

MASTERTHESIS

The attitude towards
a hospital initiated
social support
website

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Summary

This exploratory research investigates the attitude towards a social media/online social support system for patients called Patient-In. It is initiated by the MST, a hospital in the Netherlands. This system, which will be a part of the MST website, gives patients the opportunity to create a personal profile, select medical topics of interest and start or participate in discussions within these topics. According to theory self-help and self-management of a disease or ailment is becoming more and more important in the current healthcare market. Information sharing and social support exchanged between patients can help people becoming more responsible for their own health. By researching the attitude towards Patient-In this research tries to find if people are positive or negative about such a system, how this attitude is formed and what can be done to improve it.

In this research four focus groups with patients, one focus group with nurses and one focus group with the MST PR department were conducted. The results show point that form several points that form a positive attitude towards the system such as the ability to share experiences, information and tips. However, the overall attitude towards Patient-In was negative. This was due to concerns mentioned such as not achieving a critical mass of users, the posting of negative and scary stories, abundance of social support systems, lack of quality of the information shared and privacy concerns. In addition, respondents mentioned point for improving the system and thus the attitude towards it such as doctors participation and close monitoring.

The concerns mentioned in the current research are mostly expectation about the use and behavior of future participants of the system. Some research mentions these concerns rarely occur. The current research shows that these concerns may withhold patients from using systems like Patient-In even though the beneficial effects of social support are recognized. Future research might find ways to dissolve these concerns so that more patients will hopefully join online social support group systems and online patient-to-patient communication systems.

The MST is advised to lower the amount of personal information that needs to be disclosed by patients to create a profile. A second advice would be to avoid anonymous participation. Another suggestion for the MST would be to investigate the option to let healthcare professionals participate on Patient-In. A final suggestion is a follow up research during the pilot or initiation phase of Patient-In to research the actual use of the system.

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1 Introduction

1.1 Social media in health care

Over the last few years social media have become increasingly popular. They have taken a very important part in our everyday lives and they are applied in every aspect of society. Kaplan and Haenlein (2010) define social media as “a group of internet-based applications that build on the ideological and technological foundations of Web 2.0, and that allow the creation and exchange of user-generated content”. Coffield and Joiner (2010) note that social media changed the way people communicate. In their article they claim that social media enables people to create and disseminate information, ideas, and experiences. Additionally communication has become much faster and much more efficient using low cost and highly scalable internet technology.

Even in health care, social media are starting to play an important role in the communication process. Eysenbach, Powell, Englesakis, Rizo and Stern (2004) state that the availability of electronic peer-to-peer communities on the internet is very promising for the health sector. In these communities different people can come together to share their experiences, ideas, ask questions and provide social support to each other. Eysenbach, et al. (2004, p. 1) describe these virtual communities as “social networks formed or facilitated through electronic media. Although such communities already existed in the era before the world wide web (for example, in bulletin board systems and private networks that enable peer to peer communities), the primary medium for virtual communities today is the internet, in mailing lists, newsgroups or usenet discussion forums, web based discussion forums, and live chatrooms”.

McNabb (2009) explains that these social media change the way health information is spread and disseminated. She states that in the past it was one authority sharing information to many, where for example health institutions, the ministries of health or journalists communicated health information to the public. Nowadays patients are able to participate in this process because anyone with internet access can post his/her own health information. Patients are given the opportunity to step into the role of a communicator as they are able to respond to content posted by others. Because of social media and online communities, patients can now play an important role themselves in the process of spreading and disseminating health information through these media.

1.2 Online social support

It is difficult for many people to discuss their illness. It remains a subject of denial, dread and secrecy. Speaking about diseases and illness makes people feel vulnerable (Sanchez Abril & Cava, 2008). When they do speak about it, it is mostly with doctors, family or close friends. Another group that can play an important role in this matter is fellow sufferers. According to Walther and Boyd (2002), it can be very difficult or sometimes impossible to form a network of fellow sufferers in a face-to-face setting. With today's computer mediated communication patients are able to come in contact with their fellow sufferers. These patients now have the opportunity to join online networks and communities that allow them to find people with similar problems and give or receive social support. But what exactly is social support and how does it work?

The traditional definition of social support communication, according to Barnes and Duck, (1994) is "the exchange of verbal and nonverbal messages conveying emotion, information, or referral, to help reduce someone's uncertainty or stress, and whether directly or indirectly, communicate to an individual that she or he is valued and cared for by others". According to Adelman and Ahuvia, (1995), people seek social support to reduce uncertainty, increase feelings of situational control, self-acceptance, social integration and a sense of belonging.

According to Wang, Kraut and Levine (2012) there are two categories of social support which have received the most theoretical and empirical attention. These are emotional support and informational support. They explain that emotional support is received either directly, through messages of caring and concern, or indirectly, through comparisons with others who have had similar experiences. Bambina (2007) notes that messages based on emotional support provide understanding, encouragement, affirmation, sympathy, or caring. Informational support is exchanged by discussing the course of their disease, treatments, side effects, communication with physicians, and financial problems and other burdens (Wang, Kraut & Levine, 2012). Informational support messages are given and received in the form of advice, referrals or knowledge (Bambina, 2007).

Walther and Boyd (2002) state that in recent years there has been a strong movement towards more online social support exchanged via computer-mediated communication. They also note that this is done in relatively large networks among people who do not know each other or communicate in the face to face world. Eysenbach, Powell, Englesakis, Rizo and Stern (2004) state that online social support is exchanged in electronic venues such as in mailing lists, newsgroups or usenet discussion forums, web based discussion forums, and live

chat rooms. However, it should be noted that these online social support networks are no replacement for other social support networks but an addition and extension of existing social networks such as face to face social networks (Heidelberger, El-Gayar & Sarnikar, 2011).

Still, online social support is different from face-to-face communication in a lot of ways. Bambina (2007) states that online support groups are able to deliver the same benefits that a face-to-face support group could provide without limitations such as material resources, proximity and temporality. Wright and Bell (2003) also state that health related online support groups have a few unique characteristics when compared to face to face social support. They also mention the absence of geographical and temporal constraints. Additionally they mention that there is less risk for people when disclosing information compared to a face to face setting, there is a greater diversity of health information, there are more heterogeneous supportive relationships between users because of lack of social status cues in the virtual environment and there is more therapeutic value for its users when writing their own health self-disclosures online. These characteristics of online social support make it a valuable addition to the possibilities of face to face social support.

1.3 Patient-In

The MST, the hospital in Enschede the Netherlands, is developing a social media for their patients, in the form of a social network site. The social network site, which is called Patient-In, is designed to assist patients in facilitating online social support with fellow sufferers. Patients are able to build their own personal profile where they can fill in their personal information (name, birth date, gender, e-mail address, telephone number, a photo etc.). Once the patients have created their own profile they are able to subscribe to one of many topics such as diseases and ailments that are listed alphabetically. Through these subscriptions the patient is able to connect to other patients who are subscribed to the same topics and participate in discussions, fill in their own information or questions and send private messages to other participants. Patient-In, although it is still only a prototype as can be seen in Appendix C, has the same characteristics as mentioned in some definitions of a social network site.

Kaplan and Haenlein (2010) state that a social network site is one of the six forms of social media. Boyd and Ellison (2007) define a social network site as a web-based service which the user can use to create a public or semipublic profile within a bounded system, create a list of connections with other users with whom they share a connection with and look through these connection lists on their own profiles or other peoples profiles within this bounded system. Sanchez Abril and Cava (2008, p.245) describe social network sites as “websites whose main purpose is to act as a connector between users via self-generated web profiles or avatars that represent the user’s identity in cyberspace”.

Both definitions place their importance on the online profile that a user is able to create and the connection between the profiles of different uses. Sanchez Abril and Cava (2008) describe online profiles as “part diary, part autobiography, and part museum of the self. Often displaying personal information and photographs, online profiles interact with other profiles to create a rich web of social connections”. In this definition, it can be seen that yet again the connection between the profiles is important for a social network site.

Although the characteristics of a social media website are present, Patient-In is different from the more well-known social network websites like Facebook or MySpace. Patient-In is meant to be the connector among patients who can offer each other online social support. Patient-In is developed as a virtual communication platform where patients can share experiences, emotions or ask other patients questions about certain treatments, doctors, medicine use and other medical topics on forums. This happens in a virtual environment which can only be entered with a username and password.

The underlying purpose of Patient-In for the MST itself is to create a stronger bond between the patients and the MST, create a form of community among the patients of the MST and to offer an extra service for their patients. According to Eysenbach (2000) the increasing number of patient information systems and patient communities contributes to patients being able to utilize health resources more effectively. He also stresses that because of the increasing availability of these systems and communities, patients take more responsibility for their health and the costs of health care. Dumaij and Tijssen (2010) also state this same concern about the Dutch health care sector. According to them patients also need to take more responsibility in preventing and treating the disease. There is a shift towards more self-management of diseases and self-help by patients. This can help the health care industry reduce the costs. Patient-In could prove to be helpful in the self-management of diseases and ailments. It is a tool for patients to find social support and this can help them in self-managing their disease more effectively.

MST has created a prototype that will be used in a pilot on several departments within the hospital. There are actually still questions and topics concerning usefulness, advantages and disadvantages, privacy, login procedures and monitoring that have to be answered. Therefore the prototype of Patient-In is a mere concept and the some aspects of it are still vague. There are still a lot of choices that are to be made by the development team concerning the mentioned topics. Therefore, the prototype is more of a representation of the idea of the Patient-In.

Another point of interest is the fact that this is a social network site created by a hospital which tries to provide this as a service for its patients. Websites like www.patientslikeme.com, www.curetogether.com and www.carepages.com also provide social support but are not hosted by a hospital. What effects could a system like Patient-In have on the hospital?

It is still unclear how the target group thinks about these topics. The development team is interested in knowing the attitude of the potential future users towards the system. The perception of the potential users may also help to give insights in the mentioned topics and this may help to sharpen the rough edges of Patient-In.

1.4 Research Focus

Perhaps the most important question that needs to be addressed is the following; Which factors do patients take into consideration before they decide to make use of Patient-In? Because of the unsettled issues of Patient-In this question is hard to answer. Before this question can be answered, it is important to know the opinion of the potential user group about the basic idea of a system like Patient-In. This means that this research will set out to inspect patients attitude towards Patient-In. Because Patient-In is still in the development stage, it is important to measure the opinion of the potential user during this particular stage. By measuring the attitude of the target group now, valuable insights can still be translated to practical implementations. The focus of this research is therefore placed on the attitude towards the concept of Patient-In.

Now that there is a prototype available, the target group can assess the basic idea and concept of the project and help to answer the questions that still remain. To find out the attitude towards a system like Patient-In and how this attitude is formed, an exploratory approach was used in the current research. Focus groups were held with patients, nurses and communication experts to discuss certain topics to find out what role these play concerning the attitude towards Patient-In. These topics were derived from the theory that is available about social network sites and online social support groups. In the next chapter theory and these topics will be discussed.

2 Literature Review

2.1 Technology Acceptance Model and attitude

The MST hopes that a lot of their patients will use the eventual Patient-In. The attitude of potential users towards the system is an important predictor of eventual usage according to the technology acceptance model (TAM) from Davis (1989). TAM is probably one of the most well-known models describing which factors influence the intention to use a new technology. The TAM model comes forth from the theory of reasoned action and the theory of planned behavior by Ajzen and Fishbein (1975).

The TAM model by Davis (1989) tries to explain the intention to use a new technology. According to this model the attitude towards a system or the use of that system, influences the intention to use and eventually the behavior of actually using the system. Although the importance of the intention to use is recognized in this research, it was explained that the current research focuses on the attitude. However, the TAM model does explain why the attitude towards Patient-In is important for eventual usage.

Davis (1993) states that external stimuli such as objective features of the attitude object are causally linked to beliefs, attitudes and behavior. He explains that the forming of an attitude towards an attitude object, in this case Patient-In, is an evaluative process. The attitude itself is a evaluative summary of the attitude object formed by attribute dimensions such as good-bad, harmful-beneficial, pleasant-unpleasant, and likable-dislikable. The TAM illustrates that the potential users of a technology formulate a positive attitude toward the technology when they perceive the technology to be useful and easy to use (Davis, 1989).

According to Davis (1989, p.320) perceived ease of use refers to the degree to which a user believes that a particular technology is effortless to use and perceived usefulness refers to the degree to which the user believes the technology will increase his or her performance on the job. The TAM model uses perceived ease of use and perceived usefulness as its key determinants. In the current research perceived ease of use is more difficult to measure. The construct of perceived ease of use is mostly restricted to system design characteristics (Davis, 1989). As explained in the first chapter, the prototype of Patient-In is still very basic prototype and it is very likely to change a lot during the project. The focus in this research is on the idea of having a social network site for social support and less about the system itself. Therefore the usefulness of a system like Patient-In is more interesting. With perceived usefulness we can focus on the concept of a social network site meant for facilitating online social support.

2.2 Perceived usefulness

In the TAM model, perceived usefulness is a strong predictor of attitude towards a technology. Davis (1989, p.320) defines perceived usefulness as the degree to which the user believes the technology will increase his or her performance on the job. However, concerning Patient-In there is not really a job that needs to be performed. Because of this instead of a job, we look at the reasons for which Patient-In is meant. The reasons why people seek social support are to reduce uncertainty, increase feelings of situational control, self-acceptance, social integration and a sense of belonging (Adelman & Ahuvia, 1995). Therefore this research tries to discover the degree to which the potential users perceive Patient-In as useful for these reasons. To find out if the potential users of Patient-In perceive it as useful, we will look at the systems benefits and costs for the potential users.

Butler (2001) states that an online community is sustainable when the benefits provided are greater than the costs of membership to the community. Because the MST hopes that Patient-In will eventually also turn out to become an online health community, the statement by Butler (2001) is applicable to Patient-In. So potential users can assess if Patient-In is useful to them by looking at the benefits of Patient-In versus the costs of membership. From this perspective we take a closer look at the advantages and disadvantages mentioned in theory.

2.2.1 Advantages and benefits from online social support

Some advantages stated by Wright and Bell (2003) have already been stated while looking closer at the difference of characteristics in computer mediated setting compared to a face to face setting. White and Dorman (2001) also mentioned a few benefits for online social support. They state that patients have the opportunity to access the online support groups 24 hours a day, 7 days a week, when it is most convenient for them.

A second benefit that the authors mention comes forth from a state of anonymity on the internet. It increases the possibilities of self-disclosure and encourages honesty and intimacy. This anonymity is enhanced because sociodemographic factors are not always readily obvious and signs of physical appearance, social skills and vocal characteristics are not present. Patients using online support groups can find comfort in this anonymity. Because of its faceless quality other users will value them for the strength of their contributions instead of evaluating them on their physical appearances or disabilities (Barrera, Glasgow, McKay, Boles & Feil, 2002).

