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Trading-Off Privacy and Willingness to Share Personal Health Information: A Survey of Municipal Employees in Fukuoka City, Japan

Shuhei Nomura[1,2]*, Yasumasa Segawa[2], Cyrus Ghaznavi[2,3], Takanori Fujita[2,4], Keiko Maruyama-Sakurai[2], Manae Uchibori[2], Akifumi Eguchi[2,5], Masaharu Ishigaki[6], Kazuto Fujiwara[6], Masayuki Kido[6], Hiroaki Miyata[2], Takanori Yamashita[7], Naoki Nakashima[7,8]

[1]Keio University Global Research Institute (KGRI), Tokyo, Japan
[2]Department of Health Policy and Management, School of Medicine, Keio University, Tokyo, Japan
[3]Department of Medicine, University of California San Francisco, San Francisco, California, USA
[4]Tokyo Foundation for Policy Research, Tokyo, Japan
[5]Department of Sustainable Health Science, Center for Preventive Medical Sciences, Chiba University, Chiba, Japan
[6]DENTSU Inc., Tokyo, Japan
[7]Medical Information Center, Kyushu University Hospital, Fukuoka, Japan
[8]Department of Medical Informatics, Graduate School of Medical Sciences, Kyushu University, Fukuoka, Japan
Email: *s-nomura@keio.jp

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Abstract

Background: The global adoption of Personal Health Records (PHRs) has prompted discussions about data privacy and sharing preferences. Despite Japan's advancing digital health initiatives, public attitudes toward health data sharing remain understudied. **Objectives:** This study investigated the willingness to share personal health information among Fukuoka City employees as part of the "PHR Fukuoka Project." **Methods:** A cross-sectional online survey was distributed to 11,604 municipal employees from February 1st - 20th, 2023. The survey assessed willingness to share personal and family health information across 36 scenarios, combining six purposes (health maintenance, medical care, emergencies, research, product development, and family sharing) with six recipient types (family, friends, healthcare providers, employers, government, and private companies). Sociodemographic factors and digital literacy were examined through logistic regression analysis. **Results:** Of 1241 respondents (10.6% response rate), 17.1% were willing to share personal health information, 37.3% were neutral, and 45.6% were opposed, with similar patterns for family health information (15.6%, 34.0%, 50.5%, respectively). Male gender (odds ratio [OR] 1.43, 95% confidence interval [CI] 1.12 - 1.82), smartphone use (OR 2.63, 95% CI 1.12 - 6.20), and health app usage (OR 1.41, 95% CI 1.09 - 1.83) predicted increased willingness to share. Respondents were most willing to share information for emergencies and medical care with family members and healthcare providers, while least willing to share for product development or with employers. **Conclusions:** While approximately half of respondents showed potential openness to sharing health information, privacy concerns persist. These findings suggest sufficient public support for digital health initiatives in Japan, though successful implementation requires careful consideration of sharing purposes and recipients, alongside robust privacy protections.

Keywords

Personal Health Records (PHR), Health Information Sharing, Privacy Concerns, Digital Health Literacy, Cross-Sectional Survey

1. Introduction

The global shift towards patient-centric healthcare has significantly accelerated the adoption of Personal Health Records (PHRs). PHRs are electronic applications that enable individuals to access, manage, and share their health information in a private, secure, and confidential environment [1]. Nations such as Australia, the United Kingdom, Canada, Estonia, Portugal, and Sweden, have either fully integrated or are actively developing these systems [2]. PHRs empower patients by granting them greater control over their health data. Simultaneously, they prompt critical discussions concerning ethical standards and privacy regulations for the access and management of health data [3]. Despite the clear advantages, such as improved patient autonomy and better health data interoperability, the widespread adoption of PHRs also introduces substantial risks including potential data breaches and unauthorized access. These outcomes are influenced by various factors including regulatory frameworks, technological infrastructures, and societal privacy attitudes.

In response to this global trend, Fukuoka City, the capital of Fukuoka Prefecture with a population of 1.6 million in the Kyushu region of Japan, initiated the "PHR Fukuoka Project" in collaboration with Kyushu University and Dentsu Inc. in 2022 [4]. This pioneering project in Japan aims to enable a society where citizens can self-manage their medical and health data—referred to hereafter as "personal health information". The platform for this project, designed in alignment with the public electronic medical record (EHR)/PHR linkage platform specifications currently being developed by the Ministry of Health, Labour and Welfare (MHLW) of Japan, complies with HL7 FHIR (Health Level Seven International's Fast Healthcare Interoperability Resource) international standards for medical data management [5]. "Tsunagu PHR", a smartphone application developed through this project, facilitates citizen management of personal health data.

