Integration of a Personal Health Record into a self-management chronic care program: Exploring the association between effectiveness and personality

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Abstract

Background Patients with chronic diseases need skills, knowledge and motivation to self-manage their diseases on a day-to-day basis. Personal Health Records (PHR) are seen as promising self-management support tools in the chronic care and are encouraged to be integrated into the health care system. Studies suggest tailoring system designs to personality types may be of importance for adoption, but little is known about the relevance of personality for the effectivity of PHR systems to enhance self-management in patients with chronic diseases.

Objectives This study aimed to evaluate implementation of a PHR to enhance targeting tailoring to personality in design of PHR-systems. Four research questions were formulated (1) After one year, is there a difference in self-management between two groups of patients participating in a care program for chronic diseases (Diabetis Mellitus type 2, asthma, COPD, cardiovascular diseases) when the intervention group uses additionally a PHR and the controle group receives the care program alone? (2) Is there a difference in self-management within the intervention group after one year? (3) Is there a difference in Health related Quality of Life (HRQoL) within the intervention group after one year? (4) Is there a relationship between the amount of change in self-management after using the PHR for one year and personality within the intervention group?

Methods The study employed a pragmatic controlled pre-post design with 12 months follow up. Data were collected with questionnaires. Outcomes were self-management capacity measured with the 13-item Patient Activation Measurement 13 (PAM13) and HRQoL measured with 3-leveled EuroQuol (EQ5D3L). Personality traits were measured with the Ten Item Personality Inventory (TIPI). Demographics measured at baseline included gender, age, education, marital status, living situation and internet use. Data were analyzed using Covariance analysis, paired T-test, Wilcoxon Signed Rank Test and Spearman's Correlation.

Results Attrition was high. No significant improvements in self-management nor in HrQoL were observed. Higher degree of Conscientiousness tended to be positively associated with increased self-management and higher degree of Extraversion tended to be negatively associated with increased self-management.

Conclusions Effects of the PHR to enhance self-management and HrQoL in patients with chronic diseases remained difficult to determine due to attrition. However trends in associations between personality and increase of self-management were found, encouraging tailoring PHR-systems to personality types. Further studies are needed to gain more inside into characteristics

of the user of PHRs as well as into the process of integrating PHRs into primary care in order to encourage the development of a user-centred design on system level and in integration.

Keywords*:* Chronic diseases, Self-management, eHealth, Personal Health Records, Persuasive Technology, Tailoring, Personality, Health Related Quality of Life

Introduction

Chronic disease and health related quality of life

The personal and economic burden of chronic diseases is a serious challenge for the Netherlands as it concerns a large proportion of the population and has long term consequences for the concerned individuals as well as for the health care system. To deal will this reality self-management interventions are considered to be integrated into the chronic care system.

In the Netherlands about one third of the population live with a chronic disease, which are about 5.3 million people (Nationaalkompass 2013), and about 35% of those people even live with multimorbidity (Nationaalkompass 2013), i.e. having more than one chronic condition. Moreover, the number of chronic diseases increased in last decennia's and prognostic studies argue that the incidence of chronic diseases will rise, in the Netherlands as well as in a range of other predominantly western countries (Blokstra 2007). The causes of chronic diseases are diverse but usually explained by demographic changes (Blokstra 2007) as well as better care prolonging peoples life and allowing people to live longer with a chronic condition (WHO 2008). The term 'chronic diseases' has various definitions but in general it describes a disease of long duration without definite cure following a prolonged clinical course with gradual changes over time (Bentzen 2003). It includes diverse diseases referring to a variety of physical processes including metabolic, respiratory and cardiovasculare processes. Chronic metabolic diseases include diabetes mellitus type 2 (DM2), chronic respiratory diseases include chronic obstructive pulmonary disease (COPD) and asthma, and cardiovascular diseases which refer to diseases of the heart and blood vessels (WHO, 2016).

Chronic diseases have the potential to worsen the overall health of the patients and their Health related quality of life (Bentsen et al 2012, Lam et al 2000). Health related quality of life (HrQoL) is the patient's persective on domains of his/her life which might be affected by the disease (Berry et al 1999). Typically, HrQoL includes objective and subjective components of well-being and is defined as a multidimensional construct consisting of at least three domains of life which are considered to be significant to the patient − physical, psychological, and social functioning (Abbott et al 2011). The subjective aspect is crucial in the concept because erperience of well-being is personal and consequently intrinsic to the concept of HrQoL (Berry et al 1999, Cella 1992). Physical functioning in general describes the degree of which the patient is able to perform daily activities (Sprangers, 2002) e.g. to handle self-care

autonomiously. Further, physical functioning may also include the ability to cope with physical symptoms associated with the disease or with corresponding treatment (e.g. byeffects of medications) (Sprangers 2002). Psychological functioning describes the degree of wellbeing of the patient (Sprangers 2002), for instance low psychological functioning encompasses a state of psychological distress, e.g. as consequence of a psychological disorder (depression, anxiety etc.) and may also include affected cognitive capabilities (e.g. decline in concentrativeness). Social functioning describes the degree in which the patient is able to manage a satisfactory social life and to feel integrated (Sprangers 2002).

After all, it seems reasonable to assume, that a chronic disease can affect a variety of aspects of the patient's health and daily life. Therefore integrating self-management as support into health care seems to be in particular important to patients with a chronic disease, who need to deal with the day-to-day care routine over the length of the disease.

The Chronic Care Model

The integration of self-management into health care is a call on the Chronic disease management system. Chronic disease management (CDM) is a system of coordinated health interventions and communications for patients with chronic diseases (RCP/RGP/NHS alliance 2004). One guiding strategic response of the CDM to the challenge of including self-management as crucial aspect into health care is the development of the Chronic Care Model (CCM) (Figure 1). In general, this model emphasizes the shift from the actual paternalistic health care system, wherein the patient listens either more or less passive to orders of the medical professional, to a more patient-centred approach, which relies on the concept of shared decision making between medical professional and patient. The CCM identifies six essential elements: community resources and policies, health care organization, self-management support, delivery system design, decision support and clinical information system (Wagner et al 1998). It predicts that improvement in its interrelated components can produce system reform and highlights the importance of self-management support in which informed, activated patients interact with prepared proactive practice teams (Wagner et al 2001). Activated patients are ‚patients with the knowledge, confidence, and skills for self-management of their condition'(von Korff et al, 1997). Moreover, the partnership encompasses two components, collectively sometimes called patient-empowerment (Bodenheimer et al, 2002): (1) collaborative care and (2) self-management education. Collaborative care emphasizes the

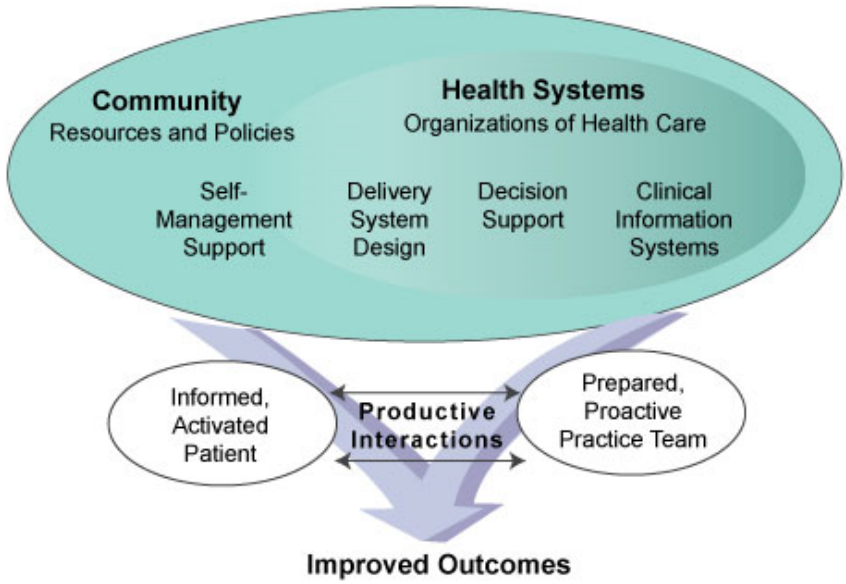

Figure 1
Schematic depiction of the Chronic Care Model

role of the patient as an expert about his life and the daily routine, whereas the encharged medical professional is the expert for biomedical issues of the chronic disease (Wagner et al 2001). Self-management education complements (rather than substitutes) traditional patient education by providing the patient with the skills to practice effective self-management (Bodenheimer et al 2002). Self-management education follows a patient-centred approach by allowing the patient him/herself to identify one‘s problems, which is in contrast to traditional patient education, where problems are defined on biomedical issues corresponding only to physical problems (Funnell et al 2011). Self-management education, then, offers techniques to help the patient find an adequate solution (Lorig & Holman 2003).

