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Faculty of Spatial Sciences

MASTER THESIS

Needs of community-living older adults for adopting a personal health record

NOA HOOGTEIJLING

S2960915
Master Population Studies
UMCG, Department of Health Sciences
UMCG-mentor: M. Jager
RUG-mentor: Prof. Dr. Ir. H.H. Haisma
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Preface

You are about to read my master thesis about the needs of community-living older adults for adopting a personal health record. This thesis was written as final product to complete the master Population Studies at the University of Groningen. I had the opportunity to conduct my research during my internship at the University Medical Center Groningen (UMCG). I would like to thank my UMCG supervisor Margot Jager for the feedback she gave me and the questions she was always willing to answer. In addition, I want to thank Klaske Wynia for providing me with feedback and giving me the opportunity to do an internship at the UMCG. Furthermore, I want to thank my main supervisor Hinke Haisma for providing me with the quickest feedback possible and for stimulating me to bring my thesis to a higher level. I also want to thank Hinke for reciting me for a key-note speech, which gave me the opportunity to present my results for a big audience during the Graduate Research Day at the University of Groningen. Finally, I would like to thank my parents, friends and boyfriend for their infinite support during this whole process. I hope you enjoy reading this thesis and that it will provide you with new insights!

Noa Hoogteijling

Groningen, July 17, 2018

Abstract

OBJECTIVE: To identify the needs of community-living older adults regarding a personal health record and to determine differences in those needs by health status (robust, frail, complex care needs), health literacy and computer literacy.

SUBJECTS AND METHODS: A questionnaire was send to 600 Dutch community-living older adults aged 75 years or older and living in the municipality of Emmen. Data was collected on the needs regarding a PHR, health literacy and computer literacy. Secondary data was used to determine the health status of the older adults. The technological needs that were assessed were: accessibility of medical records on the computer (AMR), online communication with the healthcare professional (CHP), receiving information and advice (RIA), working on your own health (WOH), confidentiality and privacy (CP), and accessibility and user-friendliness (AUF).

RESULTS: 288 older adults (48%) completed the questionnaire, with a mean age of 82.9 years. Community-living older adults reported the need for: AMR, RIA, WOH, CP, and AUF. Limited need was found for CHP. Frail older adults (n= 92, 31.9%) reported lower needs for CHP, WOH, and AUF, compared to robust older adults (n= 106, 36.8%) and older adults with complex care needs (n= 90, 31.3%). Older adults who had no intention to use a PHR, reported to have the need for AMR and CP. Older adults with high functional health literacy and high computer literacy were more likely to have the intention to use a PHR.

CONCLUSION: Community-living older adults indicated to have the need for AMR, RIA, WOH, CP, and AUF. Older adults with no intention to use a PHR, nevertheless reported the need for AMR and CP. Efforts to increase the user-rates of the PHR among older adults should address the needs that are identified by this study.

Keywords: PHR; community-living older adults; needs; health status; health literacy; computer literacy

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List of abbreviations

AAHLS	All Aspects of Health Literacy Scale
AMR	Access to Medical Records on the computer
AUF	Accessibility and User-Friendliness
CHP	Communication with Healthcare Professionals
CP	Confidentiality and Privacy
EHR	Electronic Health Record
GFI	Groningen Frailty Indicator
IFSMT	Individual and Family Self-Management Theory
IBM	Integrate Behavior Model
PHR	Personal Health Record
PHRAM	Personal Health Records Adoption Model
RIA	Receiving Information and Advice
SCT	Social Cognitive Theory
SES	Social Economic Status
UTAUT	Unified Theory of Acceptance and Use of Technology
WOH	Working on your Own Health

1. Introduction

A personal health record (PHR) is a tool that provides individuals with a complete online overview of all their health records and allows them to manage their own health information and to share this information with several healthcare providers. While previous research showed that the majority of the Dutch population is interested in using a PHR, user-rates of existing PHR initiatives are still low, especially among older adults (Pluut, 2012). Older adults were not involved during the development of the current PHR's, which caused a gap between what the PHR's offer today and what the needs of older adults are regarding a PHR (Kneale, & Demiris, 2017). As long as this disparity exists, it is unlikely that the user-rates of a PHR by older adults will increase.

The definition of a PHR most cited by scientists is: 'A set of computer-based tools that allow people to access and coordinate their lifelong health information and make appropriate parts of it available to those who need it (Markle foundation, 2006).' A PHR distinguishes itself from the already existing Electronic Health Record (EHR) by that it is controlled by the individual instead of the different healthcare providers. The individual determines which records will be included in their PHR and who can get access to those records. Individuals can also add information themselves to their PHR. This could be self-measured data, such as blood pressure, heart rate and weight, but also communication records with the healthcare provider. Functionalities of a PHR are amongst others, access to the medication list, access to personalized medical information, online ordering (repeat) recipes, references, online consultations and receiving personalized advice (Pluut, 2012).

A PHR promotes self-management and can be used to improve and manage the individual's health conditions (Kool, Verhoef, & Kremer, 2014; Kruse, 2015). Furthermore, if individuals have the possibility to get access to and control their medication list, medication errors could be reduced (Turvey et al., 2012). Medication intake notifications help individuals to remember to take their medication on time, which will increase therapy compliance. Another potential benefit is the improvement of the communication between the individual and the healthcare provider. A PHR makes contact with the healthcare provider easier and more accessible for example by using online consultations. Also, subjects that are more sensitive are discussed more easily during an online consultation (Wakefield et al., 2010).

Older adults generally have a higher need for medical care and a higher risk on chronic conditions (Taha, Cjaza, Sharit, & Morrow, 2013). People with chronic conditions receive more often care from different healthcare providers and could therefore potentially benefit of a complete overview of their medical information provided by a PHR. Not only older adults with health problems could benefit from a PHR, but also healthy older adults. Personalized advice could entail recommendations regarding daily exercising and healthy eating to promote a healthy lifestyle and prevent health problems.

So far, limited research has been conducted on PHR's, and even less with a specific focus on

older adults and their needs. Most of the research that focused on the effects of a PHR neglected the fact that a PHR is developed for the individual and should therefore also be tailored to the wishes of the individual. The aim of this study is to give insight in the needs of older adults regarding a PHR. To examine the needs of older adults for adopting a PHR, the following overall research question was formulated:

What are the needs of community-living older adults for adopting a PHR?

Previous research showed that besides age, inadequate health literacy is also a barrier for the use of a PHR (Pluut, 2012; Sarkar et al., 2010). People with inadequate health literacy are less likely to make use of a PHR. Furthermore, Pluut (2012) also showed that people with chronic conditions are more likely to use a PHR. To examine if the needs of older adults and the intention to use a PHR are associated with health literacy, health status and other socio-demographic factors, such as age, gender and living environment, the following sub-questions were formulated:

a. To what extent is health literacy of community-living older adults associated with their needs regarding a PHR?

b. To what extent is the health status of community-living older adults associated with their needs regarding a PHR?

c. To what extent are socio-demographic factors associated with the intention of community-living older adults to use a PHR?

d. To what extent are the needs of community-living older adults regarding a PHR associated with their intention to adopt a PHR?

2. Theoretical framework

This section gives an insight in the already existing theories and previous research findings related to the use of a PHR in general and in particular among older adults. First, the theory of Logue and Effken (2012) will be highlighted, followed by a literature review according to the concepts of the model of Logue and Effken (2012). Based on the theory and the literature review a conceptual model is constructed and hypotheses are formulated.

2.1 Theory

Logue and Effken (2012) developed the Personal Health Records Adoption Model (PHRAM) to identify the barriers and facilitators that influence the adoption of a PHR among chronically ill older adults. The model was validated by a panel of 16 experts, who reached consensus about the variables that are included in the PHRAM (Logue, & Effken, 2013).

The PHRAM is constructed by the incorporation of different existing theories. The base consists of elements of the Social Cognitive Theory (SCT), which assumes bi-directional interactions between personal factors, the environment and behavior. Other theories that are incorporated in the PHRAM are the Unified Theory of Acceptance and Use of Technology (UTAUT), the Individual and Family Self-management Theory (IFSMT), and the Integrated Behavior Model (IBM).

The central outcome of the model is behavior, which is defined by the intention to adopt a PHR or the actual use of a PHR. This behavior is influenced by personal factors, environmental factors, chronic disease factors and technology factors (see figure 1). These four factors interact also bi-directional with each other.
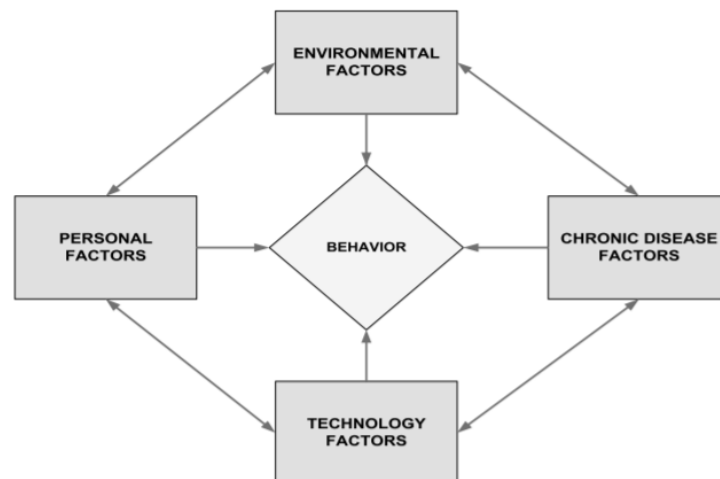

Figure 1 - PHRAM model by Logue and Effken (2012)

- Personal factors

The variables that are included in the category personal factors are: age, ethnicity, gender, E-health literacy, education level, communication preferences, self-efficacy, knowledge and skills, attitude and outcome expectations. Personal factors interact with environmental and technology factors and

influence the intention to adopt or the actual use of a PHR. Some of the personal factors are non-modifiable, such as ethnicity and gender, but other variables could be learned and developed, such as E-health literacy, knowledge and skills.