Addressing the challenges of autonomous management of personal health information involves more than technical challenges; it also includes soft issues such as securing individual consent and ensuring the ethical handling of sensitive data

[6]. The hesitance to share personal health data, due to fears of potential privacy breaches, remains a significant obstacle [7]. Furthermore, as personal health information is inherently sensitive, it requires robust security measures. However, there is notable lack of data on public awareness in Japan regarding these issues [8] [9]. To address this knowledge gap and contribute to an understanding of public perceptions and willingness to share personal health information within the framework of Japan's digital health initiatives, we conducted an online survey as part of the "PHR Fukuoka Project," in collaboration with Fukuoka City, a key stakeholder in the project. Specifically targeting city employees, the survey aimed to ascertain the prevalence of individuals willing to share personal health information, the factors associated with their willingness, and the varying circumstances under which willingness may increase or decrease.

2. Methods

2.1. Study Design and Research Process

This study employed a cross-sectional online survey design to investigate attitudes toward health information sharing among municipal employees. The research process encompassed four sequential phases. The first phase involved questionnaire development through comprehensive literature review and expert consultation. This was followed by survey implementation and data collection in the second phase. The third phase consisted of data organization and cleaning, while the fourth phase focused on statistical analysis of the results.

2.2. Data Source and Population

The participants of this study were employees of Fukuoka City. There were no exclusion criteria; every employee was eligible to participate. Employing a census technique, the survey was disseminated to the entire target population encompassing 11,604 municipal employees, utilizing their respective work email addresses. The survey link was distributed simultaneously on February 1st, with February 20th serving as the deadline for submission. Participation was voluntary, and respondents had to answer each question to avoid missing values. Electronic informed consent was obtained from the participants. Only upon providing this consent were participants allowed to proceed to the questionnaire response page. This online survey system was designed to provide us with only anonymized data. The sample size calculation was based on the assumption of a 5% margin of error and a 95% confidence interval, requiring at least 385 participants to represent the population adequately [10]. The actual sample size obtained exceeded this minimum number. All tools and questionnaires used in this study are our original creations and did not require permissions from any copyright holders. Comprehensive details of the survey and the questionnaire used are provided in the Supplement.

2.3. Survey Development and Measures

The development of survey instruments followed a systematic approach. Initially, a comprehensive review of existing studies on health information sharing was conducted. This was followed by consultation with field experts to validate and refine the questionnaire items. Based on these inputs, questions were developed with specific adaptations to the Japanese context [11]-[14].

The survey captured sociodemographic variables including sex, age, education, 2021 household income, family or relatives who live with the respondent, family members or relatives who do not live with the respondent but for whom the respondents were responsible for health management, self-reported health status, medical history, and enrollment in private insurance. Digital literacy was assessed through questions about internet device usage, social media engagement, possession of a "My Number Card" (defined in Supplement), and the use of health-related apps or wearable devices.

Regarding the willingness to share personal health information, we first asked if they would like to share information with someone if there was a purpose in mind, with four response options (yes, not sure, no, prefer not to answer). For those who answered "yes" or "not sure," we inquired about the specific purposes for sharing, and recipients of health information, with "yes" or "no" response options. Purposes and recipients were pre-identified and categorized into six types each, and respondents were asked to choose from these categories (defined in Supplement). We assessed willingness to share for all 36 combinations of these six purposes and recipients. A similar format was used to determine respondents' willingness to share their family's personal health information (defined in Supplement).

Finally, respondents were asked to weigh the convenience of personal and social benefits against privacy risks if their own personal health information were to be shared with any recipients for a specific purpose. Four response options were provided, ranging from "value personal and social benefits more," "value privacy risks more," "neither," and "prefer not to answer." The five purposes were consistent with the previous question.

2.4. Data Collection and Analysis

The data collection and analysis process proceeded systematically, beginning with online questionnaire distribution via work email addresses. This was followed by a three-week data collection period with automated response compilation. Subsequently, data cleaning was performed to verify complete responses and prepare for analysis. The statistical analysis phase encompassed descriptive analysis of survey responses, construction of logistic regression models, and analysis of relationships between variables.