A third benefit arises from the opportunity for patients break the geographical boundaries. Patients having trouble with mobility due to physical or medical problems may

find it easier to join an online support group instead of joining a face to face group (White & Doman, 2001; Madara, 1997).

The final advantage mentioned is that most of the online communities have no limit of participants. The larger an online community can get the more information will be spread among its users.

2.2.2 Disadvantages and barriers with online social support

White and Doman (2001) also mention some disadvantages. One disadvantage is that the internet is not available for everyone or is not as easy for everyone to use. Certain groups, older people for example, may not have the knowledge how to use a computer or keyboard. This disadvantage mentioned by White & Doman (2001) may be out-dated. A second disadvantage for online support groups the commitment it may take from its members. Because there are probably more participants in online support compared to offline, it may take users a lot of time to read through the many posts on a certain topic. Another issue arises from the fact that most information on an online support group is user generated content. This leads to the question if the information given is accurate and trustworthy. Demiris (2006) mentions this as a risk of non-moderated social support groups.

Dumaij and Tijssen (2010) mention a few other barriers of online social support groups. They researched online social support among the chronically ill in the Netherlands. They concluded that negative stories, whining and perceived risk are barriers to potential participants because it makes people feel worse. Perceived risk, in their research, mainly included privacy concerns. In the current research privacy is a subject that will be further discussed in Paragraph 2.3. Another disadvantage, according to Dumaij and Tijssen (2010), is difficult to estimate the quality of the messages posted the possibility of incorrect interpretation of these messages and the incomplete answering questions by other users.

Van Uden-Kraan , Drossaert, Drossaers-Bakker, et al. (2008) conducted a research to find if certain disadvantages that were mentioned in other theory actually occur. The disadvantages of social support groups and forums that they used in their research are; disadvantages due to online asynchronous communication, lack of quality of the shared information, disadvantages related to the use and evaluation of health care services and negative postings. The researchers conducted a content analysis of 1500 posts on Dutch social support websites and found that these disadvantages only occurred seldom in their selection of posts.

The disadvantages related to the use and evaluation of health care services used in the research by Van Uden-Kraan et al. (2008) may prove interesting concerning Patient-In. Mursch and Benke-Mursch (2003) found that for health care professionals it is a big concern that patients post their criticism on online health forums. However the research of Van Uden-Kraan et al. (2008) only found a small number of posts in which a health care service was criticized. Still, this remains interesting because Patient-In is connected to the MST, which may lead to more criticism being posted because of this connection. It would be interesting to see how healthcare professional thinks about a system like Patient-In in that manner.

2.2.3 Competition between social support and health information channels

Dumaij and Tijssen (2010) found that surfing the internet, searching for health information is the main source for patients to become familiar with online social support and various websites that provide online social support as a tool. The authors also concluded in their research that obtaining information and sharing experiences were seen as the most beneficial aspects of social support and the primary reasons for seeking social support online. Apparently the way patients search for health information may influence patients in becoming familiar with systems like Patient-In. The manner in which patients seek their health information and the way Patient-In provides this information may prove important.

Patients do not only have the choice to use or not to use a technology but also the choice between alternatives. There are several channels to gain health information from, either online or offline, such as other websites but also offline channels such as patient associations, patient education, doctors, folders and other written material etcetera. Taking a closer look at the channels patients use to gain social support, either informational or emotional may provide insights in further benefits/costs to asses Patient-In's perceived usefulness among alternatives.

Although there can be competition from offline channels that patients could use to gather their health information from or find social support, the online competition may prove to be challenging enough for Patient-In. Van Uden-Kraan, Drossaert, Taal, et al. (2010) investigated online social support groups initiated by patients. In their research they found that if there are too many social support groups this can lead to unwanted competition between them. If there are already enough social support groups on the internet to serve patients, it might be difficult for the MST start their own patient community. They would have to draw participants away from other online social support websites. This may prove to become a problem because Patient-In yet has to establish itself and there is only a limited

amount of people on which Patient-In focuses, namely the patients of the MST. This issue closely relates to critical mass, a topic that will be discussed in paragraph 2.2.4.

2.2.4 Health information seeking and quality of online shared health information

Cline and Haynes (2001) researched the way patients try finding medical information on the internet. They point out that a patient can access healthcare information in three primary ways: Searching directly for health information, participating in support groups and consulting with healthcare professionals. According to them, one out of four health information seekers joins an online or offline support group. De Groot (2010) found that the most important reasons to search the internet for health related information are to gather information about a personal disorder and to obtain a better understanding of the causes and prognosis of a disease. De Groot (2010) also found that the most sought after health related information by far is general and specific information about a certain disease or treatment.

The information on a social network site like Patient-In, is mostly user generated. Because most patient users of social support systems are not medical professionals, the risk of patients sharing inaccurate information seems possible. As mentioned before from the research of Dumaij and Tijssen (2010) this is seen as a disadvantage of online social support groups. There are various researches that have discussed the matter of the quality of health information shared online among patients and if this is harmful. Fox & Jones (2009) found that, concerning the quality of health information shared, more people claim to have been helped or knowing someone that has been helped by health information found online compared to people that claim to have been harmed or knowing people that have been harmed by health information found online. De Groot (2010) found that many users of health information cannot distinguish between accurate and inaccurate health information. Cline and Haynes (2001) note a possible information overload; because of the enormous amount of health information on the internet it may be even harder for the information seeker to determine which information is accurate. Van Uden-Kraan, Drossaert, Siesling, et al.(2009) found that health related internet use of their respondents was limited to seeking information about their illness once in a while. They also conclude that the risk of patients merely checking the internet for information is that patients can get lost in the wealth of information and because there is no professional helping them, patients might have difficulty finding the right and most credible information.

There is another risk when patients use information they find before they have even seen a professional. Ahmad, Hudak, Bercovitz , et al.(2006) focused their research on the fact

that patients medical information patients take to their physician appointments. They held focus groups with patients and physicians to find their experiences. They found that many physicians believed that the health information patients find on the internet and take to consultation, is problematic. It leads to confusion, distress, and possible detrimental self-diagnosis and self-treatment.

Van Uden-Kraan et al. (2008) researched if the disadvantages of lack of control and quality of information shared in online support groups are true. They investigated and analyzed a random sample of postings from Dutch online social support groups. They concluded that many of the posts shared among the participants were actually not contain medical information. The researchers state that is likely connected to the empathic and emotional function of online support. They believe that the participants are well aware of the fact that physicians provide the facts, but other patients can share information from experiences such as what to expect next and how a treatment would feel. The posts they did find to contain medical information was considered controversial and harmless.

Eysenbach and Kohler (2002) conducted a qualitative study to find out how patients appraise health information. They found several criteria for trustworthiness of the information. The criteria mentioned are websites from official authorities, a professional layout, understandable and professional writing, citation and scientific references. Accessibility and certain website features such as a sitemap, a speedy interface and search options were stated as quality criteria and outbound links to recommended websites. The article of Eysenbach and Kohler (2002) also shows that, when concerning the quality of health information, trust plays an important role. Another point of interest in this article is that respondents mentioned that posting a picture of the author that has posted certain information, makes the information seem more credible. Criteria like these seem to increase the trust in other participants and their posts.

It is important to know how patients think about these issues concerning Patient-In. What will the potential users think about the type of information patients will share amongst each other and the quality of that information. Would they use of Patient-In to gather information about their disease and what would they post themselves? Would they make use of Patient-In instead of other websites that also share health information or provide the opportunity for social support? The way patients seek information may influence their attitude towards Patient-In.

2.2.4 Critical Mass

One of the goals the MST has with Patient-In as a service for its patients is to create a community to strengthen the bond between the hospital and the patients. Soe and Markus (1993) state that communication technologies require more than a single person and can only be successful if used by multiple users. Shen, Lee, Cheung, Chen (2009) state that because communication systems are designed for collaboration and cooperation between users, the benefits from such a system could only be gained if the majority of the users accept and use the communication system. In other words. Not enough users may cause a communication system like Patient-In to be less useful.

An interesting construct used by Sledgianowski and Kulviwat (2008) is critical mass. According to Van Slyke, Ilie & Lou (2007) critical mass is the point where enough users have adopted an innovation so that there is an acceleration of adoption of it where upon it becomes self-sustaining. Sledgianowski and Kulviwat use critical mass as a separate influence on the intention to use a social network site. If a social network site states that it has a lot of members and a potential user of the site finds out that there are not enough active members, there is no perceived critical mass for that user. The user might consider a social network as less useful if there are not enough participants to gain information or social support from. Because of this critical mass is considered as a factor that could influence the perceived usefulness of Patient-In.

Butler (2001) argues that when members of a social community are the primary source of resources, the membership size provides a form of measure for the resource availability. These resources are described as information, influence and social support. He states that merely providing an electronic infrastructure for people to communicate online does not guarantee the emergence of social activity. In order to create a sustainable online social system, resources must be available. If not enough people will participate, the amount of resources created will be scarce, thus diminishing the benefit of social support. The perceived critical mass may affect the perceived usefulness of Patient-In and in this way also affect the attitude towards it.

Van Uden-Kraan, Drossaert, Taal, et al. (2010) researched patient initiated online support groups. They interviewed the webmasters that were hosting the online support groups and found out that critical mass is an important factor to keep a community going. A sufficient amount of new members must join the social support group once in a while and a sufficient amount of experienced members must stay active to support the new members (Kim, 2000 as cited in Van Uden-Kraan, et al, 2010). The fact that Patient-In is meant only

for patients connected to the MST makes “critical mass” an interesting aspect to research. The service area of the MST only consists of 264000 people. Will this be enough to sustain an online community which the MST tries to create with Patient-In?

2.3 Privacy and information disclosure

Dumaij and Tijsen report in their research that privacy concerns are the primary perceived risk by users of online health support groups for chronically ill. Sanches Abril and Cava (2008) state that patients are being empowered to share health information and experiences, and thus increasing the knowledge of the patient. Still, these benefits are gained by sharing and disclosing information on the internet. According to these researchers a patient which shares health information on the internet can have several risks by sharing their personal information. Examples they mention, employers finding out about health conditions, family members disapproving when find out about an illness or disease, identity theft and abuse of the information by marketers and commercial data-brokers. Dumaij and Tijsen report in their research that privacy concerns are the primary perceived risk by users of online health support groups for chronically ill.

According to Bansal, Sahedi and Gefen (2009) found that when patients consider disclosing health information the disposition to trust plays a very important role. They state that the intention to disclose information is influenced by their trust, privacy concerns and information sensitivity. In the case of Patient-In, patients will need to disclose medical information on their profile, which may be very sensitive. On this personal profile, patients are able to fill in personal information such as name, birthdates, age, gender, telephone number, email address and subscribe to topics of interests in the form of diseases and ailments. A combination of this information makes it easy for other users of Patient-In to make assumptions about the disease or ailment of another user, which could lead to the consequences mentioned before.

Lewis, Kaufman and Christakis (2008) researched the use of privacy settings on Facebook. They found that people are more likely to use a private profile that is only visible for friends if many of their own friends use a private profile to. They also found that women are more likely to use a private profile then men. Concerning the sensitive information about a participant’s ailment or disease, it could be possible that patients rather prefer to participate anonymous instead of filling a profile with personal information visible to all other participants.

Anonymous participation may seem ideal to improve the privacy of participants of Patient-In but anonymity carries its side effects. Chan, Bhandar, Oh and Chan, (2004) state that in virtual communities focused on specific interests, the identification of members stimulates participation. So less anonymity can lead to more participation on Patient-In because Patient-In is focused on the specific interest of health. Participants may find it important to know whom they are communicating with. Demeris (2005) states that it is important to know the identity of the of the other participants of a virtual community with whom one is interacting, to be able to understand and evaluate these interactions. Another effect of being able to participate anonymously might be the increasing of negative postings and comments as found by Kilner and Hoadley (2005). Haines, Hough, Cao and Haines (2012) found that anonymity may lead to a freeing effect for the participants to be less restrained to stick to socially desirable arguments within an online discussion. Anonymity gives participants the more freedom to post more controversial ideas. However the researchers also found that anonymous posts have less impact on opinions compared to posts that which are identified. It will be interesting to see how potential users of a system like Patient-in think about this topic and if they would rather participate anonymous or public.

Some choices concerning privacy for the Patient-In system are yet to be made and therefore it proves an important topic to discuss among potential users. It is interesting to know what they think about disclosing personal information on Patient-In and if they would not rather participate anonymously.

2.4 Research question

Theory has shown that there are many topics that can be considered that may influence the attitude of potential users towards Patient-In. The following research question was formed for the current research.

Research Question: What is the attitude towards a system like Patient-In and what is the role of perceived usefulness, health information seeking, critical mass, privacy and topics mentioned by the respondents in forming an attitude towards Patient-In?

3 Method

3.1 Research question & design

This research was set out to find which important aspects that form the attitude towards Patient-In. Through a theoretical exploration some constructs were found that may form this attitude. These aspects are information disclosure, perceived usefulness with several sub-constructs; information need and critical mass and perceived risk. In the current research we try to find the role they play when people consider using Patient-In. However, because this is an exploratory research it may be possible to find additional aspects that may influence the attitude towards Patient-In.

To find the aspects that play a role in forming an attitude towards Patient-In a qualitative research was chosen to explore these in depth with the potential users of Patient-In. Focus group discussions was the method that was chosen for the current research. Focus group discussions give the opportunity to explore the ideas, opinions and attitudes towards Patient-In and the aspects mentioned in the design. They also give the chance for the researcher to interact with the respondents themselves, to ask probing questions to find the reasons and motives for their ideas, opinions and attitudes.

3.2 Respondents

Considering that the population could be rather large because anyone could be a potential patient and thus a potential user of Patient-In it was chosen to focus primarily on patients of the MST. Patients of the MST are already familiar with the organization and they can provide valuable data because of their experiences as patients. Eventually 24 patients indicated their willingness to participate in one of the focus group discussions. Thus, four focus group discussions were held with patients.

To gather these patient respondents an invitation letter (Appendix A) was prepared. In the letter the purpose of the focus groups was shortly explained. The letter was given to patients in the waiting rooms of the hospital, because this was seen as the most direct way to approach the patients of the MST. Participants were able to enlist themselves into six specific dates. The letter also mentioned that every participant would receive a gift voucher worth €10,-. Considering that the focus group would take one and a half hour of their time and they had to come back to the hospital to participate, the gift voucher was a small compensation for the participants.

