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Patient Home Monitoring: Challenges and Opportunities

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Abstract

The need for and use of patient home monitoring (PHM) and electronic medical records (EMR) are both growing. However, there are issues with the current implementations of these systems. Some of these include collection and transfer of data, integration with existing systems and with data analysis methods, security, and patient privacy. The field of medicine could benefit from implementing a more efficient means of tracking and caring for patient's illnesses. Specifically, the recent explosion of innovation for monitoring devices that can be successfully deployed in a patient's home or on their person has transitioned from a distant vision to a present reality. This present reality provides a significant opportunity for a healthcare system to leverage these innovations. This 'at home' approach for treating patients allows health professionals to better monitor their patients with curated visualizations of that data. Simultaneously, these devices empower the patient by providing an opportunity to take their health into their own hands.

This report presents research results, based on literature review, interviews, and vision seminars to achieve successful implementation of patient home monitoring (PHM) systems. It considers data, devices, usability, and security of those devices and the data they collect. These devices monitor vital signs, blood glucose levels, respiratory proficiency, and many other indicators. Usability must be carefully considered in the planning process. A well-designed device will be rendered inadequate if the people do not embrace it. The handling of the data as well as data ownership, analytics, and means of storage need to be determined. Patients', doctors', and IT professionals' opinions were deeply considered for privacy and security due to how vital these areas are to the success of PHM solution implementation.

People capitalizing on these PHM devices will feel empowered by receiving the opportunity to play a more significant role in their own health and care. They will work much closer with health professionals, and be able to greatly reduce unnecessary trips to the hospital or doctor's office. Health professionals that were interviewed said that by allowing more care to happen in the patient's home, it will undoubtedly alleviate pressure on doctors and other health care providers. These changes will ultimately improve the hospitals' preventative service and could greatly increase overall efficiency of treatment.

Abstract

Teknikens framsteg det senaste decenniet har gjort det möjligt för sjukvården att ta nästa steg mot en effektivare patientvård. Teknik i patienters hem i form av hemvårdssystem har gått från en avlägsen vision till en nuvarande verklighet. Denna teknik är bra för patienten eftersom att den gör det möjligt för sjukvårdspersonal att ge sina patienter kontinuerlig vård och kunskap om deras hälsa.

I denna rapport har studenter från tre universitet samlat in information från omfattande akademisk forskning och intervjuer för att utvärdera möjligheterna och utmaningarna med att implementera hemvårdssystem. Från intervjuer med sjukvårdspersonal, patienter, IT-specialister och studier av tidigare implementerade hemvårdssystem är det patientdata, monitoreringsenheter, användbarhet och säkerhet som tas i beaktning vid implementation av hemvårdssystem.

Våra studier visar framför allt att för att ett hemvårdssystem ska användas av patienter och sjukvårdspersonal bör det utvecklas efter deras behov och tekniska kunskaper. Sjukvårdspersonalen som intervjuades värderade kroniska sjukdomar och de vitala tecken som påverkar dem som den patientdata som bör monitoreras. Våra studier visar även att validering av den patientdata som skickas till sjukhusen är väsentlig eftersom att patienter kan lura monitoreringsenheter genom att inte följa ansvisningar och därmed kan felaktig data skickas till sjukvårdspersonal. På grund av att felaktig data kan skickas från patienter menar sjukvårdspersonal i våra studier på att hemvårdssystem inte kan vara något som vården baseras på till fullo utan ett kompletterande verktyg.

Hemvårdssystem kan göra det möjligt för patienter att få en betydande roll i sin egen vård. Genom hemvårdsystem kommer patienter att kunna arbeta närmare med sjukvårdspersonal och tillsammans minska onödiga resor till sjukhusen. Genom att göra det möjligt för vård i patienters hem kan det minska trycket på sjukvårdspersonal, förbättra sjukhusens förebyggande arbete och öka produktiviteten. Våra studier visar att den äldre befolkningen i Sverige kommer att fortsätta växa under de kommande åren och därav också antalet kroniska sjukdomar. Hemvårddsystem kan enligt sjukvårdspersonal vara det kompletterande verktyget som gör att sjukhus kommer att kunna ta hand om det ökade patientantalet.

Contents

This report is the result of a collaboration among seventeen students in the fields of Computer Science, Software Engineering and Information Science. These students are from the Uppsala University (Sweden), Rose-Hulman Institute of Technology (Indiana, U.S.A.), and Gannon University (Pennsylvania, U.S.A.). The different fields of study covered by these students offer various perspectives, and the combined research is intended for the Uppsala County Council. Annemieke Ålenius, the head of the Electronical patientjournal department from the academic hospital of Uppsala, presented this team with problems concerning innovation around patient home monitoring in the healthcare industry. This report attempts to identify and address those problems.

1 Introduction

Patient home monitoring (PHM) includes various technologies that individuals can use by themselves or with minimal professional aid to track their medical health. These systems can be self-prescribed or prescribed by a health expert in order to better care for an individual's health. In this report, the term PHM is used to cover the wide basis of technologies that patients can use in their home to empower themselves and improve their ability to stay healthy and knowledgeable.

This report presents research results into PHM, based on literature review, interviews, and vision seminars to achieve successful implementation of PHM systems. It considers data, devices, usability, and security of those devices and the data they collect. These devices monitor vital signs, blood glucose levels, respiratory proficiency, and many other chronic conditions. Usability must be carefully considered in the planning process. A well-designed device will be rendered inadequate if the people do not embrace it. The handling of the data as well as data ownership, analytics, and means of storage need to be determined. Patients', doctors', and IT professionals' opinions were deeply considered for privacy and security due to how vital these areas are to the success of PHM solution implementation.

Successful PHM solutions depend on sharing and use of patient data, normatively stored in electronic medical record systems (EMRs). However, there are issues with the current implementations of EMR systems. Some of these include collection and transfer of data, integration with existing systems and with data analysis methods, security, and patient privacy [49]. These issues are compounded when considering PHM, which distributes the collection of patient medical data outside of the health-care practitioners' location [26]. The advantages and risks of moving medical data collection outside the practitioners' locations results in both challenges and opportunities. PHM challenges include data integration with EMR 4.3, ownership of response to PHM-triggered events 5.1, and privacy 4.4. PHM opportunities could benefit an entire healthcare system, and include establishing a more efficient means of tracking and caring for patient's illnesses, using data for research 5.2, improved personal freedom for patients and the potential for significant productivity improvements: fewer patients in need of office and hospital care 5.3 because they are better cared for an monitored at home.

These opportunities for PHM technologies have recently become more apparent. As more healthcare institutions adopt monitoring systems, [41, 44, 49, 63] the benefits are outweighing the problems. A major advantage for hospitals is the ability for the PHM device to assess a minor issue and keep the patient out of the hospital 5. A properly implemented PHM system can also benefit the patient's personal freedom. Real time updates from the PHM devices can free patients from regular appointments 4.2. Although monitoring has its place in general healthcare it can also be used to more precisely monitor specific health conditions 4.2. PHM devices that are designed with specific ailments in mind often produce less data with better results which is beneficial to the IT staff managing the system as well as the users 4.3.

