# eHealth literacy 2.0 of patients with rheumatic diseases

**Miriam de Heus**
**University of Twente**
**Master of New Media and Communication**
**Enschede, the Netherlands**
**Supervisors: Constance H.C. Drossaert, Rosalie van der Vaart, Erik Taal**
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## Abstract

### Background

Health 2.0 offers various opportunities to facilitate self-management of patients with a rheumatic disease. However, a sufficient level of eHealth literacy is necessary to be able to take full advantage of the possibilities. Previous research focused on skills necessary for the use of Health 1.0. Insight in skills related to the use of Health 2.0 is still lacking.

### Objective

The aim of this study is to provide insight into the level of eHealth literacy of patients with rheumatic diseases and the problems they experience when using Health 2.0.

### Methods

A scenario-based performance test was conducted by 16 patients with rheumatic diseases. The test consisted of ten tasks with five applications in a patient portal, a patient support discussion board and a health care rating website. Participants were asked to think aloud and screen activity was recorded.

The participants were interviewed after completing their tasks. Completion, performance, required time and encountered problems were measured and coded by two independent researchers. All actions and problems of patients were coded and categorized bottom-up in main and sub categories.

### Results

Most patients could complete more than half of the tasks; however many participants possessed insufficient skills to take full advantage of all possibilities of Health 2.0. A large diversity in eHealth literacy skills was observed. However, all patients encountered multiple problems in the following categories of skills: operating the computer and Internet, orienting and navigating on the web, searching for health information and applications and evaluating relevance and reliability. Additionally, two new categories, essential for Health 2.0, were included: adding personal health content and protecting privacy.

### Conclusions

Although Health 2.0 is promising for self-management, a number of patients with rheumatic diseases is not able to take full advantage of Health 2.0. Instruction and guidance are essential to optimize the use of Health 2.0 applications. These instructions could be given in a course or in the applications themselves and should focus on evaluating relevance and reliability, adding personal health content and protecting privacy. The results of this study may help to extend existing eHealth literacy scales to be able to measure the level of eHealth literacy for the use of Health 2.0. The results also provide directions for future research about predictors of eHealth literacy.



**Keywords:** eHealth literacy, Health 2.0, Internet, online, skills, rheumatic diseases

# 1 Introduction

It is estimated that one in ten Dutch adults has chronic rheumatic symptoms. Rheumatic diseases include more than hundred types of diseases which affect the joints and connective tissues. It can significantly impact quality of life and the possibility to participate fully in society; for example, being unable to hold a paid job and the strain of medical and non-medical costs (Janssen, 2006). Self-management can make a difference in the influence a rheumatic disease has on a patients' daily life. Self-management is the capability of patients to handle symptoms, treatment, physical and social consequences of a disease by adjusting their behavior and lifestyle (Baardman, De Booys, Heldoorn, & Meulmeester, 2009).

Patients with rheumatic diseases are increasingly encouraged to take more responsibility for their own treatment, and share decision-making with their health care professionals. Besides possessing skills for problem-solving, the motivation to take responsibility and belief that they have the skills to manage their disease, having access to information is essential to be able to perform self-management (Alpay, Blankson Henkemans, Otten, Rövekamp, Dumay, 2010; Baardman et al., 2009). Information is needed for self-management by enabling patients to have a better understanding of their own health condition, to know the consequences of their behavior, to make informed choices and to know how they can improve their skills (Baardman et al., 2009).

## 1.1 Growing possibilities Internet

The Internet offers a rising number of possibilities to facilitate and stimulate self-management of patients with a chronic disease. eHealth is associated with positive consequences for patients: it enables patients to become more active in managing their own disease (Baardman et al., 2009; Dedding, Van Doorn, Winkler & Reis, 2011; Van der Vaart, Drossaert, Taal & Van de Laar, 2010); may improve empowerment (Baardman et al., 2009; Frissen, 2010; Heldoorn, 2008); patients share information more easily with others in their surroundings (Frissen, 2010); patients may be better equipped to make informed choices (Baardman et al., 2009); and it could raise the quality of life and care (Heldoorn, 2008). It is expected that using the Internet has positive consequences for health care in general through more efficient care (Baardman et al., 2009; Alpay et al., 2010), improved self-management and reduced demand for health care or for professionals (Alpay et al. 2010).

Access to the Internet is widespread in the Netherlands. In 2011, 87% of patients with rheumatic diseases in the Netherlands had access to the Internet and more than half used it daily (Van der Vaart, Drossaert, Taal and Van de Laar, 2011a). Van der Vaart et al. (2011a) found that most of these patients use the Internet for information about their illness, treatments, lifestyle and medication. However, use of interactive applications remains low. While one in four patients used the Internet for retrieving information from discussion boards, fewer patients contributed content, monitored their symptoms online or interacted online with their health care provider (Van der Vaart et al., 2011a).

The shift towards more interaction on the web is called Web 2.0. Here, the connections between users and user-generated content become more important since users become active participants who share their own content with others (Drossaert & Van Gemert-Pijnen, 2010; Eysenbach, 2008; Van de Belt, Engelen, Berben, Schoonhoven, 2010). When Web 2.0 technologies are used for health purposes, the term Health 2.0 is used (Eysenbach, 2008; Van de Belt et al., 2010). In Health 2.0, interaction plays a central role with a focus on interaction between patients, between health care providers and between

patients and their health care providers (Drossaert & Van Gemert-Pijnen, 2010). As a result, the possibilities of patients for self-management grow.

Health 2.0 applications allow patients to interact with a health professional, interact with peers and have insight into their own medical record. They can also monitor their own symptoms and evaluate and choose health professionals and institutions. Patients engaging in Health 2.0 have easier access to information, evaluations and experiences from a discussion board and evaluation sites. With Health 2.0, patients gather more knowledge about their own health condition, which is essential for proper management of their own disease (Alpay et al., 2010). Whereas Health 2.0 offers many potential advantages, specific skills are needed to use these possibilities properly. In the next section, skills necessary for using Health 2.0 applications are further elaborated.

### 1.2 Skills for using Health 2.0 applications and research questions

Internet skills are essential to make optimal use of the Internet in general (Van Deursen & Van Dijk, 2010b). Van Deursen and Van Dijk (2010a) divide Internet skills into four categories: operational, formal, information and strategic Internet skills. *Operational Internet skills* are skills to operate a browser, a search engine and internet-based forms. *Formal Internet skills* are needed to navigate the web and maintain a sense of location while navigating. *Information Internet skills* are used for locating the required information by setting up a search strategy. *Strategic Internet skills* at last are skills to take advantage of the Internet. These four skills are sequential and of conditional nature (Van Deursen & Van Dijk, 2010a) and research in the field of Internet skills indicates that the Dutch population scores on average high for operational and formal skills, however, low for level of information and strategic skills (Van Deursen & Van Dijk, 2010ab).

When people have to deal with health issues, health literacy skills come into play. Health literacy skills are the skills of individuals to obtain, understand and use information about health when making health-related decisions (Fransen, Stronks & Essink-Bot, 2011). Other definitions of health literacy focus also on skills necessary to make decisions, participate in maintaining health and have control over health (Ishikawa, Takeuchi, & Yano, 2008; Mancuso, 2009; Nutbeam, 2000). Of the Dutch population 11% has insufficient literacy skills to participate fully in society and it is expected that the percentage of Dutch people with low health literacy skills is even higher (Fransen, Stronks, & Essink-Bot, 2011).

When the Internet is used in retrieving health information, both health literacy and Internet skills need to be combined. In literature this is called eHealth literacy. EHealth literacy is defined as “the ability to seek, understand, and appraise health information from electronic resources and apply the knowledge gained to addressing or solving a health problem” (Norman & Skinner, 2006a). Skills as numeracy, literacy, information literacy and media literacy are part of this concept (Norman & Skinner, 2006a) which is dynamic as the complete set of necessary skills changes when the context changes (Norman & Skinner, 2006a). Low eHealth literacy skills can have far-reaching consequences and it could make the difference between adequately handling their own disease and non-compliance to the treatment, as well as knowing how to access health care or not.

Until now, research in eHealth literacy has focused on retrieving information via Health 1.0 (Neter & Brainin, 2012; Norman & Skinner, 2006b; Van Deursen & Van Dijk, 2010ab). The instrument eHeals (Norman & Skinner, 2006b) to measure eHealth literacy, only considers skills related to Health 1.0. Other than this, it is a measurement instrument with validity problems, because it is not a real performance

test (Van der Vaart, Drossaert, Taal, & Van de Laar, 2011b). Van Deursen and Van Dijk (2010ab) focused in their performance test only on Internet skills relevant for retrieving information. Consequently, there is no evidence about the level of eHealth literacy of patients with rheumatic diseases when using Health 2.0 applications. In addition, most research related to eHealth literacy was carried out with healthy participants. Knowledge of the problems patients with rheumatic diseases encounter when interacting with health professionals and peers, having insight into one's own medical record, monitoring one's own symptoms and evaluating health professionals and institutions is still lacking. Insight into these skills is necessary to be able to facilitate self-management of patients with rheumatic diseases.

To study skills necessary for the use of Health 2.0, the categories of Van Deursen and Van Dijk (2010a) can be used as a foundation although this division of skills is based on Health 1.0. Based on the characteristics of Health 2.0 it can be expected that there are additional skills necessary: adding personal health content, and protecting privacy. The importance of these types of skills in using Health 2.0 is explained in the following paragraphs.

A new skills concept important for the use of Health 2.0 is *adding personal health content*. In Health 2.0 this user-generated content plays a central role (Drossaert & Van Gemert-Pijnen, 2010; Van de Belt, Engelen, Berben, Schoonhoven, 2010). Users need skills to be able to add personal health content themselves for example when monitoring their symptoms in a diary or adding an evaluation about a health care professional to the web. No evidence is available about which skills are necessary for contributing content and if the population at large has these skills. This set of skills can be given some direction by analyzing the process of adding content as follows: setting goals for contributing content; selecting a proper site or application to contribute the content; deciding what information about their health to share; formulating their contribution properly or developing content; and finally, entering the content which often includes logging in.

Because of the possibility to add own content to the web in Health 2.0 applications, *protecting privacy* is also very important. To ensure safe use of Health 2.0, users need to be aware of privacy issues and take measures to protect themselves. Users have to be aware of the type of information they share, where they share this and under which conditions. Insight in the skills needed to do this, lacks. It seems that patients active in social networks are less considerate with their privacy (Frisse, 2010) and many users are not aware of the consequences and risks of sharing data (Adams, 2010). The concept of privacy is constantly changing as can be seen by different developments, for example the application *PatientsLikeMe* where patients share their characteristics, symptoms, and feelings with peers and for research purposes. Other patients read and use information of peers and react to these personal data (Frost & Massagli, 2008).

