

Investigation of users' experiences for online access to their electronic health records in Japan

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Abstract: The solution of sharing electronic health records (EHR) with patients has the potential to improve patients' understanding and remembering of their health information. We call this solution the patient open-EHR. In Japan, this solution is not yet widespread, and experiences of actual users are not known. Our aim is to explore the needs and satisfaction of patients who are actually using one patient open-EHR system in Japan that allows registered patients online access to part of their EHR. A cross-sectional study was done using an online questionnaire. Patients registered with our patient open-EHR system were invited to participate by posting an invitation message on the system login page and sending them invitation emails. We investigated their needs regarding the system and their views regarding the system's ability to improve their understanding, remembering, and other perspectives. Answers from 95 patients, collected between August 10 and October 20, 2019 were analyzed. The need to further understand and remember the information received from the doctor was among the top four reasons behind using the system. However, only 48% of patients agreed that the system improved their remembering and 68% agreed that it improved their understanding. Thirty-seven percent of respondents expressed dissatisfaction with access to only blood test results and prescriptions. Despite this dissatisfaction, respondents were positive about the future of the system. Hospitals need to recognize the needs of patients and to consider them when providing patient open-EHR service. The EHR has potential not only for hospitals but also for patients.

Keywords: electronic health record, patient needs, user experience, understanding, remembering

Introduction

Healthcare information technology (HIT) is changing how the healthcare industry operates globally and has already begun to reduce waste and help improve health outcomes (1). Electronic health records (EHR) are major components of HIT and they were originally developed to allow sharing of medical information between health care providers. The impact of sharing electronic medical and health records with patients on different aspects of quality and safety of care was largely studied in Europe and the USA (2-6). We call this solution of sharing EHR with patients the patient open-EHR. We believe that the patient open-EHR solution, if adequately provided, could contribute to enhanced patient understanding and remembering of health condition and care plan. Patient understanding and remembering are key intermediate variables towards an effective patient-doctor communication, enhanced patient satisfaction and improved health outcomes (7,8). The OpenNotes initiative in the USA had shown positive results concerning the impact of sharing physicians' notes, which are part of the EHR, on patients' understanding and remembering and other

aspects (9-11). After reviewing their visit notes, 76% to 85% of patients reported better understanding and remembering (11).

In Japan, regional EHR networks started nearly 20 years ago in order to help and promote sharing of EHR data between hospitals or medical institutions in the same region (12). Some of them allow sharing of EHR data with patients online. However, the number of registered patients nationwide is still very low. Based on a survey done by the Japan Medical Association Research Institute (JMARI) on these regional networks in March 2016, approximately 250 regional EHR networks existed nationwide and the number of registered patients at 154 of these networks was less than 1.2 million (13,14). Out of these registered 1.2 million, approximately 700,000 patients only got access to their EHR data. To the best of the authors' knowledge, there is limited research regarding sharing of electronic medical and health records with patients in Japan (15-17). None was done on experiences of actual users of patient open-EHR systems.

The objective of the present study is to explore the needs and experiences of patients registered with one patient open-EHR system, and to investigate its benefits

by focusing on patients' understanding, remembering perspectives, and weak points in order to improve it in the future.

Materials and Methods

Overall design

A cross-sectional study was done using an online questionnaire by SurveyMonkey. The questionnaire was based on the survey done by the OpenNotes initiative original study conducted after having doctors' notes open to patients (11). This original study targeted patients after having one year intervention of doctors' notes open to patients (11). Doctors' notes, which are part of the EHR, contain a summary of the most important information discussed between the patient and doctor during the visit (9). After translation, the questionnaire items were examined and adapted through discussions with coresearchers including clinicians, public health researchers and researchers working with the Millennial Medical Record (MMR) system. Ease, usability, and comprehensibility were tested in ten users by the research team of the MMR system before launching the survey. Respondents could skip individual questions or exit at any point. Responses up to the point of exit were used in the data analysis. The questionnaire was designed to take less than 20 minutes. No incentives were given to the respondents. The institutional review board of Teikyo University approved the research protocol (Approval ID: TUIC-COI 18-0851).