- Environmental factors

The variables that are included in the category environmental factors are: facilitating conditions, incentive motivation and social influence. Environmental factors interact with personal and chronic disease factors. Technology factors are actually part of environmental factors, but Logue and Effken (2012) included it as a separate category in their model to emphasize its importance.

- Technology factors

The variables that are included in the category technology factors are: perceived usefulness, alternative strategies, complexity, trialability, observability, compatibility, cost, design variables, relative advantage, perception of external control and privacy controls. Technology factors interact with personal and chronic disease factors.

- Chronic Disease factors

The PHRAM is developed specifically for older adults with a chronic disease. Therefore, chronic disease factors are included in the model as a separate category, instead of part of the personal factors. The variables that are included in the category chronic disease factors are: attitudes on negotiated collaboration, perceived complexity of condition, access to care, number of healthcare providers, number of healthcare settings, perceived complexity of treatment, preferences for self-regulation, self-management and number of chronic diseases. Chronic disease factors interact with environmental and technology factors.

The PHRAM fits well with the research questions that are examined in this study. The scope of the PHRAM is more extensive than the scope of this study. This implies that not all the variables of the PHRAM will be examined in this study. However, most of the concepts in this study can be related to one of the four categories of the model.

The central outcome variable of the model (behavior) is similar to the outcome variable in this study: the intention to adopt a PHR. However, where the model also includes the actual use of a PHR as outcome variable, this variable has not been included in this study. Only data was collected on the intention of older adults to adopt a PHR not on the actual use of a PHR. The personal factors that will be examined in this study are health literacy, computer literacy and the health status. Furthermore, the association between different socio-demographic factors, such as age, sex and the intention to adopt a PHR are also covered by the personal factors. Logue and Effken (2012) included health literacy in the model as part of the personal factors. In this study the focus will be on health literacy and computer literacy, which are elements of eHealth literacy (Norman, Skinner, & Psych, 2006).

Where the model includes chronic disease factors as a separate category and focuses specifically on older adults with a chronic disease, this study also includes older adults who are not chronically ill. A distinction is made between robust older adults, frail older adults and older adults with complex care needs. This classification is used for all the participants in Embrace (Spoorenberg et al., 2013). The older adults with complex care needs suffer from one or more chronic conditions, but the older adults in the other groups are not chronically ill. The environmental factors that are included in this study are the facilitating conditions such as internet access and computer possession and the rural or urban living environment of the older adults.

The technology factors are in this study defined as the technological needs regarding a PHR. The different technological needs of a PHR that are examined are: accessibility of medical records on the computer, online communication with healthcare providers, receiving information and advice, working on your own health, confidentiality and privacy, accessibility and user-friendliness, and perceived usefulness. Some of these technological factors are also included in the PHRAM, such as privacy and observability. However, the other technological factors are not specifically described by the model but are also technological functionalities of a PHR that could influence the adoption of a PHR.

2.2 Literature review

So far, little research has been done regarding the adoption of a PHR among older adults. Also, almost all of the research is conducted in America. The subdivision of Logue and Effken (2012) in personal, environmental, chronic disease and technology factors will be used to describe the findings of the literature review. Most of the research conducted mainly focused on the effects of personal factors on the adoption of a PHR with less attention for the environmental factors, technology factors and chronic disease factors. While many articles focus on continuation of the use of a PHR, the focus in this literature review will be primarily on studies that focus on the adoption of a PHR.

- Personal factors

The personal factors described by Logue and Effken (2012) included age, sex, ethnicity, eHealth literacy, education level and income. Multiple articles described the effects of these personal factors on the adoption of a PHR.

Goel et al. (2011) found that individuals who were 65 years and older, were less likely to adopt a PHR. However, if older adults adopted a PHR they were more likely to use it more often compared to individuals who were younger than 35 years. This is in line with the research of Sarkar et al. (2011) who found that older adults were less likely to request a password for a PHR, but when they did they were more likely to login more often, as compared to younger users. They suggest that this could be caused by increasing health care needs among older adults.

Another personal factor that influences the adoption of a PHR is ethnicity. While previous

studies differ in the specific ethnicities that were examined, there seems to be consensus that whites are most likely to adopt a PHR. Yamin et al. (2011) found that adoption of a PHR was less likely by individuals who were black or Hispanic, compared to whites. Besides blacks and Hispanics, research showed that Asians were also less likely to adopt a PHR (Goel et al., 2011). In the research of Sarkar et al. (2011), African-Americans and Latinos were more likely to never login on a PHR compared to white individuals. This was adjusted for age, gender, race/ethnicity, immigration status, educational attainment and employment status (Sarkar et al., 2011). All these studies were conducted in the US and may therefore not be applicable to the Netherlands.

Most of the research conducted refers to health literacy instead of eHealth literacy and some of the studies take into account computer literacy. Noblin, Wan and Fottler (2012) found that individuals with higher health literacy levels were more likely to adopt a PHR, compared to individuals with lower health literacy levels. Health literacy levels were measured by the use of the eHealth Literacy Scale (eHEALS), which is a subjective questionnaire. This could have led to an overestimation or underestimation of the health literacy levels. Day and Gu (2012) found that high health literacy levels not only increases the likelihood of adopting a PHR, but that high health literacy levels and computer literacy levels also lead to a more effective use of the PHR. Kim (2016) stated that an increase of health literacy skills will be necessary for the adoption of the PHR by different population groups.

The effects of educational level and income on the adoption of PHR are sometimes examined separately, but are often taken together as social economic status (SES). Yamin et al. (2011) used annual household income as indicator for SES and found that individuals with a higher annual income were more likely to adopt a PHR. Lower educational level was found to have a negative effect on internet and computer access (Kruse et al., 2012). Sarkar et al. (2011) also found that individuals with lower educational levels were less likely to request a password for the PHR.

There seems to be inconsistency in the literature about the association between sex and adoption of a PHR. Chrischilles et al. (2014) found that men were more likely to adopt a PHR, but Yamin et al. (2011) found that men were less likely to adopt a PHR. However, Logue and Effken (2012) found that men felt more confident in using a PHR, which seems to indicate that men are more likely to adopt a PHR.

- Chronic disease factors

Patients with a chronic condition are less likely to have internet access (Yamin et al., 2011). Furthermore, Kruse et al. (2012) found that individuals who reported their health status as very good, were more likely to make use of internet. However, Yamin et al. (2011) found also that adoption of a PHR is more likely among patients with chronic conditions. This suggests that if patients with a chronic condition have access to internet, they will make more use of a PHR due to their chronic condition.

Furthermore, Emani et al. (2012) found that patients with multiple diseases were more likely to adopt a PHR.

- Environmental factors

Environmental factors include internet and computer access, as requirements to be able to adopt a PHR. Yamin et al. (2011) found that racial and ethnic minorities, people with a lower income and older adults have less often access to internet. This is in line with the finding that these population groups are less likely to adopt a PHR (Goel et al., 2011; Yamin et al., 2011).

Another environmental factor is the living environment of the older adults. Roblin, Houston, Allison, Joski and Becker (2009) found that individuals in rural areas have less internet or computer access and have lower levels of computer literacy, compared to individuals who live in urban areas. However, this research was conducted in America and may not be applicable to the situation in the Netherlands.

- Technological factors

Several technological factors were identified regarding a PHR. However, no research was found which focused specifically on the needs of older adults regarding the technological factors of a PHR. Therefore, the findings that are described are general technological needs of individuals for adopting a PHR and not specifically the technological needs of older adults.

Liu, Shih and Hayes (2011) found that many persons that made use of a PHR found it too complicated. The participants argued that the amount of information that can be obtained by the PHR is too extensive and should be organized in a better way. Furthermore, too much medical jargon was used which was experienced as too difficult to understand.

Also, confidentiality and privacy was found to be an important technological need for adopting a PHR (Liu et al., 2011). Most of the people would not be concerned about the confidentiality of the data if the PHR was operated by a major technology company. However, some others would be concerned if a PHR was managed by for example Google as they thought that also PHR information would become searchable online (Liu et al., 2011). Privacy concerns were also identified by Tang, Ash, Bates, Overhage and Sands (2006) and Anderson (2004). While reliable login systems are prioritized by the individuals, this could also lead to less easy access to the PHR.

All the participants of the study of Liu et al. (2011), were optimistic about sharing their personal health information with healthcare providers and agreed that this would be an valuable addition to the PHR.

Furthermore, Santana et al. (2010) found that individuals find it also important that a PHR offers the possibility of viewing laboratory results, ordering or renewing prescriptions, communication with the health professionals and viewing a medicines and diagnosis list. Kahn et al. (2009) found that adoption rates could be improved by increasing the number of functionalities a PHR provides.

