



Image courtesy of Adapt, Sprout Social [16]

## Improving patient understanding of health data

Studio III – Proposal - Problem Identification

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# 1 Overview

Accessibility of data is defined as the understanding of data, not only the availability of it. In many instances, a patient's data is available to them. However, there is commonly a gap between the presentation of the data and the patient's understanding.

It was found that reducing this gap, and increasing the patient's understanding of their own medical data, can benefit the healthcare of the patient and lead to improved health. This project has the aim of increasing the understand the accessibility of health data

## 1.1 Team reflection

The primary feedback from the interim report was to focus on the construction of guidelines which would allow for the development of digital solutions within our problem space (health and big data). In response to this, we focussed on developing these guidelines.

While developing these guidelines, we discussed a variety of approaches that developers could have to data visualisations, and how this addresses the needs of the various stakeholder groups.

One issue that was identified was that we would need an effective way to prove that our guidelines were fit for purpose, and so we also discussed ideas for creating a conceptual model of a digital solution that addresses the needs of a particular stakeholder group. This conceptual model would include a prototyping process that would demonstrate to us that the concept, and therefore the guidelines were a useful tool in order to develop solutions in our space.

For this exercise, we decided to develop a conceptual model of an application that visualises information about prescription medications as this was a recurrent issue that we found in the literature. We selected this space, in part because of the variety of visualisation types that we could apply, but also because of the variety of stakeholders that we could apply it to.

By the time of the final presentation, we had fully developed the guidelines, however the prototyping process was only in the initial stages. Our presentation

therefore, focussed on the guidelines, as we felt they were the primary feature to stem from our research.

Our initial prototype was a dead simple set laid out as a poster. It purposefully did not conform to our guidelines, as it included text as well as some visualisations. Basic testing on this confirmed our hypothesis, and a more detailed conceptual model and prototype of a mobile application was developed, as something that more closely fitted our guidelines.

The second iteration was a significant improvement, and demonstrated that a closer adherence to the guidelines would mean a more successful solution. There are certainly some further issues within this specific problem space which are posed within this report, however, we feel that this final iteration provides a good starting point for future development.

Our group generally worked well together, and were able to delegate tasks that were completed in time. Slack and Zoom meetings were extensively utilised as communication channels, due to the fact that we were unable to meet up in person. The main issues that needed dealing with were around interpreting feedback from tutors. At times, there seemed to be a disconnect between feedback from the various tutors (and how they were interpreting our projects aims) in addition to our own conflicting interpretations of the task sheet. These issues are likely due to the open ended nature of our problem space.

## 2 Feedback

Through the development of this report, Healthy Data's team has gone through different revisions and have synthesised feedback from peers and experts. This section will describe the teams process and evolution through the problem space.

### 2.1 First revision

The feedback received indicated that the problem space was too broad and ambitious. The original plan was to focus on a public health record system that any user could understand. This posed an issue where the previously stated stakeholders included most people. This blew up the scale of this project as the implementation of the application would take years to complete, making this project unfeasible.

To tackle this problem multiple ideas were brainstormed. One such idea was to tighten stakeholder groups. This would help decrease the workload, and provide better quality for users. A decision was made to target specific patients and cater to their needs. This included narrowing down the patient group to pregnant women, dementia patients, parents of newborns, ect. However, as the problem space was to increase the understandability of medical data , the team chose to focus on parts of the medical field which needed better patient understanding. The research suggested blood tests and medicine were the items patients had trouble understanding.

After much debate, the team was split on two ideas, a blood test visualization application and a prescription reading application. The problem however is that these have very different stakeholders. So the team came up with another solution, A software that provided a suite of health apps, named medispot, that could help different areas of medicine. This can allow a team to focus on smaller apps that can better target the needs of a very specific group of stakeholders while allowing the possibility to expand the numbers of applications in the suits in the future.

### 2.2 Second revision

The feedback from the interim presentation was that our health suite idea possibly focussed too much on the apps themselves, and not enough of the guidelines that we were incorporating that (ideally) could be applied to a number of contexts.

We shifted our approach for the run up to the final presentation to focus more on refining these guidelines. However, it was identified that in order to prove that our guidelines were useful, we should apply them ourselves to a conceptual model within a specific context (prescription medications).

While we had begun work on prototyping after the interim report, this direction was confirmed at the time of the final presentation, which, due to time limits, only focussed on the guidelines. The tutors were very interested in viewing our conceptual model, however, they would have to wait until the submission of this document.



## 3 Background research

### 3.1 Problem space

Background research has shown that there can be a lack of understanding by patients of their own medical records. Commonly, a patient may lack the ability to understand the information about their health that is being represented to them.

When a patient visits a doctor, they receive a diagnosis, but are left in the dark about the full extent of the issue. Usually the doctors recommend a treatment plan with a simple explanation of the diagnosis. Here lies the problem space, this information is communicated verbally and causes a multitude of problems. For example, a person may forget the specifics of the medication or the doctors may not have communicated clearly enough. [11] describes a scenario where a patient was interviewed about taking birth control pills. In this interview the patient admitted she would only take them when she had sex, she said “The doctor said these pills were to keep me from getting pregnant when I have sex”. These pills only work if taken daily so her use of the drug was rendered useless (sometimes harmful because of the side effects[13]) as she did not understand the medication. It could be stated the doctor gave a poor explanation of the drug, but this came from a report which studied communication barriers between doctors and patients. It is evident from the report that it’s not a problem that can be fixed by asking doctors to do a better job. Verbal communication has many difficulties, it requires both parties to have a certain level of literacy and to remember arbitrary information (e.g. like taking medicine on certain days etc.). So, expecting doctors and patients to just trade information verbally minimises the effects of the healthcare system.

### 3.2 Benefits of access to a person's medical records

Some research discussed the benefits and drawbacks of making a patient's medical information available to them through an electronic health record (EHR). The article examined a substantial dataset including various descriptive studies and randomized controlled trials. One of the studies gave patients access to their own medical case notes and found that in over half of those instances subjects found them “puzzling or unintelligible, alarming or worrying, apparently insulting, objectionable, apparently deceptive”. The student noted the difficulty in generalising the effect of a patient-accessible medical record from this study.

It was found that better charting practices would have eliminated many of the concerns, but evidence still showed that patients may well be troubled by reading their own medical case notes. This may be due to their lack of context specific training or simply a lack of ability to understand the information.

The paper also demonstrated that when medical information is communicated effectively, the patient demonstrates improved recall and understanding of their healthcare responsibilities. An example of this is a study of smokers. In the study, patients who had received a copy of their most recent progress notes were more likely to identify smoking as a problem two weeks after their appointment. Evidence demonstrated that in the vast majority of cases, these reports did not generate substantial anxiety, and a large proportion of patients followed medical advice more closely and some were even inspired to make positive lifestyle choices.

In summary, this report demonstrated the improvements that can be made when doctor-patient communication is improved. Notably, adherence to recommendations, as well as patient empowerment and education are all improved when this occurs.

### 3.3 Health literacy in Australia

Research shows that over 60% of people have less than adequate levels of health literacy. This is a significant issue, as low health literacy is a risk factor which can cause poor health, particularly through a lack of engagement in their own healthcare. It can affect people's ability to complete tasks like navigating the health system, understand medical instructions, and seek support from health professionals. [26]

Low health literacy levels have been shown to impact the safety and quality of healthcare, and contribute to higher healthcare costs. Any solution then, should aim to reduce the necessary level of health literacy required to engage with the health system.

### 3.4 Data Visualization

In order to improve a patient's understanding of their own medical information, the relevant data needs to be expressed to them in a format that they understand. In order to do this, data visualisations were considered in the context of healthcare.

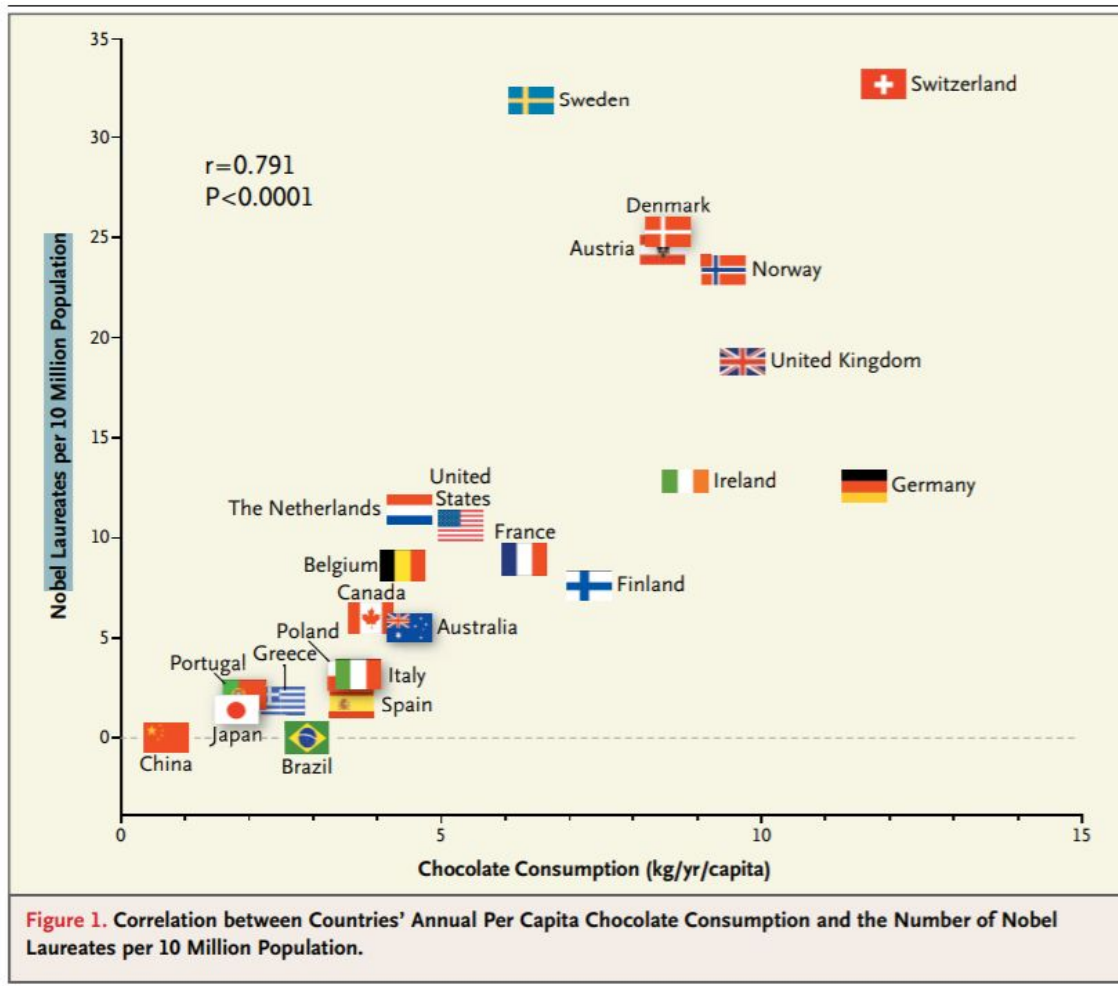
Some evidence demonstrates the importance and benefits of data visualisations. Given the inherently visual nature of the world, it makes sense to seek to express datasets visually. The aim is to reduce the cognitive overhead for the person seeking to interpret the information. [3]

In a more formal sense, Data Visualisation is the art of representing raw data as images. It can provide insight into phenomena and is a key tool for the analysis and understanding of biological, physical and engineering processes. A subset of Data Visualisation is Scientific Visualization which is already very popular for scientists and doctors in the medical industry. This may seem as though Data Visualisations the perfect solution to bridge the gaps between doctor patient communication. It is far from that, as powerful a tool visualisation is to convey a meaningful point; it can also lie. [17] The economist has shown some of it's mistakes and categorized their crime into three categories; misleading charts, confusing charts; charts that conceal their points. So how can developers ensure the quality of their Visualisations?

[18] says "we visualize data because it invites us to look differently at data and helps us understand it. Good data visualization should both engage the audience and improve both the accuracy and the depth of their understanding." And with that they attribute 3 qualities that make a good visualisation: data analysis, storytelling, design.

### *3.4.1 Data Analysis*

Data Analysis is the process of organising data to reveal some underlying pattern. Our world is filled with patterns in nature and man-made technology. [18] "It's in human nature to see patterns in the world around us... we do it because patterns help us predict what might happen next." It might not always be clear where the patterns are, however what might originally have been a chunk of random numbers can be spliced and rotated to see new emerging patterns. It's not often but patterns can be misleading. [19] An example of this is this report which claims that chocolate consumption is the reason for a country's



### [19] Chocolate Consumption, Cognitive Function, and Nobel Laureates

However, the reasoning might not be as simple as eating chocolate makes you smart. [32] tells us "The graph tells us there is an association, it does not show us causation." The pattern may reveal some correlation but there may be some underlying cause in the pattern. It may be that there are some other factors connecting those two variables. Or as the author points out it might mean smarter people just enjoy chocolate more. It's important to find patterns but just as important to find relationships.

Relationship in data analysis is the correlation between the variables set in the data. [18] or as data Labs says "does something go up as another thing goes down." There will always be reasons patterns emerge, it might not be clear at first but ensuring that the software can provide scientist backed visualization and data will help the patients understanding of the medical data.

### 3.4.2 Story telling

With data analysis the accuracy of the visualisation can be ensured. However, data in itself can be uninteresting, even presented in a visual format. For example a graph with an exponential curve may tell us that temperatures are rising but it does nothing to elicit a response from the reader. [18] "Data visualization must make the emotional, social and cultural connections between data and real life." For the same example adding colours and showing real world effects of higher temperatures can help readers develop an emotional response. [18] says that "To be meaningful to your audience, this information needs to be considered from their point of view." Storytelling is an integral part of the data visualisation process and since this software aims to help make medical data more understandable, introducing emotion can greatly affect that.

### 3.4.3 Design

There are well thought out design elements in the world arounds us that help people with their daily lives. To zebra crossings and to danger signs, these visual clues can help a person to avoid danger without even thinking about it. Any visualisation should take advantage of these design principles to help execute it's point of view. [18] "Good data visualization design ensures that everyone who sees it understands what it represents." Some examples of such design elements are visual cues, visual hierarchy, negative space, annotation.

