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Heterogeneity in willingness to share personal health information: a nationwide cluster analysis of 20,000 adults in Japan



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Abstract

Background While Personal Health Records (PHRs) are increasingly adopted globally, understanding public attitudes toward health information sharing remains crucial for successful implementation. This study investigated patterns in willingness to share personal health information among Japanese adults and identified factors influencing their sharing decisions.

Methods A nationwide cross-sectional web-based survey was conducted among 20,000 Japanese adults in December 2023. Participants were recruited through quota sampling based on age, gender, and prefecture population ratios from the 2020 National Census. The survey examined willingness to share personal health information with nine types of recipients (healthcare providers, ambulance crew, application providers, family members, local authorities, employers, pharmaceutical companies, government agencies, and research institutions), trust levels in these recipients, and 17 factors influencing sharing decisions across health benefits, convenience, economic incentives, social significance, information details, transparency, and privacy considerations. Clustering analysis using Uniform Manifold Approximation and Projection (UMAP) and Ordering Points to Identify the Clustering Structure (OPTICS) algorithms was performed to identify distinct patterns in sharing preferences.

Results Despite low PHR familiarity (88.4% unfamiliar), participants showed willingness to share health information with healthcare providers (65.0%) and family members (65.6%), but expressed lower willingness toward government agencies (28.6%) and research institutions (28.8%). Five distinct clusters were identified: family-only sharers (3.9%), mixed preference sharers (47.9%), comprehensive sharers (12.9%), non-sharers (22.1%), and healthcare-selective sharers (13.2%). Trust levels were highest for family members (85.6%) and healthcare professionals (78.8%), while significantly lower for government agencies (44.2%). Higher education, income, and PHR familiarity were associated with greater willingness to share, while privacy and security concerns were universal across all clusters.

Conclusions The heterogeneous patterns in health information sharing preferences suggest the need for tailored PHR implementation strategies that address varying privacy concerns and trust levels across different population

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segments. Success in PHR adoption requires balanced approaches to trust-building, robust data protection, and targeted communication strategies that acknowledge diverse user needs while promoting the benefits of health data sharing.

Keywords Personal health records, Health information sharing, Cluster analysis, Digital health, Japan

Text box 1. Contributions to the literature

• This study offers the first large-scale nationwide cluster analysis of personal health information sharing preferences in Japan, based on 20,000 adults.

• The findings reveal distinct patterns in trust and willingness to share health data, demonstrating significant heterogeneity in attitudes across the population.

• By identifying five user clusters, this study informs the design of more inclusive and targeted personal health record (PHR) strategies.

• The results highlight the critical role of trust, particularly in government and healthcare institutions, in promoting health data sharing.

Background

Personal Health Records (PHRs) emerge as a transformative tool in healthcare, designed to promote patient engagement, involvement, and self-management [1, 2]. These systems integrate diverse health-related information, including medical histories, medication records, and patient-generated data, enabling a comprehensive approach to health management. The integration of features supporting lifestyle management, disease control, and personalized alerts reflects healthcare's shift toward patient-centricity [3, 4].

While smartphone applications have accelerated global PHR adoption [5], significant implementation barriers persist, particularly concerning trust, privacy, and demographic variations in acceptance [6–9]. In Japan, amid the rapid digital transformation characterized by"Society 5.0" [10], the Ministry of Health, Labour and Welfare (MHLW) launched initiatives to promote PHR adoption, exemplified by the"My Number Portal"implementation [11]. This system attempts to address trust concerns through centralized government oversight while expanding functionality to include various health data types [12, 13]. The successful implementation of PHR systems requires careful consideration of diverse user attitudes and privacy concerns while maintaining their fundamental role in healthcare [14–16].

Trust emerges as a critical factor in PHR adoption and utilization [16, 17]. A Swedish population study revealed that 81.9% of respondents expressing high trust in healthcare providers'data protection capabilities showed increased willingness to share personal health information through PHRs [16]. However, contrasting findings from a 2020 survey of Japanese PHR users indicated that 47.7% of respondents expressed concerns about personal information leakage, with approximately half showing reluctance toward third-party data sharing [18]. These findings highlight the complex relationship between institutional trust and health information sharing behaviors across different cultural contexts [15, 16].

Security considerations in PHR systems span multiple dimensions, including confidentiality, availability, integrity, authentication, authorization, non-repudiation, and access rights [7]. While technical implementations such as data encryption, access controls, and digital signatures address these aspects [8], the relationship between security measures and user acceptance remains a critical area for investigation [16].

This study aims to explore the dynamics of public willingness to share health information within PHRs in Japan, where PHR implementation is rapidly advancing amid digital transformation initiatives. The study has three objectives: 1) determining the prevalence of willingness to share personal health information with specific recipients; 2) identifying patterns of information sharing preferences based on recipient types; and 3) characterizing the influence of demographic factors, trust levels, and privacy concerns on sharing preferences using advanced clustering techniques. Understanding these patterns in the Japanese context is crucial for developing targeted strategies that can address diverse user needs while promoting broader PHR adoption, with potential implications for PHR implementation in other countries undergoing similar digital health transformations.

Methods

Study population

Study participants were recruited through a panel managed by a web survey company (Cross Marketing Inc.) [19]. The panel comprised individuals aged 20 years or older who were capable of completing surveys in Japanese. Participation in the panel was voluntary, and individuals were incentivized to join by earning'points'for responding to questionnaires administered by the company. These points could be redeemed for products and services offered by partner companies. As of 2024, the survey company had access to approximately 5 million panel members representing diverse demographic, socioeconomic, and geographic backgrounds [19]. In this study, the target number of participants was initially set at approximately 20,000. To ensure national representation, a quota sampling method based on age, gender, and prefecture population ratios obtained from the 2020 National Census was employed, resulting in a final fixed number of 20,000 participants [20]. The survey was conducted from December 5–19, 2023, closing upon reaching the predetermined target population. Respondents were required to answer each question to avoid missing values.

Measures

The cross-sectional survey questionnaire was developed based on a comprehensive review of past literature on similar topics [21, 22], including a study conducted within the Japanese context by the MHLW [18] The questionnaire comprised socio-demographic variables such as gender, age, education level, household income in 2022, presence of family members or relatives living with the respondent, family members or relatives not residing with the respondent but for whom the respondent was responsible for health management, the habit of smoking and drinking, self-reported health status, medical history, and enrollment in private insurance. Digital literacy was evaluated through inquiries regarding internet device usage, engagement with social media, possession of a"My Number Card"(a personal identification card issued by the Japanese government, primarily used for social security and taxation purposes), and utilization of healthrelated apps or wearable devices.

