A Design Implication Proposal for Patient-Generated Data Integrated EMR Screen: The Case of Post-Surgery Rehabilitation

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ABSTRACT
The use of patient-generated data (PGD) is widely spreading in the medical field. Current attempts of PGD collection is bounded to sleep, food-journaling and exercising data. However, according to the departments and conditions of the patients, such data may vary of its importance, resulting different types of its prescription. This implicates that different types of Electronic Medical Records (EMR) screens are needed thus become customized according to what clinicians of each department require to the patients. Meantime, such data has the potential to be integrated to the conventional doctor-centered EMR screens. This study deducts EMR screen design implication, which applied patient generated data from breast cancer rehabilitation cases. The screen was designed twice in an agile method, and observed the use on actual outpatient sessions. We then interviewed both clinicians and patients of its usability. As a result, three design implications were deducted: raising saliency centering on adverse symptoms, mashing-up of related data, and collaborative reading while viewing with the patient should be possible. This paper suggests not only a novel type of patient-generated data usable in a particular clinical context, but also shows a strategic application while designing EMR screens.

INTRODUCTION
The use of lifestyle data has expanded to clinical purposes. Utilizing patient-generated data help enhancing the communication objectivity and its density as well. As for patients who visit general hospitals on a regular basis every two to three months, their memories may become distorted on the way of delivering to the clinician. Five to seven minutes of outpatient sessions are also not enough for both clinicians and patients to communicate under specific comments.

Recent studies show that the lifestyle data generated with devices are mainly being utilized to treat patients with chronic diseases in particular to elevate their quality of life. Such data include sleep, food-journaling and exercising and may also be applied to other types of medical care. However, the importance of data may vary according to the types of illness and conditions that the patients are facing to. For instance, patients with chronic illness may be asked to collect life style data in general. On the other hand, for the patients who just had surgery, other data which indicate better information regarding their conditions: to prevent side effects of the surgery, they are prescribed to focus more on certain exercises.

As patient-generated data start to take a crucial part during the medical session, there are also needs for Electronic Medical Record (EMR) screen to transform: in additions to the needs for EMR screens to integrate PGD to the conventional clinician-generated data, data highlights vary according to prescribed PGD, demanding that such screens should also be customized according to the sessions. In fact, if clinicians make a full use of the EMR as a method that they integrate into the existing system, it would
make it easier for them to not only to determine a patient’s activities outside the hospital, but also to merge the data with that of the clinic.

In this study, our research question is as follows: what are the elements of a patient-generated data integrated EMR screen for post-surgery rehabilitation? In particular, we focus our research on designing an EMR screen based on the data generated by breast cancer rehabilitation patients. We conducted a preliminary study to gain a better understanding of both the patients and clinicians; later we developed the screen, observed the medical check-ups, and interviewed both users for the usability feedback twice through an agile method. Based on this, we were able to derive an EMR screen design implications that embeds the data generated by rehabilitation patients.

**RESEARCH DESIGN**

This research was conducted largely through a preliminary and main study by foregrounding the example of breast cancer rehabilitation patients. For the preliminary study, semi-structured interviews were held for an hour and a half, respectively, with three clinicians consisting of rehabilitation specialist, dietitian, and physical therapist from Seoul National University Bundang Hospital. In the main study, two courses of iteration were conducted; we collected data by recruiting patients, designed the screen reflecting the data of patients based on the feedback of the aforementioned clinician, and conducted interviews with the clinicians and patients, after observing the outpatient sessions.

**Preliminary Test**

The purpose of this preliminary study was to examine the overall interaction process between patients and clinicians, along with the types of data required by clinicians and the visualization method.

**Breast Cancer Patients**

A breast cancer patient may undergo under lymph node dissection in the process of surgery based on the stage or condition of the disease and receive chemotherapy and radiation treatment by periodically visiting the hospital. In this process, in order to prevent the side effects of the surgery (e.g. lymphedema), the patient should arrange a rehabilitation outpatient visit on a regular basis. In a session of five to seven minutes, clinicians should ask patients about their experiences outside the hospital regarding strength training, lymphedema, aerobic exercise, weight control, and sleep.