After all, the two aspects of the patient professional partnership paradigm (collaborative care and self-management education) highlighted by the CCM hold that patients accept responsibility to self-manage their conditions to a certain extent. Accordingly patients need to be encouraged to solve some problems with information and/or by employing skills rather than by orders from medical professionals.

Self-management

Self-management refers to the patient’s ability to manage the consequences of chronic diseases on aspects of daily life as considered in the concept of HrQoL. This includes managing physiological, psychological as well as social functioning but also symptoms and treatments related to the chronic disease (Barlow, 2002). Consequently, self-management is effective

when the patient is able to trace his/her disease thereby attending changes in the progress and furthermore has the skills to respond cognitively, behavioral and emotional adequate to disease related issues in order to maintain a satisfactory quality of life (Barlow, 2002). According to Lorig & Holman (2003) the ability to self-management, meaning the adaption of the behavior in case of a chronic disease, incorporates five core self-management skills including (1)problem solving, (2)decision making, (3)accessing and using resources, (4)forming a patient/care provider partnership, and (5) taking action (Lorig & Holman 2003). (1)Problem solving and (2) decision making are interrelated. Problem solving refers to the ability to determine a problem and reflect on it including the solicitation of family or friends in order to formulate adequate solutions. Further, as patients with chronic diseases must respond to health changes they have to make decisions in response to their daily condition. (3)To take adequate decisions they need resources e.g. knowledge and guidelines where to rely the decisions on. Lorig (2003) suggests to enquire a variety of resources simultaneously as this might be most effective. (4)Another important aspect for self-management is the formation of a patient/health care provider partnership. Lorig (2003) emphasizes the role of the health care provider as teacher, partner and supervisor whereas the patient should be able to report accurately about the progress of the condition, make informed choices and discuss this with the health care provider. (5) The 5th core skill refers to the ability to take action involving a variety of skills on changing behavior, first of all making a short-term action plan which should suit the abilities of the patient in order to make the patient feel confident to be able to carry it out.

To conclude, if patients would have the skills necessary for self-management and be supported, they would be positioned to accurately detect and characterize and in consequence learn to identify day to day patterns of their condition. Then, as being an expert about the day to day condition and equipped with knowledge through accessible supportive resources they could adapt their behavior adequately necessary for effective management regarding their health and quality of life. Therefore, effective management of care for chronic diseases should offer supportive interventions for patients to help them adopting adequate health related behavior.

Encouraging and supporting self-management with technology

As in the last years a torrent of new information technologies became available it is considered to provide health related information by integrating interactive information technology into the healthcare system with the aim to engage and support people in healthy behavior (Intille 2003).

Information technology which is designed to change user's attitudes and/or behavior is known as persuasive technology (Fogg 2003). Moreover, persuasive systems aim to change behavior on a voluntary basis of the user by reinforcing advantageous, changing adverse or shaping desirable behaviors/attitutes (Oinas Kukkonen et al 2008) by utilizing different persuasive techniques. Persuasive techniques include e.g. the style of instruction (non-authoritative vs authoritative) and of feedback (cooperative vs competitive) as well as the type of motivator (extrinsic vs intrinsic) and of reinforcer (negative vs positive) (Halko & Kientz 2010). Persuasive technology within the frame of health describes the concept of eHealth in general. More firmly, eHealth is the ‚promotion of positive health behavior and attitudes by using a new frame of mind that incorporates information and communication technologies in the presence of a complete feedback loop, enabling the use of data and information, to generate health management knowledge and wisdom'(Gee et al 2015).

eHealth is seen as a promising intervention to support self-management of patients with chronic diseases (Baardman et al 2009) and is therefore strongly encouraged to be integrated into the health care system (Gee et al 2009). One example for an eHealth tool is the Personal Health Record, which is often discussed for its potential to support self-management (e.g.Kaelber et al 2008, Tang et al 2006, Pagliari et al 2007). Personal Health Records (PHR) are defined as 'electronic application through which individuals can access, manage, and share their health information, and that of others for whom they are authorized, in a private, secure, and confidential environment'(Markles's Foundation Connecting Health Collaboration). Accordingly, one of the most important benefits of a PHR for the user is enhanced access to credible personal health data and the possibility to self-manage the own data. But PHR can also include disease information or functions facilitating communication between patients and the care provider, e.g. through collaborative disease tracking, that is patients track their diseases in conjunction with the caregiver (Tang et al 2006). Moreover, some PHR include supportive self-management programs providing care action plans, illustration of symptoms, passive biofeedback, disease relevant instructions, motivational feedback, decision aids, and reminders (Pagliari et al 2007).

Hence, in general, PHRs combine data, knowledge and tools considerable to the individual's ability to self-manage his/her health and health data. Therefore PHR's are seen as promising self-management support intervention in particular for patients with chronic diseases as they can facilitate daily handling of the disease and consequently can encourage the patient to become an active participant in the own care.

Tailoring and Personality

However, literature suggests inconsistent results regarding the effectiveness of PHRs in disease self-management interventions as adoption often fails and interest diminishes after multiple use (Voncken-Brewster et al 2014,Tenforde et al 2011, Tang et al 2005), calling the ‘one-size-fits-all‘ notion of those technologies into question (Halko et al 2010, Archer et al 2011). Moreover, it is suggested that it might be crucial for its effectiveness to take individual differences in design of the features into account, which is tailoring technologies (Tang et al 2006). ‘Tailoring’ is the creation of an intervention by taking specific knowledge of actual characteristics of the individual who receives the intervention into account (Gibbons et al 2009). Further, it is assumed interventions would be more likely to be persuasive, accepted and effective if information provided by the intervention would be tailored to factors relevant to the user group, for example to personality traits (Halko & Kientz 2010, Oinas-Kukkonen 2009).

Personality traits are defined by the American Psychiatric Association as ‚enduring patterns of perceiving, relating to, and thinking about oneself and the environment that are exhibited in a wide range of social and personal contexts‘(American Psychiatric Association, 1994, p. 630). One widely used descriptive model for personality traits is the Big Five Model (Costa & McCrae, 1992), which proposes that dimensions of personality are broadly represented by five personality traits encompassing (a)Neuroticism, (b)Extraversion, (c)Openness, (d)Agreeableness and (e)Conscientiousness. According to this model each trait ranges on a continuum between two extremes. It describes (a) Neuroticism as a trait ranging from emotional stability and well adjustment to instability and maladjustment, (b) Extraversion ranges from sociability to preference for solitude; (c) Openness ranges from curious and imaginative to conservative, conventional (d) Agreeableness ranges from tendencies toward altruism and cooperative to egocentric and competitive and (e) Conscientiousness ranges from goal-oriented to impulsive, and tangetial behavior (Costa & McCrae 1992). It is suggested that health applications tailored for an individual’s personality type may achieve higher success rates in enhancing self-management as people seem to be responsive to different persuasive strategies dependent on their degree on specific personality traits (Artega et al 2009, Halko et al 2010). For instance, Neuroticism was found to be positive associated with social feedback techniques, Agreeableness with reinforcement techniques, and Openness and Extraversion with motivation as well as with reinforcement techniques, whereas Conscientiousness showed none positive associations but was negative associated with many kinds of social feedback (Halko et al 2010). Accordingly this is seen as indication for different preferences on system design (Halko et al 2010). Thus, a better understanding of the individual who uses a PHR might

reveal individual preferences in system design and consequently might contribute to understand how technologies can be customized to fit the needs of the user in order to motivate the user to (subsequently) use the system. Therefore this study explores whether the effect of a PHR on self-management is associated with degrees on personality traits.