Regarding the willingness to share personal health information, respondents were first presented with a definition of PHRs: "PHRs are systems that allow individuals to record and manage their own health and medical information using smartphone apps or similar tools." Following this explanation, they were asked how familiar they were with the concept of PHRs, with the following response options:"not familiar at all", "not very familiar", "somewhat familiar," and "very familiar."Subsequently, respondents were asked if they would be willing to automatically share their own medical and health information electronically with someone if there was a specific recipient of, with "yes" or "no "response options. Recipients were pre-identified and categorized into nine types, namely: healthcare and caregiving service facilities, ambulance crew, provider of application, family, local authority, employer, pharmaceutical company, government, and research institution. Respondents were asked about the importance of 7 categories with 17 factors in their decision-making process, including health benefits, convenience, economic incentives, social significance, information details, transparency and security, and privacy considerations (see resulting Table for detailed factors and response distributions). They were presented with four response options:"strongly agree,""agree,""do not agree,"and"not at all.". Finally, respondents were prompted to indicate their level of trust in each of the nine recipients of their own personal health information, should it be shared. They were presented with four response options:"strongly trust,""trust,""less trust,"and"not trust at all."The nine recipients were consistent with the previous question.

Statistical analysis

First, socio-demographic data were tabulated to provide basic information on the study population. Variables including age, gender, prefecture of residence, occupation, education levels, annual household income, and various health and lifestyle factors were categorized appropriately for analysis (see resulting Table for detailed characteristics).

Secondly, to characterize the overarching reasons for respondents' willingness to share personal health information, the data were analyzed using Uniform Manifold Approximation and Projection (UMAP) and Ordering Points to Identify the Clustering Structure (OPTICS) algorithm. UMAP was utilized to identify the data's global structure through dimension reduction techniques, reducing the 9 binary variables into a two-dimensional space for visual inspection (further details in the supplementary material) [23]. Subsequently, the OPTICS algorithm was applied to identify meaningful clusters of individuals on the reduced dimensional space [24]. In UMAP, a fixed number of nearest neighbors (default set to 15) with hamming distance were utilized for the binary questionnaire variables. Unlike many clustering algorithms, the OPTICS requires minimal input of parameter values, such as determining the minimum number of points (MinPts) required within a specified radius (epsilon) to consider a point as core point. In our implementation of the OPTICS, MinPts was set to the number of 5% of data points (default is 5 data points), and epsilon was set to 5. Following guidelines for the OPTICS usage, widely accepted procedures were employed to visually determine threshold values (in our setting, the value was 4.5) for the number of clusters, ensuring distance values were suitably large (Supplementary Fig. 1). All data analyses were conducted using R version 4.1.2 with packages uwot and dbscan [24, 25].

After identifying clusters of individuals, socio-demographic data was tabulated for each cluster to compare differences in socio-demographic characteristics across the clusters. This cluster-level analysis was adopted to capture the multidimensional nature of sharing preferences across all nine recipient types simultaneously. Considering the interrelated influence of trust, privacy

concerns, and perceived utility across recipients, clustering provided a holistic framework for characterizing user typologies. We further analyzed differences in the importance of 17 content-specific motivational factors across the clusters. In contrast, analyzing socio-demographic or motivational associations separately for each recipient would have required multiple independent models, increased the risk of multiple testing issues, and potentially fragmented interpretation. A Kruskal-Wallis test was used to assess significant differences between clusters in socio-demographic variables or digital literacy variables related to the willingness to share the respondent's own personal health information. Bonferroni correction was applied to address multiple testing procedure. 5% threshold was selected heuristically, as values smaller or larger did not distinctly differentiate characteristics from other clusters.

Large Language Models (LLM)

The Claude AI language model was utilized for proofreading to ensure grammatical accuracy and enhance clarity.

Results

The socio-demographic characteristics of the 20,000 participants are shown in Table 1. The mean age was 53.6 years (standard deviation 17.0), with a slightly lower proportion of males (48.2%) compared to females. Nearly 90% of the study participants reported using smartphones on a daily basis.

Majority of the participants (88.4%) indicated a lack of familiarity with PHR (Table 2.). When asked about their willingness to share personal health information with specific entities, 12,994 (65.0%) expressed agreement with health care service delivery organizations, 13,124 (65.6%) with family members, 5713 (28.6%) with government agencies, and 5767 (28.8%) with research institutions.

Regarding motivations for sharing personal health information, respondents exhibited the highest level of willingness to share when rating its importance as either "important" or "very important", particularly concerning early detection of diseases (81.7%). This was followed closely by sharing immediate access to medical information (81.2%), ensuring smooth medical procedures (81.2%), and enhanced coordination of treatment through information sharing (80.0%). Conversely, the lowest willingness to share information was noted regarding other social benefits (56.8%).

Respondents demonstrated the highest degree of trust, indicating "trust some extent" or "very much trust", in their families (85.6%) when it comes to handling personal health records. Moreover, a majority of respondents

expressed trust in health personnel, with 78.8% trusting health service providers and 84.1% trusting ambulance crews. Scientific research institutions also received significant trust, with 57.4% of respondents expressing confidence in them. Interestingly, more individuals placed their trust in local authorities (59.3%) compared to the government (44.2%) when it came to handling personal health records.

We applied the OPTICS clustering algorithm to identify five distinct populations (clusters) within the study cohort. The distribution of respondents within each cluster and the distributions of the clusters detected by OPTICS, achieved by employing UMAP on the twodimensional reduced representation of our dataset are displayed in Fig. 1. The five clusters regarding respondents' willingness to share personal health information with specific recipients are labeled as follows: Cluster 1 (n = 783, 3.9%) that exhibited a unique pattern of willingness to share information exclusively with family members, while being unwilling to share with all other recipients. Cluster 2 (n = 9587, 47.9%) demonstrated a mixed pattern of sharing preferences, with varying degrees of willingness across different recipients, but no consistent trend. Cluster 3 (n = 2574, 12.9%) showed the highest willingness to share, with nearly all respondents agreeing to share information with all recipients. Cluster 4 (n = 4410, 22.1%) displayed the most restrictive attitude, with almost all respondents unwilling to share information with any recipient. Finally, Cluster 5 (n = 2646, 13.2%) revealed a selective sharing pattern, with respondents willing to share information primarily with healthcare-related recipients (healthcare and caregiving service facilities and ambulance crew) and family members. The details of clusters based on respondents' willingness to share personal health information with specific entities are presented in Table 3.