When it comes to healthcare, implementation of patient empowerment is found when patients are given the ability to see their own health data and are not limited by their doctor. With PHM, patients gain the

ability to take a more active role in ensuring their own health. Empowerment lies in giving the patient a real-time analysis to see how his or her health is doing, gaining power of tracking their own health, without taking any risks in the process. This helps patients remain informed about their medical health status and reduces feelings of helplessness. Essentially, it means putting the individual in control of their health rather than forcing them to take only their doctor's opinion whether they should be treated or not. Patient empowerment is a very important topic and is beneficial to all patients because they will be more likely to actively participate in maintaining their health if they have more control and can see the usefulness of their participation.

Innovation in healthcare is a widely discussed topic [47] [7] and can be considered very complex as there are many forces that can drive innovation – or hinder it [62][42]. Summarizing some of these difficulties influencing the innovation, first, there are many different players, each with their own agenda. These players and their reasons for caring about PHM are discussed in the section Stakeholders (3). A few players that are discussed include doctors, patients, and even hospital management personnel. The difficult goal is to create a new situation in which all the players are satisfied. Also, because the healthcare sector is a high-reliability organization, it must remain compliant with changing laws and policies [62][1]. These policies need to change often in response to rapid advancements in technology that help medical professionals to find new ways to offer more effective and convenient healthcare. Lastly, there are economical demands on the healthcare sector. It is expected that their products be cost-effective relative to competing products, according to Harvard Business School professor Regina E. Herzlinger [42]. When it comes to understanding the healthcare sector, one cannot look at a single force without looking at all the others. This report will focus on the technological perspective and looking into the forces that drive that innovation.

A verbal statement received from the Uppsala County Council reports that it is expected that the elderly population in Sweden will continue to grow in size over the coming years. This is an issue not just in Sweden, but in many other parts of the world as well. According to the World Health Organization, the world population of those over 60 years of age will double from 11% to 22% between 2000 and 2050 [6]. This is due mainly to the advances in healthcare, which increase the average life expectancy. With this understanding, there will be more pressure on the hospitals to care for the rising number of people who become ill. The expansion of the elderly population also includes an increased work pressure for physicians. A news article by the *Washington Post* mentioned that, "the United States alone faces a shortage of as many as 90,000 physicians by 2025, including a critical need for specialists to treat an aging population that will increasingly live with chronic disease" [23]. There is a clear need for improved productivity, while maintaining the current quality in order to meet this growing demand of elderly population. There is also pressure on the costs of this care[24]. If there are more elderly people and there is a drop in the young and working age group, according to Javier Espinoza, *Wall Street Journal* [37], there will be an increasing demand for healthcare and a decreasing tax base to pay for that demand. This means that healthcare systems will face the problem of cutting costs per patient. The cost efficiency must be improved in order to benefit both the patients and the healthcare system.

Due to this increase in the elderly population, more people suffer from chronic diseases [50]. Chronic diseases are diseases that cannot be cured; they can only be treated as an attempt to stop their progression. Healthcare generally consists of both curative and preventative services, but a distinction has to be made between types of preventative services. Prevention has three different stages: primary, secondary, and tertiary. Primary prevention seeks to prevent the onset of specific diseases via risk reduction. Secondary prevention includes detecting and treating changes, thereby controlling disease progression. Tertiary prevention handles a disease that has developed and has been treated in its acute clinical phase, seeking to soften the impact caused by the disease on the patient's function, longevity, and quality of life [20]. Healthcare must better support chronic diseases, and one way is by offering secondary prevention.

On top of a changing demographic landscape in which there will be fewer younger people and more senior citizens, healthcare systems are also under pressure to become more efficient as patients demand a much higher quality of service [37]. The idea of a docile and uninformed patient with little say on the quality and choice of care is changing. Now, patients want to understand their own healthcare situation better and make more informed decisions.

PHM thus provides the following four aspects that can be beneficial to healthcare:

- Productivity of doctors and hospitals can be improved, leading to: [64]
- More patients, elderly and otherwise, can be helped with the same number of doctors [64]
- PHM will help with cutting costs per patient and allowing better support for chronic diseases [65][26]
- PHM can empower patients to acquire information on their own and to take charge of their own health [43]

With these benefits in mind, this report displays how PHM can potentially revolutionize the healthcare industry.

Breaking it down, PHM seems to be the better option when considering the aspects above.

- Productivity of doctors and hospitals can be improved [64]

In order to handle an increase in patients, more hospitals could be built, but that requires time and the training of new physicians. Alternatively, precautions can be taken to reduce the number of patients who need hospitalization in the first place. Preventative measures help doctors keep patients in good health, which saves time for everyone involved. Using PHM systems in patients' homes would allow for them to check on themselves and only make a trip to the hospital when truly necessary.

- More patients, elderly and otherwise, can be helped with the same number of doctors [64]

Technology can help transition those patients from being hospital dependent to having their own personal doctor through technology. Dr. Jairo Mejia of the *Access Community Health Network* says, "...it's like having a doctor not only in your house but in your pocket" [32]. Instead of waiting in long lines for a short meeting with a doctor, PHM can help patients keep constant watch over their health. Patients can be in the comfort of their own home while still receiving care (Mr. Professional 2, Personal Communication, Oct. 09, 2015) [29].

- PHM will help with cutting costs per patient and allowing better support for chronic diseases [65][26]

Patient home monitoring systems include a wide range of devices that can check the vitals of an individual in order to make sure patients are still healthy or to help monitor them in a critical situation. Patient home monitoring also has the potential to use cutting edge technology to help prevent illnesses. PHM systems are not meant to just reduce the number of unnecessary visits to the hospital, but to help maintain the overall health of patients. If something going wrong with a patient at home can be caught due to the monitoring from these devices, these devices could respond quickly and alert a doctor that an issue has come up.

- PHM can empower patients to acquire information on their own and to take charge of their own health [43]

Some individuals in the United States have already been connected to these health devices, and 86% of the patients in one instance of an implementation of PHM were satisfied [32]. It is not simply the hospitals' needs for this type of monitoring that is a driving factor here, but experts say "an explosive growth in the volume of patient-generated health data is inevitable, with patient demand being a key

driver" [32]. Patients' demand of these systems is a logical result of the desire to understand their own health and prevent diseases from further progression.