To gain additional data, the choice was made to arrange two extra focus groups. One of the focus groups was held with nurses and another focus group with the department of public relations of the MST. Nurses have close contact with patients and they might have different points of view, opinions or ideas. As for the public relations department, they keep themselves busy with internal and external communication for the hospital every day. Therefore, it was expected that they might have provided some interesting insights from a communication point of view, considering Patient-In is also a means of communication.

3.3 Focus group compositions

Six focus groups were used with a total of 36 respondents. The following table shows the composition of these groups.

Table 1: Composition of the focus groups (men/women and av. age)

Focus Group	Men	Women	Average age
FG 1	4	3	64
FG 2	5	1	40
FG 3	1	4	56
FG 4	2	4	58
FG Nurses	0	6	45
FG Public Relations	1	5	50

In the eventual selection of respondents, there was some overlap between the groups. In some patient groups some respondents were employees of the MST. There was one respondent in the patient group who was also a nurse at one of the nursing departments of the MST and there was a respondent who was part of the client council of the MST. It is not considered to be a problem because the focus of the research is not on finding difference between the groups.

3.4 Operationalisation and conducting the focus groups

The aim of the focus group was to discover what role perceived usefulness, information need, critical mass and privacy play for a patients attitude towards Patient-In. The focus group sessions were facilitated by a single moderator. All the focus groups sessions were audio recorded. The focus groups with patients took about one and a half hour and the focus group sessions with nurses and the PR department took about one hour. The nurse and PR department focus groups had less time because these were held during their one hour lunch break.

The focus groups were conducted in several different meeting rooms of the MST. The participants were placed in an U-form setting. The room offered comfortable chairs and refreshments for the respondents. In every meeting room, a beamer with a widescreen was present to use during the presentation of the prototype of Patient-In.

A focus group script (Appendix B) was created to use as a guideline during the focus groups. In this script the sequence in which the discussion subjects should be addressed was described. The script also showed the opening questions and some probing questions for every subject to start the discussion and to keep it going. The main subjects in the focus group script were discussed in every group, however not all questions were always asked in every group. The questions were not used as a checklist. Considering this is an exploratory study, it was chosen keep the discussion more open as long as the discussion was about the aspects that form an attitude towards Patient-In. The questions were primarily used by the moderator if the discussion diverged from the main subjects and get the group back on track or to keep the flow of the discussion going.

The focus groups started with a short introduction that took about five minutes. In this introduction the purpose of the research was explained and it was explained what the participants could expect during the focus groups. The participants were kindly requested to openly share their ideas, thoughts, considerations and opinions among each other. The role of the moderator was also explained as purely trying to keep the pace and steer the group if it diverted from the topics. The introduction ended with the chance for participants to ask questions before we begun the session.

After the introduction of provided by the moderator, it was time to start the focus group and give the word to the participants. The participants had a chance to shortly introduce themselves and if they wanted to, explain their relation with the MST. This was seen as an icebreaker because their relation with the MST was the one thing the respondents had in common. After all participants have introduced themselves, the discussion started by asking them to describe their experiences with social media and social support. This was discussed to examine the framework from which they would perceive Patient-In and give an image from what experiences they form an attitude towards Patient-In. The introduction of the participants and the discussion of their experiences took about 10 to 15 minutes, in the nurse and PR department focus group it was kept shorter because of less time.

The next step in the focus group was a short presentation of the Patient-In prototype which can be seen in Appendix C as screenshots of this prototype. The prototype was shown with a beamer. Prior to the presentation of the prototype the participants were requested to

state any question they had directly during the focus groups so that the participants could form a clear image during the focus groups. Each screen, as shown in the Appendix C, was presented for about 30 seconds. The presentation of Patient-In took about 10 minutes.

As shown in the script, after the presentation, a first impression of Patient-In was discussed. Finally after the first impression the topics as discussed in the literature review were treated. Privacy was chosen to be the last subject because it was considered a heavy subject which could influence the course of the focus group. During the focus groups there was however a lot of overlap between subjects and this led to the fact that the sequence as described in the script was not always the exact sequence in the focus group itself. After the four main subjects were treated two last questions were asked to create a closure of each session.

3.5 Focus group analysis and report

Audio recordings were made for every focus group session for analysis. The total of recorded audio was 502 minutes. Because the focus groups were conducted by a single moderator, which made it difficult to make a lot of notes during the focus group, the audio recordings were the most important data in this research.

Time constraints led to the choice of not creating entire transcripts of the audio data. Instead the researcher used selective reading/listening approach for analyzing. The audio tapes were carefully listened to multiple times to uncover the main themes that were discussed concerning the attitude towards Patient-In. The main themes were then analyzed and categorized to see if the themes were either about a positive or negative attitude towards Patient-In. The statements and quotes were then interpreted and analyzed to find to capture as fully as possible what meaning the highlighted material conveyed. Next, statements and quotes that appeared to be the most revealing about the themes were selected. These quotes were written down in Dutch and later translated to English.

To represent the results, the following division was chosen, namely a division in positive and negative attitudes towards Patient-In with an additional selection of recommendations from the respondents. These recommendations came forth from the yet unsettled issues surrounding Patient-In. Because issues like monitoring and login procedure were not yet clear, respondents could only explain their attitude in a recommending way. This resulted in the structure of the next chapter in which the results are presented.

4 Results

The following themes emerged in the focus groups. These themes were separated in themes that positively and negatively affect the attitude towards Patient-In. Because some issues concerning Patient-In are not clear yet and still many questions remain unclear in its development, some themes resulted in recommendations.

4.1 Experience with social media

During the focus groups, the respondents were asked which social media they used in their everyday lives. This was asked because their experiences with social media could explain certain other statements of the respondents and perhaps explain certain differences of opinions among respondents. The attitude that they form towards Patient-In may be explained by their framework of experiences with other social media.

Table 2; Use of social media

Focus Group	Using social media	Using but not actively	Not using social media
FG 1	2	1	5
FG 2	5	0	1
FG 3	1	0	4
FG 4	3	1	2
FG Nurses	4	2	0
FG PR	1	2	3

The table above show how many respondents used social media or not. Some respondents noted that they had for example a Facebook account but did not use it actively. Therefore, a middle category was added. The focus groups were relatively balanced in users

and non users of social media. Facebook was by far the most mentioned social media, followed by Twitter and Hyves.

4.2 Experience with social support

The focus groups were asked if they had experience with social support, either online or offline. This was asked to find out if they had experiences with social support that they related to Patient-In. These former experiences could influence the way the respondents perceive Patient-In and it could influence their attitude towards it.

Table 3: Experience with social support among the FGD participants

Focus Group	Experience social support online	Experience social support offline	No experience social support
FG 1	0	0	7
FG 2	3	0	4
FG 3	0	2	2
FG 4	1	2	3
FG Nurses	0	0	6
FG PR	0	0	6

This experience appeared to be low among patient focus groups. The focus group with nurses and the PR department were familiar with certain social support groups, some also organized by the MST itself, but had no direct experiences with them. Only four respondents mentioned they participated in face-to-face social support groups. These were organized meetings by organizations other than the MST. Some respondents also mentioned that they looked at online forums for patients on the internet. However, they did not actively participate but just searched for information from other patients.

4.3 Positive Attitude

4.3.1 Sharing emotional social support

Although not all respondents expressed the need for emotional support, sharing emotional support for example in the form of experiences or medical information was acknowledged as a positive aspect. Patient-In was seen as easily accessible and a place to state your concerns and share your experiences. One of the nurse respondents mentioned that Patient-In could help a patient with processing his disease. These are considered to be positive aspects of Patient-In and contribute to a positive attitude towards it. This can be seen in the following statements.

“I think this is good. If you are having a certain type of surgery and you are very insecure, you can always check what you could expect. If there are more other patients that have had the same surgery, you can check their experiences. I think this would be pleasant.” [FG Patients: Respondent 3]

“I can imagine that as a patient you could have all the information, but still it would be nice to speak to fellow sufferers.” [FG Patients: Respondent 3]

The advantage here (referring to Patient-In) is that you can tell your story here.” [FG Patients: Respondent 7]

“I think this is a positive development, that you are able to can share things with each other.” [FG Patients: Respondent 20]

“It is an advantage in that they have an outlet to post their concerns; it may help processing their disease. [FG Nurses: Respondent 4]

“It’s more easily accessible (referring to Patient-In). I think that you get more information because it is patient- to- patient and not doctor-to-patient. I would search for information from a fellow sufferer that is not just speaking in medical terms but... just in a human way, sharing information and not just spamming Latin verbs.”” [FG Patients: Respondent 15]

The PR department focus group mentioned that Patient-In could also provide the sharing of emotional support in the form of tips and hints from these experiences. The following statement explains that the tips and hints that patients can gain from experiences is something one does not find through other certain medical information channels. It explains why experiences from other patients can be useful for patients.

“The experiences differ per person. The way a surgery is done, you will find this information in a folder beforehand but if you look at the aftercare ...People can give each other hints and tips for example what did they eat after the surgery or something like that. That kind of information, you don’t find this in a folder.” [FG PR Department: Respondent 1]

One of the patient respondents explained why fellow sufferers contact can get more important in the future. She explained that the contact between the patient and their specialist is getting less because healthcare is getting more expensive. So she believed fellow sufferer contact can help to fill the gap. This resulted in a positive attitude towards Patient-In, because it was believed Patient-In could help to fill this gap. This can be seen in the following statements.

“Fellow sufferer contact is more and more important. Nowadays it’s like, you have to come back for another appointment after half a year, at least if it is needed. The time between treatments and appointments is increasing because healthcare is getting more expensive. So I think there will be more need for contacts. The contact between a patient and the doctor or nurse is getting less. So it’s more and more beneficial to have contact with your fellow sufferers.” [FG Patients: (also part of the client council of the MST) Respondent 24]

“The way I look at the website (referring to Patient-In), if I want to know something about an ailment or if I want more information, you go to a doctor and you get eight minutes and the doctor says “you have this or you have that”. You come out of the medical office and you think “Oh god help”. You have only received 40 percent of that which he told you. You go home and you want more information, then a site like this would be ideal.” [FG Patients: (also part of the client council of the MST) Respondent 24]

4.3.2 A digital space to discuss MST specific topics

Some respondents believed that Patient-In would be a place to discuss MST specific topics. The following statement is an example of this.

“With diseases that are widely known, like breast cancer etcetera, on the internet there are already a lot of forums and fellow sufferer groups, there are enough of those. So the question is for whom is Patient-In? And what we discussed earlier, it is for meeting people in the same boat, within the MST, and regularly need to come back to the hospital. But then the discussion on Patient-In will be about the treatment within the MST itself.” [FG Patients: Respondent 9]

It was discussed that the MST has its own treatments that may differ from other hospitals. Because Patient-In only focuses on patients from the MST itself, some patients saw Patient-IN s more personal, having a positive influence on attitude. The first statement below was

stated by a women who wanted to point this out. The second statement is from the same discussion and makes the point within this discussion more clear.

“If I come to this hospital with breast cancer I will have one team of doctors that have one method of treatment, at least I hope and think. And I think that you can go to this website and you can type that in, and you will get a good kind of... well.” [FG Patients: (also part of the client council of the MST) Respondent 24]

*“I am treated within **this** hospital, in **this** department, by **these** doctors. That what makes it Patient-In more personal to me.”* [FG Patients: Respondent 22]

4.3.3 Useful chronic patients or long term treatments

Respondents believed that Patient-In could have its advantages for chronic patients. In the nurse focus group it Is explained why Patient-In can be useful for chronic patients. It is stated that Patient-In could help chronic patients to deal with their disease and that it would assist patients with giving the disease or ailment a place in their lives. This advantage can contribute to a positive attitude towards Patient-In. The following statements are examples of this discussion.

“I think that patients that need to be in the hospital a lot more often would have more advantages with a social media like this.” [FG Patients: Respondent 23]

“I think it would be informative, primarily for chronic patients instead of people like (name of another respondent), who had a problem with her knee and doesn't have to come back for 10 years.” [FG Patients: Respondent 12]

“If it is a chronic disease, it (referring to Patient-In) helps to give this disease a place in their lives.” [FG Nurses: Respondent 4]

4.4 Negative Attitude

4.4.1 Informational social support need and information abundance

The respondents were asked which channels they use to gain the medical information they need. Most respondents stated they primarily use the internet search engine Google to find the medical information they need. Secondary channels that were often mentioned were patient associations and the family doctor.

“If I want to know something, I will Google it. I only read what others have to say about it. I do not post information myself.” [FG Patients: Respondent 6]

“If I wanted to know something, I would check with patient associations.” [FG Patients: Respondent 7]

“If I have a question and I want to know more about it I will search for it, and most cases I will go to the family doctor.” [FG Patients: Respondent 2]

“The first step would be to go to the family doctor, and after that I would get my information from a website.” [FG Patients: Respondent 21]

After the respondents were asked which channels they used for searching medical information, they were asked how easy it was for them to find the medical information they needed. Most patient respondents said it was particularly easy to find the medical information they need especially with the internet and from medical websites and from the websites of patient associations. But patients also explained there was an abundance of medical information they get directly from the hospital.

A response to the question if it is easy to get the medical information one needs: *“These days with the internet, it is.”* [FG Patients: Respondent 14]

“You would only have to type in” Patient” in Google and you get dozens of websites, so it is relatively easy.” [FG Patients: Respondent 15]

“If you go to the hospital, you don’t even want to know how much information you can get there and take with you.” [FG Patients: Respondent 23]

“The chronic patients all have their own patient associations with their own extensive websites. Here you can find all kinds of information and most of the time there are reactions from other patients as well.” [FG Patients: (Also a nurse) Respondent 4]

This abundance in information resulted in the belief that Patient-In would not add extra value when it comes to the need for medical information. The abundance of this information already available on other channels and the perceived ease of getting access to this medical information appeared to be the reason. The ease of gaining this medical information elsewhere may influence the value of a system like Patient-In negatively, which results in a negative attitude towards Patient-In negatively.

“Before you undergo surgery, there are all kinds of booklets that you would get in advance. In these booklets you are able to read what is going to happen to you. If you are dismissed from the hospital you get an enormous load of information in which the after care is carefully explained. From that standpoint, I don’t expect that there is going to be much need for Patient-In because the information is already available.” [FG Patients: Respondent 1]

“I see the advantages of a forum where you can state certain things or when you are worried about something. But the problem here is that it’s all behind a password. And for every ailment or disease, there is already a forum on the internet that you can find where people from all across the Netherlands are able to give their opinion.” [FG Patients: Respondent 7]

“What would be the surplus value I ask myself, because what like (other respondent) also said, there is already enough information.” [FG Patients: Respondent 3]

“What is the surplus value if systems like this (referring to Patient-In) already exist? There are plenty of other option to get this info. It doesn’t make sense for the hospital to do this.” [FG Patients: Respondent 23]

“I think that there is not so much need for Patient-In, and that every patient has its own patient associations with a lot of elaborated information.” [FG Nurses: Respondent 2]

4.4.2 Quality and accuracy of information

The respondents were also asked how they perceive the quality and accuracy of the medical information they find. The respondents noted for example that they check multiple sources for consistencies in the information to judge if it is correct. Also checking the sender was mentioned as a way to assess if information is correct. This can be seen in the following selection of statements.