Essentially, there are three main reasons for breast cancer patients to visit a rehabilitation clinic: first, to enhance their strength and recover their functions and second, to prevent lymphedema which may outbreak due to elimination of lymph node through regular check-ups; and lastly, through training, the clinician aims to define the threshold point of lymphedema. Therefore, a patient is asked to perform strength training at the right intensity and frequency since too high intensity could lead to lymphedema, whereas too low intensity could cause the same symptoms. Immediately after the surgery, the patient is required to undergo a 60-minute strength training session to practice six movements focusing on the arms and shoulders using a Thera-band™. The resistance level of the Thera-band™ is prescribed according to the condition of the patient.

In addition to this, the clinician asks whether lymphedema had occurred. If not managed properly, patients are at a high risk of developing chronic lymphedema. Usually, lymphedema can be prevented by performing strength training and maintaining a proper diet. However, excessive strength training and other intense movement may cause symptoms to develop. Hence, strength training can function as an index to understand at which point lymphedema may occur. Therefore, the clinician had to not only ask patients to keep track of their aerobic exercise and weight data, but also prescribe strength training to prevent lymphedema in breast cancer patients.

**Requested Data Form and Visualization**

The collected data that the clinician included five types of data that the clinician normally attempts to obtain in an outpatient session – strength training, aerobic exercise, sleep, weight, and lymphedema data. We realized that this can be largely categorized into prescription performance data and adverse symptoms based on the characteristics of the data. Strength training, aerobic exercise, sleep, and weight were included as prescription performance data. These data were related to activities the clinicians ordered patients to carry out. Adverse symptoms of lymphedema, was the only category of data that the clinician did not require the patient to take action regarding.

Both summary and detail pages were requested in order to show the multiple sets of data in different manners: For instance, all the data mashed-up in a single page was needed to interpret the patient’s data at a glance. In this case, every type of data was demonstrated with a representative value, such as; average
values for numeric data and for frequent symptoms for lymphedema. Raw data visualized by a line/bar graph were shown on the detail page.

**Main Study**

The purpose of conducting two courses of iterations was to verify the usability of the screen and derive other insights into actions between the clinician and patient. This study was approved by the Institutional Review Board of Seoul National University Bundang Hospital. We recruited a clinician from the Department of Rehabilitation Medicine of the same hospital and randomly selected 11 breast cancer rehabilitation patients.

There were two main forms of data collection. First, we used devices such as an electronic scale and fitness tracker, in order to collect aerobic exercise, sleep, and weight data. These data were recorded automatically in log data form. Withings and Misfits were provided to the patients. Secondly, we created two separate mobile applications to track each strength training and lymphedema data record; both types of data were recorded by one-self, either by clicking the tabs on the apps or by writing additional comments on the symptoms. The clinician instructed a patient to record the previously mentioned details on a daily basis. All of the data were sent to our server; mashed-up data summaries were sent the day after and on a daily basis once they were collected. After data collection, we designed a further screen based on the data.

When designing the screen, we referred to the requirements from the preliminary study. We derived additional requirements after observing the first screen and conducting clinician/patient interviews, and subsequently modified the screen based on the requirements. With the modified screens, we conducted another observation and interview. We worked on the screen twice per patient, amounting to a total of 22 screens. The form was made in PDF format, and we viewed the file on a 24-inch monitor that was used in outpatient sessions.

Between the two iterations, there was a period of two to three weeks -- taking approximately 30 days in total--, depending on the patient’s schedule. Observation was conducted from five to seven minutes, whenever an outpatient session was held. We tried to understand the details of interactions between the clinician and patients while the clinician was watching EMR screen. Interviews were held for an hour per iteration; we asked the clinician about inconveniences or additional requirements when watching the screen. Regarding patient, we asked for their opinions and experiences after recording and viewing their data inserted on the screen as they showed up at the outpatient session. All observations and interviews were transcribed.

For the analysis, the following steps were adhered to. First, we measured the length of each session and time spent on each screen page respectively. For the transcription we thoroughly analyzed the types of feedback the clinician gave while interacting with the patients. Last, we compared between the first and the second data sets.