In addition to presenting the descriptive results of the survey questions, a logistic regression model was constructed to identify sociodemographic variables or digital literacy variables related to the willingness to share the respondent's own personal health information. Odds ratios were estimated for the likelihood of answering "yes" or "not sure" versus "no" to whether they would like to share information with someone if there was a purpose in mind. We used a backward stepwise selection method, beginning with significant variables from univariate regression analysis and removing variables with $p \geq 0.15$ from the model while including variables with $p < 0.1$. The respondent's willingness to share information regarding their family was analyzed using a similar logistic regression model.

3. Results

The key characteristics of the respondents (n = 1241, 10.6%) are shown in Table 1 (detailed demographic characteristics are provided in Supplementary Table A1). When asked whether they would be willing to share their own personal health information, 210 (17.1%), 459 (37.3%), and 561 (45.6%) respondents reported that they would be willing, neutral, or against information disclosure, respectively. Similarly, when asked whether they would be willing to share information about the medical care and health of family members, 191 (15.6%), 417 (34.0%), and 620 (50.5%) respondents reported that they would be willing, neutral, or against information disclosure, respectively.

Table 1. Key characteristics of survey respondents (n = 1241).

	Number	Percentage
Sociodemographic characteristics		
Gender		
Female	439	35.37
Male	783	63.09
Other	4	0.32
Prefer not to mention	15	1.21
Age		
Less than 30	242	19.50
30 to 40	300	24.17
40 to 50	262	21.11
50 to 60	273	22.00
Over 60 years	164	13.22
Education level (SA)		
High school diploma	320	25.79
Junior college	164	13.22
University degree	616	49.64
Graduate school degree	120	9.67
Prefer not to answer	21	1.69
Self-reported health status (SA)		

Continued

Good	305	24.58
Somewhat good	337	27.16
Average	451	36.34
Not very good	124	9.99
Not good	13	1.05
Prefer not to answer	11	0.89
Digital literacy		
Internet devices that are regularly used (MA)		
Smartphone	1,202	97.00
Tablet	328	26.43
Laptop	535	43.11
Desktop computer	373	30.06
Game console	129	10.39
Wearable device (smartwatch, etc.)	59	4.75
IoT home appliance	61	4.92
Other	3	0.24
None in particular	2	0.16
Prefer not to answer	6	0.48
Social media that is used at least once a day (MA)		
Facebook	183	14.75
Twitter	421	33.92
LINE	1,088	88.00
Instagram	483	38.92
YouTube	693	55.84
TikTok	93	7.49
Other	5	0.40
None in particular	65	5.24
Prefer not to answer	13	1.05

SA: single-answer questions; MA: multiple-answer question.

The factors associated with being willing to share personal and family-related information are shown in **Table 2** and **Table 3**, and reflect similar findings. For both groups, using social media applications such as TikTok, using health-related apps, and interest in using the PHR app were all significantly associated with a higher willingness to share personal health information. Men were significantly more likely to be willing to share health information regarding themselves with odds ratio of 1.43 (95% confidence interval 1.12 to 1.82, $p < 0.01$).

Table 2. Logistic regression for respondents' willingness to share their own personal health information.

Variable	Odds ratio	95% CI	P value
Gender			
Female			
Male	1.43	1.12 to 1.82	<0.01
Internet devices that are regularly used			
Smartphone	2.63	1.12 to 6.20	<0.05
Social media that is used at least once a day			
LINE	1.32	0.91 to 1.93	0.15
TikTok	1.60	1.01 to 2.54	<0.05
Purpose of using a health-related app or wearable device that is used at least once a month			
Healthcare/fitness related	1.41	1.09 to 1.83	<0.05
Health examination management	2.12	1.00 to 4.47	<0.05
COVID-19 vaccination certificate	1.30	0.91 to 1.84	0.15

CI: confidence interval.

Table 3. Logistic regression for respondents' willingness to share their family members' and relatives' personal health information.

Variable	Odds ratio	95% CI	P value
Internet devices that are regularly used			
Smartphone	1.98	0.92 to 4.23	0.08
Social media that is used at least once a day			
YouTube	1.26	1.00 to 1.60	0.05
TikTok	1.63	1.04 to 2.56	<0.05
Purpose of using a health-related app or wearable device that is used at least once a month			
Healthcare/fitness related	1.34	1.04 to 1.73	<0.05
Health examination management	2.44	1.19 to 4.99	<0.05
COVID-19 contact tracing (COCOA)	1.61	1.06 to 2.44	<0.05

CI: confidence interval.