2.3 Conceptual model

The conceptual model (see figure 2) is based on the relationships found between different aspects in the literature and the theory described earlier. The central outcome of the model is the intention to adopt the PHR. This is influenced by personal factors, environmental factors, health status and technological factors. The personal factors included are: age, sex, health literacy and computer literacy. The environmental factors included are: internet access and rural/urban living environment. The health status is categorized in: robust older adults, frail older adults and older adults with complex care needs. The technological factors included are: accessibility of medical records on the computer, online communication with healthcare providers, receiving information and advice, working on your own health, confidentiality and privacy, and accessibility and user-friendliness. The research questions that will be examined during this study are visualized in the conceptual model by their corresponding letters a – d.
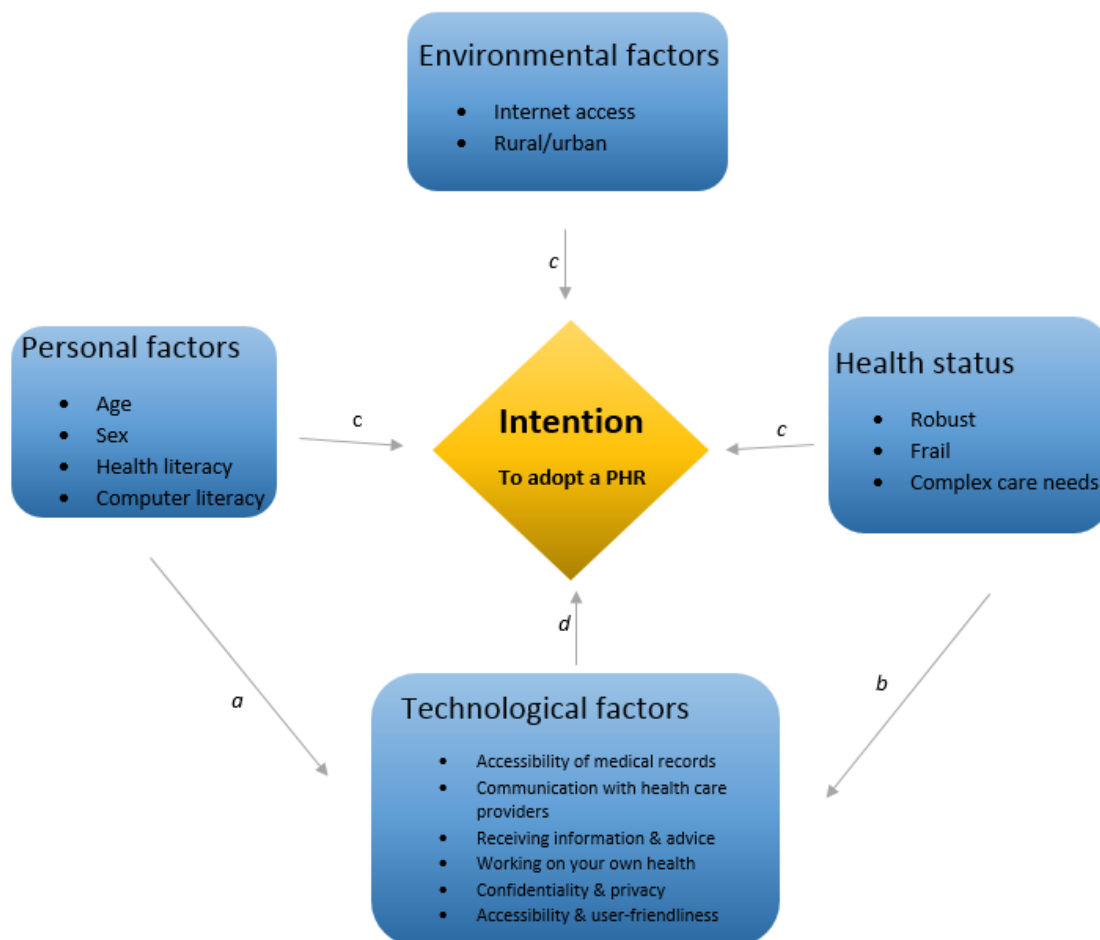

Figure 2 – Conceptual Model (Adjusted PHRAM model from Logue and Effken, 2012)

2.3 Hypotheses

Based on the theory and previous research the following hypotheses are formulated:

a. Older adults with higher health literacy and computer literacy levels will have higher technological needs regarding a PHR.
b. Older adults with a better health status will have lower technological needs regarding a PHR.
c. Socio-demographic factors are associated with the intention to adopt a PHR.
    i. A higher age is negatively associated with the intention to adopt a PHR.
    ii. Males are more likely to adopt a PHR.
    iii. Older adults with high health literacy and computer literacy levels are more likely to adopt a PHR.
    iv. Older adults with a worse health status are more likely to adopt a PHR.
    v. Internet access will have a positive effect on the intention to adopt a PHR.
    vi. Older adults living in urban areas will be more likely to have the intention to adopt a PHR.
d. Older adults with the intention to adopt a PHR will have higher technological needs.

3. Methods

3.1 Study design

A mail questionnaire (see appendix) about the PHR was used to collect the data. The questionnaire had already been developed, but questions about health literacy were added for this study. The questions included in the questionnaire were based on a literature study and a focus group study among older adults, which was held prior to this research. The questionnaire was piloted (n=3) and after small adjustments the final questionnaire consisted of 56 questions: 40 questions about the PHR, 10 about health literacy and 6 additional closing questions. The questions that were included in the questionnaire could be subdivided into twelve different sub-sections (see Table 1). Secondary data was used to determine the health status (robust, frail, complex care needs) and the living environment of the older adults (rural/urban).

Table 1 - Questionnaire themes

Section	Sub-section	Questions	# of questions
Technological Needs	Accessibility of medical records on the computer	1-3	3
	Communication with healthcare providers	4-8	5
	Receiving information and advice	9-12	4
	Working on your own health	13-15	3
	Confidentiality and privacy	16-18	3
	Accessibility and user-friendliness	19-24	6
Usefulness	Perceived usefulness	25-28	4
Internet use	Internet and technology use	29-40	12
Health literacy	Functional Health Literacy	41-43	3
	Communicative Health Literacy	47-49	3
	Critical Health Literacy	50-53	4
Closure questions	Demographic information	1-6	6

The closure questions collected data on: sex, date of birth, date of completing the questionnaire and if someone received help with filling in the questionnaire. The questions included in the section technological needs had a 5-point Likert scale rating from 'Not important at all' to 'Very important'. The answer scale of the other themes differed slightly with a 2-point answer scale, 3-point answer scale or multiple options.

3.2 Sample

The participants that were selected for this study were all participants in Embrace (SamenOud in Dutch). Embrace is an integrated care model, with the aim of integrating various approaches, resources and policies in the care for older adults (Spoorenberg et al., 2013). From this research population, 600 community-living older adults were selected at random and proportionally selected based on sex, gender, living environment and health status. The participants were residing in the municipality of Emmen and had an age of 75 years or older. The older adults received the questionnaire by mail with a stamped envelope to send the questionnaire retour. From the 600 participant who received a questionnaire, 288 participants completed the questionnaire and sent it retour, which corresponds with a response rate of 48%. Twenty-one questionnaires were send retour unanswered due to moving (n=9), death (n=5) or other reasons (n=7). The remaining 291 questionnaires were not completed or sent retour at all.

3.3 Operationalization

3.3.1 Technological needs

Definition

The concept 'Needs' does not have an unambiguous definition. Several different views exist on what needs are. Needs in healthcare generally refers to the capacity to benefit (Wright, Williams, & Wilkinson, 1998). In the literature, a distinction can be found in felt needs, expressed needs and normative needs. Felt needs are the needs that individuals themselves indicate as needs, expressed needs are needs which are expressed in action and normative needs are the needs defined by (healthcare) professionals (Grant, 2002). In this study, the needs will be assessed from the perspective of the older adults, in line with the qualitative study that was held prior to this study to identify the existing needs among older adults. The needs of the older adults can therefore in this study be defined as felt needs. The definition of felt needs is: 'Changes deemed necessary by people to correct the deficiencies they perceive in their community' (Wade, 2009). In this study, the felt needs are the technological needs regarding a PHR that older adults themselves indicate as needs.

Measurement

The questionnaire contained 24 different potential technological needs regarding a PHR, which are subdivided into the six following sections: accessibility of medical records on the computer (questions 1-3), communication with the healthcare providers (questions 4-8), receiving information and advice (questions 9-12), working on your own health (questions 13-15), confidentiality and privacy (question 16-18) and accessibility and user-friendliness (questions 19-24). Participants were asked to state how important they found each of those technological needs by choosing one of the answer categories on a 5-point Likert-scale ranging from 'Not important at all' to 'Very important'.

3.3.2 Health literacy

Definition

The definition of health literacy followed by the World Health Organization (WHO) is the definition of Nutbeam (1988): 'Health literacy represents the cognitive and social skills which determine the motivation and ability to gain access to, understand and use information in ways which promote and maintain good health.' Health literacy can be subdivided into functional, interactive and critical health literacy (Nutbeam, 2000). Functional health literacy includes the basic competences for reading and writing to be able to function well in daily life. Interactive literacy refers to more advanced literacy, cognitive competences and social competences, which are needed to engage in daily activities, gain information and apply new information to changing circumstances. Critical health literacy refers to more advanced cognitive competences, which together with social competences are applied to analyze information critically and to execute control on important life-events (Nutbeam, 2000).

Measurement

Nine questions about health literacy were included in the questionnaire, subdivided in functional health literacy (questions 41-43), communicative health literacy (questions 47-49) and critical health literacy (questions 50-53). The questions that measured functional health literacy are existing screening questions for inadequate health literacy formulated by Chew, Bradley and Boyko (2004) and have a 5-point answer scale. The questions that measured communicative and critical health literacy are from the All Aspects of Health Literacy Scale (AAHLS) and have a 3-point answer scale. The AAHLS has a Cronbach's alpha of 0.74, which indicates an adequate reliability of the measurement scale (Altin, Finke, Kautz-Freimuth & Stock, 2014).

3.3.3 Health status

Participants of Embrace received each year a questionnaire that included questions about the complexity of their care needs and their degree of vulnerability. Complexity of care needs was measured by the INTERMED self-assessment test (Huyse et al., 1999) and the degree of vulnerability was measured by the Groningen Frailty Indicator (GFI) (Steverink, Slaets, Schuurmans, & van Lis, 2001). Based on the outcome of these measurements, community-living older adults were allocated into one of the following risk groups:

- o <u>Robust older adults</u> have no or little health-related problems, but do have an increased risk of health-related problems as a consequence of aging
- o <u>Frail older adults</u> are experiencing more and more health-related problems and are becoming increasingly dependent of resources and others. They also have a higher risk of complex care needs

- o <u>Older adults with complex care needs</u> usually suffer from multiple chronic conditions and receive often care and guidance from multiple healthcare providers. They also have an increased risk of admission to a hospital or a nursing home

Participants who had an INTERMED-score below 16 and a GFI-score below 5 were divided into the risk group of robust older adults. Participants who had an INTERMED-score below 16 and a GFI-score equal or higher than 5 were divided into the risk group of frail older adults. Participants who had an INTERMED-score equal or higher than 16 and a GFI-score equal or higher than 0 were divided into the risk group of older adults with complex care needs.

