

Willingness to share personal health information: impact of attitudes, trust and control

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Abstract

Purpose – This study aims to explicate the behavioral factors that determine willingness to share personal health data for secondary uses.

Design/methodology/approach – A theoretical model is developed and tested with structural equation modeling using survey data from Finland.

Findings – It is shown that attitude toward information sharing is the strongest factor contributing to the willingness to share personal health information (PHI). Trust and control serve as mediating factors between the attitude and willingness to share PHI.

Research limitations/implications – The measures of the model need further refinement to cover the various aspects of the behavioral concepts.

Practical implications – The model provides useful insights into the factors that affect the willingness for information sharing in health care and in other areas where personal information is distributed.

Social implications – Sharing of PHI for secondary purposes can offer social benefits through improvements in health-care performance.

Originality/value – A broad-scale empirical data gives a unique view of attitudes toward sharing of PHI in one national setting.

Keywords Finland, Health care, Records management, Attitudes, Structural equation modeling, Personal health information, Control, Trust

Paper type Research paper

1. Introduction

Digitization of healthcare processes, personal health records (PHR) and medical information (Noffsinger and Chin, 2000; Agarwal *et al.*, 2010; Hawthorne and Richards, 2017; Koumaditis and Hussain, 2018) together with technological advances such as cloud computing (Kuo, 2011; Sultan, 2014) and data analytics (Khalifa and Zabani, 2016; Mehta and Pandit, 2018) are fundamentally changing clinical work, health-care management and medical R&D activities. Among the advantages of digitality and connectivity are, for example, improved quality and reduced cost of health-care, as well as safer, more affordable and more accessible services for patients (Agarwal *et al.*, 2010; Nguyen *et al.*, 2016). With the advent of artificial intelligence and machine learning applications (Kononenko, 2001; Ramesh *et al.*, 2004) also the opportunities for solving complex diagnostic and prognostic medical problems are accelerated and the efficiency and effectiveness of health-care improved.



As health-care gets digitized, the improvements enabled by technological advances become inevitably traded off against the potentially negative consequences (Anderson and Agarwal, 2011). One of the biggest challenges arises from the highly sensitive nature of health information and the various risks related to its disclosure (Beckerman *et al.*, 2008). Thus, in the health care sector, there is a need for constantly balancing the requirements for personal privacy against the benefits that may accrue to society as a whole from the more widespread use of personal health information (PHI) (Whiddett *et al.*, 2006).

Many organizations in health-care and public administration have paid attention to privacy and confidentiality questions by issuing guidelines and standards for patient information management. In the UK, for instance, the House of Commons recently published a briefing paper (Parkin, 2018) outlining safeguarding arrangements for confidential patient information based on the new requirements of the EU General Data Protection Regulation (GDPR). Another example focusing especially on the secondary use of health data is the White Paper by the American Medical Informatics Association (Safran *et al.*, 2007). Secondary use of health data refers to the non-direct care use of PHI, including but not limited to analysis, research, quality and safety measurement, public health, payment, provider certification or accreditation and marketing and other business activities.

Although digitization is advancing rapidly, relatively little is known about the people's attitudes toward the use and sharing of PHI. In a study among primary care patients in New Zealand (Whiddett *et al.*, 2006) it was found that the willingness to share information was influenced by three factors, namely, the nature of the recipient (health professionals, health administrators and researchers more acceptable); nature of information (lower willingness to share sensitive and private information); and identification (anonymity preferred). Another study in the US (Weitzman *et al.*, 2010) indicated that the willingness to share information was conditioned by anonymity, research use, engagement with a trusted intermediary and transparency around the access and use of the data. In addition, the patient's health status also affects the attitudes toward personal health data use (Lafky and Horan, 2011).

According to Anderson and Agarwal (2011), the willingness to disclose PHI is based on an individual's "privacy calculus" where trust and risks are weighed against each other to maximize positive outcomes and minimize negative ones. Contextual factors related to requesting stakeholder and the purpose for which the information is requested play an important role in moderating the relationship of the privacy calculus. In a qualitative study among patients and healthcare personnel, Stone *et al.* (2005) found little evidence of privacy concerns regarding data sharing for public research purposes; however, it seemed that the patients generally lacked knowledge about the type of data held in general practice records and the ways in which they are shared.