1.1 Scope and Goal

Upon examination of the presented problems, the research groups were divided into four major focus areas: data, devices, usability and security. These four areas are closely intertwined and impact the different issues and systems related to PHM. The groups compiled their research when writing the individual sections to ensure a well rounded view of patient home monitoring technologies. Currently, the Swedish healthcare system is not prepared to handle the volume of data that would be produced by PHM systems. Future medical policies related to data should observe a potential for increasing amounts of diverse data. The United States is an example of a country where policies drive the way data is collected and analyzed for better or for worse[32]. The stakeholders section covers the affect of current and future patient home monitoring technologies on the various user groups identified. Within the results section 4 a summary of each of the research group's findings can be found. The results section also includes the findings from interviews with medical, IT and data professionals. The usability of these devices is also an important aspect to consider. If the healthcare system wants PHM to succeed, it will involve making sure that patients are open-minded towards using new technology that monitor their health. Also the technology should not be too complicated for the average patient. "What is clear is that patients want to be empowered," and to be empowered it is essential that individuals are able to use PHM devices [32]. In the Future for Patient Home Monitoring Users section a look into the potential needs of future systems can be found. Vision seminars were conducted the results were compiled with other research. The subsections are organized by various work groups of a similar background and their vision of future needs and concerns. A section is dedicated to transitioning to PHM. This section provides details about the issues integrating with current systems as well as the results of a successful system.

The overarching goal of this project is to provide the reader with an overview of experiences, ideas and perspectives regarding the benefits and challenges of PHM. This overview was developed from each group's research involving the following topics:

- Related studies
- Security and legislation
- Data analysis
- Usability of devices
- Current implementations of PHM

Along with an overview, the project aims to develop a vision for PHM that can help medical professionals to efficiently and effectively care for patients with common medical conditions. In the end, the result will also include ways to proactively prevent privacy-related issues with proper implementation and effective methods to display the data collected from PHM devices. This report is complemented by a visual representation of the possible future of PHM.

1.2 Limitations

PHM can be very broad as it contains many different devices for various diseases. Therefore, research for this report was limited to particular potential users of PHM. The first question was on whom the project should focus: those who are currently healthy or those with a known existing condition. After

doing initial interviews with physicians to gain a better understanding of the area, it was concluded that those already diagnosed with a disease are more likely to take advantage of PHM systems than those who are not currently ill (4.1). Those who are ill feel like using a device will actively help them in controlling their disease. Also, for hospitals it is easier to reach out to this group of patients and enable them to use PHM devices. Asking people who do not have frequent contact with doctors to use PHM is more difficult because these people may not immediately see any potential benefits. These conclusions led to the exclusion of devices that are mainly used to keep one from contracting a disease rather than monitor an existing disease. As mentioned in the beginning of the introduction (1) more and more people are going to be chronically ill. As for them, a focus on secondary preventative care is needed. There are a few diseases on which the project focused because they are predicted to be increasingly important to care for in the coming years. These are congestive heart failure, diabetes and chronic obstructive pulmonary disease (4.2). This allowed the report to have a narrowed focus on few devices for specific diseases while still maintaining high effectiveness in how many patients are being helped or treated. Please see Table 1 4.2 for a list of devices considered.

2 Methodology

This research contains an analysis of the uses of patient home monitoring systems by looking at successes and failures. Industry journals, articles, websites, and other publications provided a useful overview of the patient home monitoring past and present uses. Legal documents were used to understand the requirements and restrictions around the technology. Interviews with healthcare professionals, patients, and IT staff provided a realistic set of use cases by which became the basis of the research. This was considered from the areas of Devices, Data, Usability, and Security.

2.1 Interviews

To find out the possibilities and challenges with patient home monitoring, we have interviewed people that already use home monitoring devices and people that are likely to use them in the future. We have interviewed IT specialists, patients and medical professionals to gain as broad knowledge as possible and also be able to view patient home monitoring from different perspectives and needs. The interviews were oral, in which users developed their answers quickly as opposed to answering a questionnaire. The questions asked were open-ended, meaning there were no list of answers to choose from. By having open-ended questions and letting the users talk freely allowed for qualitative feedback and for conversations to result. Interviews with all stakeholders deepened our understanding of what the needs and frustrations were for those who currently use patient home monitoring. From this group, we received their input on how they imagined their future with PHM systems which provided insight on the wide views had on PHM.

After conducting all of the interviews, it was important to look for key trends that continued to show up and organize topics of importance. Going through our notes and discussing with one another, we were able to distinguish information that was mentioned frequently. The diseases, devices, and data focus came into full view because of the interview feedback. A detailed look at the type of questions asked in the interviews can be seen at the end of the report under the appendix as Interview Questions (A). Questions asked were not limited to the list, but the list provided a framework for leading the discussions.

Interviewees have remained anonymous in this research. Recorded interviews conducted include: three doctors, two nurses, two engineers, two individuals that work directly with patient home monitoring, and two patients.

2.2 Vision Seminars

The vision seminar process [39][38] is a process used for the development of IT systems, where the computer systems are envisioned in their context of use, which often includes numerous other systems. Users of the current IT system (participants) are grouped by their role into work groups and will meet multiple times in these groups to discuss the development of the system. These seminars are guided by a process leader who is responsible for planning the whole process and guides the discussions. The vision seminar process for a work group usually consists for four to six meetings, where each meeting lasts between three to six hours.

We adapted the vision seminar process to the needs of our project and hence made it shorter. We also added new methodology such as affinity diagrams and discussions in one group based on results from the other group. Our goal with vision seminars was to understand and learn from patients and IT professionals what their thoughts of introducing PHM devices to healthcare was, and what actions has to be done before a possible launch of such systems. The vision seminar process lasted for three weeks and

we met with two work groups, one consisting of patients and one consisting of IT specialists in healthcare. The meetings lasted for two hours each and there was a total of five meetings, two with the patients and three with the IT specialists. The results from these vision seminars were then presented to a doctor during an interview.

2.3 Literature and Related Work

To develop a knowledge of PHM, we needed to first research the basics. Reading professional papers, as well as articles and other literary resources on PHM, allowed us to create a starting point for our paper. After the structure of the paper was developed, we were also able to further look into many different sources that could provide us with background information as well as medical and professional details about this topic. The term literature covers a wide range of written resources that were available for us to use in our research. Our literary sources were used to provide evidence of various scenarios and give reasoning for topics throughout this report, helping to maintain validity in the information provided.

The term related works pertains to sources of information that were formed through case studies, specifically. These related works, which detail and explain previously conducted studies, eliminate the need for us to conduct our own studies and instead provide sufficient information which is useful for this report. Research, through polling, experiments, and many other actions provides the researcher with the ability to propagate new discoveries from the data collected.

The results found using these methods are presented the section Results (4).

3 Stakeholders

In this section, various stakeholders are identified. These are: patients, doctors, politicians, medical and IT professionals, researchers, vendors. It is explained how these various stakeholders are related to PHM. It can provide an answer to the question that people who have come to hear about PHM might have: "Why should I be interested in Patient Home Monitoring?". The topics discussed below are not necessarily an all-encompassing list, but explore some of the issues that relate to patients, doctors, politicians, medical IT professionals, hospital management personnel, academics, and medical device vendors.