## 3.5 Current Context

There are currently a number of applications known as public health record systems (PHR) that track and store a patient's medical record. As of now there are none that have been widely adopted, despite being produced by familiar companies such as Google (Google Health) and Microsoft (Microsoft HealthVault). In fact, these products have been widely reported as failures [6]. Microsoft Healthvault has officially shut down and Health IT[6] reports that its downfall can be attributed to its "focus on a traditional health record over dynamic and patient-acquired data, its lack of integration with many popular wearables and other smart health devices and its limited social and sharing capabilities".

In particular, HealthVault did not offer patients many insights into their own health. This is a key issue in the problem space as it suggests that PHR systems fail if they do not offer patients actionable insights and support required. In addition, Google faced a backlash after it was revealed that some of its

employees had access to millions of patient records and there were concerns that some may have downloaded that data [7].

There are concerns about some current PHRs that don't provide users with an adequate software experience. [8] Compares HealthVault and Google Health and elicited 25 end user features that should be considered when developing a solution in the space, which will be explored in the next section.

### 3.6 Software design

There is clearly a need for patients to have better access and understanding to their healthcare. The limitations in the system could not reasonably be attributed to the medical training of doctors, nor is it reasonable to suggest that patients could simply be provided with their own abstruse medical information.

One suggestion that should be considered is a software solution, as the ubiquity of smartphones and other devices could be utilised to assist in the improvement of patient understanding and engagement.

A mobile application can increase the accessibility for users exponentially. Since smartphones today come with many features such as camera, audio recorder and fast access to the internet from almost anywhere. The user has a variety of options for entering in data at their convenience. This aspect is essential for a solution as data visualisation should be personalized for the user.

Revisiting [8], a panel of experts have compiled a list of 25 end user features which are necessary for a successful PHR implementation. (See Appendix - Necessary features of a PHR implementation)

From the previous background research, additional goals for a PHR system were identified that will be required in order for a solution to function effectively. These goals include:

- Making the information more human. The average user may not have the relevant medical knowledge to read and process medical records. Information needs to be provided in a format that is understandable by a diverse range of literacy levels.
- The system must display information in high quality formats. It should be able to produce graphs and other representations of data accurately. If this is not achieved, then providing the information may be counterproductive and possibly confuse the user.

[8] states that messaging should be secure. However, it is prudent to take the next step and ensure all information is secure. [7] There was a backlash seen when Google had failed to protect user data. Ensuring that patient data is protected will help the users feel safe and provide them a more honest experience with the software.

### 3.7 Technological Limitations

When taking into consideration technological limitations, the extensive strain of the end systems must be considered. When using low level technology such as an older generation phone, it can be hard for it to meet the graphical requirement this software might require. Since one of the software design choices was to provide an effective graphical interface a system with low hardware specifications may not be able to comply with the aforementioned requirements.

Poor internet connectivity can prevent the software reaching communities without developed network connections. A system that stores information on a cloud server may be useful for doctors and other “actors” in the healthcare profession to help patients. Meanwhile, the absence of local storage will affect the users control of their data. There is an argument to be discussed to compare the pros and cons of local storage vs cloud storage. As this report should focus on the problem space this should be addressed in future documentation.

Technological limitations also include people who have bad experiences interacting with technology. It's widely acknowledged that the older generation have trouble interacting with technology. [9] reports some causes of this as poor hearing , eyesight and ability to read and health aside it's important to have some knowledge about technology. However, this criteria does not only apply to older people, users with disabilities would also fall into this category even though they may be among those who benefit the most from a solution. It's in their best interest for both groups to improve their communication with medical experts and the software put forward can help do so.

A significant issue that presents itself then is that the people who would benefit the most from an application that tracks their conditions and explains it to them may also have the hardest time interacting with technology. [5] In this report it mentions that Microsoft HealthVault had a feature where parents can act as custodians to their children and change their health information. This interaction could be extended for people with technological limitations and can entrust their

account information to relatives or trusted parties. This still needs more consideration as there are securities issues that conflict.

### 3.8 Privacy and Security

One article showed an example of the backlash Google received when news broke that its personal health record system could have major security flaws. If the product cannot ensure the safety of the end users personal data it can cause worry and unrest. [10] reports that the misuse of personal data is the leading cause of tech industry distrust. The article found many companies are likely to stop doing business with tech companies due to the lack of trust. This misuse of personal data has also left consumers attempting to limit their online footprint. If we want consumers to engage with the proposed platform then an assurance must be made that the protection of their personal data is a top priority. [7]

[5] is an article that continues to expand the work done in [9]. It goes on to explain how Google and Microsoft have secured their programs. One thing to note is that the aforementioned security flaw in Google Health could only be abused by employees. So, this has no effect on the security they have implemented in the actual application.

Both Microsoft and Google allow users to log into the public health record in a webpage where if users are successful in accessing their account, the webpage will open an application website which redirects to the user's information. This application website is kept active until the session key has expired. These sessions are authenticated with domain-based security certificates. As Google and Microsoft have an extensive history in security the software designs can follow a similar example in creating a secure application.

### 3.9 Communication gaps

Even though blood tests are quite common, there is still an absence of efficient communication of the test results to the patients [22]. It is quite common that patients do not have the medical literacy to understand the results and have to take them to the doctors. Furthermore, blood test results generally contain lots of numbers (such as complete blood counts) and units (cmm, fL) [23] and these can be difficult to interpret. As mentioned in section 2.3, the test results can be expressed in a format that patients can understand by using data visualisations.



### 3.10 Medicine

Recent studies show that prescription labels are so badly designed they are dangerous. [25] comments on the pharmacy industries failure to provide important information in their medication bottles. The average American reads at an eighth-grade level whereas most health care information, including labels on prescriptions, is written for college graduates. "Twice ... It's a simple word to pronounce and say, but what does twice even mean? 8 a.m. and 4 p.m.? Morning and evening? It doesn't make any sense." "A prescription drug label is the last form of communication we have between the patient and the provider,"

This is an area in the medical field that leaves patients puzzled and frustrated. As we've seen in the problem space, doctor patient communications can fail. The pharmacy label should be a defence against this to help patients have the minimum required knowledge of their medication. However, it's known that these have been poorly designed and can lead to more confusion.

## 4 Guidelines<sup>1</sup>

~~Non-alarming language~~

~~Factual reports – with correct numbers~~

~~Story telling~~

~~Data in linear format~~

~~Design patterns out in the world (interface metaphors)~~

- ~~1. The visualisations should have a clearly defined purpose:
  - ~~○ What is the visual trying to communicate~~~~
- ~~2. Keep “visual integrity” (responsible visualisations)
  - ~~○ Don’t distort the data:~~
  - ~~○ Focus on representing causations rather than correlations~~~~
- ~~3. Incorporate storytelling elements
  - ~~○ Create an emotive connection between the visuals and the patient~~~~
- ~~4. Utilise common interface metaphors
  - ~~○ Make the visuals accessible to those less health literate:~~~~
- ~~5. Focus on the user
  - ~~○ Information should be focused on them~~
  - ~~○ Use non-alarming language (be gentle?) wec~~~~
- ~~6. Adding user specific information (weight, height, diet etc):
  - ~~○ Makes it less of a reference app, and something that speaks to the user.~~
  - ~~○ The user should be able to see where their data compares with the rest of the data, and this should inform them of their own health~~~~

~~Contextual Suggestions~~

- ~~1. Providing solutions~~

~~Repertoire of visualisation tools~~

- ~~— Graphs~~
- ~~— Other design patterns~~
- ~~— Mood map – feelings grid~~
- ~~— Voodoo doll visual/Maps of the body with symptoms highlighted:~~
- ~~— Calendar visuals (when to take medication etc)~~
- ~~— Chatbot (anonymised health chat)~~

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<sup>1</sup> The included strikethrough texts are intended to showcase the changes that the team has made to the original set of design guidelines that was proposed during the associated presentation of this report.

In order to achieve this project's goal of making health data more accessible and understandable, guidelines were created that support developers in making data visualisations of health data, which support patients, taking their needs into account.

Due to the depth of the problem space, the wide variety in types of health data, and the diversity of potential stakeholders, there is no universal solution that can be achieved.

What can be accomplished however, is to develop a system that focuses on a specific set of stakeholders. When doing this, the following guidelines are important to take into account:

1. Overall
  - a. Be consistent by laying out the user interface in a familiar way
  - b. Seen by Google and Apple HCI [27] & [28] adherence to the existing templated design guidelines established by both Google and Apple due to the system needs to be felt at home to the user for the both platforms, and increase the learnability of the system significantly.
2. Stick to the metaphors ([30] talk into detail about the importance of these metaphors)
  - a. The usage of the key interface metaphors will aim to increase the learnability and discoverability of the system to the users by presenting functional features in a way that is easily interpretable by the users, some examples are as follows;
    - i. the todo list,
    - ii. the gauge,
    - iii. the calendar
    - iv. the virtual human anatomy model (e.g. a voodoo doll)<sup>2</sup>
  - b. These elements should be common to the majority of the global smartphone users.
  - c. representation of the metaphors should behave in the way that is originally intended, this is of particular importance in reducing the gulf of evaluation between the users and the system, as the prior lived experience with other technologies can be also applied here,
    - i. e.g. the gauged dash board should reflect metrics readings from the underlying system, in this case, the overall health status of the user's body.

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<sup>2</sup> The team acknowledges that this might not be a common thing for users from certain parts of the world, this is primarily for demo purposes in order to eventually materialize a prototype from the conceptual model.

3. Assessment
  - a. Aim to provide feedback for all user actions to close down the gulf of evaluation
    - i. e.g. Internal/external app notification, haptic feedback for button presses.
  - b. Support users with sensory affordance in presentation of feedback while designing feedback for clarity.
  - c. The effects from audio should be non disrupting and aim to convey positive emotions, the same idea should also apply to images too.
  - d. The system has to provide competently clear and instant auditory/visual feedback for the received instructions.
4. Simplicity as seen in [32]
  - a. The system should be simple to remove any non essential distractions to the users. This aims to increase the overall user acceptance of the system for all potential users.
5. Positive emotions
  - a. The system should aim to be careful in reflecting the current user health status in a non intrusive or discouraging manner.
    - i. Key points
      1. The interface should not be directly alerting users of the symptoms they might have developed according to the metrics reading but aim to present the potential undesirable possibilities as a result of fixable bad lifestyle.
6. Don't reinvent the wheel.
  - a. Background research implied that there is redundant factual information of human bodies readily available on the internet, this means this type of information does not need to be completely replicated.
  - b. The existence of such information and their associated credited bodies also helps provide authority and validation of the information that the potential solution will have.

These guidelines provide a starting point for considering a solution in this problem space. In order to demonstrate their use, a detailed conceptual model and associated prototype was developed which focussed on the lack of patient understanding in the area of prescription medicines.

## 5 Stakeholders

The focus of this project will be on improving patient understanding of their own health data. Hence, it is the patients who are the key users who need to be engaged with in order to achieve a useful final product.

The idea of making data understandable pertains to presenting it in a manner that is easily approachable. As alluded to previously, User Centric Design principles should be applied in order to ensure that the project takes these needs into account in the final design.

It is important to note that there are a diverse range of patients that might be considered here, including patients with poor literacy and numeracy skills, or those from non-English speaking backgrounds. Further iterations of the project should narrow this focus somewhat, as it will be difficult to create a single solution for such a wide variety of users.

Health professionals should also be considered in the development of this project. While this project does not seek to design a solution for health professionals, their work is key to the health system, and any end result of this project that improves patient accessibility should not come at the expense of allowing professionals to do their jobs well. An example of something to avoid for this project is to provide WebMD type information that may not be accurate, unbiased or help, or may lead to confused or scared patients. [15]

Other stakeholders that should be considered include health regulators, existing health data companies as well as the public health system at large. These are all worth considering as any attempt to present a solution in their space will possibly affect those groups.

To demonstrate these considerations, this project decided to focus on developing a solution that addressed the poor uptake of information around prescription medicines, given that this was identified as a significant issue.

The understanding of patient interpretation is paramount to the usefulness of the solution. It should account for a user's lack of literacy and numeracy levels, as the given systems (ie, prescription labels) can commonly be ambiguous, and verbal instructions are commonly relied upon to fill in communication gaps. However, what patients desire is to be able to access and understand the

information associated with their prescription medicine independently, and this project should seek to help them achieve that aim.

Healthcare workers, specifically doctors, also make up another stakeholder group in this proposal. Doctors should also be considered and it should be ensured that any system creates no additional workload, and benefits the patient.

Additionally, pharmaceutical companies need to be considered. Their products are the focal point of the project and the variety in the conditions that they are typical to address should be carefully considered.

## 6 Conceptual model

This section of the report aims to incorporate all the critical feedback that the team has received throughout the semester into the creation for the basis of a practical conceptual model of which an initial prototype will be built upon and tested for the overall validity of the conceptual model. The future actualization of the conceptual model state here may vary and modified upon the discretion of the actual implementers.

### 6.1 Problem Statement

~~The aim of this project is to improve patient understanding of their own health data through technological means such as data visualisation. Specifically, the focus of this solution will be on assisting those users who have limited literacy and numeracy levels and on reducing the communication barriers [11] between patients and their health practitioner that exist as a result of these gaps.~~

Design and develop a mobile application designed to improve health data accessibility using technological means(e.g. Data visualization, lifelogging), for the general public with limited background literacy in order to facilitate understanding as well as aiming to reduce communication barriers between the patients and the health practitioner as a result of the lack of sufficient knowledge for the patients due to the low comprehension of health data that stemmed from the prevalent existing technologies with low data accessibility.

### 6.2 High-level description<sup>3</sup>

The solution addressing this problem space will be a mobile application that provides a health suite of different applications. These applications should aim to provide 'always accurate' and user friendly data. Each application will be targeted to a specific group of stakeholders. Each app will provide visualization aids in order to increase a patient's health literacy. Since each application is designed specifically for a certain stakeholder their visualization will have to differ to

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<sup>3</sup> This section is largely not revised due to the state of these claims are rather sufficiently descriptive for the aim of the current state of the design/development process.

ensure a high quality product. It may implement charts, gauges, as well as other infographics such as animated anatomy images of different parts of the human body to assist users in understanding the significance of their own medical information, as well as the wider context, and what the existing barriers are to their own improved health.

The system will aim to address the security concerns that some users have had during the initial evaluation questionnaires process, a utilisation embedded biometric authentication of platform specific choice should also be implemented.

The system may also aim to assist patients by providing bar code readers for the users to scan their own prescription or an OTC medicine. The plan would be for the patient to receive notifications to remind them of the correct times to take the medication [11].