In a recent review study by Kalkman *et al.* (2019), it was found that the benefits of data sharing are generally recognized among patients and the public, but there are also concerns about the breaches of confidentiality and potential abuses of the data. Another review study, by Lea *et al.* (2018), pointed out the need for privacy protection efforts to mitigate the technical, legal, social and ethical challenges related to the re-use of health data for clinical research. Delving deeper into the question of trust in relation to science and scientific research practices, Aitken *et al.* (2016) observed that the levels of support for data sharing and research access to personal medical information depended on a range of factors such as institutional arrangements for data sharing processes, transparency of process and the existence of robust accountability procedures. Moreover, the extent to which individuals anticipated that members of the public could have control over their personal medical data or could play a role in overseeing data sharing processes also influenced perceptions of trustworthiness.

To further explore the factors behind people's preparedness to health information sharing, this study aims to explicate the factors that determine willingness to share PHI. The focus is on behavioral determinants, so, for instance, demographic factors will not be examined. The study deals with the secondary use of health information for various types of medical research and health-related development activities. PHI in this study is used as a generic concept, without any specific reference to particular categories such as electronic health records, electronic medical records, and PHR.

A theoretical model is developed indicating the hypothesized antecedents of willingness to share PHI. Empirical data of a broad-scale survey study in Finland is then used for testing the theoretical model. The dimensionality of the survey variables is analyzed using exploratory factor analysis (EFA) and the proposed model is then tested with structural equation modeling (SEM). Even if the population in Finland is quite limited in size, the country is among the forerunners in the development and use of e-health and information and communication technology in health-care (Tavares, 2018), thus offering a suitable context for studying public attitudes toward sharing and utilization of personal information in health-care.

2. Research model and hypotheses

Although there is some controversy related to the relationship between attitudes and behavior (Ajzen and Fishbein, 2005), it is widely accepted in consumer research that attitudes influence a person's behavioral intentions and consequently behavior (Nicosia, 1996). Attitudes are based on beliefs and feelings that form a person's predisposition to respond in a consistently favorable or unfavorable manner with respect to a given object (Engel *et al.*, 1995). In the popular technology acceptance model, for instance, the person's beliefs regarding the usefulness and ease of use determine his or her attitude toward accepting a new technological tool or application (Davis, 1989).

Attitudes toward the disclosure of personal information in the internet and social media applications are based on an individual assessment of risks and benefits of information sharing: willingness to disclose increases when the perceived benefits justify the costs such as time consumption and privacy concerns (Olivero and Lunt, 2004). Similarly, the willingness to share PHI is based on balancing privacy and safety concerns with the possibility for personal or societal gain from information sharing between the various stakeholders (Whiddett *et al.*, 2006; Perera *et al.*, 2011). It seems that people rely on public health agencies and the willingness to share personal health data for altruistic purposes such as medical research is high (Stone *et al.*, 2005; Weitzman *et al.*, 2010). Thus, it is hypothesized in this study that:

- H1.* Attitudes toward sharing personal health data influence the willingness to share personal health data for medical and research purposes.

Positive attitude is not the only explanation for information sharing willingness – instead, the privacy concerns and other risk factors can be mitigated with the development of trust and the capability to control the information one is expected to share (Olivero and Lunt, 2004). Trust in an online environment is concerned with the expectation that one's vulnerabilities in a risk situation will not be exploited (Corritore *et al.*, 2003). In marketing, trust has been found as an effective way for managing the consumer's privacy concerns (Nam *et al.*, 2006; Campbell, 1997) and it has also been identified as a strong predictor of the intention for disclosing PHI online (Bansal *et al.*, 2010). In this study, trust is seen in a mediating role between attitudes and intention to share PHI, and so it is hypothesized that:

- H2.* Perceived trust serves as a mediator between the attitudes and willingness to share personal health data for medical and research purposes.

Besides lacking trust, the consumer's unwillingness to disclose can be based on the perceived lack of control over the use of personal information against one's interest (Olivero and Lunt, 2004). It has been shown that the support for medical data sharing diminishes if suggested uses include commercial, profit and marketing applications – in such cases, patients prioritize personal control and strict restrictions on data use as prerequisites for sharing medical data (Weitzman *et al.*, 2010). Besides the acceptability of the recipient, factors such as the sensitivity and identifiability of information affect the willingness for sharing medical data (Whiddett *et al.*, 2006). Because of differing patient preferences, it has been suggested that control should be differentiated according to data sensitivity, use, recipient, etc. (Caine and Hanania, 2013). As a general principle, however, the patient should always maintain control over the use of his/her personal information (Anderson and Agarwal, 2011; Mosquera, 2009). Following these arguments, it is hypothesized that:

H3. Perceived control serves as a mediator between attitudes and willingness to share personal health data for medical and research purposes.