To study effects of persuasive technology on self-management in association with personality traits the PHR 'Mijn Gezondheidsplatform' (MGP) was integrated into an existing primary care disease management program for patients with DM2, asthma, COPD, and cardiovascular diseases. Like most PHRs in general it gives patients the possibility to access, manage and share their health information (see Figure 2) and provides the patient with disease education. In addition MGP offers a self-management support program which employs in general two techniques to support behavioral change, (1) goal setting and planning and (2) feedback and monitoring (Otten et al 2015). Patients formulate in collaboration with their caregiver specific health goals and action plans which behavioral needs they consider in their daily life. The program, then, encourages and supports the patient to carry out the actions plans by providing advice adequate to the goals needs and by giving feedback enabling the patient to evaluate the goals. MGP further motivates healthy behavior by offering three predefined coach modules, referring to encourage exercising, healthy nutrition and stop smoking (see Figure 3).

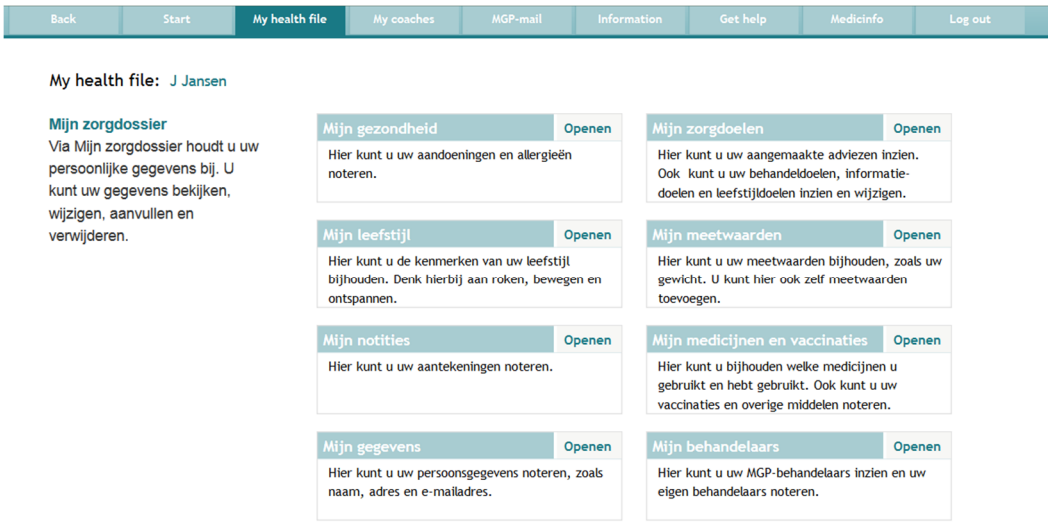

Figure 2
Overview over Health file and diverse functions within the MGP

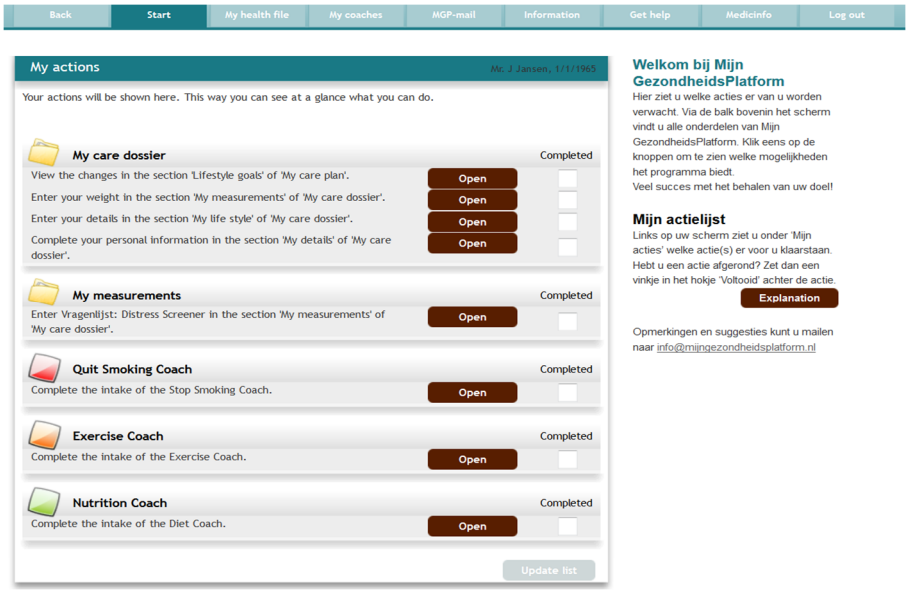

Figure 3
Elements of 'Mijn Gezondheidsplatform' with health file (My care dossier), and self-coaching functions

Aim of the study

This study has two primary objectives : 1) to evaluate the effectiveness of an eHealth tool for self-management designed for use with a heterogeneous group of patients with a chronic disease DM2, Asthma , COPD, cardiovascular diseases), and 2) to explore if effectiveness is associated with personality traits. A secondary objective is to explore the effect of PHR use on HrQoL in order to determine more subjective benefits of self-management for the patient.

Research Questions

1. After one year, is there a difference in self-management between two groups of patients participating in a care program for chronic diseases (DM2, asthma, COPD, cardiovascular diseases) when the intervention group uses additionally MGP and the controle group receives the care program alone without using MGP?

2. Is there a difference in self-management amongst a group of patients who take part in a care program for chronic diseases (DM2, asthma, COPD, cardiovascular diseases) after one year use of MGP?

3. Is there a relationship between the amount of change in self-management after using MGP for one year and personality within a group of patients who take part in a care program for chronic diseases (DM2, asthma, COPD, cardiovascular diseases)?

4. Is there a difference in HrQoL amongst a group of patients who take part in a care program for chronic diseases (DM2, asthma, COPD, cardiovascular diseases) after using MGP for one year?

Method

Design

The study employed a non-randomized, observational, pragmatic controlled before-after design with 12 months follow-up. Participants were allocated to an intervention group or a control group. The intervention group participated in a care program and used additionally MGP whereas the controle group received the care program alone without using MGP.

Setting

Within participating medical offices which integrated the MGP in their care programs all MGP-users were invited to participate in the study. Accordingly, when users logged in to the MGP they were asked for agreement to get contacted by email for eventual participation in the study. Those users who agreed to take part in the study received information and a digital form of declaration of consent. MGP-users who agreed on consent formed the MGP group.

For the controle group a sample of patients was drawn within a group of participating medical offices which did not integrate MGP in their care program. The sample consisted of patients who were registered in the KIS of the medical offices (Care2U) for the care programs DM2, Asthma, COPD or CVRM. They received a letter with information about the study, an invitation to participate in the study and a paper form of a declaration of consent. Those people who agreed to take part and provided a completed form of declaration of consent formed the controle group.

Participants

Inclusion criteria

The inclusion criteria were participation in at least one of three definite care programs of the PoZoB (Diabetes mellitus type 2, Asthma or COPD, Cardiovascular Risico Management),

being at least 18 years old, owning a tablet/PC, having access to internet in home environment, and agreeing to participate in the study (informed consent).

Exclusion criteria

Exclusion criteria were life-threatening (co)morbidity and/or a short life expectancy, cognitive restrictions, insufficient knowledge of Dutch and the participation in other studies which might conflict with the study at hand.