**RESULTS**

**First Iteration Screen Rationale**

*Main Concept: Chronological Raw Data*

The basic idea of the first screen was to provide chronological raw data for the clinicians, to enable them to make own decision by interpreting the correlation among the data. The first iteration screen was consisted of total five pages, one summary page and four detail pages. All data were recorded on a daily basis, arranged as line graphs to determine the changes that occurred every day, except for the strength training data, for which the amount of exercise was converted into accumulated bar graphs. The maximum and minimum rates are also given to offer an easy understanding of the individual patient’s data range in graphs. Chronological raw data were applied as follows.

*Linearity: Process Implementation* The order of the data was arranged according to that of outpatient sessions, and equal data values and their depths were given equally so that the clinician could treat the patient data with equal proportion. According to the interview with the clinician, the usual outpatient session process started by checking strength training, followed by a check-up to determine if any signs of lymphedema had occurred as a result. The clinician also checked aerobic exercises followed by body weight and sleeping data. Based on this process, the data on the screen was placed in the order of strength training, lymphedema, aerobic exercise, sleeping data, and weight data. This order was also reflected in the tab orders on the summary page, which linked to the detail page as well as summary page.

*Equivalence: Data Importance* The importance and emphasis of data were placed in equal proportion. Clinicians have a tendency to use every possibly collectable data to diagnose the patients. Data were considered to have equal values, which are reflected in the screen distribution and data depth. The
summary page showing all data was partitioned into equal proportions. On the detail page, except for lymphedema data, the doctor's prescription and measurement task data were all connected to each ‘detail’ page via the tab on the summary. For the depth of the data as also briefly mentioned earlier, except for the lymphedema data, the doctor's prescription and measurement task data were given at the same level of depth represented as mean values or symptoms.

**Mash-ups: Correlated Data Layers** The data layer has been mashed up in the form of a detail page, where specific data is shown chronologically. On the chronologically visualized data page, correlated data were also mashed up and laid out. Despite wanting to diagnose patients with all available data, due to the limited outpatient session time, only strength training and lymphedema data were mashed up. According to the interviews, adverse symptoms meant lymphedema, and lymphedema and strength training were directly related to each other. Through this, a correlation of data that can reveal the patient's symptom patterns can be found more quickly. In this research, the chronologically arranged strength training page contains lymphedema data, which represents adverse symptom data, along with additional comments by the patients. Lymphedema data were collected based on an ordinary lymphedema outbreak and self-logged data in the strength training application. In the application, colored dots were presented to distinguish between two types of lymphedema (orange for ordinary lymphedema and blue for lymphedema caused by strength training).

**First Iteration Result**

The average overall session length was 451 seconds, with 301 seconds spent on looking at the EMR, which took 66.8% of the entire session. This implies that EMR is a crucial information provider for making decisions regarding the related patient. Notable observations from the first iterations are as follows:

**Most Time Spared: Strength Training and Lymphedema**

The observation results show that most of the time which clinician spent on the screen was allotted to strength training data and lymphedema data. The overall percentages of the observed rate are as follows: 45.5% for strength training data and lymphedema data together, 34.8% for the summary, 8.4% for body weight, 8.0% for aerobic exercise, and 0.8% for sleep. According to the interview with the clinician, their priorities were the strength training data and the issue of lymphedema.

Even on the summary page, it was verified that the clinician focused on these two data types mostly. The summary page was the second-most observed page following the strength training data and lymphedema page. However, out of all the figures displayed on the screen, the strength training and lymphedema data were particularly used to diagnose the conditions of patients. Except for P08 and P10, the two data types above were the main topics most frequently discussed by the clinician and patient.

On the other hand, the screen least used by the clinician was the sleep data screen. The clinician observed sleep data only for about three seconds on average, which occupied only 0.8% of the whole observation time. Mostly, the clinician provided irrelevant feedback such as “You sleep less than I do” (P01, P03, P05, P06, P08, P09, P10 and P11), feedback only through the summary page (P06), or no feedback at all (P02, P04, and P07). In fact, the clinician mentioned in the interview that “It’s better to have a specialized reference from a sleep medicine clinician rather than hearing from me. It should be more useful.”