A graphical illustration of the proposed research model is presented in Figure 1. The hypothesized main effect (*H1*) is shown as the direct relationship between the attitude and intended behavior regarding PHI sharing. The hypothesized mediating effects of perceived trust (*H2a* and *H2b*) and perceived control (*H3a* and *H3b*) supplement the main effect in the proposed model. The intended behavior is represented by two dimensions of willingness to share PHI (*H4a* and *H4b*) – one describing PHI generally and the other focusing on health information in combination with demographic, lifestyle and other additional personal data.

A mediation effect involves the mechanism that underlies an observed relationship between the independent variable and the dependent variable via the inclusion of an intervening variable, the mediator. Thus, the mediator variable serves to clarify the nature of the relationship between the independent and the dependent variables (MacKinnon, 2008). In this study, the two mediators are included to complement the main effect because it is assumed that the privacy concerns related to the willingness to share personal information will not be fully captured by the attitudinal determinant in the model. The dependent variable is divided into two dimensions because the sensitivity of information has been shown to affect the willingness to share personal information. By combining lifestyle and demographic data with PHI (even if the data is unidentifiable), an element of sensitivity is added and the distinction can thus, offer analytical richness to the study.

3. Data and method

The empirical data was collected in Finland in June 2016 by Kantar TNS Oy, a leading market research company in Finland, on commission from the Finnish Innovation Fund, Sitra for a national project titled "Secondary Use of Health and Social Care Data 2016".

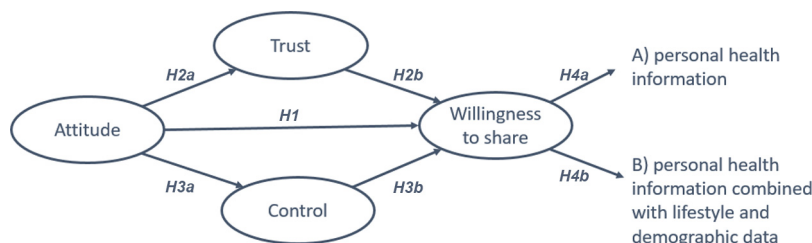


Figure 1.
Antecedents to
willingness for
sharing personal
health information

The data is available for research purposes at the Finnish Social Science Data Archive, www.fsd.uta.fi/en/data/catalogue/FSD3132/. In total, the data set includes 2,338 usable responses from the Finnish population aged 15–79 years. The data was collected as a stratified sample from the national respondent panel administered by Kantar TNS Oy. The sample was weighted to correspond with the target population in terms of gender, age and place of residence. The language of the original survey was Finnish, English translations have been used for this study.

The questionnaire was designed to cover a variety of information needs by the research commissioner (Sitra) – all in all 153 variables were included in the original survey questionnaire. A subset of questions relevant for this study was chosen for measuring the concepts in the proposed research model (28 variables, [Appendix](#)). In this paper, we have kept the original variable labels for replicability and continuing analysis purposes. Before the statistical analysis, the “no opinion” answers were recoded into missing values.

The representativeness of the sample was analyzed with two demographic variables, age and gender. As can be seen in [Table 1](#), there is a slight under-representation among the younger and male respondents in the sample if compared with the entire Finnish population. Nevertheless, the overall composition of the sample is considered entirely satisfactory and the representativeness of the data is therefore, deemed acceptable for this study.

The empirical analysis methods include EFA for examining the constructs that underlie the measurement variables in the survey data, and SEM for testing the hypothesized relationships between the latent constructs as proposed in the theoretical model. In SEM terminology, the dependent construct of the model can be described as a second-order factor as the construct (willingness to share information) is formed of two distinct but related lower-order constructs (two types of PHI). The IBM SPSS statistical software package was used for computing descriptive statistics and EFA while SEM was performed with the MPlus software package.

4. Analyses and results

To gain an overview of the dimensionality of data, a preliminary analysis was conducted with EFA using the principal axis factoring method. In this analysis, five factors were identified that conform with the constructs of the proposed theoretical model. The rotated factor solution ([Table 2](#)) shows high factor loadings for all the variables used in the study. Hence, this five-factor solution (Q24 attitude; Q12 trust; Q14 control; Q17 willingness to share A; Q21willingness to share B) was adopted as the foundation for model testing with the SEM procedure.

