PATIENT DATA VISUALIZATION

FINAL REPORT

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ABSTRACT

With wearable sensors such as Fitbits and smartphones becoming more pervasive, medical communities have taken an interest in leveraging the data collected to provide more comprehensive health care. With increased access to the details of patients' lifestyles outside of exam rooms, providers[1] are afforded the unique opportunity to preempt, monitor, and appease patients' concerns about their well being. This additional insight can prove especially useful in post-operative care, when patients often find themselves overwhelmed by their transition out of 24/7 care and are most susceptible to complications.

Our client, the UPMC Biobehavioral Oncology Program (BOP), has been collecting patient generated health data (PGHD) for a recent study on readmission rates for pancreatic surgery, utilizing the AWARE framework[2] to consolidate behavioral data collected via Fitbit and smartphone. These data are currently being used in research efforts for predictive modeling of readmission and also have the potential for being beneficial tools for providers who otherwise have limited objective data to supplement patients' self-reportings. Our client's goal was to make these data available to and easily digestible by providers, ultimately enhancing patient care and potentially reducing readmission rates as a consequence.

Through domain research, literature reviews, and interviews, we were able to gain insight into the potential benefits and limitations of our solution, which ended up being a dashboard displaying PGHD. After understanding the intricacies of provider needs, we were able to identify nurses and physician's assistants as our target audience. After we narrowed

1 For this purpose of this report, providers are defined as all medical professionals who at some point interface with the patient such as surgeons, physicians' assistants, nurses, and principal investigators.

2 "AWARE is an Android framework dedicated to instrument, infer, log and share mobile context information, for application developers, researchers and smartphone users. AWARE captures hardware-, software-, and human-based data" (http://www.awareframework.com/what-is-aware/)

down our target audience, we had a better idea of what the content of our dashboard should focus on. We also gained a deeper understanding of data visualization standards in medical fields and how we might apply these features in a way that serve our target users' needs. We developed and iterated prototypes of increasing fidelity based on literature reviews, feedback from user testing on providers of different kinds, and through distributing a survey soliciting preferences about specific visualizations. Our final deliverable is a coded prototype that displays patient generated health data in a way that reflects our research findings.

In this report, we synthesize the insights we gained through the course of the project that informed our design and implementation rationale. Additionally, we provide our client recommendations for future testing and development.

INTRODUCTION

PGHD, or Patient Generated Health Data, is data collected from one of three ways:

1. Consumer wearable devices like Fitbits
2. Sensor data from smartphone apps like AWARE Framework
3. Patient-reported data in the form of daily symptom ratings

Previous studies have shown that PGHD is related to clinical cancer outcomes and is indicative of readmission factors. By collecting PGHD, patients are empowered to play an active role in their treatment by facilitating collaboration and communication between patients and medical providers.

Our project and final solution will address the following problems:

- Bridging gaps between patients and medical providers by allowing providers to view data about patient symptoms, patterns in activity level and sleep, and other important quality of life information to guide decisions about care.

- In a busy outpatient clinic environment where providers have less than fifteen minutes with each patient, providers have limited time and cognitive capacity to process additional information unless it clearly provides values and actionable insights. We aim to design a user-centric data visualization tool that the medical team could utilize to quickly grasp a patient's state over time, essentially providing a glimpse into the patient's life post-surgery once they've been discharged from the hospital. Developing a customizable patient-centered data visualization tool would allow providers to review quality of life data prior to meeting with a patient so that they can focus their limited time together on the patient's most critical symptoms and concerns, track side effects of and responses to different treatments, and provide better comprehensive cancer care.

METHODS

Our process of developing a solution can be broken down into four distinct phases: research, low-fidelity prototyping, medium-fidelity prototyping, and high-fidelity prototyping. At every stage of prototyping, we made sure to incorporate feedback and make iterations on our designs based on such feedback.

RESEARCH

This phase consisted primarily of domain research and literature review. Our literary reviews of PGHD focused primarily on other research about how it can be predictive of medical conditions and symptoms. This particular research provided our team with insight into how PGHD is currently being used and studied in the medical field. The PGHD literary reviews also helped our team gain a better understanding of the patient side of personal informatics. Because IRB and rules about patient confidentiality effectively made it so that we could not interact directly with patients, we used these articles to gain valuable insights about how patients use and feel about PGHD. We learned that patients are primarily concerned about under or over-reporting metrics and data that do not matter and also feel uncertain about their data and symptoms are “normal” or not. The literature also indicated that patients typically receive little education to help facilitate their transition out of the hospital. While we ultimately decided that our project would not be something that is patient-facing, it was valuable to understand patient sentiments about the While our project does not directly focus on patients, having the background knowledge of how patients feel about the process is valuable to keep in mind as we move forward in the design process. A spreadsheet consolidating our research can be found in the appendix.

In addition to conducting literature reviews to understand the various aspects of our problem space, our team gathered insights from various providers about what is most valuable to them in terms of patient care and patient data. When we initially started out, there were several considerations we had to make. First, we were needed to decide whether our solution would be more targeted for provider use or for patients. We quickly decided against having our solution be something that was patient facing, since we didn't want to alarm patients further during a period of their lives that may already be high-stress. And especially given that we wanted our solution to be something that gave better insight into a patient's life at home post-surgery, it also made more sense for the solution to be targeted for provider use, since patients would presumably already know what their status at home has been.

As we were establishing that our solution should be provider-facing, we began to conduct interviews with providers, which our client and her team arranged for us. The interviews were with a variety of providers, from surgical oncologists to in-patient nurses and physician's assistants. These interviews were effective tools for our team to gather insights about what is important to providers and also to understand the specifics of their interactions with patients.

LOW FIDELITY PHASE

During this phase we further researched visual principles and design best practices of dashboards, specifically in medical contexts. We then created storyboards (which can be found in the appendix) for potential users and use cases of our dashboard and moved into testing physical prototypes.

