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Personal health records in the Netherlands: potential user preferences quantified by a discrete choice experiment

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Abstract

Objective: To identify groups of potential users based on their preferences for characteristics of personal health records (PHRs) and to estimate potential PHR uptake.

Methods: We performed a discrete choice experiment, which consisted of 12 choice scenarios, each comprising 2 hypothetical PHR alternatives and an opt-out. The alternatives differed based on 5 characteristics. The survey was administered to Internet panel members of the Dutch Federation of Patients and Consumer Organizations. We used latent class models to analyze the data.

Results: A total of 1,443 potential PHR users completed the discrete choice experiment. We identified 3 latent classes: "refusers" (class probability 43%), "eager adopters" (37%), and "reluctant adopters" (20%). The predicted uptake for the reluctant adopters ranged from 4% in the case of a PHR with the worst attribute levels to 68% in the best case. Those with 1 or more chronic diseases were significantly more likely to belong to the eager adopter class. The data storage provider was the most decisive aspect for the eager and reluctant adopters, while cost was most decisive for the refusers. Across all classes, health care providers and independent organizations were the most preferred data storage providers.

Conclusion: We identified 3 groups, of which 1 group (more than one-third of potential PHR users) indicated great interest in a PHR irrespective of PHR characteristics. Policymakers who aim to expand the use of PHRs will be most successful when health care providers and health facilities or independent organizations store PHR data while refraining from including market parties.

Key words: personal health records, preferences, discrete choice experiment

BACKGROUND AND SIGNIFICANCE

A personal health record (PHR) can be defined as "an 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."[1] In contrast to clinicians' medical records, PHRs are managed by patients.[2] PHRs are sometimes also called patient portals,[3] although some define patient portals in a narrower way: "Applications provided and maintained by health care institutions that primarily allow access to clinical electronic health record data and secondarily may offer functions and services that are targeted towards enhancing medical treatment," and state that they can be implemented as part of a PHR.[4] PHRs can have varying characteristics, for example, they can offer secure patient-provider communication and can hold various sources of static and dynamic information for patients.[5] Furthermore, both providers and patients may be able to add data[6] either self-entered or through "wearables." Additional convenience features include online appointment scheduling and medication refill requests. Large-scale implementation of PHRs[5,7] is expected to yield cost reductions,[8,9] increase quality of care,[10] and increase efficiency of care.[5] They are seen as a tool to empower patients and give them control over their health care process.[11] As such, PHRs can serve as a clinical information system in patient-centered care and support well-informed, engaged, and empowered patients.[8]

PHRs are generating increased interest and are high on the agenda of policymakers in the Netherlands.[12] In contrast to other countries, such as Australia, where a national PHR was implemented in 2012,[13] there is currently no national PHR initiative in the Netherlands. However, a number of PHR platforms are available, eg, Microsoft's HealthVault and Patient1.[14] Comparable platforms in other countries include Dossia Health Management System in the United States and Patients Know Best in the United Kingdom.[15] Involving potential users in the development, testing, and implementation of PHRs could provide a base for further implementation.[16] Furthermore, insights into the value that citizens place on various PHR characteristics can help developers improve their products and advise policymakers on furthering conditions for the use of PHRs.[2,17]

To our knowledge, there is little quantitative information available on the number of users of PHRs in developed countries. However, sources report that the current uptake of PHRs is limited.[18,19] A recent study among members of a panel of patients and consumers in the Netherlands reported that 9% of people have a PHR.[20] It has been argued that PHRs that are currently available on the market are not based on patients' needs.[21] The limited uptake may be an important reason for the scarce evidence of PHR advantages.[2,4,22–25] If significant diffusion of PHRs is to take place, it is essential that potential users envisage sufficient added value relative to the status quo.[26] Individuals with poorer digital literacy are less inclined to adopt PHRs.[16,26,27] Moreover, chronically ill people, frequent health care users, and those acting as caregivers are more likely to use PHRs.[28–32] However, the design and usability of PHRs will also affect the eventual uptake[32] for these groups. A barrier to PHR use expressed in many studies is concern about security and privacy of the data in the PHR.[16,26,27,30,33,34] Another barrier is a lack of standardization of the formats in operational systems,[35] ie, data must be entered manually into most PHRs.