“Yes, I can check the sender of the information, who has put this on a site. And most of the time I will check three or four publications and then I got just about an idea how it works.” [FG Patients: Respondent 6]

“Eventually you will find the quality that you seek, maybe not the first time but if you continue searching, especially on the internet, you will find what you need.” [FG Patients: Respondent 15]

Relating the quality of information to Patient-In, respondents were concerned that the medical information shared among the users on Patient-In could be inaccurate. In the nurse focus group, it was also discussed that patients on Patient-In could give each other incorrect information. The following statement from this discussion shows the concern.

“In many cases people are going to give each other inaccurate information.” [FG Patients: Nurses 6]

In the PR department focus group it was mentioned that there is a difference between sharing medical information and sharing experiences. Experiences were seen as correct because these are people’s own experiences. Patients answering each other’s questions however, was seen as not trustworthy because this information could be incorrect.

“If you talk about experiences, that one hundred percent trustworthy because these are someone’s own experiences and the way they perceive it. If patients start answering each other’s questions, well that’s completely unreliable. It could be true and correct, but it doesn’t need to be. That’s dangerous.” [FG PR Department: Respondent 3]

The patient focus groups mentioned the same concern about sharing inaccurate information on Patient-In. The following statement shows this concern. He also explained that there is a difference between other forums and Patient-In. The patient expects that medical information that is placed on a hospital website is correct. If it is not it could lead to a negative attitude towards Patient-In.

*“That’s another problem. On forums anyone can say anything. If I say “you can die from an angioplasty treatment” and I post this, well there it is on your website. I can state this without getting any trouble and no one would shut me down. And everyone would think “what an idiot”. The problem is, you do read this on **the** hospital site.* [FG Patients: Respondent 6]

“It is unacceptable as a hospital because on many forums it is just easy accessible and stuff, but on a hospital website you expect information that’s accurate.” [FG Patients: Respondent 6]

The following statements show the concern of the respondents that experiences do not always give accurate information. There is a risk for patients to listen to advice and experiences from other patients.

“Experiences from patients are not always based on expertise.” [FG Patients: Respondent 5]

“Sometimes you see that there are people who do not stick to what the doctor is telling them and that they don’t listen to the doctor’s advice. If something goes wrong it’s the doctor who gets the blame. But if other patients will complain like “the doctor did not do it correctly” which isn’t true because the patient himself did not listen to the doctor’s advice. And if a patient like that would post its experiences on the internet and if you listen to a patients like that, well you will have a problem. You will be doing the wrong things because of advice from that patient. ” [FG Patients: Respondent 2(this respondent was also a nurse)]

There was another discussion among some patients about a situation which could also cause inaccurate information. The discussion was about the question; when am I a patient of the MST? Patients who, for example, had surgery a few years ago and are not treated anymore should they still have access? In this debate it was mentioned that patients who are treated in the past could post medical information on Patient-In that would no longer be up-to-date, and thus may be inaccurate. The following statements from that discussion.

“Medical developments and advances move so quickly. I mean what we know now is considered old news in about half a year.” [FG Patients: Respondent 9]

“Maybe the treatment methods are different compared to ten years ago. So if someone would post something from ten years ago, I don’t think that is useful. It must be something recent.” [FG Patients: Respondent 14]

One of the risks associated with inaccurate information was wrong self diagnosis. It was discussed that if patients have not yet visited a doctor and they decide to participate in Patient-In without a diagnosis, patients could end up forming a diagnosis on the basis of false information.

“If you get professional information everything is fine but if you’re going to discuss things on a forum with people without knowing exactly what the problem is (referring to a disease or ailment)... Well that’s just not the correct way of doing it.” [FG Patients: Respondent 1]

People always have an urge to, when they are on the internet, create their own self-diagnosis. For example when they search for medical information and read things like ‘hey have you thought of this, maybe this is what you have?’. [FG Nurses: Respondent 2]

The probability of inaccurate, low quality medical information sharing on Patient-In was one of the reasons why respondents pointed out that monitoring of Patient-IN was an important issue. This can be seen in the following statements.

“I would participate if there would be a specialist participating that is able to say ‘what is being said here is not correct’.” [FG Patients: Respondent 20]

“I would use it if there was a specialist involved in this. He can remove all nonsense that is posted, because you can fool each other here. But someone like that could say ‘what this person says is not correct’. Then this (referring to Patient-In) is interesting.” [FG Patients: Respondent 5]

“Then there needs to be some one who checks this information. If there is a doctor that could say ‘What Pete, is saying is true, that is how it goes nowadays’ or if it is not he would say ‘Well Pete, that is not true, it had changed now’.” [FG Patients: Respondent 8]

Monitoring the information that patients post on Patient-In and the way monitoring should be implemented was also discussed in the focus groups but it will be treated as a recommendation and will be discussed in Paragraph 4.3.

4.4.3 Expected negativity and scary experiences

Some patient respondents raised the concern that Patient-In will be used to post negative reactions about the MST. There was a concern that Patient-In would just become a billboard for complaints about doctors, treatments and everything that goes wrong. Some experiences posted on Patient-In could scare other patients as well. This leads to a negative attitude towards Patient-In. An example of this can be seen in the following statements from that discussion.

“I am concerned that the people that are dismissed from the hospital, that they will write; “this doctor didn’t do this correctly and that doctor didn’t do that correctly”. You would get all kinds of negative impressions from this site.” [FG Patients: Respondent 1]

“My wife had an open heart surgery and afterwards she heard. Well, we already knew because we heard in the waiting room, that she went through the eye of the needle and that they had to reanimate her and some things happened that should not have happened. What if I were to put this story on the site? Even a dog would turn it down. Because she has been on the intensive care for a week and she has been opened up three times Those are nasty experiences, I can tell you. If people were to read these kind of reactions on Patient-In it would seriously scare people and they would think ‘what kind of hospital is this?’.” [FG Patients: Respondent 1]

Another patient respondent related the scary experiences people would post on Patient-In to her own experience with other forums. She explained that some reactions on other forums describe nasty experiences with a lot of misery. She stated that when she read these she believed she had to close these forums and that you do not want to read these experiences. This can be seen in the following statement.

“Sometimes you enter these forum sites and you think, I have to click and close this. Really nasty thing that you read there. A lot of misery, with one story being more miserable than the other. You don’t even want to know these things.” [FG Patients: Respondent 14]

The same concern was raised in the nurse focus group. The following statements are examples from the discussion about negativity and scaring patients.

“You must be careful that you are going to get people to participate, who are just being negative all the time. You can scare a lot of people that way, and that’s not necessary.” [FG Nurses: Respondent 5]

The nurse focus group connected this problem with their own experiences. In the following statement a nurse explains that she expected it would be like the patients waiting in the daycare room, telling each other their experiences. She explained that these experiences can sometimes scare other patients that much, that they do not want to go through with a certain treatment. This can be seen in the following statement.

“Sometimes you see people before the treatment sitting in the daycare room and suddenly some people start telling each other the most horrible experiences of a surgery, what the other patients shouldn’t take very seriously. And then they would come back and they did not want to go through with it anymore.” [FG Nurses: Respondent 2]

In the PR department a similar statement was made. Here Patient-In was compared to a waiting room in the hospital. This is evident in the following statement.

“It is sort of the waiting room in which the patients will just chatter away. If you look at what happens in a waiting room, and people would still hold back here because you see each other physically, but the wildest stories are being shared and the one providing the treatment will get the difficulties.” [FG PR department: Respondent 2]

The issue of negative and scary experiences was one of the reasons respondents suggested monitoring would be a positive attribution to Patient-In. The following statement is an example.

“There needs to be someone who can delete all this stuff but then you could ask yourself if not every message needs to be modified.” [FG Patients: Respondent 6]

Monitoring will be treated in paragraph 4.3.

Within the discussion about the posting of negative and scary experiences one of the nurses made a comment about why she expects this would happen. She tried to explain that patients from the MST post critique about the MST on Patient-In because of their connection. She expected that participants of Patient-In think their reactions will be read by the MST. Apparently she expects that patients want their negative experiences to be known to the hospital.

“Patients are free to visit other forums to post reactions like “the MST this or MST that”, but because Patient-In is linked to the MST patients will see that connection. They will think “oh well I think the hospital is going to read this so let’s go post some criticism ”.” [FG Nurses: Respondent 4]

There was a difference between the nurse focus group and the other focus groups. The nurse focus group mentioned that the negativity could have a negative effect on the hospital and the nurses and doctors.

Mentioned in the discussion about posting criticism on doctors: *“You can damage a doctor’s career.”* [FG Nurses: Respondent 2]

“As a nurse I would not put myself on Patient-In because...I would not be happy to read things here (referring to Patient-In) like “Watch out for nurse Debby because everything goes wrong when she comes close”. I would not be happy if such things were posted and new patients would be coming in.” [FG Nurses: Respondent 3]

“What if I had a big problem with a certain department, and I go home, a maximum amount of about ten people will hear about this from me. Then I would have shared my story, I will become a little bit more nuanced in time. But if I post my story on this forum (referring to Patient-In, and there is a huge amount of people who read this, I think that the MST will have big problems.” [FG Nurses: Respondent 2]

4.4.4 Critical mass

Some respondents expected that there would not be many of participants on Patient-In. In this discussion they noted that if this was the case Patient-In would not be useful for them. Some respondents noted there needed to be a sufficient amount of reaction from other participants

on a certain topic, for Patient-In to be useful. This expectation forms a negative attitude towards Patient-In. The following statements are examples of this discussion.

“If only a few people are going to make use of this (referring to Patient-In) it is not going to be much use.” [FG Patients: Respondent 10]

On the internet there are a lot of other forums which discuss the same topics and have many more reactions than this one (referring to Patient-In). If I will not get or find a reaction, I have no idea why I should be going to Patient-In. If you are looking for something, then at least about ten people need to have posted something.” [FG Patients: Respondent 6]

“Negative, the way I look at it now because for one it is too limited. You can only reach a selective group of people who are treated in the same hospital as you. This would mean that if people have Asthma or whatever, just like you, who I actually wish to come in contact with but are treated in Hengelo or Almelo. Well I can’t reach them. [FG Patients: Respondent 10]

The PR department discussed the same concern. They also expected that there would be not enough participants for Patient-In to be useful for patients. One of the respondents believed that because Patient-In was only meant for patients of single hospital it would not attract enough users. In this discussion, it was also noted that patients are also separated across all the different medical practices. This can be seen in the following statements.

“I ask myself how many people will place a reaction on this (referring to Patient-In), for example if there is a person who is participating on Patient-In alone and no one else from that specialties subscribes himself to that subject, you cannot force people to make use of this (referring to Patient-In). I mean, if you would make Patient-In open to a wider audience, probably on a national scale, then perhaps there would be enough people to participate. But just one hospital in Enschede? Probably only three people would give a reaction to this one person.” [FG PR department: Respondent 1]

One of the patient respondents compares this issue with his own experiences with camping reviews. He explains that when concerning a camping review, you need enough reaction to form an opinion.

“It’s the same thing with camping reviews, if I only see about two or three reactions, I mostly skip them. I mean, what does that tell me? Mostly you need about five or ten reaction to be able to form an image.” [FG Patients: Respondent 12]

In some focus groups there were discussions and statements about Patient-In being less interesting for patients with short treatments. Only one statement explains why this could be

true. The respondent explains that patients with short treatments only have a short time span in which they need information or social support. If such a patient would use Patient-In to gain this information or social support, there needs to be a fellow sufferer with the same treatment, active on Patient-In in that same time span. The respondent from the following statement expected this to be unlikely. Because he expects that there will not be enough participants, Patient-In may prove less useful for patients with shorter treatments. This can be derived from the following statements.

“I don’t think they will make use of this. Most treatments are very short, and then you have a short period in which you have need for an enormous amount of info and exchange of thought. You would need someone that has the same treatments in that exact same period of time.” [FG Patients: Respondent 6]

A later addition to his statement above: *“I think this is highly unlikely.”* [FG Patients: Respondent 6]

The same respondent pointed out that he did not expect that people who are done with a certain treatment would still go to Patient-In to share their experiences again. This was also discussed in other focus groups. The following statements are examples from this discussion.

“I ask myself; if you are interested in angioplasty, how long does that take? A week? Only in that specific week you are interested in angioplasty and afterwards you would not return to some website to talk with other people about it. People who have already had that treatment....I don’t think they will make use of this.” [FG Patients: Respondent 6]

“It’s difficult to get people back, when their leg is fixed again for example. Would someone stop, or will they be tempted to come back to Patient-In once in a while?” [FG Patients: Respondent 12]

One of the respondents has a rare disease called the disease of Kahler. He explained that because his disease is rare, he does not expect to find anyone in the same situation as him in this region, participating on Patient-In. So for people with a rare disease it could be difficult to find fellow sufferers on Patient-In because it limits itself to patients of a single hospital. This can be seen in the following statement.

“For me it is difficult to find social support anyway. Not that I need it, but there probably won’t be a lot of people in this region who have the disease of Kahler. I doubt that I will find anyone on this site (referring to Patient-In) anyway.” [FG Patients: Respondent 17]

Concerning the expectation of not enough participants, there is one important last topic to highlight. Patients mentioned the importance of the distinction between users in total and active users on Patient-In. This can be seen in the following statement.

“The amount of active members is way more important than “30000 have subscribed themselves to Patient-In.” Those are often the numbers you see, like...”We have 80000 members!” but in the end only 100 members use their account.” [FG Patients: Respondent

The expectation that there will be not enough participants on Patient-In which is a concern for a lot of respondents. The reasons for this concern seem to be the fact that it is limited to the MST, the already limited amount of participants would be spread across many specializations and the expectation that patients of short treatments would not come back after their treatment. Because of this it could prove difficult for patients to find similar active participants to communicate with, especially for people with short treatments or rare diseases, on Patient-In. This affects the perceived usefulness and the attitude towards Patient-In in a negative way.

4.4.5 Privacy and information disclosure

Many respondents believed Patient-In to be too sensitive and that their privacy would be threatened. The respondents noted that people needed to fill in personal information on their profile. Many respondent did also not like the idea of making the selection of interests on someone’s profile, public. This influences the attitude towards Patient-In negatively. The following statements are examples of this issue.