A heatmap displaying how frequently respondents reported willingness to share personal health information, stratified by situation and recipient of said information, is shown in Figure 1. With respect to motivations, respondents were most willing to share health information for the purposes of health maintenance, the receipt of appropriate medical care, and in emergency situations (e.g., loss of consciousness); they were least willing to share information for the purpose of product development. With respect to recipients, respondents were most willing to share information with families and medical providers and least willing to share information with friends, the government, and their employers. Corresponding results for the sharing of family-related health information are shown in Supplementary **Figure A1** and recapitulate the findings shown in **Figure 1**.

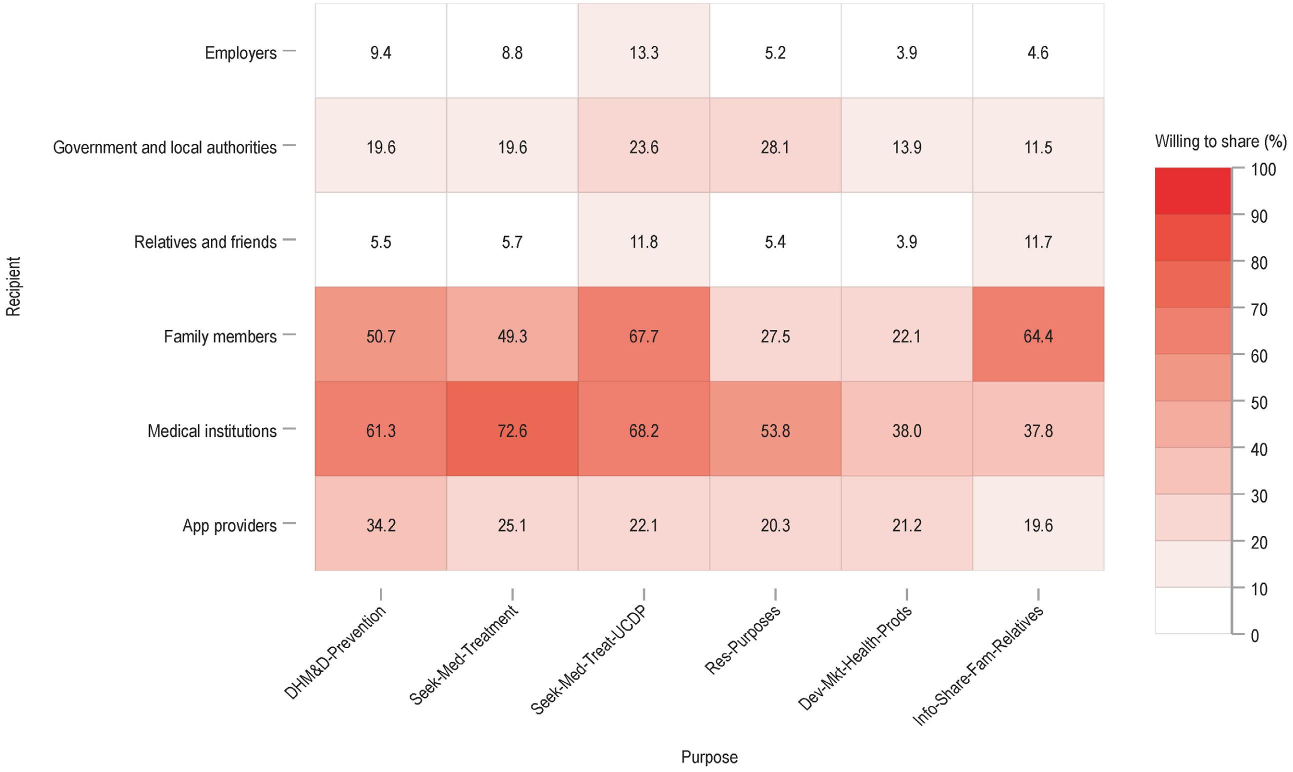

Figure 1. Heatmap of respondents' willingness to share their own personal health information, stratified by purpose and recipient.