Here are a few examples. BloodGraph is an app for patients suffering from chronic diseases, who are recommended to receive blood tests every 3-12 months. This app will take a scan of the blood test results, visualise the results and track the data over time. Ideally the app will support the patient through offering insights into their health, based on their blood test results over time.

PillX is an app which will take a scan of a patient's prescription, and deliver to them information around their medicine (This is similar to the factsheets that are often provided by pharmacies). However, in the background research it has been stated that pharmacy prescription labels do a poor job of displaying these informations, PillX will use high level design techniques which will provide detailed information around side effects, and how the medicine works. In addition, the patient can choose to be sent reminders as to when they should be taking their medicine, or even when they are running low and will need to get a new script for it.



### 6.3 Interaction paradigm

The application will initially be implemented as a smartphone application, as opposed to a website base solution. There are a number of reasons for this. First of all, the portability of smartphones offers advantages of a patient having control over the input of data, in the sense that they don't have to necessarily rely on their chosen health location to be accessing the application for them.

This however, after incorporating the feedback received during some of the presentation critic section is to be expected to be boarden to include ubiquitous computing too. This means technologies such as wearable tech should also be considered too as this reflects the current technological trend of improving the overall societal welfare through the uses of ubiquitous computing of which the intended users group is widely expanded as seen in [28].

~~The health suit aspect of the software allows for the developers to create a high quality product to specific stakeholders needs, but also allows for future expansion as many more suits are added and taken away. The user can also have a say in how much storage this app can take as they have the ability to download specific apps that will fit their needs.~~<sup>4</sup>

Additionally, future iterations of the solution may incorporate lifelogging data using wearable devices or other sensors. The ease with which these could be paired with a mobile device further supports the choice of a mobile-wearable paradigm.

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<sup>4</sup> This was deemed irrelevant for the interaction paradigm section.

## 6.4 Initial system requirements

~~In order for this system to be initialised, there are baseline expectations that need to be addressed.~~

~~The primary functionality of the system is that it should present selected health metrics or information in graphical ways, in order to assist a patient in their own understanding of it. The information could be presented using graphical interfaces paired with language.~~

~~This software provides the users with a high level graphical interface. This includes the visualizations and design practices that will require colour and dynamic shapes. Usually when a system is overwhelmed by the task of calculating an almost endless number of bytes it resorts to the gpu which will handle a lot of simplistic but plentiful calculations. Usually for normal 2-D pictures most CPUs should handle that, however, if this software decides to use 3-D models then this software should accommodate the most basic GPU's.~~

~~At this point in the project's development, this expectation is very broad, and will need to be refined. The focus should be based on feedback in order to find an optimal cross section of simplicity and usefulness.<sup>5</sup>~~

Overview of feature	The system should present the health metrics in graphical ways whenever possible.
Rationale	<p>The bare minimum that the system is hoping to achieve is to present the received data back to the users in a more accessible way, this just means a eradication of all the jargons that could possibly exist in a text format and converts the data/reading into simple dashboards,</p> <ol style="list-style-type: none"><li>1. e.g. line graph showing trend in weight, blood pressure readings</li><li>2. bar graphs showing the magnitude of exercise which the user might have performed how it will reduce certain disease that is likely to be caused by lack of fitness training (e.g. heart attacks)</li></ol>

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<sup>5</sup> This was deemed irrelevant for the initial system requirements section. For the final deliverable of the project, the team realized more specific system requirements should be expected.

Notes	See background research 3.4
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2.

Overview of feature	The system must be configured to alert the users of drastic changes in their health status
Rationale	There is an inherited importance of notifying the users of drastic changes in their health status of which at times is likely to be signals of unwanted diseases or other undesirable development that is likely to be taking place inside of their body.
Notes	See appendix 14.1 - Necessary features of a PHR Implementation

3.

Overview of feature	The system must be ready to provide psychological support in the event of likely detection of major irreversible negative development of health.
Rationale	Be able to provide readily available emotional support should the metrics reading from the system's lifelogging behavior detect any comparable pattern to the existing diseases,(e.g. tumors). The system should be well equipped to inform the users of the potential outcomes of these readings and well prepared to motivate them for the duration before the final verdict is confirmed by a licensed health practitioner.
Notes	seen in background research 3.2 "One of the studies gave patients access to their own medical case notes and found that in over half of those instances subjects found them "puzzling or unintelligible, alarming or worrying, apparently insulting, objectionable, apparently deceptive." In some instances access to medical data can cause psychological stress. This product will do as much as possible to mitigate these damages. However, there should be help provided for those who need it.

4.

Overview of feature	The system should provide a variety of possible visualizations to suit the need of different types of potential stakeholders.
Rationale	The ability to provide a variety of visualization presentation of the human anatomy, this might come in the form of some form of voodoo doll model - where the drug effect can be visualized in a more straightforward way, i.e. such visualization will aim to show the entire process of a medication's effect once it has entered the human body. This is an attempt to reduce the gulf of evaluation for the users as plain warnings on parts of the potentially affected area in the body by the medicine will not be easily comprehensible for the users with limited medical literacy.
Notes	as seen in background research 3.3 "Research shows that over 60% of people have less than adequate levels of health literacy" and in 3.4 "The aim is to reduce the cognitive overhead for the person seeking to interpret the information."

5.

Overview of feature	The system should be able to utilise external hardware such as camera to scan barcode
Rationale	The ability to retrieve information by scanning a barcode will be particularly useful when the medicine is not commonly sold in the pharmacy. This will increase the overall error prevention of the system as well as improve accessibility for the overall system by reducing the traditional workflow of input searching based systems.
Notes	Making the visualisation as personal as possible can greatly increase a patient's engagement in their own health. If the software has access to data as soon as possible with technologies like cameras. The patients can actively engage with their personalised health data at their convenience.

6.

Overview of feature	The system should have in place authentication mechanism to help securely store user information
Rationale	The entire system is expected to be built on mobile devices primarily, due to the sensitivity of the users' health information, a consideration is therefore taken to make sure the application can securely store the user information by utilising the biometric authentication mechanism that is widely prevalent in the modern devices.
Notes	[7] shows the backlash major companies received after it was found user data has been leaked. This type of scandal can injure the trust between a business and its customers. Thus, user data should be kept as private as possible and access should only be given to users.

7.

Overview of feature	The system should make an emphasis on the potential side effects of the drugs in a visually expressive way.
Rationale	The side effects of any drugs are mostly described in text, which in themselves is a difficult task to understand at times, hence the system hopes to have a series of animated models demonstrating the side effect as a tool to better inform the users.
Notes	See section 9.1 - Questionnaire results

## 6.5 Key Interface metaphors

In order to increase the learnability of the system, the team has decided to consider incorporating the following metaphors in order to better match with the potential mental model of the users' as well as increase learnability and hence the acceptance of the system:

1. An voodoo doll(virtual)
  - a. this should be a virtual abstraction of the human body such that it will be widely accepted by the users from all age groups in the meantime provides a detailed description of the human body such that it is capable of animating the effects that a potential medicine will have on the overall system of the body (i.e. neural, muscular, etc).
2. Calendar
  - a. to inform the users the system has the ability to record dates in consecutive and logical sequence.
3. To-do list/ reminders
  - a. to reflect the unfinished task and to give an overall summary of the users' upcoming intake schedules to prepare the users in the case that the medicine is expected to run low or there would be a scheduling conflict between the intake time with other activities in the day.
4. A gauge based dashboard
  - a. To reflect the current level of health status

## 6.6 Interaction modes<sup>6</sup>

~~A variety of interaction modes should be considered, depending on which focus for the project is selected.~~

~~Exploration could be considered as a mode that is used when the user attempts to search for more information regarding their health data. This would encourage users to educate themselves about their health through their medical information and assist them in learning about other issues surrounding their health.~~

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<sup>6</sup> Please note, the listed modes aren't exhaustive and it will largely depend on the implementation of the actual digital system.

~~Additionally, Responding could be considered as a useful mode as notifications could be sent to a user reminding them of information such as when to take medication.~~

~~These above modes represent a non-exhaustive list of interaction modes, and as the project develops, the system may incorporate additional modes.~~

For the final deliverable of the project, the team has collectively, based on received feedback throughout the semester, the following set of possible interaction modes that would be the most appropriate list of interaction modes to consider and a maximized usability as well as user acceptance should be expected.

In order to facilitate the usage of the potential solution for the widest public as possible, a variety of consideration was undertaken in order to achieve such aim, the interaction modes of the potential solution currently should aim to have the following interaction modes considered:

1. Instructing
  - a. Call doctors for further verification/clarification for any drastic changes in health status
  - b. and is evident in the parts where the user is required to make a decision with some of the menu items of the system.
2. Conversing
  - a. The virtual human anatomy model (e.g. a voodoo doll)
    - i. This hopefully also acts as a virtual assistant to a certain degree while providing users with the positive emotions by withholding the complex internal human anatomy from the users.
  - b. Video
    - i. This will be primarily optimized for the general public/elderlies who might require extra accessibility means of interacting with the technology, being able to communicate and receive feedback from the system would be ideal in reducing the cognition load for these groups of target users.
3. Exploring
  - a. This would become representative when the user attempt to search for more information regarding a health metrics,
  - b. encourage the users to learn more about the meaning of different health data and learn basic medical related information to indirectly

achieve the overall system vision of bridging the gap between the general public and the professional trained doctors.

4. Responding

- a. Alerting the users and prompts to take appropriate action, i.e. scheduled notifications that would remind the users of critical information regarding their medicine, such as its dosage, and when to take medication.)

5. Manipulating and navigating

- a. the ability for the users to directly interact with the virtual objects, in this case, the visual dashboard/model that will be consisting of a variety of graphs. Would greatly facilitate the accessibility of the data by letting the user have a sense of direct control of their own health status

## 6.7 Potential future enhancement

~~As previously stated, future iterations of this project may incorporate representations of data collected from wearables and sensors. In addition, the system could utilise bar code readers to scan medicines and assist in reminding patients of their prescription schedule.~~

~~Other considerations might include incorporating the public health system through linking to the 13 SICK home doctor service, or even pairing with MyHealthRecord data.~~

The team was made aware of the fact that a more detailed guidelines for the potential future iteration should be included in order to maximized the design/refinement effort of the current state of the conceptual model, the team would like to proposed a several tools that would be helpful in the next stages of design process:

1. User profiling (Personas/Interaction scenarios)

- a. The future team should aim to access the state of their respective iteration with personas created from the underlying background data that they might have decided to collect in complements to the existing data provided by the team. It is worth noting out that these personas should therefore aim to emphasis with the potential goals and motivations that a typical user of the system would have, and followed interaction scenarios should also be expected in order to reflect as well as further identifying any significant issues that a user of the system might have during their typical usage of the system.



- i. Please note, a minimum of three personas accompanied by three interaction scenarios is recommended to give a suitable level of analysis into the potential user group of the system.
- 2. UX goals
  - a. The future iteration on the design of the current conceptual model should aim to expand the assessment on the usability of the system by providing a set of more detailed UX goals that would aim to address different usability aspects of the system by matching user requirements in further comprehensive details.
    - i. Please note, a minimum of five UX goals is recommended to give a suitable level of analysis into the overall usability of the system and UX goals should follow the S.M.A.R.T design guidelines as outlined.
- 3. Future iteration evaluation
  - a. Once the future development team has incorporated the data has been gathered in the preliminary prototype staging in combination with the subsequent user profiling and usability assessment, the future team is also advised to complete an accompanying evaluation on the state of the prototype at the time, the current team would like to suggest the following:
    - i. Conduct a heuristic walkthrough, as this is a very common evaluation that is conducted alongside the overall usability of the system and it is also a very cost-effective way to get feedback on the overall state of the system without the ethical and practical dimension and costs.
      - 1. However, the disadvantages of this evaluation method should be stated here to help inform the evaluation decision of the future development team. It is worth point out that the common pitfalls that tend to be overlooked when conducting this particular evaluation method is it is likely that the evaluators might identify issues that are not usability problems and the selection of the right heuristics is also of uttermost importance as potential inappropriate/inapplicable heuristics would be counterproductive in terms of evaluating the state of the system at the time.

## 7 Prototyping

In executing our plan for improving health data understanding, there will be a focus on the current interaction paradigms. Currently, patients get information through:

1. Verbal Interaction : In the medical realm the primary way the medical information is shared is through verbal communication. Doctors who have knowledge and experience in medicine provide information to patients. The benefits of this are that the patient requires little to no knowledge of the medicine field to know why they are experiencing certain issues with their health. Information from another person also has the added benefit of emotional interaction where a doctor may be able to sympathise with their patient
2. Visual interaction: A doctor may be able to share knowledge with a patient through showing them visual images to help them understand. An example of this is demonstrating on their X-ray where a fracture has occurred. In addition, certain websites and applications may have readily available information, though this information may not always be understandable.
3. Response from health gadgets: Clinical devices such as a blood pressure monitor or a heart rate monitor can provide health information if a user chooses to use them. These are becoming more pervasive with their integration to everyday devices such as smartwatches. As an example, the latest Apple Watch is able to output ECG and can monitor blood pressure and oxygen levels

The project's approach will be a mixture of the above mentioned interaction paradigms. It will be mainly focused around visual interaction and may incorporate responses from medical devices. In regards to visual based interaction, smartphones tend to be a predominant way for users to interact visually, and will be heavily utilised by the system.