3.1 Patients

Patients are the end-users of PHM devices and it is essential that devices are designed to fulfill the patient's needs, to assist patients in their everyday life, and to give the patients a better overall quality of life (see section 4.2.4). Future PHM devices that are implemented with the proper electronic health record technologies can give hospitals an opportunity to treat patients outside of their four walls. With a PHM device that is discrete and easy to use, it should be easy for the patients to send their data to healthcare professionals throughout the day (see section 4.2). The healthcare professionals can then review the data and contact the patients in case it becomes necessary. It will no longer always be necessary for the patient to travel to the hospital for the check-up [64].

PHM devices will allow the patients to be more involved in caring for their health [43]. When using the device, the patients can get immediate feedback. This allows for patients to take an active role in their healthcare. It is possible to see the data represented graphically over adjustable time periods to give the patients a better understanding of how their health is looking over time (4.3).

The data that patients are sending to healthcare professionals will be sent securely and stored in a central repository, ensuring data integrity (4.4). This data could be anonymized and sent in to medical researchers, which can lead up to new medicines and work processes on treating specific diseases (3.6). PHM devices are the way of the future in treating diseases in healthcare, and they will give patients more personal freedom and a better quality of life. It will enable research on a new scale and will allow patients to get better medicine and instructions on treatment.

3.2 Doctors

PHM can benefit doctors and other healthcare professionals. Enabling people to take control of their own health alleviates some of the pressure from medical care, but it still maintains the high level of care that healthcare professionals provide [64]. It has been found in one study that PHM actually increases patients' adherence to their care plan, which reduces re-admittance [49], benefiting doctors and hospital staff. PHM empowers patients to have greater understanding and control of their health, but also empowers doctors to be able to give an even higher level of care to those who really need it. These methods allow healthcare professionals to perform quick checkups and write prescriptions for those who need minimal help since their situations remain stable, and then re-allocate their expertise towards patients that really need extra time and care.

Having electronic systems can also help for the quick input of patient data back to a central repository, allowing health professionals to share data collected and make the best decisions for their patients. It can also help to ensure that data is correct, for example, that a blood pressure value is collected with a well-calibrated and reliable PHM device. Having an PHM device delivered by the hospital rather then allowing patients to bring their own device to the doctor, allows for better reliability (see section 5). This

also allows for analytic insights into the patient data, allowing doctors to look at graphs and trends rather than looking at raw data and trying to draw the correct conclusions (4.3).

3.3 Politicians

In the future, a growing elderly population will put a large strain on our healthcare systems [23]. PHM devices could increase efficiency and help alleviate some of this strain. Handling some routine health care functions through automated PHM systems can give doctors more face time with the patients who need it most, thus saving resources and reducing queue time at hospitals and health centers.

However, the potential of PHM is dependent on the laws and policies that regulate the system. According to our seminar with a group of IT specialists in healthcare (see section 5), legal complications are hindering the development of PHM systems. Furthermore, the new technology brings problems that lawmakers should be aware of. In the section Security and Privacy (4.4) we discuss many such issues further. For example, leaks of health-related data could be very damaging to an individual. For this reason, all organizations that handle such data should follow common standards of security and confidentiality. These standards will need to be international, as both systems and data might be shared between countries.

PHM has the potential to save money for the healthcare system [26]. However, exactly how practically feasible or cost-effective it could be is beyond the scope of this report. There is still a lot more work to be done, as outlined in the section "Future Work" (6), and a big part of this concerns the legal framework. The choices that need to be made in the implementation of PHM have both medical, technical, and political aspects: Where will the data be stored and who will manage it - hospitals, government entities or third-party companies? Who will pay for the technology? And who should own the data? If PHM systems are to become a reality politicians will need to handle these issues, and also to make sure the public opinion is taken into consideration.

3.4 Medical Information Technology Professionals

The implementation of PHM devices will require a leap forward in effective data standardization for medical technology 5. With all of the data being stored for every patient, it can be very troublesome to keep the data organized without a standard way of storing it. Medical information technology (IT) management should be able to provide the patients and doctors with simple representations of all data received that is related to the diagnosis of the patient. With an efficient means of storage and data visualization, doctors will be able to allocate time away from understanding the patient and put it towards providing patients with treatment or dealing with important issues. In addition, patients will have an easier time understanding their health problems and the care that is needed. With the population growing and tangible space for hospitals being finite, efficiency is an important advancement to make in order to treat all patients at a high level. If data can be visualized easily and organized based on the patient's health, hospitals will see a large increase in efficiency.

3.5 Hospital Management Personnel

The hospital management personnel will particularly find financial benefits from PHM. First of all, being one of the first hospitals in the world to successfully implement PHM will allow a hospital to become an internationally attractive hospital. This means that the number of international people who want to come to the academic hospital for treatment might increase 5.2. For the Swedish hospitals, this part of their

income is important, thus lessening health budget stress. Moreover, due to the increased effectiveness and efficiency of the healthcare in general, some of the burden on health budgets will be alleviated.

3.6 Academics

PHM has the possibility of fostering growth in the area of research, health, medicine, and ICT, as it will provide more valid and standardized data from patients 5.2,5.3. This can then be used to improve disease prevention, diagnostics, and treatment. The data will in turn not only improve PHM healthcare, but also improve healthcare as a whole.

3.7 Medical Device Vendors

As a medical devices vendor, there are countless new opportunities ahead in the field of PHM. Notably, PHM allows for large gains, as it creates new job opportunities and business plans, as new companies are needed to produce PHM devices as well as provide analysts to review the data. This is only possible if the vendors are able to respond to the needs of all the potential stakeholders.

There are many benefits to stepping into the medical devices market now. A medical device vendor entering this market now, would be a 'late mover', since there are already pioneers in the field. Entering the market later is often more successful than being the first [57]. Anderson [27] explains the Second Mover Advantage: "While the pioneer pays a steep price in creating the product category, the later entrant can learn from the experience of the pioneer, enjoying lower costs and making fewer mistakes as a result."

4 Results

The results of literature study and interviews are cataloged in this section. The objective is to provide the groundwork of patient home monitoring (PHM) and discuss common questions while providing approaches to possible solutions. A broader definition of PHM involves the process of monitoring patients at home involving medical professionals, data collection devices, generated data as well as the transmission, storage and use of that data and the interaction of these people and systems with patients and the hospitals and organizations supporting their home care. We chose to study the following grounding questions: What kind of PHM devices are in use now? How does data from such a device get to the hospital? How does a patient or doctor interact with such a device? The section is divided into several sections:

- Information Technology and Medical Professionals - This section discusses investigation into the medical professionals involved in PHM, how they interact with current PHM systems and the issues they see with these systems.
- Devices and systems - Recent developments in technology has led to a new and ever-expanding set of devices and systems that can be applied to PHM. This section outlines some of these developments, and uses several types of devices to provide some depth to how PHM devices do and can improve home patient care.
- Data - This section discusses the kind of data that comes from PHM devices and reasons for why this data is useful to the care of patients with specific diseases. In addition, it describes how it is possible for medical professionals to effectively monitor these diseases using the collected data. This includes a brief discussion of the difficulties with organizing effective visual representation of this data.
- Security and Privacy - This section discusses the main threats to the security of PHM data and systems. This discussion includes looking at issues surrounding privacy, safety of the data, and reasonable restrictions on the data.