In summary, having a rheumatic disease can have a high impact on an individual's life. Patients with rheumatic diseases are increasingly encouraged to manage their diseases themselves. Health 2.0 could play a role in facilitating and stimulating self-management. Whereas Health 2.0 offers many potential advantages, specific skills, so-called eHealth literacy skills, are needed to use these possibilities properly. Until now not much is known about the level of eHealth literacy of patients with rheumatic diseases. Although some research has been conducted on Internet skills, health literacy skills and eHealth literacy skills, it has focused predominantly on information retrieval and left skills for using Health 2.0 outside consideration. In order to use Health 1.0, the skill sets of Van Deursen and Van Dijk (2010a) are necessary. For the use of Health 2.0, two additional skills categories seem to be important: adding

personal health content and protecting privacy. The aim of this study is to gain insight into the eHealth literacy of patients with rheumatic diseases and the types of problems they experience when using Health 2.0 applications. This study answers the following research questions:

1. What is the level of eHealth literacy of patients with rheumatic diseases?[1]
2. Which types of problems do patients with rheumatic diseases experience using typical Health 2.0 applications, such as having insight in medical record, monitoring symptoms, sending and interpreting an e-consult, using a discussion board and evaluating and choosing a health institution?
3. To what extent can eHealth literacy be predicted by education, age and self-reported Internet skills?[2]

[1] *Although an absolute level of eHealth cannot be measured, an estimation will be made by analyzing performance of patients with rheumatic diseases on a number of Internet tasks.*

[2] *Due to the qualitative nature of this study and the relatively small sample, only indications for possible predictors can be found.*

# 3 Methods

## *3.1 Research design*

To answer the research questions, an actual scenario-based performance test was conducted in combination with an interview. A performance test was chosen because it can provide insight into actual problems; when people are asked about problems encountered they are inclined to report fewer problems and give a higher estimation of their own skills (CBS Statline, 2011; Merrit, Smith & Di Renzo, 2005; Van Deursen and Van Dijk, 2010a; Van Vliet et al., 1994). Following the performance tests a short interview was conducted to ask for thoughts and feelings that could not be derived from the performance on the tasks.

## *3.2 Participants*

A health care professional selected patients from the database of patients with rheumatic diseases who had an appointment scheduled at the UMC Utrecht in May, June or July 2012. Patients with an insufficient health condition or who were not able to speak Dutch were excluded.

An invitation letter was sent to 45 patients containing the purpose and process of the study and that they would be contacted to participate. After providing consent, an appointment was scheduled on the same date the participant already had an appointment in the hospital. Participants received a letter to confirm their appointment. Seventeen participants started the performance test; one participant stopped after one task because the participant did not want to proceed anymore. This participant was excluded from the study.

### 3.3 Procedure

On the day of the study, participants received an explanation of the study and were asked to sign a consent form and they answered questions about their characteristics and use of the Internet.

Participants were asked to perform ten tasks with five applications (see below) and were asked to think aloud. The participants received the tasks in random order, to prevent the occurrence of learning effects. Participants always received task A and B within one application together. To prevent confusion about the location where a task had to be performed, tasks within the patient portals were offered in combination with each other.

After completion of a task or if a participant wanted to give up on a task, the participant continued with the next task. If participants gave up on task 4a or 5a, task 4b or 5b could not be performed either. Not all participants started with every task because of fatigue, the discussion board not being accessible or giving up on a related task. After finishing every two tasks, participants were interviewed by the researcher about these tasks. The tests lasted between 50 and 140 minutes.

A laptop with high speed Internet connection was used and the use of Internet Explorer 7 recommended; Mozilla Firefox or Google Chrome was also available to those who requested that. The browser was reset after each session.

### 3.4 Materials

#### *3.4.1 Tasks*

The tasks were ten typical Health 2.0 tasks relevant for patients with rheumatic diseases (see Box 1). For all ten tasks basic as well as advanced skills are necessary. All tasks are expected to appeal onto basic Internet skills operating the computer and Internet and orienting and navigating on the web and on the advanced Internet skills searching for information and applications and evaluating relevance and reliability of personal content and content from other users. But not for all ten tasks all skills would be necessary. It is expected that tasks 2a, 3b, 4b and 5b will put a greater appeal onto the skills adding personal health content and protecting privacy because this tasks involve adding own content.

The tasks did not include precise instruction where to click. Open-ended questions were posed to resemble the natural situation and let participants go through all steps from initial question to answer. Both the process to find the answer as the answer itself were important for identifying problems.

#### *3.4.2 Interview questions*

Before starting the performance tasks, participants were interviewed about characteristics of their disease, demographics and their use of the Internet. After each task interview questions were posed about previous use of the application, relevance of the task in their daily life and the problems they experienced during the task. Special attention was paid in the interviews to the reliability and privacy. Questions were asked about their ways to evaluate reliability of content and about their willingness to share personal health content about themselves, family or health care professionals.

Box 1: Health 2.0 tasks used in the study

1. Your complaints have increased.

    a) Your doctor carried out some blood tests. With that data the level of creatine, alat and thrombocytes in your blood can be checked. The previous time your blood was tested, you had the following levels: creatine 60; alat 32 and thrombocytes 210. Did your blood levels improve, stayed the same or worsened? What would you do with this knowledge?

    b) During the previous consultation with your doctor, you made a treatment plan. You do not remember exactly what you agreed on. Can you mention two important aspects from your treatment plan?

2. You would like to have more insight in your disease. Therefore you keep notes in the portal. You enter your activities in that day and the amount of pain.

    a) Enter notes for one day.

    b) Compare two notes from the previous week. When did you experience more complaints?

3.

    a) You know you have to exercise more. A few weeks ago you sent your health professional an e-consult with the question how you could best tackle this. Your health professional answered your question via e-consult. Find this e-consult. Mention the most important aspects from the answer.

    b) You will leave in one and a half week for a holiday to Morocco. It is very warm there at the moment. You need advice about taking your medication with you. You do not know if this is possible due to the heat. The next appointment in the hospital is in two months. You decide to pose your question via e-consult. Pose your question via e-consult.

4. Go to www.reumaforum.nl

    a) You have a new medicine Methotrexate against rheumatic complaints. You get nauseous from it. Select two suggestions from other patients to prevent nausea.

    b) You have other experiences with nausea after taking medication and would like to react on the message. Log in on the discussion board [name and password are given]. Add your own suggestion. Introduce yourself. Do not click on 'Add'.

5. You would like to add a review about UMC Utrecht.

    a) Go to www.zorgkaartnederland.nl. Find the UMC Utrecht. Read two complete reviews of other users about UMC Utrecht.

    b) Add your own review. You do not have to click on 'Send you review', but you may do it if the review represent your opinion.

### *3.4.3 Portal and websites used in this study*

Of all tasks, six had to be performed in the patients portal of the UMC Utrecht. Screen shots of the applications can be found in Appendix A. This portal facilitates patients in performing self-management by offering several Health 2.0 functionalities. Patients can retrieve information, interact with their health professional, look into parts of their own medical record, monitor their own symptoms by using diaries, filling in questionnaires, see into to their own list of medicines used now and in the past, ask for a repeated prescription or see what activities they need to perform. Patients can also add their own notes and see into their own characteristics and those of their health care professionals. Appointments with some departments can be made online.

Participants were granted access during this study to a test account to guarantee their privacy. Patients were placed on the homepage of this website and did not have to log in themselves. Participants had to perform two tasks on a patient support discussion board (www.reumaforum.nl, see Appendix B), chosen because it is a frequently visited discussion board for patients with rheumatic diseases. Additionally, two tasks were performed on a health care rating website (www.zorgkaartnederland.nl, see Appendix C). This is a frequently visited website to evaluate and choose health professionals and institutions. Patients did not select the website themselves, rather were guided to via the urls of these sites.

#### *3.4.4 Measures*

Screen activity of the patient was recorded with the help of the computer program Morae and observations of participants recorded with a webcam. To obtain more insight into the level of eHealth literacy several measures were performed: completion of a task, performance, time required and encountered problems. All variables were coded independently by two researchers and consensus was reached by discussion.

***Completion*** was coded into three categories: not completed, completed with help and completed without help. A task was coded as completed if, according to both coders, a participant answered the question in the task or did what was asked. Tasks were coded as completed with help when participants got stuck and received a suggestion from the researcher to be able to continue. This could be for example a suggestion about a button or link to click or an explanation about date and time of content.

***Performance*** was coded into three categories: good, reasonable and poor. Performance was rated as good, if according to both coders, the participant knew what he was doing and performed all necessary steps to complete the task in an efficient manner. Performance did not have to be without any problems. Performance was rated as reasonable, if according to both coders, the participant carried out the majority of the steps in a good way, but encountered more problems and also some serious problems, such as not being able to filter out relevant suggestions, formulating an unclear question or having difficulty with finding a good search strategy. Performance was coded as poor if participants did most of the steps incorrectly and made multiple serious mistakes, such as not being able to orient on his own location, not having a search strategy or filling out incorrect fields that did not allow sending or saving content.

***Required time*** to complete a task was registered in seconds. Participants who did not complete the task were excluded from the time measurement.

***Encountered problems*** were coded as a problem if, according to both coders, an action was not adequate.

### 3.5 Data analysis

Coding of encountered problems was conducted bottom-up. All actions and problems of patients were coded and categorized into main categories and sub categories. This yielded six categories similar to those of Van Deursen and Van Dijk (2010a). The categories of operational and formal Internet skills of Van Deursen and Van Dijk (2010a) could be used, only the name of the category was adjusted: operating the computer and Internet (operational) and orienting and navigating on the web (formal). The category of information Internet skills was further divided in two different categories: searching for health

information and applications and evaluating relevance and reliability. A clear distinction was observed in problems with locating the necessary information and applications and with difficulties in using information applications for their own benefit. The strategic Internet skills category was not used, because this category was too abstract to be able to code problems. Two additional, and for Health 2.0 essential skill categories were adding personal health content and protecting privacy. A distinction is made in the results between basic Internet skills and advanced Internet skills. Basic skills are skills for operating the computer and Internet and for orienting and navigating on the web. These types of skills are always necessary regardless what a task consist of. The more advanced skills search for health information and applications, evaluate relevance and reliability, adding personal health content and protecting privacy are skills which are more related with the task. If the task is more complicated, a larger appeal will be practiced on these types of skills.