## 7.1 Example of Prototypes

Based on the interaction paradigm, multiple ideas on prototype examples have been produced by team members. These are moodmap, bloodgraph, virtual human anatomy model and pill calendar. From these ideas, we have created a prototype that gives the best example of our interaction paradigm.



image 7.1 – example idea of moodmap

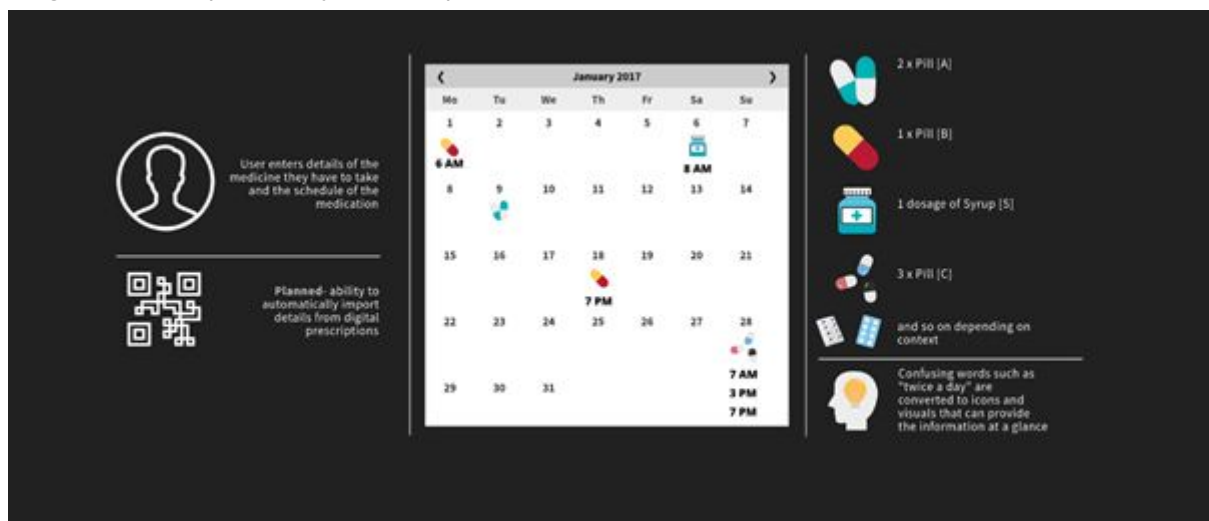


image 7.2 – example idea of pill calendar

## 7.2 Low Fidelity Prototype

First the prototype was created in a low fidelity model which looked more of a poster type in paper. This was a more visualised explanation of medication information, which included an image of pill, table of time to take medication and some additional information in graphs.

Instead of full text, the tables, images and graphs allow the user to understand them easier than reading long texts multiple times to understand. Such an image of a person taking medicine orally and table showing times to take the medicine clearly explains that this medicine should be taken at these times orally.

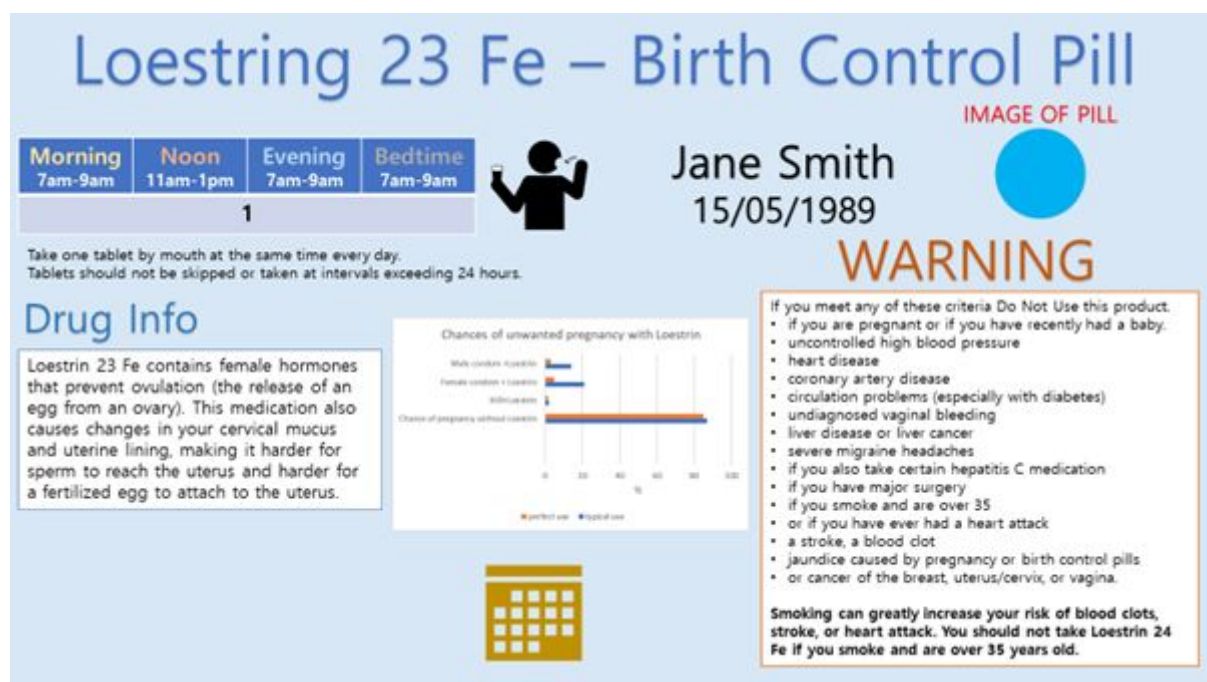


image 7.3 – low fidelity prototype example of Loestrin 23 Fe

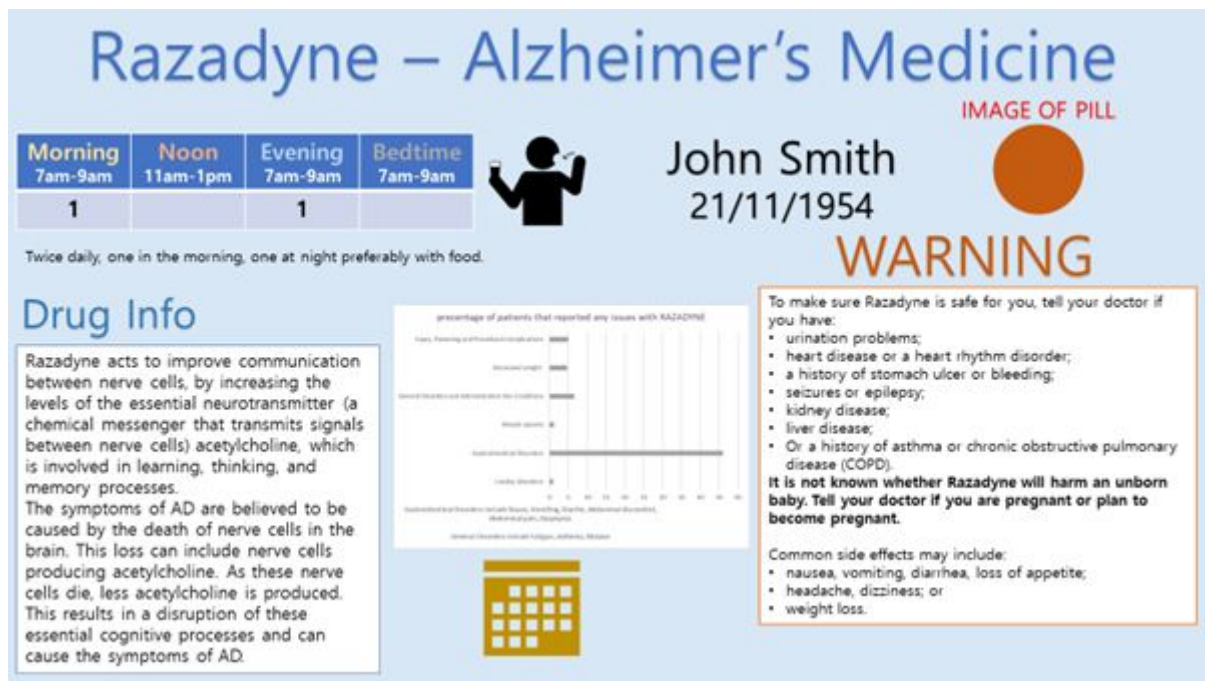


image 7.4 – low fidelity prototype example of Razadyne\

### 7.3 Medium fidelity prototype

Medium fidelity prototype has been developed in an application format. It was chosen to be developed in application format as a camera was required for users to take QR code or Barcode to scan the medicine from their original packaging and people carry phones everywhere.

This prototype is only an example and does not contain correct data or images, but just some to show how this application will show when this is developed. The prototype contains more images and less texts, to show that visualisation can explain better than texts.

Medium fidelity prototype can be found here :

<https://xd.adobe.com/view/f185a9a3-e122-4635-b383-e8bcb3f0e5cd-a4d6/screen/a419d2fc-4fde-45b9-b134-d506af81b7e8/Loading-Screen>