The patient open-EHR system: Millennial Medical Record

We recruited patients who were registered with the MMR system. The MMR project started in 2015 as a national EHR, which was financially supported by the Japan Agency for Medical Research and Development (AMED) (12). As of January 2020, 112 medical institutions participated in the project (18). The MMR system allows the sharing of EHR data not only between participating institutions involved in patient care but also with the registered patients. The EHR data to be shared online is classified into 18 documents that include test results, prescriptions, medical history and other medical records. Currently, access rights for patients and participating facilities are set by the medical institution according to department, physician and the document (12). Regarding patient accessibility, the patient doesn't have a choice regarding what documents he or she can access online but he or she can select the medical institutions from the history of examining medical institutions to which he or she does not want the medical information to be shared (12). The official number of registered patients who access their EHR online is unknown, but the number of active users is assumed to be still very low. The operating

agency of the MMR project is the NPO Japan Medical Network Association (JMNA).

Participants

Participants were patients registered with the MMR system. They were recruited through an invitation message in the login page and an icon to jump to our survey link in the top page of the MMR system after login (only people registered with the MMR system could see and access) and also through sending an invitation email to all registered patients who had registered their email addresses in the MMR system. The email invitation was sent by the chairman of the NPO JMNA that is operating the MMR system. While the icon on the homepage was activated in the beginning of August 2019, the email was successfully sent to 353 valid registered email addresses. The first email was sent on August 10, 2019 and a reminder was sent on September 16, 2019. Answers collected up to October 2019 were used in the analysis.

Measurements

We investigated the reasons behind using the MMR system, using multiple-choice style questions, and participants' views on experiencing some benefits (better understanding, remembering, and others) and risks (confusing and others). Our key questions regarding experiencing potential benefits and risks asked about participants' views on the statements listed in Table 1. Participants could respond to each item on a five-point Likert scale, where the response choices ranged from "strongly disagree" to "strongly agree". Short expressions in Table 1 would be used when summarizing results in the later part below for space purpose. The following socio-demographic data were collected: age, gender, educational level, and overall health status. Other patients' characteristics were also evaluated using already validated scales' questions as follows: Patient preference for decision making (DM), measured using decision making preference scale (19); health literacy (HL), measured using communicative and critical HL score (20); patient trust in physicians, measured using trust in physician score (21); and patient ability to ask/understand/remember, using ask understand remember assessment (AURA) score (22). Participants needs/expectations from the MMR system were further investigated using free comments/requests' section and also by additional question asking views on some new features that were thought to be useful for better patient understanding and remembering (a patient-input feature that allows patient users to input their own comments to their EHR and another feature to allow other family members or friends to access their own EHR). Participants' care feeling about the MMR system was investigated by asking participants on their views

Table 1. Key statements used in the questionnaire

| | | Statement | Short expression |
|--------------------|----|---|------------------|
| Potential benefits | 1 | In general, making EHR accessible to patients on a secure Internet website or application is a good idea. | Good idea |
| | 2 | After starting using the MMR system, I better understand my health and medical conditions. | Understand |
| | 3 | After starting using the MMR system, I better remember the plan for my care. | Remember |
| | 4 | After starting using the MMR system, I take better care of myself. | Self-care |
| | 5 | After starting using the MMR system, I am more likely to take my medications as prescribed. | Take medication |
| | 6 | After starting using the MMR system, I feel more in control of my health care. | In control |
| | 7 | After starting using the MMR system, I am better prepared for visits. | Prepared |
| Potential risks | 8 | After starting using the MMR system, I worry* more. | Worry |
| | 9 | After starting using the MMR system, I am concerned about my privacy. | Privacy |
| | 10 | After starting using the MMR system, the EHR is more confusing** than helpful. | Confusing |

*Worry about health condition. **The contents make me feel confused about my understanding of health condition.