Supplementary Table 1 presents the distributions of cluster-specific socio-demographic characteristics. Compared to Cluster 4, which exhibited the most restrictive attitude towards data sharing, the other clusters showed significant differences in various socio-demographic factors. Age distribution varied significantly across clusters. In addition to differences in median ages (e.g., Clusters 1, 2, and 5 had higher medians of 60, 57, and 62 years, respectively, compared to Cluster 4 at 48 years), we observed distinct patterns in categorical age groups. For instance, older age groups (e.g., 70-79 years) were more represented in Clusters 1, 2, and 5, while younger age groups (e.g., 20-39 years) were more common in Cluster 4. Gender composition was significantly different for Clusters 2 and 5 (p < 0.001), with these clusters having a higher proportion of females (53.2% and 57.5%, respectively) compared to Cluster 4 (48.6%). Educational

Variables	Overall <i>N</i> =20000
	Number (%)
Age (mean, (SD*))	53.6 (17.02)
Gender	
Female	10329 (51.6)
Male	9622 (48.1)
Other	49 (0.2)
Prefecture	
Hokkaido	856 (4.3)
Aomori	210 (1.0)
lwate	187 (0.9)
Miyagi	447 (2.2)
Akita	149 (0.7)
Yamagata	163 (0.8)
Fukushima	236 (1.2)
Ibaraki	323 (1.6)
Tochiai	202 (1.0)
Gunma	223 (1.1)
Saitama	1119 (5.6)
Chiba	985 (4.9)
Tokyo	2545 (12.7)
Kanagawa	1545 (7 7)
Nijata	290 (1 5)
Toyama	165 (0.8)
Ishikawa	166 (0.8)
Fukui	99 (0.5)
Yamanashi	94 (0.5)
Nagano	272 (1.4)
Gifu	318 (1.6)
Shizuoka	539 (27)
Aichi	1405 (7 0)
Mie	235 (1.2)
Shiga	187 (0.9)
Kvoto	397 (2.0)
Osaka	1508 (7.5)
Hyogo	895 (4 5)
Nara	186 (0.9)
Wakayama	103 (0.5)
Tottori	97 (0.5)
Chimano	97 (0.5)
Okavama	34 (0.5)
Hiroshima	482 (2.4)
Vamaquichi	104 (10)
	194 (1.0)
	II/ (U.D)
Nayawa Ehima	(0.8)
Linne	
	85 (0.4)
FUKUUKd	1045 (5.2)

 Table 1
 Socio-demographic characteristics of 20,000 adults participating in the nationwide Japanese personal health information

 sharing survey, December 2023
 Socio-demographic characteristics of 20,000 adults participating in the nationwide Japanese personal health information

Variables	Overall
	N=20000
	110 (0.6)
Sdyd	119 (0.0)
Kumamata	219 (1.0)
Oite	210(1.1)
Old Minoroli	149 (0.7)
Wilydzaki	157 (0.8)
Ndgoshima	195 (1.0)
	137 (0.7)
Junior High School	000 (3.3)
High School	0857 (34.3)
College	3808 (19.3)
University	7819 (39.1)
Post Graduate	/90 (4.0)
Occupation	
Health care	951 (4.8)
Education	559 (2.8)
Management	824 (4.1)
Information Technology	751 (3.8)
Art	277 (1.4)
Sales	1654 (8.3)
Administrative	2846 (14.2)
Service	2603 (13.0)
Student	308 (1.5)
Housewife	3908 (19.5)
Other	5319 (26.6)
Household income	
<200 million	3626 (18.1)
200-399 million	5933 (29.7)
400-599 million	4373 (21.9)
600-799 million	2718 (13.6)
800-999 million	1528 (7.6)
1000 million <	1822 (9.1)
Living together with	
Spouse	11370 (56.9)
Children (<6 years old)	1235 (6.2)
Children (6-17 years old)	2118 (10.6)
Children (over 18 years old)	3254 (16.3)
Parents	3725 (18.6)
Parents in law	308 (1.5)
Friends, others	1432 (7.2)
None	4280 (21.4)
Family members and relatives who do not "live" with you and who need to ta	ke the initiative in managing and supporting their health
Spouse	1915 (9.6)
Children (<6 years old)	299 (1.5)
Children (6-17 years old)	424 (2.1)
Children (over 18 years old)	1208 (6.0)
Parents	1945 (9.7)

Variables	Overall <i>N</i> =20000
	Number (%)
Parents in law	725 (3.6)
Friends, others	861 (4.3)
None	14751 (73.8)
Smoking	
Everyday	3307 (16.5)
Sometimes	312 (1.6)
More than one month after quitting smoking	3290 (16.4)
No	13091 (65.5)
Drinking alcohol	
Everyday	3212 (16.1)
5-6 days/week	1183 (5.9)
1-2 days/week	1259 (6.3)
1-2 davs/week	2253 (11.3)
1-3days/month	1758 (8.8)
Sometimes	3160 (15.8)
Ouit	574 (2.9)
No	6601 (33.0)
Health status	
Good	3121 (15.6)
Fairly good	5343 (26.7)
Average	8122 (40.6)
Notivervide	2627 (13.1)
Poor	787 (3.9)
Frequency of using device	, 0, (0.5)
Smartphone	
Almost every day	17828 (89.1)
2-5 days/ week	600 (3 0)
Once a week or less/ Not used	1572 (7.9)
Tablet	1372 (1.5)
Almost every day	2024 (14 6)
2-5 days/wook	1277 (64)
	15700 (70 0)
	(7.0)
Almost every day	8144 (40.7)
2-5 days/ wook	2184 (10.0)
Once a week or less/ Not used	9672 (48.4)
Deskton BC	5072 (1 0, 1)
	4180 (20 0)
	4109 (20.9) 1254 (6 0)
2-5 udys/ week	1334 (0.0)
Video Como Consolo	14457 (72.5)
Almost a varu dav	925 (4.2)
	655 (4.2) 1102 (C.0)
2-J uays/ WEEK	1192 (0.0)
	17973 (89.9)
	1100 (50)
Aimosi every day	1198 (6.0)
2-5 days/ week	405 (2.0)

