

A Survey of the Situation and Attitudes towards the Handling of Electronic Clinical Information in Japanese Citizens

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Abstract

Objectives: The use of personal health records (PHRs) can be beneficial for healthcare management because it can facilitate the accumulation and administration of lifelong healthcare information, which can aid the clinical process. However, for PHRs to be used appropriately while ensuring the protection of patient privacy, patients must be able to decide how their clinical information will be used. Therefore, it is important to thoroughly evaluate the situation and needs of the public.

Methods: In this study, an online survey was conducted in Japan in July 2012. The survey was composed of 35 questions on the status of the respondent, how individuals want their clinical information to be handled and opinions towards PHR. A total of 3,090 individuals ≥ 20 years of age living in Japan responded to the survey.

Results: Results indicate that most of the respondents agreed that PHR service was a necessity. However, concerns

regarding privacy issues were raised by most participants. The respondents also preferred that handling of their PHRs be done by public institutions. Moreover, there was a tendency for the respondents to prefer the primary use of their PHRs for personal healthcare purposes and gave less importance to secondary PHR use (i.e., research/development and public health).

Conclusion: On the basis of both cost burden and clinical information privacy, Japanese respondents preferred that PHRs be appropriately managed by a public institution. A similar trend has been observed in the United States. With consideration of also the differences in systems and legislation, further studies are needed to identify the needs of individuals to establish an adequate PHR service.

Keywords

Personal health records; Electronic clinical information; Information security; Privacy protection

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1. Introduction

The computerisation of clinical information has been progressing steadily in Japan, with medical institutions and other institutions collecting large quantities of clinical and pharmaceutical data during examinations. Privacy principles give patients the right to control the use of their own clinical information. However, because of a potential knowledge gap in medical care between medical workers and patients, [1-3] patients themselves may not be able to understand and properly manage all clinical and drug information. With the use and implementation of personal health records (PHRs), [4,5] accumulation of lifelong healthcare information of patients will be possible, which can aid in their healthcare management. Furthermore, such information can be used for the research and development of future medical treatments.

For the appropriate operation of PHRs, patients should be able to choose the types of clinical information contained in their PHR. Because of significant changes in related systems, such as the revision of the Act for Protection of Computer Processed Personal Data held by Administrative Organs, as well as personal credit card numbers being unlawfully distributed, individuals are now becoming increasingly involved in the protection of their privacy and use of their clinical/drug information. Therefore, it is crucial that a study be conducted to identify the opinions and demands of the public [6-8]. In Japan and many other countries, measures associated with PHRs or their applications are being implemented. In the United States, there are several PHR services, one of which is the Blue Button, mostly used by Veterans. Blue Button is the PHR service widely used across the United States [9]. Another PHR service is OpenNotes [10] which is operated by Harborview Medical Center.

In Japan, PHRs are created at various scales, in different areas and for different purposes. One example of a PHR service is for the self-management of diabetes treatment and health maintenance with the use of patients' smartphones [11,12]. Another example is a paper medication notebook used for recording drug dosage and dispensing information, but these have been used only experimentally and have not been widely distributed [13]. Unlike in other countries, Japan has a medical system where patients have free access to medical care at any medical institution of their choice. Therefore, a unique medical identifier for each patient is required to develop PHRs that cover all medical institutions, including large-scale hospitals, clinics and pharmacies.

On the basis of the previously described situation, we aimed to conduct a survey to examine the direction that future PHRs should take based on thorough evaluation of the opinions of patients regarding the types of clinical and drug prescription information they will allow for use and how they prefer such information be used.

2. Methods

2.1 Overview of the Survey

The survey in this study was administered *via* an online questionnaire to registered monitors of a research company in Japan in July 2012. Informed consent was obtained from the respondents before they were asked to answer the survey, after which they proceeded to respond to the questionnaire. The respondents were 3,090 individuals older than 20 years and were chosen from Tokyo, Miyagi, Aichi, Wakayama and Fukuoka. The questionnaire focused on topics directly associated with PHRs.

2.2 Questions

The survey questionnaire was composed of 35 questions. Some questions were on the respondent's demographic profile, such as age, gender, health status and family structure. The main part of the questionnaire included questions to determine the respondents' use of mobile devices, the status of the medication notebook (whether they had one and, if they did, whether they carried it with them), their views on how their clinical information should be handled and the respondents' opinions on PHR services regarding the desired service entity, consent frequency, cost burden and factors they considered important for the implementation of PHR services.