However, for the aerobic exercise and weight, the clinician took 24 seconds and 25 seconds, or taking 8% and 8.4%, respectively, of the entire EMR view length. One conspicuous behavior of the clinician regarding these data was that she did not ask additional questions; instead, she gave feedback immediately after looking at the graphs as she pointed out with her hand how the trend line should appear. This implies that both data types had enough information about the patient. “7000 steps five times a week would be good. I see you walk 7000 steps once a week for now (drawing the trend line with her hand). This is your goal for next time. I also see a change in your weight, but there isn’t much you can do about it. You do not need to work on losing it” (outpatient session with P11).

**Focusing on Lymphedema**

According to the derived result, the most observed data on the summary page was for lymphedema. Apart from P08 and P10, the clinician dealt with lymphedema either by simply making comments (P03, P05, P06, and P09) or asking questions (P01, P02, P04, P07, and P11), such as “Did you feel heaviness in your body when exercising?” (outpatient session with P01); “You have experienced swelling after training, haven’t you? If the swelling is not too serious, you don’t have to worry about it. Just imagine that you don’t have it” (outpatient session with P02).
The diagnosis and prescription of strength training were also closely associated with the issue of lymphedema. According to the monitoring, for all patients, the clinician diagnosed and prescribed in relation to lymphedema: “Doing strength training this little can’t be any good. Too much training, however, may cause lymphedema, so you have to find a middle ground. Here’s the deal. Next time, increase the amount of exercise and reach the level just before lymphedema occurs. When you feel swelling as you increase the amount of strength training, that’s the point where you should stop” (outpatient session with P02).

On the other hand, every lymphedema record should require the process of verification. It is uncertain whether every lymphedema record is exactly the right one, so it must be verified. “It is necessary to distinguish lymphedema from muscle swelling. Patients may confuse muscular atrophy, muscle stiffness, or sore muscles after workout with lymphedema, which requires careful confirmation in turn.”

**Screen Flipping**

Moreover, the clinician showed the pattern of viewing the page for strength training and lymphedema, going back and forth between the lymphedema and strength training pages. This case was particularly observed more when a patient claimed lymphedema had occurred; this case, also, happened mostly between the summary and strength training and lymphedema data pages. The page alteration occurred at least twice (P04, P07, P11), to three times (P02), and four times (P03) at most.

<table>
<thead>
<tr>
<th>Page Flipping (times)</th>
<th>Turning between Summary and Strength+Lymphedema (times)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1st Iteration</strong></td>
<td>5.0</td>
</tr>
<tr>
<td><strong>2nd Iteration</strong></td>
<td>3.5</td>
</tr>
</tbody>
</table>

**Table 1 Average Number of Pages Flipped and Turned**

The main cause for flipping was the insufficiency of data on the summary page. The clinician claimed that “When the lymphedema event occurs and accompanies arm heaviness, it becomes necessary for the screen to display data regarding the color of the Thera-Band™ along with the number and the type of warm-ups on a single page.”

**Second Iteration Screen Rationale**

**Main Idea: Emphasizing event-driven data**

In the course of the research, we focused on laying out the data based on events, although it was also crucial to display raw data in the second rationale based on the first outpatient results and interview. In the second iteration, the screen consisted of three screens in total: one summary page and two detail pages. The arrangement method preferentially shows when an event happened – in this case adverse symptoms – and displays when and in which context the event occurred. That is to say, chronological and raw data are utilized as context data to analyze event data. In particular, these event-driven data do not arrange data respectively, but are reflected in the following three details along with other data.
**Salient Data Value** Based on a finding that reminded us of the necessity to examine the correlation between the occurrence of lymphedema and other data, we reflected on the finding of space division and data depth: on the second screen we emphasized saliency for the data that have a direct relation with the event data and the event itself. Meanwhile, we reduced other data that have comparatively less correlation with the event.

We made a single summary page to convey all data and especially tried to arrange all layouts, putting the event at the center. In the second iteration in particular, we helped the clinician to grasp the correlation between the data and existence of adverse symptoms. In effect, the clinician recognized the adverse effect of lymphedema, and subsequently determined the amount of strength training that could also have a negative effect on the patient’s health. For the data sequence, we put the event (symptoms of lymphedema) at the top left of the screen where the clinician’s attention was foremost drawn, and then displayed strength training that had a correlation with the event.