Variables	Overall <i>N</i> =20000
	Number (%)
Once a week or less/ Not used	18397 (92.0)
IoT Home Appliance	
Almost every day	468 (2.3)
2-5 days/ week	357 (1.8)
Once a week or less/ Not used	19175 (95.9)
Frequency of using social media	
Facebook	
Almost every day	1776 (8.9)
2-5 days/ week	1353 (6.8)
Once a week or less/ Not used	16871 (84.4)
X (Twitter)	
Almost every day	4802 (24 0)
2-5 days/ week	1831 (9 2)
Once a week or less/ Not used	13367 (66.8)
LINE	15567 (66.6)
Almost every day	10788 (53.9)
2-5 days/weak	3670 (18.4)
Once a week or less/ Not used	55/2 (27.7)
Instagram	JJTZ (21.7)
Almost every day	4443 (22 2)
2-5 days (wook	1816 (0.1)
Once a week or loss/ Not used	137/11 (68 7)
	15/41 (00.7)
Almost every day	7504 (37.5)
	1465 (22.2)
2-5 days/ week	9021 (40 2)
	0051 (40.2)
Almost every day	1632 (8.2)
	000 (4.5)
2-5 udys/ week	900 (4. <i>3)</i> 17/60 (07.2)
Currently under treatment, or providually had any medical condition	17408 (87.5)
	101 (0.5)
Capeor	1242 (6.2)
	1242 (0.2)
	(9.1) 606 (2.0)
Mental illess	000 (5.0)
	1019 (5.1)
Diabetes Cerebrougesular disease	224 (1 7)
	554 (I.7) 1410 (7.1)
Other Name	1419 (7.1)
None	13831 (69.2)
Enrollment in private insurance	10700 (540)
	10/99 (54.0)
	9869 (49.3)
	5985 (29.9)
Registration for the use of Health Insurance with My Number Card	
Have not had My Number Card	1849 (9.2)
Aireauy nave or registered for use	15304 (76.5)

Variables		
	<i>N</i> =20000	
	Number (%)	
Do not intend to register in the future	2847 (14.2)	
Purposes of health-related apps and wearable devices		
Exercise-related (i.e. step counting, calorie consumption, and exercise logs)	5444 (27.2)	
Health management-related (such as weight, blood pressure, blood sugar management, and health examination records)	2680 (13.4)	
Diet and nutrition-related	841 (4.2)	
Sleep-related	1208 (6.0)	
Medication management-related (i.e. medication records and pill reminders)	1705 (8.5)	
Mental health-related	302 (1.5)	
Menstrual cycle and pregnancy-related	1015 (5.1)	
Other	31 (0.2)	
None in particular	12180 (60.9)	
* Standard deviation		

attainment was significantly different for Clusters 2, 3, and 5 (p < 0.001), with these clusters having a higher proportion of university graduates (40.1%, 43.7%, and 41.5%, respectively) compared to Cluster 4 (33.4%). Household income also varied significantly across all clusters (p < 0.001), with Clusters 1, 2, 3, and 5 having a lower proportion of households earning less than 200 million yen annually (19.2%, 17.0%, 13.9%, and 14.1%, respectively) compared to Cluster 4 (25.3%). Notably, familiarity with PHR differed significantly across all clusters (p < 0.001), with Clusters 1, 2, 3, and 5 showing higher levels of familiarity compared to Cluster 4.

When given the opportunity to automatically and electronically share healthcare-related information, significant differences were observed among clusters in responses regarding important decision-making factors (Supplementary Table 2). Cluster 4, characterized by the most restrictive attitude towards data sharing, served as the reference group for comparisons. Cluster 3, in contrast, demonstrated the most open attitude towards data sharing with all recipients, including both medical and non-medical entities. Compared to Cluster 4, Cluster 3 participants consistently rated a wide range of factors as more important. For health management, 21.2% of Cluster 3 participants considered it"very important"versus 8.0% in Cluster 4. This pattern extended beyond medical factors to areas such as contributing to product development (16.7% vs. 6.4% rating it"very important") and providing information for other societal benefits (16.0% vs. 5.9%). Cluster 3 also showed higher trust levels across various entities, including non-medical ones. For instance, 8.1% of Cluster 3 participants" very much trust" application providers compared to 3.9% in Cluster 4.

Cluster 1, which favored data sharing only with family members, showed a more nuanced approach compared to Cluster 4. While they generally rated health-related factors as more important than Cluster 4, the differences were less pronounced than those observed in Cluster 3. For example, 5.1% of Cluster 1 participants rated health management as"very important"compared to 8.0% in Cluster 4. Notably, Cluster 1 exhibited significantly higher trust in family members for data handling (50.8%"very much trust") compared to Cluster 4 (22.4%), aligning with their preference for family-only data sharing.

Cluster 5, open to data sharing with both healthcare professionals and family members, demonstrated higher importance ratings for health-related factors compared to Cluster 4. For instance, 18.8% of Cluster 5 participants rated early disease detection as"very important"compared to 10.0% in Cluster 4. Cluster 5 showed notably higher levels of trust in healthcare organizations (79.0%"trust to some extent") compared to Cluster 4 (51.3%), reflecting their openness to sharing data with healthcare professionals.

Across all clusters, factors related to information security, privacy protection, and transparency in data usage were rated as more important compared to Cluster 4. Regarding methods for anonymizing personal information and protecting privacy, 23.0%, 27.9%, and 40.8% of participants in Clusters 1, 3, and 5 respectively rated this as"very important,"compared to 16.5% in Cluster 4. This suggests that even among those more open to data sharing, there is a stronger desire for robust data protection measures compared to the most restrictive group.