Table 2. Characteristics of respondents to the study questionnaire (n = 95)

| Characteristic | Value |
|-------------------------------------|------------|
| Age, n (%) | |
| 18-29 | 1 (1) |
| 30-39 | 9 (10) |
| 40-49 | 18 (19) |
| 50-59 | 28 (29) |
| 60-69 | 20 (21) |
| ≥ 70 | 19 (20) |
| Female, n (%) | 40 (42) |
| Education, n (%) | |
| Elementary or junior high school | 4 (4) |
| High school | 18 (19) |
| Some college or 2-year degree | 14 (15) |
| 4-year university graduate | 45 (47) |
| Graduate school | 14 (15) |
| Overall health, n (%) | |
| Good | 8 (9) |
| Fairly good | 25 (26) |
| Fair | 24 (25) |
| Fairly poor | 33 (35) |
| Poor | 5 (5) |
| Smartphone users, n (%) | 74 (78) |
| Decision making preference score | |
| Mean (SD) | 11.9 (3.9) |
| Median | 12.0 |
| Communicative and critical HL score | |
| Mean (SD) | 19.1 (3.4) |
| Median | 19 |
| Trust in physician score | |
| Mean (SD) | 16.6 (2.9) |
| Median | 17 |
| AURA score | |
| Mean (SD) | 13.5 (2.6) |
| Median | 14 |

AURA, ask understand remember assessment; HL, health literacy; SD, standard deviation.

if the MMR system was turned off and if its existence would influence their decisions in selecting a doctor in the future.

Statistical analysis

The software used for statistical analysis was SAS 9.4. The responses, regarding the views on experiencing the potential benefits and risks, were dichotomized into two

Table 3. Answers to the question "Why do you use the MMR system? (check all that apply)" (n = 95)

| Answer | n | (%) |
|---|----|------|
| I want to know about my health condition | 65 | (68) |
| I want to remember what happened in the visit | 52 | (55) |
| I have a right to see what's in my medical record | 45 | (47) |
| I want to be sure I understood what the doctor said | 42 | (44) |
| I want to check the records to see if they were right | 24 | (25) |
| I want to know what my doctor thinks of my condition | 17 | (18) |
| Other (please specify) | 14 | (15) |

categories: the "agree" category that combined the "agree" and "strongly agree" responses, and another category that combined other responses. We examined the relationship between patients' responses, on the potential benefits and risks of the system, and patients' characteristics, such as sex, age, education, health status, preference for decision making, health literacy and patient trust in physicians, with a chi-square test. A p-value < 0.05 was considered statistically significant for a two-sided test.

Results

Respondents' characteristics

As of October 20, 2019, 122 users participated in our survey from which 95 completed responses to our analysis questions. Table 2 shows respondents' characteristics. Overall, respondents were more likely to be male (58%) and 89% were 40 years old and older. Respondents were well educated; 77% with a 2-year college degree and more. Only 35% of the respondents reported that their overall health was good or fairly good.

Reasons behind using the MMR system

When asked about the reasons behind using the MMR system, three out of the top four answers were related to understanding and remembering (Table 3). Sixty-eight percent of the participants wanted to know about their health condition, 55% wanted to remember what happened in the visit and 44% wanted to be sure of their own understanding regarding what the doctor said.

Respondents' views on experiencing potential benefits/risks while using the MMR system

Table 4 shows participants' views on experiencing the potential benefits and risks. Respondents were positive about the patient open-EHR concept; 99% of participants agreed that sharing the EHR with patients through a secured site was a good idea. Only 48% agreed that the MMR system helped them remember their health plan and 68% agreed that the MMR system helped them understand their health condition. On the other hand, for concerns on potential risks of the system, the respondents

were not very concerned about risks; about 2% agreed with the concern regarding being confused, about 7% agreed with the concern about worry and 15% agreed with the concern regarding privacy.

