 1 cannot be accepted. The findings from the research show that the correlation between information sufficiency and information seeking behavior is statistically not significant, r(121)=.02, p>.05. This implies that people who score lower on information sufficiency do not look up medical information on the Internet more often than people who score higher on information sufficiency. Second, an additional correlation analysis was conducted. The correlation between information sufficiency and ever looking up symptoms was investigated and also in this case, no statistically significant correlation can be found, r(121)=-.003, p>.05. This does not mean that people who score lower on information sufficiency cannot be equated with people who at least once looked up a symptom. In consequence, there were no groups that could be compared with each other. This means that hypothesis 1 is statistically rejected but actually it is just not measurable.

Furthermore, hypothesis 2 was tested. It states that there is a negative correlation between information sufficiency and making wrong self-diagnoses. Actually, a statistically significant negative correlation between those two constructs can be found, r(121)=.3,p<.05. This means that, like expected, people who score low on information sufficiency significantly more often reported that they miss the knowledge in order to make proper self-diagnoses. Thus, hypothesis 2 can be accepted. Moreover, an additional analysis was conducted using the variable about actual knowledge for making self-diagnoses and the test score of the scenarios. Contrary to the expectations, stating that one misses information in order to make self-diagnoses accurately does not correlate with making more mistakes in the scenario. As such, no correlation between those two variables can be found, r(121)=.09,p>.05.

Finally, the research question was checked. In this case, it was stated that there is a negative correlation between information sufficiency and risk perception. Such a correlation can statistically not be verified. The analysis has shown that information sufficiency does not correlate with risk perception at all, r(121)=.05,p>.05. This means that people who score lower on information sufficiency are not more likely to perceive higher levels of risk.

#### Discussion

The purpose of the study was to investigate what kind of people are using the Internet in order to look up medical information. Knowing about the people's character traits can be helpful regarding the adjustment of online pages. Adjusting those medical pages should then enhance the conditions for both, consumers and medical professionals. On the one hand for

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consumers, because they are then better able to handle medical information. By adjusting those pages, one hopes to lower the consumer's panic and anxiety of being seriously ill. However, medical pages should offer an opportunity to evaluate the seriousness of the consumer's symptoms without dramatizing those. Furthermore, by adjusting medical pages, an enhancement of the conditions for professionals is aimed. Professionals are suffering from those medical online pages because of patients not believing that they are not seriously ill though they looked up their symptoms. And even more at-risk are patients taking unnecessary medication on their own because they looked up their symptoms on the Internet. Because of the increasing popularity of medical pages on the Internet, it is important to investigate types of consumers and information seeking behaviour in order to improve medical web pages.

In this study, the main focus was put on the character trait uncertainty. Uncertainty was measured by the variable information sufficiency that is the individual's assessment of having enough information. The statistical analysis of the first hypothesis showed that information sufficiency does not predict the frequency of information seeking behaviour which was contrary to what was expected based on the literature. Consequently, it can be concluded that there is no difference to be found between people lacking information about the risk of misdiagnoses and people with a sufficient amount of information. Atkin (1973) stated that the need for information is a function of uncertainty (Atkin, 1973). If uncertainty arises, people begin to worry and this initiates the process of information seeking (Kuhlthau, 1993). This result cannot be supported in the current study.

Although the hypothesis is not accepted, this result is quite interesting because it states that there are people who are not sufficiently enlightened about the risks of misdiagnoses when using the Internet in order to look up medical information. In this case it would be important to first inform the people about those risks when visiting medical pages on the Internet. This could be easily done by developing a sort of informed consent that visitors of those sides have to agree with before entering the actual page. Nevertheless, information sufficiency is no predicting factor regarding the type of people who frequently look up medical information.

This causes the problem that provider of medical pages have to deal with people with high levels of knowledge about risks as well as people lacking information about those risks. Anyway, an elucidation about the risk of misdiagnosing would lower or even prevent the negative consequences of dealing with medical information and making self-diagnoses.

Regarding the first hypothesis, there was a second analysis conducted in order to investigate whether there exists a correlation between information sufficiency and ever

looking up a symptom. In this study, every single participant stated that he or she at least once looked up a symptom. In literature, estimates of Internet health-information seeking vary widely, but are uniformly high, evidencing exponential growth (Lacroix et al., 1994). No significant result could be acquired because there was no group to compare with because everyone looked up medical information once. One has to regard this result with caution because the statistical analyses showed that the hypothesis is not significant. This is not exactly correct. The statistical program takes a hypothesis as non-significant though it is not measurable because of a lacking group to compare. This is one of the study's limitations. Nevertheless, this is an important result. It emphasizes the popularity of medical pages on the Internet and the phenomenon of looking up symptoms. Round one third of the participants stated that they on average use the Internet once or twice per month for seeking medical information. The remaining two thirds after all used the Internet once or twice per half year. And even because of the proof that everyone at least once looked up a symptom and the frequent use of such web pages, is it to such an extent important to adjust and enhance those online pages.