Study Variables

Independent Variables

Demographic variables

For reasons of group comparability a range of demographic variables were measured. Furthermore, as among other demographics, gender, age, education and social support were identified as determinants of self-management capacity in chronic disease patients (Connelly 1993) those demographics were measured at baseline via self-report: gender, age, education, marital status and living situation. In addition, the daily amount of hours using the internet was also included because it was seen as indication for familiarity with the internet and the effort to use is. The effort to use the internet was seen as considerable for the effect of utility of MGP on the outcome variables.

Personality traits

Personality traits were measured with the Ten Item Personality Inventory (TIPI), which is a 10-Item questionnaire taking about a minute to complete. Each dimension of the Big Five (Extraversion, Agreeableness, Conscientiousness, Emotional Stability, Openness) is represented by two items, one represents the positive pole of the dimension and the other the negative pole. Each item is rated on a 7-point scale ranging from 1 (disagree strongly) to 7 (agree strongly). After recoding the negative scaled items 2, 4, 6, 8 and 10, the score for each personality dimension is calculated by summing up the two relevant items and average the sum. The test-retest reliability of the TIPI is r=.72 (Gosling et al 2003).

Outcomes

Patient activation

The PAM 13 is a 13-item questionnaire on patient activation, assessing patient's self-reported knowledge, skills and confidence for self-management of one's health or chronic condition (Hibbard et al 2005). It classifies respondents into 4 level of patient activation (Hibbard &

Gilburt 2014). It includes items such as ‘I know how to prevent problems with my health’, ‘I am confident that I can tell a doctor my concerns, even when he or she does not ask’, which the respondent can answer with degrees of agreement or disagreement, ranging from 1= disagree strongly to 4= agree strongly, including a neutral response option = 5. Responses are summed up and averaged. This raw score is converted into a standardized activation score according to the distributor Insignia Health (see Appendix table 1). It results into the activation score, ranging from 0 to 100, which is then classified into four levels of patient activation. Level 1 (score ≤ 47.0) represents poor activation (‘May not yet believe that patient role is important’) and level 4 (score ≥ 67.1) the highest (‘Has difficulty maintaining behaviors over time’) (Rademakers, 2012). Level 2 (‘Lacks confidence and knowledge to take action’) and Level 3 (‘Beginning to take action’) are divided at a score of 55.1 (Hibbard et al 2007). A higher score on the PAM 13 is positively associated with self-management capacity (Hibbard et al 2007). PAM-13 was translated into Dutch and is considered to be a reliable instrument to measure patient activation (Rademakers et al 2012, Hibbard et al 2005). The internal consistency was found to be good, α=0.88, inter-item correlations were moderate to strong, ranging from r = 0.46 to r= 0.66, and test-retest reliability was moderate, r =0.47 (Rademakers et al 2012).

Health related Quality of life

EQ-5D is an instrument for describing and valuing health condition. It is a 2-part instrument which includes a descriptive system and a visual analogue scale (EQ VAS). As the study of health related quality of life is of secondary objective it was considered that the descriptive system would give sufficient insight into HrQoL for this study. Therefore the descriptive system only was included. The descriptive system comprises 5 dimensions of health: (1) mobility, (2) self-care, (3) usual activities, (4) pain/discomfort and (5) anxiety/depression. Each dimension has 3 levels: (1) no problems, (2) some problems, and (3) severe problems. The respondent is asked to indicate his/her health state by responding with the most appropriate level in each of the 5 dimensions. The response results in a 1-digit number expressing the level selected for that dimension. The digits for 5 dimensions can be combined in a 5-digit number describing the respondent’s health state. The numerals 1-3 have no arithmetic properties and should not be used as a cardinal (Reenen et al 2015). The rating assumes the score 1 = no problems for each dimension, which equals full or optimal health. If some problems on one dimension are reported the health score decreases. In order to produce a combined health utility score ranging from 1 = full health to 0 = equivalent to being dead, the responses were weighted

using the Dutch population preferences for each health domain. The weights reflect differences in morbidity associated with different health domains. For instance, reporting some mobility problems only (reporting no problems in other domains) equates to a score of 0.96, whereas reporting some pain problems only equates to a score of 0.91, indicating that the general population perceives some problems with pain as more severe when referring to health quality than some mobility problems. The utility scores of the 5 dimensions are summed up and averaged, resulting in a single health utility score ranging from 0 to 1 for each respondent.

Statistical Analysis

All data were analyzed using Statistical Package for the Social Sciences (SPSS) version 21.0. Respondents who did not fill in each questionnaires to an extent of at least 50% were excluded from analysis. Missing values within surveys were handled according to the respective guidelines. Items in the PAM 13 were scored as 'missing' when left blank or with a response of 5 ('not applicable') and were coded as '-1'. Calculation of the raw score had to be adjusted accordingly. Further, respondents who answered all items with 1 ('disagree strongly') or 4 ('agree strongly') were excluded from analysis. In EQ5D3L and TIPI if responses were left blank they were treated as 'missing value' and coded as '9'.

Median, interquartile range as well as min-max when considered of valuable complement were used to describe continuous baseline characteristics. Distribution of categorical baseline characteristics were established by frequencies and percent. In order to compare baseline characteristics, chi-square tests were used for nominal (categorical) variables and Mann-Whitney U tests were used for continuous variables. Continuous variables were tested on normality by Shapiro-Wilk test as well as by assessing skewniss and kurtosis and graphical representations (boxplots and/or histogram).

Effects of MGP on self-management between MGP group and controle group were determined using analysis of covariance (ANCOVA) applied on activation scores, with post-measurement as dependent variable and pre-measurement as Covariate. Grouped scatterplots were produced to confirm linearity between the dependent variable and the Covariate. Interaction between group and covariate was assessed to make judgements about the homogeneity of regression slopes. Normality of within-group residuals was assessed by applying Shapiro Wilks test on the standardized residuals of the dependent variable. Standardized residuals plotted against the predicted values were inspected in order to confirm homeoscedasticity. A Levene's test of equality of error variances was run in order to confirm

homogeneity of variances. Cases with standardized residuals greater than ± 3 were assessed as they were considered as outliers and excluded from analysis.

Change of activation within the MGP group was assessed with a paired T-Test with as dependent variable the difference score of baseline measure and follow up measure. A Boxplots was produced and a Shapiro-Wilk test conducted to test for outliers and confirm normality of distribution.

If amount of change in patient activity within the MGP group was associated with personality a correlation matrix was produced to explore. Preliminary analysis showed the relationship between activation change and each personality trait to be not linear, as assessed by visual inspection of a scatterplot. As the assumption of linearity was not met a Spearman's rank-order correlation was run. Cronbach's alpha for the overall scale and the 5 subscales of TIPI were conducted to estimate the reliability.

To examine the change of health related quality of life within the MGP group central tendencies of baseline and post-measurements were compared with each other. As the assumption of normal distribution was not met a Wilcoxon signed rank test was conducted to compare baseline measurement with post-measurement. In order to confirm an approximately symmetrical distribution of the difference score the shape of the distribution was assessed by a histogram.

Ethical considerations

Informed consent was obtained from all participations prior the study as follows:
(1) At the first log in on MGP patients were asked to consent with the service characteristics of MGP. The consent was required to make use of MGP. Without consent the patient was not enabled to use MGP. (2) A separate declaration of consent was obtained via a pop-up in MGP wherein the MGP group were asked for permission to be contacted per email regarding a participation in a scientific study. The given consent was visible for the user as it appeared in the menu 'Mijn gegevens'. Via the menu the user was able to resign from consent. (3) Regarding the declaration of consent for study participation, patients were approached via two different manners depending on if they used MGP or not. MGP users were asked to fill in a digital form of consent, whereas patients who did not use MGP were asked to fill in a paper form of declared consent. The informed consent included patient information about the characteristics of the study regarding independence of the study and the preservation of the participant's anonymity. Responsible employees of the participating medical centra were

informed by letter and personally about the study progress and about the influence of their contribution. The study was approved by the METC of the Maxima medical Centrum.