“I think it is too privacy sensitive” [FG Patients: Respondent 1]

“The first page you showed us, the one with the personal information, that should not be visible for others, that also counts for your ailment.” [FG Patients: Respondent 1]

“The entire medical history, that does not need to be public for me, I think if that would be the case, I would not participate.” [FG Patients: Respondent 14]

Besides I saw that you were able to fill in your topics of interest (referring to subscribing to a disease or illness as a topic on Patient-In). As soon as these become publicly visible and other people would be able to see that I am interested in sexually transmitted diseases when I subscribe to that topic... That they’re able to look through these interests like a list, and think that I have a lot of diseases, but I don’t want everybody to know.” [FG Patients: Respondent 10]

“If it (referring to personal medical interests that can be selected) is visible for everyone on that forum, I wouldn’t place anything.” [FG Patients: Respondent 10]

One respondents noted that the information disclosure and the perceived risk that comes along with it, is connected to the sensitivity of the disease. He also explained when it could be too sensitive. This can be seen in the statement below.

“It depends on the sensitivity of the illness. If it has no consequences for the way people treat you, like employers, health insurance companies or your social environment, then it does not matter. But if you have a disease that could have impact on these things, well you would be more careful of course.” [FG Patients: Respondent 9]

The following statements explain that the patients and nurses were concerned that people will check each other’s profiles just for fun or out of curiosity. The respondents expected this behavior from other users, because of their experiences with other social media. Within this discussion people noted that they thought Patient-In was like Facebook. It was also noted that Patient-In will be more abused instead of used because patients would not use it for fellow sufferers contact but just for checking other peoples profiles out of curiosity. The following statements are fragments of this discussion from this discussion

“I think that a lot of people will search other people on Patient-In for fun.” [FG Patients: Respondent 1]

“this is just a little bit to Facebook-like.” [FG Patients: Respondent 14]

“I think the Facebook principle would take over. And that people will be curious and look for others.” [FG Nurses: Respondent 3]

“You get things like:” Hey, let’s see what the neighbor has!” [FG Nurses: Respondent 2]

“I think there will be more abuse instead of use.” [FG Nurses: Respondent 4]

“It is just what people do, that urge to be curious.” [FG Nurses: Respondent 5]

A patient respondent related this issue to one of his own experiences with a real estate website called Funda. He explained that his house was for sale on Funda and he needed buyers but instead he only has “lookers” that view his house online.

"I have the same experience with another media called Funda.. Our house is for sale on this website and each week I have about a hundred people looking at our house online. I do not need that kind of nonsense, I need a buyer and no lookers." [FG Patients: Respondent 1]

The issue of privacy and the information that is disclosed on Patient-In leads to a negative attitude towards Patient-In. Although this is not the way Patient-In is intended, many people noted that anonymity is desirable. Because this is considered a recommendation this will be discussed in paragraph 4.3.

4.5 Point for improvement from the perspective of the focus group participants

4.5.1 Monitoring & doctors participation on Patient-In

Most patients believed participation of doctors would be a positive addition to Patient-In. Patients believed doctors could help verify if the information provided by other participants on Patient-In is correct and they can answer questions of participants on Patient-In. The following statements are examples.

“I would make use of it if a doctor would be involved, that could separate sense from nonsense. Someone who is able to say “what is being said here isn’t right because...”” [FG Patients: Respondent 7]

“It is nice to hear things from other people but I think that it gives a sort of confirmation if you hear the same from a doctor who is participating.” [FG Patients: Respondent 8]

“If there are a lot of questions of patients during a discussion, and a doctor could answer these questions, that would be useful in my eyes.” [FG Patients: Respondent 19]

4.5.1.1 Participation of patients already following a medical track

The PR department took the discussion about doctors participation a little further. This started with the issue of wrong self diagnosis which was discussed in the patient, nurse and PR department focus groups. Respondents mentioned, forth coming from this discussion, that it is better to visit a doctor or specialist before the patient decides to participating on Patient-In.. The following statement is an example of a patient explaining that it is very easy to get lost in the health information on the internet. He explains that it is important to know what your diagnosis is before you search for health information. If the patient does not know this he might be searching for the wrong information.

“If you search your information on the internet, it is very difficult to... like, you need to know exactly what you have (referring to an disease or ailment), if your search is slightly off, you will be looking for the wrong thing. It’s better to get the information from a doctor or nurse first and then look for information on forums.” [FG Patients: Respondent 20]

In The PR department focus group the issue of patients forming a wrong self diagnosis on the basis of wrong information, raised the idea that there has to be a certain amount of control on the patients and the information they share. It was discussed that the concept of Patient-In would better if only patients inside a medical track could use Patient-In. These are patients that already visit a doctor or a specialist a few times a year and already have a diagnosis. The

PR department focus group mentioned that these patients should receive a login code from their doctor or specialist to participate on Patient-In. They also mentioned that the doctors and specialists should participate as well, assisting and guiding their patients in the discussions on Patient-In. The PR department expected that if Patient-In was established in this way it might work. This is however a very different approach to Patient-In compared to the intended approach. The following statements are taken from his discussion.

“The point is, there are patients that will look on these forums (referring to Patient-In) if they have something (referring to a disease or ailment), that’s something completely different compared to giving patients a place like... alright you have been to the doctor, you are part of a medical track and now you can speak to people on this forum about this medical track.” [FG PR Department: Respondent 1]

“The hospital itself, or perhaps the even specialists should be handing out the login codes after the first consult, and then redirect the patients to Patient-In.” [FG PR Department: Respondent 3]

“Actually there should be a form of guidance from doctors, that can read through the posts and respond with answers or medical advice, then you would have more control over what happens on Patient-In.” [FG PR Department: Respondent 1]

4.5.1.2 Difficulties mentioned by respondents concerning monitoring

There are some issues that were discussed in which monitoring and answering questions by a doctor may prove difficult. The following statement is an example given by a patient respondent who presents the issue of the difficulty on the part of a doctor to give advice online. In some cases the doctor must see the patient physically to be able to answer certain questions.

“They (referring to doctors) can’t even answer half of it because, if for example you have a little hump on your foot and the patient would ask “how do I get rid of this wart?” and instead of a wart it actually is cancer. Well a doctor needs to see this. He cannot just say “Just put some anti wart crème on it.”” [FG Patients: Respondent 6]

Concerning inappropriate behavior and the posting of negative reactions by participants on Patient-In the nurse focus group believed it would be difficult to monitor these participants. It was stated that it could be difficult to create boundaries of communication on Patient-In. It was believed even with monitoring it would be difficult to control what is being said by the

participants. It was also discussed that you cannot change a posted experience. This can be seen in the following statements.

“The approach should be to focus purely on people willing to meet each other on this forum to talk about their diseases but you cannot create these boundaries, you can’t put up those borders. [FG Nurses: Respondent 4]

“And what is considered inappropriate. The organization can decide something is inappropriate but maybe the opinion of the patients differs. To what extent can you touch a patient’s own experiences?” FG Nurses: Respondent 4]

4.5.3 Links to professional websites on Patient-In

Some respondents stated that would like to see links to other professional websites. They stated that it also shows that the hospital is professional if it shows that it works together with other professionals. This can be seen in the following statements.

“I have one thing concerning the information on Patient-In. The information comes primarily from the users. You don’t see any links towards other websites. Concerning diseases, there are a lot of professional websites that treat these diseases and its symptoms. On Patient-In I see nothing about that. I think that is too bad because if you want to use Patient-In and need information, it is not bundled together.” [FG Patients: Respondent 9]

“The link towards independent professional information is complete absent. I think if you are a patient and you want to talk about it, you need all the information available when discussing it. Of course I can open a new tab and look for different websites but think it shows that the hospital is professional if it works together with other professionals.” [FG Patients: Respondent 9]

“It is very important to link other professional sites on the hospital site. Then you know that these are professional and trustworthy.” [FG Patients: Respondent 23]

4.5.4 Additional information on Patient-In

By some respondents, the suggestion was made, to add more information about diseases and ailments by the hospital itself. Some suggested a short description of every disease or ailment and combine these with a the forum. Some respondents stated in this discussion that it is important the MST works proactively with the medium and that the content on Patient-In is not only delivered by the patient themselves. This can be seen in the following statements.

“The hospital needs to needs to proactively when using Patient-In. I think that is something we have all concluded here now.” [FG Patients: Respondent 8]

“Or a short piece of information from a doctor about a certain ailment. And I don’t mean they have to write something every day but just general pieces of information” [FG Patients: Respondent 8]

“It would be a good addition if you have like a professional description of every disease, explained by doctors of the MST, perhaps even with information about the doctors of a certain department and then combined with a forum so that people can discuss about it.” [FG Patients: Respondent 23]

One of the reasons why it was suggested was because to lure initial participators. This can be seen in the following statement.

“Especially if you don’t have a large group of people that will go to Patient-In because it is limited to the MST. Because Patient-In must have at least something to offer, so the MST must initially come with information itself to lure people to participate.” [FG Patients: Respondent 9]

4.5.5 Using the experiences of patients to improve service

There was a suggestion by one of the respondents that the MST should use the experiences posted on Patient-In. The respondent thought it would be useful if the hospital would use these experiences to see what goes wrong and improve these aspects. This can be seen in the following statements.

“Indeed, to get know things, and also to report my experiences with the hospital. I hope there will be a interaction, that the hospital will use my experiences. So to share information and experiences but also to share experiences with the hospital so they can do something with it. That would be useful to me.” [FG Patients: Respondent 16]

“If there is more people posting the same reaction or experience (referring to negative experiences), That the hospital can use these to improve things in the hospital itself.” [FG Patients: Respondent 16]

4.5.6 Anonymous participation

Most respondents noted that they preferred to participate on Patient-In anonymously, although this is not the way Patient-In is intended. Using one’s own name was a sensitive subject in the focus groups.

“If it were anonymous it could be very useful” [FG Patients: Respondent 7]

“Anonymous it would be ok” [FG Patients: Respondent 17]

“If you have a fictive name, you would clearly give more information and when you are using your own name, it would be way to personal.” [FG Patients: Respondent 15]

“My name and personal info doesn’t need to be visible to others, to be honest.” [FG Patients: Respondent 18]

Some respondents believed it should be optional to participate anonymously. The following statements are examples.

“I think in the sense of talking about certain things, the patient must be able to decide for himself what is visible to others because these are things they post themselves. It’s just the same way with a Facebook profile. But if you make these things visible for friends of friends of friends, this would be their own choice.” [FG Nurses: Respondent 4]

“Participating anonymously should be optional to patients” [FG Patients: (also part of the client council of the MST) Respondent 24]

There were some respondents that noted that being able to participate anonymous might decrease the feeling of community forming. One respondent from the PR department explained that to make Patient-In as reliable as possible, people would need to disclose more information of themselves. However this endangers the privacy. She also explained that when Patient-In is less strictly and participants have to disclose less information about themselves, the information posted on Patient-In would be less trustworthy. She noted his was because participants would not know whom they were communicating with. The following statements come forth from this discussion.

“If you are constantly talking anonymous about things, it seems difficult to create a community.” [FG Patients: Respondent 6]

“To make it as reliable as possible, you will create certain policies and boundaries, and especially when you do this, you get close to who someone is and what someone has and that endangers the privacy. If it is completely anonymous, you don’t know who you are talking to. In that case, In my opinion, the information is less trustworthy. But if you make all kinds of rules and regulations to make it more trustworthy, then the privacy would be an issue again.” [FG PR Department: Respondent 4]

4.5.7 Creating subgroups

Some respondents noted that it could be interesting to add the option to create subgroups. One of the respondents wanted to be able to select the more serious patients on Patient-In. He explained that if Patient-In became too large with too many participants, he would lose

interest. With for example a friend button, the participants could make a selection of people they want closer contact with. The following statements come forth from that discussion.

“If there are about 100 people...if a discussion were to get out of hand because there is about a 100 people discussing and for example 80 of them are not serious and the other 20 are serious and I would like to have more contact with just them. Is it possible to make groups?”
[FG Patients: Respondent 23]

“If it gets to big you will lose interest eventually.” [FG Patients: Respondent 23]

“The you can select people you want more serious contact with, like with a friend button.”
[FG Patients: Respondent 23]

5 Conclusion

The current study set out to discover the attitude towards the system of Patient-In and to find the themes that influence the attitude. By looking at perceived usefulness of the system and its benefits and costs, advantages and disadvantages, these themes influencing the attitude towards the system emerged that either influence it positively and negatively. Respondents also came forward with suggestions for improvement of the Patient-In system.

The positive reactions towards Patient-In however were scarce in the focus groups. This is also due to the fact that it was very difficult for the respondents to form a positive opinion since the system itself and many important aspects are yet unfinished. This resulted in the view of respondents that Patient-In could only be a positive development if certain requirements and conditions were met such as monitoring or anonymous participation.

The overall ability to share experiences, information, emotions and tips on Patient-In was seen as a positive development. As mentioned in the first chapter of this research the healthcare sector has changed over the last few years. As confirmed by the respondents, the patient is becoming more and more responsible for managing their diseases, and ailments themselves because there is less and less interaction with professionals. Therefore fellow sufferers are seen as a group of ever more importance. The respondents in the current research pointed out the belief that Patient-In could help in that manner, to facilitate social support and give patients an online environment to do so.

Respondents mentioned several reasons why they thought contact between patients could be important. The communication between patients was seen as more easily accessible because of, for example, less jargon compared to communication with professionals. The subjective information that can be shared among patients is also a good addition to the professional or non-subjective information patients can gain through other sources such as folders. Patient-In could serve as a Patient-In was also seen as personal. The patients who are treated in the MST find Patient-In useful for discussing MST specific topics. Because hospitals have their own treatments, procedures and doctors, patients found Patient-In interesting to discuss these specific topics with other patients of the MST.

In contrast to only a few positive aspects of Patient-In there were many concerns mentioned that appeared to form a negative attitude towards Patient-In. The most often mentioned concerns were negative and scary stories, the posting of too much criticism towards the hospital, lack of high quality and accurate information, not achieving a critical mass of participants and privacy concerns. One of the most concerning issues was the difficulty for respondents to find the surplus value of Patient-In compared to other channels

and systems to gain health information and social support. This was evident in the discussion about the way patients seek their health information. It became clear that the respondents believed there are more than enough ways to gain health information and social support besides Patient-In. Apparently this made it hard for the potential users to see why they should make use of Patient-In instead of other websites or sources.

