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

Abstract

Purpose: The study explicates 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 towards information sharing is the strongest factor contributing to the willingness to share personal health information. Trust and control serve as mediating factors between the attitude and willingness to share personal health information.

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 healthcare and in other areas where personal information is distributed.

Social implications: Sharing of personal health information for secondary purposes can offer social benefits through improvements in healthcare performance.

Originality/value: A broad-scale empirical data gives unique view of attitudes towards sharing of personal health information in one national setting.

Key words

personal health information; attitude; control; trust; structural equation modeling

1. Introduction

Digitization of healthcare processes, personal health records and medical information (Noffsinger and Chin, 2000; Agarwal et al., 2010; Hawathorne and Richards, 2017; Koumaditis and Hussein, 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, healthcare management, and medical R&D activities. Among the advantages of digitality and connectivity are, for example, improved quality and reduced cost of healthcare 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 healthcare improved.

As healthcare 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 healthcare 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 (Whiddett et al., 2006).

Many organizations in healthcare 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 personal health information, 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 towards the use and sharing of personal health information. 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: 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 towards personal health data use (Lafky and Horan, 2011).

According to Anderson and Agarwal (2011), the willingness to disclose personal health information 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 personal health information. The focus is on behavioral determinants, so for instance demographic factors will not be examined. The study deals with secondary use of health information for various types of medical research and health-related development activities. Personal health information (PHI) in this study is used as a generic concept, without any specific reference to particular categories such as electronic health records (EHR), electronic medical records (EMR), personal health records (PHR), etc.

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 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 ICT in healthcare

(Tavares, 2018), thus offering a suitable context for studying public attitudes towards sharing and utilization of personal information in healthcare.

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 (TAM), for instance, the person's beliefs regarding the usefulness and ease of use determine his or her attitude towards accepting a new technological tool or application (Davis, 1989).

Attitudes towards 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 personal health information 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 towards 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 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 personal health information 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 recipient, also factors such as the sensitivity and identifiability of information affect the willingness for sharing medical data (Whiddett et al., 2006) Due to 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 personal health information sharing. The hypothesized mediating effects of perceived trust (H2a, H2b) and perceived control (H3a, H3b) supplement the main effect in the proposed model. The intended behavior is represented by two dimensions of willingness to share personal health information (H4a, H4b) – one describing personal health information generally and the other focusing on health information in combination with demographic, lifestyle and other additional personal data.

Figure 1 here

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 personal

health information (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". The data is available for research purposes at the Finnish Social Science Data Archive, http://www.fsd.uta.fi/en/data/catalogue/FSD3132/. In total, the data set includes 2338 usable responses from 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, see Appendix 1). In this paper, we have kept the original variable labels for replicability and continuing analysis purposes. Before the statistical analyses 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.

Table 1 here

The empirical analysis methods include exploratory factor analysis (EFA) for examining the constructs that underlie the measurement variables in the survey data, and structural equation modeling (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 personal health information). The IBM SPSS statistical software package was used for

computing descriptive statistics and exploratory factor analysis while structural equation modeling 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 exploratory factor analysis 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; Q21 willingness to share B) was adopted as the foundation for model testing with the structural equation modeling procedure.

Table 2 here

The theoretical model was next tested with structural equation modeling 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.

Figure 2 here

Table 3 here

The main effect between the attitude and the willingness to share personal health information (H1) is the strongest of the hypothesized relationships in the model. As expected, trust plays in important role as a mediating variable (H2a, H2b) facilitating the willingness to share personal health information. The mediating impact of control appears to be more complicated. While the attitude towards 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 towards the sharing of personal health information may actually decrease. The distinction between two dimensions of willingness to share information (H4a, 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.

4. 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 willingness to share personal health information (PHI) for secondary uses. These antecedents include: 1) the attitude towards sharing of PHI; 2) trust in appropriate use of PHI by the concerned health care institutions; and 3) the ability to control the use of PHI for secondary purposes.

The main effect between the attitude towards 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 healthcare professionals (e.g. 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 towards healthcare 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 towards 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: 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.

5. 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 utilizes structural equation modeling 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 continuing 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 personal health information for secondary uses. However, also trust and control play an important mediating role in mitigating the privacy concerns related to 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 towards 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 General Data Protection Regulation 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: transparency, accountability and empowerment. It could also be a direction for future research in the area of personal health information 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 1. Survey questionnaire (selected questions)

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 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 utilized effectively for 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, Church Aid, etc.
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   Travelling information

Table 1. Comparison of sample and target population

	Survey sample (N 2338)	Finnish population
Age group		
- 15-27	14.8 % (345)	19.4 %
- 28-40	15.2 % (356)	21.1 %
- 41-53	25.6 % (599)	20.5 %
- 54-66	25.6 % (599)	22.0 %
- 67-79	18.8 % (439)	17.1 %
Gender		
- Female	56.2 % (1315)	50.1 %
- Male	43.8 % (1023)	49.9 %

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	2.10	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	0.90			0.774		
q12_7	2.23	0.93			0.600		
q14_1	1.41	0.60				0.598	
q14_2	1.28	0.55				0.746	
q14_3	1.30	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	0.60	0.701				
q17_5	1.65	0.58	0.621				
q17_6	1.70	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		0.660			
q21_5	1.97	0.73		0.776			
q21_6	2.00	0.70		0.790			

*) Factor and variable id's are based on the variable labels used in the original survey data.