OBJECTIVE

In this study, we aim to investigate potential users' preferences for PHR characteristics. Individuals who face the decision to opt for a PHR trade the negatively valued aspects for positively valued aspects. This study aims to mimic this trading behavior by imitating the real choice situation, adopting or not adopting a PHR, by means of the discrete choice experiment (DCE) methodology.[36] A DCE is a survey-based stated-preference method that has been increasingly used in health care to address a wide range of policy questions.[37] To date, no DCEs have been conducted to explore PHR preferences. The research questions of this paper are: (1) Can we identify subgroups of potential users with different PHR preferences across groups? (2) What PHR characteristics are most important within subgroups? and (3) What is the potential uptake of PHRs?

MATERIALS AND METHODS

Discrete choice experiments
DCEs originate from mathematical psychology[38] and have a strong theoretical foundation in random utility theory[39,40] and Lancaster's theory of value.[41] In a typical DCE survey, respondents are presented with a series of hypothetical scenarios (called choice sets) for which they are asked to choose between 2 or more alternatives that are distinguished from one another by systematically varying characteristics (called attributes).[42–45] Random utility theory assumes that respondents will choose the alternative within a choice set that yields the highest utility (benefit or satisfaction). Based on respondents' choices, preferences can be elicited, willingness-to-pay (WTP) estimates can be calculated (if a cost attribute is included), and uptake rates can be predicted.

Experimental DCE design
We selected 5 attributes with 2 to 6 levels each (Table 1) based on a literature search, expert interviews (policymakers and researchers; $N = 5$), and focus group discussions with the general population ($N = 4$, 25 participants in total). Each of the 4 focus group discussions included at least 6 members of the Dutch adult population, with mixed characteristics based on age, gender, educational level, and health status. Following semistructured discussions, participants ranked a list of attributes according to the nominal group technique.[46] For this matter, a predefined attribute list ($N = 17$) based on the literature and expert interviews was completed with additional attributes that were mentioned during the focus group discussions (with a maximum of $N = 23$ attributes to rank). The attributes that were ranked highest were considered for inclusion in the DCE. The attribute "data storage provider" relates to the trust that respondents have in institutes/companies with respect to security/privacy of (sensitive) information that is stored in a PHR, and thus serves as a proxy for privacy concerns.

A choice set consisted of 2 unlabeled hypothetical PHR alternatives, PHR A and PHR B, with systematically varying attribute levels, and an opt-out alternative (ie, no PHR). This opt-out was necessary, since, as in real life, respondents were not obliged to have a PHR. Supplementary Material 1 shows an example of a choice set. By minimizing the D-error, a Bayesian efficient design based on best-guess priors was generated using Ngene design software (version 1.1.1.). These priors (small positive and negative values) were used to increase the efficiency of the design by avoiding dominant choice sets. We generated a subset of 12 choice sets to ensure level balance, as well as enough degrees of freedom to estimate a main-effects-only model (assuming that the cost attribute is noncategorical). For more information on these more technical elements of a DCE, see, eg, Reed Johnson et al.[47]

Table 1. Attributes and corresponding levels included in the DCE

Attributes	Short name	Attribute levels
Data storage provider	Data storage	Commercial company Independent organization or platform Government Health care provider or health facility
Level of connectivity	Connectivity	Stand-alone Tethered to the system of your GP Tethered to the system of your hospital Interconnected
Use of anonymized data by third parties	Use of data	No, never Yes, after permission
Option to upload one's own data into PHR	Data adding	No Yes
PHR cost per capita per year as a proxy of the price that people would pay for a PHR[a]	Cost	€0, €15, €30, €50, €70, €95

Notes: [a]We included the following cost levels in the pilot survey based on earlier research by the Dutch Federation of Patients and Consumer Organizations (NPCF)[20]: €0, €2, €5, €15, €30, and €50. The results of the pilot study showed the need to expand the range of cost levels by increasing the highest level, and to broaden the intervals between levels.

Abbreviations: PHR, personal health record; GP, general practitioner.

