

Surveys Aimed at General Citizens of the US and Japan About Their Attitudes Toward Electronic Medical Data Handling – 10 Years Change, Before and After Covid-19

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Abstract. *Objectives:* To clarify the views of the general population of two countries (US and Japan), concerning handling of their medical records electronically, disclosure of the name of disease, secondary usage of information, compiling their records into a lifelong medical record, access to their medical records on the internet, questionnaire filling for delicate history, comprehensive consent for laboratory results, chart and genome profile, and AI use in diagnosis and explanation. *Methods:* The authors contacted people nationwide in the United States at random via Random Digit Dialing (RDD) in 2008. Same questionnaire plus some new items were surveyed in 2022 by mail invited web entry. The authors had also surveyed people in Japan in 2007 and 2017 using same questionnaires sent by mail. *Results:* In US, accessing own chart by internet became accepted (positive 52% to 61%) and popular in these 14 years. Japan showed small change, as regional medical record sharing is yet to come. About medical records in un-identifiable manner to be used for the purpose of medical error precautions, infectious disease measures and device/drug developments, in US, positive answers are constantly low, even for infectious disease prevention like CoVID-19. About preference to compile medical record into one file as a lifelong medical record, sharp contrast was observed. US people became favor of lifelong record (46% to 71%), while Japanese people decreased (76% to 57%). As for comprehensive consent, Japan positive answers are more than US for all situations, except if genome profile is included. US answers are almost same, even genome profile is included. About AI (artificial intelligence) application to healthcare, both US and Japan survey showed best preferred is “Doctor may use AI and everything, and explains in person”. Japanese people largely prefer explanation in person, while US showed small preference.

Keywords. Surveys, public opinion, electronic health records, privacy, AI use in medicine, comprehensive consent

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1. Introduction

The authors conducted questionnaire surveys in US and Japan to investigate the awareness of people regarding medical data handling. In these studies, it was hypothesized that the sharing medical data among different healthcare providers, compiling them into one lifelong record, secondary use of anonymous data, are not yet enough accepted in these countries.

The target population for this survey was not physicians or patients, but the general population. Similar surveys have been conducted with physicians [1,2,3,4,5] and patients [6,7,8,9,10,11], but few studies have targeted citizens [12,13,14,15,16]. As public funding allocated to healthcare services is expected to expand, taxpayers' views should be of significant concern as well as the opinions of patients and healthcare professionals. The general population includes healthy people, people that are, and had been in therapy.

The first survey was in Japan on 2007, then with same questionnaire translated, in US on 2008[17]. To see 10 years change, the author conducted again in Japan on 2017 with same questionnaire with some news topics added. They were; 1) questionnaires filling for treatment, health check-up and insurance contract 2) comprehensive consent for laboratory results, medical chart text, genomic profile, and all of them 3) AI use in medicine for diagnosis and explanation.

2018 US survey was postponed due to COVID-19 breakout, as a result, however, change before and after COVID-19 was observed.

The research questions are:

- (1) What kinds of doctors, public organizations, private companies, people are allowed to access their medical data?
- (2) Is a scheme allowing healthcare providers or private companies to access people's unidentifiable medical data for the purpose of healthcare cost savings accepted?
- (3) Do people prefer to compile their medical records into one lifelong record?
- (4) Is access to their medical data via the internet considered acceptable and safe?
- (5) Do the results differ between these two countries, considering the differences in their healthcare policy?

Above items were for 2007/2008 survey. New items added to 2017/2022 are:

- (6) Do people fill questionnaires even about their delicate history?
- (7) Do people accept comprehensive consent?
- (8) How should AI be used in diagnosis process and explanation to them?

2. Methods

2.1. Survey in the US

The target of this survey was ordinary citizens who live in the US. In 2022 US survey, the author used commercial survey company. On July 26 – Aug 3, 2022, 3296 requests were mailed to the registered respondents, and answers were collected until they got 200 valid answers. Registered members were of many groups of people, like airline members,

net shopping users, etc., mixed in order to avoid bias. They were awarded small amounts, like 500 miles.

For the 2008 US survey, On 28 September 2008, people were contacted at random via US nationwide Random Digit Dialing (RDD) to obtain 200 eligible responders aged 19 years old and over who completed the telephone interview.