The numbers indicate the percentage of respondents who answered "yes" to the question of whether they want to share their information. DHM&D-Prevention: Daily health maintenance and disease prevention; Seek-Med-Treatment: Seeking appropriate medical treatment; Seek-Med-Treat-UCDP: Seeking appropriate medical treatment in case of unconsciousness or dementia progression; Res-Purposes; Research purposes; Dev-Mkt-Health-Prods: Development and marketing of new health-related products; Info-Share-Fam-Relatives: Information sharing with family members and relatives.

Figure 2 displays the trade-off between convenience and privacy with respect to sharing personal health information. Respondents were most likely to report convenience and the benefits to society trumping the need for privacy with respect to situations such as losing consciousness and receiving appropriate medical care. They were most likely to report the need for privacy trumping convenience and the benefits to society in situations such as product development.

DHM&D-Prevention: Daily health maintenance and disease prevention; Seek-Med-Treatment: Seeking appropriate medical treatment; Seek-Med-Treat-UCDP: Seeking appropriate medical treatment in case of unconsciousness or dementia progression; Res-Purposes; Research purposes; Dev-Mkt-Health-Prods: Development

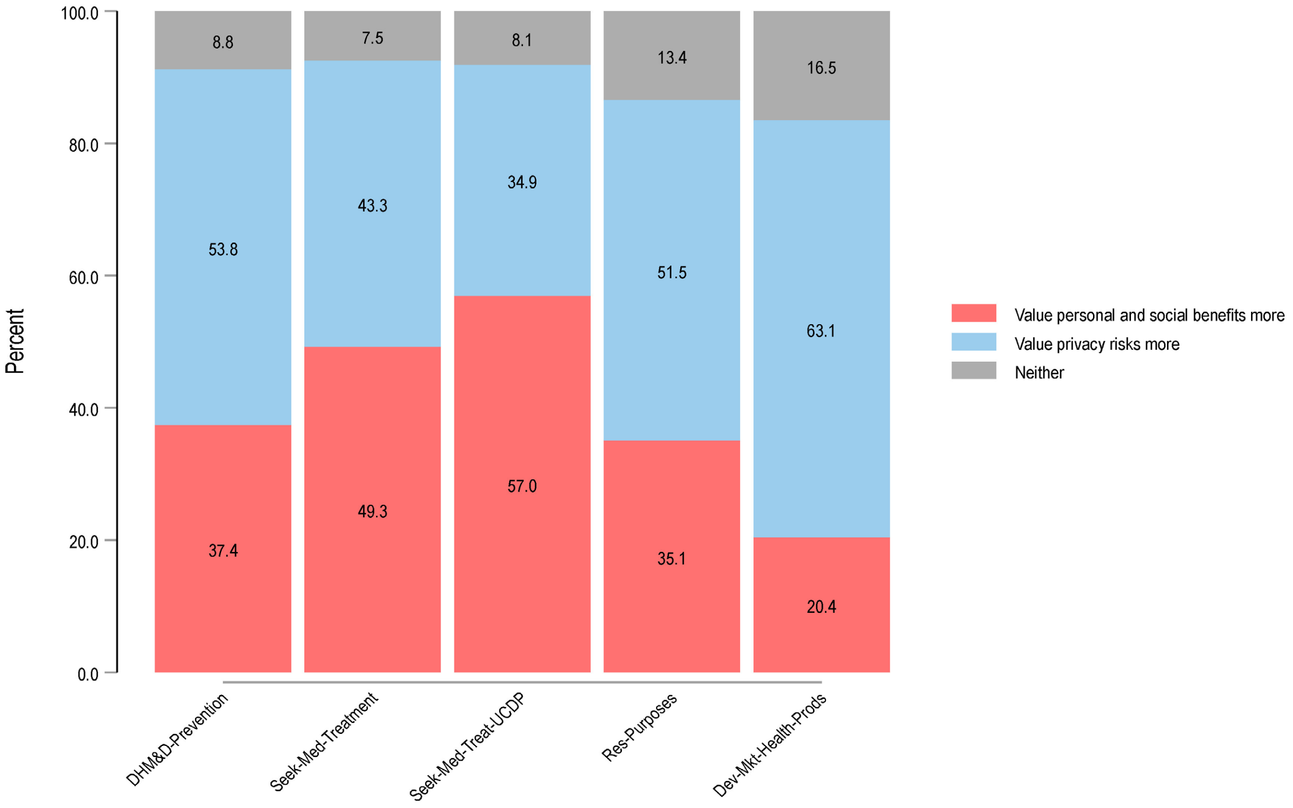

Figure 2. Interplay of the personal and societal benefits and privacy risks associated with sharing personal health information.

and marketing of new health-related products.