3.3.4 Other variables

- The intention to adopt a PHR was determined by question 26: 'Would you like to use a personal health record?'. The three possible answer categories were: Yes, No and Maybe.
- The current age was calculated by subtracting the date of birth from the date of completing the questionnaire. Seven participants did not fill in the date of completing the questionnaire. The mean date 12.04.2018 was filled in for those participants.
- Participants living in the city of Emmen were defined as 'urban' participants and participants living in the surrounding villages were defined as 'rural' participants.
- Computer literacy was measured by question 40: 'How easy can you handle devices such as a tablet, mobile phone or computer?'. The five possible answer categories were: Not at all, Minimal, A little, Easily and Very easily.
- Internet access was determined by question 30: 'Do you have an internet connection at home?'. The three possible answer categories were: Yes, No and I don't know.

3.4 Quality of data

Not all questions included in the questionnaire were validated. The questions about functional, communicative and critical health literacy were derived from the validated measurements AAHLS and the questions formulated by Chew et al. (2004). The other questions included in the questionnaire were primarily based on outcomes of a focus group, which was held prior to this research and on literature study and were not validated.

The use of an invalidated questionnaire causes uncertainty about the ability of the questionnaire to measure what it is intended to measure.

The questionnaire consisted of closed questions, which increased the consistency of the instrument. Furthermore, close-ended questions lead to more adequate answers and less missing data, compared to open-ended questions (Reja, Lozar Manfreda, Hlebec, & Vehovar, 2003). However, closed-questions may not capture all the answer possibilities that are present so that useful data could be lost.

3.5 Plan of analysis

First, the entered data in SPSS was checked on incorrect and missing values. Incorrect values were replaced by the right values or otherwise coded as missing values. List wise deletion was applied to the data set for further analysis. After the data set was prepared for analysis, descriptive statistics were given for the total population as well as for the different subgroups: robust older adults, frail older adults, and older adults with complex care needs. The means ($\bar{x}$) and standard deviations (SD) were assessed or the number of participants (n) and the accompanied percentages were given. Characteristic differences between the respondents and non-respondents were calculated using the Mann-Whitney U test and chi-square test.

The Cronbach's Alpha was calculated to examine if the questions subdivided into the different sections could be merged to one scale. The Cronbach's Alpha was calculated for all the 24 questions about the technological needs. At least 50% of the questions had to be answered to calculate the mean. For example, for the questions about the accessibility of medical records on the computer, two out of three questions had to be answered to calculate the mean for one scale.

The outcome variable was not normally distributed, so the non-parametric test Friedman's ANOVA was used to examine if the means of the technological needs were significantly different from each other. Mann-Whitney U tests were used as post hoc tests.

A Kruskal-Wallis test was used to examine if there was a difference in the needs for the three different health status groups (robust older adults, frail older adults, older adults with complex care needs). The Kruskal-Wallis test turned out to be significant for some of the needs, so Mann-Whitney U tests were used as post-hoc tests to find between which groups significant differences appeared.

Mann-Whitney U tests were also used to examine the associations between health literacy and computer literacy and the needs regarding a PHR. The 25th percentile was used as cut-off point to divide the participants according to low or high health literacy levels. The cut off point for functional health literacy was nine (scale 3-15) , for communicative health literacy seven (scale 3-9), for critical health literacy five (scale 4-12), and for computer literacy one (scale 1-5).

To determine differences between the three different intention groups (Yes, No, Maybe) on their needs, a Kruskal-Wallis test was used with Mann-Whitney U tests as post hoc tests.

Univariate and multivariate backward binary logistic regression and multinomial backward logistic regression were used to examine the association between the outcome variable intention to adopt a PHR and the independent socio-demographic variables: age, sex, living environment, internet access, health status, health literacy and computer literacy. A probability of 0.1 was set as a limit for variable removal in the backward regression. The intention variable was dichotomized as 'Yes' or 'No' and the answer category 'Maybe' was left out to be able to perform the binary logistic regression. All statistical analyses were performed with the use of SPSS 25.0 for Windows (SPSS Inc., Chicago, IL, USA) and a p-value below 0.05 was considered as significant.

3.6 Ethics

This research was conducted within the research population of Embrace. METC-permission and informed consent was obtained for all the participants that participated in Embrace. Participants had the right to refuse participation at all times. Besides informed consent, also minimization of harm and anonymity and confidentiality are important ethical aspects that needed to be considered. Minimization of harm was considered during participant recruitment and data collection. This research consisted of questionnaires, which excluded possible physical harm as a consequence of the research that was conducted. Mental harm was also not likely, because the questionnaire was about the importance of a PHR. This is generally not perceived as a sensitive topic. Confidentiality was guaranteed by anonymizing the data by providing each participant a research number, which was used for further analysis of the data.

4. Results

4.1 Internal consistency of the questionnaire

The Cronbach's α found for the technological needs were all higher than 0.8 (see table 2), which indicates good internal consistency (Tavakol & Dennick, 2011). The Cronbach's α for functional, communicative and critical health literacy were all between 0.7 and 0.8 and therefore indicates acceptable internal consistency (George & Mallarey, 2003). As all sections had good or acceptable internal consistency, means were calculated for each technological need and sum scores were calculated for functional, communicative and critical health literacy. The calculated means and sum scores were used in the further analysis.

Table 2 - Cronbach's Alpha for the technological needs and health literacy

Section	Cronbach's α
Accessibility of medical records on the computer (AMR)	0.95
Communication with healthcare providers (CHP)	0.93
Receiving information and advice (RIA)	0.93
Working on your own health (WOH)	0.82
Confidentiality and privacy (CP)	0.84
Accessibility and user-friendliness (AUF)	0.91
Functional health literacy	0.73
Communicative health literacy	0.77
Critical health literacy	0.78

4.2 Non-response

The personal characteristic differences between respondents and non-respondents are displayed in Table 3. Non-respondents were older with a mean age of 84.2 years, compared to the respondents who had a mean age of 82.9 years, $U = 37969$, $p < 0.01$. Furthermore, the non-respondent group consisted of a higher percentage female, $x^2(1) = 8.195$, $p < 0.01$. 60.3% was female among the non-respondents and 48.6% among the respondents. No differences were found between the two groups for health status and living environment.

Table 3 - Characteristic differences between respondents and non-respondents

	Response	Non-response	Δ n (%)	p
Participants, n (%)	288	312	24	-
Age in years, mean (SD)	82.9 (4.5)	84.2 (5.0)	1.3	0.001**
Female, n (%)	140 (48.6)	188 (60.3)	48 (11.7)	0.004**
Emmen, n (%)	153 (53.1)	147 (47.1)	6 (6)	0.141
Complex care needs, n (%)	90 (31.3)	110 (35.3)	20 (4)	0.218
Frail, n (%)	92 (31.9)	108 (34.6)	16 (2.7)	0.218
Robust, n (%)	106 (36.8)	94 (30.1)	12 (6.7)	0.218

** $p < 0.01$

4.3 Characteristics of respondents

Descriptive statistics for the total group and for the different health status groups are displayed in Table 4. The majority of the participants was male and lived in the city of Emmen. The mean age of the total group was approximately 83 years and 71.7% of the older adults had access to internet. Nearly 30% of the participants answered 'Yes' to the question if they would like to use a PHR. Kruskal-Wallis tests showed that the health status groups differed significantly from each other on age (x^2 (2) = 11.027, $p < 0.01$), functional health literacy (x^2 (2) = 10.119, $p < 0.01$), and critical health literacy (x^2 (2) = 9.331, $p < 0.01$). Frail older adults were older compared to robust older adults ($U = 3578.5$, $p < 0.01$) and older adults with complex care needs, $U = 3298.5$, $p < 0.05$. Robust older adults had higher functional health literacy levels, compared to frail older adults, $U = 2902$, $p < 0.01$. The functional health literacy levels did not differ between robust older adults and older adults with complex care needs. Frail older adults scored the lowest on critical health literacy, compared to robust older adults ($U = 3094$, $p < 0.05$) and older adults with complex care needs, $U = 2638.5$, $p < 0.01$. Also, on critical health literacy no difference was found between robust older adults and older adults with complex care needs. The different health status groups did not differ from each other on gender, living in Emmen, internet access, communicative health literacy, computer literacy and the intention to use a PHR.

Table 4 - Participant characteristics for the total group and by health status

	Total	Complex care needs	Frail	Robust	*p*
Participants, n (%)	288 (100)	90 (31.3)	92 (31.9)	106 (36.8)	
Age in years, mean (SD)	82.9 (4.5)	82.5 (4.2)	84.2 (4.8)	82.1 (4.1)	0.004**
Female, n (%)	140 (48.6)	44 (48.9)	49 (53.3)	47 (44.3)	0.455
Emmen, n (%)	153 (53.1)	46 (51.1)	51 (55.4)	56 (52.8)	0.841
Internet access, n (%)	200 (71.7)	63 (72.4)	59 (65.6)	78 (76.5)	0.242
Functional health literacy, mean (SD)	10.6 (3.0)	10.5 (3.1)	9.9 (3.2)	11.4 (2.6)	0.006**
Communicative health literacy, mean (SD)	7.9 (1.4)	8.1 (1.2)	8.0 (1.4)	7.7 (1.6)	0.290
Critical health literacy, mean (SD)	6.6 (2.1)	7.0 (2.2)	6.0 (1.8)	6.9 (2.2)	0.009**
Computer literacy, mean (SD)	2.5 (1.3)	2.3 (1.1)	2.4 (1.3)	2.6 (1.3)	0.191
Intention to use (yes), n (%)	81 (28.1)	27 (30.0)	21 (22.8)	33 (31.1)	0.683

** p < 0.01

4.4 Technological needs

Table 5 shows the technological needs regarding a PHR for the total group and by health status. Significant differences were found for the total group for the mean scores of the different technological needs regarding a PHR, x^2 (5) = 294.398, $p < 0.01$. The highest need was found for accessibility of medical records on the computer ($\bar{x} = 3.87 \pm 0.95$) and the lowest need was found for communication with the healthcare provider ($\bar{x} = 2.86 \pm 1.0$).