2.2. Survey in Japan

A survey using the same questions was conducted in Japan on 2007, a year before the 2008 U.S. survey, and on 2017 with some new questions added. The methods were all the same with 2007 and 2017. The target was the general population including men and women aged 20 to 69 years old who live in Shizuoka Prefecture (population in 2019 was 3,638,000, about 1/35 of that of all Japan).

The questionnaire was sent to 2,000 households which were selected at random from the telephone directory. We asked that the responder should be a person whose birthday was nearest to the received date among the family members aged 20–69 so that we could obtain responses from different age groups. This was done because without this assignment, the elderly are more likely to become responders because they are likely to stay at home. The surveys offered 500 yen (4USD) stored value card for valid answers. The survey period was 16–31 October 2007, and 1–31 January 2018 (Survey planned and mailed in December 2017).

2.3. Limitation of Comparison

In 2008 in US survey, method was RDD, while 2022 survey was internet survey for pre-registered “general citizen”, which makes the comparison only for observing trends and not for statistical validity.

Japan 2007 and 2017 methods were same, but different from both US survey.

2.4. Explained Definition of “Identifiable” and “Un-identifiable”

About the terms “identifiable” and “unidentifiable,” we consciously use these terms with only some explanation in both surveys due to limited response time and not too long sentences. There are many methods and guidelines of making information de-identified [18,19,20,21,22,23]. The explained definition of “identifiable” was “with your name and address,” and of “unidentifiable” was “without your name, address, your other access, and your profile and clinical history are made anonymous such that nobody can spot you.”

3. Results

3.1. Responder Attributes

The cooperation rate was calculated based on the definition of the American Association for Public Opinion Research (AAPOR) [24]. Each case was coded according to one of the AAPOR categories. These categories were as follows:

US 2008 survey: I (Completed Interviews) = 200, P (Partial Interviews) = 28, R (Eligible, Non-interview, Refusal) = 443, NC (Eligible, Non-interview, No Contact) = 8,649, O (Eligible, Non-interview, Other) = 81, UH (Unknown Eligibility) = 10,141, and NE (Not Eligible) = 1,367. The Cooperation Rate (AAPOR CR4) was calculated by employing the formula: $CR4 = (I + P)/(I + R + P)$. The cooperation rate of this survey was 34.0%.

The average session period, for the US 2008 survey, was 23 minutes 25 seconds.

US 2022 survey was conducted by mailing 3296 requests and answer period was cut off as soon as 200 valid answers were collected. Cut off was not by each category of age and gender, but just total numbers of 200. Rough response rate before cut off was 6.07%.

Japan 2007 survey: I = 457, P = 53, R (Refusal, no return) = 1,379. The valid response rate (AAPOR CR4) of this survey was 27.0%.

Japan 2017 survey: I = 225, P = 101, R = 873. The valid response rate of this survey was 27.2%.

The attributes of eligible respondents in the US and the Japan survey have been summarized in the following Figure 1.