Next to this, the second hypothesis was analysed. Overall, there was a significant difference between people with low levels and high levels of information sufficiency. People with low levels of information sufficiency, thus people who felt they were lacking information to make self-diagnoses properly, also stated that they do not have enough knowledge to make self-diagnoses sufficiently. And people who stated that they do have a sufficient amount of information about the risk of making wrong self-diagnoses also stated that they are able to evaluate medical information properly. At first glance, this seems good news. People tend to rate their own abilities of making self-diagnoses adequately. But this result emerges from the participants' self-evaluation. In practice, this seems to be a bit different. People who indicated that they have sufficient knowledge in order to make selfdiagnoses did not differ in the number of correct answers in the scenarios from people stating insufficient levels of knowledge. The scenario was established by the researcher on the basis of a web page and can therefore be criticized. Nevertheless this result does underline that there exists a dissonance between indicating that one has a sufficient amount of knowledge regarding making self-diagnoses properly and actual having that certain knowledge. And also in literature search equal results can be found: Internet searches may yield false and deceptive service, product and treatment claims without providing supportive evidence or sources permitting verification (Dow et al., 1996). Rudin and Littleton (1997) state that even savvy Internet users 'can have trouble distinguishing the wheat from the chaff' (Rudin & Littleton,

1997). And also Sonnenberg (1997) claims that 'most people will be unable to determine the qualifications of Web authors and separate truth from opinion' and 'even well-educated users are unlikely to have the background required to critically evaluate medical information' (Sonnenberg, 1997). As a result, consumers lacking evaluation skills and knowledge are particularly vulnerable (Cline & Haynes, 2001).

Important now is that one has to take this into account when creating those medical pages where people can look up symptoms on the Internet. This research showed that the common people cannot handle that kind of medical information without professional help. There might be a few that do, e.g. people with some medical training, but in general they need professional help. This conclusion again underlines the huge importance of adjusting medical web pages.

The research question was about the correlation between information sufficiency and risk perception. The results indicated that people who experience higher levels of uncertainty about their knowledge of making self-diagnoses in general do not show higher levels of risk perception. Consequently, uncertainty does not predict risk perception. Thus, according to this research, risk perception is not a factor that one has to take into account when creating medical web pages.

Against all expectations, only one out of the two hypotheses was shown to be significant. Therefore is it important to have a look at the circumstances and factors under which those hypotheses were tested in order to have a look at the overall validity of the results. But first of all, it must be stressed that those hypotheses were tested on a basis of only little existing literature. The risk of making wrong self- diagnoses is quite a novel approach in research. The popularity of medical web pages arose in the last half decade which means that there is only little research done on this topic. Nevertheless, there are some limitations that can be improved in further research.

The first limitation is about the online survey. There was the Domain-Specific Risk-Taking Scale (DOSPERT)- RT Scale (Weber et al., 2002) which measured risk perception. For this research, only the items about risk in health were taken and items about other domains, such as financial risks, were left out. Nevertheless, the content of those items were about risk in the health domain in general and not explicit about the risk of self-diagnoses. In consequence, the analyses were based on the participants' risk perception in general. For further research, it would be interesting to investigate whether a specific scale would result in a difference. As such, it can be suggested to add a further questionnaire to the existing DOSPERT-Scale.

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Furthermore, the scenario can be criticized. The scenario questions were purely fictional. As such it is unclear to what extent participants identified with the scenarios. The scenario questions were not comparable with a real-life scenario where one looks up medical information that is suitable to the participants' symptoms. Otherwise, participants would be more interested in the outcome and would take the scenario more seriously. One could think about taking a different target group for further research. For example, one could find participants that are suffering from certain symptoms or are already in treatment. Changing the target group would ensure that participants are interested in looking up symptoms and illnesses. Moreover it would guarantee that participants take the scenario seriously.

Second, the scenarios were designed as multiple choice questions. In a real-life situation one would enter a web page and search for information by scrolling and clicking through it. For further research it would be eligible to conduct the scenario with the help of a computer simulation instead of multiple choice questions. This would be closer to reality and could help the participants to put themselves in the position of someone who really is suffering from symptoms in terms of simulating their real-time research and reading pattern.