 Table 2
 Personal health record familiarity, sharing preferences, motivational factors, and institutional trust among Japanese adults in a nationwide survey (N=20,000), December 2023

Variables	Overall <i>N</i> =20000
	Number (%)
Familiarity of personal health record (PHR)	
Not familiar at all	11638 (58.2)
Not very familiar	6022 (30.1)
Somewhat familiar	1683 (8.4)
Very familiar	657 (3.3)
Disagreement to sharing PHR with	
Healthcare and caregiving service facilities	7006 (35.0)
Ambulance crew	6671 (33.4)
Provider of application	14042 (70.2)
Family	6876 (34.4)
Local authority	13175 (65.9)
Employer	15124 (75.6)
Pharmaceutical company	14911 (74.6)
Government	14287 (71.4)
Research institution	14233 (71.2)
Importance of factors in making decision for sharing PHR	
Health management	
Not important at all	969 (4.8)
Somewhat important	3135 (15.7)
Important	13466 (67.3)
Very important	2430 (12.2)
Early detection of diseases	
Not important at all	837 (4.2)
Somewhat important	2828 (14.1)
Important	12471 (62.4)
Very important	3864 (19.3)
Immediate access to medical information (medical history, prescriptions, medical record	ds, etc.)
Not important at all	887 (4.4)
Somewhat important	2865 (14.3)
Important	13070 (65.3)
Very important	3178 (15.9)
Smooth medical procedures (such as scheduling or changing appointments for tests or	treatments, issuing prescription refills, etc.)
Not important at all	907 (4.5)
Somewhat important	2838 (14.2)
Important	12810 (64.0)
Very important	3445 (17.2)
Enhanced coordination of treatment through information sharing among multiple heat	Ithcare institutions
Not important at all	919 (4.6)
Somewhat important	3094 (15.5)
Important	12774 (63.9)
Very important	3213 (16.1)
Electronic money or points	
Not important at all	1815 (9.1)
Somewhat important	6539 (32.7)
Important	9521 (47.6)

Variables	Overall
	<i>N</i> =20000
	Number (%)
Very important	2125 (10.6)
Reduction of insurance premiums	
Not important at all	1128 (5.6)
Somewhat important	4135 (20.7)
Important	10840 (54.2)
Very important	3897 (19.5)
Receiving feedback on lifestyle improvement suggestions and exercise methods	
Not important at all	1308 (6.5)
Somewhat important	5485 (27.4)
Important	11368 (56.8)
Very important	1839 (9.2)
Contributing to product development	
Not important at all	1590 (8.0)
Somewhat important	6468 (32.3)
Important	10438 (52.2)
Very important	1504 (7.5)
Providing information as part of research	
Not important at all	1564 (7.8)
Somewhat important	6195 (31.0)
Important	10724 (53.6)
Very important	1517 (7.6)
Providing information for other societal benefits	
Not important at all	1703 (8.5)
Somewhat important	6929 (34.6)
Important	10064 (50.3)
Very important	1304 (6.5)
Specific types and amounts of shared information	
Not important at all	1257 (6.3)
Somewhat important	5920 (29.6)
Important	11163 (55.8)
Very important	1660 (8.3)
Information sharing under specific conditions only (e.g., during disasters)	
Not important at all	1159 (5.8)
Somewhat important	4758 (23.8)
Important	11897 (59.5)
Very important	2186 (10.9)
Transparency in information usage (how information will be utilized)	
Not important at all	1241 (6.2)
Somewhat important	4344 (21.7)
Important	9729 (48.6)
Very important	4686 (23.4)
Information security measures	
Not important at all	1252 (6.3)
Somewhat important	4220 (21.1)
Important	9464 (47.3)
Very important	5064 (25.3)

Variables	Overall <i>N</i> =20000
	Number (%)
Methods for anonymizing personal information and protecting privacy	
Not important at all	1282 (6.4)
Somewhat important	3843 (19.2)
Important	8868 (44.3)
Very important	6007 (30.0)
Ease and clarity of consent process for information sharing	
Not important at all	1272 (6.4)
Somewhat important	4239 (21.2)
Important	10218 (51.1)
Very important	4271 (21.4)
To what extent of trust with regard to information security measures and the handling of personal data	
Organizations in which you receive health and care services	
Do not trust at all	834 (4.2)
Not very much trust	3410 (17.0)
Trust to some extent	13755 (68.8)
Very much trust	2001 (10.0)
Ambulance crew	
Do not trust at all	655 (3.3)
Not very much trust	2522 (12.6)
Trust to some extent	13286 (66.4)
Very much trust	3537 (17.7)
Provider of application	
Do not trust at all	2233 (11.2)
Not very much trust	8836 (44.2)
Trust to some extent	8285 (41.4)
Very much trust	646 (3.2)
Family	
Do not trust at all	711 (3.6)
Not very much trust	2174 (10.9)
Trust to some extent	9392 (47.0)
Very much trust	7723 (38.6)
Local authority	
Do not trust at all	1550 (7.8)
Not very much trust	6578 (32.9)
Trust to some extent	10829 (54.1)
Very much trust	1043 (5.2)
Employer	
Do not trust at all	2827 (14.1)
Not very much trust	6760 (33.8)
Trust to some extent	9247 (46.2)
Very much trust	1166 (5.8)
Pharmaceutical company	
Do not trust at all	1894 (9.5)
Not very much trust	7342 (36.7)
Trust to some extent	9773 (48.9)
Very much trust	991 (5.0)

Variables	Overall	
	<i>N</i> =20000	
	Number (%)	
Government		
Do not trust at all	3233 (16.2)	
Not very much trust	7922 (39.6)	
Trust to some extent	8022 (40.1)	
Very much trust	823 (4.1)	
Research institution		
Do not trust at all	1739 (8.7)	
Not very much trust	6769 (33.8)	
Trust to some extent	10343 (51.7)	
Very much trust	1149 (5.7)	
With regard to information security measures and the handling of personal data, would you disagree to delegate authority to a family member to share information about your medical or health care electronically when you are unable to make your own consent choices,	5244 (26.2)	

e.g. in an emergency situation or when you are unconscious?