2.3 Statistical Analysis

This survey includes the results based on respondents' answers to the questions. We confirmed the trend on respondents' awareness from the frequency distribution of answers in each question. In July 2012, individuals older than 20 years comprised 104.9 million individuals out of the total population in Japan. With a confidence level of 95% and margin of error of 5%, the minimum sample size required for this study is 385. The total of number of respondents to the survey (N=3,090) is highly sufficient on the basis of the minimum number of participants needed.

3. Results

3.1 Profiles of the Respondents

Table 1 shows respondent information (N=3,090). The ratio of male to female respondents was 43:57, with a slight prevalence of women. The table shows the respondents' characteristics, such as gender, marital status, presence of children and health status of a family member, summarised according to age groups.

3.2 Online Use of Mobile Devices

Figure 1 & Table 2 shows the results for the multiple-choice question on ordinary use of mobile devices. Healthcare applications on mobile devices were being used by 14.2% (n=439) of respondents; 36.4% (n=1,124) of the respondents were not using any such applications and used their mobile phones only for making/receiving phone calls and managing e-mails. A similar trend was observed in the results of a survey conducted by the Ministry of Internal Affairs and Communications in 2012 [14].

3.3 Status of Paper Medication Notebook

Figure 2 shows the results for the question on the status of the respondents' paper medication notebook (N=3,090). This item contained the question 'Have a medication notebook or not,' answered with a yes or no. Of the total respondents, 31.4% had no medication notebook and 39.3% (those who carry one always/when necessary) had and used a paper medication notebook (medication notebook is a type of paper PHR, which is a record of dispensing information held by a patient in Japan).

3.4 Handling of Received Clinical Information

Figure 3 shows the responses (N=3,090) to the question on how the respondent handles clinical information, such as clinical summaries and laboratory test results, that they receive on paper. Although it seemed that handling of clinical information depended on the severity of the disease, most of the respondents kept their clinical information on paper on hand.

Figure 4 shows the responses to questions on respondents' preferred mode and conditions for receiving clinical information, including laboratory tests and imaging results. The results show that receiving clinical information on paper rather than only in an electronic format was preferred by most of the respondents.

3.5 Personal Health Records

We included questions on the desired service entity, consent frequency, cost burden and other important factors to determine respondents' views concerning the future implementation of PHR services in Japan. The results are as discussed in the following sections.

3.6 Desired Service Entity to Handle PHR Services (3.5.1)

Figure 5 shows the results of the question 'Who should operate PHR services in Japan?' Most of the respondents indicated that they wanted to have administrative authority or control over the

Table 1: Respondents' profile.

Profile		Age						
		20's	30's	40's	50's	60's	70's	Total
Gender	Male	129	279	428	278	148	61	1323
	Female	360	610	503	207	75	12	1767
Marital Status	Single	346	312	321	113	30	11	1133
	Married and living together	136	567	587	357	187	60	1894
	Married and living Separately	7	10	23	15	6	2	63
Children	No	404	476	441	137	30	7	1495
	Yes and living together	84	410	474	280	102	13	1363
	Yes and living separately	1	3	16	68	91	53	232
Health Status	Under treatment	85	161	223	148	98	40	755
	Treatment within 2 years	31	66	41	27	20	9	194
	Health check problem within 2 years	17	81	117	57	21	6	299
	Neither	366	605	584	272	102	23	1952
Health status of Family	Outpatient Treatment	172	374	406	204	79	20	1255
	Inpatient treatment	48	83	110	92	40	12	385
	Neither	269	432	415	189	104	41	1450
Total		489	889	931	485	223	73	3090

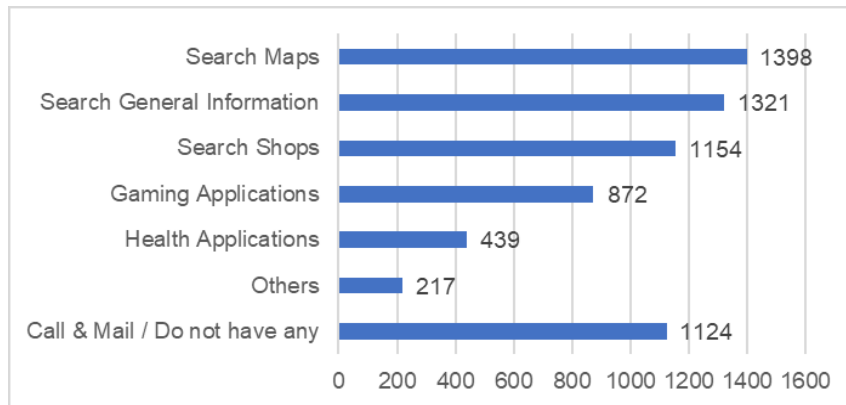


Figure 1: Online use of mobile devices.