Results

At baseline there were 60 participants in the intervention group and 152 participants in the controle group. After one year, in the intervention group 22/60 patients (37% of original) provided data at follow-up versus 82/152 participants (54 % of original) in the controle group. Figure 4 shows the flow of subject through the study.

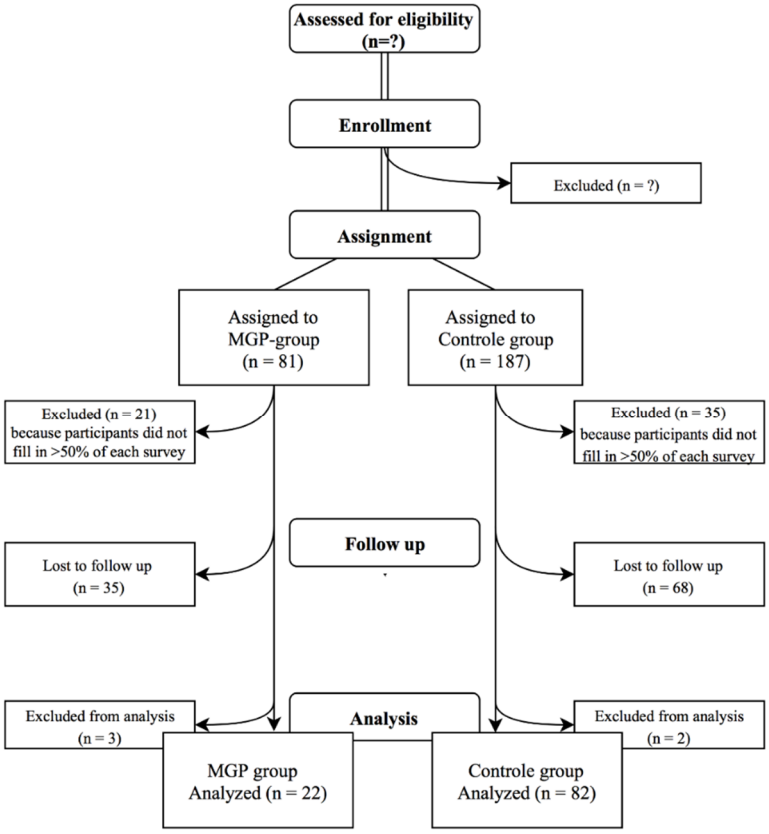

Figure 4
Flow of participants through the stages

Sample characteristics

Table 1 shows baseline characteristics of patients who participated in both pre-measure and in post-measure. Among the 22 and 82 participants who completed the study, at baseline there were no significant differences between demographics of the intervention and the controle group. However, there were indications that participants in the MGP group spent more hours using the internet than the controle group, but this was not statistically significant (p = .08). For the total group the amount of daily internet use was at a mean of 2h 13min (as equal to 2.21hours) and ranged between 0 and 10 hours. Participants had an average age of 63 years (+-

8.3, range 22 - 84) and most participants were male (67%). Almost half of the patients (42%) had a high education (university degree) and there were indications that more people in the intervention group had an university degree (60%) compared to people in the controle group (37%), however this was not confirmed to be statistically significant. About 90% were married and about the same quantity (90%) were living with their partner and/or children.

Table 1
Baseline characteristic of patients who participated in both baseline-measure and post-measure

Variables	Total n = 104	MGP n = 22	Controle n = 82	*P* value
Demographics				
Gender				.19
male	73 (67%)	19 (76.0%)	54 (64.3%)	
not specified	5 (4.6%)	-	5 (6.0%)	
Age, years	63 (10)	64 (8)	63(11)	.50
Min	22	49	22	
Max	84	77	84	
Education				.11
University/tertiary	46 (42.2%)	15 (60.0%)	31 (36.9%)	
Secondary	28 (25.7%)	3 (12.0%)	25 (29.8%)	
Primary or less	28 (25.7%)	4 (16.0%)	24(28.6%)	
other	2 (1.8%)	-	2 (2.4%)	
Marital Status				.77
married	90 (82.6%)	20 (80.0%)	70 (85.4%)	
divorced	7 (6.4%)	2 (8.0%)	5 (6.0%)	
widowed	2 (1.8%)	-	2 (2.4%)	
unmarried	5 (4.6%)	-	5 (6.0%)	
Living situation				1.0
living alone	11 (10.1%)	2 (8,0%)	1 (10.7%)	
with partner and/or children	90 (82.6%)	20 (80,0%)	70 (83.3%)	
with other relatives or friends	3 (2.8%)	-	3 (3.6%)	
Internet use in hours	2 (1.8)	2 (1.8)	2 (1)	.08
Min	0	0.5	0	
Max	10	10	8	
Personality				
Emotional stability	5.5 (1.5)	5.5 (1.13)	5.25 (2.0)	.22
Conscientiousness	5.75 (1.0)	5.5 (1.5)	6.0 (1.13)	.13
Agreeableness	5.5 (1.5)	5.5 (1.63)	5.5 (1,5)	.42
Openness	4.5 (2.5)	4.5 (2.0)	4,5 (2.0)	.38
Extraversion	4.5 (2.0)	4.5 (1,75)	4.5 (2,0)	.61
Outcome measures				
Self-management	66 (19.33)	70.8(12.20)	66 (18.48)	.03
Health related quality of life	0.89(0.19)	0.92 (0.19)	0.87 (0.19)	.54

For continuous variables data are displayed as median (IQR); For categorical variables data are displayed as frequency (%)
P values for continuous variables refer to Mann-Whitney U. *P* values for categorical variables refer to Fisher's exact.

Overall, self-management was high as patient activation score was > 60 in both groups which equals to the third level of activation (‘Beginning to take action’). Activation score was statistically significant higher in the intervention group (median = 70.8) than in the controle group (median = 66), $U = 629.0$, $z = -2.179$, $p = .03$.

Health related quality of life in total (median = 0.89, IQR = 0.19; mean = 0.878, SD = 0.137) was about equal to the Dutch norm scores of the EQ5D5L (mean = 0.869, SD = 0.170) (Versteegh et al 2016, see Appendix Table 2). No significant difference between groups was found in health related quality of life.

No significant differences referring personality traits between the groups were found. The internal consistency of the TIPI had a low level as determined by a Cronbach's alpha of 0.635.

Attrition group

As attrition rate was high a table of baseline characteristics of patients who dropped out was included (see Table 2) in order to evaluate aspects of the excluded subsample which may help to indicate potential attrition bias (Dumville et al 2006). About 103/207 (50%) of the total group who provided data at baseline measure did not provide data one year later. Attrition was higher in the MGP group, 35/60 (58%), compared to 68/152 (45%) in the controle group.

Table 2
Baseline characteristics of participants in total and per group who did not provide data one year later

	Participants lost to follow up		
Baseline variable	Total n = 103	MGP n = 35	Controle n = 68
Demographics			
Gender			
male	64 (62.%)	23 (66%)	41 (60%)
not specified	4 (4%)	-	4 (6%)
Age, years	63 (10)	60 (8)	62.5(12)
Min	22	33	29
Max	84	75	77
Education			
University/tertiary	42 (41%)	18 (51%)	24 (35%)
Secondary	26 (25 %)	10 (29%)	16. (24%)
Primary or less	34 (33%)	7 (20 %)	27 (40%)
other	-	-	-
Marital Status			
married	78 (83%)	24 (69%)	54 (79%)
divorced	14 (14%)	7 (20%)	7 (10%)
widowed	4 (4%)	2 (6%)	2 (3%)
unmarried	7 (7%)	2 (6%)	5 (7%)

Living situation			
living alone	16 (16%)	8 (23%)	8 (12%)
with partner and/or children	83 (81%)	27 (77%)	56 (82%)
with other relatives or friends	3 (3%)	-	3 (4%)
Internet use in hours	2 (1.8)	2 (2.0)	2 (2.0)
Min	0	0.5	0
Max	10	6.0	8
Personality			
Emotional stability	5.5 (1.5)	5.5 (1.75)	5.5 (1.5)
Conscientiousness	5.5 (1.5)	5.5 (1.5)	5.5 (1.5)
Agreeableness	5.5 (1.0)	5.5 (1.5)	5.5 (1,0)
Openness	4.75 (1.5)	4.75 (1.63)	4,75 (1.5)
Extraversion	4.5 (2.0)	4.5 (1,13)	4.5 (2,0)
Outcome measures			
Self-management	60 (20.20)	60.0 (16.13)	60.0 (25.40)
Health related quality of life	0.84(0.23)	0.84 (0.19)	0.84 (0.27)

For continuous variables data are displayed as median (IQR); For categorical variables data are displayed as frequency (%)

Further, as it is suggested that differing baseline characteristics between attrition and study group might be of importance for the study generalizabilty (Gustavson et al 2012) MGP group and MGP attrition group were tested on significant differences. Patient's level of self-management in the MGP attrition group was significantly lower compared to participants in the MGP group $U = 529.0$, $z = -2.408$, p=.016 (see Table 3).