Fig. 1 a Distribution of five identified clusters of Japanese adults (N = 20,000) detected by Ordering Points To Identify the Clustering Structure (OPTICS) on the two-dimensional reduced representation of personal health information sharing preferences, December 2023; **b** Uniform Manifold Approximation and Projection (UMAP) visualization of clusters for two-dimensional reduced representation of data annotated by the OPTICS generated clusters from a nationwide Japanese survey

Discussion

Our study reveals that a significant majority of participants (88.4%) were unfamiliar with PHR, highlighting a critical knowledge gap in the Japanese population. However, this question was preceded by a clear explanation of what PHRs are, ensuring that participants had at least a basic understanding before answering. Thus, their responses can be interpreted as attitudes toward the general idea of self-managed digital health records, rather than specific technical functionalities. Similar

	Cluster 1 <i>N</i> = 783	Cluster 2 <i>N</i> = 9587	Cluster 3 <i>N</i> = 2574	Cluster 4 <i>N</i> = 4410	Cluster 5 <i>N</i> = 2646	
Recipients	Number (%)	Number (%)	Number (%)	Number (%)	Number (%)	P-value
Healthcare and caregiving service facilities	0 (0.0)	7788 (81.2)	2560 (99.5)	0 (0.0)	2646 (100.0)	< 0.001
Ambulance crew	0 (0.0)	8128 (84.8)	2555 (99.3)	0 (0.0)	2646 (100.0)	< 0.001
Provider of application	0 (0.0)	3384 (35.3)	2574 (100.0)	0 (0.0)	0 (0.0)	< 0.001
Family	783 (100.0)	7121 (74.3)	2574 (100.0)	0 (0.0)	2646 (100.0)	< 0.001
Local authority	0 (0.0)	4251 (44.3)	2574 (100.0)	0 (0.0)	0 (0.0)	< 0.001
Employer	0 (0.0)	2302 (24.0)	2574 (100.0)	0 (0.0)	0 (0.0)	< 0.001
Pharmaceutical company	5 (0.6)	2497 (26.0)	2574 (100.0)	13 (0.3)	0 (0.0)	< 0.001
Government	0 (0.0)	3140 (32.8)	2573 (100.0)	0 (0.0)	0 (0.0)	< 0.001
Research institution	10 (1.3)	3183 (33.2)	2574 (100.0)	0 (0.0)	0 (0.0)	< 0.001

Table 3 Five identified clusters of Japanese adults (N = 20,000) based on willingness to share personal health information with specific recipients in a nationwide survey, December 2023

trends have been observed internationally; for instance, a study in Germany reported that consumer unfamiliarity with electronic health records posed a significant barrier to their adoption [26]. Despite this lack of familiarity, approximately two-thirds of respondents expressed willingness to share their personal health information with healthcare service delivery organizations and family members. This encouraging finding suggests that with proper education and awareness initiatives, there is substantial potential for successful PHR implementation in Japan, particularly when the benefits are clearly communicated to users [8, 9].

The markedly lower willingness to share information with government agencies and research institutions (approximately 28%) may represent a trust deficit that requires strategic intervention. This hesitancy could potentially limit the broader public health benefits of PHR systems and needs to be specifically addressed through targeted trust-building initiatives. This pattern is consistent with previous studies that have highlighted privacy and security concerns as potential barriers to PHR adoption [8, 9]. Internationally, research has shown that individuals' willingness to share personal health data varies depending on the perceived trustworthiness of the data recipient and the intended use of the data [27]. Comprehensive education about PHR benefits, combined with transparent communication about security measures and data protection protocols, can effectively reduce resistance to change and address concerns associated with using such systems [8].

The motivations for sharing personal health information provide valuable insights into public priorities. Specifically, our analysis accounted for heterogeneity in the content and purpose of shared information, as respondents evaluated the importance of a wide range of sharing motivations-from health benefits to broader societal contributions. These purpose-specific factors, enabled us to capture differential willingness to share based on information content. The high importance placed on early disease detection, immediate access to medical information, and smooth medical procedures (all above 80%) underscores the perceived value of PHR in enhancing personal health management and care coordination. These findings align with previous research highlighting the potential benefits of PHR in improving patient outcomes and healthcare efficiency [18, 28-30]. The relatively lower willingness to share for broader social benefits (56.8%) points to a critical gap in public understanding of collective healthcare advantages. This suggests a need for enhanced communication strategies that effectively convey how individual data sharing can contribute to population health improvements, medical research advancement, and healthcare system optimization [13].

Trust emerges as a crucial factor influencing willingness to share personal health information [17]. The high trust levels in family members (85.8%) and health personnel (78.8% for health service providers, 84.2% for ambulance crews) reflect the importance of personal relationships and professional credibility in health information sharing [15, 16]. The notable trust disparity between government institutions (44.2%) and local authorities (59.4%) reveals a complex dynamic in institutional trustworthiness. This finding suggests that trustbuilding strategies should be particularly focused at the national government level, while potentially leveraging the higher trust in local authorities to build broader institutional credibility. Research has shown that this trust gap can be narrowed through enhanced transparency, improved communication channels, and demonstrated commitment to data protection [31]. Similar observations have been made in other cultural contexts; for example, a study in China found that patients'willingness to share personal health data was significantly influenced by their trust in the data recipient and perceived risks and benefits [32].

The application of OPTICS clustering analysis revealed five distinct groups with varying attitudes toward PHR sharing, with the largest cluster (47.9%) displaying mixed sharing preferences. While this cluster's large size offers statistical stability, its internal heterogeneity-reflecting diverse and often inconsistent sharing attitudes across recipient types-makes it challenging to draw conclusive interpretations. This underscores the importance of implementing flexible and nuanced PHR strategies that can accommodate diverse privacy preferences and sharing comfort levels [33]. To better address the complexity within such heterogeneous groups, future research should complement cluster-based typologies with recipient-specific multivariable analyses. The identification of a cluster with high willingness to share (12.9%) suggests the potential for early adopters who could serve as champions for PHR implementation, while the more restrictive cluster (22.1%) highlights the importance of addressing privacy concerns comprehensively. The selective sharing pattern observed in the final cluster (13.2%) emphasizes how recipient identity significantly influences sharing decisions [34].

These findings demonstrate notable parallels with a 2020 study of Japanese healthcare institutions, which found that 49.5% of facilities shared patient information with external entities [35]. This alignment between individual preferences and institutional practices suggests that selective data-sharing behaviors are deeply embedded in Japanese healthcare culture and regulatory frameworks. Understanding these cultural and systematic patterns is crucial for developing effective PHR implementation strategies that respect existing norms while promoting beneficial innovation [36].