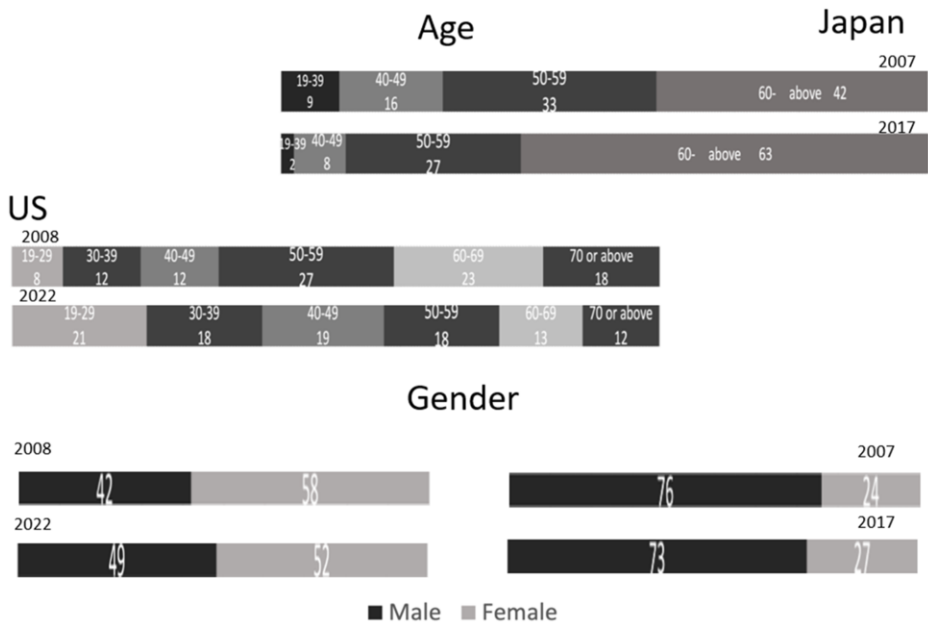


Figure 1 Respondent attributes

3.2. Questionnaires and Results

The questionnaires and results have been presented in the figures inserted in each discussion paragraph.

4. Discussions

4.1. RDD vs mail-evoked web survey

Kwak, et al. reported difference between web-based and RDD[25], Pierannunzi et al pointed out issues of mail-, telephone- based surveys transfer to web-based [26] because of cost benefit and quickness of web-based survey. Schonlau et al. reported RDD vs propensity-weighted web survey[27]. All pointed out that web survey is quicker and less response rate. Schonlou resulted that propensity weighing makes response rate improved. Therefore, the authors' surveys are for limited to reference, except for Japan 2007/2017 survey.

4.2. Respondent attributes (Figure 1)

About age distribution, Japan results became old age dominant even more. The mailed survey requested to answer by “a person in your family whose birthday comes first.” Generation became even older, family size became smaller, are the reasons. In US, 2008 survey was RDD, while 2022 survey was mail invited web based. US 2022 survey showed very equal respondents among age categories. This is because of pre-balanced population of survey company registrants. Although the authors did not set limit of respondent to each category, over limit category respondents can be refused at the entrance of the survey.

The questionnaire was sent to 2,000 households which were selected at random from the telephone directory. We asked that the responder should be a person whose birthday was nearest to the received date among the family members aged 20–69 so that we could obtain responses from different age groups. This was done because without this assignment, the elderly are more likely to become responders because they are likely to stay at home. The surveys offered 500 yen (4USD) stored value card for valid answers. The survey period was 16–31 October 2007, and 1-31 January 2018 (Survey planned and mailed in December 2017).

4.3. Q1. How would you feel if only you could view your medical records on the internet?

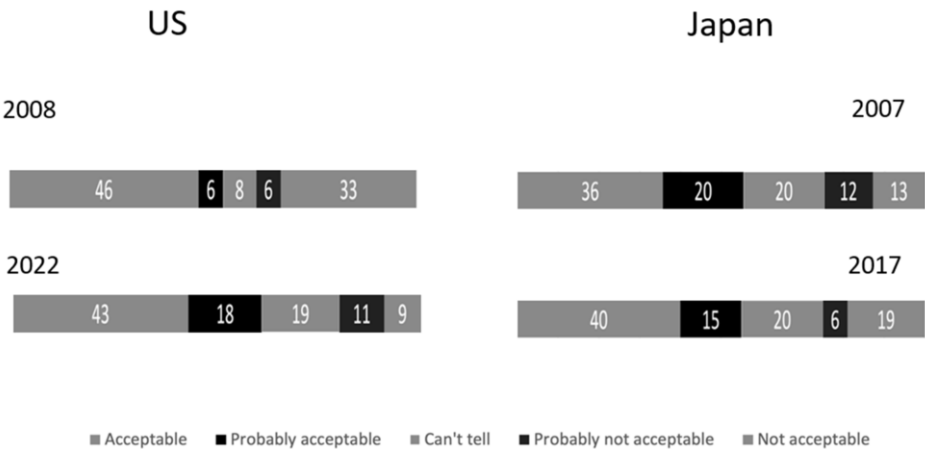


Figure 2 Medical record on internet

In US, sum of “acceptable” and “probably acceptable” (positive answers, hereafter) became significantly large ($p=0.034$), as well as negative answers (“probably not accepted” and “not accepted”) became smaller. Accessing by internet became accepted and popular in these 14 years. In Japan, both positive and negative are unchanged, though definite answers increased at both sides. In Japan, still regional patient record sharing is minor practice, while CD/DVD and envelop based sharing is mainly taking place. In 2020, Japan Ministry of Health Labour and Welfare reported the status of regional patient record sharing[28]. It reported that though 218 regional sharing were subsided and surviving, 59 of them have only one provider presenting patient record. Participating providers are total of 15,492, among all providers in Japan are more than 80,000.