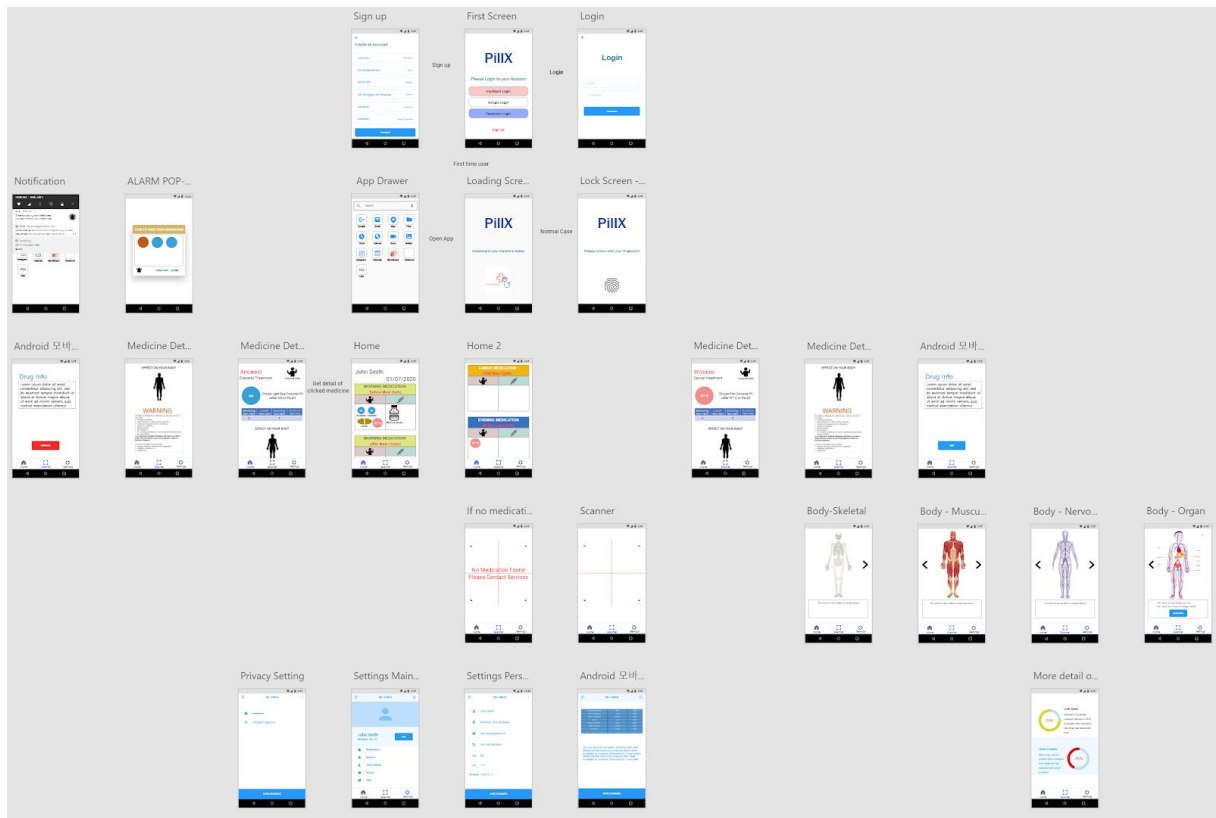


image 7.5 - Images of medium fidelity Prototype

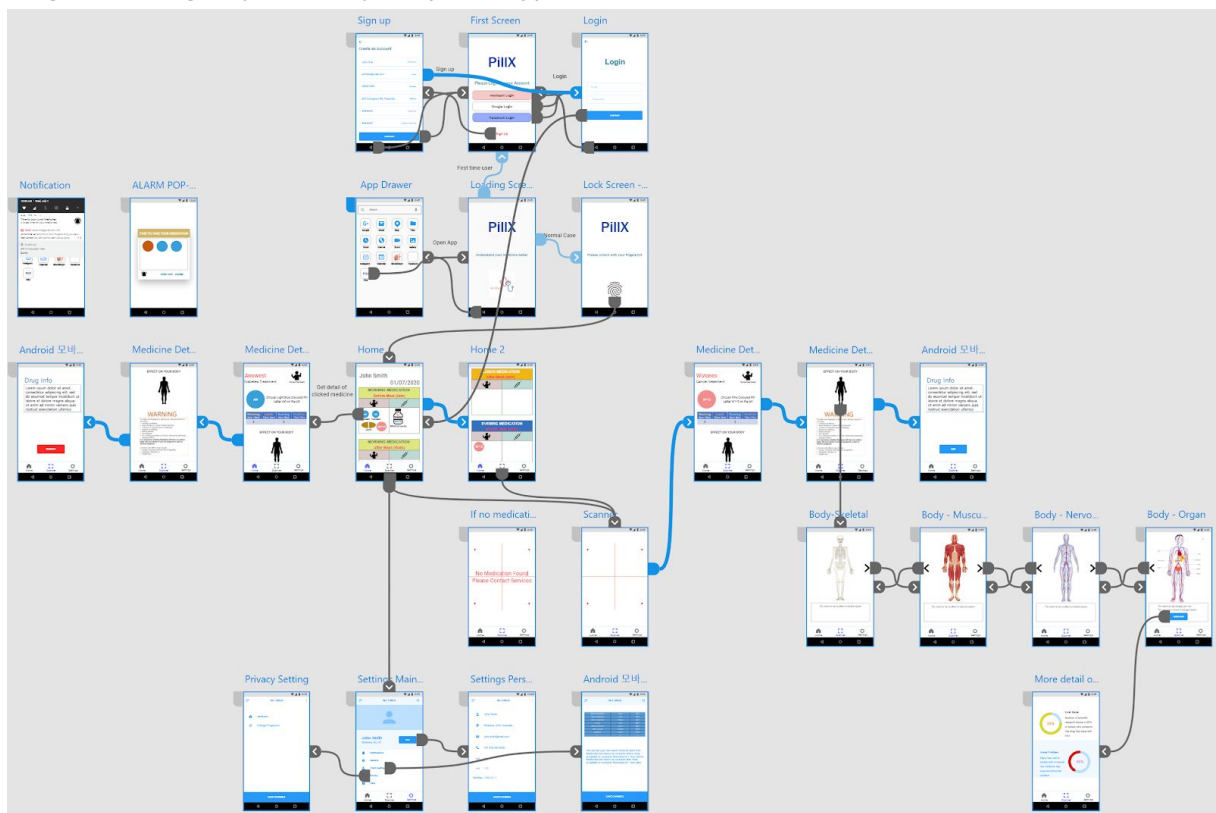


image 7.6 - Images of medium fidelity Prototype wireframe

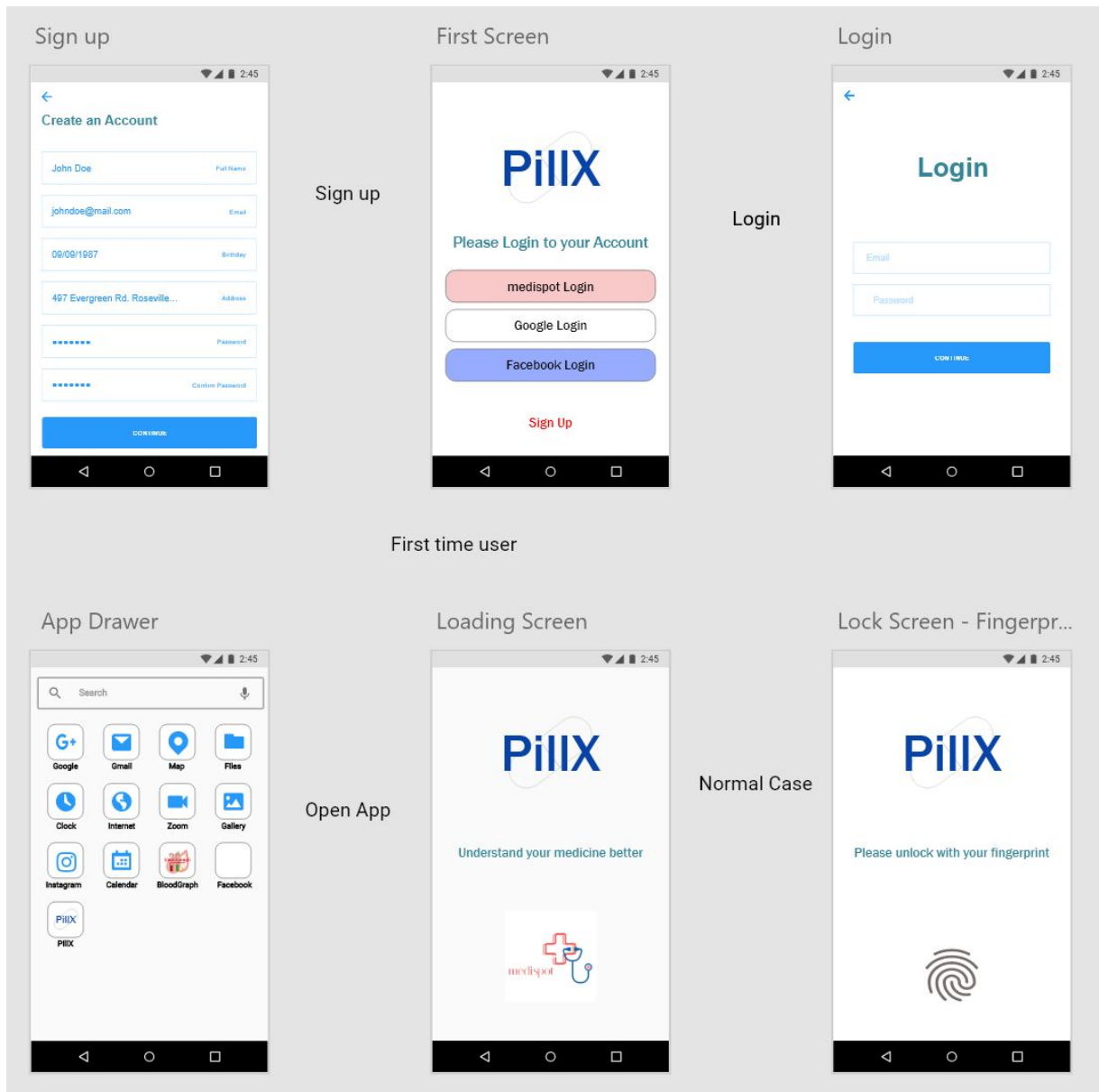
## 7.4 Prototype Explanation

The prototype can be separated into 6 main parts.

1. Start Screen and Sign-up/Login
2. Home
3. Scanner
4. Medicine Information
5. Settings
6. Notification

### *7.4.1 Start Screen and Sign-up/Login*

Just like any other application, it will be turned on by pressing the button of this app. When it is started, it will ask for the user to sign in to the page. Users can create a medispot ID or signup with google and facebook ID. Once it's been created users can sign in and the home page will show up. If the user has set a fingerprint lock, it will show the next time the user turns this application on.



*image 7.7 - image of start screen and sign-up/login*

#### 7.4.2 Home

The home screen is the main function of this app. This will show the medications that the user needs to take by time. Each color of the table will be different and change by the time. In example morning will be in yellow and night will be in dark blue.

All medications that need to be taken will be shown in the image of the medication so users can understand what to take easily, and to avoid any confusion between similar medicines, it will still have a text label under. The



table will show in 2 sections dividing whether the medication should be taken orally or by syringe.

When the image of medication is double clicked or pushed long, it will take the medicine information screen, where it will show the details of medicine and allows the user to remove the medicine.

When the time for medication consumption is passed, it will automatically be removed and show the current or most nearest medication table at top followed by next ones.

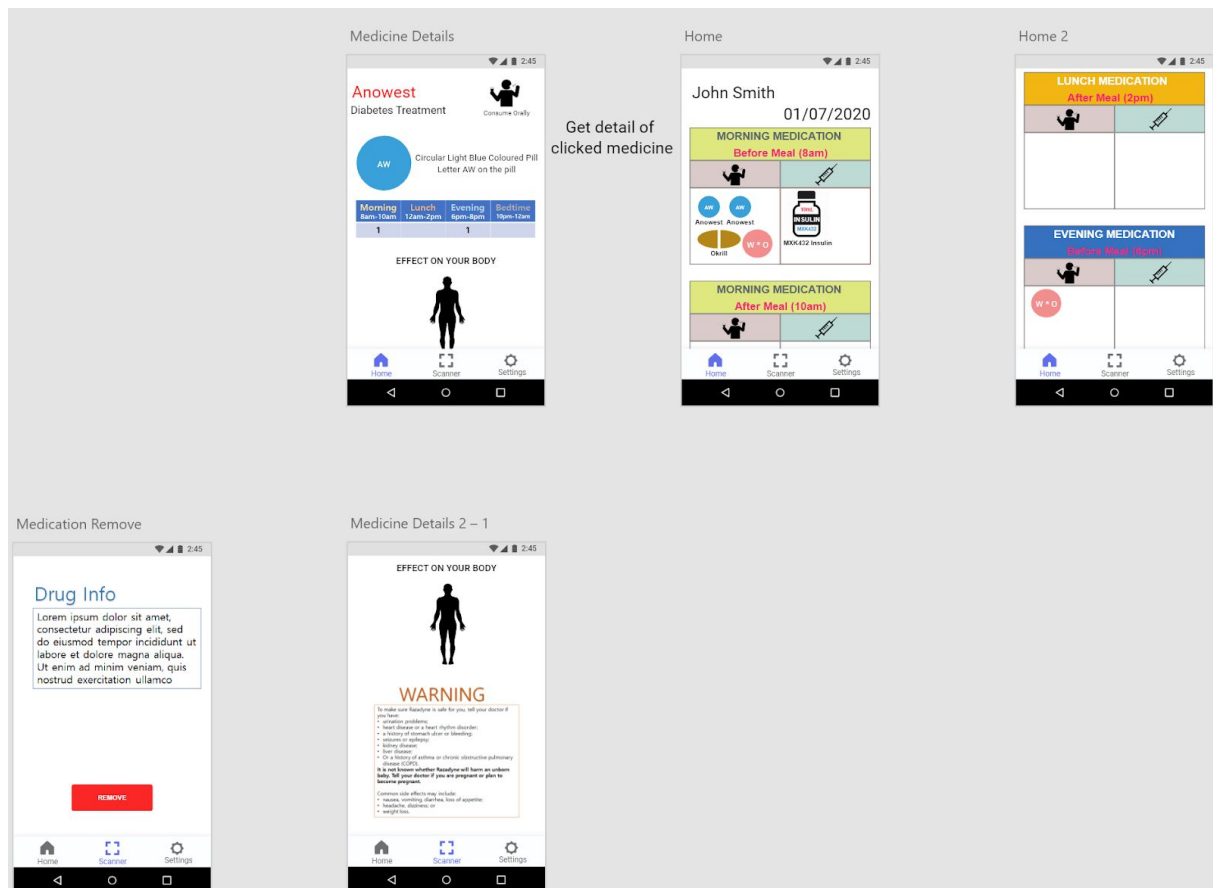
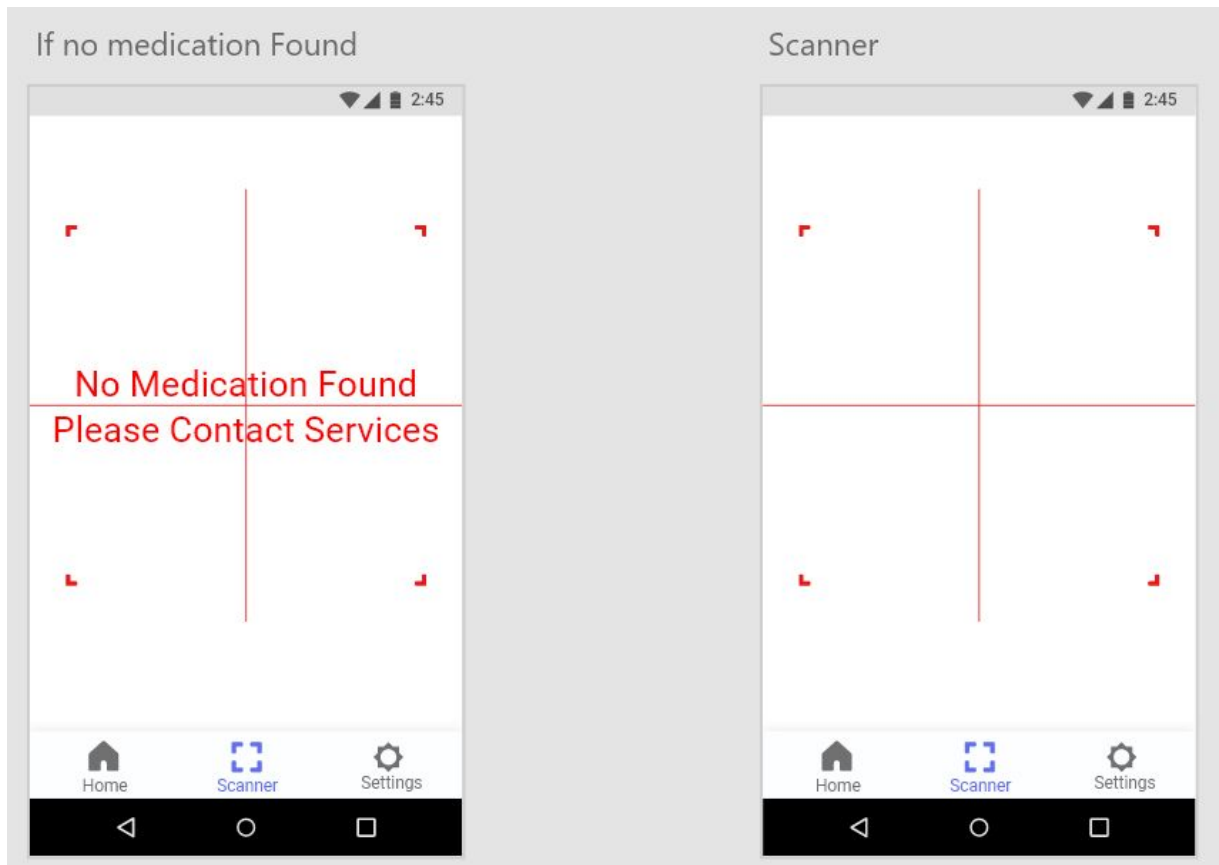


image 7.8 - image of home screen and medication information followed

### 7.4.3 Scanner

Users can get into the scanner screen by pressing the scanner button in the bottom navigation menu. This will open the scanner which can scan the barcode or QR code. Once it is read it will open up the medication information screen, or if it is unavailable to scan, it will show an error message.



*image 7.9 - image of scanner page and error message*

#### **7.4.4 Medicine Information**

This screen will show the visualised information of medicine. This page will be opened when the medication is scanned by scanner or when the medicine is pressed from the home screen.

This page will show the name of medicine, the purpose in big text and show the image of medicine, with text explanation. Then on the top right it will show whether this drug is to be taken orally or taken by syringe.

Under the information of medicine, it will show the time to take the medicine in a table format which is clear and easy to understand when and how many to take.

Under the table, there will be a human shaped body figure, which will show the effects of this medicine. Once this is clicked it will take in to the human virtual model screen where it will show the human body in skeletal, muscular, nervous and organ structure model. On this model any affected area will be colored and under the model text descriptions will show how they affect the body. For more information, a button labelled 'more info' will show more information in graphs and texts. These information should be relevant and verified by professionals.

If the medication is scanned by scanner, under the drug information user can select to add this medicine to their profile. If they do it will be automatically added and be put into one of timetables.