Quantitative data such as socio-demographics, health characteristics, Internet use, performance, completion, required time, number of encountered problems in general, per task, per participant and within basic and advanced skills and were analyzed using descriptive statistics.

# 4 Results

## 4.1 Patient characteristics

A heterogeneous group participated in the study as can be seen in Table 1, although women and people with rheumatoid arthritis were overrepresented.

**Table 1** Participants' self-reported socio-demographic and health characteristics (n=16)

| **Participant characteristics** | **n (%)** |
|---|---|
| Gender | |
| male | 3 (19) |
| female | 13 (81) |
| Age | |
| median | 48,5 |
| range | 24-72 |
| Education | |
| low | 6 (38) |
| middle | 4 (25) |
| high | 6 (38) |
| Years since diagnosis | |
| median | 6,5 |
| range | 2-25 |
| Diagnosis | |
| Rheumatoid arthritis | 12 (75) |
| Bechterew | 3 (19) |
| SLE | 1 (6) |

All participants had access to the Internet either at home or at work as is shown in Table 2. Most participants were experienced Internet users and used the Internet on a frequent basis. However, reported skills were diverse. Almost half of the participants reported good or excellent Internet skills. Only six participants reported physical problems in varying intensity during computer use, which were related to their chair, table, key board, mouse and screen for example tingling fingers by use of the mouse or finding a comfortable chair. Two participants were impaired by a drip or by a splint; they were

hindered during the test when using the mouse and keyboard. The problems of these participants were included in the measures.

**Table 2** Participants' Internet use (n=16)

| Participant characteristics | n (%) |
|---|---|
| Years of Internet experience | |
| <5 years | 2 (12) |
| ≥5 years | 14 (88) |
| Point of access to the Internet | |
| At home | 9 (56) |
| At home and at work | 7 (44) |
| Frequency of use | |
| Every day | 14 (88) |
| Multiple times a week | 1 (6) |
| (almost) never | 1 (6) |
| Self-reported internet skills | |
| Excellent | 1 (6) |
| Good | 6 (38) |
| Average | 3 (19) |
| Reasonable | 4 (25) |
| Poor | 2 (13) |
| Asking others for help with using Internet | |
| Yes | 7 (44) |
| Sometimes | 4 (25) |
| No | 5 (31) |
| Use of online portals | 14 (88) |
| Practical physical problems during computer use | 6 (38) |

Use of the Internet for disease-related tasks was not as common as Internet use for general purposes as is shown in Table 3. Almost all participants had previously searched for information about rheumatic diseases, however only few or none had participated in Health 2.0 tasks, such as participating in an online self-management course or placing a review. The only exceptions were having contact with a health professional online and ordering medication at the pharmacy online.

**Table 3** Disease related Internet use

| Number of participants who have ever performed the following tasks via the Internet | n (%) |
|---|---|
| Searched for information about rheumatic diseases | 15 (94) |
| Read on a discussion board or community of patients with rheumatic diseases | 8 (50) |
| Put a question to own health professional | 7 (44) |
| Ordered medication at pharmacy | 6 (38) |
| Searched for a review of a health professional or health care institution | 5 (31) |
| Used the patient portal of hospital | 3 (19) |
| Placed a message in a discussion board or community of patients with rheumatic diseases | 3 (19) |
| Had insight in own medical record | 3 (19) |
| Shared personal medical data with others | 1 (6) |
| Monitored symptoms | 0 (0) |
| Made an appointment with own health professional or hospital | 0 (0) |
| Placed a review about a health professional of health care institution | 0 (0) |
| Participated in an online self-management course | 0 (0) |

### 4.2 Level of eHealth literacy

Performance of the participants per task is shown in Table 4. The level of eHealth literacy on the tasks is relatively good when considering completion as an indicator. All tasks were completed by the majority of the participants, most without help. Task 1a, in which blood levels had to be interpreted, was completed

by all participants. However, completion does not always mean that participants had a good performance during a task. In general, when compared with completion of a task, fewer participants displayed good performance. The biggest difference between completion and performance can be seen in task 4a where participants were asked to find suggestions for nausea related to taking specific medication. The difference between completion and performance lies, for example, in participants searching in a wrong way, losing their orientation but find their way back eventually. Time spent can also be used as an indicator of the eHealth literacy of participants and the difficultness of the tasks. Three tasks, 2a, 4a and 4b, attract attention because the median duration to complete was 262 to 270 seconds, while the median duration of task 2b was only 70 seconds. Diversity between participants in time spent is obvious. The slowest participants spent five to thirteen times as many seconds at a specific task than the fastest participant.

**Table 4** Performance on tasks and relevance for each of the ten tasks

| | n/N | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | **Have insight in medical record** | | **Monitor symptoms** | | **Send and interpret an e-consult** | | **Use a discussion board** | | **Evaluate and choose a health institution** | |
| | **1a** | **1b** | **2a** | **2b** | **3a** | **3b** | **4a** | **4b** | **5a** | **5b** |
| n participants who started with this task | 15 | 15 | 16 | 16 | 15 | 15 | 12 | 10 | 15 | 15 |
| Completion | | | | | | | | | | |
| Without help | 12/15 | 14/15 | 10/16 | 11/16 | 9/15 | 13/15 | 10/12 | 8/10 | 12/15 | 10/15 |
| With help | 3/15 | 1/15 | 3/16 | 2/16 | 2/15 | 1/15 | 0/12 | 1/10 | 1/15 | 0/15 |
| Not completed | 0/15 | 0/15 | 3/16 | 3/16 | 4/15 | 1/15 | 2/12 | 1/10 | 2/15 | 5/15 |
| Duration in seconds[1] | | | | | | | | | | |
| Median | 151 | 119 | 265 | 66 | 163 | 115 | 270 | 262 | 159 | 226 |
| Minimum | 57 | 24 | 91 | 27 | 71 | 24 | 128 | 156 | 101 | 108 |
| Maximum | 746 | 263 | 782 | 158 | 544 | 723 | 629 | 1406 | 674 | 672 |
| Performance | | | | | | | | | | |
| Good | 7/15 | 8/15 | 6/16 | 10/16 | 8/15 | 12/15 | 3/12 | 4/10 | 9/15 | 6/15 |
| Reasonable | 5/15 | 6/15 | 5/16 | 3/16 | 2/15 | 1/15 | 7/12 | 4/10 | 6/15 | 6/15 |
| Poor | 3/15 | 1/15 | 5/16 | 3/16 | 5/15 | 2/15 | 2/12 | 2/10 | 0/15 | 3/15 |
| Experience with task | | | | | | | | | | |
| Yes | 3/16 | 3/15 | 0/16 | 0/16 | 0/15 | 0/15 | 6/13 | 3/13 | 2/16 | 0/16 |
| No | 13/16 | 12/15 | 16/16 | 16/16 | 15/15 | 15/15 | 7/13 | 10/13 | 14/16 | 16/16 |
| Considers task relevant | 14/16 | 8/13 | 4/16 | 4/16 | 11/15 | 11/15 | 4/13 | 1/13 | 10/16 | 5/16 |
| Yes | 2/16 | 5/13 | 12/16 | 12/16 | 4/15 | 4/15 | 9/13 | 12/13 | 6/16 | 11/16 |
| No | | | | | | | | | | |

* the duration in seconds of participants who did not complete the tasks is not included

Almost all participants had no experience with the tasks. The only exception was reading on a discussion board which half of the participants had experience with, while this was the task at which performance was notably less well than on the other tasks. Tasks which involved direct information from health professionals via their medical record and e-consult were considered more relevant than tasks which involved users placing content online themselves. According to participants tasks in general would become more relevant if the disease was not stable: *"Generally you go to the discussion boards at the moment the disease bothers you.[…] The moment you feel better, you do not have such a need for information, because then you feel good." [female, 35].*

Table 5 provides an overview of the median, minimum and maximum performance per participant. When considering eHealth literacy per participant, it can be seen that the median of completed tasks is

almost eight out of ten tasks. The completion score shows a large diversity, it varied between one to ten completed tasks per participant. The median of tasks participants had a good performance on was five and a reasonable performance on almost three. This varied strongly between none of the tasks to all tasks. Only one participant had a good performance on all tasks. Seven participants had a good performance on less than half of the tasks.

**Table 5** Number of completed tasks, tasks with a good performance and number of problems per participant (n=16)

| | Median | Minimum | Maximum |
|---|---|---|---|
| Number of completed tasks | 7,5 | 1 | 10 |
| Number of tasks | | | |
| with good performance | 5 | 0 | 10 |
| with reasonable performance | 2,5 | 0 | 6 |
| with poor performance | 0 | 0 | 7 |
| Number of problems | | | |
| with all skills | 11,5 | 5 | 29 |
| with basic Internet skills | 4,5 | 0 | 11 |
| with advanced Internet skills | 7,5 | 1 | 17 |

The median of problems participants encountered was almost 12. None of the participants was able to perform any of the tasks without encountering any problem. There was one participant who encountered no problems during all tasks with the basic internet skills such as operating the computer and Internet and orientating and navigating on the web. However, all participants encountered one or more problems with the more advanced skills such as searching for information and applications, evaluating relevance and reliability and adding personal content to the web. The diversity in eHealth literacy can be seen in the number of encountered problems; this varies between five and 29 problems per participant. With both basic and advanced eHealth literacy skills, the number of encountered problems per participant was diverse, although the median of encountered problems was higher for advanced internet skills.

### 4.3 Numbers and categories of encountered problems with eHealth literacy skills

Participants encountered problems with 38 skills (see Table 6), which can be categorized in five different types of eHealth literacy skill: operating the computer and Internet, orienting and navigating on the web, searching for health information and applications, evaluating relevance and reliability and adding personal health content. The problems encountered are described per type of eHealth literacy skills. The results about the type of skill protecting privacy could not be observed during the performance test and are not included in the table. Results about this type of skill were derived from the interviews.

Having one or more problems in different categories of skills performing Health 2.0 tasks seem almost inevitable. In every category of eHealth literacy skills 13 to 15 participants encountered one or more problems.

Different problems come to the front in different tasks. Performing tasks in which participants had to add personal content, caused most problems for all participants together, 15 to 17 problems. The least amount of different problems is accounted for by looking into conclusions about treatment and comparing diaries.

### *4.3.1 Operating the computer and Internet*

Operating the computer and Internet is one of the basic skills categories. Participants encountered 12 different problems in this category. The majority of the participants encountered problems within this category of skills.