4. Discussion

We found that approximately half of respondents would be willing or neutral regarding sharing their own or their family's personal health information, depending on the circumstances and the recipient. This observation aligns with the findings of a prior study conducted in Japan in 2020 [14]. This suggests that there is a general willingness to proceed with the digitalization of healthcare. Yet, recognizing potential biases in our sample, we must consider the impact of forced responses and to address the concerns people might have with sharing this kind of sensitive information [15]. Harahap *et al.* (2021) emphasized the need for patients to choose what information to share and who can see that information [6]. Their findings align with our observations suggesting that user autonomy in information sharing is critical. Benevento *et al.* (2023) further revealed that despite a trend towards digitalization, there is no unified tool to measure willingness to share PHR [16], underscoring the need to tackle public concerns. While our findings indicate a promising trend towards acceptance, there remains a significant portion of the population with concerns, highlighting the importance of addressing these concerns to ensure successful implementation of digital health initiatives in Japan.

The evolution and globalization of the digitalization of healthcare brings with it the promise of expanding healthcare access, standardizing care, and creating real-world, big-data datasets for researchers [17] [18]. However, alongside these advantages, there emerges a global ethical dilemma where an inherent infringement of privacy which occurs when personal health information is shared with physicians, industry, governmental organizations, family, and friends [7]. Flaumenhaft *et al.* (2018) detailed the current legislative landscape across five different legislative jurisdictions, emphasizing that the European Union (EU)'s General Data Protection Regulation (GDPR) is the most comprehensive, but also leaves room for ambiguity [3]. This reinforces our point regarding the differing ethical and private rules associated with health data [1] [19]. Naturally, each individual has their own perspective when deciding whether sharing personal health information is in their net best interests. While our study indicates a willingness to proceed with healthcare digitization initiatives in Japan, it is imperative to acknowledge and address the reservations and concerns of the public for the successful execution of such endeavors [15]. This becomes particularly relevant as we contemplate utilizing these findings as a framework for initiatives in Fukuoka, and subsequently extending them across Japan, in accordance with the Japanese Government's goal of transitioning to a digital healthcare society.

Consistent with prior findings, we found that individuals were most willing to share data for the purposes of receiving medical care [7] [14] and research purposes [20]. Conversely, many were reticent about sharing information for product development, mirroring results from previous studies assessing willingness to disclose health information to pharmaceutical companies or for marketing purposes [11]. Though there was a notable hesitancy to share information with governmental entities in our sample, this reflects a global trend wherein varying cultural and regulatory landscapes influence public trust. Prior research has found some willingness to do so, especially for the purposes of public health [12], though results have been mixed [7]. We also found that use of social media and other health-related apps predicted willingness to share information, as would be expected given that such individuals are already participating in the digitization of modern society.

5. Limitations

This study has limitations. First, during the section where respondents were asked about their willingness to share their personal health information, a text asking about their family information was accidentally included in the question description. However, we believe that the respondents were not confused in the survey. Second, while the survey methodology of this study was significantly influenced by expert advice and a thorough review of related literature, we must acknowledge certain limitations due to the lack of pilot testing and the absence of repeat measurements from participants. These elements are generally essential for some forms of statistical validation, including reliability testing. As such, the findings from our survey should be interpreted within the context of these methodological limitations.

Third, because this study was conducted in collaboration with Fukuoka City, the target population of the survey was limited to municipal employees, which potentially constraining the generalizability of the findings. Furthermore, this survey had a response rate of 10.6%, and those who opted to take the survey may differ from those who did not.

6. Conclusion

The use of digital health technology requires a balance between the benefits to health and potential privacy breaches. Each individual has their own calculus when considering the trade-offs. Our findings suggest that there is significant willingness among respondents to share health-related information, supporting the advancement of digital health initiatives. However, addressing the concerns and reservations of the public is crucial for successful implementation and widespread adoption of these initiatives.

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Author Contribution

SN, TF, HM, TY, and NN researched literature and conceived the study. SN, YS, TF, KMS, MI, KF, KM, MH, TY, and NN was involved in protocol development, gaining ethical approval, and participant recruitment. SN conducted data analysis. SN, CG, MU, and AE wrote the first draft of the manuscript. All authors reviewed and edited the manuscript and approved the final version of the manuscript.