Table 4. Proportion of respondents who agreed or somewhat agreed with statements about the potential benefits/risks (n = 95)

| Statement (short expression) | | n | (%) |
|------------------------------|-----------------|----|------|
| Potential benefits | Good Idea | 94 | (99) |
| | Understand | 65 | (68) |
| | Remember | 46 | (48) |
| | Self-care | 53 | (56) |
| | Take medication | 29 | (31) |
| | In control | 44 | (46) |
| | Prepared | 38 | (40) |
| Potential risks | Worry | 7 | (7) |
| | Privacy | 14 | (15) |
| | Confusing | 2 | (2) |

Relationship between participants' views on Understand/Remember and respondents' characteristics

Tables 5-6 show results on the relationship between the agree proportion on experiencing some of the potential benefits of the system. A statistically significant relationship between overall health and the agree proportion on Remember statement was demonstrated. A smaller proportion of participants with fair and poor health status (25% of those with fair health condition and 47% of those with poor or fairly poor health condition) agreed that the system could help them remember their health care plan.

Expectations from the future of the MMR system

Regarding the need for new features in the future, we found that the patient-input feature idea was welcome but giving access to others involved in their care was not. When asked about wishing to be able to add their comments to the EHR in the future, 54% agreed or somewhat agreed on the idea (Table 7). When asked about wishing to be able to let others have access to their

Table 5. Relationship between the agree proportion on Understand and respondents' characteristics (n = 95)

| Characteristic | Total n | Agree | | p-value |
|-------------------------------------|------------|-------|------|---------|
| | | n | (%) | |
| Sex | | | | 0.778 |
| Male | 55 | 37 | (67) | |
| Female | 40 | 28 | (70) | |
| Age | | | | 0.094 |
| 18-29 | 28 | 24 | (86) | |
| 30-39 | 28 | 18 | (64) | |
| 40-49 | 20 | 13 | (65) | |
| ≥ 50 | 19 | 10 | (53) | |
| Education | | | | 0.730 |
| Up to 2 years college degree | 36 | 26 | (72) | |
| 4-year university graduate | 45 | 29 | (64) | |
| Graduate school | 14 | 10 | (71) | |
| Overall health | | | | 0.079 |
| Good/Fairly good | 33 | 25 | (76) | |
| Fair | 24 | 12 | (50) | |
| Poor/Fairly poor | 38 | 28 | (74) | |
| Decision making preference score | | | | 0.431 |
| Low (< 10) | 32 | 23 | (72) | |
| Moderate (≥ 10 and ≤ 16) | 52 | 33 | (64) | |
| High (> 16) | 11 | 9 | (82) | |
| Communicative and critical HL score | | | | 0.405 |
| Low (< 15) | 10 | 8 | (80) | |
| High (≥ 15) | 85 | 57 | (67) | |
| Trust in physician score | | | | 0.467 |
| Low (< 15) | 21 | 13 | (62) | |
| High (≥ 15) | 74 | 52 | (70) | |

HL, health literacy.

Table 6. Relationship between the agree proportion on Remember and respondents' characteristics (n = 95)

| Characteristic | Total n | Agree | | p-value |
|-------------------------------------|------------|-------|------|---------|
| | | n | (%) | |
| Sex | | | | 0.325 |
| Male | 55 | 29 | (53) | |
| Female | 40 | 17 | (43) | |
| Age | | | | 0.714 |
| 18-29 | 28 | 15 | (54) | |
| 30-39 | 28 | 14 | (50) | |
| 40-49 | 20 | 10 | (50) | |
| ≥ 50 | 19 | 7 | (37) | |
| Education | | | | 0.429 |
| Up to 2years college degree | 36 | 16 | (44) | |
| 4-year university graduate | 45 | 21 | (47) | |
| Graduate school | 14 | 9 | (64) | |
| Overall health | | | | 0.008 |
| Good/Fairly good | 33 | 22 | (67) | |
| Fair | 24 | 6 | (25) | |
| Poor/Fairly poor | 38 | 18 | (47) | |
| Decision making preference score | | | | 0.906 |
| Low (<10) | 32 | 15 | (47) | |
| Moderate (≥ 10 and ≤ 16) | 52 | 25 | (48) | |
| High (>16) | 11 | 6 | (55) | |
| Communicative and critical HL score | | | | 0.218 |
| Low (<15) | 10 | 3 | (30) | |
| High (≥ 15) | 85 | 43 | (51) | |
| Trust in physician score | | | | 0.283 |
| Low (< 15) | 21 | 8 | (38) | |
| High (≥ 15) | 74 | 38 | (51) | |

HL, health literacy.