Using the keyboard is important for all tasks with the computer, especially when adding personal content, but half of the participants had problems with this skill, for example typing very slow or making many typos. Participants who had trouble with this skill were slower and their content was more difficult to understand.

Recognizing loading of a site also caused problems for half of the participants, more frequent when the website was slow. Participants clicked links multiple times or became impatient: *"It does not work, great." [female, 60].*

Almost half of the participants had trouble sending or saving content added by themselves. Most of them could not find the right button, because the 'save button' was not immediately visible. One participant tried to save the content with a shortcut key which was not correct.

Some of the participants experienced problems with the url bar, because they did not know which button to press after typing in the address or how to remove an old url: *"Do I have to use 'delete' to get rid of that [old url]?" [female, 64].*

Other problems experienced were: using a slider to evaluate a hospital, using the mouse, mostly a lack of control over the mouse and scrolling or knowing that there was a possibility to scroll. Problems with scrolling caused other problems; participants did not know there was more information than they could see or even missed the top navigation. There were also some problems encountered by only one participant: closing a pop-up screen, getting back information which was minimized in a table, using pdf-files, using multiple tabs in the browser, dealing with a browser screen with an empty homepage instead of Google and using a selection box in an advanced search.

### *4.3.2 Orienting and navigating on the web*

Orienting and navigating on the web, one of the basic skills categories, caused seven problems. Almost all participants, except one, experienced problems with this category of skills. Problems with this skill had an impact on reaching the right information or applications or even getting lost.

Orientating on own location seem to be a difficult skill, which ranged from confusing a list of results in a search engine with the discussion board itself to using the navigation to go to a specific page while the participant was already at the correct location: *" Shall I go to the homepage first or was I already there?" [female, 65].*

More than half of the participants experienced problems using menu structures. Most participants used either the navigation bar at the left or the top navigation, but not both, which hindered efficient use.

Opening messages was a problem for more than half of the participants. If only the first line of a message was visible not all participants knew there was more information or how they could go to that information. This caused participants to miss parts of the information available. Participants selected for

**Table 6** Number of participants who encountered problems with eHealth literacy skills

| | Having insight in medical record | | Monitoring symptoms | | Sending and interpreting an e-consult | | Using a discussion board | | Evaluating and choosing a health institution | | Number of participants who encountered problems with this skill at least once |
|---|---|---|---|---|---|---|---|---|---|---|---|
| | 1a | 1b | 2a | 2b | 3a | 3b | 4a | 4b | 5a | 5b | |
| **n=** | **15** | **15** | **16** | **16** | **15** | **15** | **12** | **10** | **15** | **15** | |
| **Operating the computer and Internet[1]** | **1** | **0** | **9** | **1** | **6** | **2** | **5** | **4** | **8** | **8** | **14** |
| Using the keyboard | | | 4 | | 3 | | | 4 | | 2 | 8 |
| Recognizing loading of site | | | 1 | | | | 1 | | 5 | 1 | 8 |
| Saving/sending | | | 6 | | 3 | | | | | | 7 |
| Using the url bar | | | | | | 1 | 4 | | 4 | | 6 |
| Using a slider | | | | | | | | | | 6 | 6 |
| Using the mouse | | | 4 | | | 1 | | | 1 | 1 | 5 |
| Scrolling | | | 2 | 1 | | 1 | | | | | 3 |
| Closing page | | | | | 1 | | | | | | 1 |
| Minimizing/maximizing information | 1 | | | | | | | | | | 1 |
| Using a pfd-file | | | | | 1 | | | | | | 1 |
| Using multiple tabs in browser | | | | | | | 1 | | | | 1 |
| Dealing with empty browser screen | | | | | | | 1 | | | | 1 |
| Using a selection box | | | | | | | | 1 | | | 1 |
| **Orienting and navigating on the web[1]** | **9** | **9** | **7** | **0** | **7** | **3** | **4** | **3** | **6** | **1** | **15** |
| Orientating on own location | 1 | 2 | 5 | | 4 | 1 | 3 | 2 | 3 | | 10 |
| Using of menu structures | 9 | 9 | | | | | | | | | 9 |
| Opening messages | | | | | 1 | 3 | 1 | | 4 | | 9 |
| Using links | | | 2 | | 6 | | 1 | 1 | | 1 | 7 |
| Using bread crumbs | | | | | | | | 1 | | | 1 |
| **Searching for health information and applications[2]** | **5** | **3** | **8** | **5** | **8** | **2** | **7** | **5** | **4** | **11** | **15** |
| Understanding task | | | 2 | 2 | 6 | 2 | 4 | 1 | 1 | 2 | 10 |
| Flexible use of search terms | | | 1 | | | | | | | 10 | 10 |
| Searching via navigation | 4 | | 5 | 3 | 5 | 2 | 5 | 2 | | | 10 |
| Focusing on task | 3 | 3 | 5 | 1 | 3 | | | 1 | 2 | | 9 |
| Using a search engine | | | | | | | 4 | 1 | 2 | | 5 |
| Navigating to location visited before | | | | | | | | 3 | | | 3 |
| **Evaluating relevance and reliability[2]** | **8** | **3** | **1** | **6** | **3** | **1** | **5** | | **2** | | **14** |
| Reading and interpreting information | 7 | 3 | | 6 | | 1 | 5 | | 2 | | 13 |
| Assessing relevance of content | | | 1 | 1 | 3 | 1 | 3 | | | | 7 |
| Assessing if action is necessary | 4 | | | | | | | | | | 4 |
| Having insight in dates and time of data | 3 | | | | | | | | | | 3 |
| **Adding personal health content[2]** | **-** | **-** | **14** | **-** | **12** | **-** | **-** | **9** | | **7** | **15** |
| Using capital letters and punctuation marks | | | 11 | | 6 | | | 4 | | 2 | 12 |
| Using header and conclusion | | | | | 7 | | | 6 | | | 10 |
| Formulating a question | | | | | 7 | | | | | | 7 |
| Formulating own content | | | 4 | | | | | 2 | | 4 | 7 |
| Adding an addressee | | | | | 6 | | | | | | 6 |
| Notion of location for adding content | | | 1 | | | | | 5 | | | 5 |
| Using fields for adding data | | | 2 | | 3 | | | | | | 5 |
| Notion of how to add own content | | | 2 | | | | | | | | 3 |
| Filling in a captcha | | | | | | | | | | 3 | 3 |
| Logging in | | | | | | | | 2 | | | 2 |
| **Number of problems encountered within one task** | **8** | **3** | **17** | **6** | **15** | **9** | **12** | **15** | **9** | **10** | |

[1] *basic skills*
[2] *advanced skills*

example suggestions from a list with different messages in a discussion board without reading the whole message and being able to interpret the suggestions.

Some participants had difficulties with using links. They clicked for example not on the link itself or could not locate the link on the page how they could fill out a diary. Using bread crumbs, a navigation aid which helps users to orient on their location and navigate back, was a problem for one participant. That was the only participant who used the bread crumb. The participant tried to click on the last link of the bread crumb and did not realize that the last link in the bread crumb was the place she was already located.

### *4.3.3 Searching for health information and applications*

The category searching for health information and applications let users find the information and applications they need in an efficient way. Participants who had difficulty setting up and carrying out a search strategy, were less likely to complete the task without any help. Six different problems were encountered. All participants, except one, experienced problems with these skills.

Understanding the task caused problems for more than half of the participants. Some participants did not understand the task at all, others understood part of it, but put a question in the e-consult that did not correspond to the task.

While understanding the task, participants could still lose their focus on the task. Participants performed activities such as browsing through the navigation or opening an e-consult and then suddenly asked what they had to do: *"What was it again?" [female, 24].*

Flexible use of search terms was also a relatively large problem. Terms used in the tasks were not always the same as used on the buttons and navigation in the portals and sites and this caused frustration (*"I think they really do not want to have evaluations here." [female, 57]),* and cost time for participants who had to recognize the button "evaluate" when they were asked to add a review.

Setting up a search strategy was difficult for more than half of the participants, via the navigation or via a search engine. Many participants just clicked around without systematically looking to all the options or which part of the site would be most relevant for the task. Searching via a search engine caused problems, but less frequent. Participants had difficulty using 'advanced search', and did not recognize the message which accompanied zero results or did not enter a search term.

After logging in, some participants had difficulty to navigate back to the place they visited before logging in.

### *4.3.4 Evaluating relevance and reliability*

The skills of evaluating relevance and reliability caused only four different but serious problems. Only two participants completed the tasks without experiencing this type of problems.

Reading and interpreting relevant information caused problems for more participants than any other skill. It also has a big impact because the skills are essential to be able to make use of content. Interpreting the number of markers in the blood caused most of the problems with participants assuming that rising levels were always bad ("*They [levels] rose, so it worsened." [female, 46]*), or

admitting that they did not know if it worsened or not. Or participants wrongly concluded from a diary that one day there were more complaints than the other day. A related skill is having insight in dates and time of data. A few participants had trouble seeing which content belonged to which date and time or confused dates and times, which in some cases let them draw wrong conclusions.

Problems with assessing relevance seemed to affect less than half of the participants, because they could not assess if they were on an relevant or irrelevant page. One participant for example read the whole message 'much pain in legs and feet' before she decided that this had nothing to do with suggestions against nausea.

Assessing if action is necessary leads to problems for a few participants in task 1a where advice about action is not included in the content. While participants did not always know what the blood levels implied, most of the times the action they suggest is suitable, for example because they would ask a health professional to explain the blood levels: *"Yes, I do not know what creatinine and alat is, but I would in any case contact the rheumatologist if he did not already contact me." [male, 47].*

While none of the participants assessed reliability of the information during the test, the majority of the participants indicated in the interviews that they really think about reliability of user-generated content. A part of the participants indicated that they believed other people were honest and would not make stories up: *"No I would not doubt about it being true or not. Look I assume that if you are involved with peers, that they do not write trash." [male, 48].* Other people think on the contrary that content from other users should always be considered unreliable: *"These are all own experiences. I do not attach any importance to that. I believe that it is their experience, but I would never apply it to myself."[female, 24]*. The majority of participants would try to evaluate reliability of content. They would do this evaluation in many different ways: see if they recognize experiences or suggestions, read multiple suggestions, analyze if evaluations of hospitals are primarily positive or negative, check with their physician, play a hunch, try some suggestions if it is not too deviant or analyze style and choice of words: *"It depends on the style. […] What it says, if that seems logical to you and yes… if you read something of which you think 'does he know what he is talking about?' then you can think, I do not know." [female, 46].*

### *4.3.5 Adding personal health content*

The typical Health 2.0 skill adding personal health content caused ten various problems for participants with four of the tasks. The problem most prevalent was using capital letters and punctuation marks which could influence readability of the content and the ease to understand what was meant by a message. Performance on this skill was better when adding public accessible content than for their own health professional and when content was added for oneself performance was even worse.