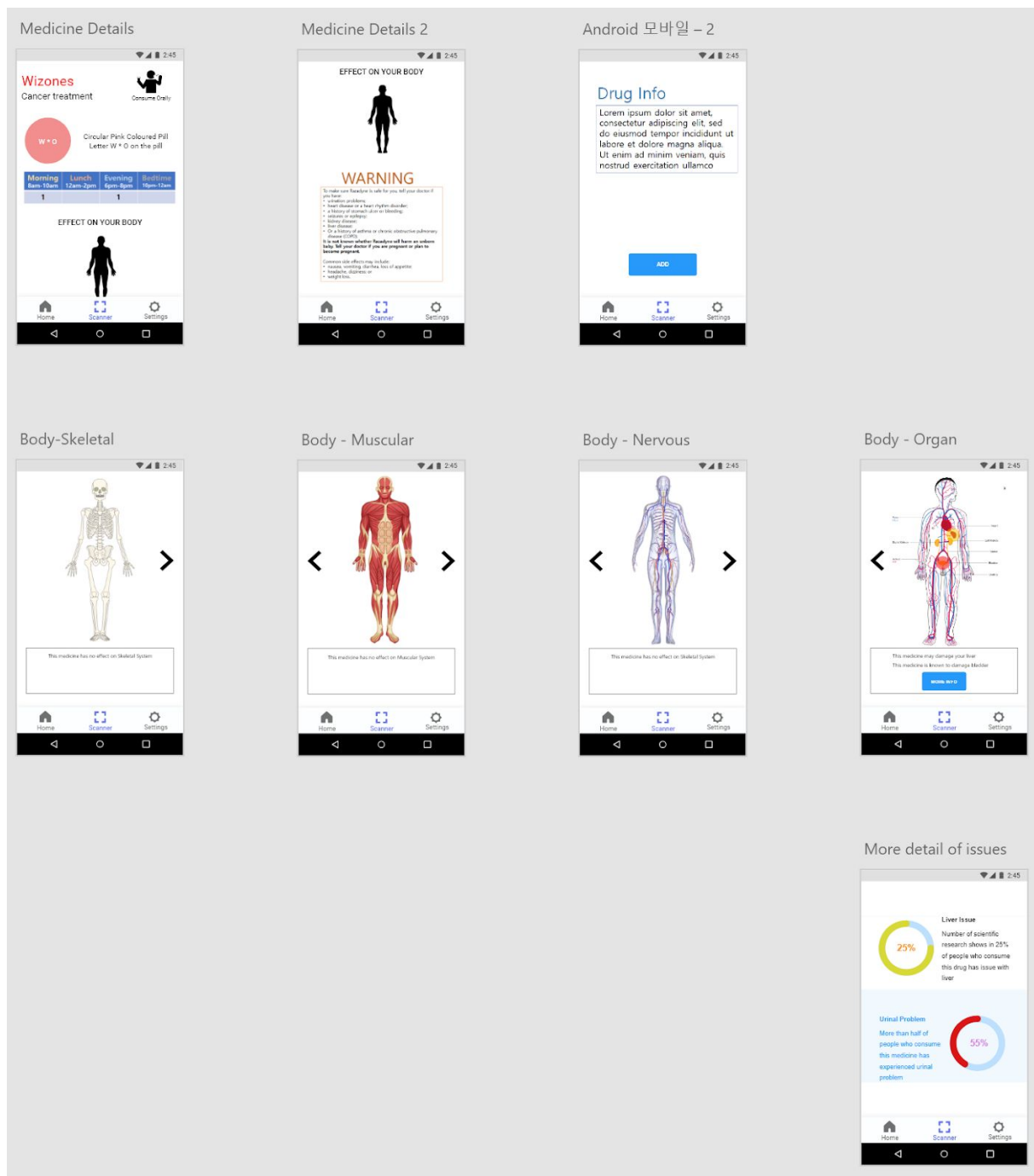


image 7.10 - image of medicine information and human virtual model screen

### 7.4.5 Settings

In the settings page, users can set their personal information, notification, alarm times, privacy/security and can get help from the support team.

Users can input their name, location, contact details, weight, height and age. This information will be used to calculate the correct time and dosage for users.

Also users can set times for the alarm to ring for set medication time. In example setting a bedtime medication alarm at 11pm.

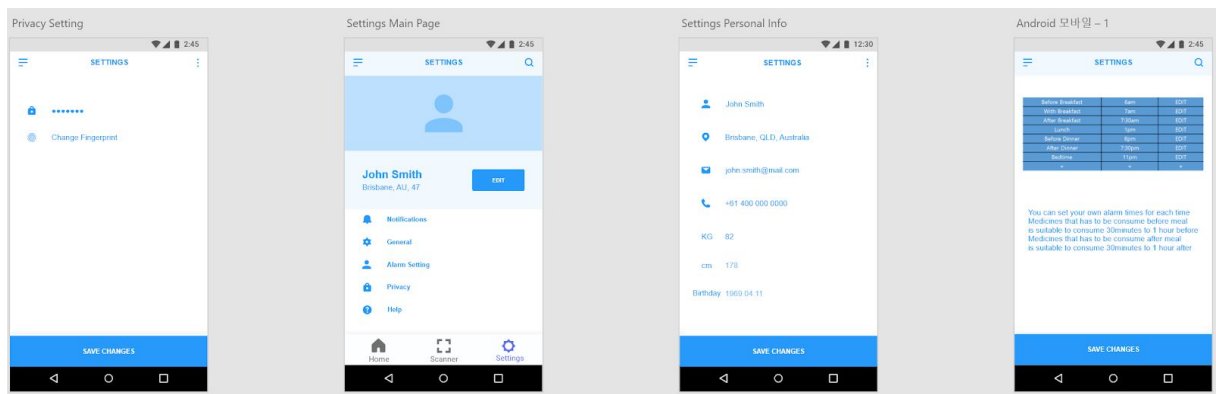


image 7.11 - image of settings screen

### 7.4.6 Notifications

Users will get notifications and pop-up alarm screens when it is time to take the medication. The pop-up screen will show the user which medicine to take in each medicine's image, so they don't have to open the app, but just see it quickly.

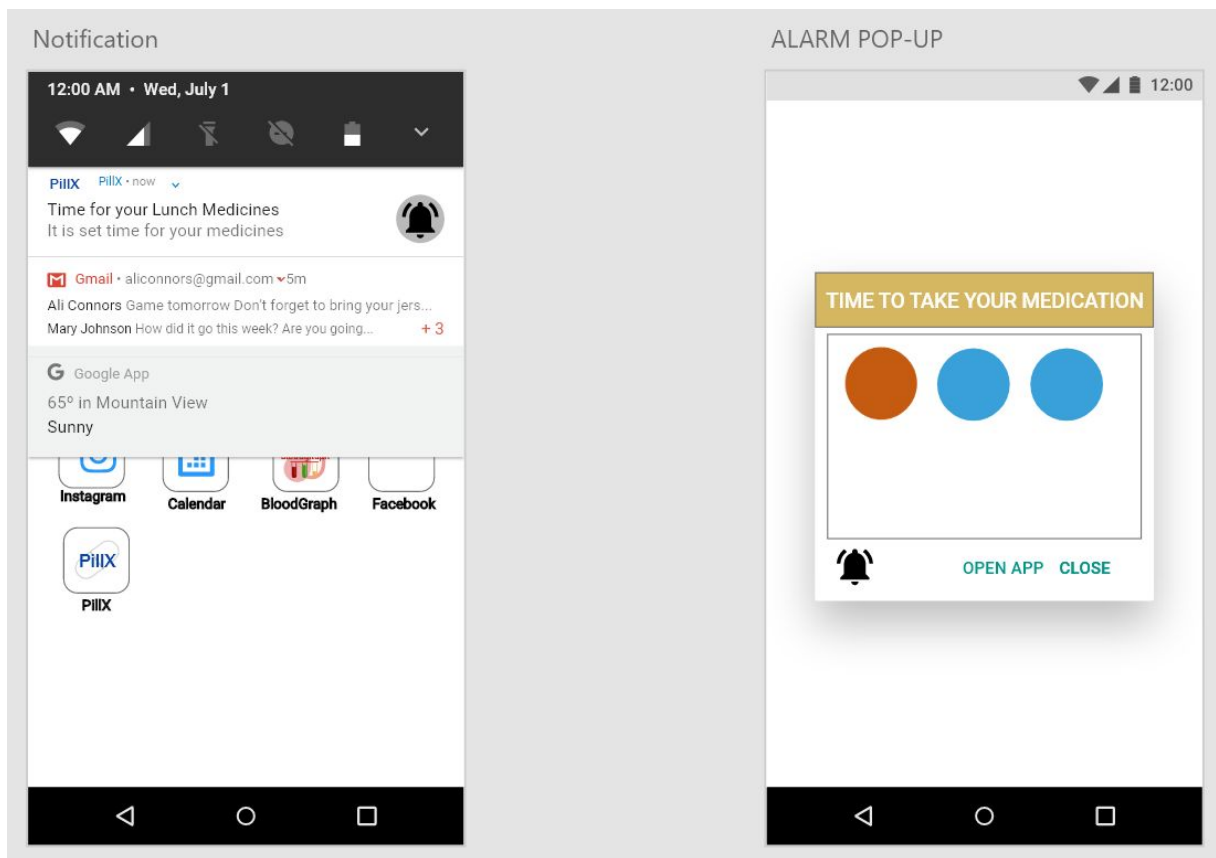


image 7.11 - image of notification and pop-up screen

## 8 Preliminary user evaluation

### 8.1 Questionnaire results

Early iterations of our solution were prototypes developed as low fidelity prototypes which contained a variety of prescription medication information. These posters were given to participants in order to ascertain their effectiveness in achieving the goal of making health information more understandable. The individuals were selected from a group that were not medically trained, and generally did not have extensive experience interpreting health data.

The questionnaire asked the subject to answer information based on the prescription information that was displayed in a sample poster. The poster included a combination of text based information in addition to some data visualisations. The results showed that in many of the cases, the subjects were able to simply regurgitate the drug information as it is displayed on the poster. This result did not demonstrate the aims of the project being met, as this result did not show understanding. Details of the questionnaires and their results are displayed in Appendix 14.2.

What was inferred through this process was that symbolism and design metaphors should be the focus of this proposal, as these can impart a greater depth of understanding to those that are not already literate with medical information. As a result, a second prototype for a mobile application was developed, and tested to pursue this line of thinking.

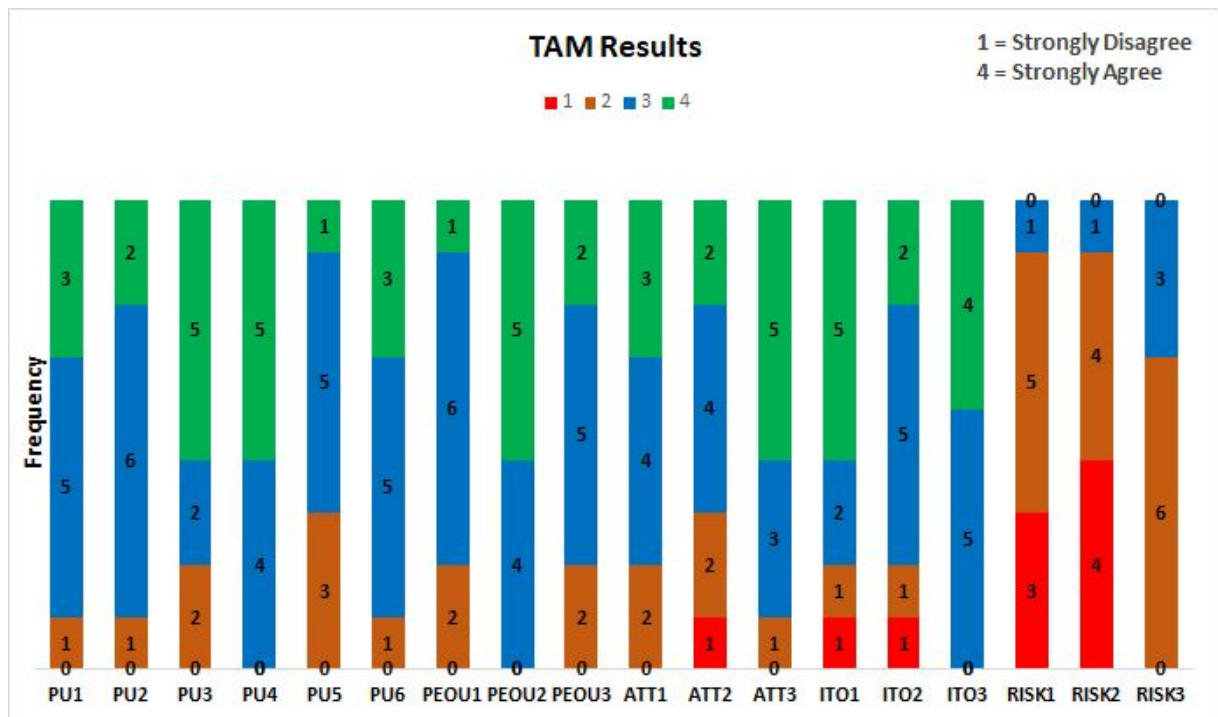
### 8.2 TAM

TAM is a widely used information systems theory that illustrates how users come to accept and use a technology [24]. When users are presented with new technology, a number of features influence their decision about how and when they will use it, these features (also known as dimensions) are what the test focuses on. For our TAM survey, we have used the following dimensions:

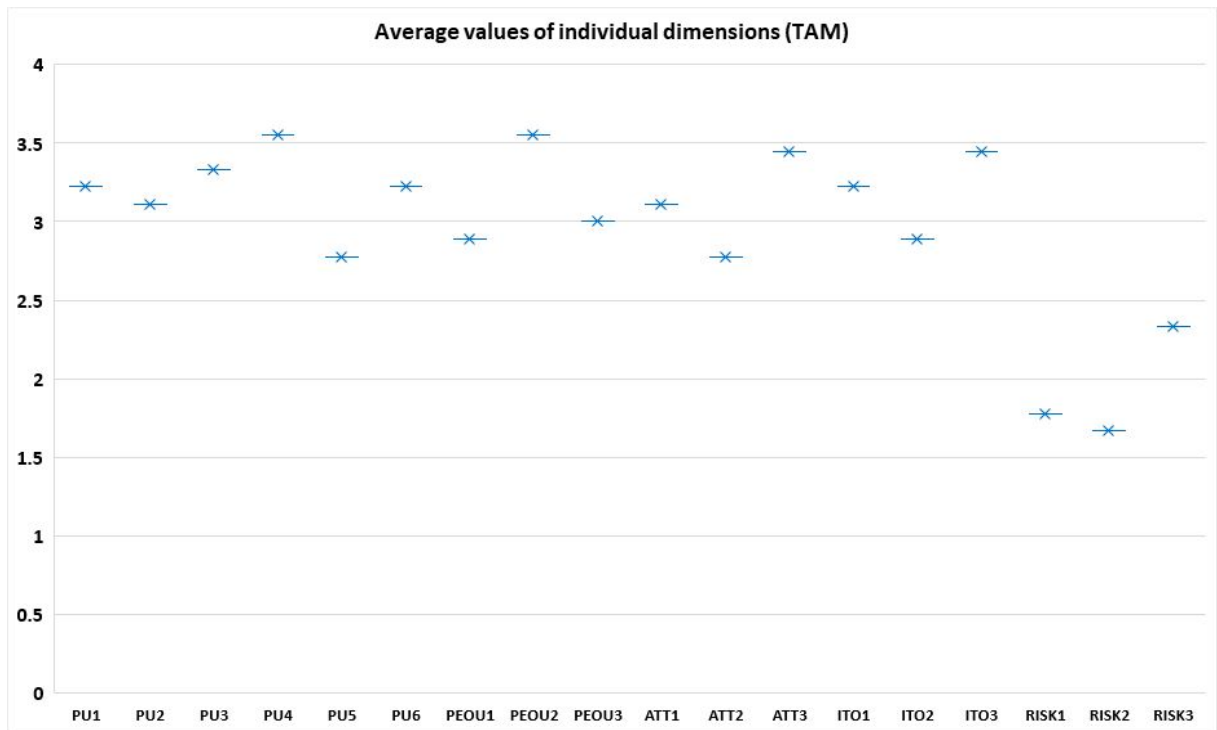
- Perceived Usefulness (PU) - the degree to which a person believes that using a particular system would enhance their job performance
- Perceived ease-of-use (PEOU) - the degree to which a person believes that using a particular system would be free from effort
- Attitude (ATT) - the attitude of the user toward using the system

- Intention To Use (ITO) - the degree of intention of using the system
- Risk assessment (RISK) - the magnitude of risk perceived by the user

Generally, RISK is not involved in the TAM metrics, however, for our system, it is very valuable to get an idea of what users feel about the potential risks involved in using it, since health data is a very sensitive and personal type of data. The questions that have been used and the raw data have been included in Appendix C. Here are the results:



As illustrated by the figure above, the overall responses from the users are positive. Adapting to use an app to perform an everyday task that people have been doing for years (such as taking medicine) is not easy and requires working against habit. Therefore, we were particularly interested in the responses to “Intention To Use” questions, to see if people would actually want to use this app and recommend it to others. As we can see from the ITO columns, the responses are in fact, in favor. If we have a look at the average values for each dimension in figure (shown below), we can see that other than our three questions related to risks, the average values for other dimensions are over 2.5. The values for the risk related questions being low means that users would feel safe and secure in using the app.