In a questionnaire survey conducted in five clinics in Australia and New Zealand [7], patients’ attitudes toward sharing their electronic health records (EHR) were found to be influenced by three factors which were identity of recipient: level of anonymity: and type of information: In this survey, the authors obtained similar results.

4.4. Q2. Assuming that you are needed to visit the hospital or physician’s office, please rate how you’d feel if, without your consent, but for the purpose of treating your illness, your medical records were disclosed in an identifiable manner to the following recipients?

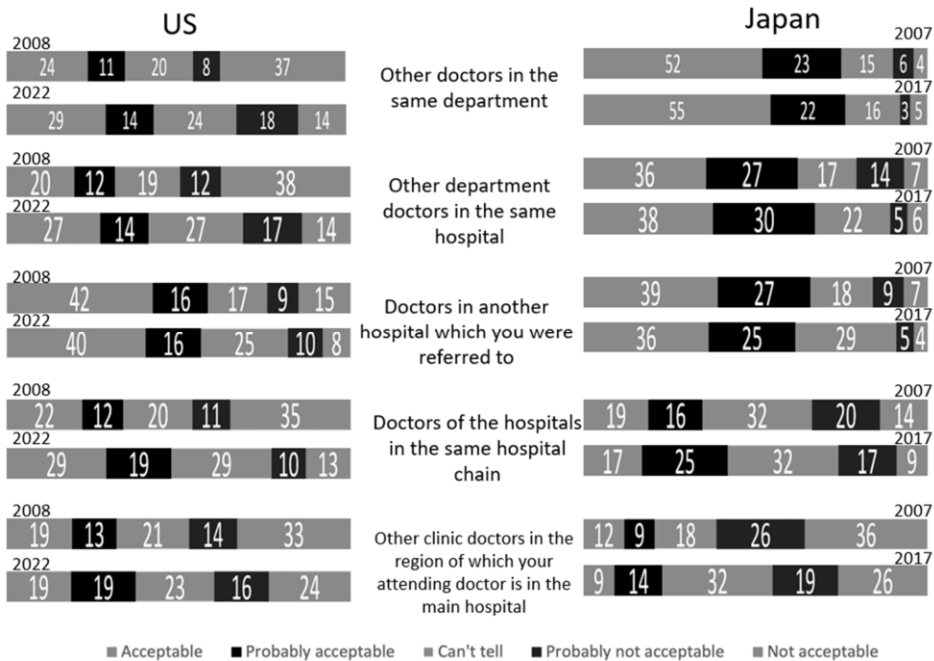


Figure 3 Medical record seen by other doctors

Except for “referred doctor”, positive answers in US survey show small numbers and minimal difference among remaining four, while Japan survey show apparent decrease from high at the top of the column to low at bottom column. Same as in 2007/2008 report [17], still in US 2022, patients are cared by “the attending doctor”, while in Japan 2017, by “the hospital or clinic”.

In US, positive answers increased in all four through 14 years, which again the authors conclude that regional sharing became popular in US.

4.5. Q3. Your medical records are disclosed in un-identifiable manner to pharmaceutical companies and DHHS/MHLW for the purpose of error precautions, infectious disease measures and device-drug developments