Survey instrument

An inclusion criterion for the current study was that respondents currently did not have a PHR. The survey started with an introduction to the study and the topic (Supplementary Material 1). Thereafter, the included attributes and their corresponding levels as well as the DCE task were explained to respondents, followed by a clearly explained choice set example. Subsequently, respondents completed the 12 choice sets. An example of a choice set is shown in Supplementary Material 1. Following the 12 choice sets, respondents were asked a question to assess whether they experienced difficulties when completing the survey (5-point Likert scale, very hard to very easy) and a question to assess whether they were confident when providing their answers (5-point Likert scale, very uncertain to highly certain). The survey concluded with questions on respondents' intention to use a PHR and on sociodemographic characteristics, a question on whether or not respondents had previously experienced a medical error (eg, a wrong drug prescription or diagnosis), and questions on digital literacy (self-perceived Internet skills and type of Internet use) and risky digital behavior. Risky digital behavior was measured by means of 4 statements, where respondents had to mark on a scale of 1–7 how likely or unlikely this behavior was for them (maximum score was thus 28, indicating high-risk behavior). We adapted the statements included in the domain-specific risk-taking scale for adult populations[48] to fit our research question. The survey was pilot tested using think-aloud interviews ($N = 4$) to test for respondent understanding and improve the wording of the survey. Next, a formal pilot test ($N = 51$, from the same Internet panel as was used for the final data collection, see below) was conducted to test randomization and improve the wording of the survey. Pilot data was analyzed using multinomial logit models, and estimates were used as priors for the final DCE design.

Data collection

The survey was administered to Internet panel members of the NPCF in December 2015 and January 2016. All panel members ($N = 22 841$) received an e-mail with the URL of the online survey and were asked to complete it on a voluntary basis. Data collection was terminated once the number of respondents completing the survey had decreased to a few per day. Because of practical limitations at the NPCF, no reminders were sent out.

Ethics statement

Formal testing of the study protocol by a Medical Ethics Committee was not necessary. Neither the focus group discussions or the survey among volunteers of an Internet panel fell within the scope of the Dutch Act on Medical Research Involving Human Subjects, because participants were not subjected to procedures, nor were they required to follow rules of behavior.

Discrete choice data analysis

The choices respondents made in the choice sets were used to estimate the impact of the attributes (independent variables) on their choices for PHR or opting out (dependent variable). A significant independent variable indicates that the attribute level has a significant impact on PHR preference, and the sign of the coefficient reflects whether this impact has a positive or negative effect. Several types of discrete choice models can be estimated. We chose to perform a latent class analysis, since this is a model that can take both preference heterogeneity and the panel nature of the data (ie, dependencies between choice observations by a single respondent) into account.[49] In addition, it is a closed-form model (ie, does not rely on complex simulations).[49] A latent class analysis assumes the existence of subgroups (called classes) of respondents that differ with respect to preferences. The researcher decides on the number of classes based on the model fit (Aikake information criterion [AIC], Bayesian information criterion [BIC], pseudo-R^2) and sound interpretation of classes. Class membership is latent in that the researcher does not determine, a priori, who belongs to which class. Instead, class membership is expressed as class probabilities that may depend on the respondent's characteristics. We thereto fitted a class probability model in addition to the choice model where we tested the presence of individual-level drivers (age, health status, previous experience of a medical error) and individual-level barriers for the use of PHR (health literacy and digital literacy [self-perceived Internet skills, type of Internet use, and risky digital behavior]) as predictors of the classes. These characteristics were selected based on the

literature.[16,26–32] Choice data were analyzed in Nlogit version 4.0 (Econometric Software).

The class-specific relative importance of the attributes was calculated by dividing the difference in utility between the highest and lowest levels of a single attribute by the sum of the differences in utility of all attributes for that class. The higher the proportion, the more important the attribute is for PHR choice. We calculated annual WTP estimates by taking the ratio of the attribute level of interest over the negative coefficient of the cost attribute. We calculated the class-specific uptake of PHRs by dividing the exponential of the total utility for a particular PHR by the exponential of the sum of utilities for the particular PHR and the opt-out (no PHR). In addition, we calculated the average uptake (weighted average, based on class probabilities).