Problems with using a header and conclusion consisted of participants not using a header or conclusion at all or doubting about what to type.

Both formulating own content or a question caused problems for almost half of the participants. Problems consisted of not being able to formulate a clear question in which it is clear what kind of information they asked for, not giving an explanation or substantiation of a suggestion, not writing in complete sentences, using incorrect syntaxes. Someone typed for example: *"what can I do best for the trip to Morocco Which medication or vaccinations I need" [female, 64].* Other problems were having trouble thinking about what to write down (*"What did I do today? This morning my dinner… How do I*

*write that? [male, 54]*), formulating content which is not complete or leaving important background information out, such as the medication the question or message is about. One participant even did not type in a question at all in her e-consult. Besides that, there were some people who did not want to fill it in, because they were not able to do it at all or at that moment: *"Then I will write something and then sleep a night and look what I will add or eliminate, because I think it has to make a good impression." [female, 60].*

Other problems include adding an addressee. Participants did not know how to add the addressee, used the url-bar for it, could not handle the pop-up box in which an addressee could be selected or even left the addressee field empty.

Using the right fields to add data caused problems because some participants place the message or question in the wrong field or does not add a subject which makes the e-consult not being sent.

A few participants were not able to choose the right place to add content. Participants added for example content in an irrelevant thread on a discussion board or placed diary notes in an e-consult.

Other problems were: not having a notion of the need to save content, not being able to fill in a captcha. A captcha is a test to ensure that a user who wants to add content is a human being and not a program to spread viruses or spam. A captcha usually requires users to enter letters or digits from a distorted image. The participants in our study clicked on it several times, did not fill it out or indicated that they did not know what to do with it. Others had problems with logging in, because they did not know how to log in at all or confused username and password.

#### *4.3.6 Protecting privacy*

Protecting privacy is one of the skills which became more important because of the rise of Health 2.0. Participants protected privacy in different ways as can be seen primarily in the interviews.

During the performance test only a few participants showed to think about privacy issues. They gave a statement when they checked off the box to agree with the privacy statements but did not show awareness about the implications of the privacy conditions. This varied from considering agreeing with the privacy statements as inevitable, to finding it too much trouble reading the complete statements to stating that this task is not real life.

From the interviews it seemed that participants were more aware of privacy concerns than could be observed in their actions. The majority of the participants would protect their own privacy by being cautious which personal information to share online, such as name, address, things spoken about in a consult, life style, financial data, relationships, date of birth: *"I think you can put much information about your evaluation without indicating who you are, how you live or what exactly is your disease or where you live. I think you can be honest without that becoming clear."[female, 45].* Information about the disease was considered private by some participants while others considered this as necessary to share to reach a goal:

*"Because I think that this does not belong on the Internet. I think that by definition it does not belong on the Internet. I think those are personal data." [female, 49]*

*I do not often tell much personal things, but here it is different. […] Here you want to be helped as good as possible, so then you can say you only have a little bit of pain. […] Here it is your interest that you say clearly what bothers you. So when I'm honest, also tell as much as possible." [female, 35]*

The website *PatientsLikeMe* is a good example of using Health 2.0. Only four of the participants would use this application to be able to share experiences with peers while nine others would not. Only one participant had privacy reasons for not using it.

Only a few participants would protect their privacy by checking who had access to certain information. For two of them this is a reason not to fill in online diaries.

The notion of privacy participants showed almost all had to do with other people seeing their personal data. Only two participants showed awareness by talking about the company or website collecting data: *"Often I look why they want to know everything." [female, 35].* Participants were even more reluctant to share information about family. All participants would first think about it and almost half of the participants would not share any content about their family members: *"I'm not going to write something down about a family member. He can be really angry about that, like 'what have you done?'. Yes I think you have to keep it to yourself." [female, 65].* A few others might add content about family members but would ask permission or add the content without writing down their names.

The majority of participants were cautious about adding content about a health care professional. Of these group of participants, six participants would not add any information about a health care professional but would go to the health professional in person. Adding some information, would maybe done by two participants, one of them only when it would be positive information, the other when it would be a complaint. Only two participants would add information about health care professionals and would not have concerns about the privacy of the health care professionals: *"No, if it would irritate me very much, then I think I would write everything down what would irritate me. I would not know why I would leave something out." [female, 57].*

### *4.3.7 Problems reported by participants*

Apparently there was a difference between problems observed and problems reported afterwards. Most of the problems observed were not reported by the participants after the task. Participants did only report zero to two problems per task. An example is the use of the slider. Of seven participants who had difficulty using the slider, only one reported it as a problem.

The problem reported most frequently, by twelve participants, is having difficulty finding the information and the applications: *"Yes what I thought was difficult was that I do not know where to go in this program and then I'm fumbling and clicking erroneous. And then I ask myself, what on earth do I have to do? I sometimes do not know." [female, 65].* Most participants did not explain what this trouble finding included. Some participants reported having problems with interpreting the blood levels, treatment conclusions and diaries. Other problems reported by some participants were: not having the notion of the right place to add content and difficulty sending and saving content.

Remarkable is that in some cases participants reported problems which were not observed. For example one participant reported having problems with formulating her own thoughts, while her contribution had been evaluated as a good performance: "*What I consider difficult is giving a description, but yes… On*

*the other side you can't do it wrongly, because it is a personal opinion, so… I think it is difficult to write down my thoughts on paper." [female, 32].* Other problems which were reported but not always observed were: filling out the diary, for example because of difficulty with remembering medication or thinking about performed activities, using the captcha, finding a specific button, interpreting blood levels and treatment conclusions and having difficulty reading the small characters on the screen.

### 4.4 Prediction of eHealth literacy by various characteristics

The study sample was not large enough to provide evidence to state that eHealth literacy can be predicted by age, education and self-reported Internet skills, but some indications for relationships between these variables and eHealth literacy are found.

There is an indication that the level of education could be related to the number of completed tasks, performance and number of encountered problems as can be seen in Table 7. Participants with a low level of education had the lowest score on the number of completed tasks, encountered more problems and had a lower performance than participants with a middle to high level of education. Most participants with a low level of education even had a good performance on less than one task. In both categories of participants with a low or middle to high level of education the proportion of basic and advanced skills was comparable. So this proportion does not seem to relate to the level of education.

**Table 7** Completed tasks, performance and number of encountered problems per level of education, age and self-reported Internet skills

| Characteristics of participants | Median of completed tasks without help | Median of tasks per participant with performance | | | Median of encountered problems | | |
|---|---|---|---|---|---|---|---|
| | | Poor | Reasonable | Good | All skills | Basic skills | Advanced skills |
| Level of education | | | | | | | |
| Low (n=6) | 4,5 | 4 | 3,5 | 0,5 | 20 | 6,5 | 12,5 |
| Middle to high (n=10) | 10 | 0 | 2,5 | 6,5 | 8,5 | 4 | 6 |
| Age | | | | | | | |
| Young (<50, n=9) | 10 | 0 | 2 | 6 | 8 | 4 | 6 |
| Elder (≥50, n=7) | 6 | 3 | 3 | 1 | 15 | 6 | 9 |
| Level of Internet skills reported by participants | | | | | | | |
| Poor to average (n=9) | 6 | 1 | 3 | 4 | 14 | 5 | 9 |
| Good to excellent (n=7) | 10 | 0 | 2 | 6 | 9 | 4 | 6 |

The results showed indications about a possible relationship between age and the number of completed tasks, performance and number of encountered problems. The youngest participants under 50 years of age scored better on all measures than the older participants. However, age did not seem to influence the proportion of problems with basic and advanced skills.

There were also a few indications that people could estimate their own skills. Participants with self-reported poor to average skills had a slightly worse performance and completed less tasks than participants with a self-reported good to excellent skills. Participants with poor to average skills also encountered a few more problems.

# 5 Discussion

## 5.1 Level of eHealth literacy

This study is the first study to focus on eHealth literacy in the context of Health 2.0. Most patients could complete more than half of the tasks, but only half of the participants had a good performance on half or more of the tasks and all participants encountered multiple problems. The median of completion of tasks is 7,5 task and the median of tasks with a good performance is five tasks. This is somewhat higher than found by Van Deursen and Van Dijk (2011) who studied computer skills in the health domain. They found a completion percentage at comparable tasks of 35 to 50%. The difference could be explained by the fact that in this study the participants were sent to a website and did not have to select a website themselves as they did have to do in the study of Van Deursen and Van Dijk (2011). A substantial part of the participants were not able to take full advantage of Health 2.0 applications. A few participants even had insufficient eHealth literacy skills and completed less than half of the tasks or had a poor performance at more than half of the tasks. But also patients with a reasonable performance could be able to perform the tasks while also experiencing frustration and not being able to take full advantage. The low level of experience with Health 2.0 tasks and the fact that not all participants considered the tasks as relevant could have played a role in this. Although the level of Internet experience and frequency of use of the group of participants was not representative for the whole population of patients with a rheumatic disease, participants did not have much experience with the use of Health 2.0 applications. Participants indicated that they would find tasks more relevant if their disease was not stable. This is consistent with the findings of Meesters, De Boer, Van den Berg, Fiocco and Vliet Vlieland (2011) that lower physical functioning was associated with a higher information need of patients with rheumatoid arthritis. Further research is necessary to investigate if the physical functioning of the participants had an influence on their performance.

However, the level of eHealth literacy was very diverse. This can be seen in the number of encountered problems which ranged from five to 29 and the time required was sometimes even thirteen times more for a slower participant than for the fastest participant. These results would even be more diverse when participants who did not complete the tasks would also be considered in the measurement of time. These results cannot be compared to any other study, but it gives an indication for the difference between participants in their speed of completion of different tasks. So measures to be undertaken to facilitate use of Health 2.0 applications should take into account the big differences in eHealth literacy. Patients with a rheumatic disease who would have to fill out a diary daily and this would take half an hour to complete every day would need different instructions or motivation than participants who could perform this within a few minutes.