Table 3
Group comparison in baseline self-management capacity of MGP group and MGP attrition group

Outcome measure baseline	MGP n = 22	MGP attrition n = 35	*P* value
Self-management	70.8 (12.20)	60.0 (16.13)	0.2

Date are displayed as median (IQR); *P* value refers to Mann-Whitney U test

Outcomes

Table 4 shows the results of the effect analyses on self-management and health related quality of life.

Effects on self-management between groups

An ANCOVA was run to determine the effect of MGP and control group on follow up activation score after controlling for baseline activation score. After adjustment for baseline score there was no statistically significant difference in follow up activation score between the groups, $F(1, 101) = 1.99$, $p = .16$.

Table 4
Results for Self-management and Health related Quality of Life

Outcome measures	Baseline value *To*	Change from Baseline *T* = 12 months
Self-management		
MGP	69.58 (11.93)	-6.5 (10.77)*
Controle	63.63 (13.68)	-0.8 (13.02)
Health related Quality of Life		
MGP	0.92 (0.19)	0.0 (0.03)
Controle	0.87 (0.19	0.0 (0.05)

For PAM13 data are presented as mean scores (SD) at baseline and as mean change from baseline (SD) at follow up assessments. Negative change indicates decline.
For EQ5D3L central tendencies of data are presented as medians (IQR).
*P = 0.01 for post-MGP change from baseline within intervention group (paired t-test)

Effects on self-management within MGP group

A paired T-test was run to investigate the change in self-management between baseline measure and follow up measure within the MGP group. There was a statistically significant mean decrease in patient activation score after one year compared to baseline measurement, t (21) = -2.831, p = 0.1. The effect was medium, d = -0.6 (Cohen, 1988). (see Table 4)

Effects on Health related Quality of Life within MGP group

To test if quality of life within the intervention group was affected the difference between the central tendency of baseline measure and post measure was examined. Within the intervention group there was no significant change in health related quality of life in the follow up measure compared to baseline measure, z = 0.566, p =.57.

Association between change in self-management and personality

A correlation matrix with change of patient activation among the MGP group with each personality dimension as measured by TIPI is shown in Table 4. As no relationship between activation change with any personality dimension was linear a spearman's correlation was used to determine the association between the change of patient activation and personality. There were no significant associations found between the change of patient activation and personality traits within the intervention group. There were indications that the amount of activation change was positive associated with Conscientiousness (p= 0.8) and negative with Extraversion (p = 0.6), however this was not proven to be significant.

Table 4
Correlation Matrix of Activation Change and Personality Trait in the MGP group

	Activation Change	
	Coefficient	*P* Value
Emotional Stability	-.018	.86
Conscientiousness	.175	.08
Agreeableness	.082	.41
Openness	-.058	.56
Extraversion	-.192	.06

For Activation Change the difference score between activation score in follow up assessment (*T* = 12 months) minus activation score at baseline measure (*To*) was calculated per individual. Negative correlations illustrate inversely proportional relationships. Positive correlations illustrate directly proportional relationships.

Discussion

The study had three aims, two primary and one secondary. (1) Assessing the effect of a personal health record on self-management of a group of patients with chronic diseases treated in primary care. (2) In order to determine the meaning of individual differences for effectiveness of the PHR associations between effect and personality were examined. (3) The effect of the PHR on Health related Quality of Life was assessed to determine subjective benefits of the intervention.

Self-management in patients with chronic diseases who were allocated to the MGP group and who provided data after one year did not appear to show improvements when compared to patients in the controle group. However, examining group baseline self-management revealed that the groups differed in their level of self-management. The MGP group had an activation score equaling the 4th and highest level of self-management whereas the controle group had a self-management score equaling the 3rd level, in other words, well-managed patients who were active in maintaining their self-management level were compared to patients who were less self-managed and began to become activated. As baseline self-management proved to have effect on the outcome measure of interventions (Hibbard et al 2007) the result might be affected by the group's difference. In conclusion, the difference of self-management level at baseline between the groups might put the comparability of the groups referring to self-management after one year into question. This might also explain why the level in the MGP group had decreased at post-measure compared to baseline, dropping from the 4th level to the 3rd (when referring to the PAM scale). The dropping of self-management from baseline to post-measure in the MGP group confirms the expectation of high level patient activation, as a high level of patient activation is expected to be difficult to maintain over time (Hibbard & Gilburt 2014). As a consequence, the dropping in the MGP

group after one year while self-management in the controle groups stayed constant may be caused by different levels of self-management in the groups at baseline measure.

Reported HrQoL did not show improvement within the MGP group. The reason might be that there was little room for improvement as HrQoL was about equal to the Dutch norm scores of the relatively similar questionnaire EQ5D5L (Versteeg et al; see Appendix Table).

There were two trends in the relationship between effect of MGP and personality which referred to Conscientiousness and Extraversion. Self-management tended to have a direct proportional relationship with Conscientiousness, and an inverse proportional relationship with Extraversion. Accordingly, the trends suggests that MGP might be more qualified to support self-management in patients who are highly conscientious and less extraverted than in patients who are less conscientious and highly extraverted. Consequently, considering the trend, the MGP in its actual design might correspond more to the needs of highly conscientious patients rather than to the needs of highly extraverted patients. As extraverted individuals were in particular responding to social feedback (Halko & Kientz 2010) the integration of a social feedback feature into MGP may be reconsiderable in order to take the needs of extraverted patients in the design into account.

The study results confirm earlier results of evaluations on self-management interventions which included a PHR in the way that interest in use diminished over time and that effects were difficult to determine due to small sample size and/or attrition bias (Vedel et al 2013, Eysenbach 2005). Furthermore, the trends regarding the association between personality and self-management change ascribed to the use of the PHR might indicate individual preferences for system design and consequently provides support for tailoring technologies in the frame of eHealth.

Limitations and further research

Even though the TIPI had proven to be a valid and reliable measurement as it reached adequate levels in a variation of tests on validity and reliability it is less reliable compared to the standard multi-item measures of the Big Five and is not appropriate to reveal narrower facets of the trait constructs (Gosling et al 2003). This loss of detailed information might be acceptable in studies wherein personality traits are of secondary interest. However, as personality traits were central to the actual study this loss of information limits the validity and power of the study. To deepen understanding of the actual results further research should focus on facets of personality traits in order to investigate which facets of personality might

play a key role regarding self-management and how a PHR system can be customized accordingly. Therefore, studies should employ more precise measure instruments for personality; but as time is limited this might be difficult to realize in large sample sizes. Consequently, in-depth studies with small sample sizes might be a more adequate choice to deepen understanding of the role of personality regarding enhancing self-management capacity by utilizing a PHR.