This issue also appears strongly connected to the construct of critical mass. Patient-In was seen as too limited because it only allows patients of the MST to participate. The users of Patient-In would also be scattered across all the different diseases and ailments that they could subscribe to as topic of interest. It was believed that other websites that are more easily accessible could offer much more information because of the expectation that these websites do not limit themselves to participants of a single hospital and therefore have more participants. Patients clearly did not see the use in participating if there were only a few participants within their own selected topic of interest.

The results show that it was believed that if there are not enough participants present on Patient-In, patients having short medical treatments might find Patient-In less useful. Patients with short-term ailments were considered to only need information in a short period of time. For them to receive social support or answers to their questions on Patient-In, there needs to be someone present within that short period of time to answer questions or offer support. This was believed to be difficult to achieve because of the focus of Patient-In on just the 264000 people within the service area of the MST. The chance of someone participating on Patient-In in that same time span was seen as highly unlikely. The idea that patients who are finished with their treatment would not return to Patient-In to discuss about it, may also add to this believe.

The quality of the shared information formed a large concern as well. There was a low expectation that the health information shared among patients on Patient-In would be trustworthy and accurate with the wrong self-diagnosis forming as a potential risk. This raised the preference of professionals monitoring and moderating Patient-In. The negativity and scary stories was, according to the respondents, one of the concerns that also required moderating. Another interesting find was that respondents actually expect the information placed on a system like patient in to be correct and true because it is facilitated by a hospital. The respondents expect it to be moderated.

A major topic for the nurse focus group proved to be the concern of negative posting or the posting of criticism about the hospital. They mentioned it could be possible to damage a doctors career or that of a nurse. They feared that, because Patient-In was linked to the MST,

patients would post their negative experiences and criticism instead of discussion about their illness or disease.

The length of the disease also seemed to be an important factor considering Patient-In to be useful or not. Patient-In was seen to be useful for chronic patients and long term patients to help to give these diseases a place in their life and also to aid to self manage their diseases. However Patient-In was seen as less interesting and useful for patients with short term ailments. This was mentioned many times, however only one reason for this was named. It appeared that for short term ailments, patients would only need information for a short time and the possibility of finding a patient having the same ailment on Patient-In to gain information from at that same period of time was seen as very unlikely. It could become difficult to create a community within these short term ailments because it was expected that people who have finished their treatment would not stay or go back to Patient-In to participate in the community. As Patient-In may be perceived as less usefulness by patients with short term diseases this may also effect the attitude and thus the eventual adoption of the system.

The last concern that proved to form a negative attitude towards Patient-In is the lack of privacy. Many respondents rather participate anonymously on Patient-In with fictive names. It was especially sensitive in combination with the publicly visible diseases and ailments one could select as topics of interest which would be visible on someone's profile. Patients considered this as the most sensitive information. However this also depends on the sensitivity of the disease. Still, it is not meant to participate anonymously on Patient-In. Patients expected that participants would use Patient-In for the wrong reasons such as patients checking other peoples accounts and profiles purely for fun and out of curiosity. This behavior was compared to the experiences the respondents had with other social media like Facebook.

The respondents also mentioned certain steps and directions the hospital could take with Patient-In, which could improve the system, and thus improve the attitude towards it. The two most frequent mentioned monitoring and doctors participation. The reasons mentioned for monitoring are; to check the accuracy and correctness of the information shared among participants and to keep negative stories and criticism in check. Doctors and health care professionals participating on Patient-In was also seen as a very interesting addition by the respondents. Patients also mentioned the ability to ask questions to doctors or start discussion topics with them as a welcome option. In addition to subjective information respondents really wanted factual information from professionals. Although some respondents

believed that it would be difficult for doctors to answer questions online before patients are correctly diagnosed.

The issue of healthcare professional participation was an important difference between the PR department group and the other groups. The PR department group believed Patient-In should be used in an entirely different approach. This group also believed it was important for health care professionals to participate on Patient-In. In fact they believed these professionals should direct their patients to Patient-In and guide their patients online in the discussions and forums. They advised that patients following a certain medical track, already being diagnosed, visiting the a health professional a few times a year, should be the patients participating. In this way they believed Patient-In could be a valuable asset for the patient. However this is not the way Patient-In is intended.

Other mentioned additions that might improve Patient-In were; additional information posted by the hospital itself, providing links to other professional websites, using patient experiences and criticism posted on Patient-In to improve service and the ability to create subgroups among patients. There was clearly a need for more professional information in addition to information and posts provided by other participants. Creating subgroups among participants was only mentioned by two respondents. They wanted to be able to invite other participants of Patient-In and compared this to “friending” someone on Facebook. This way they could select people they want closer contact with. These options can be considered implementing on Patient-In.

6 Discussion

Many of the findings in the current research correspond with finding by Dumaij and Tijssen (2010), who have also conducted their research in the Dutch health care market. One of their findings was that information gain and experience sharing are the most important positive aspects of online social support. These researchers also found that patients are feeling more and more confident to take an active role in health decision making and self-management of their diseases and ailments. The current research acknowledges this and shows that patients believe that self-management and self-help becoming more important and that online social support will empower the patients to become more responsible for their health.

As the reactions have shown, there were also many concerns while discussing Patient-In. Many of the concerns mentioned by the respondents in this research also correspond with the findings of Dumaij and Tijssen (2010) such as negative stories, whining and the difficulty for patients to assess the quality of shared information, and perceived risk in the form of privacy concerns. These concerns were mostly based on future expectations. Research by Van Uden et al. (2008) found that these issues did not occur or only in a very small percentage. Because the concerns mentioned by the respondents in the current research are mere predictions, it may be possible that they indeed will not occur on Patient-In. However the results in the current research shows that many of these expectations of the respondents relate to experiences they had with other social media or other comparable systems. This is not so strange, as the perceived usefulness of Patient-In may be based on the frame of reference that respondents formed by using other social media. However, it is yet to be seen if any of these expected scenarios will come to pass.

As for the respondents that find it difficult to find the extra value of Patient-In compared to other systems and websites already present, Van Uden-Kraan et al.(2010) mentioned the competition between online support websites to gain members. They also state that it is difficult for patients to be committed to multiple online support groups. Therefore they advise the party that wishes to start a support group to carefully check if there is room and need for a new online space for social support. Apparently the respondents in the current research did not think there was need for a system like Patient-In in its current form. If the internet is indeed saturated with online social support sites, it will become difficult for the MST to create a steady community on Patient-In.

In addition, Van Uden-Kraan et al. (2009) found that only a small amount of health related internet use by patients is either community or communication based. They report that

most patients just seek health information instead of participating in communities or communication activities. This could mean that, because MST already has a limited target group for Patient-In, only a very small percentage of this target group will actually use Patient-In as a community or for communication means. However, in the research by Van Uden-Kraan et al. (2009) the reason why these figures of participation are so low are not stated.

Perhaps the concerns and beliefs mentioned in the current research are to blame. The concerns as mentioned by the respondents may not even occur. As discussed before, research by Van Uden-Kraan et al.(2008) found that many of the feared concerns such as lack of quality and accurate information, whining, negative posting, and criticism on healthcare services rarely occur in online social support groups. Perhaps it is the fear of such disadvantages that withholds people from participating in online medical communities and online communication. Future research can perhaps show the true nature of these beliefs and find ways to prove them wrong. This may lead to more patients participating in online health communities, sharing more information and thus stimulating self-help and self-management of diseases and ailments.

The concern that Patient-In would create a portal for patients to criticize the MST and health care services is a topic that deserves some separated attention. Van Uden-Kraan et al.(2008) found that criticism on healthcare services rarely occurred. However, their research did not focus on online forums or social support systems connected to a hospital. The nurse focus group in this research mentioned that this connection may lead to patients posting their criticism on Patient-In because they expect that the hospital would read these comments. This may become a difference between easy accessible online support groups and online support groups connected to a health care organization. Future research is advised to find out if the latter online support groups generate more criticism.

Van Uden-Kraan et al. (2009) found that interaction with healthcare professionals was not commonly practiced on the internet. The researchers argue however that there are still not many possibilities for patients to do so. The current research underlines the need for these possibilities because in some cases respondents note they rather communicate with professionals online instead of fellow sufferers. Future stimulation of such systems may prove a good asset to the healthcare market.

Privacy and anonymous participation were topics that raised a lot of discussion in the focus groups. The discussion about privacy showed that most respondents would only participate on Patient-In if they were able to participate anonymously. Haines, Hough, Cao

and Haines (2012) found that if the sender of information cannot be identified, this may lead to posts being taken less serious by the readers. According to the researchers anonymous participation may also lead to more controversial ideas being shared because there are less boundaries because of social desirability. However, their research does not focus on health forums specifically.

These issues were also mentioned by the respondents in the current research. Participants like to know who is responsible for the information being posted but do not want to disclose much information about themselves. It was also mentioned that anonymity could increase negativity and criticism on Patient-In. This idea could come forth from having less boundaries because of social desirability and thus being able to speak more freely.

In the end it remains important for patients to trust a system like Patient-In. The current research has shown that the overall attitude towards a system like Patient-In is negative. If the negative concerns about the systems can be proven wrong and enough serious participants can be gathered, systems like Patient-In may prove to be a become more appreciated in the future. In this way creating strong online health communities sharing a vast amount of medical information and patient experiences to stimulate self-help and self-management for patients in the health care market.

7 Recommendations

7.1 Recommendations for the MST

For the MST it is important that their patients will eventually use Patient-In. Therefore the current research was conducted to discover the attitude towards the system. It is a positive finding that patients recognize the need for social support in a health sector in which patients are becoming more responsible and need to take a more proactive role by means such as self-help and self-management of their illness. Online social support was seen as a positive development. Yet they are not sure if Patient-In possess the right characteristics to fulfill this role.

Concerning the mentioned abundance of already present systems and websites to gain online social support and even offline abundance of face-to-face support groups it would be a good suggestion to investigate and make inventory of the social support sites and systems already present for each disease. This way, the MST will know if there is room and need for more online support groups concerning specific diseases.

There are some choices that have to be made concerning Patient-In concerning topics such as monitoring and privacy settings. Although many respondents would only participate anonymously, it is expected side effects such as more criticism, whining and more controversial ideas may occur. Patients seemed to have difficulties with the information that needs to be disclosed if they want to participate. Especially the combination of the name and the diseases or ailment a participant selects as topics of interest was seen as very sensitive. In order to prevent too much negativity and criticism it is a good decision to make patients participate with their own names visible. This may decrease the amount of criticism and negativity and may also see to it that the patients who are most serious about seeking social support will participate. However, to make the disclosure of information on Patient-In less sensitive, filling in the topics of interest should be made optional. Also the sharing of other personal information on someone's profile should be made optional. Carefully moderating and monitoring in the pilot stage is advised in combination, to regularly check the way participants communicate with each other. . It is also wise to create a disclaimer about norms and rules about how participants should communicate on Patient-In. Also to create extra awareness that most communication on Patient-IN is patient-to-patient and that participants must appraise this in that manner.

Healthcare professional participation is also good to implement. The combination of subjective and factual information may give Patient-In an extra dimension and in the current research it proved very welcome. However if the MST really want to offer Patient-In for all

diseases and ailments this might prove unfeasible. Several specialists from many different departments would have to participate and they must be able and willing to participate. Perhaps it is interesting to implement this for only a few departments or very common diseases in the initial pilot phase to test this.

Another wise addition to also gain more initial participants is to fill Patient-In with professional information, links to other websites and information about the treatments within the hospital itself on each topic of interest the participants can subscribe them to. Respondents mentioned they did not see the surplus value compared to other online social support groups. Providing these assets may have several effects. Initial participants must be drawn in using this information. It will give them something to initially visit Patient-In for. With links to other professional websites the MST will show a form of professionalism by having contacts with other important healthcare parties. These links also increase trustworthiness of the information posted on Patient-In. With MST information about treatments, doctors and departments, the MST will create an online room to discuss these MST specific issues which is not present on other websites. Perhaps even post videos and let doctors participate on the system. Hopefully this may help to achieve a critical mass so that Patient-In might become and stay active and lively.

7.2 Recommendations for future research

All in all, a lot of aspects forming the attitude towards Patient-In are discussed. They tend to be more negative instead of positive. However, most negative aspects are based on expectations that have yet have to occur. Research has mentioned low participation rates for online social support groups in the Netherlands (Uden-Kraan et al., 2009). Perhaps the negative concerns mentioned in this research are to blame. Future research investigating ways to free people of these expectations might find answers to get more patients involved in online social support groups.

Concerning research in hospital initiated online support groups, research in effective ways of monitoring, doctors participation and negativity/criticism control is advised. Because apparently hospitals are expected to present accurate and correct information on a website, even if it is a social support websites on which the information is provided by other patients, this may prove important. Also research concerning the differences of patients assessing information provided on a hospital initiated social support site and other social support websites might be interesting to investigate.

In the current research only few respondents with experience with social support. This may explain why, in many focus groups, the respondents placed the focus on the informational aspect of social support and not the emotional side of social support. Some respondents mentioned they did not feel the need to speak to other about their diseases. There were some respondents who, for example, were considered patient but were not involved with the hospital for several years anymore. Perhaps respondents who are chronically ill or feel more need for emotional social support could have had different perspectives. Perhaps research focusing on actual users of a hospital initiated social support group site, perhaps future research of Patient-In, might confirm the findings or find that the expected issues such as critical mass and criticism which could damage hospital reputation do not occur. Other advised research would be to find out if there is different use of social support online between short-term ailments or diseases and long-term/chronic ailments or diseases.

The current research does know some limitations. The first limitation of the current research resides in the fact that the researcher did not form transcripts from the gathered audio tapes. This was chosen because of time constraints. The researcher selected the primary topics and quotes, directly from the audio tapes. This may have caused a less accurate overview of the 500 minutes of audio although every audio tape was at least listened to 5 times.

A second limitation has to do with the interpretation of the statements. Considering every statement was interpreted while analyzing the audio, there is always a chance of misinterpretation of a certain statement. The research and focus groups were done by a single researcher who had no prior experience with focus groups or even interviews. Therefore the researcher may also lack the experienced competence of interpreting focus group data. The quotes were also translated from Dutch to English and this proved difficult in some cases. Sometimes the context or the order of the quote had to be changed to keep it understandable, though changing the context is also dangerous if the interpretation may not be correct.

The final limitation has to do with fact that the respondents only had a relatively short time to form the attitude discussed in this research. The prototype was only shown 10 minutes and it was even far from finished. Therefore the it is logical that the respondents could only form a very shallow attitude towards the attitude object which is Patient-In. If they were more familiar with Patient-In and if it was more complete, more attitude influencers could have been gathered from this research. Perhaps future research with participants that already formed an implicit attitude towards a hospital initiated social support website can offer different findings.