A third limitation regarding the scenario question was the level of difficulty. The first two scenarios were answered correctly by 45% of all participants. Whereas in the third and fourth scenario question, only 16% and 17% of the participants gave the right answer. One can assume that the last two scenario questions were answered correctly just by guessing. The statistical probability of guessing correctly when there are eight items is 100/8 which is 12,5%. 16% and 17% do not deviate that much from this value so one can assume that the majority of the participants who gave a correct answer did this by random guessing. The first two scenarios that were answered correctly by 45% argue against a random choice. The probability that 45% or at least a significant proportion of them gave the right answer by guessing is not really high. As such, there are only four items to compare with and if two of four are obviously too difficult to give a proper answer, one has to cut back the validity of the scenario items. For further research it would be more valid to first test scenario items, for example by conducting a pilot study. If items are too simple or difficult then they should be changed or deleted.

Conclusively it can be summarized that in face of the limitations, the survey was conducted successfully. The number of participants was for all intents and purposes satisfactory with 121 participants. Some of the participants gave personal feedback which was on average very positive. The survey questions were easy to answer and it took only 7 to 8 minutes to finish the survey, which is a quite passable expenditure of time for an online

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survey. Next to this was the fact that participants could answer the survey on the Internet an advantage in order to collect participants. As such, the survey was easily accessible and also the sample range qua age got broader. The sample was a convenience sample which meant that primarily students under 30 would fill in the survey. But because of sharing the survey on the Internet (e.g., on social media like Facebook and Whatsapp), the survey also reached participants who were older than 40 years.

Finally, one can proudly conclude that this study, in its first implementation, run satisfyingly as a sufficient basis for further research on this topic. Therefore is it important to invest in further research regarding the usage of medical web pages.

Besides do challenges to consumers, public health professionals and researchers alike include the rapidity of change of content, structure and technology embedded in the Internet (Cline & Haynes, 2001). Sometimes analysts are challenged to research and publish findings before they obsolete (Cline & Haynes, 2001). The challenge of future research is to devise methods and conceptual frameworks appropriate for investigating the richness of the Internet's dynamics relative to health issues (Cline & Haynes, 2001).

Further research needs to address the (demographic) characteristics of participants, to more precisely indentify the underserved, as well as the kinds of information consumers are seeking, what they locate, how they judge the quality of information found, what they learn (Wyatt, 1997) and how they are influenced behaviourally (Cline & Haynes, 2001).

In general are the existence of medical web pages and the phenomenon of looking up symptoms on the Internet both quite young ones. In consequence is there till today only little research done on this topic. And even because of that is it that important to further investigate what kind of people are using medical web pages, how and how often they do it and what are the (positive and negative) consequences of using those pages. In order to lower the negative consequences and increasing the positive ones, one should focus on the adjustment of 'the doctor in the mouse' and take this phenomenon seriously.

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## **Appendix A – Survey Questions**

1. What is your age?



- 2. What is your gender?
  - o Male
  - o Female
- 3. What is your nationality?
  - o Dutch
  - o German
  - Other:

0	

- 4. What is the highest level of education you have completed?
  - Grammar school
  - High school or equivalent
  - Vocational/technical school (2 years)
  - Some college
  - Bachelor's degree
  - Master's degree
  - Doctoral degree
  - Professional degree (MD, JD, etc.)
  - Other:



### Information about Using the Internet for Seeking Medical Information

- 5. Have you ever used the Internet to search for medical information (e.g. looking up symptoms)?
  - o Yes
  - o No
- 6. How often do you use the Internet to look up symptoms/diseases?

· 1	· 2	• 3	• 4	· 5
Never	1-2 per half year	1-2 per month	1-3 times per week	3+ times per week

7.

7. How **useful** do you feel the Internet is in helping you in making decisions about your health?

• 1	• 2	• 3	• 4	· 5
Not useful at all	Not useful	Unsure	Useful	Very Useful

8.

8. How **important** is it for you to be able to access health resources on the Internet?

• 1	• 2	• 3	• 4	· 5
Not important at all	Not important	Unsure	Important	Very important

9.

9. I know **how to use** the Internet to answer my questions about health

- Strongly Disagree
- Disagree
- Undecided
- Agree
- Strongly Agree

### 10. I know how to use the health information I find on the Internet to help me

- Strongly Disagree
- Disagree
- Undecided
- Agree
- Strongly Agree

## 11. I have the skills I need to evaluate the health resources I find on the Internet

- Strongly Disagree
- Disagree
- Undecided
- Agree
- Strongly Agree

## **Information about Information Sufficiency**

The following statements are about your knowledge of wrong online self-diagnoses. Please indicate to what extent you agree with these statements.

	Strongly disagree	Disagree	Undecided	Agree	Strongly agree
12. My knowledge about the risks of online self-diagnoses satisfactory to me.					

