Image courtesy of Adapt, Sprout Social [16]

Improving patient understanding of health data

Studio III – Proposal - Problem Identification

Healthy Data

Hyun Jeon 42865320

David Cunningham 40988980

John Roby John 44314804

Abdullah Shahzad 44807351

Zezheng Shi 44856078

Mujibul Islam Dipto 44961374

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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

2 Background research

2.1 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.

2.2 Benefits of access to a person's medical records

[12] discusses 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.

2.3 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.

[3] 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.

In the context of health and medical data, this approach seems to be an appropriate solution. This project should aim to convert perplexing medical information into a graphic that is easily understood.

2.4 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 adaquate 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.

2.5 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.

Revisiting [8], a panel of experts have compiled a list of 25 end user features which are necessary for a successful 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

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.

2.6 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.

2.7 Privacy and Security

[7] is one example of the backlash Google received when news broke that it's 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.

[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 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.

4 Conceptual model

4.1 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.

4.2 High-level description

The solution addressing this problem space will be a mobile application that aims to provide 'always accurate' and user friendly data. It will provide visualization aids in order to present the data in a more graphic way. 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 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].

4.3 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.

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.

4.4 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.

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.

4.5 Interaction modes

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.

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.

4.6 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.

5 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.

6 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..

6.1 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].

6.2 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.

6.3 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.

7 Next steps

This report has demonstrated the scale of the problem space, and the difficulties involved in implementing a single solution covering all the associated issues. Reflecting on this, the next step in the project should be to narrow the focus on a subset of the target group (patients), and to revise the associated issues.

Once this has been achieved, stakeholders should be redefined and the conceptual model should be iterated on in order to hone in on what the requirements of the final system will be.

Additionally, questionnaires should be developed and distributed to members of the target group and associated stakeholders in order to uncover issues that may arise from the system. This feedback can also be used to further iterate the conceptual model of the project.

Finally, once the project focus has been narrowed, the risks and areas of investigation should be reconsidered in order to prepare fully for future project development.

A detailed breakdown of upcoming tasks and role assignment has been included as a form of a Gantt Chart. (See appendix 1)

A team charter has been created detailing the agreed processes for team maintenance. (See appendix 2)

8 References

[1] Beard, L., Schein, R., Morra, D., Wilson, K., & Keelan, J. (2012). The challenges in making electronic health records accessible to patients. Journal of the American Medical Informatics Association : JAMIA, 19(1), 116–120. https://doi.org/10.1136/amiajnl-2011-000261

[2] Urowitz, S., Wiljer, D., Apatu, E., Eysenbach, G., DeLenardo, C., Harth, T., Pai, H., & Leonard, K.J. (2008). Is Canada ready for patient accessible electronic health records? A national scan. BMC Medical Informatics and Decision Making, 8, 33 - 33.

[3] Kassirer, J. P. (2000). Patients, Physicians, And The Internet: Coming generations of doctors are ready to embrace new technology, but few incentives now exist to encourage their older peers to do likewise. Health Affairs, 19(6), 115-123.

[4] Hoffman, S., & Podgurski, A. (2009). E-Health hazards: provider liability and electronic health record systems. Berkeley Tech. LJ, 24, 1523.

[5] Ali sunyaev, Evaluation of Microsoft HealthVault and Google Health personal health records, ResearchGate, Cologne, Germany, April,10,2020,[online], https://www.researchgate.net/publication/256997582_Evaluation_of_Microsoft_HealthVault_and_Google_Health_personal_health_records

[6] Donal brown. What The Failure of Microsoft's HealthVault Means for the Future of EHRs. HIT CONSULTANTS.

https://hitconsultant.net/2019/04/19/what-the-failure-of-microsofts-healthvault-means-for-the-future-of-ehrs/#.XqF0_sgzaUk (accessed 16, April, 2020).

[7] Mary Beth Griggs. Google reveals 'Project Nightingale' after being accused of secretly gathering personal health records. The Verge.com https://www.theverge.com/2019/11/11/20959771/google-health-records-project-nightingale-privacy-ascension(accessed 18,April, 2020).

[8] Ali sunyaev, Demitry Chornyi, Christian Mauro, Helmut Krcmar ,Evaluation Framework for Personal Health Records: Microsoft HealthVault Vs. Google Health

, ResearchGate, Garching, Germany, April,10,2020,[online], https://www.researchgate.net/publication/221177010_Evaluation_Framework_for_Personal_Health_Records_Microsoft_HealthVault_Vs_Google_Health

[9]No isolation. Why do many seniors have trouble using technology?. No Isolation.https://www.noisolation.com/global/research/why-do-many-seniors-have-trouble-using-technology/(accessed 23, April, 2020).

[10]Marketing Charts. Misuse of Personal Data Is the Leading Cause of Tech Industry Distrust. Marketing Charts. https://www.marketingcharts.com/customer-centric/privacy-and-security-108199 Accessed(23, April, 2020).

[11] Suzanne Graham, John Brookey. Do Patient Understand. The Permanente Journal.https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3037129/ (accessed 14, April, 2020)

[12] Stephen E. Ross, Chen-Tan Lin MD. The Effects of Promoting Patient Access to Medical Records: A Review.JAMIA.https://www.ncbi.nlm.nih.gov/pmc/articles/PMC150366/ (Accessed 14,April,2020).

[13]L. Anderson. What are the benefits and risks of taking birth control pills?. Drugs.com. https://www.drugs.com/article/birthcontrolpill-risks-benefits.html (accessed 14,April,2020).

[14] R. Hartson and P. S. Pyla, The UX Book: Process and guidelines for ensuring a quality user experience. Elsevier, 2012.

[15] J. Belluz, The truth about WebMD, a hypochondriac's nightmare and Big Pharma’s dream. Vox.com https://www.vox.com/2016/4/5/11358268/webmd-accuracy-trustworthy

[16] Ryan Frazier, Adapt, In-network care: why healthcare orgs should invest in social listening, stat https://sproutsocial.com/adapt/healthcare-social-listening/?utm_campaign=SproutSocial&utm_medium=social&utm_source=pinterest&utm_content=1531883764

9 Appendix

Gannt Chart of plan and team charter
https://drive.google.com/open?id=171fIBycaneLdTN_SdAwcCgMBr30RSLEk