Table 7. Opinions on statements regarding the future of the MMR system

| Answer | Statement 1* | | Statement 2** | |
|-------------------|--------------|------|---------------|------|
| | n | (%) | n | (%) |
| Agree | 26 | (28) | 9 | (10) |
| Somewhat agree | 25 | (26) | 21 | (22) |
| No opinion | 23 | (24) | 26 | (27) |
| Somewhat disagree | 18 | (19) | 25 | (26) |
| Disagree | 3 | (3) | 14 | (15) |

*"In the future, I should be able to add my own comments to the EHR" (n = 95). **"In the future, I would like the option of letting family members or friends who help me with my health care have their own access to my EHR" (n = 95).

EHR in the future, only 32% agreed or somewhat agreed on the idea. Forty-one percent disagree or somewhat disagree (Table 7).

When asked about the feeling if the MMR system was turned off, 92% answered they would be very or somewhat disappointed (Table 8). When asked about the importance of the availability of the patient open-EHR in selecting a doctor in the future, about 97% answered that it is very or somewhat important.

Free comments regarding the MMR system

Seventy-eight percent (n = 74) of respondents provided a comment/request in the free comments section. Forty-seven percent (47%, n = 35) of these comments showed dissatisfaction from the limited contents disclosed; currently only blood test results and prescriptions are accessible online. All these respondents requested the disclosure of more records. Some given examples were X-ray images, computerized tomography (CT) scan results, magnetic resonance imaging (MRI) scan results, bone density test results, pulmonary function test results, cardiovascular testing results, consultation notes, summary reports, and radiologists' findings.

Discussion

We found that respondents' demand for the MMR system was driven by their need to further understand and remember information exchanged during consultation with the doctor (Table 3). However, the proportions of respondents, who agreed on the ability of the MMR system in improving understanding of their health condition and remembering their care plan were low (Table 4). These proportions were much lower than the results of the OpenNotes initiative, where 77% to 85% of patients agreed that open notes could help improve understanding of their health condition and 76% to 84% agreed open notes could help improve remembering their care plan (11). The main cause for these low proportions is, as understood from the free comments, due to the limited contents disclosed in the current system; mainly

Table 8. Answers to the question "How would you feel personally if the MMR system was turned off?" (n = 95)

| Answer | n | (%) |
|--|----|------|
| Very disappointed- I do not want my online access to my EHR turned off | 65 | (69) |
| Somewhat disappointed | 22 | (23) |
| Would not care | 8 | (8) |
| Somewhat pleased | 0 | (0) |
| Very pleased- I would like to stop being able to read my EHR online | 0 | (0) |

only blood test results and prescriptions are available online and doctors' summary notes are not available online. For hospitals and physicians, the EHR is a tool for sharing data with other healthcare providers. Therefore, when sharing these data with patients, we assume that doctors mainly intend to provide convenience to patients who need to show their health records to other medical providers who do not have direct access to the MMR system. This is because for patients, as demonstrated from our survey, they want to have access to their health records online to further understand their health condition and remember the visit. There seems to be a gap between users' needs from the MMR system and provider's objectives.

On the other hand, regarding respondents' experiencing potential risks while using the MMR system, we found that a minor proportion of respondents were worried or confused by the contents or concerned about their privacy after starting to use the MMR system (Table 4). This could be also due to the limited contents currently accessible online. There might be a tradeoff between the amount of information disclosed and the potential benefits and risks that patients perceive for the patient open-EHR system.

No significant relationship was detected between the studied patients' characteristics and the agree proportion on Understand statement (Table 5). This could be also due to the limited contents currently accessible online. Due to this limitation, understanding of the medical condition for different categories of patients was not impacted. On the other hand, a statistically significant relationship between overall health and agree proportion on Remember statement was seen (Table 6). A small proportion of participants with fair and poor health status agreed that the MMR system could help them remember their health care plan. This maybe because the currently accessible contents online might not be enough to help these patients remember their care plan. Patients with fair and poor health status might feel they need more information accessible online to remember their care plan. Additional attention and information should be given to patients from this category to help them better remember their care plan. On the other hand, participants with good/fairly good health responded in more agreement than those in the other categories. This could be because patients from this category might not

be receiving a large amount of medical information from their care provider regarding their health condition and plan, and that they need to remember, unlike patients with more severe health condition.