As we moved into creating and testing our prototype, we identified layout and content as the two foundational components of our dashboard. The focus of our process outlined below was to construct our prototype in a way that tests these variables independently while preserving their inherent relationship.

Content

To test the most effective ways of depicting patients through our dashboard, we created various data visualizations of the patient profiles described prior. In doing so, we sought to frame real patients' medical journeys in terms of the categories we identified and validate with providers the extent to which they could then interpret an accurate and holistic picture of the patient. This strategy also allowed us to test multiple visualizations of the same kind of data and understand which best conveyed the information in a way most valuable to providers.

Layout

In order to be able to test for optimal layouts, we made our visualizations moveable, allowing providers the flexibility to position them in a way that best suits their needs. This method of testing affords providers the ability to rearrange metrics in alignment with the sequence of their interpretation. Additionally, providers can now physically prioritize the kinds of data they want to see, both above the fold and secondarily.

Testing

The driving force of our testing plan was ultimately to determine which kinds of visuals most accurately and insightfully depict the patient, while learning about how different layouts can aid in their interpretation. Some of the tactics we employed included soliciting initial impressions, and then progressively disclosing details of the patients' recovery, assessing how they change the providers' approach to the both patients and their data. Finally, we probed further by asking specific questions about their perspective, conclusions, and potential next steps. Our prototype and a more detailed testing script can be found in the appendix.

MEDIUM FIDELITY PHASE

Based on conclusions from the prior phase, we developed medium fidelity prototypes with a focus on depicting real patient data in a way that most efficiently and effectively meets our target user's needs. In order to garner insights from a larger number providers, our team developed a survey to gather feedback about these prototypes. With our survey, we hoped to reach a wider audience, including both our main targeted users as well as other related providers. Our survey was distributed to 19 medical professionals, ranging from nurses to surgeons. Given the providers' time constraints, we designed our survey to take approximately 15 minutes to complete. We wanted to simplify our survey and make the answer options as straightforward as possible, so many of our questions asked providers to do simple things such as indicate which graph was most easily interpretable. However, we also sought additional insights about individuals' rationale for preferring certain graphs, so we included the option of open-ended responses while making sure they weren't required to answer. In our survey, we also tried to reduce the amount of time that providers would have to spend on our survey by repeatedly providing the user profile on every section of the survey and using the same profile throughout the entire survey.

In our survey, we compared variations of the four main metrics providers are interested in - sleep, pain, activity, and appetite. Graphs included in the survey spanned the same period of time to ensure quick and easy interpretation. Our goal in comparing different variations of the same data was to see which graphs were more intuitive to the providers. We also included combinations of various data visualizations (such as pain and sleep, and pain and activity), to gauge which metrics in conjunction with other metrics were most useful to providers and how they rated the patients well being based on multiple (sometimes intentionally correlating) metrics

At the end of the survey, we had providers rate a patient's state, based on the visualizations they had seen. Since the visualizations included in the survey reflected the lifestyle of a specific patient, we wanted to understand whether providers accurately assessed a given patient's state given the visualizations that were provided to them.

Before distributing our survey, we were able to receive feedback about it from CMU students, a nurse practitioner, and from Dr. Low. In these users tests with students and with a nurse practitioner, we mainly tested for content, layouts, and ease of use of the survey. Our goal was to ensure that the graphs were easy to read, the survey was the right length, and that it was easily comprehensible. Snapshots of the survey can be found in the appendix.

HIGH FIDELITY PHASE

For our final phase of prototyping, we developed an interactive, coded prototype that reads and renders patient data. We then translated our patient profiles into JSON files as input for our dashboard. By being able to display multiple kinds of patients' data with the same dashboard, we were able to more accurately assess if our visualizations were informative and useful for varying types of recovery. We then tested this prototype with multiple nurses and physician's assistants and further honed our prototype to produce our final deliverable. A detailed testing plan for this phase can be found in the appendix.

The patient profiles used in each phase of testing can be found in the appendix.

DES. AND DEV. RATIONALE

Inference 1

Our target audience consists of nurses and physician's assistants.

When we began to consider which kind of providers would most benefit from having greater insights into patient generated health data, it began clear that nurses and physician's assistants would benefit the most. Once a patient is discharged from the hospital after surgery, nurses and physician's assistants are the first individuals that a patient may interact with if they were to call the hospital with concerns. When these providers then interact with patients, having a "summary" of what the patient's life post-surgery has been like at home would allow them to focus their attention on certain areas while interacting with patients.

Inference 2

The main metrics we will be representing are activity, sleep, pain, and intake.

Initially, when we began our interviews with providers, we interviewed a wide of providers, ranging from surgical oncologists to physician's assistants. At these interviews, we asked providers about what they would use to measure patient success metrics. Although there were differences between providers, a common pattern emerged. No matter what other metrics providers may be interested in, all providers were interested in activity levels, pain levels, the amount of sleep that a patient was getting, and a patient's appetite. Once we narrowed down our providers to nurses and physician's assistants, we got additional confirmation that our choice for metrics was correct, given that patient generated health data is available at a low-level of granularity. Nurses and physician's assistants are the providers that are most likely to be interested in data at such a granularity.

Inference 3

Patients are evaluated against themselves.

As we began to create our dashboard, we speculated that having some form of comparison would be helpful. However, we quickly found out in talking with providers that the comparison wouldn't be to other patients. Providers wanted to instead compare patients to their baseline pre-surgery, since recovery and even a patient's state before and after surgery are so individualized and cannot be generalized. Having patient generated health data be available across a period of time affords providers the ability to see how a patient has been doing.

Inference 4

Data should be represented as time series visualizations.