When looking at the different health status groups, differences were found for the technological needs: communication with the healthcare provider ($x^2(2) = 6.85$, $p < 0.05$), working on your own health ($x^2(2) = 10$, $p < 0.01$) and accessibility and user-friendliness ($x^2(2) = 6.024$, $p < 0.05$). Robust older adults reported higher needs for communication with the healthcare provider ($U = 3217$, $p < 0.01$) and working on your own health ($U = 3270.5$, $p < 0.01$), compared to frail older adults. Frail older adults reported a higher need for accessibility and user-friendliness ($U = 2702$, $p < 0.05$), compared to older adults with complex care needs. No differences were found in the technological needs between robust older adults and older adults with complex care needs.

Table 5 - Needs regarding a PHR for the total group and by health status

	Total	Complex care needs	Frail	Robust	p
	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	
Accessibility of medical records on the computer	3.87 (.95)	3.97 (.83)	3.72 (1.15)	3.98 (.83)	0.536
Communication with the healthcare provider	2.86 (1.0)	2.88 (1.07)	2.63 (1.08)	3.05 (.96)	0.033*
Receiving information and advice	3.34 (1.0)	3.44 (.96)	3.16 (1.13)	3.40 (.93)	0.283
Working on your own health	3.06 (.91)	3.11 (.89)	2.85 (.95)	3.31 (.87)	0.007**
Confidentiality and privacy	3.53 (.95)	3.57 (.897)	3.47 (1.07)	3.59 (.87)	0.966
Accessibility and user-friendliness	3.18 (.91)	3.31 (.87)	2.96 (1.03)	3.24 (.82)	0.049*

*$p < 0.05$

**$p < 0.01$

Table 6 shows the differences in technological needs between older adults by health literacy and computer literacy levels. Older adults with high functional health literacy skills reported higher needs for communication with healthcare providers ($U = 4256$, $p = 0.000$), receiving information and advice ($U = 5169.5$, $p = 0.004$) and accessibility and user-friendliness ($U = 5242$, $p = 0.01$), compared to older adults with low functional health literacy skills. No differences were found between older adults with low and high functional health literacy skills for accessibility of medical records on the computer, working on your own health and confidentiality and privacy.

Older adults with high communicative health literacy, critical health literacy and computer literacy reported higher needs for all the technological needs: accessibility of medical records, communication with healthcare providers, receiving information and advice, working on your own health, confidentiality and privacy and accessibility and user-friendliness, compared to older adults with low communicative health literacy, critical health literacy and computer literacy levels.

Table 6 – Needs regarding a PHR by health literacy and computer literacy levels

	Functional health literacy			Communicative health literacy			Critical health literacy			Computer literacy		
	Low	High	p	Low	High	p	Low	High	p	Low	High	p
Accessibility of medical records	3.8 (0.96)	3.9 (0.92)	0.184	3.6 (1.19)	4.0 (0.80)	0.006**	3.6 (1.10)	4.0 (0.85)	0.004**	3.7 (1.2)	4.0 (0.9)	0.154
Communication with health care providers	2.4 (1.12)	3.1 (0.91)	0.000**	2.4 (1.10)	3.0 (0.99)	0.000**	2.3 (1.02)	3.1 (0.96)	0.000**	2.3 (1.1)	3.1 (0.9)	0.000**
Receiving information and advice	3.0 (1.16)	3.5 (0.90)	0.004**	2.9 (1.16)	3.5 (0.93)	0.001**	3.0 (1.12)	3.5 (0.93)	0.002**	2.9 (1.2)	3.5 (0.8)	0.000**
Working on your onw health	2.9 (1.07)	3.2 (0.82)	0.090	2.8 (1.06)	3.2 (0.86)	0.032*	2.7 (0.96)	3.2 (0.87)	0.000**	2.8 (1.1)	3.2 (0.8)	0.009**
Confidentialiy and privacy	3.3 (1.09	3.6 (0.87)	0.082	3.2 (1.09)	3.7 (0.85)	0.001**	3.3 (1.02)	3.7 (0.89)	0.006**	3.4 (1.1)	3.6 (0.9)	0.149
Accessibility and user-friendliness	2.9 (1.05)	3.3 (0.80)	0.010*	2.8 (1.05)	3.3 (0.81)	0.001**	2.9 (0.98)	3.3 (0.85)	0.001**	2.7 (1.1)	3.4 (0.7)	0.000**

*p < 0.05

**p < 0.01

4.5 Intention

Figure 3 shows the mean scores for the technological needs by the intention to use a PHR. The question to measure the intention was: 'Would you like to use a PHR?'.

Older adults who answered 'Yes' (n = 81), compared to older adults who answered 'No' (n = 87), reported significantly higher needs for all the technological needs: AMR ($U = 1587.5$, $p < 0.01$), CHP ($U = 1043$, $p < 0.01$), RIA ($U = 1200.5$, $p < 0.01$), WHO ($U = 1548.5$, $p < 0.01$), CF ($U = 1730$, $p < 0.01$) and AUF ($U = 1018$, $p < 0.01$). In addition, older adults who answered 'Maybe' (n = 109), compared to older adults who answered 'No', reported significantly higher needs for all the technological needs: AMR ($U = 3126.5$, $p < 0.05$), CHP ($U = 2125$, $p < 0.01$), RIA ($U = 2459$, $p < 0.01$), WHO ($U = 2887$, $p < 0.01$), CF ($U = 3322$, $p < 0.01$) and AUF ($U = 2479$, $p < 0.01$).
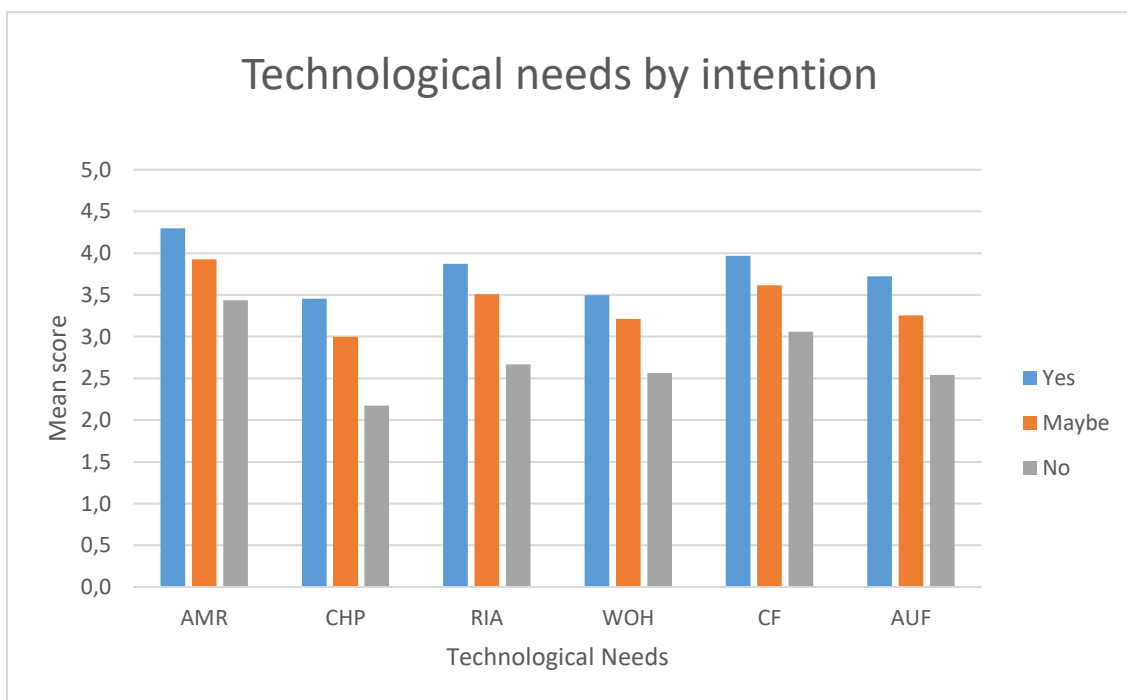

Figure 3 – Technological needs by intention to adopt a PHR

Furthermore, older adults with the intention 'Yes' or 'Maybe' had a mean score of higher than three on all the technological needs, which indicates that those older adults found every technological need important. Older adults with the intention 'No' scored only on accessibility of medical records on the computer and accessibility and privacy higher than three. They had a mean score lower than three for communication with healthcare providers, receiving information and advice, working on your own health and accessibility and privacy, which indicates limited needs for those technological needs.

Table 7 shows the outcomes of the univariate and multivariate backward logistic regression. The Hosmer and Lemeshow test did not turn out to be significant ($p = 0.20$), which indicates a good model fit. Functional health literacy and computer literacy were found to be associated with the intention to use a PHR. Older adults with low functional health literacy were 3.7 times more likely to have the intention 'No', compared to older adults with high functional health literacy. Older adults with low computer literacy were 4.5 times more likely to have the intention 'No', compared to older adults with high computer literacy.

Table 7 - Logistic regression analysis on associations between personal factors and the intention to adopt a PHR

	No intention to adopt a PHR[1]	
	Univariate OR (95% CI)	Multivariate OR (95% CI)
Age	1.0 (1.0, 1.1)	
Sex (male = 0, female =1)	0.7 (0.4, 1.3)	
Living environment (villages = 0, Emmen = 1)	1.0 (0.5, 1.8)	
Functional health literacy (0=low, 1=high)	5.4 (2.5, 11.4)**	3.7 (1.7, 8.3)**
Communicative health literacy (0=low, 1=high)	2.7 (1.4, 5.5)**	
Critical health literacy (0=low, 1=high)	2.5 (1.3, 4.9)**	
Computer literacy (0= low, 1=high)	7.2 (3.4, 15.3)**	4.5 (2.0, 10,0)**
Robust older adults[2]	0.8 (0.4, 1.8)	
Frail older adults[2]	1.4 (0.6, 3.0)	
Internet access (0 =yes, 1=no/don't know)	0.3 (0.2, 0.7)**	
Hosmer and Lemeshow Test (p-value)		0.20

** $p < 0.01$
[1]= reference category is: Intention to adopt a PHR
[2]= reference category is: Older adults with complex care needs

Table 8 shows the outcomes of the univariate and multivariate backward multinomial logistic regression, with as reference category the intention to adopt a PHR (answer category: Yes). Significant associations were found between sex, functional health literacy, computer literacy and the intention to use a PHR. The odds of choosing 'Maybe' compared to 'Yes' for males were 0.5 times the odds of females. The odds of choosing 'No' compared to 'Yes' for older adults with low functional health literacy were 3.0 times higher than the odds of older adults with high functional health literacy. The odds of choosing 'No' compared to 'Yes' for older adults with low computer literacy were 4 times higher than the odds of older adults with high computer literacy. To sum up, males as compared to females, were less likely to choose 'Maybe' instead of 'Yes'. In addition, older adults with high functional health literacy and high computer literacy were more likely to choose 'Yes' instead of 'No'.