Socio-demographic factors play a significant role in shaping attitudes towards PHR sharing [15, 37]. Our analysis revealed that higher education and income levels correlate strongly with greater openness to data sharing, while older age groups demonstrate more selective and cautious sharing patterns. These demographic variations emphasize the need for tailored PHR implementation strategies that address the specific concerns and needs of different population segments. Previous studies have shown that individuals with higher educational attainment are more likely to be aware of and positively inclined towards sharing their health data, while those from lower socioeconomic backgrounds often demonstrate hesitance due to privacy concerns [38, 39]. Internationally, research has indicated that psychological factors, such as optimism and psychological flexibility, also influence individuals' willingness to share personal health data, suggesting the importance of considering psychological traits in understanding data-sharing behaviors [40].

A consistent and crucial finding across all identified clusters was the universal emphasis on information security, privacy protection, and transparency in data usage. This widespread concern underscores the critical importance of implementing robust data protection measures and maintaining clear communication about data handling practices. Research indicates that comprehensive security frameworks incorporating confidentiality, integrity, and availability are essential for fostering user trust and promoting system acceptance [7, 41].

Limitations

Several methodological constraints warrant consideration when interpreting this research. The study's geographical focus on Japan potentially limits the external validity of our findings to other cultural contexts. Our sampling methodology, utilizing an online survey format with point-based incentives, may have helped mitigate traditional self-selection bias. While our quota sampling was based solely on age, gender, and prefecture population ratios, in accordance with the fixed specifications of the web survey company (Cross Marketing Inc.), and aligned with the 2020 National Census data to enhance representativeness, the online survey format introduces its own methodological considerations [42]. Importantly, educational background was not included as a stratification variable in the sampling framework, although such information was available in the survey panel. This was a methodological constraint beyond our control. As a result, our sample included a disproportionately higher percentage of individuals with a university degree or higher (43.1%) compared to the national average of 21.3% among adults aged 20 years and older, based on the 2020 Census [20], potentially affecting the generalizability of our findings. Moreover, while this study provides valuable quantitative insights, it has inherent limitations in uncovering the underlying motivations and concerns behind individuals' willingness or unwillingness to share PHRs. Future qualitative research is essential to explore these perspectives in depth and to complement our findings.

Conclusion

Our findings reveal a complex landscape of PHR attitudes in Japan, characterized by low initial familiarity yet notable willingness to share health information with trusted stakeholders. Importantly, this willingness was expressed after participants were provided with a standardized explanation of what PHRs are, allowing their responses to reflect attitudes toward the concept rather than detailed technical knowledge. The identification of distinct user clusters and varying trust levels across different entities suggests the need for sophisticated, targeted approaches to PHR implementation. Success in PHR adoption will require a careful balance of trust-building strategies, robust data protection measures, and tailored communication approaches that address the diverse needs and concerns of different population segments. These insights should guide policymakers and healthcare providers in designing PHR systems that effectively address privacy concerns while advancing patient-centered care and realizing the potential benefits of health data sharing in Japan.

Abbreviations

MHLW	Ministry of Health, Labour and Welfare
MinPts	Minimum number of points
MyNaPortal	My Number Portal
OPTICS	Ordering Points to Identify the Clustering Structure
PHR	Personal Health Record
UMAP	Uniform Manifold Approximation and Projection

Supplementary Information

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Supplementary Material 1

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Authors' contributions

The contributions of the authors to the study were as follows: AE, KMS, TF, HM, TY, NN, and SN conceptualized the study. Data curation was performed by KMS, TF, HM, TY, NN, and SN. AE and SN were responsible for the formal analysis. SN secured the funding for the project. The investigation was carried out by MS, AE, YK, TK, YT, DY, and SN. Methodology development was led by AE, KMS, TF, TY, NN, and SN. Project administration was handled by KMS and SN. KMS, TF, HM, TY, NN, and SN. Provided the necessary resources. SN also developed the software used in the study. SN supervised the project. Validation. The original draft of the manuscript was written by MS, AE, TK, and SN, while the review and editing were done by all authors.

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Data availability

Due to ethical restrictions, the data is available on request from the corresponding author.

Declarations

Ethics approval and consent to participate

Ethical approval was granted by the Ethics Committees of Keio University School of Medicine under authorization number 20231130. Instead of traditional paper-based written informed consent, electronic informed consent was obtained from the participants. Only upon providing this consent, participants were allowed to proceed to the questionnaire response page.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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References

- 1. Mora F. The demise of Google Health and the future of personal health records. Int J Healthc Technol Manag. 2013;13(5–6):363–77.
- Wang CK. Security and privacy of personal health record, electronic medical record and health information. Probl Perspect Manag. 2015;13(4):19–26.
- Tang PC, Ash JS, Bates DW, Overhage JM, Sands DZ. Personal health records: definitions, benefits, and strategies for overcoming barriers to adoption. J Am Med Inform Assoc 2006;13(2):121–6.
- Anwar MJJ, Tan J. Anytime, anywhere access to secure, privacy-aware healthcare services: issues, approaches and challenges. Health Policy Technol. 2015;4:299–311.
- Bouri N, Ravi S. Going mobile: how mobile personal health records can improve health care during emergencies. JMIR Mhealth Uhealth. 2014;2(1):e8.
- Flaumenhaft Y, Ben-Assuli O. Personal health records, global policy and regulation review. Health Policy. 2018;122(8):815–26.
- Hosseini AEH, Sadat Y, Paydar S. Integrated Personal Health Record (Phr) security: requirements and mechanisms. BMC Med Inform Decis Mak. 2023;23(1):116.
- Alsahan A, Saddik B. Perceived challenges for adopting the Personal Health Record (PHR) at Ministry of National Guard Health Affairs (MNGHA)- Riyadh. Online J Public Health Inform. 2016;8(3):e205.
- Yousef CC, Salgado TM, Burnett K, et al. Perceived barriers and enablers of a personal health record from the healthcare provider perspective. Health Informatics J. 2023;29(1):14604582231152190.
- Cabinet Office J. Society 5.0. https://www8.cao.go.jp/cstp/english/socie ty5_0/index.html. Accessed 3 Sep 2024.
- Ministry of Health LaW, Japan. Data health reform promotion headquarters. https://www.mhlw.go.jp/stf/seisakunitsuite/bunya/0000148743. html. Accessed 3 Sep 2024.
- Ministry of Health LaW, Japan Working Group on the Utilization of Health Checkup Information - Private Sector Utilization Task Force. https://www. mhlw.go.jp/stf/shingi/other-kenkou_520716_00009.html. Accessed 3 Sep 2024.