Once we had the four main categories of data that we wanted to present we began to research and test multiple ways of visualizing our data. We initially user tested many different types of visualizations including pie charts, donut charts, bar charts, graphs of the human body to show pain location and stacked area charts. After user testing multiple forms of graphs and gaining a better understanding of the use cases of the dashboard we settled upon time series visualizations and specifically line graphs. Time series visualizations were the best way to concisely present the patient data we had and help providers gain a holistic view of how the patient has been doing since the surgery. Given the estimated 30-60 seconds providers will have to scan our dashboard, simple line graphs were the best of the various time series visualizations. Line graphs are simple and allow easy scanning, especially across uniform x axises in the four graphs. Having all of the metrics visualized the same way, also allows for an easier learning curve for providers and simpler scanning. We also incorporated the ability for users to adjust the time-frame that the visualizations are presenting. This is because users want to be able to see different dates, over different periods of time for certain use cases.

Inference 5

Our dashboard should take into account standards and best-practices of such interfaces in medical contexts.

In our final dashboard we incorporated design principles frequently found in other medical and electronic medical records. We created an information heavy, single page dashboard because our target providers are used to viewing information heavy documents. The current EMR that UPMC uses (called EPIC) is very information dense with multiple pages of features. While the providers are used to information heavy text, they did not like how many interactions were required with EPIC, and because of this feedback we kept our dashboard to be one page. Nurses are also used to very information dense rounds sheets that sometimes include visualizations as well. We also utilized top down information hierarchy because many medical sheets use this principle and it is a commonly used principle in dashboard design. For each metric we created a summary statistic in the form of a colored dot on the title to provide a high level summary of the metric, and for more in depth information the provider can use the graph below. We incorporated interactive visualizations to assist in our top down approach: using the interactive touch point users are able to see the metrics for a certain day. We also included an information hierarchy in the notes sidebar of the dashboard.
Our final dashboard is in a grid layout because this is a common practice of dashboards and also allows for the most efficient comparison across our four metrics. Our early iterations included multiple columns of visualizations, but we finally settled upon a 2X2 grid layout because it allowed for all metrics to be compared against each other at once. This ability to easily scan and compare metrics was very important to our providers during user tests and the 2x2 grid was the best outcome.

Inference 6

Basic patient data should be readily available.

Through our research, we discovered that providers found it helpful to know information about patient's previous visits, medications, marital status, date since surgery etc. These information help the providers gain a better sense of who their patients are and what their social activity may be like and they want to be able to see this information easily. To account for this need, we included a patient profile section on the left side of the dashboard so that the necessary information will be readily available.

TECHNICAL IMPLEMENTATION

GitHub Repository: https://github.com/drmohan/PGHD
Hosted at: https://drmohan.github.io/

Other ample patient profiles can be found at:
https://drmohan.github.io/index2.html
https://drmohan.github.io/index3.html

Our final prototype is a front-end implementation of our proposed dashboard. It is built with HTML, CSS, JavaScript, and utilizes Highcharts for the data visualizations. Highcharts reads and displays the patient data as defined in the JSON files in the patient_data folder. The sidebar consisting of static patient data can be defined in the HTML partials under the partials folder. The patient + being displayed in the dashboard can be changed by altering one variable in the main.js file (details can be found in the repository's README). The appropriate JSON file and sidebar partial will be automatically rendered in response to this change.

An example JSON structure is provided and explained below as well as in the repository's README:

```
{
    "title": "Sleep",           // metric to be displayed
    "status": "green",          // status indicator (must be "red", "yellow", or "green")
    "name": " ",                // only applies to metrics displaying multiple series (i.e. Activity)
    "data": [8,8,7,8,6,6,       // array with y-values
             9,8,9,8,9,9,
             10,11,8,9,9,9,
             10,10,9,9,8,9,
             9,10,9,9,8,9,
             6,9,9],
    "unit": "hours",            // unit of measurement
    "type": "line",             // type of graph
    "valueDecimals": 1          // decimal point accuracy
}
```

The four graphs displayed are synchronized. All of the cursors move together and the numbers at the top right of every graph reflect the value at the point of time in focus. Similarly, customizing the time frame using the controls at the top right of the dashboard zooms all the graphs at once. The 'From' and 'To' inputs allow more granular customization of time frames and is built using jQuery's datepicker.

The next evolution of this prototype is likely to be a standalone web application (built on Node.js, Ruby on Rails, Django, etc.) that reads patient data stored in a SQL database.

Interactions and Features

1. ***The data for a selected day is displayed at the top right corner of a graph***

When a provider hovers over a specific date, the numbers at the top right corner of each graph will change to display the specific value for that day

2. ***All graphs are linked***

Hovering over a data point on any graph will display the data for that date on the graphs for all four metrics

3. ***Colored dots for each graph***

The dots offer a high level overview on how a patient is performing in a certain metric graph, with green representing good, yellow representing average, and red representing bad/concerning.

4. ***Patient profile on the left***

For providers to easily access basic patient profile data

5. ***Customizable zoom to specific date range***

Most post-operative visits happen 1 to 2 weeks after surgery so the graphs can either show data from that time period or can be customizable by selecting certain date ranges

6. ***Show and hide lines for intake graph***

The graph by default displays two different y-axis data but toggling the buttons on the bottom can hide lines

NEXT STEPS

For our next steps, we have identified several areas to improve. First, we want to address the case of missing data. There's always a chance that a person's phone may just be out of battery or he or she may not have forgotten about their phone. However as s a result, there may be missing data points that we need to account for. One possible solution is to just leave the data point blank and somehow communicate to the user that there is missing data, not 0 steps taken. We also hope to include more specific statistics such as predicted readmission rates (as that research evolves). We hope that a predictive algorithm may be developed such that we can provide an even higher level visualization of the patient's wellbeing. Alongside this, an alert system may be implemented so that providers may be notified if patients have worrisome beahviors.

Following this research, we hope that a fully developed system with our dashboard may be developed to be used in conjunction with current systems or even potentially integration. While our providers gave positive feedback in regards to our technical prototype, a user study could be conducted to see if our dashboard can fit into the providers' workflows and if they will actually use it in conjunction with their current systems.