RESULTS

Descriptive statistics

The URL of the survey was e-mailed to all 22 841 panel members. A total of 3404 responded (response rate 15%). Of these, 1443 were eligible for the present study, which focuses on respondents who currently do not have a PHR. Table 2 shows that respondents were on average 61 years of age, and half were highly educated (50%). A majority of respondents suffered from 1 or more chronic diseases (77%). Compared to the general population, our sample is older, more highly educated, and more often chronically ill. About one-third of respondents had experienced a medical error (eg, receiving a wrong drug) at least once. The stated intention to use a PHR within 2 years from now was high for a quarter of the sample (25%). A total of 38% of respondents found the survey hard or very hard to complete, while 19% indicated that they were uncertain or very uncertain about their answers to the choice sets.

Discrete choice data

The improvement in model fit (AIC, BIC, pseudo-R^2) was very limited for a model with more than 3 classes. The final latent class model therefore included 3 latent classes (Table 3). The average class probabilities were: 43% for class 1 (we refer to this class as "refusers"), followed by 37% for class 3 (referred to as "eager adopters") and 20% for class 2 (referred to as "reluctant adopters"). Tests for class probability showed that those with 1 or more chronic diseases had a significantly higher probability of belonging to class 3 than class 1 (P = .03) or class 2 (P < .01). The other individual-level drivers and barriers were not significant class probability predictors.

The constant for no PHR was large and positive in class 1, indicating that all else being equal, respondents of this class preferred not to have a PHR. On the other hand, the constant for no PHR was very large and negative in class 3, indicating that all else being equal, respondents of this class preferred to have a PHR. Respondents of class 2 were somewhere between the other 2 classes. Their constant for no PHR was small and positive, indicating that they might prefer to have a PHR if the characteristics met their preferences. For both the eager and reluctant adopters, the data storage provider was the most important attribute, followed by cost. For the refusers, cost was by far the most decisive attribute, followed by the data storage provider.

Across all classes, independent organizations and care providers were the most preferred providers of data storage (largest positive WTP estimates, Table 4). Although the government level was not significant for refusers and reluctant adopters, it was significantly

Table 2. Descriptive statistics

Characteristics	Sample (N = 1443) Mean (SD)	Census data[a] Mean
Age	61 (11)	41.3
	N (%)	%
Age groups in years		
18–40	57 (4.3)	33.7
40–65	704 (53)	44.0
65–80	533 (40)	16.9
80 or older	44 (3.3)	5.5
Gender		
Female	698 (51)	50.5
Male	671 (49)	49.5
Education[b]		
Low	254 (18)	32.9
Average	443 (32)	39.3
High	706 (50)	27.8
Self-reported health status		
Healthy	325 (23)	69.9
One or more chronic diseases	1118 (77)	30.1
Subjective health literacy[c]		
Low	29 (2.0)	–
Adequate	1395 (98)	–
Experienced a medical error		
No	926 (65)	–
Yes	500 (35)	–
Digital literacy	N (%)	
How easy is it for you to find your way on the Internet? (self-perceived Internet skills)		
Easy	1187 (83)	–
Not easy, not hard	216 (15)	–
Hard	23 (1.6)	–
Type of Internet use		–
Mainly for fun	765 (53)	–
Mainly for other purposes	678 (47)	–
	Mean (SD)	
Risky digital behavior[d]	10.9 (4.4)	–
PHR	N (%)	
Stated intention to use a PHR within 2 years from now		
Low (0–4)	727 (51)	–
Average (5 or 6)	346 (24)	–
High (7–10)	364 (25)	–

Notes: [a]Based on numbers provided by Statistics Netherlands, 2015.[50]

[b]Educational level was categorized into 3 groups: low (primary education and lower secondary education), average (higher secondary education and intermediate vocational education), and high (tertiary education).

[c]Subjective health literacy was measured based on the validated Dutch questions of the Set of Brief Screening Questions of Chew.[51]

[d]Risky digital behavior was measured by means of 4 statements where respondents had to mark on a scale of 1–7 how likely or unlikely this behavior was for them (maximum score was thus 28, indicating high-risk behavior). We adapted the statements included in the domain-specific risk-taking scale for adult populations[48] to fit our research question.