Table 1.
Comparison of
sample and target
population

Categories	Survey sample (N 2,338)	Finnish population (%)
<i>Age group</i>		
– 15-27	14.8% (345)	19.40
– 28-40	15.2% (356)	21.10
– 41-53	25.6% (599)	20.50
– 54-66	25.6% (599)	22.00
– 67-79	18.8% (439)	17.10
<i>Gender</i>		
– Female	56.2% (1,315)	50.10
– Male	43.8% (1,023)	49.90

Table 2.Descriptive statistics
of variables and
factor loadings

Variables*					Factors*		
Var. id.	Mean	Std.	F1 (Q17)	F2 (Q21)	F3 (Q12)	F4 (Q14)	F5 (Q24)
q24_1	1.56	0.63					0.668
q24_2	1.63	0.65					0.768
q24_3	1.63	0.65					0.772
q24_4	1.76	0.67					0.682
q12_2	2.1	0.92			0.754		
q12_3	2.17	0.95			0.793		
q12_4	2.34	0.89			0.682		
q12_5	2.67	1.01			0.666		
q12_6	2.11	0.9			0.774		
q12_7	2.23	0.93			0.6		
q14_1	1.41	0.6				0.598	
q14_2	1.28	0.55				0.746	
q14_3	1.3	0.53				0.767	
q14_4	1.42	0.65				0.667	
q14_5	1.38	0.59				0.776	
q17_1	1.59	0.58	0.809				
q17_2	1.72	0.62	0.756				
q17_3	1.72	0.59	0.747				
q17_4	1.68	0.6	0.701				
q17_5	1.65	0.58	0.621				
q17_6	1.7	0.59	0.756				
q17_8	1.75	0.59	0.726				
q21_1	1.87	0.64		0.537			
q21_2	1.92	0.68		0.754			
q21_3	1.85	0.69		0.709			
q21_4	1.85	0.66		0.66			
q21_5	1.97	0.73		0.776			
q21_6	2	0.7		0.79			

Note: *Factor and variable ids are based on the variable labels used in the original survey data

The theoretical model was next tested with SEM using the maximum likelihood method. The proposed model showed a good fit to the data. All relationships in the model were found to be statistically significant and the test values show adequate reliabilities for the concepts. The empirical model is shown in [Figure 2](#) and a summary of the test values is presented in [Table 3](#).

The main effect between the attitude and the willingness to share PHI (*H1*) is the strongest of the hypothesized relationships in the model. As expected, trust plays an important role as a mediating variable (*H2a* and *H2b*) facilitating the willingness to share PHI. The mediating impact of control appears to be more complicated. While the attitude toward information sharing affects the demand for control positively (*H3a*), the impact of control on information sharing willingness (*H3b*) is negative. By increasing the control opportunities, the willingness toward the sharing of PHI may actually decrease. The distinction between two dimensions of willingness to share information (*H4a* and *H4b*) appears to be valid: the willingness to share is lower if demographic and lifestyle information is combined with health information, which can probably be explained by the increasing feeling of sensitivity even if the data were unidentifiable.