CONCLUSION

During the course of this project, we came up with a solution that would make patient generated health data from wearable sensors such as Fitbits and smartphones usable for providers. Such wearable sensors allow providers the unique opportunity to have deeper insight into a patient's life at home post-surgery, and this will further allow providers to be targeted in their post-operative care. By creating an easy-to-digest dashboard that displays information about four main metrics, providers will have a better picture of a patient's state post-surgery, which will in turn make postoperative appointments more effective and direct.

APPENDIX

Spreadsheet of Papers from Research Phase

Click here to view.

Low Fidelity Testing Script

Click here to view.

Medium Fidelity Survey

Click here to view.

High Fidelity Tesvting Script

Click here to view.

Storyboards

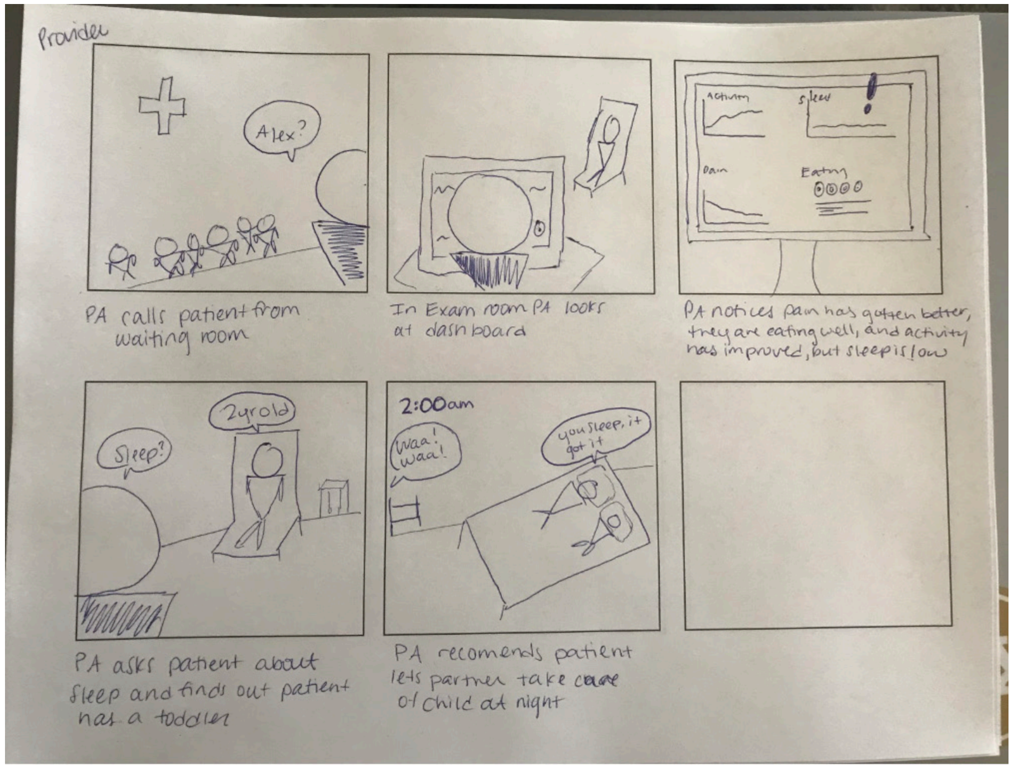
Low Fidelity Prototype

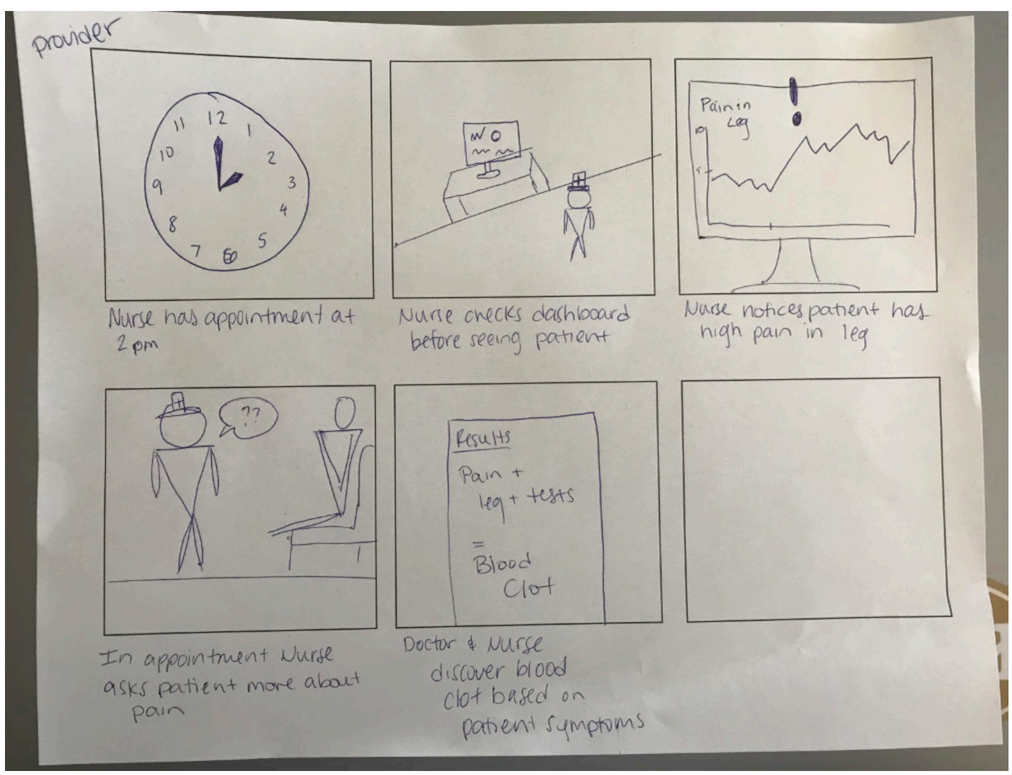
Patient Personas

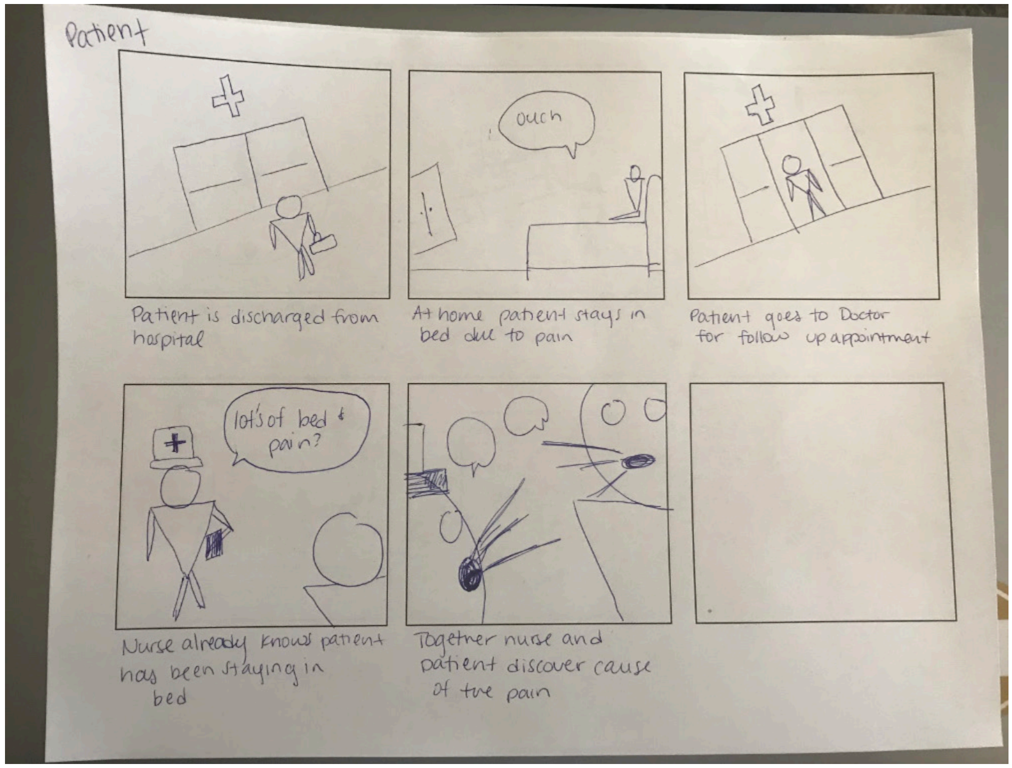
Medium Fidelity Prototype

High Fidelity Design Prototype

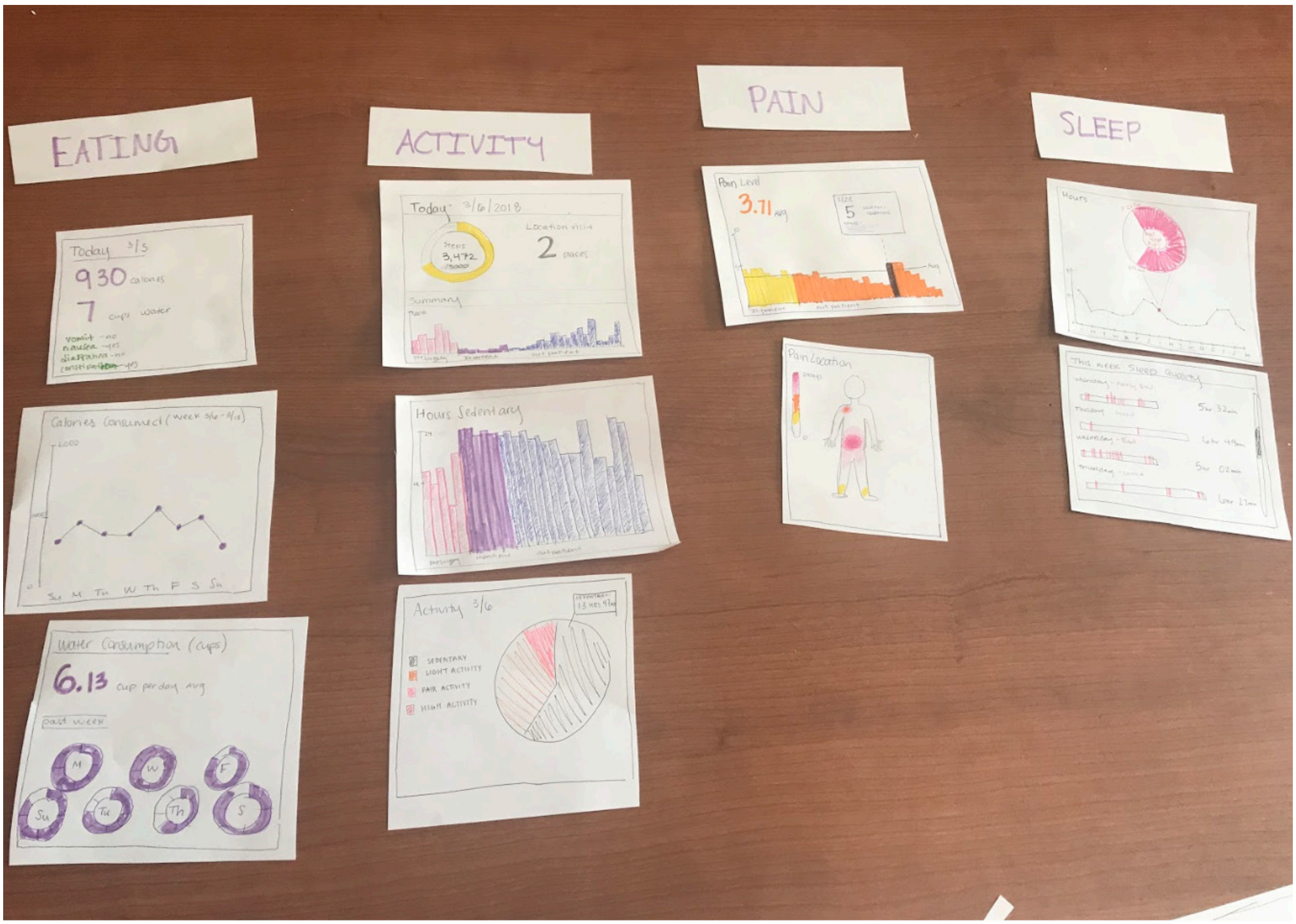
STORYBOARDS






Patient
ouch
Patient is discharged from hospital
At home patient stays in bed due to pain
Patient goes to Doctor for follow up appointment
lot's of bed & pain?
Nurse already knows patient has been staying in bed
Together nurse and patient discover cause of the pain