Abbreviations: SD, standard deviation; PHR, personal health record.

preferred over commercial companies by reluctant adopters. The reluctant adopters preferred a PHR that is tethered to their general practitioner (GP), with an interconnected PHR being the next best alternative. The eager adopters preferred a PHR tethered to their GP as well, although this was followed by a PHR tethered to their hospital. The WTP estimate for the latter was significantly higher than for the reluctant adopters. Although the interconnected level was

Table 3. Latent class model results (N = 1443)

Short name of attribute[a]	Attribute level	Class 1: Refusers			Class 2: Reluctant adopters			Class 3: Eager adopters		
		β (SE)	P-value	RI	β (SE)	P-value	RI	β (SE)	P-value	RI
Constant	No PHR	3.57 (0.13)	<.01	N/A	0.51 (0.03)	<.01	N/A	−4.13 (0.09)	<.01	N/A
Data storage	Commercial company	−0.50 (0.17)	<.01	0.17 (2)	−0.83 (0.04)	<.01	0.32 (1)	−0.49 (0.03)	<.01	0.31 (1)
	Independent organization or platform	0.38 (0.14)	<.01		0.44 (0.04)	<.01		0.27 (0.03)	<.01	
	Government	0.02 (0.17)	.91		−0.06 (0.04)	.10		−0.10 (0.03)	<.01	
	Care providers or health facility	0.10 (0.15)	.52		0.45 (0.03)	<.01		0.32 (0.03)	<.01	
Connectivity	Stand-alone	0.10 (0.15)	.52	0.10 (4)	−0.28 (0.04)	<.01	0.13 (4)	−0.31 (0.02)	<.01	0.20 (3)
	Tethered to GP system	−0.14 (0.17)	.39		0.24 (0.04)	<.01		0.20 (0.03)	<.01	
	Tethered to hospital system	0.28 (0.14)	.04		−0.15 (0.04)	<.01		0.09 (0.03)	<.01	
	Interconnected	−0.24 (0.17)	.16		0.19 (0.04)	<.01		0.02 (0.02)	.36	
Use of data	No, never	−0.12 (0.10)	.24	0.05 (5)	−0.24 (0.02)	<.01	0.12 (5)	−0.22 (0.01)	<.01	0.17 (4)
	Yes, after permission	0.12 (0.10)	.24		0.24 (0.02)	<.01		0.22 (0.01)	<.01	
Data adding	No, not possible	−0.40 (0.09)	<.01	0.16 (3)	−0.34 (0.02)	<.01	0.17 (3)	−0.12 (0.01)	<.01	0.10 (5)
	Yes, possible	0.40 (0.09)	<.01		0.34 (0.02)	<.01		0.12 (0.01)	<.01	
Cost	Per €	−0.03 (0.01)	<.01	0.52 (1)	−0.01 (<0.01)	<.01	0.26 (2)	−0.01 (<0.01)	<.01	0.22 (2)
Class probability model[b]										
Constant		0.42 (0.13)	<.01		−0.19 (0.16)	.23		–	–	
Having 1 or more chronic diseases		−0.33 (0.15)	.03		−0.54 (0.18)	<.01		–	–	
Class probability										
Average class probability			.43			.20			.37	
Model fit[c,d]										
Number of observations	17316									
Log likelihood	−9996									
AIC	1.158									
BIC	1.174									
Pseudo-R^2	0.475									

Notes: [a]All attributes (except the cost attribute) were effects coded. The cost attribute was included as a linear term, as transformations (log linear, quadratic, and square root) did not improve the model fit. We tested for left-right bias and found it to be insignificant.

[b]Class 3 does not have parameters in the class probability model, as the parameters of classes 1 and 2 are relative to class 3.

[c]Note that the pseudo-R^2 is not the same as the R^2 that is used in a linear regression model. A pseudo-R^2 of 0.4–0.5 is equivalent to a R^2 between 0.8 and 0.9.[42]

[d]The AIC, BIC, and pseudo-R^2 for a model with 2 classes were 1.252, 1.262, and 0.431, respectively; for a model with 4 classes, 1.140, 1.160, and 0.483, respectively; and for a model with 5 classes, 1.124, 1.148, and 0.491, respectively.

Abbreviations: SE, standard error; RI, relative importance; GP, general practitioner; AIC, Aikaike information criterion; BIC, Bayesian information criterion.