Figure 2.
The empirical model

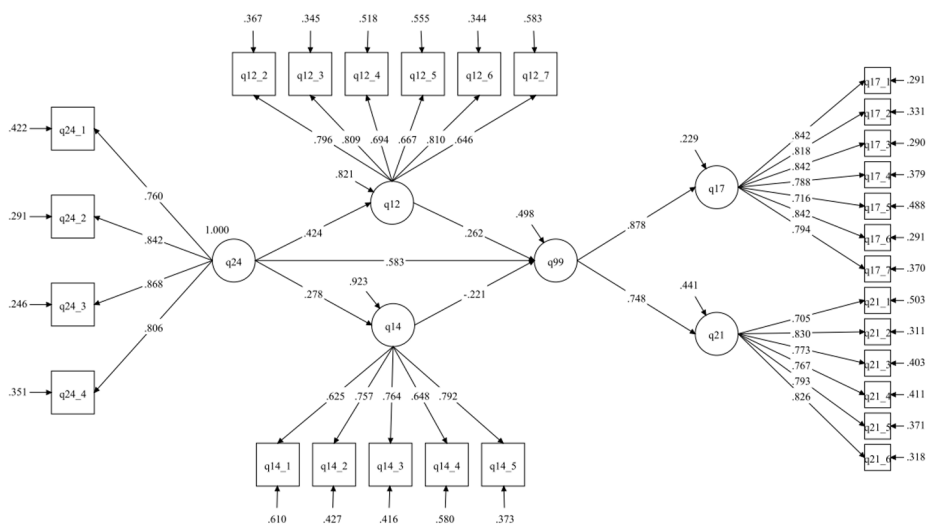


Table 3.
Test statistics of the
empirical model

Model fit					
Chi-square test of model fit					1,654.056, d.f. 343, P 0.000
Root mean square error of approximation (RMSEA)					0.041
Standardized root mean square residual (SRMR)					0.045
Comparative fit index (CFI)					0.964
Tucker-Lewis index (TLI)					0.961
Construct reliabilities	Q24	Q12	Q14	Q17	Q21
Average variance extracted (AVE)	0.729	0.769	0.721	0.82	0.787
Composite reliability (CR)	0.891	0.878	0.842	0.929	0.905
Cronbach's alpha	0.889	0.881	0.835	0.932	0.905

5. Discussion

The purpose of this study was to explicate the factors that determine willingness to share personal health data for various secondary uses such as medical research and health care development activities. Based on a review of earlier literature, a theoretical model was developed outlining the behavioral antecedents that explain the willingness to share PHI for secondary uses. These antecedents include:

- The attitude toward sharing of PHI.
- Trust in appropriate use of PHI by the concerned health care institutions.
- The ability to control the use of PHI for secondary purposes.

The main effect between the attitude toward sharing PHI and willingness to share PHI (*H1*) was found to be the strongest relationship in the empirical model. This finding is in line with previous studies related to health information sharing and reuse among patients and health-care professionals (Whiddett *et al.*, 2006; Perera *et al.*, 2011; Joo *et al.*, 2017). However, as has been shown in earlier research, also this study indicates that there are contingency factors affecting the main effect between the attitude and willingness toward health-care information sharing.

Previous studies recognize the critical role of trust in mitigating privacy concerns when sharing sensitive information such as PHI (Stone *et al.*, 2005; Bansal *et al.*, 2010). In this study, too, the positive path coefficients for *H2a* and *H2b* indicate that trust has a complementary impact alongside attitude as an antecedent to personal information sharing willingness in the health care context.

The mediating effect of control turned out to be an intriguing one. A positive relationship is observed between the attitude toward information sharing and perceived control (*H3a*), while the relationship between control and the willingness to share information is negative (*H3b*). This is unexpected but not unexplainable: control is closely associated with privacy protection (Smith *et al.*, 2011) and the willingness to share PHI is subjected to privacy concerns that explain the negative path coefficient for *H3b*. It can be noted that also in other contexts, such as e-commerce, there is evidence showing contrasting effects of trust and control on information sharing willingness among online consumers (Olivero and Lunt, 2004).

Previous research has shown that the nature and recipient of information affects the willingness to share PHI. For instance, Whiddett *et al.* (2006) found that respondents were increasingly unwilling to share their information as it took on a more personal nature. In the present study, the willingness to share information was measured by two types of PHI, namely, the willingness to share general PHI (*H4a*) and the willingness to share PHI when combined with demographic and lifestyle data (*H4b*). Even if the information is unidentifiable, the respondents obviously find the latter type of PHI more sensitive, and therefore, the path coefficient of *H4a* is higher than *H4b*.

6. Conclusions

The results of this study contribute to the research of PHI by explicating the behavioral constructs and their relationships that determine the willingness to share PHI. It builds on previous research related to attitudes of sharing PHI (Whiddett *et al.*, 2006; Perera *et al.*, 2011) and uses SEM for hypothesis testing and model estimation. Using an extensive survey data collected in Finland, the proposed model showed to be statistically significant, and therefore, it offers a good starting point for continuous testing and development. Although the empirical material of this study is limited to one country, the model itself is generic and should be easily testable also in other contexts.

As can be expected from previous literature, attitude is the strongest behavioral determinant of the willingness to share PHI for secondary uses. However, also trust and control play an important mediating role in mitigating the privacy concerns related to the sharing of sensitive information such as personal health data. For the administrators of health information, giving attention to these mediating effects can be tricky: while trust-promoting efforts create a complementary impact to the attitude toward information sharing, the outcome of control-enhancing measures can be the opposite, i.e. reduced willingness of information sharing. At the same time, new legislation (e.g. EU's Data Protection Regulation) is increasing the opportunities for individuals to control their personal information in health care and other contexts.