LOW FIDELITY PROTOTYPE



PATIENT PROFILES

Patient 1 - Good
50 year old male
Married
Lives with wife and 3 children

All stats start low but increase over the two weeks ever so slightly
Days with higher activity have higher pain

Spike in pain and decrease in sleep for three days
Barely eats during these days
Readmitted to hospital (shows in notes?) for blood clot
Start antibiotics after hospital stay for 5 days

Patient 2 - Not so good
63 year old female
Widowed
Lives alone (2 weeks in moves into an assisted living)
Has previous health conditions

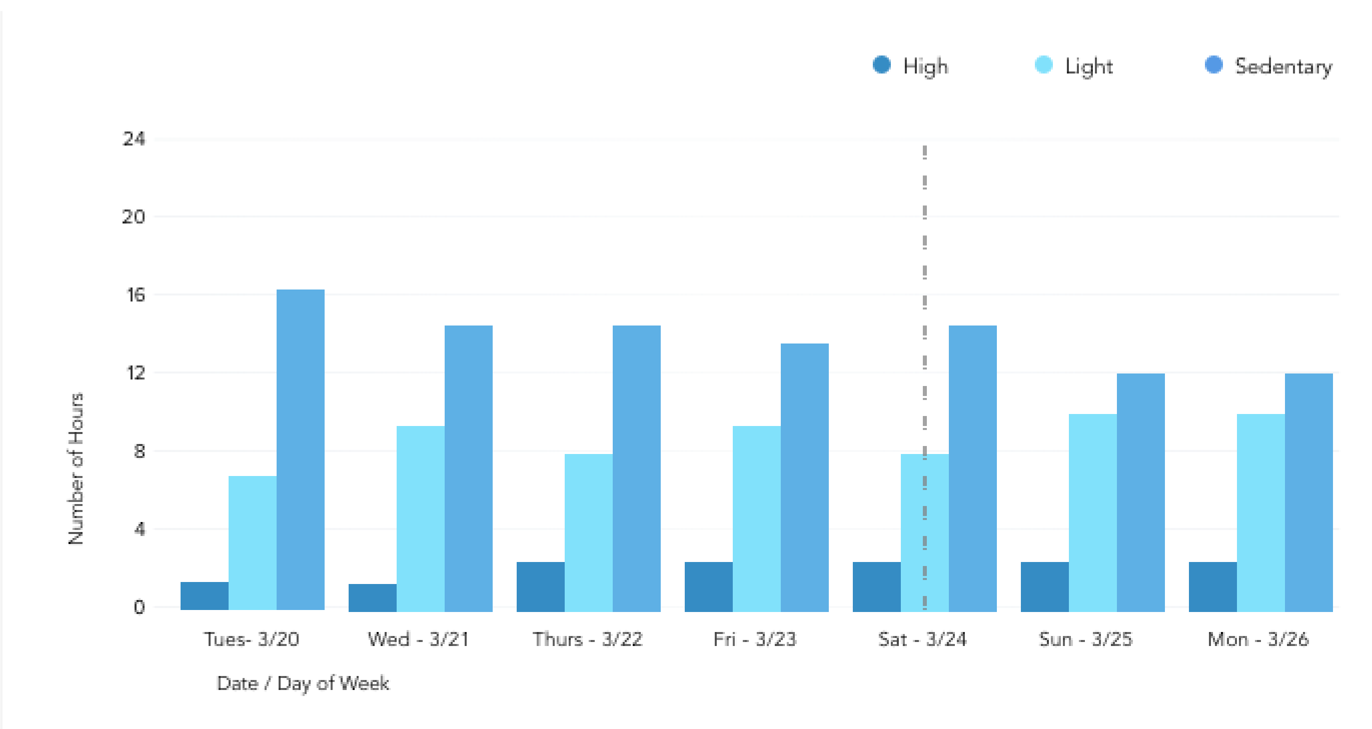
Has consistently higher pain
Sleeps a lot
Activity low, spikes associated with even higher pain