Another limitation of this study was the high attrition rate. As attrition was higher than 20% it prevented conducting a complete intention to treat analysis and heightens the possibility of a bias on the study results; this in particular when the attrition group differs in characteristics relevant for analyses from the analyzed study group (Hollis 1999, Schulz & Grimes 2002). This was the case, as baseline self-management level was significantly lower in the MGP attrition group than in the MGP group, therefore the introduction of a selection bias is likely. As a consequence, the results of the study apply only to patients who are already well-managed and engaging in maintaining their self-management level. Further, it appears as if patients in the MGP group who provided data one year later were more activated, meaning more skilled and educated in and motivated to self-manage, than patients in the MGP attrition group. Accordingly, PHRs might address in particular highly activated patients or, vice versa, highly activated patients seem to be more responsive to adoption of a PHR than less activated patients. However, this study does not give insight if patients were actually using the PHR or if they just filled in questionnaires to provide data. Further research is needed to gain more insight into the actual user of a PHR to understand the user's motivation to adopt and to continue using the PHR system. From actual users can be learned how the system works effectively for the user group e.g. which usage patterns might be effective and in consequence how system design can be customized.

Reasons for attrition may be because of both provider and patient. It is suggested that low provider awareness and preparedness can reduce the chances of successful adoption and/or continuous use of PHRs when patients have high expectations (Archer et al 2011). Further, computer literacy of the patient may influence adoption and use, and in particular among older user the issue of technical support to handle access might be critical for adoption (Archer et al 2011). Differences in computer literacy might also have influenced the outcomes in this study, if daily time spent online counts as an indication for computer literacy. There was the tendency that patients within the intervention group made more use of the internet than patients in the controle group. It was unclear if this might have influenced the outcomes because information about the integration of the MGP into the primary care was scarce e.g. how patients were

introduced to the MGP system (did they receive help/instruction?). Further research needs to investigate the diffusion of PHRs into the chronic care in order to understand its influence for outcomes, encouraging not only the development of guidelines for tailoring the PHR system but also for a user-centred design of the integration of the PHR into the daily care routine of the patient.

As health literacy is seen as considerable aspect of patient activity (Monteagudo & Moreno, 2007) health literacy of the patient might also influence adoption and use (Archer et al 2011). Even though the PAM 13 is seen as reliable instrument to measure self-management, it's measured concept of patient activation seems to give insufficient insight into the degree of patient's health literacy (Rademakers et al 2012). Therefore the study misses information about this aspect of patient activity. As the user's level of health literacy is crucial for the choice which content and how to present it within the PHR system in order to be usable and useful for the user, more research is needed to investigate the influence of health literacy on self-management and consequently for a user-centred design of a PHR system.

Patients in this study had high levels of HrQoL and no improvements have been detected. However, small changes might not have been detected because the scale of the used version of EQ5D covers only 3 levels to describe the intensity of a health condition. This is particularly considerable in association with a relatively high HrQoL as it restricts the potential to detect small changes, (Veersteg et al 2016). Consequently, an instrument providing more than 3 levels might have been more appropriate, for instance the EQ5D5L. The EQ5D5L is a new version of the EQ5D3L and provides 5 levels. It has proven to have a higher discriminatory potential (Veersteg et al 2016). Because the 5-level version gives more insight than the 3-level version whilst about equal in handling (e.g. regarding time consuming) future studies may be advised using the 5-level version, particularly in studies wherein time is limited, patients are expected to have already a relatively high HrQoL and/or wherein only small changes in HrQoL are likely to be observed.

Conclusion

Overall, the study confirmed that introducing PHR's into health care is difficult. Even though the design of ‚Mijn Gezondheidsplatform' is conceived in the way that it is plausible to assume that it supports the formation of a patient/health care provider relationship as highlighted by the CCM and techniques to change behavior (goalsetting and planning, feedback and monitoring) which correspond to the core self-management skills emphasized by Lorig &

Holman (2003) the attrition rate was high and effectiveness remained vague. This might indicate that attrition may not be only due to the system design but also to the process of integrating the PHR into the routine of the patient's daily care and the routine of health care providers. For instance, in this study not much information was available about how the PHR was actually integrated into the patients daily care routine nor how the medical centres did handle the PHR. How did they use it? This lack on information might be seen as lack of attention to this process. Accordingly, attending the integration process might be the next step in studying the potential of the PHR. The aim of those studies should be to develop guidelines on how the PHR is effectively integrated into the care system. Effectively here means useful for the patient and the health care provider in the way that it is easy to integrate and valuable in the care. To realize this patients and health care providers need to be directly included in the design of the process of integration. Guidelines of the integrational process should be designed. Then tried out by carrying out pilot studies with small sample sizes and evaluated with qualitative feedback from participating patients and health care providers.

Own ideas regarding the integration of PHRs

As long as the decision to use it or not stays on the side of the user I think PHRs have the potential to become a valuable support tool for patients with chronic diseases but also for every individual who feels responsible and wants to manage part of the own health. Problems may arise from that health care providers might feel observed and critizised by an active patient who is able to question the provider's decisions. As the health care system in our days is still authoritative (the doctor tells the patient what to do) and the PHR shifts it to a more democratic communication the role of patient and of the health care provider are new defined. Doctors should therefore be prepared on how to react adequately to ideas/critic from a patient. An adequate reaction of the doctor in turn ecourages the patient to further practice self-management (and to continue using the PHR). Therefore I think teaching the health care provider communication skills on how to react adequately to active patients should be taken into account in the process of integration of the PHR into primary care.

References

Abbott, J., Hart, A., Havermans, T., Matossian, A., Goldbeck, L., Barreto, C., ... & Staab, D. (2011). Measuring health-related quality of life in clinical trials in cystic fibrosis. *Journal of Cystic Fibrosis*, *10*, S82-S85.

Archer, N., Fevrier-Thomas, U., Lokker, C., McKibbon, K. A., & Straus, S. E. (2011). Personal health records: a scoping review. *Journal of the American Medical Informatics Association*, *18*(4), 515-522.

Arteaga, S. M., Kudeki, M., & Woodworth, A. (2009). Combating obesity trends in teenagers through persuasive mobile technology. *ACM SIGACCESS Accessibility and Computing*, (94), 17-25.

American Psychiatric Association. Diagnostic and statistical manual of mental disorders. 4th ed.Washington, DC: Author; 1994.

Barlow, J., Wright, C., Sheasby, J., Turner, A., & Hainsworth, J. (2002). Self-management approaches for people with chronic conditions: a review. *Patient education and counseling*, *48*(2), 177-187.

Berry, C., & McMurray, J. (1999). A review of quality-of-life evaluations in patients with congestive heart failure. *Pharmacoeconomics*, *16*(3), 247-271.

Bentsen, S. B., Rokne, B., Klopstad Wahl, A.(2013). Comparison of health-related quality of life between patients with chronic obstructive pulmonary disease and the general population. *Scandinavian journal of caring sciences*, *27*(4), 905-912.

Bentzen, N. (Ed.). (2003). *WONCA dictionary of general/family practice*. Wonca International Classification Committee.

Blokstra, A., Baan, C. A., Boshuizen, H. C., Feenstra, T. L., Hoogenveen, R. T., Picavet, H. S. J., ... & Verschuren, W. M. M. (2007). Vergrijzing en toekomstige ziektelast. Prognose chronische ziektenprevalentie 2005-2025.

Bodenheimer, T., Wagner, E. H., & Grumbach, K. (2002). Improving primary care for patients with chronic illness: the chronic care model, Part 2. *Jama*, *288*(15), 1909-1914.

Cella, D. F. (1992). Quality of life: The concept. *Journal of Palliative Care*.

Connelly C.(1993). An empirical study of a model of self-care in chronic illness. *Clin Nurse Spec*.,7:247–53.

Costa, P. T., & McCrae, R. (1992). NEO-PI-R: Professional Manual: Revised NEO Personality Inventory and NEO Five-Factor Inventory. Odessa, FL: Psychological Assessment Resources.