Table 8 - Associations between personal factors and the intention to adopt a PHR

	No intention to adopt a PHR[1]		Maybe the intention to adopt a PHR[1]	
	Univariate OR (95% CI)	Multivariate OR (95% CI)	Univariate OR (95% CI)	Multivariate OR (95% CI)
Age	1.0 (1.0, 1.1)		1.0 (1.0, 1.1)	
Sex (male = 0, female =1)	0.7 (0.4, 1.3)	0.9 (0.4, 1.9)	0.4 (0.2, 0.8)**	0.5 (0.2, 0.9)*
Living environment (villages = 0, Emmen = 1)	1.0 (0.5, 1.8)		1.1 (0.6, 1.9)	
Functional health literacy (0=low, 1=high)	5.4 (2.5, 11.4)**	3.0 (1.3, 6.9)**	2.1 (1.0, 4.5)*	2.1 (0.9, 4.5)
Communicative health literacy (0=low, 1=high)	2.7 (1.4, 5.5)**	2.0 (1.0, 4.4)	0.89 (0.4, 1.9)	0.8 (0.4, 1.6)
Critical health literacy (0=low, 1=high)	2.5 (1.3, 4.9)**		1.5 (0.8, 2.9)	1.3 (0.6, 2.5)
Computer literacy (0= low, 1=high)	7.2 (3.4, 15.3)**	4.0 (1.8, 9.2)**	1.9 (0.9, 4.0)	1.2 (0.5, 3.0)
Robust older adults[2]	0.8 (0.4, 1.8)		1.0 (0.5, 2.0)	
Frail older adults[2]	1.4 (0.6, 3.0)		1.5 (0.7, 3.2)	
Internet access (0 =yes, 1=no/don't know)	0.3 (0.2, 0.7)**		0.7 (0.3, 1.4)	

* p < 0.05
** p < 0.01
[1]= reference category is: Intention to adopt a PHR
[2]= reference category is: Older adults with complex care needs

5. Discussion

5.1 Needs regarding a PHR

This research explored the needs of community-living older adults regarding a PHR. It was expected that older adults would report a high need for all the technological needs, as the needs that were assessed in this study were based on outcomes of a focus group discussion with older adults. The older adults indeed indicated to have the need for accessing medical records on the computer, receiving information and advice, working on your own health, confidentiality and privacy, and accessibility and user-friendliness. However, limited need was found for the opportunity for online communication with the healthcare professionals by means of a PHR. One older adult wrote in a personal note that he would find it unfortunate if personal face-to-face contact with the general practitioner would be lost and replaced by online contact. He considers communication with healthcare professional important, but prefers face-to-face contact instead of online contact through a PHR. This is in line with the study of Tieu et al. (2015), who found that people are concerned that online communication will replace or reduce face-to-face communication with the healthcare provider. This could especially be a concern of older adults, as they are often less used to and have less skills to communicate online in general (for example mail, chat, WhatsApp). Santana et al. (2010) found that different online communication opportunities, such as requesting medication, making an appointment and communication with the healthcare professional were most appealing for the age group below 25, followed by the age groups 26-35 and 36-45. The limited need found for online communication in this study, could be caused by the fact that all participants were 75 years old or older and less used to online communication. Furthermore, it was hypothesized that higher levels of functional health literacy, communicative health literacy, critical health literacy and computer literacy would increase the technological needs regarding a PHR. This study found indeed that older adults with high communicative and critical health literacy skills reported higher needs on all the technological needs, compared to older adults with low communicative and critical health literacy skills. However, this study could not confirm that higher levels of functional health literacy would increase the need for accessibility of medical records, working on your own health and confidentiality and privacy. Also, no differences were found in the needs between older adults with low and high computer literacy for accessibility of medical records and confidentiality and privacy. So, older adults seem to have the need for accessibility of medical records and confidentiality and privacy regardless to what their functional health literacy and computer literacy level is. To my knowledge, no research has been conducted so far on the association between the needs regarding a PHR and health literacy and computer literacy. Therefore, exact comparisons with previous research cannot be made. Tieu et al. (2015) found that people with adequate health literacy understand better how a PHR could improve communication with the healthcare professional. While this does not necessarily mean that people with adequate health literacy also have a higher need for online communication with healthcare professionals, it could be that if they understand the benefits better that they will also report a higher need. However, it is recommended to conduct more research

to the association between the needs of older adults regarding a PHR and health literacy and computer literacy to increase the amount of literature on this specific topic.

Besides health literacy and computer literacy, this study also examined if the needs differed for different health status groups. It was expected that older adults with a better health status would have less need for all the technological needs. Contrary to this expectation, robust older adults reported the highest needs, followed by frail older adults and older adults with complex care needs reported the lowest needs. This study showed that robust older adults have a higher need for online communication with the healthcare provider and the opportunity to work on your own health with a PHR, compared to frail older adults. A reason for this higher need among robust older adults, compared to frail older adults could be that robust older adults were younger and had higher functional and critical health literacy levels. As mentioned before, online communication with the healthcare provider is less appealing with increasing age (Santana et al, 2010). Therefore, the robust older adults could have reported a higher need to online communication, because they are younger then the frail older adults. Also, the higher functional and critical health literacy could have contributed to the higher needs of robust older adults. In addition, this study found that frail older adults have a higher need for accessibility and user-friendliness compared to older adults with complex care needs. This could also be caused by the fact that frail older adults were older and had lower critical health literacy, which could have increased their concerns regarding the accessibility and user-friendliness. No differences were found between the different health status groups in the needs for accessibility of medical records, receiving information and advice and confidentiality and privacy. This indicates that robust older adults, frail older adults and older adults with complex care needs have similar needs for those aspects regarding a PHR.

5.2 Intention of using a PHR

It was hypothesized that the socio-demographic factors: age, gender, health literacy, computer literacy, health status, internet access and urbanity would have an effect on the intention to use a PHR. As expected, older adults with high functional health literacy levels and high computer literacy levels were more likely to have the intention to use a PHR. It was also expected that males were more likely to have the intention to use a PHR, compared to females. However, no association was found between age, communicative health literacy, critical health literacy, health status, internet access and urbanity and the intention to use a PHR, which is in contrast with the theory of Logue and Effken (2012).

It was expected that an increase in age would decrease the intention to adopt a PHR. This could not be confirmed by this study, as no significant effect was found for age. This is in contradiction with the theory of Logue and Effken (2012) and other previous studies (Goel et al., 2011; Sarkar et al., 2011). Lack of a significant effect could be caused by the older age of the population group. The age of participants in this study ranged from 75 to 97 and 75% of the participants were between 79 and 85 years old at the time of completing the questionnaire. In most research the ages between 80 and 85 are

taken together, which seems to indicate that participants in this age group have similar characteristics. Goal et al. (2011) compared the intention of older adults under 65 and above 65 years of age and found that older adults above 65 years were less likely to adopt a PHR. This also indicates that older adults above 65 years have similar intentions to adopt a PHR and this could be the reason why our study did not find any association between age and intention. It is recommended to use a broader age range in further research to examine the possible association between age and the intention to use a PHR more extensively.

Where this study did find that older adults with high functional health literacy were more likely to adopt a PHR, this was not found for communicative and critical health literacy. It could be that the use of a PHR mostly depends on basic skills like reading and writing, which are related to functional health literacy. However, communicative and critical health literacy are also important skills for using a PHR, although these skills may relate more to the effective use of a PHR rather than to the intention to adopt a PHR.

Another finding which is in contrast with the theory (Logue, & Effken, 2012) is that no association was found between the health status and the intention to adopt a PHR, while it was expected that complex older adults would be more likely to have the intention to use a PHR. This could be caused by a different way of assessing health status. Where the theory is based on chronic disease factors, in this study a distinction was made between robust older adults, frail older adults and older adults with complex care needs. Frail older adults could suffer from a chronic condition, but this was not always the case and older adults with complex care needs could suffer from only one, but also from multiple chronic diseases. Another reason could be that it was not clear for the frail older adults and older adults with complex care needs, how a PHR could support them with managing their health issues. It is recommended for further research to include qualitative research in order to be able to understand why we did not find an association in this study.

The theory of Logue and Effken (2012) provided a good overall framework for this study. However, the lack of direction (positive or negative) of the given associations between personal, environmental, chronic disease and technology factors made it hard to formulate the hypotheses. Where the theory only stated that there was an association between personal factors and the intention to use a PHR, additional literature research was needed to find out if an increase or decrease in for example age would have a positive or negative effect on the intention to use a PHR. Therefore, it is recommended to extend the theory and include the directions of the concepts which are included in one of the four factors of the model.

5.3 Needs and the intention

It was expected that the needs regarding a PHR are associated with the intention of older adults to use a PHR. This study indeed found that older adults who have the intention to use a PHR reported the highest need for all the technological needs, followed by the older adults who maybe have the

intention to use a PHR. Older adults with no intention to use a PHR reported the lowest technological needs. It is remarkable that older adults who did not have the intention to make use of a PHR, nevertheless reported to have the need for online access of their medical records and confidentiality and privacy. The concerns about privacy are supported by several studies (Liu et al., 2011; Tang et al., 2006). It could be that some of the older adults indicated to have no intention to use a PHR, because they are concerned about the privacy and confidentiality of the PHR tool. However, more qualitative research is needed to examine if older adults would like to use a PHR when their privacy is guaranteed.