Table 3. Test statistics of the empirical model

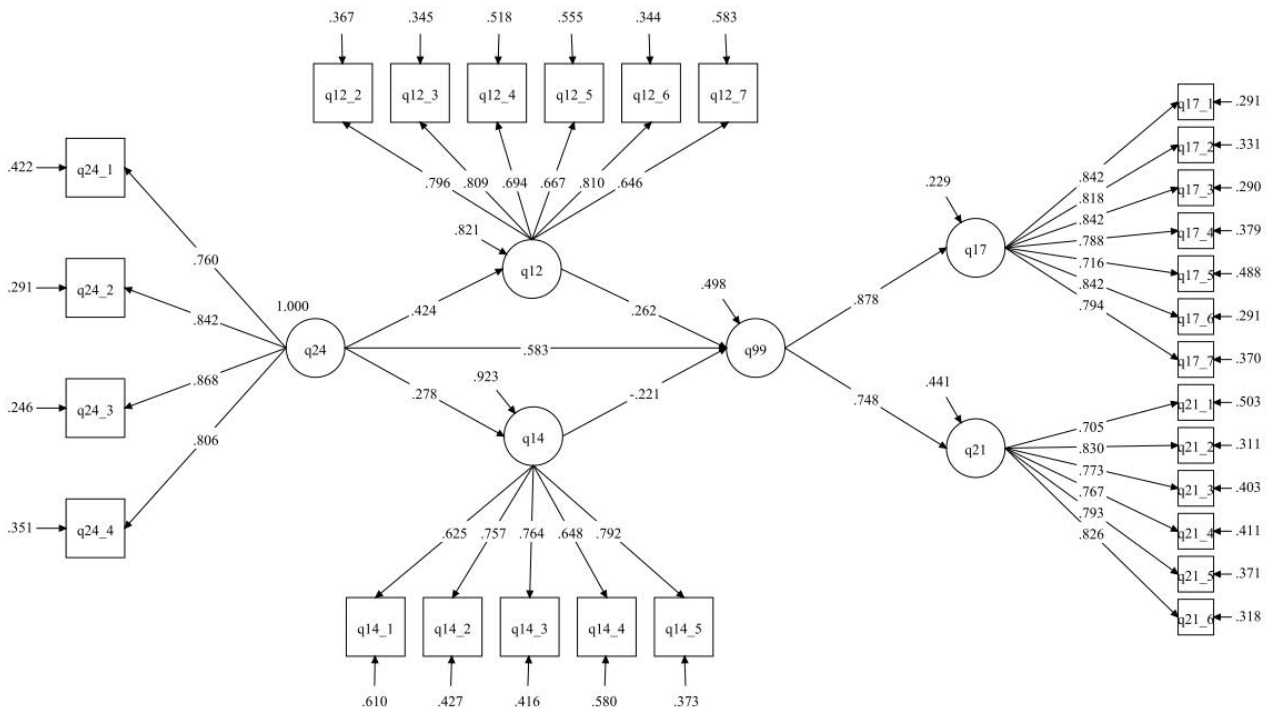| Model fit					
Chi-square test of model fit	1654.056, d.f. 343, P 0.000				
Root mean square error of approximation (RMSEA)	0.041				
Standardized root mean square residual (SRMR)	0.045				
Comparative fit index (CFI)	0.964				
Tucker-Lewis index (TLI)	0.961				
Construct reliabilities	Q24	Q12	Q14	Q17	Q21
Average variance extracted (AVE)	0.729	0.769	0.721	0.820	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
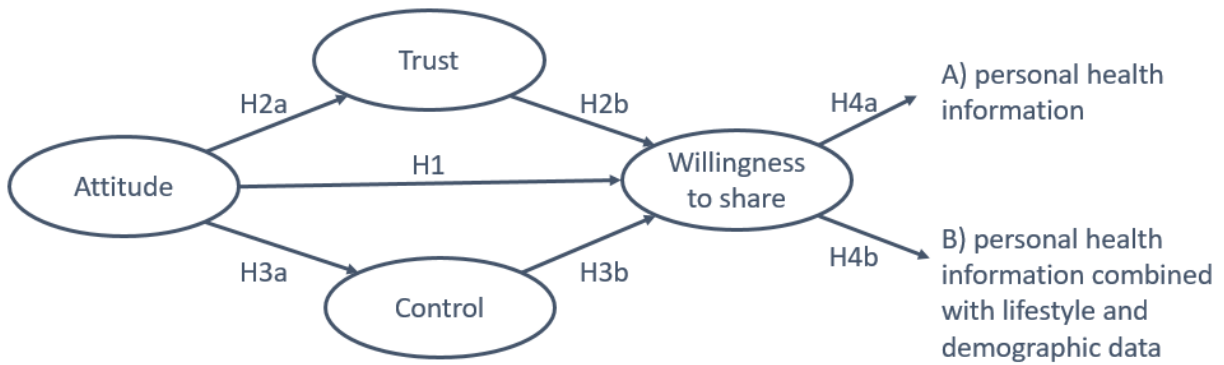
Figure 1. Antecedents to willingness for sharing personal health information

Figure 2. The empirical model