8 Literature

Adelman, M. B. & A. C. Ahuvia (1995), Social Support in the Service Sector: The Antecedents, Processes, and Outcomes of Social Support in an Introductory Service. *Journal of Business Research*, 32 (3), 273-282.

Ahmad, F., Hudak, P.L., Bercovitz, K., Hollenberg, E., & Levinson, W. (2006). Are physicians ready for patients with Internet-based health information? *Journal of Medical Internet Research*, 8 (3) , pp. 8P.

Ajzen, I., Fishbein, M. (1975). *Belief, Attitude, Intention, and Behavior: An Introduction of Theory and Research*. Addison-Wesley, Boston, MA.

Barnes, M. K., & Duck, S. (1994). Everyday communicative contexts for social support. In B. Burlinson, T. Albrecht, & I. G. Sarason (Eds.), *Communication of social support: Messages, interactions, relationships and community*. Thousand Oaks, CA: Sage.

Bansal, G., Zahedi, F.M., & Gefen, D. (2010) The impact of personal dispositions on information sensitivity, privacy concern and trust in disclosing health information online. *Decision Support Systems*, 49(2), 138-150.

Bambina, A. (2007). Online social support: the interplay of social networks and computermediated communication: Cambria Press.

Barrera Jr., M., Glasgow, R.E., McKay, H.G., Boles, S.M., & Feil, E.G. (2002). Do internet-based support interventions change perceptions of social support?: An experimental trial of approaches for supporting diabetes self-management. *American Journal of Community Psychology* 30 (5), 637-654.

Boyd, D. M., & Ellison, N. B. (2007). Social network sites: Definition, history, and scholarship. *Journal of Computer-Mediated Communication*, 13(1).

Butler, B.S. (2001). Membership Size, Communication Activity, and Sustainability: A Resource-Based Model of Online Social Structures. *Information Systems Research* 12 (4), 346-362.

Chan, C. M. L., Bhandar, M., Oh, L.-B. and Chan, H.C. (2004). Recognition and Participation in a Virtual Community. *Proceedings of the 37th Hawaii International Conference on System Sciences, Hawaii, USA*.

Cline, R.J.W., & Haynes, K.M. (2001). Consumer health information seeking on the internet: the state of the art. *Health Education Research* 16 (6) , 671-692.

Coffield, R.L., & Joiner, J.E. (2010). Risky business: Treating tweeting the symptoms of social media. *AHLA Connections*, 14(3):10-4.

Davis, F.D. (1989), Perceived usefulness, perceived ease of use, and user acceptance of information technology. *MIS Q.* 13(3), 319–340.

Demiris, G. (2006). The diffusion of virtual communities in health care: concepts and challenges. *Patient Educ Couns*, 62(2):178-88. : [doi:10.1016/j.pec.2005.10.003](https://doi.org/10.1016/j.pec.2005.10.003)

Dumaij, A.C.M., & Tijssen, E.C.G. (2010). On-line Health Companion Contact among chronically ill in the Netherlands. *Health and Technology I* (1), 5-23. doi: 10.1007/s12553-011-0003-2

Eysenbach, G., Powell, J., Englesakis, M., Rizo, C. & Stern, A. (2004). Health related virtual communities and electronic support groups: systematic review of the effects of online peer to peer interactions. *BMJ*, 328(7449), 1166. [doi:10.1136/bmj.328.7449.1166](https://doi.org/10.1136/bmj.328.7449.1166)

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. *British Medical Journal*, 324 (7337), 573-577.

Eysenbach, G. (2000). Consumer health informatics. *BMJ*, 320, 1713-1716.

Fox, S., & Jones, S. (2009). The Social Life of Health Information. Pew Research Center's Internet & American Life Project. Retrieved from <http://www.pewinternet.org/Reports/2009/8-The-Social-Life-of-Health-Information.aspx>.

Groot de, M.J.A.M. (2010) Playing doctor: the risks of seeking health-information on the internet.

Haines, R., Hough, J., Cao, L., & Haines, D. (2012). Anonymity in Computer-Mediated Communication: More Contrarian Ideas with Less Influence. *Group Decision and Negotiation*, 1-22, Article in Press.

Heidelberger, C.A., El-Gayar, O., & Sarnikar, S. (2011). Online Health Social Networks and Patient Health Decision Behavior: A Research Agenda. *System Sciences (HICSS), 2011 44th Hawaii International* 4-7 Jan. 2011 (1-7). doi: [10.1109/HICSS.2011.328](https://doi.org/10.1109/HICSS.2011.328)

Hoadley, C. M., & Kilner, P. G. (2005). Using technology to transform communities of practice into knowledge-building communities. *ACM SIGGROUP Bulletin*, 25(1), 31–40. ACM.

Kaplan, A.M., & Haenlein, M. (2010). Users of the world, unite! The challenges and opportunities of Social Media. *Business Horizons*, 53(1) , 59-68. [:doi:10.1016/j.bushor.2009.09.003](https://doi.org/10.1016/j.bushor.2009.09.003)

Lewis, K., Kaufman, J., & Christakis, N. (2008). The taste for privacy: An analysis of college student privacy settings in an online social network. *Journal of Computer-Mediated Communication, 14*(1), 79-100.

Madara, E.J. (1997). The mutual-aid self-help online revolution. *Social policy, 27*, 20-26.

McNabb, C. (2009). What social media offers to health professionals and citizens. *Bulletin of the World Health Organization, 86*, 566-566. doi: 10.2471/BLT.09.066712

Sanchez Abril, P., & Cava, A. (2008). Health Privacy in a Techno-Social World: A CyberPatient's Bill of Rights. *Northwestern Journal of Technology and Intellectual Property, 6*(3), 244-277.

Shen, A.X.L., Cheung, C.M.K., Lee, M.K.O., & Chen, H. (2009). How social influence affects we-intention to use instant messaging: The moderating effect of usage experience. *Information Systems Frontiers, 13*(2), 157-169.

Sledgianowski, D. & Kulviwat, S. (2009). Using Social Network Sites: The Effects Of Playfulness, Critical Mass and Trust In A Hedonic Context. *Journal of Computer Information Systems, 49*(4), 74-83.

Soe, L. & Markus, M.L. (1993). "Echnological or Social Utility? Unraveling Explanations of Email, Vmail, and Fax Use," *The Information Society, 3*(9), 231-236.

Walther, J. B., & Boyd, S. (2002). Attraction to computer-mediated social support. In C. A. Lin & D. Atkin (Eds.), *Communication technology and society: Audience adoption and uses*. Cresskill, NJ: Hampton Press.

van Uden-Kraan, C.F., Drossaert, C.C., Taal, E., Smit, W., Moens, H.J.B., Siesling, S., Seydel, E.R., & van de Laar, M.A.F.J. (2009). Health-related Internet use by patients with somatic diseases: Frequency of use and characteristics of users. *Informatics for Health and Social Care, 34* (1), 18-29.

van Uden-Kraan, C.F., Drossaert, C.H.C., Taal, E., Lebrun, C.E.I., Drossaers-Bakker, K.W., Smit, W.M., Seydel, E.R., & van de Laar, M.A.F.J. (2008). Coping with somatic illnesses in online support groups: Do the feared disadvantages actually occur? *Computers in Human Behavior, 24* (2), 309-324.

van Uden-Kraan, C.F., Drossaert, C.H.C., Taal, E., Seydel, E.R., & van de Laar, M.A.F.J. (2010). Patient-initiated online support groups: Motives for initiation, extent of success and success factors. *Journal of Telemedicine and Telecare, 16* (1) , 30-34.

Van Slyke, C., Ilie, V. & Lou, H. (2007). Perceived critical mass and the adoption of a communication technology. *European Journal of Information Systems, 16*, 270-283.

Wang, Y.C., Kraut, R., & Levine, J.M. (2012). To Stay or Leave? The Relationship of Emotional and Informational Support to Commitment in Online Health Support Groups. *CSCW 2012 Proceedings*, 833-842. doi>[10.1145/2145204.2145329](https://doi.org/10.1145/2145204.2145329)

White, M., & Dorman, S.M. (2001). Receiving social support online: Implications for health education. *Health Education Research* 16 (6) , 693-707.

Wright , K.B., & Bell, S.B. (2003) Health-Related Support Groups on the Internet: Linking Empirical Findings to Social Support and Computer-Mediated Communication Theory. *Journal of Health Psychology*, 8(1), 39–54.

9 Appendix

A: Invitation letter for the focus groups.

Medisch Spectrum Δ Twente



Bezoekadressen
 Δ Ariënsplein 1
Telefax (053) 4873071
 Δ Haaksbergerstraat 55
Telefax (053) 4873072

Postbus 50000
7500 KA Enschede
Telefoon (053)4872000

De ontvanger van deze brief

Enschede

Maart 2012

Uw kenmerk

Ons kenmerk

uitnodiging discussiegroep

Geachte heer / mevrouw,

Graag willen wij u middels deze brief uitnodigen voor deelname aan een onderzoek omtrent social media georganiseerd door Medisch Spectrum Twente (MST).

Social Media

MST gaat met de tijd mee. Ook op het gebied van sociale media wil het ziekenhuis vooruitstrevend zijn. MST ontwikkelt momenteel een eigen social medium voor patiënten genoemd Patiënt-In. Het doel van Patiënt-In is een online sociaal netwerk te creëren waar MST patiënten onderling met elkaar kunnen communiceren omtrent medische zaken en specialisten.

Patiënt-In

Om Patiënt-In te optimaliseren en ervoor te zorgen dat het een sociaal medium wordt waar patiënten graag gebruik van gaan maken zijn wij benieuwd naar uw mening als potentieel gebruiker. Doel van het onderzoek is dan ook om na te gaan wat de wensen van de patiënt zijn omtrent dit medium. Om u als patiënt een kans te geven uw mening te delen worden er een zestal bijeenkomsten georganiseerd.

Graag nodigen wij u uit voor één van deze bijeenkomsten die worden gehouden in MST. De bijeenkomsten nemen ongeveer anderhalf uur in beslag. Voor koffie / thee wordt gezorgd. Elke deelnemer ontvangt een VVV- bon ter waarde van €10,-.

Programma

Thema: Patient-In: Sociaal medium voor patiënten

- voorstelronde;
- bespreken ervaringen met MST;
- presentatie prototype Patiënt-In;
- bespreken Patiënt-In;
- afsluiting.

Reageren

Om de voorbereidingen voor deze bijeenkomst in goede banen te leiden, verzoeken wij u uiterlijk vrijdag 23 maart 2012 aan ons door te geven of u wenst deel te nemen aan één van de zes bijeenkomsten. U kunt zich aanmelden door het sturen van een e-mail naar l.hulskers@mst.nl waarin u aangeeft:

Naam;
Geslacht;
Geboortedatum;
Voorkeur datum en tijd bijeenkomst;

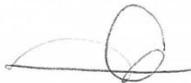
Datum	Tijd
1 Woensdag 28 maart	15:00 - 16:30 uur
2 Woensdag 28 maart	19:00 - 20:30 uur
3 Donderdag 29 maart	20:00 - 21:30 uur
4 Vrijdag 30 maart	12:15 - 13:45 uur
5 Woensdag 4 april	19:00 - 20:30 uur
6 Donderdag 5 april	19:00 - 20:30 uur

Om een goede mix deelnemers aan de bijeenkomsten te bereiken, vragen wij u aan te geven welke poli u regelmatig in het MST bezoekt.

U ontvangt uiterlijk 26 maart 2012 een e-mail of u bent uitgenodigd voor één van de bijeenkomsten en op welke locatie u zich moet melden.

Wij vertrouwen er op met deze uitnodiging en korte uitleg uw interesse om deel te willen nemen aan één van de zes bijeenkomsten te hebben gewekt en zien uw reactie graag tegemoet. Voor eventuele vragen kunt u mailen naar l.hulskers@mst.nl of bellen naar 06 23 07 04 46.

Met vriendelijke groet,



Leslie Hulskers
Stagiaire Afdeling Public Relations & Patiëntenvoorlichting

B: Focus group script.

Introductie (5 min)

- *Welkomstwoord*
- *Voorstellen van de gespreksleider*
- *Uitleggen waarom dit onderzoek*
- *Uitnodigen om alle ideeën, meningen en persoonlijke ervaringen te delen. Wat vindt u belangrijk, wat zijn uw ideeën, bedenkingen en vooral suggesties?*
- *Wat kunnen de deelnemers verwachten?*
- *Rol van de gespreksleider uitleggen. Het is goed als u zoveel mogelijk onderling discussieert. De discussieleider is er alleen om het tempo erin te houden en af en toe te sturen. Er zijn geen goede of foute antwoorden. Het gaat erom wat u vindt en waarom u dat vindt?*
- *Er wordt (anoniem) verslag gemaakt van de bijeenkomst en vermelden dat er een bandopname wordt gemaakt.*
- *Op basis van de groeps gesprekken (in totaal doen we ... gesprekken) maken we een verslag en bespreken we welke relevante implicaties we kunnen gebruiken.*
- *Als u belangstelling heeft kunt u een eindverslag krijgen. Noteren na afloop focusgroep.*
- *Heeft u nog vragen voor we beginnen?*

Eerste deel gesprek (meer gericht op eerdere ervaringen) (15 min)

Organisatie (MST)

- *Wat zijn de ervaringen van patienten met het Medisch Spectrum Twente?*
- *Nadere toelichting*

Social Media

Algemene openingsvraag:

- *Hebben de deelnemers eerder of maken ze momenteel nog steeds gebruik van social media?*

Verdieping:

- *Welke Social Media gebruikt u?*
- *Welke overwegingen nam u toen u wel of niet besloot deel te nemen aan deze Social Media?*
- *Wat zijn de voornaamste redenen waarom u ervoor heeft gekozen om zich aan te melden voor een of gebruik te maken van deze Social Media?*

Social Support groepen

Algemene openingsvraag:

- *Heeft u eerder gebruik gemaakt van sociale support groepen (zowel offline als online, bijv patiëntenverenigingen, bijeenkomsten, forums etc.)?*

Verdieping:

Wat is de voornaamste reden geweest om deel te nemen aan sociale support groepen?

- *Wat waren uw verwachtingen van de social support groep? In welke behoefte moest de social support groep voorzien?*
- *Wat zijn de positieve/ negatieve ervaringen hiermee?*

Introductie Patient-In (prototype) (10 a 15 Min)

1. Inlog scherm

2. *Gebruikersprofiel*
3. *Dashbord*
4. *Beoordelingen*
5. *Groepen*
6. *Aandoeningen*
7. *Berichten*

Tweede deel gesprek (60 Min)

Eerste indruk

Algemene Openingsvraag:

Wat is de eerste indruk van Patient-In?