From our study we can conclude that although Health 2.0 applications are promising for self-management it has to be taken into consideration that a significant number of patients is not able to use Health 2.0 applications for their own benefit and that a substantial part of the patients needs assistance

in varying degrees. In a hospital setting instructions would be essential to optimize the use of Health 2.0 applications and by that effects on self-management of patients. Patients could for example be guided when starting to use Health 2.0 applications or during use. The content of these instructions depends on the problems encountered by the patients. Because of the importance of patients to recognize the relevance of the applications, extra attention should be paid to motivate people.

This study confirms the statement of Norman and Skinner (2006a) that the set of necessary skills changes when the content changes. This set would differ considerably when measured at specific tasks. EHealth literacy is thus not static but depended also in this study on the requirements of the participants. This means that continuous studies have to be performed when Health 2.0 and 3.0 applications are developing. Other and more extended skills might be necessary, so measures of eHealth literacy should be adapted to this development in necessary skills.

### 5.2 Encountered problems during the use of Health 2.0 applications

This is the first study to observe problems with using Health 2.0 applications. Previous studies (Frisse, 2010; Ishikawa, Takeuchie & Yano, 2008; Neter & Brainin, 2012; Norman & Skinner, 2006a; Van Deursen & Van Dijk, 2010a) studied concepts related to eHealth literacy, but only considered Health 1.0. Most participants had little experience with the use of Health 2.0. Problems with using Health 2.0 were encountered with almost all categories of skills by all participants. These problems are not all specific for Health 2.0, but could also be present when using Health 1.0. Not all problems had a big impact, some problems such as difficulty using the mouse did only slow down the performance on the tasks while other problems such as orientating on one's own location really hindered completion. Most serious problems, which hindered users to use Health 2.0 for their own benefit, were found in evaluating relevance and reliability, adding personal health content and protecting privacy. Although reading and interpreting content is not exclusively prevalent in the use of Health 2.0, difficulties with this skill are an important threat for eHealth literacy. Norman and Skinner (2006a) described the similar problem 'difficulty to understand content'. Participants also indicated that they are cautious with taking content of other users to be correct and have different strategies to evaluate this. This is consistent with Ishikawa, Takeuchi and Yano (2008) who found out that the majority of people considers the credibility of information. As adding user-generated content is one of the most important characteristics of Health 2.0, the skill category adding personal content is essential for use of Health 2.0. It was not described in literature previously. Problems ranged from little problems such as problems with using capital letters and punctuation marks to more serious problems such as formulating own content or questions. Participants had difficulties formulating a clear question or did not know which information they would have to share. Problems around sending or saving content could not be analyzed in all tasks, because in some of the tasks this step was not included. The possibility to add own health content also makes protecting privacy an important skill category. In this study protecting privacy was for the first time studied as a skill. These skills were not studied in the performance test, because there were no tasks which threatened the participants' own privacy, because they could for example log in with a fake account and by this did not have to take measures considering privacy. The interviews however offered much data about the awareness of participants of privacy and measures they would normally undertake to protect privacy. When participants are adding personal health content they need to be aware which content they share, who would have access to their content and what websites or organizations could do with their content or with the personal data which have to be filled out before content can be added. Although participants indicated to be aware of privacy issues, most participants only focused on being

cautious which information to share, especially when it would consider family of health professionals. But almost all participants would not take additional measures. Almost all participants did not talk about the privacy threat by companies or websites which are collecting data or about who had access to data. Moreover, some participants would share information if it would benefit them. This finding is related to the statement of Frisse (2010) that patients active in social networks are less considerate with their privacy. This can also be seen in the rise of applications like PatientsLikeMe, where patients share everything to take advantage of it themselves. So privacy seemed to be a concept where the level of skills could be improved. Problems found in the lower categories of skills, operating the computer and internet and orienting and navigating on the web were comparable with the results of Van Deursen and Van Dijk (2011a) and Norman and Skinner (2006a). The category of skills searching for information and applications included frequent problems with searching via navigation, a search engine and links and buttons in the text. According to Neter and Brainin (2012) eHealth literacy is strongly related to the performance of these skills. Problems found in this study which were not described before are problems with understanding and focusing on the task.

Although the study population of 16 patients with rheumatic diseases was not enough to draw conclusions about the prevalence of certain problems, it gave a complete overview of problems patients encounter with performing Health 2.0 tasks. According to Maguire (2001) and Nielsen (1994) this is a good number to do user testing. To be able to really measure the exact level of eHealth literacy in various groups, a new instrument has to be developed which, above Health 1.0 skills, also takes into consideration specific skills necessary for Health 2.0 tasks: adding personal content and protecting privacy. These two categories should be taken into consideration when measuring eHealth literacy with respect to Health 2.0 and be added to existing eHealth literacy scales. In a measurement instrument or questionnaire questions should be posed about the skills to formulate a question or own content, skills which seem to have a big impact on performance. This could for example be included in a measurement instrument in a statement such as: “I have the skills to formulate my own experiences and questions in a clear message.” With respect to the skills to protect privacy, important aspects where questions have to be posed on, are access to content and about awareness of websites or organization which are collecting data. Awareness about which content to share is an essential skill and should thus be included, but the expected differentiated potential of this skill might not be high because most participants said they have these skills. Research should be performed to validate these scales. In future research also special attention should be paid to study privacy in performance tests.

From our results it seems that it is essential to give instructions to users of Health 2.0 applications. As can be seen in the results, instructions made, for part of the users, the difference between completing and not completing a task. Many serious problems were found with adding personal content, so the instructions should be focused on helping patients to add relevant and clear content in an efficient way. Instructions could be given by health professionals or by instructions in the application. Applications developed should include more instructions for example about which information to add in different fields by placing the instructions in the right field. In some fields even concrete questions could be posed to help people to add relevant content in the right fields. But users could also be helped with evaluating relevance and reliability of content by mentioning the source of the content or indicating more clearly what the target group is and where the content is about. A course for patients with low eHealth literacy could help patients to take advantage of Health 2.0. Important aspects of such a course are not only basis Internet skills such as the use of menu structures, but special attention should be paid to

interpretation of health content, ways to consider relevance and reliability of information, formulating own content and questions and measures to protect their own privacy and that of others.

### 5.3 Possible predictors of eHealth literacy

All participants encountered problems with all tasks, but there was a clear diversity in eHealth literacy skills. Although the study sample was too small to draw conclusions about predictors of eHealth literacy, age, education and self-reported Internet skills showed indications for relationships with eHealth literacy. The results of this study give indications that level of education, age as well as self-reported Internet skills might relate to the level of eHealth literacy. Participants with a lower level of education, a higher age or lower self-reported Internet skills scored lower on all measures. A relationship of education with the level of Internet skills and eHealth literacy was found in other studies (Neter & Brainin, 2012; Van Deursen & Van Dijk, 2010a; Van Deursen & Van Dijk, 2011). Mixed results can be seen in previous studies about the relationship between eHealth literacy and age. Studies which measured the level of eHealth literacy with eHeals found mixed results. Neter and Brainin (2012) found a relationship between age and the level of eHealth literacy while Norman and Skinner (2006b) did not. Problems with validity of eHeals, studied by Van der Vaart et al. (2011b) could be a reason for this difference. Ishikawa, Nomura, Sato and Yano (2008) found no relationship between health literacy and age but they left Internet skills outside consideration. With respect to self-reported Internet skills, other studies throughout time found that self-reported skills tend to be higher than actual skills measured in a performance test (Merrit, Smith & Di Renzo, 2005; Van Vliet, Kletke, & Chakraborty, 1994), so it should be taken into consideration that self-reported skills might not be able to predict the absolute level of eHealth literacy.

The study results give indications about possible relationships between age, level of education and self-reported Internet skills. These relationships have to be researched further in a quantitative study and with a larger sample before any conclusion can be drawn about possible predictors. When possible predictors are found these could help estimating the level of eHealth literacy without having to carry out performance tests.

In conclusion, although Health 2.0 is promising for self-management, a part of the patients with rheumatic diseases are not able to take full advantage of Health 2.0. Instruction and guidance are essential to optimize the use of Health 2.0 applications. These instructions could be given in person or in the applications themselves and should focus on evaluating relevance and reliability, adding personal health content and protecting privacy. The results of this study may help to extend existing eHealth literacy scales to be able to measure the level of eHealth literacy for the use of Health 2.0. The results also provide directions for future research about predictors of eHealth literacy.

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## References


Adams, S.A. (2010). Revisiting the online health information reliability debate in the wake of "Web 2.0": an interdisciplinary literature and website review. *International Journal of Medical Informatics, 79*, 391-400.

Alpay, L.L., Blanson Henkemans, O., Otten, W., Rövekamp, T.A.J.M., & Dumay, A.C.M. (2010). E-health applications and services for patient empowerment: directions for best practices in the Netherlands. *Telemedicine and e-Health, 16*(7), 787-791.

Baardman, J., De Booys, M., Heldoorn, M., Meulmeester, M. (2009). *Zelfmanagement 2.0. Over zelfmanagement van de patiënt en wat eHealth daaraan kan bijdragen.* Utrecht: Nederlands Patiënten Consumenten Federatie.

CBS Statline (2011). *ICT gebruik van personen naar persoonskenmerken*. Retrieved on October 27, 2012: http://statline.cbs.nl/StatWeb/selection/?DM=SLNL&PA=71098NED&VW=T .

Dedding, C., Van Doorn, R., Winkler, L., & Reis, R. (2011). How will e-health affect patient participation in the clinic? A review of e-health studies and the current evidence for changes in the relationship between medical professionals and patients. *Social Science and Medicine, 72*, 49-53.

Drossaert, S. & Van Gemert-Pijnen. (2010). eHealth. In L. Lechner, I. Mesters, C. Bolman (Eds.), *Gezondheidspsychologie bij patiënten*. Assen: Van Gorcum.

Eysenbach, G. Medicine 2.0: social networking, collaboration, participation, apomediation, and openness. (2008). *Journal of Medical Internet Research, 10*(3):e22. [doi: 10.2196/jmir.1030]

Fransen, M.P., Stronks, K., & Essink-Bot, M.L. (2011). Gezondheidsvaardigheden: Stand van zaken. In: Gezondheidsraad, *Laaggeletterdheid te lijf. Signalering ethiek en gezondheid 2011*. Den Haag: Centrum voor Ethiek en Gezondheid.

Frissen, V. (2010). *Health 2.0: "It's not just about medicine and technology, it's about living your life".* Den Haag: Raad voor de Volksgezondheid en Zorg.