Through our investigation regarding users' needs and expectations from the MMR system, we understood from the free comments of respondents that patients are wishing for a wide range of EHR contents to be disclosed. Some examples of these contents were: X-ray images, CT scan results, MRI scan results, bone density test results, pulmonary function test results, cardiovascular testing results, consultation notes, summary reports, and radiologists' findings. Some respondents even wished for full disclosure of all EHR data. However, there could be several reasons for not disclosing a wide range of contents: burden on the server caused by image data that needs huge capacities; limited understanding caused by the lack of patients' medical knowledge; healthcare providers' anxiety about giving unnecessary confusion to patients; and healthcare providers' feelings of fear from the increased workload that would be caused by patients' further inquiries. We also found that 54% of the respondents wished they would be able to add their comments to their EHR (Table 7), which suggests that such tool could make patients more engaged in their care. It could also be used for "e-communication" between patient and doctor. This result was similar to the OpenNotes initiative study where 59% to 62% of respondents agreed on the idea of adding their own comments (11). On the other hand, regarding the idea of letting family members have access to their own EHR, in our study 32% agreed or somewhat agreed with the idea (Table 7), which was low as compared to the OpenNotes study where 49% to 56% of patients agreed or somewhat agreed (11). This result was not consistent with the result of a previous study comparing attitudes toward ethical decision making and autonomy issues among patients in Japan and the USA, where it was suggested that family opinions were accorded a larger role in clinical decision making by the Japanese patients than by those in the USA (23). However, in our survey the proportion of participants with "No opinion" was 27% (Table 7). We suspect that respondents who were not satisfied with the current system might be hesitant on giving their opinion regarding the future of the system. We believe that as the level of satisfaction with the system increases, the proportion of patients who agree on giving access to their family would increase as well.

Despite the respondents' dissatisfaction, which was basically due to the MMR system's limited contents, respondents were positive about the patient open-EHR concept (Table 4). Ninety-two percent of respondents claimed they would be very or somewhat disappointed if the system is turned off, meaning they want it to continue (Table 8). Moreover, 97% think that availability of patient open-EHR would matter when selecting doctors and health plans in the future. These results were similar

to the OpenNotes study where nearly 99% of patients wanted continued access to their visit notes and 86% to 89% agreed that open notes would matter when selecting doctors and health plans in the future (11).

Regarding future studies, doctors' attitudes toward patient open-EHR should also be addressed. Previous studies, such as in the OpenNotes original study, had suggested that physicians are more skeptical of the potential benefits of patient open-EHR and more sensitive to potential risks (10,11). This is mainly because for hospitals and physicians, the EHR is a tool for sharing data with other hospitals/physicians. For physicians to be supportive of programs to increase patients' access to their EHR, the potential benefits of these programs will need to be demonstrated more definitively. Before-and-after studies will better reveal how to enhance patients' experience using the patient open-EHR and how to mitigate any serious problem that may arise as the EHR becomes not only a sharing tool between medical professionals but also a tool for patients as well.

Our study has some limitations. The number of valid responses used in our analysis was relatively small and may not represent all users of the MMR system; users who had not registered their email addresses did not receive the notification email, and they might have not accessed the MMR system recently to notice the survey icon; and those who were invited to participate in the survey through email might have just ignored or forgotten the request in the email. However, we expect that active users were fairly approached through our recruiting methods. Also, our results may not be generalized for all patient open-EHR users since the MMR system used is just one example of such a system. However, it is considered to be the widest coverage for all national regions in Japan.

In conclusion, patients' needs regarding the patient open-EHR solution were indicated through our study targeting actual patient-users in Japan. This solution could bring benefits toward improving patient understanding and remembering of information received from the doctor and therefore improve doctor-patient communication efficiency and patient satisfaction. Providers of this kind of solution need to recognize their patients' needs and try to address them when deploying the system.

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