Verdiepingvragen

• Hoe zou de patiënt in één woord Patient-In omschrijven? Indien noodzakelijk een aantal voorbeelden noemen: Handig, functioneel, bruikbaar, professioneel, innovatief etc.

Bruikbaarheid

Algemene openingsvraag: Hoe staat de patiënt tegenover een technologie als Patient-In? (Attitude)

Verdieping:

- Wat vindt de patiënt het voordeel aan een technologie als Patient-In?*
- Zou de patiënt zelf gebruik maken van een technologie/ sociale media als Patient-In?*
- Wat zou voor patiënten de voornaamste reden zijn van gebruik van Patient-In?*
- Hoe staat de patiënt tegenover een technologie als Patient-In?*
- Welke functionaliteiten zou de patiënt voornamelijk gebruiken?*
- Met welk doel zou de patiënt deze functionaliteiten voornamelijk gebruiken?*
- Zijn er nog bepaalde functionaliteiten die ontbreken op Patient-In?*
- Wanneer denken patiënten gebruik te maken van Patient-In?*
- Eventueel voorbeelden noemen: Slechts bij informatie behoefte, bij behoefte aan social support, sociaal contact, etc.*
- Wat nemen patiënten mee in hun overweging om wel dan wel niet gebruik te maken van Patient-In? (voorbeelden:*
- Ziet de patiënt nog negatieve aspecten van Patient-In of bij het gebruiken van Patient-In?*

Informatie zoekgedrag

• Welke middelen gebruikt de patiënt momenteel om aan medische informatie te komen?
- Voorbeelden: Folders, google, via kennissen en vrienden, mede patiënten, patiëntenverenigingen.

Verdieping:

• Vinden de patiënten het eenvoudig om de informatie te vinden die zij normaalgesproken zoeken?

Zou Patient-In ook door de patiënt gebruikt worden om aan informatie te komen en zo ja, welke soort medische informatie?

• Wat vindt men van de kwaliteit van de informatie die men vindt en hoe beoordelen ze deze informatie?

• Kan Patient-In andere bestaande kanalen vervangen in de behoefte aan informatie en social support?

• Wat denkt u dat de kwaliteit is van de medische informatie die u op Patient-In denkt aan te treffen?

Sociale aspect (Community forming)

- *Algemene openingsvraag: Kan Patient-In uitgroeien als community?*

Verdieping:

- *Zou “de behoefte aan contact” op zich een reden kunnen zijn om voor de patiënten om deel te nemen.*
 - *Let de patiënt ook naar het aantal deelnemers aan Patient-In en welke rol kan dit spelen?*
 - *Welk soort social support zoekt de patiënt? Uitleg aandoening/ behandeling, uitlaat klep voor problemen, ervaringen andere patiënten, sociaal contact met andere patiënten?*
- Scenario:*
- *Stel dat andere bekenden van de patiënt gebruik maken Patient-In, kan dit een reden zijn om zelf ook gebruik te maken van Patient-In.*

Privacy en vertrouwen in andere gebruikers/organisatie

Algemene openingsvraag: Welke informatie zouden mensen voornamelijk op hun profiel zetten?

Verdieping:

- *Wie mag wat zien? Wat wil men het liefst afgeschermd hebben voor bepaalde personen?*
- *Welke informatie zouden mensen voornamelijk op hun profiel zetten?*
- *Neemt de patiënt het feit dat bepaalde informatie te zien is door andere gebruikers, mee in zijn overweging om gebruik te maken van Patient-In?*
- *Wat zou u ervan weerhouden persoonlijke informatie te plaatsen Patient-In?*
- *Heeft u als potentieel gebruiker van Patient-In vertrouwen in de medegebruikers op Patient-In?*
- *Verwacht de patiënt dat de organisatie (MST) uw informatie en persoonlijke gegevens kan beschermen wanneer hij deelneemt aan patiënten?*

Afsluiting (5 Min)

- *Stel u bent deel van het team dat Patient-In ontwikkeld. Wat zou u veranderen, toevoegen of anders doen?*

Samenvatting en conclusie

- *Samenvatting van de vragen.*
- *Hebben we iets niet gevraagd vandaag?*

Afsluiting en dankwoord

C: Screenshots prototype Patient-In as shown in the focus groups

Opening screen Patient portal

The screenshot shows the opening screen of the Medisch Spectrum Twente Patient portal. At the top, there is a navigation bar with icons for Home, Vergroten, Geluid, E-mail, Printen, Thema, and Inloggen. Below this is a large green header with the text "Medisch Spectrum Twente" and a search bar. A secondary navigation bar contains links for Home, Patient, Bezoeker, Wachttijden, Kinderen, Professionals, Faciliteiten, and De organisatie. Below this is a menu with tabs for Aandoening, Behandelingen, Poliklinieken, and Specialisten. The main content area is divided into three columns: "Aandoening" (with a dropdown menu for "Ank" and a "Meer aandoeningen..." link), a list of services (Afspraken, Route, Bezoekuren, Registreer, Wachttijden, Mijn medicatie, Mijn dossier, Vragen), "Nieuws" (with three news items), "Persberichten" (with three news items), and "Agenda" (with three agenda items). At the bottom, there are three buttons: "alle nieuws artikelen", "alle persberichten", and "alle agendapunten".

Home Vergroten Geluid E-mail Printen Thema Inloggen

Medisch Spectrum Twente

Home Patient Bezoeker Wachttijden Kinderen Professionals Faciliteiten De organisatie

Aandoening Behandelingen Poliklinieken Specialisten

Aandoening
Selecteer een aandoening uit de lijst.
Ank
Meer aandoeningen...

- Afspraken
- Route
- Bezoekuren
- Registreer
- Wachttijden
- Mijn medicatie
- Mijn dossier
- Vragen

Nieuws

Nieuw afdelingshoofd radiologie
Lorem ipsum dolor sit amet, consectetur adipiscing elit...

Patienten zijn positief over het MST
Aliquam erat volutpat. Vestibulum gravida congue uma sed...

De kunst van het bloedsuiker meten
Dolor sit amet, consectetur adipiscing elit. Etiam non libero urna...

Persberichten

Zorg traumapatiënt stopt niet meer bij de grens
8 juni 2010

Versorgung von Traumapatienten endet nicht mehr an der Grenze
8 juni 2010

Stemmen Tweede Kamerverkiezingen in Medisch Spectrum Twente
2 juni 2010

Agenda

27 mei 2010
Avondsymposium Vrouw Kind Centrum

25 mei 2010
Voorlichtingsavond prostaatkanker in MST

10 juni 2010
Symposium Trends in Trauma: Über die Grenze

alle nieuws artikelen alle persberichten alle agendapunten

Login screen Patient-*In*

Start Hoe werkt PatientIN

Gebruikersnaam: Wachtwoord: [Wachtwoord vergeten](#)

80% van onze patiënten gebruikt PatientIN

Meer dan: ✓ **30 000 leden**
✓ **2 000 arts beoordelingen**
✓ **200 000 connecties**

[Lees meer over PatientIN](#) →

Maak GRATIS een account aan

Gebruikersnaam:
Email:
Wachtwoord:

Patient recenties [Lees meer recenties](#)

Ed posuere diam lacus quis leo. Integer eu urna sit amet mi ultrices convallis sit amet ut lorem. Quisque magna magna, aliquam eu blandit non, accumsan a ante. Vivamus a hendrerit nibh. Pellentesque laoreet adipiscing ultrices.

Eliam elit nisi, lacinia et sagittis a, malesuada pulvinar nunc. Phasellus lobortis libero id velit.

— Omare Dictum, 21 November 2011

1 2 3 4 5

Gereed Lokaal intranet 100%

The page to add and adjust profile information

Jan Berichten (3) Instellingen Help Uitloggen

PatientIN

Dashboard Nieuwe beoordeling Groepen Aandoeningen

Gebruikers profiel

Algemene informatie

Naam
Leeftijd
Geslacht
Nationaliteit
Aandoening
Gebruikersnaam
Email
Tel. nummer
Interesse gebieden

Profiel foto

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Lokaal intranet 100%

Personal Dashboard

Jan Wijnand Hoek Berichten (3) Instellingen Help Uitloggen

Dashboard Nieuwe beoordeling Groepen Aandoeningen

Jan

Let op: U heeft nog 1 arts beoordeling open staan. [Wil hem hier in!](#)

Plaats foto hier

Activiteiten (65%)

- ✓ Profiel foto uploaden
- ✓ Interesse gebieden aangeven
- ✗ Arts beoordelen (1/2)
- ✓ Connectie toevoegen

Jouw interesse gebieden

1. Acute blindedarmonsteking
2. Hartfalen
3. Open been

Jouw laatste reacties

1. Welke medicijnen?
2. Wordt dit vergoed door de ZV?
3. Bezoekuren

Algemene mededelingen MST

1. MST en Saxion organiseren symposium ...
2. Marianne Lensink medeondertekent char ...
3. wenkse samenwerking in de gynaecologis ...
4. Medisch Spectrum bvente besteld derde MRI

Lees meer MST mededelingen

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Review page

Dashboard Nieuwe beoordeling Groepen Aandoeningen

Beoordeling behandeling

Afdeling: -- Selecteer --
 Arts: -- Selecteer --
 Datum / tijd:

Algemeen Waardering Geen mening

Was er voldoende tijd en aandacht voor u?

Welk cijfer geeft u het resultaat van de behandeling?

Was er voldoende en juiste nazorg?

Afspraak Waardering Geen mening

Verliep het maken gemakkelijk?

Was de afspraak volgens de juiste tijd?

Arts Waardering Geen mening

Welk cijfer geeft u de deskundigheid van de arts?

Was er voldoende respect voor u als patient?

Was de informatie/uitleg van de arts begrijpelijk?

Overige

Overige opmerkingen:

Verwacht u een reactie n.a.v. deze beoordeling? Ja Nee

Zichtbaarheid beoordeling?

Verstuur

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Groups and discussions


PatientIN

Dashboard
Nieuwe beoordeling
Groepen
Aandoeningen

Groepen

Algemene onderwerpen

Algemeen	Laatste reactie	Aantal reacties
<input checked="" type="checkbox"/> Parkeergelegenheid	Door: Wouter (02-07-2011 (21:04))	23
<input checked="" type="checkbox"/> Restaurant mogelijkheid	Door: Marleke (27-07-2011 (18:49))	65
<input checked="" type="checkbox"/> Bezoeken	Door: Rob (20-10-2011 (19:22))	34

[... Bekijk alle algemene onderwerpen](#)
+ Nieuw onderwerp

Interesse gebieden

Acute blindedarmontsteking

	Laatste reactie	Aantal reacties
<input type="checkbox"/> Buikpijn	Door: Annette (16-11-2011 (00:03))	35
<input type="checkbox"/> Welke medicijnen?	Door: Rene (07-09-2011 (05:42))	18
<input type="checkbox"/> Kan ik wel blijven werken?	Door: Connie (10-08-2011 (19:30))	3

[... Bekijk alle aandoeningen in "Acute blindedarmontsteking"](#)
+ Nieuw onderwerp

Enkel versteking

	Laatste reactie	Aantal reacties
<input type="checkbox"/> Hoe lang kan he duren?	Door: Connie (11-05-2011 (04:59))	9
<input type="checkbox"/> Is dit te voorkomen?	Door: Tom (31-03-2012 (02:19))	56
<input type="checkbox"/> Wordt dit vergoed door de ZV?	Door: Veronique (26-12-2011 (04:29))	43

[... Bekijk alle aandoeningen in "Enkel versteking"](#)
+ Nieuw onderwerp

Hartvaten

	Laatste reactie	Aantal reacties
<input type="checkbox"/> Hoe gaat het onderzoek in zn werk?	Door: Veronique (19-04-2011 (11:27))	34
<input type="checkbox"/> Zijn en complicaties?	Door: Anneke (29-11-2011 (22:29))	23
<input type="checkbox"/> Hoe lang moet je in het ziekenh...	Door: Jan Wijnand (12-09-2011 (22:10))	47

[... Bekijk alle aandoeningen in "Hartvaten"](#)
+ Nieuw onderwerp

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Page to subscribe to an ailment or disease


Berichten (3)
Instellingen

Help
Uitloggen


PatientIN

Dashboard
Nieuwe beoordeling
Groepen
Aandoeningen

Aandoeningen

All
A
B
C

A

Aambeien	Naar het onderwerp	⌵
Ablatie	Naar het onderwerp	⌵
Achillespees - Achillespeesruptuur	Naar het onderwerp	⬢
Actinische keratose	Naar het onderwerp	⌵
Acute blindedarmontsteking	Naar het onderwerp	⌵
Afweesklier - Acute afweesklierontsteking	Naar het onderwerp	⌵
Angina pectoris	Naar het onderwerp	⌵
Angiografie	Naar het onderwerp	⌵
Antegrade pyelografie	Naar het onderwerp	⌵
Anticonceptie	Naar het onderwerp	⌵

B

Baarmoederhalskanker	Naar het onderwerp	⌵
Baarmoederkanker	Naar het onderwerp	⌵
Baarmoederverwijdering	Naar het onderwerp	⬢
Baarmoederverwijdering bij een verzakking	Naar het onderwerp	⬢
BAEP-onderzoek	Naar het onderwerp	⌵
Barbotage schouder	Naar het onderwerp	⌵
Basaalcarcinoom	Naar het onderwerp	⌵

Filter

Lichaams categorie

- Armen en handen
- Benen en voeten
- Borst
- Bloed
- Buk

Specialisme

- Algemeen chirurgie
- Allergologie
- Apotheek
- Ergotherapie
- Fertiliteit

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Messages page

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Dashboard Nieuwe beoordeling Groepen Aandoeningen

Berichten

- Postvak in
- Verzonden items
- Prullenbak
- Mijn connecties

Postvak in [Stuur nieuw bericht](#)

Van	Onderwerp	Datum / tijd		
<input type="checkbox"/> Stefan	Curabitur accumsan	25-05-2011 (01:04)	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Willem	Praesent a lacus diam, plac	07-04-2011 (06:04)	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Annette	Praesent a lacus diam, pl	02-01-2012 (21:03)	<input type="checkbox"/>	<input type="checkbox"/>

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User profile

Jan Berichten (3) Instellingen Help Uitloggen

Dashboard Nieuwe beoordeling Groepen Aandoeningen

Gebruikers profiel

[Bewerk profiel](#)

Algemene informatie

Naam: Jan
Leeftijd: 19
Geslacht: Man
Nationaliteit: Nederlands
Aandoening:
Gebruikersnaam: Jan

Contact informatie

Email:
Tel. nummer: 06

Interesse gebieden

- Acute blindedarmontsteking (3)
- Enkel verstuijing (3)
- Hartvaten (7)

[Connecties](#)
[Blogs](#)

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