Frost, J.H. & Massagli, M.P. (2008). Social uses of personal health information within PatientsLikeMe, an online patient community: what can happen when patients have access to one another's data. *Journal of Medical Internet Research, 10*(3), e15. [doi: 10.2196/jmir.1053]

Heldoorn, M. (2008). *Gezondheid 2.0. Toekomst en betekenis van e-health voor de zorgconsument.* Utrecht: Nederlandse Patiënten Consumenten Federatie.

Ishikawa, H., Nomura, K., Sato, M., & Yano, E. (2008). Developing a measure of communicative and critical health literacy: a pilot study of Japanese office workers. *Health Promotion International, 23*(3), 269-274.

Ishikawa, H., Takeuchi, T., & Yano, E. (2008). Measuring functional, communicative, and critical health literacy among diabetic patients. *Diabetics Care, 31*(5), 874-879.

Janssen, Y. (2006). Nationale peiling bewegingsapparaat 2006. *Reumatische klachten in Nederland onderzocht.* Leiden: TNO. http://www.reumafonds.nl/_sana_/handlers/getfile.ashx/245278e0-b57b-433f-9f0f-91317139af4e/TNO_Reumatische_klachten_in_Nederland2006.pdf

Maguire, M. (2001). Methods to support human-centred design. *International Journal of Human Computer Studies, 55*, 587-634.

Mancuso, J.M. (2009). Assessment and measurement of health literacy: An integrative review of the literature. *Nursing and Health Sciences, 11*, 77-89.

Meesters, J., De Boer, I., Van den Berg, M., Fiocco, M., Vliet Vlieland, T. (2011). Unmet information needs about the delivery of rheumatology health care services: A survey among patients with rheumatoid arthritis. *Patient Education and Counseling, 85*, 299-303.

Merrit, K., Smith, K.D., & Di Renzo, J.C. (2005). An investigation of self-reported computer literacy: is it reliable? *Issues in Information Systems, 6*(1), 289- 295.

Neter, E., & Brainin, E. (2012). eHealth literacy: Extending the digital divide to the Realm of health information. *Journal of Medical Internet Research, 14*(1). [doi: 10.2196/jmir.1619]

Nielsen, J. (1994). Estimating the number of subjects needed for a thinking aloud test. *International Journal of Human-Computer Studies, 41*, 385-397.

Norman, C.D., & Skinner, H.A. (2006a). eHealth literacy: Essential skills for consumer health in a networked world. *Journal of Medical Internet Research, 8*(2): e9. [doi:10.2196/jmir.8.2.e9]

Norman, C.D., & Skinner, H.A. (2006b). eHeals: the eHealth literacy scale. *Journal of Medical Internet Research, 8*(4):e27. [doi: 10.2196/jmir.8.4.e27]

Nutbeam, D. (2000). Health literacy as a public health goal: a challenge for contemporary health education and communication strategies into the 21st century. *Health Promotion International, 15*(3), 259-267.

Van de Belt, T.H., Engelen, L.J.L.P.G., Berben, S.A.A., Schoonhoven, L. (2010). Definition of Health 2.0 and Medicine 2.0: A systematic review. *Journal of Medical Internet Research, 12*(2): e18. [doi: 10.2196/jmir.1350]

Van der Vaart, R., Drossaert, C.H.C. Taal, E., Van de Laar, M.A.F.J. (2011a). Patient preferences for a hospital-based rheumatology interactive health communication application and factors associated with these preferences. *Rheumatology, 50*, 1618-1626.

Van der Vaart, R., Van Deursen, A.J.A.M., Drossaert, C.H.C., Taal, E., Van Dijk, J.A.G.M., & Van de Laar, M.A.F.J. (2011b). Does the eHealth Literacy Scale (eHeals) measure what it intends to measure? Validation of a Dutch version of the eHeals in two adult populations. *Journal of Medical Internet Research, 13*(4): e86. [doi: 10.2196/jmir.1840]

Van der Vaart, R., Drossaert, C.H.C., Taal, M.A.F., & Van de Laar, J. (2010). Experiences and preferences of patients with rheumatic diseases regarding an interactive health communication application. *2010 Second International Conference on eHealth, Telemedicine, and Social Medicine*. [doi: 10.1109/etelemed.2010.16]

Van Deursen, A.J.A.M., & Van Dijk, J.A.G.M. (2011). Internet skills performance tests: Are people ready for eHealth? *Journal of Medical Internet Research, 13*(2), e35. [doi: 10.2196/jmir.1581]

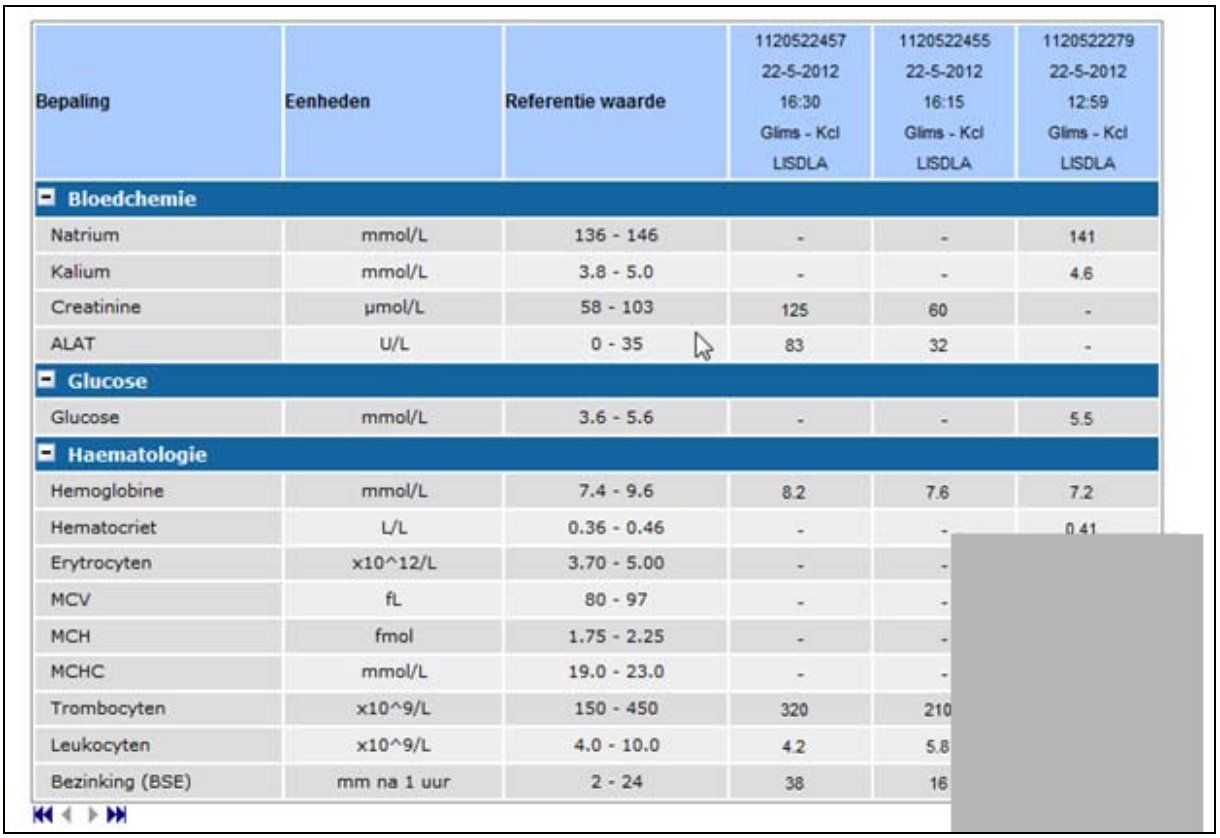
Van Deursen, A.J.A.M., & Van Dijk, J.A.G.M. (2010a). Measuring Internet skills. *International Journal of Human-Computer Interaction, 26*(10), 891-916.

Van Deursen, A.J.A.M., & Van Dijk, J.A.G.M. (2010b). Internet skills and the digital divide. *New Media and Society, 13*(6), 893-911.

Van Vliet, P.J.A., Kletke, M.G., Chakraborty, G. (1994).The measurement of computer literacy: a comparison of self-appraisal and objective tests. *International journal of Human-Computer Studies, 40*, 835-857.

## Appendix A Screen shots of the patients portal

**Image 1** Task 1a - lab results



| Bepaling | Eenheden | Referentie waarde | 1120522457 22-5-2012 16:30 Glims - Kcl LISDLA | 1120522455 22-5-2012 16:15 Glims - Kcl LISDLA | 1120522279 22-5-2012 12:59 Glims - Kcl LISDLA |
|---|---|---|---|---|---|
| **Bloedchemie** | | | | | |
| Natrium | mmol/L | 136 - 146 | - | - | 141 |
| Kalium | mmol/L | 3.8 - 5.0 | - | - | 4.6 |
| Creatinine | µmol/L | 58 - 103 | 125 | 60 | - |
| ALAT | U/L | 0 - 35 | 83 | 32 | - |
| **Glucose** | | | | | |
| Glucose | mmol/L | 3.6 - 5.6 | - | - | 5.5 |
| **Haematologie** | | | | | |
| Hemoglobine | mmol/L | 7.4 - 9.6 | 8.2 | 7.6 | 7.2 |
| Hematocriet | L/L | 0.36 - 0.46 | - | - | 0.41 |
| Erytrocyten | x10^12/L | 3.70 - 5.00 | - | - | |
| MCV | fL | 80 - 97 | - | - | |
| MCH | fmol | 1.75 - 2.25 | - | - | |
| MCHC | mmol/L | 19.0 - 23.0 | - | - | |
| Trombocyten | x10^9/L | 150 - 450 | 320 | 210 | |
| Leukocyten | x10^9/L | 4.0 - 10.0 | 4.2 | 5.8 | |
| Bezinking (BSE) | mm na 1 uur | 2 - 24 | 38 | 16 | |

**Image 2** Task 1b - treatment plan

## Behandelafspraken Reumatologie

Hier kunt u lezen wat zorgverleners van het specialisme Reumatologie & Klinische Immunologie in uw elektronisch patiëntendossier hebben geschreven.