Table 4. Willingness-to-pay estimates in euros per year[a]

	Class 1: Refusers	Class 2: Reluctant adopters	Class 3: Eager adopters
Short name of attribute			
Attribute level	WTP (95% CI)[b]	WTP (95% CI)[b]	WTP (95% CI)[b]
Constant			
No PHR	126 (85, 166)	48 (37, 58)	−676 (−759, −593)
Data storage			
Commercial company	−18 (−31, −5)	−77 (−91, −63)	−81 (−97, −65)
Independent org. or platform	14 (3, 24)	41 (33, 49)	45 (35, 55)
Government	1 (−11, 13)	−6 (−13, 1)	−17 (−26, −8)
Care providers or health facility	3 (−7, 14)	42 (35, 48)	53 (43, 62)
Connectivity			
Stand-alone	3 (−7, 14)	−26 (−35, −18)	−51 (−64, −39)
Tethered to GP	−5 (−17, 7)	23 (16, 29)	33 (23, 43)
Tethered to hospital	10 (−0.3, 20)	−14 (−27, −7)	15 (5, 24)
Interconnected	−8 (−20, 3)	17 (11, 24)	3 (−4, 10)
Use of data			
No, never	−4 (−11, 3)	−22 (−25, −19)	−37 (−41, −32)
Yes, after permission	4 (−3, 11)	22 (19, 25)	37 (32, 41)
Data adding			
No, not possible	−14 (−21, −7)	−32 (−36, −28)	−20 (-24, −17)
Yes, possible	14 (7, 21)	32 (28, 36)	20 (17, 24)

Notes: [a]WTP estimates are based on effects coded levels.
[b]95% confidence intervals were calculated using the Delta method.[52]
Abbreviations: WTP, willingness-to-pay; CI, confidence interval; GP, general practitioner.

not significant for the eager adopters, it was significantly preferred over a stand-alone PHR. Both reluctant and eager adopters preferred to give permission for anonymized data use by third parties, compared to no use of their personal data. Across all classes, having the possibility to add one's own data was preferred over not having this possibility. The WTP estimate for data adding, however, was highest for the reluctant adopters.

Irrespective of the PHR characteristics and their ranges considered in the DCE, the predicted PHR uptake for the refusers was always below 9%, while the uptake of the eager adopters was predicted to always be above 91%. Among the reluctant adopters, uptake was highly sensitive to PHR attribute level. The expected uptake for the worst imaginable PHR (commercial company, stand-alone, no use of data, not possible to add one's own data, €95) was 4%, while the expected uptake for the best imaginable PHR (care provider, tethered to their GP, use of data after permission, adding one's own data, zero cost) was 68%. On average, over all 3 classes, the predicted uptake was 35% for the worst PHR (if constructed as above), while it was 52% for the best PHR (if constructed as above).

DISCUSSION

We identified 3 classes of potential PHR users with different preference structures: those who prefer not to have a PHR ("refusers," average class probability 43%), those who prefer to have a PHR ("eager adopters," 37%), and those who prefer a PHR only if the tool is designed in accordance with their preferences ("reluctant adopters," 20%). Those with 1 or more chronic diseases had a higher probability of belonging to the class of eager adopters. The data storage provider was the most decisive aspect for the eager and reluctant adopters, while cost was most decisive for the refusers. Across all classes, care providers or facilities and independent organizations were the most preferred data storage providers. The predicted uptake for the reluctant adopters ranged from 4% in the case

of worst PHR to 68% in the case of a PHR with the best attribute levels. The predicted uptake for the refusers was always below 9%, while it was always above 91% for the eager adopters.

Our study, like earlier studies,[16,26,27,30,33,34] shows that privacy concerns are a barrier to adoption of PHRs. Privacy thus outranks the potential improvement in quality of care that PHRs yield. The data storage providers that respondents preferred most were health care providers or health facilities and independent organizations or platforms. Where a commercial organization or government would store their data, this would reduce their willingness to use a PHR.

The finding that chronically ill patients had a higher probability of belonging to the eager adopters class might be explained by the fact that these individuals have an elevated concern about their health and thus are more eager to have easy access to test results, medications, and educational materials that would be available through GP- or hospital-tethered PHRs. In addition, chronically ill individuals interact frequently with multiple care providers and need to rely on their cooperation to get the best possible care. This can only be realized when all health care providers have access to up-to-date information on the care that was delivered to their patients by other providers. Use of PHRs also promotes sharing of information among health care providers and, as such, enables patient-centered care.[53,54] This could best be achieved by an interconnected PHR. However, we found that the eager adopters prefer a PHR that is tethered to either their GP or their hospital system. This result could be interpreted as respondents being hesitant about such integration of data for privacy reasons.