This section attempts to provide a better understanding of the technological obstacles of PHM implementation, some of the current successes of PHM, and sets up a more detailed investigation into the future opportunities of PHM.

4.1 Information Technology and Medical Professionals

An initial approach to establish a useful knowledge base surrounding PHM was to start with interviewing medical professionals, patients, and Information Technology (IT) professionals. Their opinion on PHM and their thoughts on how they could benefit from PHM devices proved to be very helpful in the research. Some good input would be which data they were interested in monitoring and what diseases would benefit most from PHM. It was important to compare the differences/similarities of input between Swedish and American medical professionals. A final goal of the interviews was to learn their thoughts of a PHM implementation's effect on healthcare. See appendix A for interview template. Medical professionals and IT professionals in favor of PHM thought the group that would benefit from home monitoring the most are the people who already are sick. It should not be complex for the patients to use, since the technical skill and age varies from patient to patient. They also conveyed that the most important thing with home monitoring devices is that the systems should be easy to use. It should be easy to send data to the hospital and it should be as easy to visually create overview of the data for the people who will look at it. The data that professionals would be interested to look at in this stage is the data that is easy to monitor at home. For example, respiratory, blood pressure, pulse oximetry (or pulse-ox), and weight measurements are all easy measurements that can be monitored at home. They ultimately suggested a

closer look at some of the more common diseases that could be monitored at home. The diseases that were specifically suggested to focus on were the following: diabetes, congestive heart failure, and chronic obstructive pulmonary disease.

Medical professionals said data should preferably be presented in easy to read graphs that can indicate early stages if the respective patient is showing abnormal health issues. It would be beneficial if these graphs could be categorized for different health problems. For example, data that is relevant to a heart problem would be separate from data pertaining to a stomach problem. A large setback today is that some elderly patients are less interested in learning a new system for recording data than other groups of patients. This makes it very difficult to give the elderly motivation to use them, and they represent a significant portion of the target audience.

Another common response from the interviews, is the emphasis on the simplicity of these devices and that setting up these devices should be as simple as "plugging and playing". It is essential that potential users understand that these devices will assist on treating them efficiently.

Interviewed IT professionals stated that the security issue of electronic medical records (EMR) has halted the process of implementing IT systems which can assist doctors. A small portion of patients do not want their data to be accessible online, and, in conflict, want restrictions on what all can be accessed in the EMR. The pro-PHM medical professionals conveyed that it would be best for the IT development of EMR if a medical record system would simplify the data in the medical records for doctors through concise graphs.

The owners of the journals should be the patients, according to the medical professionals. The patients should be responsible for their own health. If patients are the owners of their journals, monitor their own health with PHM systems and devices, and take medications suggested by these PHM devices, it would be easier for doctors to understand the patient's health with consistent measurements through each day.

There were also medical professionals who were skeptical about PHM. They were doubtful of the implementation of PHM without a realistic cost analysis. Most of these medical professionals were from Sweden. Presumably, this is due to the hospitals in Sweden being financed by a strict budget from the County Council. How can patient home monitoring be effectively funded with the money Swedish hospitals receive today? Ultimately, they thought it will be too expensive to have people to review all of the data from patients. These objections require consideration of cost and value beyond the scope of this report.

A large obstacle unearthed in interviews dealt with smartphone implementations. Will it be secure enough? Can companies access this sensitive data and contact the patients directly to sell devices that could be used for monitoring their respective disease? How can patients be assured that their data is kept safe? An example the medical professionals proposed was if a patient is calling the doctor and telling that some values are not what they should be. The doctor would want to look at the data represented in a clear manner, preferably as a graph. The patient should then be able to send this data representation securely to the doctor. The graph could at the same time be documented in the journal to be analyzed in future occasions.

Further research on current devices and systems was greatly needed for us to better understand all aspects of a successful PHM implementation.

4.2 Devices and Systems

There are many different devices currently used for patient home monitoring. Monitoring chronic diseases was something that the majority of medical professionals interviewed felt could be very helpful for their

patients to do at home (4.1). They argued that PHM could be particularly helpful for the following three diseases:

- Congestive Heart Failure
- Diabetes
- Chronic Obstructive Pulmonary Disease

All three of these diseases cause numerous deaths per year that can be avoided with simple monitoring at home. Some of the data that was most beneficial for the medical professionals to monitor in regards to these diseases were weight, blood glucose, and pulse oximetry, which gives blood oxygen saturation levels. This input pointed the research toward devices that monitor this data and the interaction between the patients and these devices. The following table breaks down those devices considered into the four categories shown.

Table 1: List of PHM Devices Considered

Pulse Oximetry	Respiratory
SHL Telemedicine TelePulse Oximeter Philips WristOx2 Wrist-worn Pulse Oximeter iHealth Wireless Pulse Oximeter DigiDoc Pulse Oximeter - Heart and Oxygen Monitor App	SHL TeleBreather™ Philips Stardust II
Blood Glucose	**Personal Scale**
OneTouch Veiro Sync Meter w/ Mobile App GlucoTrack Tuvie Gluco Wristband	SHL TeleWeight™ Philips Steady Scale Withings Smart Body Analyzer

4.2.1 Scale

For patients with congestive heart failure, the accumulation of fluids within the body is a clear sign that something is wrong and that medical attention is needed. The easiest way to determine if fluid is building up within the body is to have the patient weigh themselves daily and recognize any strange increases in weight. However, this can be difficult for patients and unhelpful to doctors if the results are reported incorrectly or sporadically.

The way that most patients currently record and analyze their weight is by hand. They record their own weight frequently and alert their doctor to any strange changes. Often, each time a patient visits their healthcare provider they are weighed as well, but these weigh-ins alone are not frequent enough to be reliable or very helpful in predicting any cases of congestive heart failure.

The first thing to consider when analyzing the usability of a scale, is how the user directly interacts with it. Most scales have a relatively similar user interface, where a patient steps onto the device and it displays their weight on a readable screen. For able-bodied patients this is a simple and straightforward task.

Disabled patients, on the other hand, could be incapable of performing such a task. This is an important aspect to consider, especially because congestive heart failure and diabetes are more common in patients who are unable to exercise regularly due to a disability. In order for a patient to willingly weigh themselves every day, the device they use must be something they can operate without much difficulty. For patients who are bed-bound, or unable to stand on their own, a traditional floor scale is useless.