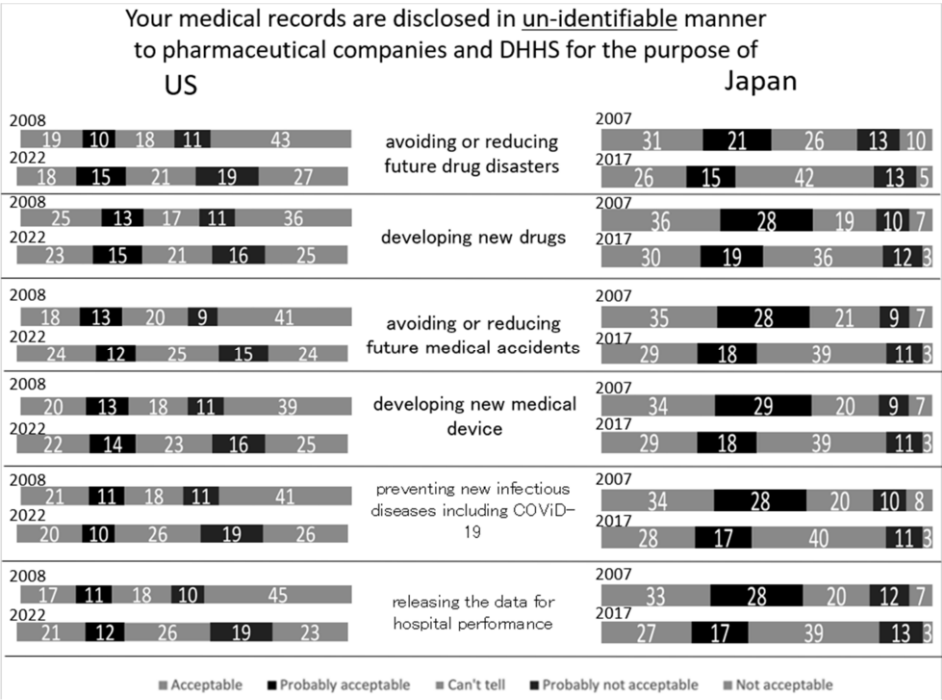


Figure 4 Use for health policies

In US, positive answers are constantly low, even for infectious disease prevention. In Japan, positive answers are larger compared to US, but decreased in all purposes. It should be noted that both in US and Japan, both in 2000's and recent, skeptical answers (Can't tell) became larger.

Willison's survey [14] of the Canadian public, concerning consent of secondary use of unidentified data in 2007 showed that 11% felt no need for notification or consent, 24% supported notification and opt-out, while 32% needed consent for each use. 22% favorable attitude of our study is considered almost similar to sum of 11 and 24 of the Canadian survey.

4.6. Q4 Do you want your medical records to be compiled into one database as a lifelong medical record? How about 5% discount on healthcare cost, insurance payment. How about IC-chip card security?