We allowed the details regarding lymphedema as well as other strength training that had a direct correlation with the symptoms to occupy one third of each page. Aerobic exercise, sleep, and weight, furthermore, took up another one third of each page. We also put saliency in data depth. The first lymphedema data set displayed the overall occurrence frequency before the outpatient visit and representative symptoms that appeared most frequently; in the second lymphedema data set, however, it provided information vital to the judgment on the first screen and, summary page, as well as not only the number of lymphedema occurrences, but also the occurrence date, symptoms, and causes (exercise or in daily life) regarding all lymphedema cases in a list form. Furthermore, in the case of strength training data, we only provided the average amount per day in the first session but additionally provided the band color and average number of movements. For the other three data sets, we solely provided the average values.

**Enhancing Data Layer Mashed-Up Data Reliability** We also emphasized the pith of event-driven as its visual brevity that allows clinician to determine the correlation of other data in terms of the event. In detail, amidst all the data that we had collected, we attempted grouping according to two main correlations. We mashed up the aerobic exercise and weight data in a single page, applying a previously attempted mash up of lymphedema and strength training data in the first session. This is because the amount of aerobic exercise on the day before affects weight. However, since the two data types are visualized through a line graph in the first session, we marked aerobic exercise data with an area graph in the second session in order to differentiate between them.

By mashing up lymphedema data with the strength training page as well as the aerobic exercise and weight mash-up page, we also enabled the clinician to see the correlation between lymphedema occurrence and the physical condition of the patient. On the page where the aerobic exercise data is mashed up with weight, therefore, we mashed up the visualized lymphedema data identical to those in the first session.

**Data Contrast** In the research, we provided chronological raw data in a graphical form. Based on this, the clinician can compare the data between the term before the latest outpatient and other previous terms, and utilize the comparison in analyzing the condition of the patient. Making a comparison between the status before and after in terms of an event supports the diagnosis for a patient. The method that refers to data based on before and after an event or the color of the band used during the same period can be a good example of such a comparison.

It is possible to control the intensity of strength training with the number of repetitions as well as the color of the Thera-band™. The clinician can prescribe a new band color according to the condition of the patient or the patient can voluntarily perform exercise with a new band to increase intensity. Since judging performance based on the rapid decrease in the amount of exercise when using a new band can cause confusion, we marked the color of the Thera-band™ under the strength training graph.

**Second Iteration Result**

The average overall session took 422 seconds, which is 29 seconds less than the previous iteration. Time spent simultaneously looking at the EMR screen decreased to 288 seconds. However, it took 68.1% of the entire session, showing a slight increase. Although a small number, this suggests that the screen usability had been stretched to a certain extent.

**Increase in the Proportion of the Summary**
In the summary part, the proportion of lymphedema mashed up with strength was maintained. The proportion was manifested in the following order: summary (43.8%) > lymphedema mashed up with strength training (33.9%) > lymphedema mashed up with aerobic exercise and weight (14.4%) > EMR (7.9%). This is different from the first result. The sequence between lymphedema mashed up with strength and summary had changed. Nevertheless, we mainly focused on the lymphedema data mashed up with the strength data. Regarding this matter, the clinician replied that they preferred the second screen summary page, which has more of an array of information than the first screen. “The summary was convenient in that we were able to see events in a single view. When the summary synthetically provides lymphedema symptoms and types/frequency of exercise per event, it is easier to view” (from the second interview of the clinician).

The outcome of the remaining time for lymphedema mashed up with the aerobic exercise and weight page was 14.4%. This percentage accords with 41 seconds on average. In the case of aerobic exercise, the data visualized in an area graph received a particularly positive assessment. “We were able to distinguish aerobic exercise from the weight data, and the display was quite intuitive in terms of area, since the data automatically flowed in when the patient was wearing Misfit” (from the second interview of the clinician).

Increase in Flipping

The total number of page flips decreased from five times in the first iteration to 3.5 times in the second. This does not mean that the actual number of page flips was decreased; we must remember that in the first iteration, the screen consisted of five pages in total, whereas in the second, there were only three pages. This means that the number of page flips has relatively increased.

One interesting observation mentioned beforehand in the first observation was that the flipping action was intensive for going back and forth between the summary and strength and lymphedema pages in particular, flipping twice on average. The clinician’s flipping behavior did not change this time and the same number was maintained.