Some common alternatives to the basic bathroom scale include the addition of handrails, like the Philips Steady Scale (as Seen in Figure 1), which allow the patient to support themselves while on the scale.

Figure 1: Philips Steady Scale with handles vs. more traditional ground scale

There are also scales designed for wheelchairs, like the Lillypad scale [25]. In this case, the patient wheels the entire chair onto the scale, which then accounts for the chairs weight when determining the weight of the patient. Although these specialty scales can be very helpful, they are often very expensive, with prices ranging from 600 to over 2,000 dollars. Many patients would not be able to afford such a scale, no matter how much it would benefit them.

A benefit of these newer devices is that they can transfer data to the doctors or other healthcare professionals. A traditional bathroom scale has no way for this transfer to occur. The user must record their weight manually and then send or report it orally to their doctor. An alternative to this design is a scale that can automatically send information to a database which the doctors then have access to. A couple systems have been suggested to send the information over Bluetooth or through SMS text messages [67].

These methods involving Bluetooth or SMS text messaging would benefit users who are not very comfortable with new technologies, because the ways they interact with their devices and data are more familiar with applications of Bluetooth and SMS. A scale that automatically sends information would also be ideal for disabled patients, since it would simplify their use as well. That being said, the sending of this information and its analysis would create security and big data issues, as well as problems with integration into existing systems. Those issues are analyzed in the section Data (4.3) and in the section Security and Privacy (4.4).

There are some Bluetooth enabled scales on the market currently, and they are fairly modestly priced, like the Withings Smart Body Analyzer. These scales range from about 30 to 80 dollars, which most patients requiring home monitoring would be able to afford, especially with the help of insurance.

For congestive heart failure, home monitoring is a process that takes dedication to make the patients' health the best it can be. It starts just like any other PHM process, with data being transmitted from a patient's location. The data is then analyzed and professionals determine whether more or less medication is to be used for treatment. The patient is then contacted about such medication, and the monitoring

cycle continues. Ongoing monitoring allows for optimal treatment and care provided for the patient. This process could also be used throughout the PHM industry for other diseases also, as constant monitoring is effective to prevent and treat life-threatening diseases.

4.2.2 Blood Glucose Meter

Type I Diabetes is a serious health condition that must be monitored to avoid heart disease, loss of consciousness, strokes, or even death [22]. Common symptoms include unquenchable hunger, extreme fatigue, blurry vision, and drops in blood sugar level. The most common symptom to monitor is blood sugar level because it can cause serious complications if it gets too high. If someone's blood sugar level is too high, they must inject insulin, which helps to bring their blood sugar level down to an acceptable level. In extreme cases, patients have had to get amputations of toes, feet and even an entire leg. In addition, some patients go blind or suffer from kidney failure because of low blood sugar levels [40]. Luckily, there are common ways to monitor these symptoms and track blood sugar levels to avoid serious complications.

In order to monitor blood sugar levels, a device is used to prick a patient's finger to collect a small sample of blood. The sample is then analyzed by the device to determine the level of glucose in a person's blood. In order to be effective, this must be done several times a day, every day. This can be a hassle if the patient is busy or does not want to carry the device around with them all the time.

In recent years, devices have been created that continuously monitor blood sugar levels. These Continuous Glucose Monitoring (CGM) devices, like Abbott FreeStyle Libre [21], allows patients to not have to prick a finger in order to test their blood sugar level. The way Abbot's device works is through a tiny chip that is placed under the patient's skin and monitors the blood sugar level by collecting blood information when scanned, which can be send to the handheld device through clothing. The patient can then review this information, and take any necessary action. This prevents the patient from having to prick their finger every time they need to know their blood sugar level. The only time they need to prick themselves is when placing the sensor on their arm, which has been found to cause little to no pain [14], similar to the finger prick, but not recurring many times per day.

The chip under the patient's skin needs to be replaced every five to seven days and could cost up to 100 dollars a chip. Using the data collected by the device, patients can predict where their blood sugar levels are going and avoid highs and lows. This device can prevent patients from having to visit the hospital or a doctor by providing them with the information they need as well as alerting the patient when their blood sugar level is abnormal [21].

For diabetes, smartphone applications and blood glucose monitoring systems exist that allow for monitoring type 2 diabetes among relevant patients. These systems monitor the disease and work effectively by notifying the patient when they need to exercise more, eat healthier, or take medications. A positive characteristic of these applications is that they are easy to use, and alert the user immediately when actions are to be taken. The idea of analyzing disease related characteristics and sending a push notification or email to the patient to alert them for any reason, is something that can be used throughout the medical industry and patient home monitoring systems.

4.2.3 Respiratory Devices

Chronic obstructive pulmonary disease (COPD) is a lethal respiratory related disease which is characterized by chronically poor airflow. It is a common disease and in 2004 the World Health Organization (WHO) estimated that 64 million people had COPD and that 3 million people died of COPD that year [54]. WHO predicted that COPD would become the third leading cause of death worldwide by 2030.

The symptoms for COPD are[4]:

- Shortness of breath,
- Coughing,
- Sputum production (a mixture of saliva and mucus coughed up from the respiratory tract)

The most common cause of COPD is tobacco smoking [4], but other causes can be:

- Indoor air pollution (such as biomass fuel used for cooking and heating)
- Outdoor air pollution
- Occupational dusts and chemicals (vapors, irritants, and fumes)

In Sweden and the United States of America, COPD causes the following statistics:

Sweden:

- At least 500,000 Swedes have COPD today,
- 1/12 of adult Swedes have COPD,
- Each year 2,800 Swedes died due to COPD

USA:

- For men, 47.6 per 100,000 died due to COPD in 2010,
- For women, 36.4 per 100,000 died due to COPD in 2010

The interviewed medical professionals conveyed that most interesting data to monitor would be the patient's oxygen levels, breathing and pulse oximetry. SHL Telemedicine makes a device called the TeleBreather^{TM} [60]. It is used by the individual in the home to test how well their lungs are working. It measures the volume of air forcibly exhaled, as well as the speed at which the air is expelled from the lungs. SHL also makes a device called the TelePulse Oximeter which is clipped onto one of the patient's fingertips and then reads the saturation levels and the pulse rate [61].

These devices can be used along with SHL's suite of medical monitoring devices to monitor various respiratory problems, including COPD. This device collects respiratory information, then transmits the data gathered via a device SHL calls the Central Communication Module^{TM} (CCM)[30]. This module can forward the data in a variety of different ways back to SHL's Telemedicine centers. It is then analyzed by healthcare professionals and feedback is made available to the patient. The CCM has built in memory to retain large amounts of medical data. It also has software on board to preserve data integrity and encrypt the data before sending back to the analysis center.

The professionals at the center will offer advice on how to proceed to the patient if an issue arises. This makes for a more expedited admission process when the patient arrives at the hospital, and will also assist first responders in treating the patient quickly due to the accessible, critical information. This data is sent to the responsible doctor to ensure rapid diagnosis and treatment. This process makes SHL's center recognized as one of the leading monitoring centers for telemedicine.