Table 2: Online use of mobile devices.

Usage	Ages					Total
	20's	30's	40's	50's	60's+	
Health Applications	92	145	114	47	41	439
Call & Mail only	74	252	366	239	193	1124

information in their PHR. The option 'PHR services could be operated under free competition by commercial companies' was chosen by only 13.4% of the respondents.

3.7 Desired Consent Frequency for Primary Use

Figure 6 shows the results regarding the frequency desired by participants' regarding requesting for their consent on the primary use of clinical information by PHR services. Of the

total respondents, 80.8% indicated that they wanted requests for consent, but there were differences on the desired frequency.

3.8 Cost Burden of PHR Services

Figure 7 shows the opinions of respondents on the cost burden associated with a PHR service. The results show that most of the respondents wanted a very low-cost burden associated with a PHR service as an infrastructure to store their clinical information.

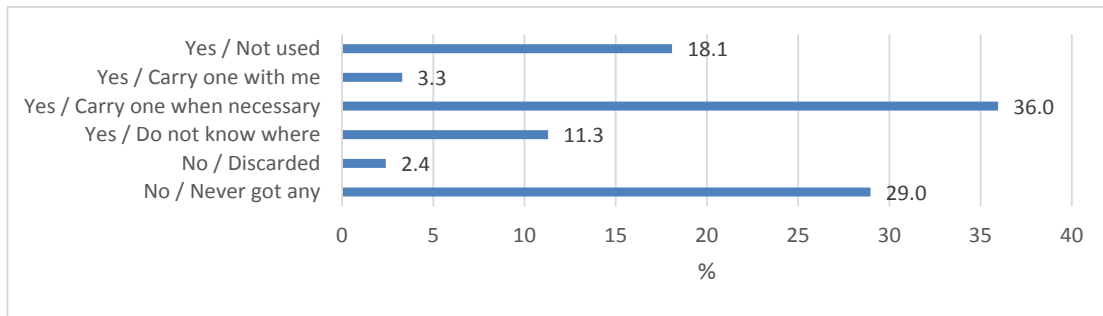


Figure 2: Status of the paper medication notebook.

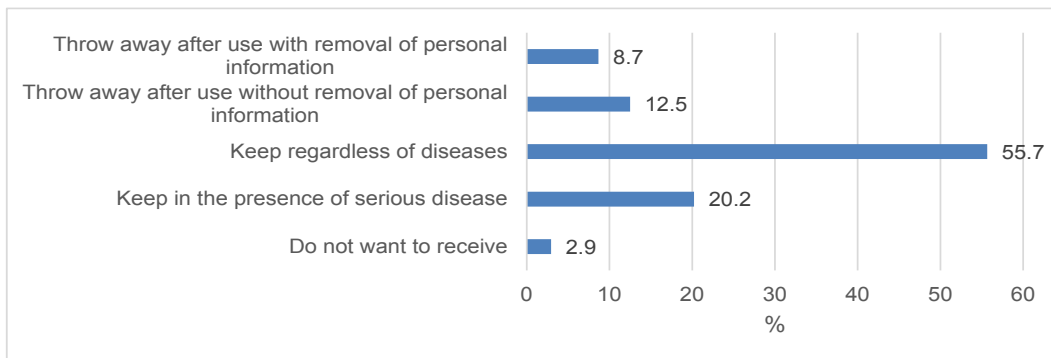


Figure 3: Handling of received clinical information.