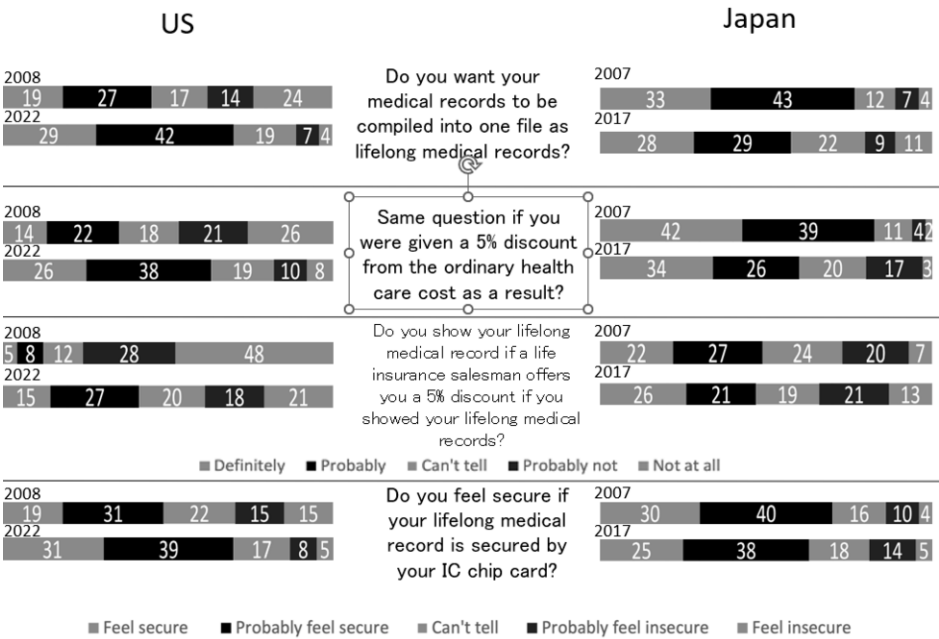


Figure 5 Compiling into one lifelong record

Sharp contrast was observed. US people became favor of lifelong record (46% to 71%), while Japanese people decreased (76% to 57%). US people said yes to both 5% discount, while refusing Japanese people increased. Reason of US increase lifelong medical record is some providers are already offering the service, and people saw advantages. Japan's insurance allow patients free access to any provider nationwide, which makes compiling into one record difficult, therefore Japanese people have not seen one (except for drug dispense record in paper book, which is very popular). Hoerbst's survey for EHR among Austrian and German citizens [15] showed that between 80% and 90% were supportive of the idea of exchanging health related data between health care providers. Also, Perera's survey citizens of Ontario, Canada [16] showed that most (>90%) supported the computerized sharing of the patient's health record among their health care providers. Thinking that our questionnaire is clearly stating "compiling as one database", these Austrian/German and Ontario answers are nearer to 2007 Japanese 74.6% positive answers.

The result, however, indicates that people in both countries may fear the possibilities of cherry picking by insurance companies (trying to contract only with low risk people). In the US, people can choose insurance, and at the same time, insurance companies can choose the people to whom they offer the policy. This discount is thought to be an invitation for people with lower health risks, while those with high risk may lose a chance to avail a moderate price. In Japan however, healthcare insurance coverage is universal. This resulted in lesser change in the unfavorable response of the participants.

The 2012 Commonwealth Fund survey [29] revealed that the percentage of doctors who used electronic patient medical records in their practice varied among countries. In this context, more than 90% of the doctors in the Netherlands, UK, Norway, New Zealand, and Australia used such electronic records, while the same was found to be 69% in the US. Japan has not joined this survey; however, a Japan Association of Healthcare Information System Industry survey in 2012 shows this figure to be 18.7% [30]. The surveyed countries were found to exhibit a low use of EMR as compared to other countries of Commonwealth survey. As a result, doctors are less accustomed to using digital medical records and the internet for healthcare.

This is in contrast to the fact that that Taiwan started IC chip card identification for healthcare professionals since 2007 [32].

It is important to note the difference between the healthcare systems of the two countries surveyed in the present study. A universal coverage policy is maintained in Japan, while citizens have the choices to select their insurance provider (including none) in the US. Further, the consumption tax is rather low in these two countries (US less than 10%, Japan 10%), which is generally high, especially in the northern European countries, which cover healthcare mainly by tax budget.

IC chip card acceptance rise in US, sink in Japan is of the same reason. US people are starting to see this security measure, which caused less trouble than predicted.