4.2.4 Usability

Usability is defined by the International Organization for Standardization (ISO) norm 9241-11 as follows (ISO, Guidance on usability):

"This part deals with the extent to which a product can be used by specified users to achieve specified goals with effectiveness (Task completion by users), efficiency (Task in time) and satisfaction (responded by user in term of experience) in a specified context of use (users, tasks, equipment and environments)" [16].

Usability is, in a strict sense, an overall measurement of the quality of a product (or service). There are some other elements, including privacy and security, that are dealt with in other sections of this report.

Although the concept is often associated with digital systems and products, such as web services or other computer programs, any product can be measured by its usability. In the report's case, it pertains to patient home monitoring devices.

Since there are other definitions of usability, everyone interprets the concept differently and therefore it is difficult to measure usability. The Human-Computer Interaction (HCI) researcher Jakob Nielsen proposed five aspects that are usually used to measure usability [53]:

- How easy is it for users to accomplish basic tasks the first time they encounter the design?
- Once users have learned the design, how quickly can they perform tasks?
- When users return to the design after a period of not using it, how easily can they reestablish proficiency?
- How pleasant is it to use the design?
- How many errors do users make, how severe are these errors, and how easily can they recover from the errors?

These five aspects were kept in mind while the usability of the present-day patient home monitoring devices were researched. The analysis was developed via research into these devices by reading user stories about them and also interviewing patients and medical professionals that are using them.

A product can be both easy and pleasant to deal with, and work effectively or efficiently, but still does not create any user benefit or interest. This is the difference between usability and usefulness. It is possible to compare it with a patient who uses a patient home monitoring device but does not understand the feedback given from the device, which leads to the device being branded useless. On the other hand it still can have great usability since it is easy to use.

The ISO definition clearly states that usability means different things to different users, as not everyone needs or expects the same interaction. A successfully usable system meets those needs expected from their target user groups. For example, a computer interface should offer intuitive help for a new user. On the other hand, an expert should be able to perform sophisticated operations without unnecessary interference. It is important to remember that most users are somewhere between these contrasting examples and need a system that is sufficiently powerful yet moderately helpful.

Effective usability of PHM systems should therefore be linked to audience analysis. For PHM systems, this involves the workflows of the multiple stakeholders, starting with patients, then doctors, nurses and other health care professionals charged with their care, the IT professionals and system that facilitate or support home monitoring, the hospitals, companies and other organizations that enable PHM, support monitoring, and/or manage the data flowing through the systems. As the world's population grows and ages, doctors continue to have difficulties tending to all of the patients needs. In the vision seminar section of the report (5), there are patient's and IT professional's thoughts and wishes about how the usability of the devices is today and how future devices could and should look and work.

This report prioritizes patients because if more patients utilized patient home monitoring systems, less people will go to the hospitals and doctors will have more time to evaluate patients who really need

professional medical help. Also, medical professionals will be able to utilize more relevant data during those visits with the vision of improving both effectiveness and quality of care. PHM data flow, use and visualization form another major category of investigation.

4.3 Data

In an article titled "Harnessing the Power of Big Data in Biological Research" the issues of big data are summarized using a set of four words, "volume, variety, velocity, and veracity," [48]. This alliteration outlines the obstacles that need to be addressed in order to allow for data from patient home monitoring to work in unison with the existing electronic medical records (EMR). The first word, volume, is the most straight forward and simple to understand. Big data is a large amount of data and the amount of data is exponentially increasing as time moves forward. How can the EMR be prepared to handle more big data from patient home monitoring? The second word, variety, is again simple to understand in that it means the data collected is not all uniform. In the case of patient home monitoring, many symptoms and vital signs are being monitored, and various types of data are being collected. How can variety be accounted for? The third word, velocity, is describing the high rate of data collection and how that rate is constantly increasing. The data coming into the EMR from patient home monitoring, on top of having great volume and variety, is coming fast. Data is collected in intervals ranging from seconds to minutes, hours, days, and so on. How can data coming into the EMR with a high velocity be quickly integrated and analyzed? Lastly, veracity, would best be defined as accuracy in the context of big data. As stated earlier patient home monitoring will bring a large volume of various data with a high velocity into the EMR, but this is all useless if the data is inaccurate. So how can metadata be analyzed for accuracy? It is the questions presented above focusing on the issues of big data collection that hold the answers of how to smoothly integrate a large expansion in patient home monitoring to the current EMR. After all, in the most broad sense, the data collected from patient home monitoring are big data. Volume, variety, velocity, and veracity have no simple solution, and neglecting any one of these factors can lead to errors in the interoperability of patient home monitoring and the EMR.

Data collected from patient home monitoring devices can be used to analyze and potentially diagnose diseases related to patient health. Using this new data that is transmitted to, for example, telemedicine centers, professionals can compare previous results with the current patient data. If there are differences in test results that require immediate attention, a phone call will be made to the patient in order to notify them of their situation [19]. The outlook for patient home monitoring devices transmitting accurate data to be analyzed by professionals is encouraging and motivational for the future of healthcare.

Hospitals and medical facilities are beginning to allow patients to bring in personal devices to be tested against clinical systems in-house at the doctor's office. This allows for effective standardization with patient devices that they are using at home. Ensuring that patient data is accurate when coming to the telemedicine centers, makes the analysis of previous test results more trustworthy and exact. It is important that patients see the doctor more than one time a year for regular check-ups as well as to testing their device(s) for accuracy.

After collecting data, it is important to visually represent the data clearly. Data visualization is vital for doctors and patients to understand critical information. Data visualization is anything but standardized when it comes to PHM devices. A good example of a popular device is the Fitbit. Fitbit records basic information including weights, sleep time, walking distance, and much more. Fitbit has its own standard to assess whether the user is healthy or not. For other devices, the parameters of defining a healthy patient vary. Because different data structures from different devices will be sent to medical professionals to analyze, standardization is a basic requirement for an efficient visualization.

To visualize the data, there are several steps: data acquisition, data analysis, data governance, data management and data mining. Data visualization requires different parameters depending on the disease being monitored. For example, blood glucose levels will be key data to diagnose diabetes. However, pulse-ox measurements and respiratory measurements are vital to diagnosing a patient with chronic obstructive pulmonary disease. Therefore, data becomes relative when creating a visualization that maximizes efficiency. To avoid reducing efficiency, it is important to reduce the amount of data trying to be visualized by isolating important data and avoiding redundant data. Simply put, identify key data and store the rest. As data visualization becomes standardized, the security of data as well as the preservation of the patient's confidentiality comes into question.