Cramm, J. M., & Nieboer, A. P. (2012). Self-management abilities, physical health and depressive symptoms among patients with cardiovascular diseases, chronic obstructive pulmonary disease, and diabetes. *Patient education and counseling*, *87*(3), 411-415.

Dumville, J. C., Torgerson, D. J., & Hewitt, C. E. (2006). Reporting attrition in randomised controlled trials. *Bmj*, *332*(7547), 969-971.

Eysenbach, G. (2005). The law of attrition. *Journal of medical Internet research*, *7*(1), e11.

Fogg, B. J. (2002). Persuasive technology: using computers to change what we think and do. *Ubiquity*, *2002*(December), 5.

Funnell, M. M., Brown, T. L., Childs, B. P., Haas, L. B., Hosey, G. M., Jensen, B., ... & Siminerio, L. M. (2009). National standards for diabetes self-management education. *Diabetes care*, *32*(Supplement 1), S87-S94.

Gustavson, K., von Soest, T., Karevold, E., & Røysamb, E. (2012). Attrition and generalizability in longitudinal studies: findings from a 15-year population-based study and a Monte Carlo simulation study. *BMC Public Health*, *12*(1), 1.

Gosling, S. D., Rentfrow, P. J., & Swann, W. B. (2003). A very brief measure of the Big-Five personality domains. *Journal of Research in personality*, *37*(6), 504-528.

Hibbard, J., & Gilburt, H. (2014). Supporting people to manage their health. *An introduction to patient activation. London: The King's Fund*.

Hibbard, J. H., Mahoney, E. R., Stock, R., & Tusler, M. (2007). Do Increases in Patient Activation Result in Improved Self-Management Behaviors?. *Health services research*, *42*(4), 1443-1463.

Hollis, S., & Campbell, F. (1999). What is meant by intention to treat analysis? Survey of published randomised controlled trials. *Bmj*, *319*(7211), 670-674.

Krebs, P., Prochaska, J. O., & Rossi, J. S. (2010). A meta-analysis of computer-tailored interventions for health behavior change. *Preventive medicine*, *51*(3), 214-221.

Otten, W., Rövekamp, T., Keer, M., Graaf, A. D., & van Keulen, H. M. (2015). *Mogelijkheden voor webbased ondersteuning bij zelfmanagement van Type 2 Diabetes Mellitus* (No. TNO 2015 R11352). TNO.

Intille, S. S. (2004). Ubiquitous computing technology for just-in-time motivation of behavior change. *Stud Health Technol Inform*, *107*(Pt 2), 1434-7.

Lam, C.L.K., & Lauder I.J. (2000)The impact of chronic diseases on the health-related quality of life (HRQOL) of Chinese patients in primary care. *Family Practice* 17.2: 159-166.

Lorig, K. R., & Holman, H. R. (2003). Self-management education: history, definition, outcomes, and mechanisms. *Annals of behavioral medicine*, *26*(1), 1-7.

Monteagudo, J. L., & Moreno, O. (2007). e-Health for patient empowerment in Europe. *Ministerio de Sanidad y Consumo, Instituto de Salud Carlos III. Madrid*.

Nationaalkompass (2016). Chronische ziekten en multimorbiditeit. http://www.nationaalkompas.nl/gezondheid-en-ziekte/ziekten-en-aandoeningen/chronische-ziekten-en-multimorbiditeit/

Oinas-Kukkonen, H., & Harjumaa, M. (2009). Persuasive systems design: Key issues, process model, and system features. *Communications of the Association for Information Systems*, *24*(1), 28.

Te Poel, F., Bolman, C., Reubsaet, A., & de Vries, H. (2009). Efficacy of a single computer-tailored e-mail for smoking cessation: results after 6 months. *Health Education Research*, cyp036.

Rademakers, J., Nijman, J., van der Hoek, L., Heijmans, M., & Rijken, M. (2012). Measuring patient activation in the Netherlands: translation and validation of the American short form Patient Activation Measure (PAM13). *BMC Public Health*, *12*(1), 1.

Royal College Physicians, Royal College General Practitioners; NHS alliance. Clinicians, services and commissioning in chronic disease management in the NHS. RCP/RGP/NHS alliance 2004

Smeets, T., Brug, J., & de Vries, H. (2008). Effects of tailoring health messages on physical activity. *Health Education Research*, *23*(3), 402-413.

Sprangers, M. A. (2002). Quality-of-Life assessment in oncology. *Acta Oncologica*, *41*(3), 229-237.

Schulz, K. F., & Grimes, D. A. (2002). Sample size slippages in randomised trials: exclusions and the lost and wayward. *The Lancet*, *359*(9308), 781-785.

Ursum, J., Rijken, M., Heijmans, M., Cardol, M., & Schellevis, F. (2011). NIVEL Overzichtstudies: zorg voor chronisch zieken: organisatie van zorg, zelfmanagement, zelfredzaamheid en participatie.

Von Korff, M., Gruman, J., Schaefer, J., Curry, S. J., & Wagner, E. H. (1997). Collaborative management of chronic illness. *Annals of internal medicine*, *127*(12), 1097-1102.

Voncken-Brewster, V., Tange, H., Moser, A., Nagykaldi, Z., De Vries, H., & Van Der Weijden, T. (2014). Integrating a tailored e-health self-management application for chronic obstructive pulmonary disease patients into primary care: a pilot study. *BMC family practice*, *15*(1), 1.

Vedel, I., Akhlaghpour, S., Vaghefi, I., Bergman, H., & Lapointe, L. (2013). Health information technologies in geriatrics and gerontology: a mixed systematic review. *Journal of the American Medical Informatics Association*, *20*(6), 1109-1119.

Versteegh, M. M., Vermeulen, K. M., Evers, S. M., de Wit, G. A., Prenger, R., & Stolk, E. A. (2016). Dutch Tariff for the Five-Level Version of EQ-5D. *Value in health*.

Wagner, E. H. (1998). Chronic disease management: what will it take to improve care for chronic illness?. *Effective clinical practice: ECP*, *1*(1), 2.

Wagner, E. H., Austin, B. T., Davis, C., Hindmarsh, M., Schaefer, J., & Bonomi, A. (2001). Improving chronic illness care: translating evidence into action. *Health affairs*, *20*(6), 64-78.

WHO 2016, Cardiovascular diseases. http://www.who.int/mediacentre/factsheets/fs317/en/

Appendix

Raw Score	Activation
13	0.0
14	8.2
15	13.3
16	16.5
17	18.9
18	20.9
19	22.7
20	24.3
21	25.7
22	27.1
23	28.4
24	29.7
25	31.0
26	32.2
27	33.5
28	34.7
29	36.0
30	37.3
31	38.7
32	40.1

Raw Score	Activation
33	41.7
34	43.4
35	45.2
36	47.4
37	49.9
38	52.9
39	56.4
40	60.0
41	63.2
42	66.0
43	68.5
44	70.8
45	73.1
46	75.3
47	77.5
48	80.0
49	82.8
50	86.3
51	91.6
52	100.0

Table 1
Table of Insignia Health for converting the raw PAM-13 score into an activation score

Table 5 – Dutch general population EQ-5D-5L reference values.

Characteristics	Mean ± SD	Min.	Max.	N
Age (y)				
<20	0.958 ± 0.07	0.743	1	26
20 through	0.908 ± 0.146	0.031	1	158
30 through	0.903 ± 0.134	0.141	1	134
40 through	0.85 ± 0.196	−0.16	1	202
50 through	0.857 ± 0.183	−0.137	1	186
60 through	0.839 ± 0.179	−0.003	1	158
70 and high	0.852 ± 0.148	0.335	1	106
Sex				
Men	0.881 ± 0.172	−0.012	1	480
Women	0.858 ± 0.168	−0.16	1	497
Average	0.869 ± 0.170	−0.16	1	979

EQ-5D-5L, EuroQol five-dimensional questionnaire five-level; Max., maximum; Min., minimum.

Table 2
Dutch general population EQ-5D-5L reference values for the index summary score