4.7. Q5. When filling questionnaire, are you going to fill delicate history?

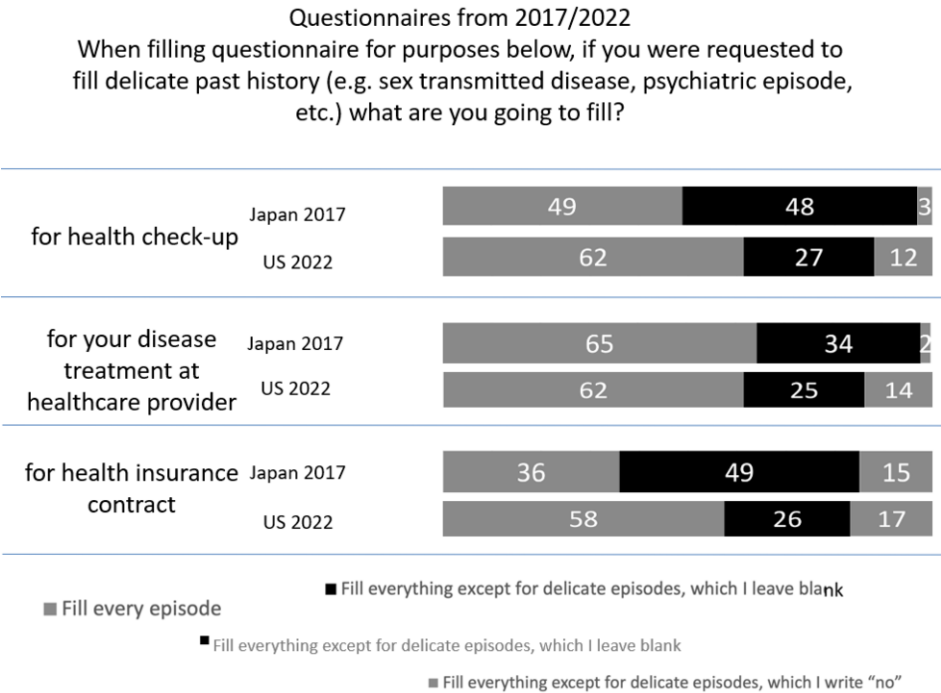


Figure 6 Filling delicate history in questionnaire

The results show that Japanese people say everything to attending doctor, but not for check up and insurance. US answers are almost same among three. Sharp contrast is shown at insurance questionnaire. It seems like failure of notification may cause failure of insurance coverage and consequently, payment.

4.8. Q6. “Comprehensive consent” is a consent which you allow your blood sample, medical chart text, genome profile to be used in future research (medical research purpose only) in unidentifiable manner. Do you accept?

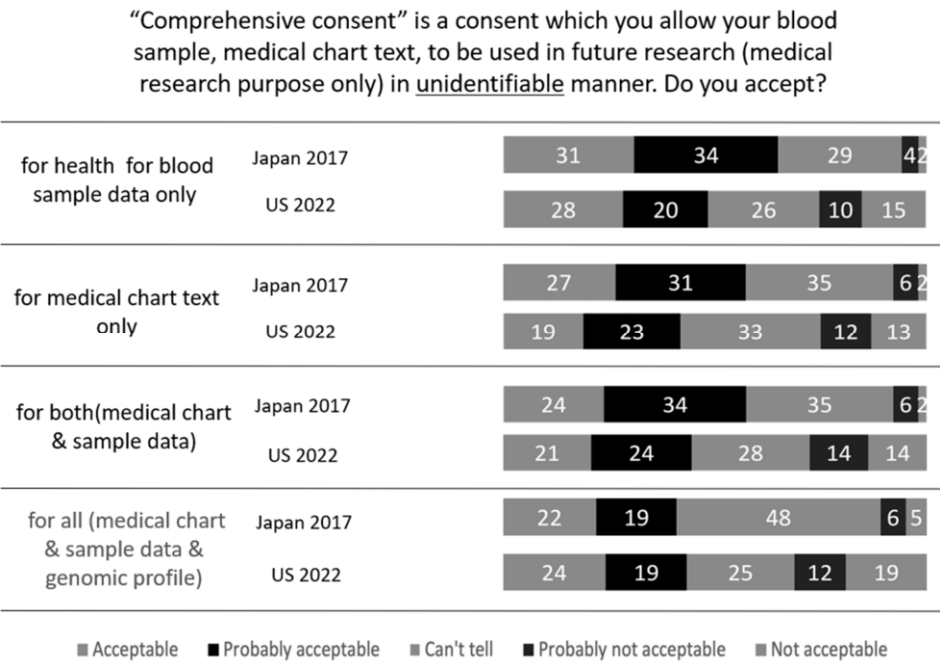


Figure 7 Comprehensive consent

Japan positive answers are more than US for all, except if genome profile is included. US answers are almost same, even genome profile is included.

As long as there is such a substantial negative attitude in both countries, an opt-out consent approach is not considered to be acceptable, not only in the US. In other words, an opt-in approach should be required when considering the possibility of commercial secondary usage. As indicated in a study about possible forms of consent in an electronic environment [4], comprehensive consent cannot always serve the needs of each subject and the content should be designed on a case-by-case basis, although this could be time consuming.

It is a surprise that US answers are not affected even if genomic profile was included. As genomic profile itself is an “identifier”, there are two ways to protect privacy; limitation of collection, and limitation of spotting. The latter should be also considered to protect people’s privacy.