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Ethical Statement

This study was conducted in accordance with the Declaration of Helsinki and received ethical approval from the Ethics Committees of both Kyushu University (Authorization Number: 22073-05) and Keio University School of Medicine (Authorization Number: 2022-6037). Respondents had to provide their consent before they proceeded to the questionnaire response page.

Conflicts of Interest

The authors declare no conflicts of interest regarding the publication of this paper.

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Appendix

Table A1. Characteristics of survey respondents (n= 1,241).

	Number	Percentage
Sociodemographic characteristics		
Gender		
Female	439	35.37
Male	783	63.09
Other	4	0.32
Prefer not to mention	15	1.21
Age		
Less than 30	242	19.50
30 to 40	300	24.17
40 to 50	262	21.11
50 to 60	273	22.00
Over 60 years	164	13.22
Education level (SA)		
High school diploma	320	25.79
Junior college	164	13.22
University degree	616	49.64
Graduate school degree	120	9.67
Prefer not to answer	21	1.69
Household income in 2021 (SA)		
Less than 4 million yen	222	17.89
4 to 6 million yen	246	19.82
6 to 8 million yen	305	24.58
8 to 10 million yen	203	16.36
Over 10 million yen	173	13.94
Prefer not to answer	92	7.41
Family composition (MA)		
Spouse	778	62.69
Children under 6 years old	198	15.95
Children aged 6-18 years old	292	23.53
Adult children (over 18 years old)	177	14.26
Parents	141	11.36
Spouse’s parents	22	1.77
Other relatives or friends	48	3.87

Continued

No one in particular (living alone)	260	20.95
Prefer not to answer	38	3.06
Family members or relatives who do not live with the respondent but for whom the respondents are responsible for managing their health (MA)		
Spouse	5	0.40
Children under 6 years old	9	0.73
Children aged 6-18 years old	15	1.21
Adult children (over 18 years old)	57	4.59
Parents	321	25.87
Spouse's parents	116	9.35
Other relatives or friends	51	4.11
No one in particular	782	63.01
Prefer not to answer	28	2.26
Self-reported health status (SA)		
Good	305	24.58
Somewhat good	337	27.16
Average	451	36.34
Not very good	124	9.99
Not good	13	1.05
Prefer not to answer	11	0.89
Medical history (MA)		
COVID-19 infection	362	29.17
Cancer	33	2.66
Heart disease	35	2.82
Cerebrovascular disease	21	1.69
Diabetes	25	2.01
Mental illness	67	5.40
Genetic disease	7	0.56
Other	147	11.85
None in particular	628	50.60
Prefer not to answer	31	2.50
Enrolment in private insurance (MA)		
Life insurance	973	78.40
Medical and nursing care insurance	833	67.12
None in particular	112	9.02

Continued

Prefer not to answer	31	2.50
Digital literacy		
Internet devices that are regularly used (MA)		
Smartphone	1,202	97.00
Tablet	328	26.43
Laptop	535	43.11
Desktop computer	373	30.06
Game console	129	10.39
Wearable device (smartwatch, etc.)	59	4.75
IoT home appliance	61	4.92
Other	3	0.24
None in particular	2	0.16
Prefer not to answer	6	0.48
Social media that is used at least once a day (MA)		
Facebook	183	14.75
Twitter	421	33.92
LINE	1,088	88.00
Instagram	483	38.92
YouTube	693	55.84
TikTok	93	7.49
Other	5	0.40
None in particular	65	5.24
Prefer not to answer	13	1.05
Possession of My Number Card (SA)		
Have obtained	1,048	84.00
Intend to obtain in the future	165	13.30
Do not intend to obtain in the future	0	0.00
Prefer not to answer	28	2.26
Purpose of using a health-related app or wearable device that is used at least once a month (MA)		
Healthcare/fitness related	357	28.77
Sleep management	129	10.39
COVID-19 contact tracing (COCOA)	108	8.70
COVID-19 vaccination certificate	165	13.3
Health examination management	39	3.14
Medical expense management	6	0.48

Continued

Disease management (such as diabetes or cancer)	2	0.16
Medication management	142	11.44
Menstruation management	169	13.62
Maternity/child-rearing management	32	2.58
Other	13	1.05
None in particular	588	47.38
Prefer not to answer	13	1.05

SA: single-answer questions; MA: multiple-answer question.