Study limitations

This study has a number of limitations. First, as in all DCEs, the number of attributes and levels that can be included is limited. We aimed to include all relevant attributes and levels by carefully studying the literature, interviewing experts, conducting focus group discussions with potential PHR users, and pilot testing the DCE. However, we cannot exclude the option that we missed an attribute

or a level that would have affected our results. Second, although we thoroughly pilot tested the survey, a proportion of respondents experienced difficulties when completing the DCE. These respondents might have been unfamiliar with the PHR terms that were used in the survey or may have lacked attention to the information provided. In addition, a proportion of respondents stated that they were uncertain of their answers to the choice sets, which might have an impact on the findings. We performed a sensitivity analysis to test this impact (Supplementary Material 2). This analysis shows that the predicted PHR uptake changes only minimally when the answers of (very) uncertain respondents are excluded from the analysis. Third, although we obtained enough power for the analysis in this paper, the response rate was low. We were unfortunately not able to track how many respondents read the invitation, or started but did not complete the survey. We expect that the reason for the low completion rate is that panel members of NPCF are not used to this type of questions, and no reminders were sent. Those panel members who were not interested in PHRs might not have accessed the survey. It could therefore be argued that the size of class 1 may be even bigger than estimated, and therefore that the majority of the Dutch population at present is not interested in using a PHR. Fourth, our sample may not be fully representative of the Dutch general adult population. Respondents were older, more highly educated, and more often had chronic diseases. This pattern is similar to earlier surveys that used the same panel.[20,55] We performed sensitivity analyses to test the robustness of our findings with respect to uptake in subsamples that are representative of the general population based on age, education, or health status (Supplementary Material 2). Except for the uptake of refusers in the representative sample based on health status, predicted uptakes are relatively stable. Despite the fact that our sample is not representative of the general population, it is an interesting sample because of the overrepresentation of people with chronic illness. Fifth, PHRs have been defined differently in different countries, and our results may only be generalizable to settings that resemble a PHR as defined in our DCE.

Implications of the study

The first practical implication of this study is that it is important that policymakers and PHR producers target their information campaigns to chronically ill people, given our finding that those respondents had a higher probability of belonging to the eager adopters class. This large class of respondents (more than one-third of the sample) were shown to have great interest in PHRs irrespective of their characteristics, with an uptake that was predicted to always be above 91%. Given that our sample consisted of people who currently do not have a PHR, they might be willing to have one but not know how to get one, or the PHRs that are currently on the market are not interesting to them. The reasons for this might be an area for further research.

The second practical implication is that it appears to be extremely difficult to increase uptake of PHRs by creating a better product, given our finding that the PHR uptake of only 20% of respondents was influenced by the characteristics of a PHR. The ideal PHR of this group would be one for which the data is stored by the care provider and tethered to the GP system. The data would be used for other purposes after permission only, and adding one's own data would be possible at zero cost to the user. There were no incongruences across reluctant and eager adopters with respect to the best imaginable PHR. Policymakers who aim to expand the use of PHRs will be most successful when health care providers and health facilities or independent organizations store PHR data, and refrain from including market parties for data storage. Low cost, some form of connection with other systems, and the option to upload one's own data are valued by potential users, but our results suggest that these aspects will only affect uptake marginally. Producers of PHRs need to convince potential users that they can secure the privacy of PHR data.

CONCLUSIONS

More than one-third of potential PHR users indicate great interest in a PHR irrespective of its characteristics. Policymakers who aim to expand the use of PHRs will be most successful when health care providers and health facilities or independent organizations store PHR data, and refrain from including market parties for data storage.

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COMPETING INTERESTS

The authors have no competing interests to declare.

CONTRIBUTORS

DD, MSL, DGH, EWdBG, and LBP designed the study and contributed to the analysis. All authors contributed to the interpretation of the data. DD and MSL drafted the manuscript. DGH, EWdBG, EWS, MH, LBP, and GAdW critically revised the manuscript. All authors read and approved the final manuscript.

SUPPLEMENTARY MATERIAL

Supplementary material is available available at *Journal of the American Medical Informatics Association* online.

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