However, utilizing the second screen, the clinician seemed to understand the patient much more easily by merely looking at the data. Specifically, while the clinician previously made inquiries of the patient in order to understand the context of the observation results, she showed a stronger tendency of diagnosing and prescribing by looking at the data. “This screen was better than the first screen in overall. Each summary and detailed page showed the right correlation between other mashed-up data.” The clinician stayed on the second outpatient screen for a longer time than the first one, which can be interpreted as indicating an increase in patient-clinician conversation based on the accumulated information.

Good Use of Comparison with Data Contrast

A distinctive feature of our program is that it provides graphical comparison between present and previous outpatient records in a single page, which received a favorable evaluation from not only the clinician, but also from the patients. “By enabling comparison between the current average value and previous ones, we were able to give feedback, such as ‘You worked out better than before’ or ‘the amount of exercise decreased than compared with your previous visit’ to patients” (from the second interview of the clinician).

During the research, in the middle of the first and the second outpatient session overlapped the Korean national holiday, Gujeong. Conspicuously, both the clinician and patients could see the less amount of strength training performed between the sessions as the patients were generally too busy to during this period. “Viewing the screen, it helped me realize that the average amount of strength training has increased, but I also found out that I didn’t work out at all during the holiday; I felt more obliged to work out more for the next time” (P11).

In the case of switching to a new Thera-band™, contrasting the colors also provided a conspicuous interpretation regarding the change. Some patients managed to ascend the vertical level (exercise degree)
in the graph by changing the color of the Thera-band™. The page displayed the graphical juxtaposition of two different Thera-band™ colors (horizontal) and the increase of exercise degree (vertical) helped the clinician to intuitively determine the overall change in the exercising frequency/intensity of the patient. “Nice. It was easy for us to grasp the exercise amount of each patient, since we were able to observe its increasing phase at a glance in tandem with the changing color of the band” (from the second interview of the clinician).

**DESIGN IMPLICATIONS**

**Event-driven Saliency**

It is important to increase saliency by foregrounding data not only on adverse symptoms but also on direct factors that have the potential to cause adverse symptom. In particular, on the dashboard type screen that shows multiple data on a page, it is necessary to expand the screen portion of the main data as well as to display the data depth at a deeper level. When the case does not have a direct relation with the data, it can be de-emphasized by decreasing the portion.

For a breast cancer patient, lymphedema is an adverse symptom, and it is crucial to collect data on various cases in order to control the fundamental lymphedema occurrence event beforehand. In the research, we increased the portion of the strength training related screen that had a direct correlation with lymphedema. Moreover, we emphasized not only the average value, but also the occurrence date, factor, symptoms, and other contexts for occurrence or the greater importance of the lymphedema occurrence by showing the average value of the intensity of the instrument and individual detailed motion.

**Data Layer Mash-up**

The aim of data layer mash-up is to grasp the correlation by foregrounding adverse symptoms. It might be meaningless to study multiple data individually. If a particular adverse symptom occurs, it should be possible to check its direct factors within a single page. On the detail page, however, along with the chronological visualization of various data, we arranged the lymphedema data layer and text bubbles. Likewise, strength, lymphedema, and the text bubbles were arranged in the same manner. Another mash-up of aerobic exercise, weight, and lymphedema data in the second session can also be understood in the same context.

In the case of the rehabilitation of a breast cancer patient, when the lymphedema event occurs, it is possible to derive a meaningful interpretation when the chronological data of strength training, amount of activity, and weight are mashed-up with the lymphedema data rather than the graph, which only displays chronological data.

**REFERENCES**


conference on Pervasive and ubiquitous computing. ACM, 587-596. DOI: http://dx.doi.org/10.1145/2493432.2493495
28. Seung Ah Lee, Ji-Young Kang, Yong Duck Kim, Ah Ra An, Sung-Won Kim, Yeon-Soo Kim, and Jae-Young Lim. 2010. Effects of a scapula-oriented shoulder exercise programme on upper limb dysfunction in breast cancer survivors: a randomized controlled pilot trial. Clinical rehabilitation, 24(7), 600-613. DOI: http://dx.doi.org/10.1177/0269215510362324