5.3 Limitations

Limitations of this research are the use of non-parametric tests, the use of a partial invalidated questionnaire and the existence of characteristic differences between the respondent and the non-respondents. Non-parametric tests had to be used as the data was not normally distributed and could not be transformed. The use of non-parametric tests decreased the power, which increased the probability of a type II error. Therefore, it is possible that existing relevant associations were not found in this study. Another limitation is the use of a partial invalidated questionnaire, which increased the risk of not measuring what was intended to be measured. The questions about the technological needs were not validated, which leaded to uncertainty if these questions actually measured the needs of those functionalities. However, the questions about the needs were based on a literature review and a focus group discussion with the target group, which makes it presumable that it measured the needs of older adults. Also, the non-respondents were significantly older and a higher percentage was male, which could have led to bias results.

5.4 Recommendations

This study provided insight in the needs of community-living older adults for adopting a PHR. The first recommendation is that the needs of older adults that are established through this study, should be taken into account during the development of new PHR's. Also, already existing PHR's should adjust or expand their functionalities to better meet the needs of older adults. This means that PHR's should offer the possibility to access medical records online, to communicate online with healthcare professionals, to receive information and advice, to work on your own health, guarantee the privacy and be accessible and user-friendly. Furthermore, older adults who had no intention to use a PHR still reported the need for online accessibility of medical records and that their privacy should be guaranteed. Therefore, my second recommendation is that policies to increase the user-rates of PHR users among older adults should emphasize those two aspects of the PHR. Older adults who have currently no intention to use a PHR should be made aware of the possibility to access medical records online and be assured that their privacy is guaranteed.

The third recommendation is that further research should be conducted to build further on some of the findings of this study. This study established differences in the needs regarding a PHR for different

health status groups and for different health literacy levels. Qualitative research is advised to be able to understand why the needs differ for those groups. If we know the reason behind it, policies could be developed to support low health literate older adults with the use of PHR's. Also, future PHR's could be personalized to the health status and health literacy levels of the users. The final recommendation is that the actual user rates of a PHR should be examined in further research rather than just the intention to use a PHR. The intention to use a PHR will not automatically lead to the actual use of a PHR. To conclude, this study provided insight in the needs of older adults regarding a PHR, which will hopefully contribute to the development of better suited PHR's in the future and an increase in user-rates among older adults.

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Toegang tot medische gegevens op de computer

Door de komst van internet, computers en andere technologie is het mogelijk om meer grip te krijgen op uw gezondheid. Dit kan bijvoorbeeld met een persoonlijk gezondheidsdossier. In een persoonlijk gezondheidsdossier is het mogelijk om informatie uit informatiesystemen van verschillende zorgverleners overzichtelijk te bekijken. U krijgt zo inzicht in uw medische gegevens zoals deze door bijvoorbeeld de huisarts, het ziekenhuis en de fysiotherapeut worden opgeslagen.

De volgende vragen gaan over hoe belangrijk u het vindt dat uw medische gegevens toegankelijk zijn via een persoonlijk gezondheidsdossier.

Kruis het vakje aan dat uw gevoel het beste weergeeft.

		Helemaal niet belangrijk	Niet belangrijk	Neutraal	Belangrijk	Heel erg belangrijk
1.	Een lijst met namen van al mijn zorgverleners (bijv. huisarts, medisch specialist, fysiotherapeut)	☐	☐	☐	☐	☐
2.	De gegevens die zorgverleners over mij opslaan (inzage in mijn zorgdossiers)	☐	☐	☐	☐	☐
3.	Een overzicht van alle medicijnen die ik gebruik	☐	☐	☐	☐	☐

Communicatie met zorgverleners

Met een persoonlijk gezondheidsdossier is het ook mogelijk om via de computer contact te leggen met zorgverleners. Zo kunt u bijvoorbeeld vragen stellen aan uw zorgverleners of afspraken maken. Ook kunt u reageren op wat uw zorgverlener opschrijft in zijn dossier. Bijvoorbeeld als u vindt dat iets niet helemaal klopt of als u een aanvulling heeft.

De volgende vragen gaan over hoe belangrijk u het vindt om te communiceren met zorgverleners via een persoonlijk gezondheidsdossier.

Kruis het vakje aan dat uw gevoel het beste weergeeft.

		Helemaal niet belangrijk	Niet belangrijk	Neutraal	Belangrijk	Heel erg belangrijk
4.	Via de computer medicatie kunnen aanvragen (herhaalrecept)	☐	☐	☐	☐	☐
5.	Een afspraak maken met mijn zorgverleners	☐	☐	☐	☐	☐
6.	Een overzicht van mijn afspraken met zorgverleners (agenda)	☐	☐	☐	☐	☐
7.	Communiceren met mijn zorgverleners (bijv. chatten of e-mailen)	☐	☐	☐	☐	☐
8.	Een reactie kunnen plaatsen bij verslagen van mijn zorgverleners	☐	☐	☐	☐	☐

Informatie en advies ontvangen

Met de komst van internet heeft u toegang tot een grote hoeveelheid informatie over ziekte en gezondheid. Niet alle informatie is echter even betrouwbaar. In een persoonlijk gezondheidsdossier is het mogelijk om betrouwbare informatie te bekijken die voor u relevant is. U kunt ook vragenlijsten invullen over uw gezondheid. Op basis van de antwoorden die u geeft, ontvangt u persoonlijk advies over gezond ouder worden (bijv. op het gebied van gezonde voeding of bewegen).

De volgende vragen gaan over hoe belangrijk u het vindt om persoonlijke informatie en advies over gezond ouder worden te ontvangen via een persoonlijk gezondheidsdossier.

Kruis het vakje aan dat uw gevoel het beste weergeeft.

		Helemaal niet belangrijk	Niet belangrijk	Neutraal	Belangrijk	Heel erg belangrijk
9.	Toegang hebben tot betrouwbare informatie over ziekte en gezondheid	☐	☐	☐	☐	☐
10.	Vragenlijsten over mijn gezondheid invullen	☐	☐	☐	☐	☐
11.	Resultaten van ingevulde vragenlijsten direct bekijken	☐	☐	☐	☐	☐
12.	Persoonlijk advies ontvangen om zo lang mogelijk gezond te blijven	☐	☐	☐	☐	☐

Werken aan uw gezondheid

Behalve de computer en het internet zijn er steeds meer mobiele apparaten waarmee u zelf gegevens over uw gezondheid kunt verzamelen. Denk bijvoorbeeld aan smartphones en stappentellers. Gegevens die u met deze apparaten verzamelt kunnen ook worden opgenomen in een persoonlijk gezondheidsdossier. Als u bijvoorbeeld met uw huisarts afspreekt om meer te gaan wandelen, kan een stappenteller helpen om dit bij te houden. Ook kunt u zelf doelen instellen en bijvoorbeeld contact zoeken met anderen die aan dezelfde doelen werken (bijv. samen wandelen of gezond koken).

De volgende vragen gaan over hoe belangrijk u het vindt om te werken aan uw gezondheid in een persoonlijk gezondheidsdossier.

Kruis het vakje aan dat uw gevoel het beste weergeeft.

		Helemaal niet belangrijk	Niet belangrijk	Neutraal	Belangrijk	Heel erg belangrijk
13.	Aan doelen kunnen werken om zo lang mogelijk gezond te blijven	☐	☐	☐	☐	☐
14.	Contact kunnen leggen met anderen om samen dingen te ondernemen	☐	☐	☐	☐	☐
15.	Metingen van apparaten zoals een stappenteller, bloeddrukmeter of weegschaal opnemen in mijn gezondheidsdossier	☐	☐	☐	☐	☐

Betrouwbaarheid en privacy

Een persoonlijk gezondheidsdossier is in eerste instantie bedoeld voor u. Het kan nuttig zijn om anderen ook toegang te geven tot uw gezondheidsdossier. Bijvoorbeeld zorgverleners of naasten (familieleden, mantelzorgers).

De volgende vragen gaan over hoe belangrijk u het vindt dat u zelf kunt bepalen wie in uw persoonlijk gezondheidsdossier kunnen kijken.

Kruis het vakje aan dat uw gevoel het beste weergeeft.

		Helemaal niet belangrijk	Niet belangrijk	Neutraal	Belangrijk	Heel erg belangrijk
16.	Een betrouwbaar inlogsysteem (bijv. DigiD)	☐	☐	☐	☐	☐
17.	Zelf kunnen bepalen welke zorgverleners in mijn gezondheidsdossier kunnen kijken	☐	☐	☐	☐	☐
18.	Zelf kunnen bepalen wie van mijn naasten in mijn gezondheidsdossier kunnen kijken	☐	☐	☐	☐	☐

Toegankelijkheid en gebruiksvriendelijkheid

Voor ouderen is het niet altijd makkelijk om te werken met nieuwe technologie zoals een persoonlijk gezondheidsdossier. Er is veel mogelijk om de toegankelijkheid en gebruiksvriendelijkheid te vergroten.

De volgende vragen gaan over hoe belangrijk u toegankelijkheid en gebruiksvriendelijkheid van uw persoonlijk gezondheidsdossier vindt.

Kruis het vakje aan dat uw gevoel het beste weergeeft.