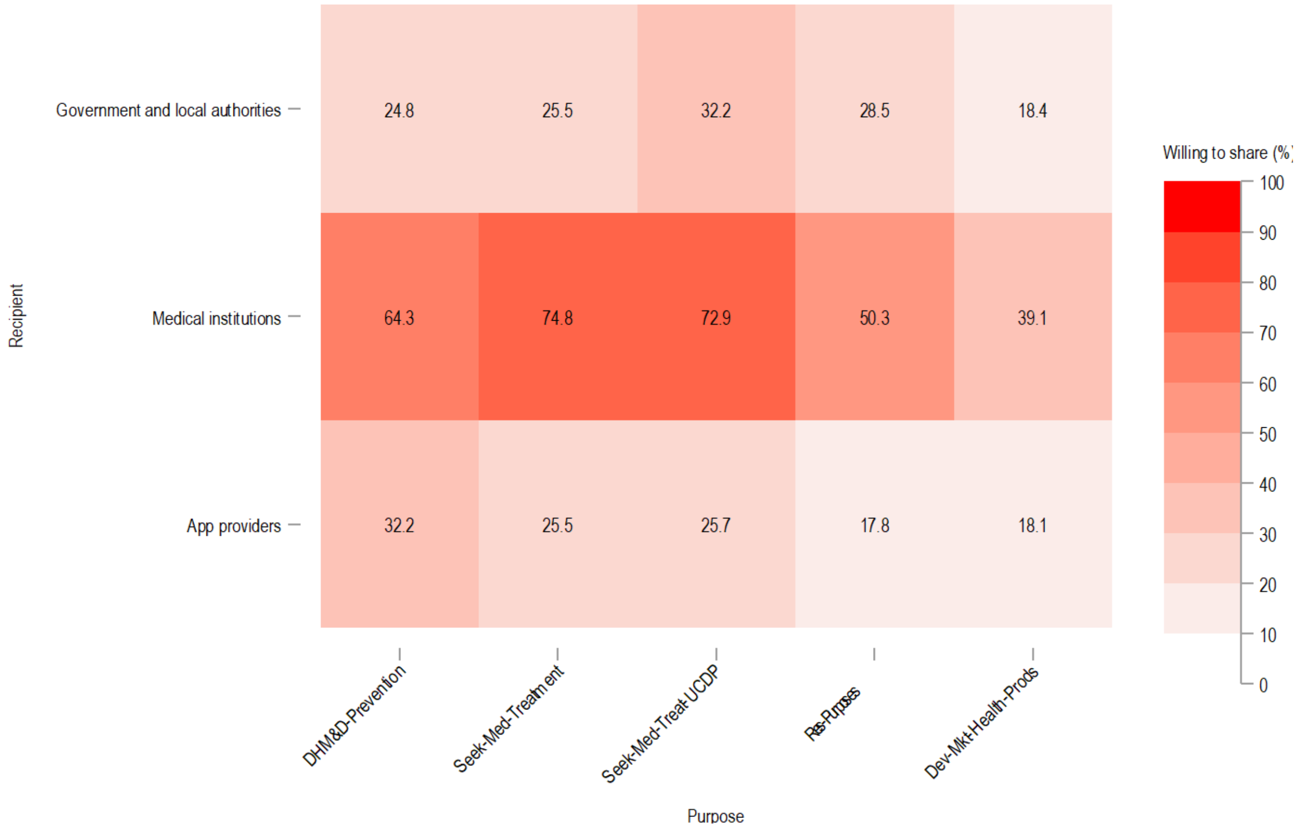

Figure A1. Heatmap of respondents' willingness to share their family members' and relatives' personal health information, stratified by purpose and recipient. The numbers indicate the percentage of respondents who answered "yes" to the question of whether they want to share their family members' and relatives' information. DHM&D-Prevention: Daily health maintenance and disease prevention; Seek-Med-Treatment: Seeking appropriate medical treatment; Seek-Med-Treat-UCDP: Seeking appropriate medical treatment in case of unconsciousness or dementia progression; Res-Purposes; Research purposes; Dev-Mkt-Health-Prods: Development and marketing of new health-related products; Info-Share-Fam-Relatives: Information sharing with family members and relatives.