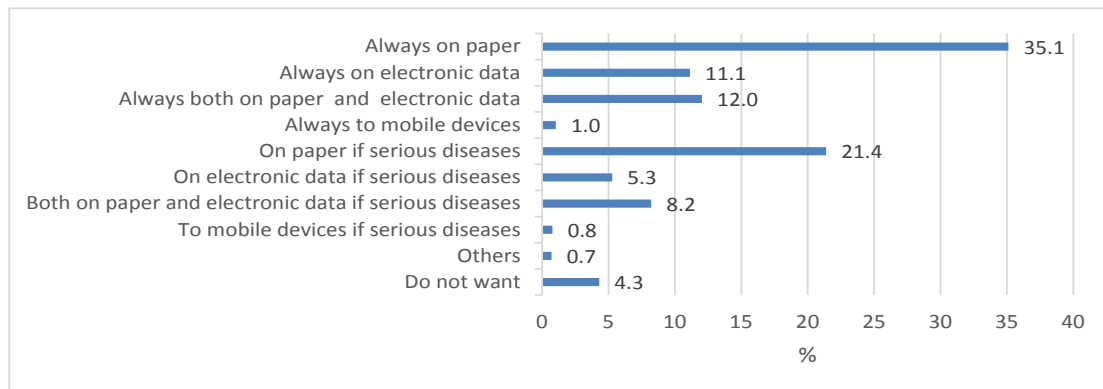


Figure 4: Desired medium and conditions for receiving clinical information.

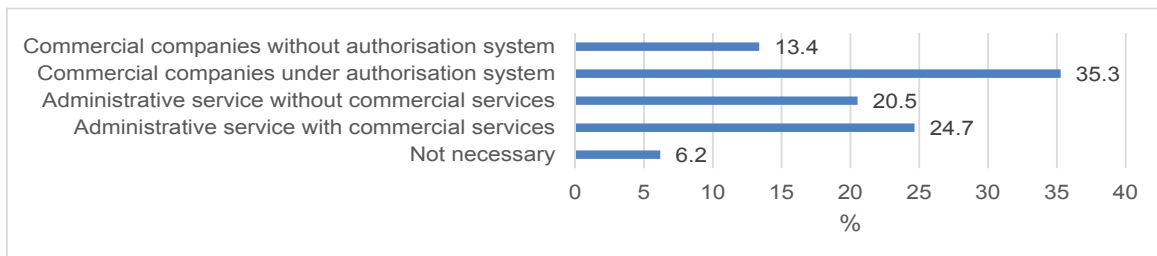


Figure 5: Desired service entity to handle patient health record services.

3.9 Desired Secondary Use of PHR

Figure 8 shows the results of the question exploring how the respondents want their information in PHR services to be used after anonymisation. The results show a high positive response supporting public use of clinical information but a low positive response regarding commercial use, including drug development.

3.10 Important Features of PHR Services

Figure 9 shows the responses to the multiple-choice questions on the features of PHR services that respondents considered as important (N=3,090). The concern of most of the respondents was on information security and the primary use of PHRs for their own healthcare in ordinary and emergency situations. The

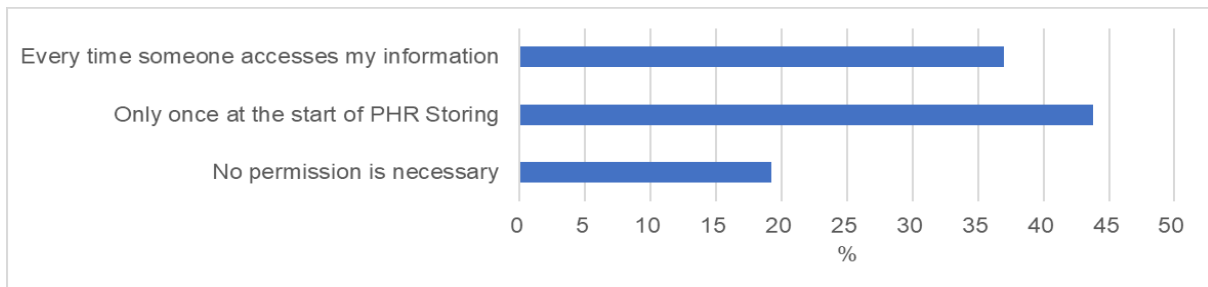


Figure 6: Desired consent frequency for primary use of patient health records.