All behavioral research struggles with the measurement of concepts such as attitudes. In this study, the attitudinal component was limited to the positive aspect (perceived benefits of information sharing) whereas the flip side (perceived risk) was excluded. In continuing research, both sides of the patient's "privacy calculus" could be included to fully capture the attitudinal dimension and measure the respective impacts on intended behavior. It should also be noted that the survey of this study was conducted before the Facebook data scandal and the introduction of the GDPR in 2018. In Finland, a severe data breach was revealed in

2020 related to patient health records of a private psychotherapeutic center, causing strong resentment and raising questions about general information security in healthcare. All the factors and incidents have probably increased the privacy concerns among the general public and a follow-up study to assess the presented results is therefore, recommended.

In a dialogue paper recently published by the [World Economic Forum \(2014\)](#), three core objectives are laid down for strengthening trust on personal data use, namely, transparency, accountability and empowerment. It could also be a direction for future research in the area of PHI to establish measures guided by these general objectives and evaluate their impacts on information sharing attitudes. Experimental studies and use cases of health information sharing over different platforms could be elaborated to investigate the impact of attitudes and privacy concerns on information sharing willingness. Also, qualitative research, in the line of [Aitken et al. \(2016\)](#), for instance, can offer insights for deepening the understanding of personal information sharing and its antecedents in different contexts.

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Appendix

Attitude

Question: Please indicate how important the following factors are for you:

Scale: 1 very important, 2 quite important, 3 not very important, 4 not at all important, (5 no opinion)

- q24_1 My physician has access to as comprehensive information as possible about treatments and results that have been achieved earlier in Finland with patients like me
- q24_2 Treatment results are monitored on the national level so that patients are in equal position and treatments are directed to patients who get the most benefit from them
- q24_3 Existing information is used effectively for the development of services and health care
- q24_4 Information is provided about the possibilities for utilization of health information (e.g. in research)

Trust

Question: Please indicate how much you trust that the following institutions use information about you in an appropriate manner and with consideration for your personal privacy. I trust:

Scale: 1 very much, 2 quite much, 3 not much nor little, 4 quite little, 5 very little, (6 no opinion)

- q12_2 The Social Insurance Institution of Finland (Kela)
- q12_3 Registration and statistics authorities (e.g. National Institute for Health and Welfare, Statistics Finland)
- q12_4 Universities
- q12_15 Civic social and health care organizations such as Red Cross, Unicef, Child Welfare and Church Aid
- q12_6 Public social and health care provider organizations
- q12_7 Private social and health care provider organizations

Control

Question: With regard to your personal social and health information and its use, how important do you consider the following factors? Please indicate the importance of each statement from your point of view:

Scale: 1 very important, 2 quite important, 3 not very important, 4 not at all important, (5 no opinion)

- q14_1 Public authorities supervise the appropriate use of your personal health information
- q14_2 You have an opportunity to see the information that concerns you
- q14_3 You have the opportunity to correct possible mistakes related to information about you
- q14_4 You can refuse the use of information that concerns you
- q14_5 You can see what purposes the information about you is used for and who the users are

Intention to share (A)

Question: Would you allow the use and combination of your unidentifiable social and health information for the following purposes? Unidentifiable means that it is not possible to recognize your identity from the information and your name, social security number of other similar information is not transferred to the recipient

Scale: 1 yes, my information can be used freely, 2 my information can be used upon my separate consent, 3 my information is not to be used, (4 no opinion)

- q17_1 For the development of treatments and more effective cures for diseases
- q17_2 For the development of new (precision) medicines
- q17_3 For the development of new social and medical instruments and services
- q17_4 For the identification of possible health risks in my residential area
- q17_5 For the identification of possible health risks related to me personally
- q17_6 For the development of effectiveness and quality of social and health services
- q17_7 For other medical research purposes

Intention to share (B)

Question: Would you allow the use of your unidentifiable information for the development of medicine when combined with your personal health and patient information? Unidentifiable means that it is not possible to recognize your identity from the information and your name, social security number of other similar information is not transferred to the recipient

Scale: 1 yes, my information can be used freely, 2 my information can be used after my separate consent, 3 my information is not to be used, (4 no opinion)

- q21_1 Genetic information
- q21_2 Physical activity information
- q21_3 Alcohol consumption information
- q21_4 Residential area information
- q21_5 Grocery shopping information
- q21_6 Traveling information

Table A1.
Survey questionnaire
(selected questions)