### 8.3 Cognitive Walkthrough and Think Aloud Protocol

#### Testing Plan:

A Cognitive walkthrough is a commonly used way of determining how easily people can respond or use a new system. For our testing, we have combined it with think aloud protocol, where the user is encouraged to be vocal about their thought process while performing the tasks. This means that we have prepared a set of tasks for the user and given them our prototype for them to use to accomplish those tasks. Furthermore, it complies well with the cognitive walkthrough ideology of “exploratory learning” - which signifies first time using without formal training or directions [31]. This created a formalised way for us to imagine people’s thoughts and actions when they use our app and helps us identify any issues a new user may face.

Our goals of the observation is to:

- Observe users interacting with the app; understand how users interact with the app and their expectations
- Unveil difficulties encountered by new users
- Understand feelings towards UI features such as buttons, positioning, navigation etc.
- Evolve and enhance prototypes using the feedback collected.



Being primarily a cognitive walkthrough testing, the tasks were formatted in such a way that a group of short tasks together accomplished a complete objective or goal. These tasks are listed below.

#### Objective 1: Determine the risk of a given medicine

- Open PillX app
- Login with our provided login details
- Find the scanner
- Scan the medication
- Find visual information regarding the side effects of that medication

#### Objective 2.1: Setup a schedule for your medications (automatically)

For this objective, the user was provided with a prescription that contained detailed timings for the medications such as ("take this medicine every morning before breakfast") so the app can automatically create a schedule for the user.

- Open PillX app
- Login with our provided login details
- Find the scanner
- Scan your medication
- Add the medicine
- Review the automatically generated schedule for the medications

#### Objective 2.2: Setup a schedule for your medications (manually)

For this task, the user was given a prescription that did not contain clear direction form timings and the user could choose time slots such as "Before Breakfast", "After Lunch" etc. to quickly allocate time for their medication.

- Open PillX app
- Login with our provided login details
- Find the scanner
- Scan your medication
- Select time slots for your medications
- review your medication schedule

### Objective 3: Browse and explore the app (focused on **think aloud**)

- No proper directions were given for this task other than asking the user to talk about their thoughts and thinking process

#### Results:

All eight people who agreed to participate managed to successfully complete the tasks. Indeed the tasks are not meant to be complex or intellectually challenging, rather what we are most interested in is the user's experience and thought process while completing the tasks.

The app navigation is fairly simple and straightforward and no user required assistance in finding relevant sections of the app. However, we did get some questions regarding the visualisations. When asked to be vocal about their thought process, a couple of users expressed concerns regarding the size of their phones' display, thinking it'd be too small to have a proper look at what the visualizations were trying to say. This is a very important point, which means in future iterations of the app, we need to competently consider smaller screen devices and ensure the visualisations are clearly visible and that users can zoom in to have an even better view. People also questioned how accurate the visualisations are and even though we are aware that our visualisations will be created based on research on unaltered, statistical data, this made us realise that people may still hesitate to take medical advice from a non-human entity. A potential mitigation for this issue is to have a disclaimer pop up at the initial start up of the app, stating that it only aims to assist people in better understanding the medical data they already have and medications they already use, and is not going to give them diagnosis or medical advice.

## 9 Areas for Investigation

It is evident that there is a communication gap between doctors and patients due to varying levels of literacy, language barrier and the inherent complications that come with relying on verbal communications. However, there are a number of issues to consider when developing a solution to this problem.

A project of this magnitude and significance will come with challenges at every stage, many of which will not have simple solutions. Some of the most critical areas have been identified below and require further research.

### 9.1 Privacy

The stakeholders of the project have been identified, but what will facilitate their own engagement with the suggested system? It is clear that the privacy of medical data is a major concern of many patients. The problem with a generalised solution for making health data accessible is that different people have different privacy preferences. The data needs to be private between the patients and their associated healthcare professionals, since health data can be highly sensitive. These healthcare professionals could be subject to multiple lawsuits regarding negligence, if the digital health data of a patient is leaked, since that has the potential to compromise the patient in various ways [1]. It is therefore imperative to research the underlying security infrastructure that needs to be in place ensuring proper encryption, protecting data from third parties and most importantly, giving privacy control to the users. The first step to achieve this would require that the stakeholders have proper communication, so that everyone is made aware of the implications of online information networks [1].

### 9.2 Cost and security

A study conducted in Canada discovered that the biggest obstacle in digitizing health data is the lack of financial resources. For this system to work, an extensive integration process will have to be undertaken, so that the patients not only get access to digitized medical data from here onwards, their previous data can also be imported. It is difficult to predict the cost of such an operation and thus thorough investigation in this area is critical. A patient may go to different healthcare organisations, therefore, a proper, generalised way of storing all these data is essential. [2]

Another inherent concern that is ever present with the digitisation of any valuable or sensitive information is security. When dealing with people's medical data, the concern for security will raise legal questions and will require approval from the appropriate governing body. Furthermore, adapting new technology may lead to unpredictable issues including security compromises, as well as technical problems. The developers will need to work closely with the governing body, healthcare professionals and the patients to ensure that the integrity of the infrastructure is strongly built and legal terms have been agreed upon.

### 9.3 Adaptability, Liability and Responsibility

Perhaps one of the biggest problems this project may face is meeting the expectations of the patients and being able to match our conceptual model with their mental model. The area of investigation that is required here is researching the possible typical use cases of our solutions. For example, patients may want to use this newly acquired health data and use it to gather information about any health related complications they are facing, on online services. Further research into this matter could unveil ways ensuring they get "authoritative" answers.

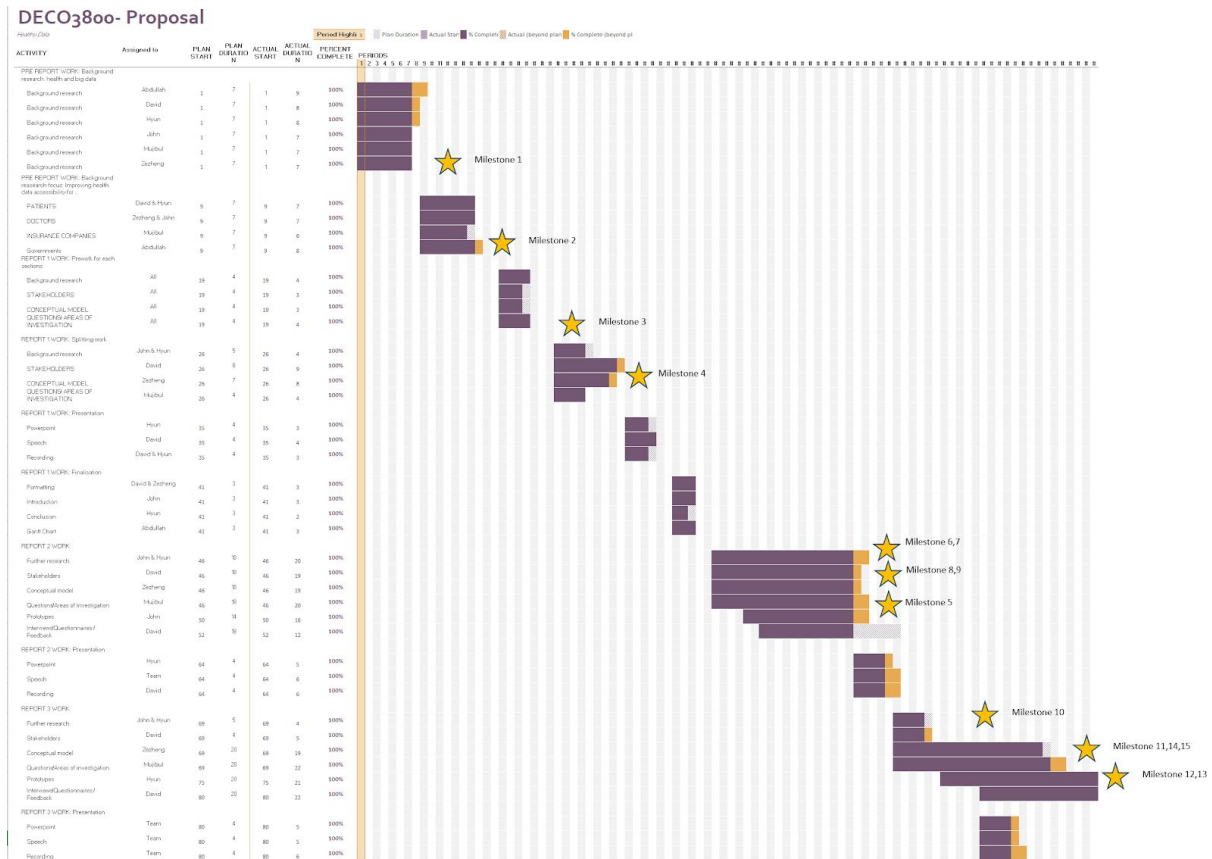
Certainly, to make this project possible, some familiarity with technology is a prerequisite for both patients and doctors. A study conducted by Kassirer [3] has unveiled that a rise in patients' expectations of their doctors using electronic communication is seen, when they start doing the same. Doctors will definitely have to adapt to this new system and this may lead to further complications as they have varying levels of proficiency using technology.

The emergence of electronic health data may also foresee patients having greater expectations from their healthcare providers, expecting faster and more thorough information [4]. Furthermore, this may also lead to other liability concerns regarding online communications that may be a consequence of adapting this system. Further research is required here, to ensure the healthcare workers are deprived of professional liability and the system's infrastructure provides a clear, concise and responsible use of this new technology.

# 10Process Documentation

The following section contains documentation that was utilised in the planning of this proposal. It is evidence of work done and displays the projects progress throughout the semester.

## 10.1 Project plan



## 10.2 Task Breakdown

- Milestone 1: Background research into Big data and Health
  - Goal: We aim to do further research into the big data and health fields to get a clearer understanding of the problem domain we are working in.
  - Risk: Research into such a broad area may cause complications later on when narrowing down scope
- Milestone 2: Background research into the problem statement: Improving health data accessibility for x
  - Goal 1: Narrowing down the problem space to a particular target audience so the problem space is focused on addressing a particular target audience
  - Goal 2: Narrowing down the research with the help of problem statement so it is specific and workable
  - Risk: This may not be the best way to narrow down research area- misleading us into wrong direction
- Milestone 3: Research into STAKEHOLDERS
  - Goal: Have a better understanding of our stakeholders and analysing the impact of the problem space on our stakeholders
  - Risk: An incorrect understanding of stakeholders is formed causing the product to not suit the stakeholders
- Milestone 4: Developing conceptual model
  - Goal: Conceptualise the problem space and hence work towards a clearer problem
  - Risk: It may be difficult to capture the research as a conceptual model which would further negatively affect the final product
- Milestone 5: Questions/Areas of investigation
  - Goal: Questions to be answered to fill in our gaps in knowledge and areas of further research
  - Risk: Questions and areas of investigation may cause an incorrect direction of work

- Milestone 6: Sketches/Studies
  - Goal: Analyse and compare similar/existing products on the market to improve upon and draw inspiration from
  - Risk: Our product may become too much like existing products with little original ideas
- Milestone 7: Narrowing down problem space: Decide type of health data
  - Goal: As the idea of improving health data understandability for patients is still broad, research and decide what type of health data we will work with
  - Decision: Blood test data and Medicine data
  - Risk: Incorrect decision will cause more difficulty when developing the product due to lack of research information
- Milestone 8: Further research into TARGET AUDIENCE
  - Goal: Narrowing down the target audience: Define the audience in terms of types of patients in addition to age so that the product is directly beneficial to them
  - Risk: By limiting our target audience, we may miss some features which may appeal to greater audience than the ones selected
- Milestone 9: Research into medical processes
  - Goal: To pinpoint where our product would fit into a patient's medical process and how it will better the current process.
  - Decision: Before taking medicinal pills
  - Risk: Insufficient understanding in regards to where product fits into process causing it to not be allowed into the process due to the nature of health data privacy laws

- Milestone 10: Risks
  - Goal: To get an in depth understanding of the risks involving our product and factors that may help mitigate them risks.
  - Risk: An insufficient understanding and mitigation of risks may unknowingly cause great damage to product both in development and deployment
- Milestone 11: Revising conceptual model
  - Goal: Revise the conceptual model to account for new ideas and integrate research
- Milestone 12: Prototyping
  - Goal: To create a simple prototype reflecting our conceptual design
  - Risk: Due to the nature of prototyping, the prototype may not sufficiently be able to display the research and the new ideas, conveying a poor understanding of the problem and solution space and of conceptual design and design guidelines
- Milestone 13: User testing
  - Main goal: To collect user feedback for the prototypes. This would reflect real world usage and would provide greater insights into the usage of the product
  - Goal 1: Check to see if type of solution is compatible with type of patient
  - Goal 2: Collect data on how comfortable users are with the medical data visualised in another manner
  - Risk: Due to the nature of prototyping, the prototype may not sufficiently be able to display the research and the new ideas, conveying a poor understanding of the problem and solution space and of conceptual design and design guidelines



- Milestone 14: Update Questions/Areas of investigation
  - Goal: As many of the previous questions and areas of investigation were already addressed, new ones need to be brainstormed. This will allow for further improvement and development
  - Risk: Incorrect judgement of areas of investigation may lead to an incorrect way of research and development causing more harm than good.
  