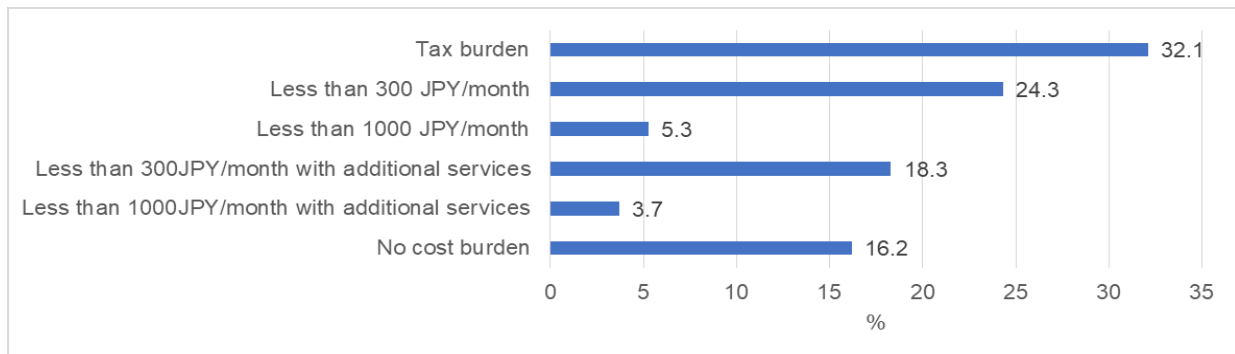


Figure 7: Desired cost burden of patient health record services.

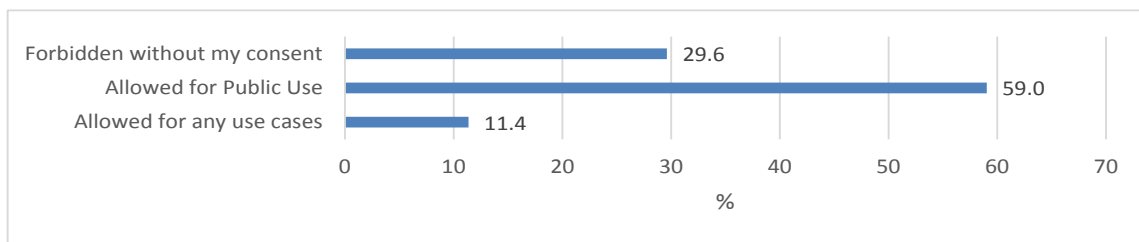


Figure 8: Secondary use of anonymised patient health record data.

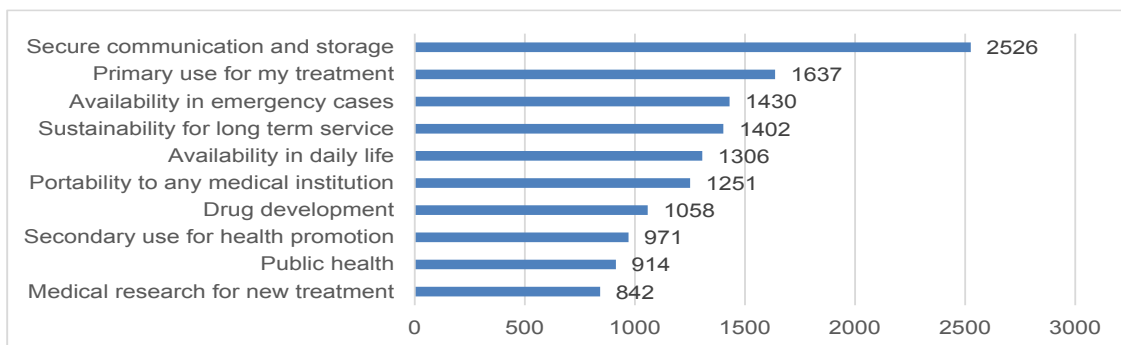


Figure 9: Features of patient health record services.

least important features were secondary use of information for research or development, compared with that for primary use and the availability of such information for daily life.

4. Discussion

4.1 Limitations

Given the unique methodology used in this study, the main limitation is that the survey was presented online, introducing a potential bias with the exclusion of individuals with low computer

literacy. Thus, the current results cannot be generalised to all Japanese citizens. However, because the purpose of this survey was to examine respondents' preferred handling of their electronic medical information, we assume that the survey methodology used here is appropriate. Therefore, this preliminary study was conducted with a relatively large sample size.

Moreover, despite the fact that 36.4% of the respondents used their mobile devices only for calls and e-mails (no online searching or use of mobile applications), only 6.2% replied 'PHR

is not necessary'. It is not clear whether, in the event that any PHR service becomes available, the entire Japanese population will be able to use the medical information in their PHR.

Another limitation might be the fact that the survey was conducted in 2012. Thus, the results might not completely reflect the current situation, as use of Internet has rapidly growing through the years and the penetration rate of smart devices in Japan has changed drastically since then. In return, this may have also affected the use of health apps and medication notebooks in the last years since the survey was conducted.