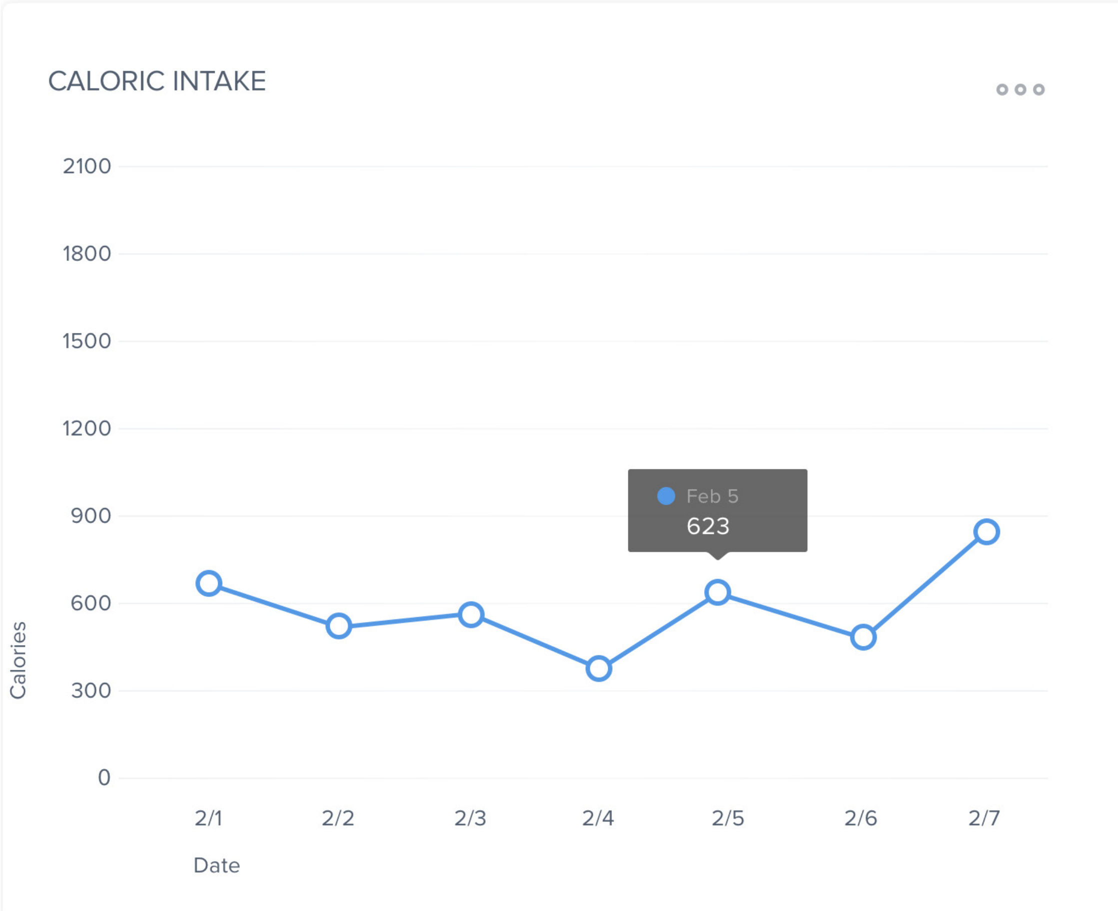
Has already had multiple checkups

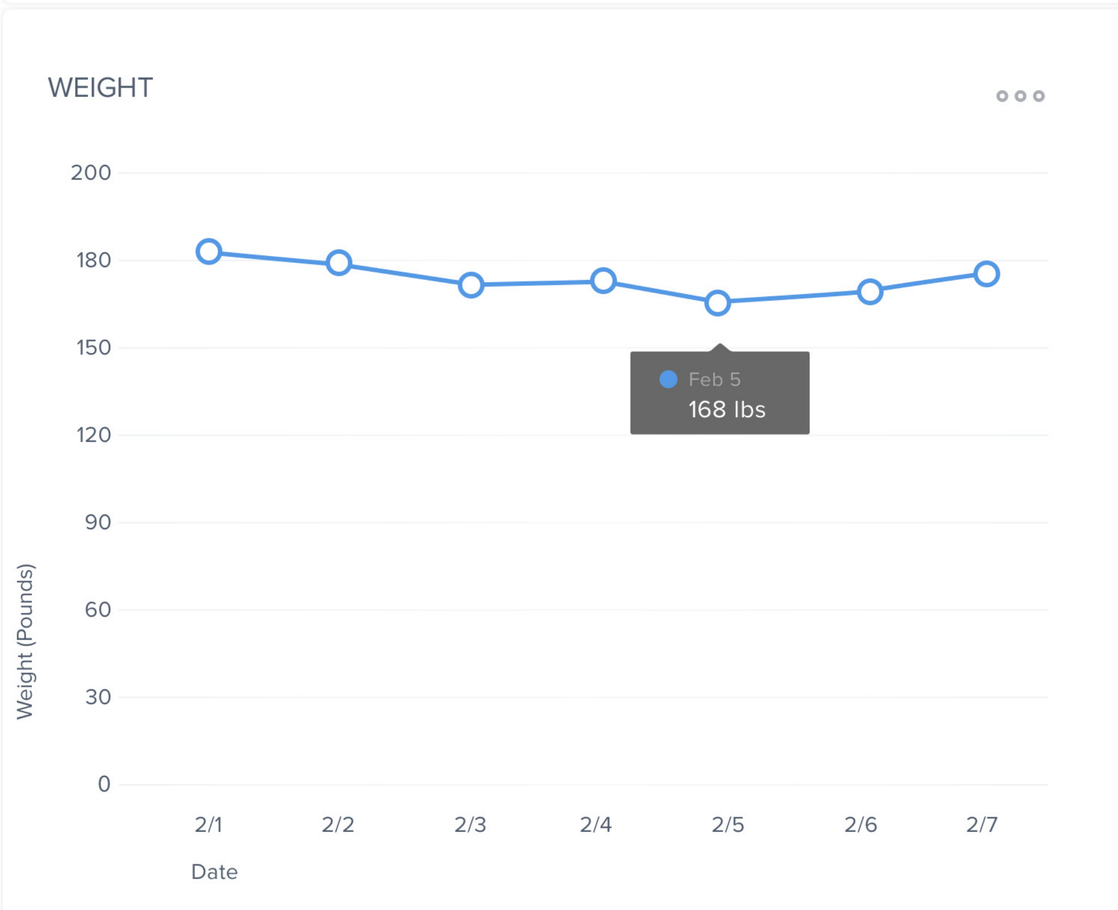
Patient 3 - Not too bad
80 year old male
Married
Lives with wife, but she has trouble caring for him (also old)

Under reports pain the entire time with little spikes
Calories stay low, but weight increases
Activity is constantly low
Starts a new medication?