Hebt u vragen? Stuur een e-consult

Vorig jaar 4-7-2011 - 4-7-2012 Volgend jaar

| Datum | Wie | Behandelafspraken |
|---|---|---|
| 28-06-2012 | Reumaverpleegkundige | Niet geheel rustige RA. Medicatie verhogen, bij onvoldoende resultaat contact opnemen. Nu lab. 1 +2 maand VRC (lab controle), over 3 maanden reumatoloog.<br><br>Gaat redelijk. Toch veel pijn in gewrichten MCP 1-3 rechts. Knie opgezwollen en pijnlijk. Geen warmte. Geen functiebeperking. OS 30min.<br>Medicatie: MTX 10 mg, 1 keer per week. FZ 5 mg, 1 keer per week. Naproxen z.n. Laatste 3 dagen niet ingenomen. Geen bijwerkingen van de medicijnen, niet misselijk.<br><br>MCP 1-3 rechts, pijn en zwelling. Knie rechts pijn en zwelling. Geen warmte. Elleboog links beperkt in strekken en buigen.<br>Geen bijzonderheden bij verder lichamelijk onderzoek.<br><br>MTX ophogen naar 15 mg, 1 keer per week. Naproxen 500 mg 2 maal daags. FZ |

**Image 3** Task 2b **–** place to add own notes

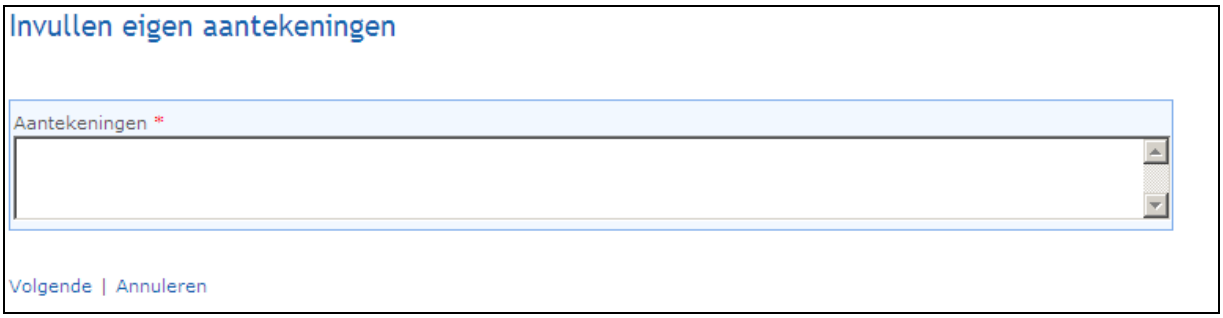
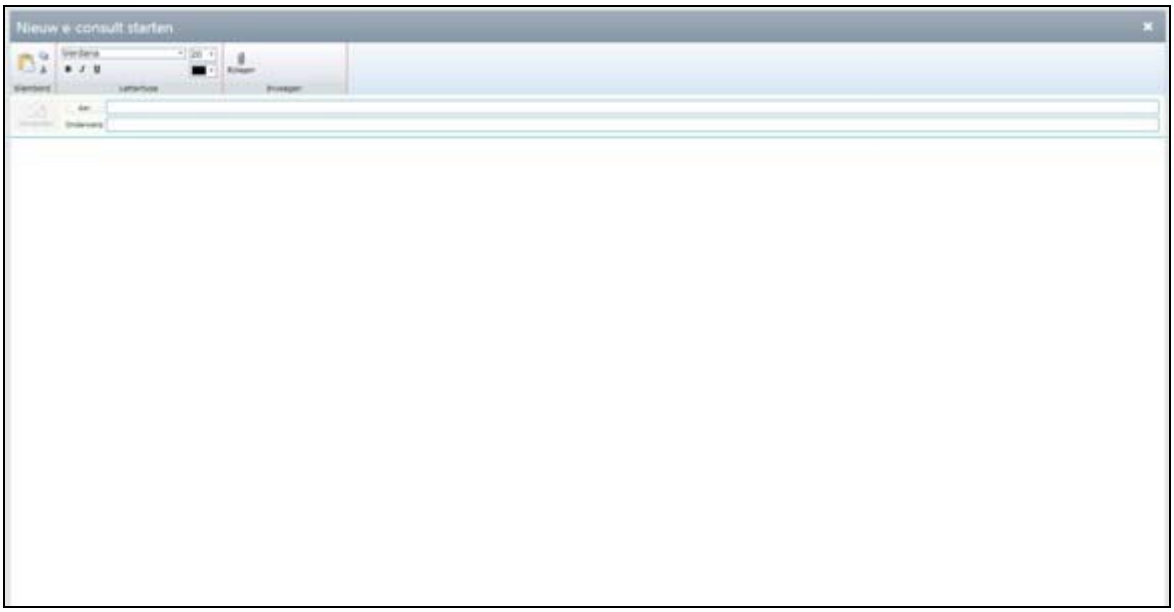



**Image 4** Task 3a – e-consult

**Image 5** Task 3b – place to add an e-consult



# Appendix B Screen shots of the discussion board for patients with rheumatic diseases

**Image 6** Task 4 – homepage discussion board

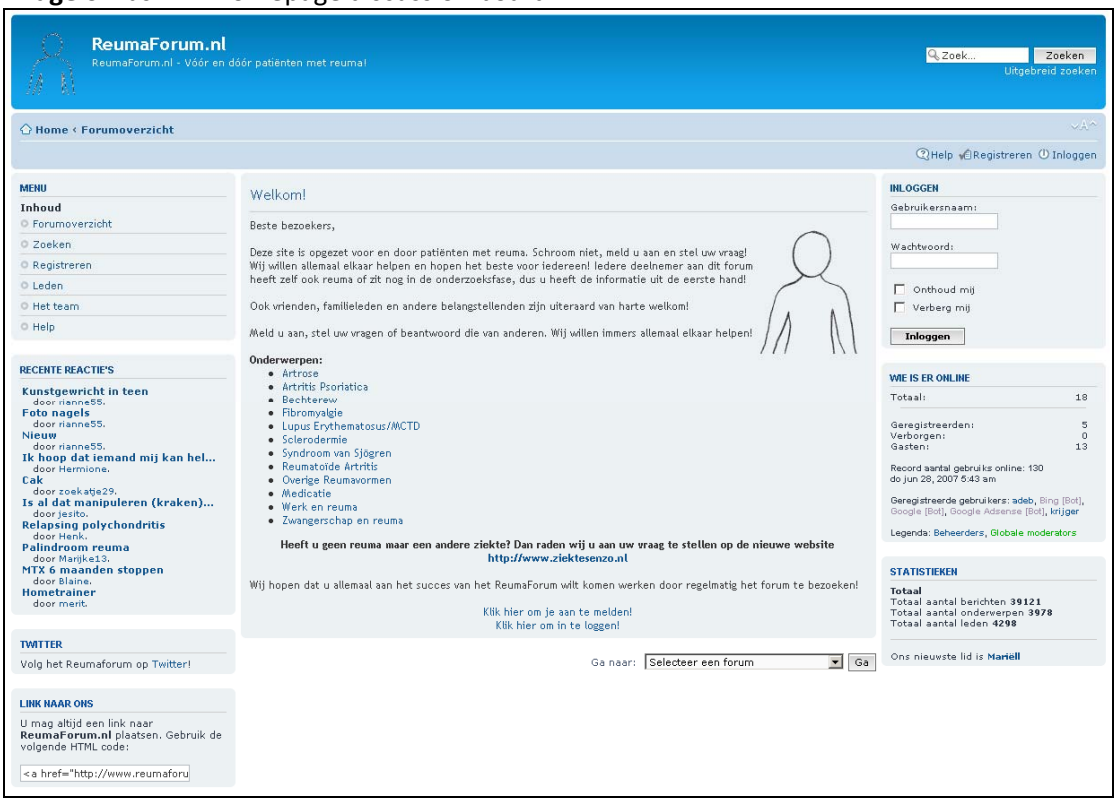
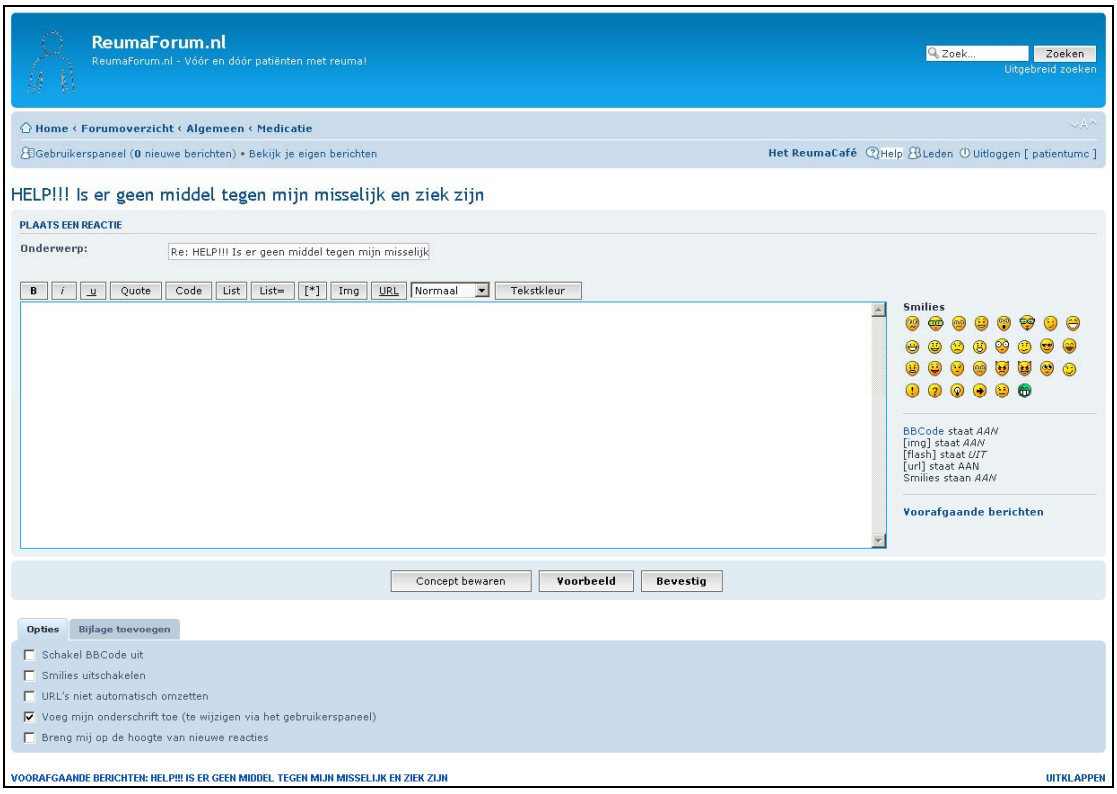



**Image 7** Task 4b – place to add own experience or question



# Appendix C Screen shots of the health care rating website

**Image 8** Task 5a - reviews about UMC Utrecht

**Image 9** Task5b – place to add a review