4.2 Current Situation

According to a survey by the Ministry of Internal Affairs and Communications, for the fiscal year 2011, the number of individuals who use the Internet is increasing annually and was 79.1% at the time of the survey. Therefore, even if individuals with low computer literacy were excluded by the methodology of this survey, a significant gap in the actual state of affairs is unlikely. In terms of the age of the population of Internet users, although the proportion of Internet users older than 49 years was greater than 90% in 2011, the proportion of Internet users older than 60 years was only approximately 20%. This may have produced a possible gap in opinions between the respondents of the online questionnaire and senior citizens of the general population. However, in the future, there may be further increases in the percentage of Internet users older than 60 years. Taking this into consideration, further studies need to be conducted.

Despite the previously mentioned level of mobile/computer literacy, the present study was conducted to understand the current situation in Japan. For a PHR in Japan that is generally recorded on paper, we chose the medication notebook as an example. The results indicate that only 3.3% of the respondents carried their notebook all the time, and most of the respondents did not carry a notebook. Furthermore, only 14.2% of the respondents were using healthcare applications on mobile devices. Although the survey results showed that 75.9% of the respondents maintained their clinical information on paper on hand, the low use of healthcare apps on mobile devices might not be suitable for emergency care. In addition, it can be assumed, based on the low rate of use of healthcare applications in this survey, that patients prefer receiving clinical information on paper and tend to keep it at hand. We believe that this is because patient's right states that Japanese people can visit any medical institution of their choice, including pharmacies, making it difficult to predict which hospital or pharmacy a patient will visit. This then makes a patient-based information collection across medical institutions technically difficult to accomplish. Furthermore, most of the respondents wanted administrative institutions to provide such services with consideration of concerns regarding information security and service costs.

Sharing information on paper gives the user the advantage of easily recording notes. However, continuously accessing written information may be difficult, particularly in emergency cases. Nevertheless, people still prefer handling such clinical information on paper. A primary reason why respondents expressed the need for PHR services may be the fact that many individuals do not use

medication notebooks (which is the most common medium used to provide medical information on paper).

4.3 Desired PHR Implementation

The results show that many respondents expressed the importance of information security in PHRs and did not show much interest in allowing the use of their anonymised information for commercial use. In addition, the respondents were concerned about commercial enterprises operating PHRs. Furthermore, regarding cost burden, most of the respondents stated that it was a tax burden or a low-cost burden, and from that point of view, it was better for public institutions ran and administered PHRs. The results of the present survey indicate a need to conduct a more detailed survey. These results may allow us to determine a method to provide a service that would promote a reliable and secure use of information. In addition, an important factor for individuals who apply to PHR services and for the sustainability and utilisation of these services is cost burden. The present results show that individuals prefer a very low-cost burden, and most of the respondents indicated that public institutions should carry such a burden.

More than 80% of the respondents stated that their consent would be necessary for the use of clinical information by PHR services. Of these respondents, approximately half indicated that they wanted consent to be requested each time that clinical information is exchanged to PHRs. One of the important aspects that can be controlled by patients is consent frequency. In this study, most of the respondents suggested that patients should be able to control their own information. This indicates that patients wanted to provide consent for medical treatments at most medical institutions but they believed that handling of information between PHRs and electronic medical records should be managed according to a different legislation.

4.4 Future Discussion

Although revisions made to Act on the Protection of Personal Information have resulted in improvements in data protection, it seems that enhancements in the system must be made regarding customising the use of information based on each individual's desire. Although many respondents indicated that they were predisposed to share their data for public use, many suggested that consent should be requested for use in primary care as well. Thus, the rationale for use of patient information must be clearly explained to patients, particularly for secondary use. Furthermore, individuals must be given the opportunity to decide how their information will be used (i.e., for the good of the individual or for the public at large). For that purpose, to manage a patient's consent and information control, a standard unique identifier system in medical fields and an infrastructure are required. The method of establishing a suitable common infrastructure for managing the consents and clinical information of patients remains a subject for future discussion.

5. Conclusion

The results of the survey in this study show that the respondents want an electronic clinical information handling

system that can safely handle and provide their medical healthcare information. In addition, the survey also shows that regarding PHR services, the respondents were specifically concerned about the cost burden and security issues, including consent management. Because of the growing population using mobile devices in Japan, handling of electronic clinical information will also continue to grow. However, further studies are needed to evaluate the use of PHR models other than the medication notebook.

6. Conflict of Interest

The authors declare that there is no conflict of interest.

7. Funding

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