- Milestone 15: Incorporate tutor feedback into report
  - Goal: To ensure the team is on the right track and keeps on the right track, it is important to not only integrate feedback of users but UX experts. The tutor feedback is therefore imperative to be integrated into development
  - Risk: The tutor feedback may be clashing/opposing user feedback.

## 10.3 Risk Assessment

### Risk Assessment

		Consequences				
		Insignificant (1) Minimal financial loss	Minor (2) Medium financial loss	Moderate (3) High financial loss	Major (4) Large financial loss	Catastrophic (5) Massive financial loss
Likelihood	Almost Certain (5) Often Occurs / once a week	Moderate (5)	High (10)	High (15)	Catastrophic (20)	Catastrophic (25)
	Likely (4) Could easily happen / once a month	Moderate (4)	Moderate (8)	High (12)	Catastrophic (16)	Catastrophic (20)
	Possible (3) Could happen or known it to happen / once a year	Low (3)	Moderate (6)	Moderate (9)	High (12)	High (15)
	Unlikely (2) Hasn't happened yet but could / once every 10 years	Low (2)	Moderate (4)	Moderate (6)	Moderate (8)	High (10)
	Rare (1) Conceivable but only on extreme circumstances / once in 100 years	Low (1)	Low (2)	Low (3)	Moderate (4)	Moderate (5)
Reference: Cole, S. (2015)						

Item No.	Risk Item	Effect	Cause	C	L	R	Action to Mitigate	Owner
1	Meeting Project Deadlines	Assessed aspects of Project not met in a timely manner	Poor planning, time management and execution	3	4	12	Project plan is <u>created</u> and team leader keeps members on task and on time	Hyun, Abdullah
2	Problem space investigation	Research into such a broad area may cause complications later on when narrowing down scope	The broad area of investigation	1	3	3	Reflect on each members research but as a team decide a certain direction of the project	Team
3	Narrowing down problem space according to problem statement	This may not be the best way to narrow down research area-misleading us into wrong direction	Poor wording of problem statement	2	4	8	Consult with all team members and consult with tutors to reach a consensus	Team
4	Research into Stakeholders	An incorrect understanding of stakeholders is formed causing the product to not suit the stakeholders.	A very shallow understanding of stakeholders	2	3	6	Stakeholders can be identified and be iterated over the course of the whole project to ensure product suits them	David
5	Developing conceptual model	It may be difficult to capture the research as a conceptual model which would further negatively affect the final product	Inability to conceptualise the background research	3	4	12	Iterate over the conceptual model to express the research as well as possible	Kevin
6	Questions/Areas of investigation	Questions and areas of investigation may cause an incorrect direction of work	Poor decision making due to influence of investigative questions and areas of investigation identified	3	2	6	The questions and areas of investigation should be broad and cover a range of topics rather than narrowing down into a specific section	Mujibul
7	Studies and sketches	Our product may become too much like existing products with little original ideas	Copying components of other products rather than using them for inspiration	2	2	4	As a group discuss the features of the product while consulting with tutors to ensure originality and creativity	Team

8	Narrowing down problem space: decide type of health data	Incorrect decision will cause more difficulty when developing the product due to lack of research information	An incorrect decision was made in regards to selecting the type of health data	3	2	6	Consult with all team members and consult with tutors to reach a consensus	Team
9	Further research into TARGET AUDIENCE	By limiting our target audience, we may miss some features which may appeal to greater audience than the ones selected	Narrowing down the target audience (in terms of types of diseases and age)	2	2	4	After an initial set of requirements is created due to the research into target audience, it can be iterated to include other features benefitting a greater target audience	David
10	Research into medical processes	Incorrect understanding in regards to where product fits into process causing it to not be allowed into the process due to the nature of health data privacy laws	Insufficient understanding of medical process	5	3	15	Do in depth research into this field as well as consulting professionals in this field	John
11	Research into risks	An insufficient understanding and mitigation of risks may unknowingly cause great damage to product both in development and deployment	Insufficient understanding of risk factors	4	3	12	Use industry standard risk management criteria. Mitigation can be researched into and discussed with industry professionals	Abdullah, Kevin

12	Prototyping	Due to the nature of prototyping, the prototype may not sufficiently be able to display the research and the new ideas, conveying a poor understanding of the problem and solution space and of conceptual design and design guidelines	Difficulties translating design guidelines and conceptual model into the prototype	2	4	8	Iterate over prototypes to ensure as much of conceptual model is translated into the prototype as possible	Hyun
13	User testing	The feedback may not be collected correctly and may cause the product to become worse than better	Incorrect method of collecting feedback	3	2	6	Use multiple methods of collecting user feedback, both quantitative and qualitative	David
14	Update Questions/Areas of investigation	Incorrect judgement of areas of investigation may lead to an incorrect way of research and development causing more harm than good.	Incorrect judgement of areas of investigation	3	2	6	Questions and areas of investigation will be justified why they are being investigated. Although new areas can be explored there is no necessity to incorporate those areas into the end product	Mujibul
15	Incorporate tutor feedback into report	The tutor feedback may be clashing/opposing user feedback and if integrated may directly cause the product to become worse	The tutor feedback may be clashing/opposing user feedback.	3	1	3	To be dealt with individual basis, giving more weighting to user feedback	Mujibul

## **Additional discussion**

For any potential use case of health apps, risks and potential hazards must be minimized to reduce any chance of causing undesirable effects to the users. There has been different health literature prompting the general public of the various dangers that could arise from the misuse of smartphone applications in the health context. However, it seems apparent that most of the data protection is not in place and are frequently reported but as to the danger that could be caused through using the health application, the number is not statistically significant to cause a serious discussion.

It is to note, that in the field of medical devices, the closest analogy we can observed with the creation of our potential health app, that there are several possibilities that hazards may arise:

On one hand, malfunctions(incorrectly implemented functionalities as a result of incompetent initial design iterations) could be potentially damaging, while on the other hand, incorrect usages/user - errors, due to the inherient nature of the design of the system could be problematic, this tends to arise when the application is been used in without the intended purpose in mind or if the requirements of specific usage scenarios were not been given due consideration.

Furthermore, since current mobile systems all have the ability to enable internet communications, it is therefore, while attempting to make the application itself more accessible, the potential of misinformation as a result or been distributed by the system could be a serious source of danger. This becomes more critical if the information that the system aims is part of the decision making process, hence inaccurate diagnosis, as well as potential identification of unsuitable treatment can cause dire consequences, therefore pose a significant damage potential for the health of the users of the system.

## **Some ethical consideration**

The lifelogging capabilities that are evident on some of the modern IoT devices has proven to be a great opportunity to improve care. However, this is one of the many known issues regarding the transparency of the usage of such large amounts of data to the benefit of many.

In the context of ethics, the means of protecting user data and its security forms the basis of the term 'privacy' in our context, and it is also a subject of both legal and technical discussion.

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# 12Appendix A

## Necessary features of a PHR Implementation

- 1) Patients should be able to access and view their medical records through a PHR system.
- 2) Information in the PHR system should be up-to-date.
- 3) Medical Information should be presented in a cognitively accessible way.
- 4) Patients should be able to edit their medical records, annotate them or in the least request the responsible medical professionals to make corrections for them.
- 5) PHR should be accessible
- 6) Each individual should control access to their PHR.
- 7) A possibility for an emergency access should exist.
- 8) The individual should know who accessed their account and what actions were performed.
- 9) Capturing cost information
- 10)Documentation printing
- 11)Secure messaging
- 12)Prescription refills
- 13)Appointment scheduling
- 14)Reminders
- 15)Notifications
- 16)Educational information
- 17)Support groups
- 18)Device integration
- 19)Decision support
- 20)Filing referral requests
- 21)Medicine information.
- 22)Address book
- 23)Quality comparisons
- 24)Localization
- 25)Searching

# Appendix B

## User testing - Questionnaire results

Drug: Razadyne - Alzheimer's			
What does the drug do?	When should the drug be taken?	If you were prescribed this drug, what information is relevant?	If you were prescribed this drug what information would you like to know?
Improves communication between nerve cells by increasing the levels of the essential transmitter, acetylcholine	One in morning, one at night, with food if possible	Dosage times, side effects, what the drug does	Dosage times, side effects, what the drug does, how common the side effects are, implications if its missed.
Improves communication between nerve cells	One in morning, one at night, with food if possible,	Dosage side effects, what it does	Dosage and time, side effects, what it does, how common are the side effects, what happens if I miss a dosage
Improves communication between nerve cells	2x a day, one in the morning, one at night	When I should take it, what it does, side effects, is it safe for me to take	The same as above, - more so of side effects and when I should take it.
Improves communication between nerve cells, increasing levels of acetylcholine which is involved in learning etc,	2 times a day - 1 in morning, 1 in the evening	All of it	What it does, side effects, when to take it
Razadyne is analzheimer's medication that improves communication between nerve cells by increasing the levels of neurotransmitters	1 in the morning 1 in the evenings Twice a day with food	Common side effects may include -nausea, vomiting, diarrream, loss of appetite - headache dizziness or weight loss	Side effects, warning not to take if.. When to take it
Improves communication between nerve cells	Twice daily, one in the morning and one in the evening	The side effects - nausea, vomiting, diarrhea etc	Side effects, when to take it, what it does and if it is safe for you
Improves communication between nerve cells	Twice daily, one in morning and one at night	Side effects of: Nausea, vomiting, diarrhea, loss of appetite, headache, dizziness or weight loss	Side effect, when to take, dosage
Acts to improve communication between nerve cells by increasing the levels of the essential neurotransmitter actylcholine	Twice a day, one in the morning, one at night	Warning information, dosage information	Drug information, additional information (eg, side effects
Boosts/helps people with Alzheimer's by increasing the	Twice daily, one in the morning, one at night preferably	Warning, side effects, times to take drug, what it does	Drug info, side effects, intake times

levels of essential neurotransmitters	with food		
Acts to improve communication between nerve cells	Twice daily - one in the morning, once at night preferably with food	The warning section, when to consume	Drug info, warning info, when to take the drug
Improves communication between nerve cells by increasing the levels of the essential neurotransmitter (involved in learn, thinking and the memory process)	Twice daily - on in the morning, one at night	To ensure it is safe, check if any pre-existing conditions are affected by it	Known side effects and other safety info included
Improves communication between nerve cells	2 times a day, Once in the morning and the evening	Checking beforehand if Razadyne is safe for you Common side effects	Same as Q3 + what to do if dose is missed
Improves communication between nerve cells	Twice daily - one in the morning and once at night, preferably w/food	The dosage times, side effects & what it does	Dosage times, side effects, what it does, how common are side effects, implications if it is missed
Razadyne improves nerve cell communications by increasing the essential neurotransmitter acetylcholine	One in the morning and one in the evening (2 a day with food)	When to take it, common side effects, what the drug is meant to do and how it helps	Same as Q3
Drug: Loestrin 23 - Birth control			
What does the drug do?	When should the drug be taken?	If you were prescribed this drug, what information is relevant?	If you were prescribed this drug what information would you like to know?
Prevents ovulation, changes in cervical mucus and uterine lining and make contraception harder	1 a day, whenever you choose but the same time every day	Dosage times, side effects, what the drug does	Dosage times, side effects, what it does, how common the side effects are, implications if missed
Prevents ovulation, changes cervical mucus & uterine lining	At the same time everyday	Dosage side effects, general info, when not to take it	How many people have side effects, how severe are the side effects
Prevents ovulations, makes it difficult for sperm to reach uterus	Once per day at the same time	Warning section, when to consume	Drug info, warning info, when to consume
Reduces chances of conception, is a	Once every day at the same time	Criteria for pre-existing conditions	Side effects, warning about pre-existing

form of birth control			conditions, the effectiveness of the drug
Contains female hormones that prevent ovulations & causes changes in cervical mucus & uterine lining	Once at the same time every day	Dosage time, side effects, when not to take it	Dosage times, side effects, implications, when a dose is missed, when not to take it.
Prevent ovulations, changes in your cervical mucus	1 time each day at the same time	All of it	Warnings, chances of unwanted pregnancy
Prevents ovulation, changes cervical mucus and uterine lining, making it hard for sperm to fertilise egg	1 times a day at the same time	When not to take, effects from taking it and the chance of it working	Same as Q3

Appendix C

TAM data

Dimension	Question	R1	R2	R3	R4	R5	R6	R7	R8	R9
PU1	I can find information about the medicine I take quickly using Pilix	3	3	2	3	4	3	4	4	3
PU2	I can manage my daily medicine dosages easily with Pilix	3	3	3	2	3	4	3	4	3
PU3	I can determine when to take my medicine more quickly using Pilix	3	4	4	4	3	2	2	4	4
PU4	I can understand what my medicine does more easily using Pilix	4	4	3	3	3	4	4	3	4
PU5	Pilix enables me to make better decisions about my health	3	2	2	3	3	2	3	3	4
PU6	Overall, I find Pilix useful	3	3	4	3	2	3	3	4	4
PEOU1	Learning to use Pilix is easy for me	2	2	3	3	4	3	3	3	3
PEOU2	It is easy to use Pilix to schedule my medication times	3	3	4	4	3	4	4	4	3
PEOU3	Overall, I believe Pilix is easy to use	3	3	2	3	3	4	4	3	2
ATT1	In my opinion, it is desirable to use Pilix	3	2	2	3	3	4	3	4	4
ATT2	I think it is good for me to use Pilix	1	3	2	3	3	2	4	4	3
ATT3	Overall, my attitude towards Pilix is favourable	2	3	3	4	4	3	4	4	4
ITO1	I will use Pilix on a regular basis in the future	1	3	2	4	4	4	4	3	4
ITO2	I will frequently use Pilix in the future	1	3	2	3	3	4	3	3	4
ITO3	I will strongly recommend others to use Pilix	3	3	4	4	3	3	4	4	3
RISK1	I think using Pilix has a potential risk	2	2	3	2	1	1	2	1	2
RISK2	I think using Pilix may compromise my privacy	2	2	1	1	1	2	1	2	3
RISK3	I clearly understand the possible risks of using my medicine using Pilix	2	2	2	3	2	3	2	2	3