4.9. Q7. About AI (artificial intelligence) application to healthcare

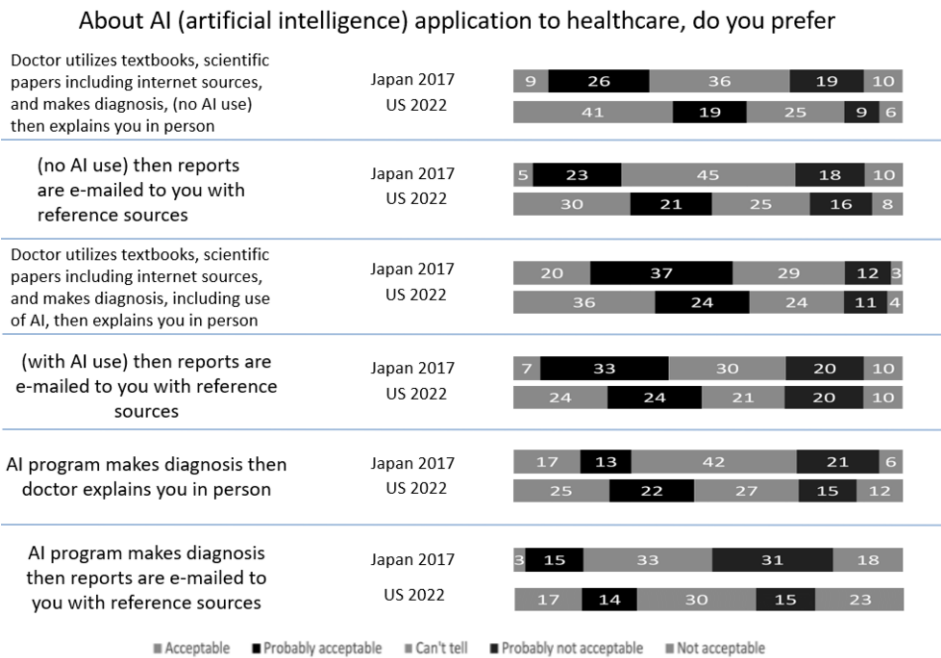


Figure 8 AI use in diagnosis and explanation

Both US and Japan survey showed best preferred is “Doctor using AI and everything, and explains in person”. Japan results shows sharp drop at all three diagnosis process, if explanation is not in person, while US showed small changes.

It seems like both in US and Japan, advantage of AI use in diagnosis has not yet to be seen by the survey of this time.

4.10. Limitations of This Survey

The sample size (200 for both US and 457, 225 for Japan, respectively) was not very large to exhibit the phenomenon tested by the hypotheses sufficiently. Further, different methods were applied in the two surveys (RDD and by mail). In addition, RDD is known to involve a significant level of bias [25].

Respondents of these surveys were living in their house, either contacted through the RDD in the US, or mail in Japan. Consequently, patients suffering from severe diseases may have been eliminated from this survey. Such patients may have a higher motivation to compile their medical records into one.

5. Conclusions

In US, accessing chart of their own by internet became accepted (positive 52% to 61%) and popular in these 14 years. Japan showed small change, as regional medical record sharing is yet to come.

Same as in 2007/2008 report, in US, patients are cared by “the attending doctor” while in Japan, by “the hospital or clinic”, judging from answers about chart seen by other doctors.

Even for infectious disease prevention like CoVID-19, in US, positive answers are constantly low for medical records in un-identifiable manner to be used by pharmaceutical companies and DHHS/NHLW for the purpose of error precautions, infectious disease measures and device/drug developments. In Japan, positive answers are larger compared to US, but decreased in all purposes. It should be noted that both in US and Japan, both in 2000’s and recent, skeptical answers (Can’t tell) became larger.

Preference to compile medical record into one database as a lifelong medical record, showed sharp contrast was observed. US people became favor of lifelong record (46% to 71%), while Japanese people decreased (76% to 57%). US people said yes to both 5% discount, while refusing Japanese people increased. Reason of US increase lifelong medical record is some providers are already offering the service, and people saw advantages. Japan’s insurance allows patients free access to any provider nationwide, which makes compiling into one record difficult, therefore Japanese people have not seen advantages.

As for comprehensive consent, Japan positive answers are more than US for all, except if genome profile is included. US answers are almost same, even genome profile is included. Not only collection, but also spotting procedure should be limited to protect privacy.

About AI (artificial intelligence) application to healthcare, both US and Japan survey showed best preferred is “Doctor using AI and everything, and explains in person”. Japanese people largely prefer explanation in person, while US showed small change, both regardless of diagnosis process, which people think “Use whatever good and available.”

Acknowledgments

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