13. I am satisfied with the knowledge I have about the risks of online self- diagnoses in my life.			
14. What I know right now about the risks of self-diagnoses is enough for me.			
15. I think that I know enough about the risks of self-diagnoses to be able to deal with them in my daily life.			

## Information about Risk Perception (items out of health/safety sector)

The following statements are about risk perception. For each of the following statements, please indicate how risky you perceive each situation. Provide a rating from *Not at all Risky* to *Extremely Risky*, using the following scale:

	1 Not at all risky	2	3 Moderatel y risky	4	5 Extremel y risky
16. Buying an illegal drug for your own use.					
17. Consuming five or more servings of alcohol in a single evening.					
18. Engaging in unprotected sex.					
19. Not wearing a seatbelt when being a passenger in the front seat.					
20. Not wearing a helmet when riding a motorcycle.					
21. Exposing yourself to the sun without using sunscreen.					
22. Walking home alone at night in a somewhat unsafe area of town.					
23. Regularly eating high cholesterol foods.					

## **Knowledge/Scenario Testing**

24. I want you to imagine the following scenario: You are lying in your bed and you are unable to sleep. You are tossing and turning and getting up out of bed. You feel tingling and sometimes burning sensations in your leg. The next day, you really feel the sleep deprivation during the day: You are tired and fatigued and you woke up with a morning headache. You feel irritable and it is hard for you to concentrate. You are suffering from those conditions since several weeks, so you decide to look your symptoms up on the Internet: There are a lot of suggestions from which diseases you might suffer. What disease do you think fits best to your symptoms?

- o ADHD
- Sleep disorder
- Sugar snack before bedtime
- Obtrusive sleep apnoea
- Restless Leg Syndrome
- Chronic stress
- o Foot paresthesia
- Tingling toe

25. Imagine the following scenario: Since more than a half year you are suffering from fatigue and lack of energy. You sometimes feel pain in the abdomen and you feel a loss in your sex drive. Sometimes you think that your skin looks a little bit bronze, but you are not sure. After half a year you decide to look your symptoms up on the Internet. What disease do you think fits best to your symptoms?

- o Flu
- Chronic fatigue disease
- o Hepatitis
- Chronic depression
- Colorectal cancer
- Hemochromatosis
- Anxiety Disorder
- Pregnancy

26. Imagine you are suffering from pain in your stomach. Your nose is running and sometimes stuffy. You feel a shortness in breath which is quite uncomfortable. Besides, you see rashes on your skin. More frequently, you are vomiting after you have eaten some food. What disease do you think fits best to your symptoms?

o Asthma

## • Food allergy

- Food intolerance
- o Lactase deficiency
- Food poisoning
- Gluten intolerance
- o Gastrointestinal cancer
- Oral allergy syndrome

27. Imagine the following scenario: Since two or three days, you are suffering from a runny nose and frequent sneezing. You feel a nasal congestion. Moreover you feel very uncomfortable because you experience from time to time a high body temperature. You are coughing and suffering from body aches. Your throat feels very sore. So you decide to look up those symptoms on the Internet. On the basis of those symptoms, which disease do you think fits best?

- $\circ$  Common cold
- o Flu
- Respiratory syncytial virus
- Primary bacterial pneumonia
- o Acute HIV infection
- Meningitis
- Infectious mononucleosis
- Food poisoning

### **Appendix B - Informed Consent**

You are being invited to participate in a research study about online self-diagnoses. This research project is being conducted by Katharina Schulte. The objective of this research project is to attempt to understand which people use the Internet to make self-diagnoses.

The survey consist of 27 multiple choice questions or statements. Thus, completing it will not take longer than 10-15 minutes.

Your participation in this research project is completely voluntary. You have the right to withdraw from the research study at any time. Online survey participants can withdraw at any time prior to the completion of the online survey by simply abandoning the survey.

There are no known risks to participation in this research project. By consenting to participate in this research project, you have not waived your rights to legal recourse in the event of research related harm.

This survey is anonymous. No one will be able to identify you. No one will know whether you participated in this study.

Participant privacy and confidentiality will be protected throughout this study. Electronic data (survey results) will be stored on a password protected laptop. All information and data collected, including any hard copy items, will be stored safely. Information from the online survey will be coded to preserve participant anonymity and confidentiality, and will be summarized, in anonymous format, in the body of the final report. At no time will any specific comments be attributed to any individual unless specific agreement has been obtained beforehand. All documentation will be kept strictly confidential. Data collected in support of this research project will be retained for a period of one year following the completion of the study.

If you have any questions or concerns about completing the questionnaire or about being in this study, you may contact me at k.schulte-1@student.utwente.nl