- Davis S, Smith MA, Burton L, Rush KL. Personal health record implementation in rural primary care: a descriptive exploratory study using RE-AIM framework. PLOS Digit Health. 2024;3(6):e0000537.
- Ministry of Health LaW, Japan. Study Group on the Utilization of Health, Medical, and Nursing Care Information - Working Group on the Utilization of Health Checkup Information. 2020. https://www.mhlw.go.jp/stf/shingi/ other-kenkou_520716_00005.html. Accessed 3 Sep 2024.
- Busch-Casler J, Radic M. Trust and health information exchanges: qualitative analysis of the intent to share personal health information. J Med Internet Res. 2023;25:e41635.
- Belfrage S, Helgesson G, Lynøe N. Trust and digital privacy in healthcare: a cross-sectional descriptive study of trust and attitudes towards uses of electronic health data among the general public in Sweden. BMC Med Ethics. 2022;23:19.
- Flaherty SJ, Duggan C, O'Connor L, Foley B, Flynn R. What influences a person's willingness to share health information for both direct care and uses beyond direct care? Findings from a focus group study in Ireland. HRB Open Res. 2022;5:36.
- NTT Data Institute of Management Consulting I. Survey results for users of private PHR services. 2021. https://www.mhlw.go.jp/content/10904 750/chosakekka.pdf. Accessed 3 Sep 2024.
- Cross Marketing Inc. Web surveys [Japanese]. https://www.cross-m.co.jp/ service/netresearch/. Accessed 7 May 2024.
- Statistics Bureau of Japan. Population census 2015 statistical maps of Japan. 2020. https://www.stat.go.jp/english/data/chiri/map/c_koku/ 2020.html. Accessed 5 May 2024.
- 21. Lin CTP, Beitsch LM. Confidence and receptivity for COVID-19 vaccines: a rapid systematic review. Vaccines (Basel). 2020;9(1):16.
- Robinson EJA, Lesser I, Daly M. International estimates of intended uptake and refusal of COVID-19 vaccines: a rapid systematic review and meta-analysis of large nationally representative samples. Vaccines (Basel). 2021;39(15):2024–34.
- McInnes L, Healy J. UMAP: Uniform Manifold Approximation and Projection for Dimension Reduction. ArXiv e-prints 1802.03426. 2018.
- 24. Ankerst MBM, Kriegel HP, Sander J. OPTICS: ordering points to identify the clustering structure. Sigmod Record. 1999;28(2):49–60.
- Hahsler MPM, Doran D. dbscan: fast density-based clustering with R. J Stat Softw. 2019;91(1):1–30.
- Kroner S, Schreiweis B, Strotbaum V, Brandl LC, Pobiruchin M, Wiesner M. Consumer perspectives on the national electronic health record and barriers to its adoption in Germany: does health policy require a change in communication? BMC Health Serv Res. 2025;25(1):33.
- Baines R, Stevens S, Austin D, et al. Patient and public willingness to share personal health data for third-party or secondary uses: systematic review. J Med Internet Res. 2024;26:e50421.
- Conti J, Fix GM, Javier SJ, et al. Patient and provider perspectives of personal health record use: a multisite qualitative study in HIV care settings. Transl Behav Med. 2023;13(7):475–85.
- Kaelber DC, Jha AK, Johnston D, Middleton B, Bates DW. A research agenda for personal health records (PHRs). J Am Med Inform Assoc. 2008;15(6):729–36.
- Assadi V, Hassanein K. Consumer adoption of personal health record systems: a self-determination theory perspective. J Med Internet Res. 2017;19(7):e270.
- OECD. OECD survey on drivers of trust in public institutions 2024 results: building trust in a complex policy environment; 2024. https:// www.oecd.org/en/publications/oecd-survey-on-drivers-of-trust-in-public-institutions-2024-results 9a20554b-en.html, Accessed 3 Sept 2024.
- 32. Shi J, Yuan R, Yan X, et al. Factors influencing the sharing of personal health data based on the integrated theory of privacy calculus and theory of planned behaviors framework: results of a cross-sectional study of chinese patients in the Yangtze River Delta. J Med Internet Res. 2023;25:e46562.
- 33. Alsyouf A, Lutfi A, Alsubahi N, et al. The use of a technology acceptance model (TAM) to predict patients' usage of a personal health record system: the role of security, privacy, and usability. Int J Environ Res Public Health. 2023;20(2):1347.
- Mawditt CSK, Katanoda K, Gilmour S. The clustering of healthrelated behaviors in the adult japanese population. J Epidemiol. 2021;31(8):471–9.

- 35. Kikuchi D, Tsuchiya M, Hatakeyama S. et al. Actual status of patient information sharing among healthcare delivery facilities: a survey by the third subcommittee, committee on academic research, the Japanese society of hospital pharmacists. J Pharm Health Care Sci. 2022;8:30.
- Suzuki K, Yokozeki D. Data governance for achieving data sharing in the IOWN Era. NTT Techn Rev. 2023;21(4):49.
- Cascini F, Pantovic A, Al-Ajlouni YA, Puleo V, De Maio L, Ricciardi W. Health data sharing attitudes towards primary and secondary use of data: a systematic review. eClinicalMedicine 2024;71:102551.
- Scaioli G, Martella M, Lo Moro G, et al. Knowledge, attitudes, and practices about electronic personal health records: a cross-sectional study in a region of Northern Italy. J Med Syst. 2024;48(1):42.
- Alam P, Bolio A, Lin L, Larson HJ. Stakeholders' perceptions of personal health data sharing: a scoping review. PLOS Digit Health. 2024;3(11):e0000652.
- Eversdijk M, Douma ER, Habibovic M, Kop WJ. The association of psychological factors with willingness to share health-related data from technological devices: cross-sectional questionnaire study. JMIR Form Res. 2025;9:e64244.
- Tang PC, Ash JS, Bates DW, Overhage JM, Sands DZ. Personal health records: definitions, benefits, and strategies for overcoming barriers to adoption. J Am Med Inform Assoc. 2006;13(2):121–6.
- 42. Szolnoki G, Hoffmann D. Online, face-to-face and telephone surveys comparing different sampling methods in wine consumer research. Wine Econ Policy. 2013;2(2):57–66.

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