MEDIUM FIDELITY PROTOTYPE




CALORIC INTAKE
2100
1800
1500
1200
900
600
300
0
Calories
Feb 5
623
2/1
2/2
2/3
2/4
2/5
2/6
2/7
Date


WEIGHT
200
180
150
120
90
60
30
0
Weight (Pounds)
Feb 5
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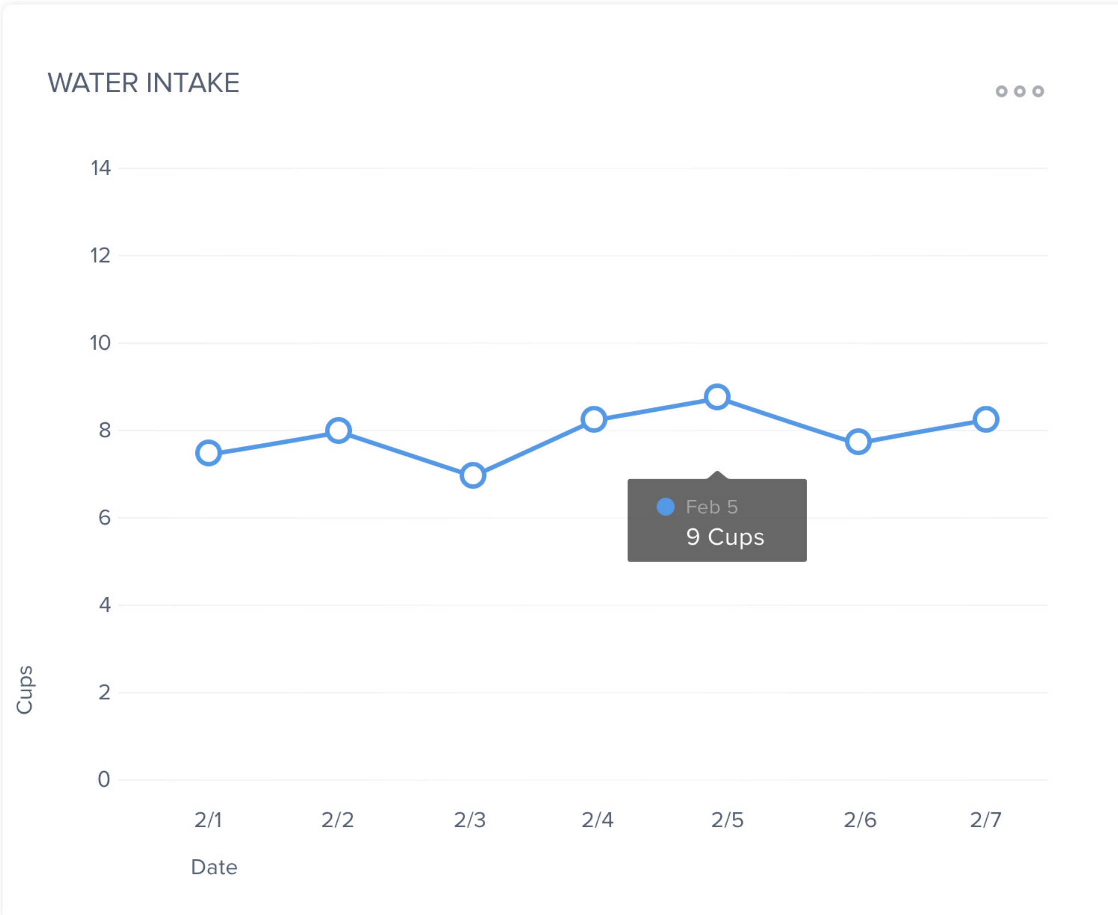
2/1
2/2
2/3
2/4
2/5
2/6
2/7
Date


WATER INTAKE
14
12
10
8
6
4
2
0
Cups
Feb 5
9 Cups
2/1
2/2
2/3
2/4
2/5
2/6
2/7
Date


Self Reported Pain Since Surgery
10
8
6
4
2
0
Pain Rating
Inpatient
Outpatient
1/27
1/28
2/1
2/2
2/3
2/4
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2/6
2/7
2/8
2/9
2/10
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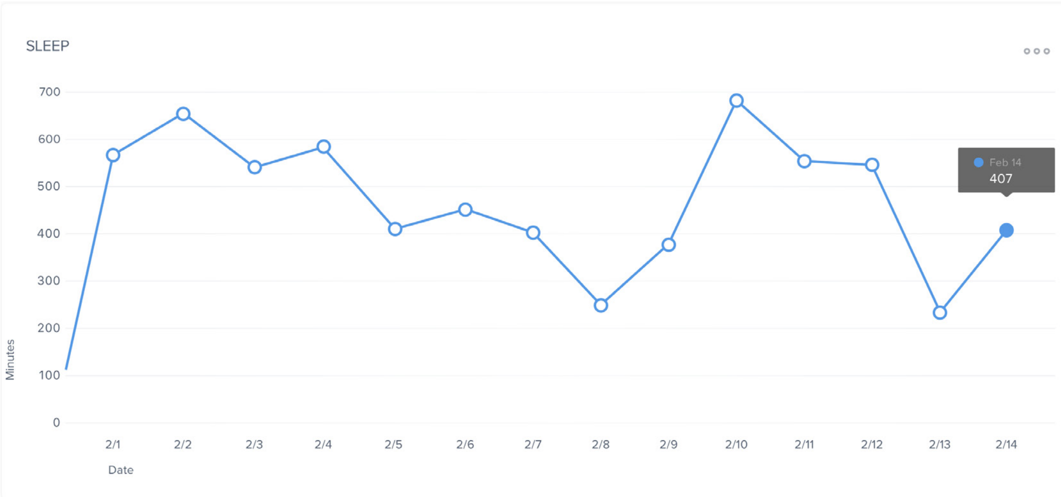
2/12
2/13
2/14
Date


SLEEP
700
600
500
400
300
200
100
0
Minutes
2/1
2/2
2/3
2/4
2/5
2/6
2/7
2/8
2/9
2/10
2/11
2/12
2/13
2/14
Date
Feb 14
407

HIGH FIDELITY DESIGN PROTOTYPE