		Helemaal niet belangrijk	Niet belangrijk	Neutraal	Belangrijk	Heel erg belangrijk
19.	Gegevens uit mijn dossier kunnen printen	☐	☐	☐	☐	☐
20.	Een melding ontvangen als er iets nieuws gebeurt (bijv. als er een bericht van de huisarts binnenkomt)	☐	☐	☐	☐	☐
21.	Herinneringen ontvangen (bijv. voor afspraken of medicatie-inname)	☐	☐	☐	☐	☐
22.	Korte video's met uitleg over mijn gezondheidsdossier	☐	☐	☐	☐	☐
23.	Simpel en vanzelfsprekend in gebruik	☐	☐	☐	☐	☐
24.	Een helpdesk die ik kan bellen als ik vragen heb over het gebruik van mijn gezondheidsdossier	☐	☐	☐	☐	☐

Persoonlijk gezondheidsdossier

Met een persoonlijk gezondheidsdossier kunt u op de computer, tablet of telefoon inzage krijgen in uw medische gegevens. Daarnaast kunt u contact opnemen met uw zorgverleners. Ook kunt u zelf gegevens over uw gezondheid opslaan die voor uw zorgverleners van belang kunnen zijn.

25. Denkt u dat een persoonlijk gezondheidsdossier nuttig kan zijn voor ouderen?

☐ Ja

☐ Nee

☐ Misschien

----

26. Zou u zelf een persoonlijk gezondheidsdossier willen gebruiken?

☐ Ja

☐ Nee

☐ Misschien

----

27. Denkt u dat het zinvol is als uw naasten (bijv. kinderen, mantelzorgers) uw persoonlijk gezondheidsdossier kunnen gebruiken?

☐ Ja

☐ Nee

☐ Misschien

---

28. Denkt u dat een persoonlijk gezondheidsdossier ouderen kan helpen om langer gezond te blijven?

☐ Ja

☐ Nee

☐ Misschien

Gebruik van technologie en internet

De volgende vragen gaan over uw gebruik van verschillende apparaten en internet.

29. Over welke apparatuur beschikt u thuis? (*U mag meerdere antwoorden aankruisen.*)

☐ Televisie

☐ Vaste telefoon

☐ Mobiele telefoon

☐ Spelcomputer

☐ Personal Computer (PC) of desktop computer

☐ Laptop

☐ Palmtop

☐ Tablet (bijv. iPad)

☐ Anders, namelijk:

----

30. Heeft u thuis een internetverbinding?

☐ Ja **(ga verder met vraag 31)**

☐ Nee (**ga verder met vraag 32**)

☐ Weet ik niet (**ga verder met vraag 33**)

----

31. Met welke van de volgende apparaten heeft u thuis toegang tot internet?
(*U mag meerdere antwoorden aankruisen.*)

☐ Personal Computer (PC) of desktop computer

☐ Laptop

☐ Palmtop

☐ Tablet (bijv. iPad)

☐ Mobiele telefoon met toegang tot het internet (smartphone)

☐ Televisie met internetverbinding (bijv. digitale tv)

☐ Spelcomputer

☐ Anders, namelijk

Ga verder met vraag 34

32. Wat zijn de redenen waarom er thuis <u>geen</u> toegang tot internet is?

(*U mag meerdere antwoorden aankruisen.*)

☐ Ik heb de mogelijkheid om elders te internetten

☐ Ik wil geen internet

☐ Ik heb geen interesse, het is niet zinvol voor het huishouden

☐ Ik vind de internetkosten te hoog

☐ Ik heb onvoldoende kennis of vaardigheden om internet te gebruiken

☐ Ik heb een fysieke beperking (handicap) waardoor het onmogelijk is om internet te gebruiken

☐ Ik ben bezorgd om mijn privacy en/of veiligheid

☐ Een andere reden, namelijk:

----

33. Zou u thuis graag toegang tot het internet willen hebben?

☐ Ja

☐ Nee

----

34. Wanneer heeft u voor het laatst een computer gebruikt?

☐ In de afgelopen 3 maanden

☐ Tussen de 3 maanden en 1 jaar geleden

☐ Meer dan 1 jaar geleden

☐ Ik heb nog nooit een computer gebruikt

☐ Ik weet niet wat een computer is

----

35. Wanneer heeft u voor het laatst een tablet (bijv. iPad) gebruikt?

☐ In de afgelopen 3 maanden

☐ Tussen de 3 maanden en 1 jaar geleden

☐ Meer dan 1 jaar geleden

☐ Ik heb nog nooit een tablet gebruikt

☐ Ik weet niet wat een tablet is

36. Wanneer heeft u voor het laatst een smartphone (een mobiele telefoon met toegang tot het internet) gebruikt?

- [ ] In de afgelopen 3 maanden
- [ ] Tussen de 3 maanden en 1 jaar geleden
- [ ] Meer dan 1 jaar geleden
- [ ] Ik heb nog nooit een smartphone gebruikt
- [ ] Ik weet niet wat een smartphone is

----

37. Wanneer heeft u voor het laatst internet gebruikt?

- [ ] In de afgelopen 3 maanden
- [ ] Tussen de 3 maanden en 1 jaar geleden
- [ ] Meer dan 1 jaar geleden
- [ ] Ik heb nog nooit internet gebruikt (**ga verder met vraag 40**)

----

38. Hoe vaak maakt u gebruik van internet?

- [ ] (Bijna) dagelijks
- [ ] Wekelijks
- [ ] Maandelijks
- [ ] Bijna nooit
- [ ] Nooit (**ga verder met vraag 40**)

39. Waarvoor heeft u internet in het afgelopen jaar gebruikt?

(*U mag meerdere antwoorden aankruisen.*)

- [ ] Informatie opzoeken (bijv. via een zoekmachine zoals Google)
- [ ] E-mailen
- [ ] Internetbankieren
- [ ] Belastingaangifte
- [ ] Het nieuws of weerbericht lezen
- [ ] Producten kopen of verkopen (bijv. kleding, witgoed, tweedehands artikelen)
- [ ] Online spelletjes spelen (bijv. Wordfeud, online kaartspelletjes)
- [ ] Chatten (bijv. via WhatsApp)
- [ ] Bellen (bijv. via Skype)
- [ ] Sociale media (bijv. Facebook, Instagram, Twitter)
- [ ] Foto's of bestanden opslaan en delen met anderen (bijv. via Dropbox, Google Drive)
- [ ] Anders, namelijk:

- [ ] Ik maak nooit gebruik van internet

----

40. Hoe gemakkelijk kunt u overweg met apparaten zoals een tablet (bijv. iPad), mobiele telefoon of computer?

- [ ] Helemaal niet
- [ ] Minimaal
- [ ] Enigszins
- [ ] Gemakkelijk
- [ ] Heel erg gemakkelijk

Informatie over behandeling of hulpverlening

De volgende vragen gaan over hoe u omgaat met informatie over behandeling of hulpverlening. De vragen gaan over informatie van de huisarts, de thuiszorg, het ziekenhuis of andere zorgverlener.

U kunt de vragen ook invullen als u op dit moment zelf <u>geen</u> hulp ontvangt.

41. Hoe vaak helpt iemand u bij het lezen van informatiemateriaal van het ziekenhuis of een andere zorgverlener?

☐ Altijd

☐ Vaak

☐ Soms

☐ Af en toe

☐ Nooit

----

42. Hoe zeker bent u van uzelf als u zelf medische formulieren invult?

☐ Heel erg

☐ Behoorlijk

☐ Enigszins

☐ Een klein beetje

☐ Helemaal niet

----

43. Hoe vaak heeft u problemen met het begrijpen van uw medische situatie doordat u moeite heeft met de schriftelijke informatie?

☐ Altijd

☐ Vaak

☐ Soms

☐ Af en toe

☐ Nooit

Hieronder staan 3 vragen over praten met zorgverlener.

Kunt u per vraag aangeven hoe vaak u deze dingen heeft gedaan, nu doet of in de toekomst zou doen?

		Vaak	Soms	Zelden
47.	Als u met een zorgverlener praat, geeft u hem of haar dan alle informatie die hij nodig heeft om u te kunnen helpen?	☐	☐	☐
48.	Als u met een zorgverlener praat, stelt u dan alle vragen die u moet stellen?	☐	☐	☐
49.	Als u met een zorgverlener praat, zorgt u er dan voor dat hij alles uitlegt wat u niet begrijpt?	☐	☐	☐

Hieronder staan 3 vragen over het omgaan met informatie over ziekte en gezondheid.

Kunt u per vraag aangeven hoe vaak u deze dingen heeft gedaan, nu doet of in de toekomst zou doen?

		Vaak	Soms	Zelden
50.	Bent u iemand die graag veel over zijn gezondheid te weten wil komen en daarvoor meerdere informatiebronnen raadpleegt?	☐	☐	☐
51.	Hoe vaak denkt u zorgvuldig na over welke informatie over uw gezondheid past bij uw persoonlijke situatie?	☐	☐	☐
52.	Hoe vaak probeert u erachter te komen of informatie over uw gezondheid betrouwbaar is?	☐	☐	☐

53. Bent u iemand die het advies van een zorgverlener in twijfel zou kunnen trekken gebaseerd op uw eigen onderzoek (bijvoorbeeld wat u zelf leest in boeken of op internet)?

☐ Ja, absoluut

☐ Misschien/ soms

☐ Nee, niet echt

Tot slot

1. Bent u man of vrouw?

☐ Man

☐ Vrouw

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2. Wat is uw geboortedatum?

     (DAG)   (MAAND)   (JAAR)

    ☐   ☐   ☐

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3. Wilt u hier de datum invullen waarop u deze vragenlijst heeft <u>afgerond</u>?

     (DAG)   (MAAND)   (JAAR)

    ☐   ☐   ☐

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4. Heeft iemand u geholpen bij het invullen van deze vragenlijst?

☐ Ja, iemand heeft mij geholpen met het invullen van de lijst.

☐ Nee, ik heb de lijst alleen ingevuld → *U bent klaar met invullen!*

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5. Zo ja, waaruit bestond de hulp?

☐ Iemand anders heeft de antwoorden genoteerd; ik heb de antwoorden zelf gekozen.

☐ Ik heb de antwoorden samen met iemand gekozen en genoteerd.

☐ Iemand heeft de antwoorden voor mij gekozen en genoteerd.

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6. Als u geholpen werd bij het invullen van de vragenlijst of de vragenlijst werd door een ander ingevuld, wie was dit dan?

☐ Partner

☐ Familielid

☐ Anders, namelijk:

Hartelijk bedankt voor het invullen van de vragenlijst!