4.3.1 Understanding Patient Home Monitoring Data

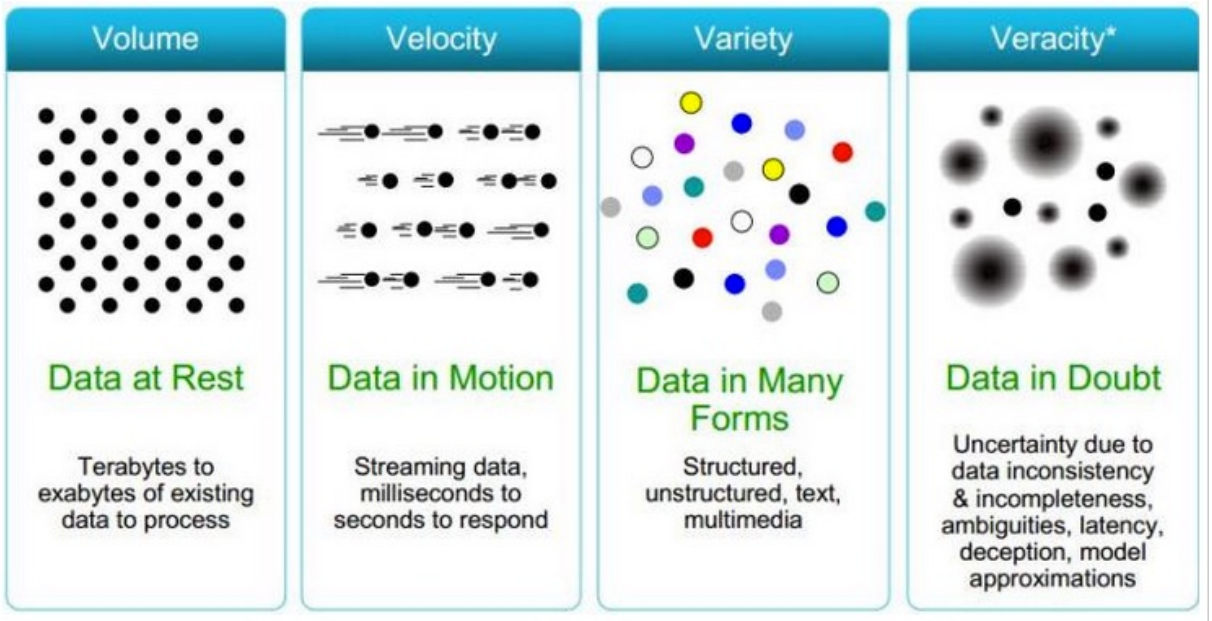


Figure 2: Examples of volume, velocity, variety and veracity

To address the issue of volume in relation to patient home monitoring data, one question to consider is: How can the EMR be prepared to handle more big data from patient home monitoring? A commonly assumed misconception is that increasing storage capacity regularly solves this issue of volume. Data is not only constantly being collected, but in some cases it is being duplicated as well. Buying more storage to combat this problem can be costly, and with the exponential rate of data collection it can also be seen as an obsolete solution to the problem at hand.

> What most people don't know is that the vast majority of Big Data is either duplicated data or synthesized data. Let's take a look at a leading medical research facility that generates 100 terabytes of data from various instruments.
>
> This data is then copied by 18 different research departments that further process the data and add 5 terabytes of additional synthesized data each. Now they must manage a total of over a petabyte of data, of which less than 150 terabytes is unique. Yet, the entire petabyte of data is backed up, moved to a disaster recovery site, consuming additional power and space

> used to store it all. So now, the medical center has used over 10 petabytes of storage to manage less than 150 terabytes of real unique data. This is not efficient. [28]

The solution lies in the management of the data. If collected intelligently with a set of guidelines, the data can be broken down into unique sets. Using sets of unique data reduces IT administrative burdens, as well as the burden of the EMR as a system. Virtualization can also be used as a powerful tool to solve this issue of the amount of data. Server virtualization is the splitting of physical memory storage into virtual partitions to increase usage of server resources [52]. Ash Ashutosh, the CEO of the data management software providing company Actifio, calls virtualization the "hero" of managing big data [28]. Virtualization of data reduces the data's footprint, allows for easier data reuse, and makes the data manageable from a central point. Additional benefits include lower costs, flexible data use, and better organization. Through the process of virtualization, big data can be managed similar to small data, and therefore most of the issues produced by a large volume of the data can be eliminated.

Variety, or the diversity of data collected in big data, is unavoidable. "It could be text from social networks, image data, [or] a raw feed directly from a sensor source. None of these things come ready for integration into an application," [36]. This is a core issue with the collection of medical data and, in this case specifically, patient home monitoring data. All of which includes readings from sensors, notes from doctors, and other diverse data collected. The previously presented question needs to be answered: How can variety be accounted for? The first step is simple. When processing data, creating unique data sets, or virtualizing data, it is important to retain as much of the data as possible. Some data will be lost; however, with advancements in technology almost all the data collected has potential to create value. Any system developed to handle large amounts of data should be tailored to handle the needs of its data.

> Despite the popularity and well understood nature of relational databases, they should not always be the destination for data, even when tidied up. Certain data types suit certain classes of database better... Even where there's not a radical data type mismatch, a disadvantage of the relational database is the static nature of its schemas. In an agile, exploratory environment, the results of computations will evolve with the detection and extraction of more signals. Semi-structured NoSQL databases meet this need for flexibility: they provide enough structure to organize data, but do not require the exact schema of the data before storing it. [36]

Data is messy, but if the variety of data coming into the system is accounted for upfront, the hassle can be minimized. Organizing the data from the start will mean that IT staff will not have to spend massive amounts of time cleaning up the data for use, and the loss of potentially valuable data will be diminished.

The topic of data velocity encompasses more than just the issue of fast-moving data in the system. The world today revolves around the Internet. Individual people constantly generate data from the majority of their everyday tasks. This constant influx of data is what is driving the investigation into patient home monitoring. The tools are there to be used, but how can they be taken advantage of in order to quickly integrate and analyze data brought into the EMR from the patient's home? While it may be assumed that fixing the issue of high data velocity is as simple as maintaining high data streaming speeds, this is not entirely true. "The importance lies in the speed of the feedback loop, taking data from input through to decision," Dumbill [36]. Edd Dumbill, a principal analyst for O'Reilly Radar and program chair for the O'Reilly Strata Conference/O'Reilly Open Source Convention, writes that streaming processing is needed in situations dealing with big data and high velocity. "Stream processing is designed to analyze and act on real-time streaming data, using 'continuous queries'" [66]. Dumbill discusses the following two reasons to consider streaming processing:

- When input data is too fast to store in it's entirety.
- When an application mandates immediate response to the data.

It is possible that the mass amounts of data being pushed into the EMR from PHM, and the velocity that accompanies that data, will be overwhelming for most systems. Fast moving data has the potential to incur losses of information during the transfer from the patient's home to the EMR and then onto the doctors. A patient's medical data is critical information that can have an immense effect on their life. Therefore, losing any of this data is not an option. A wide expansion of PHM will test these systems and may indeed carry with it input data that is too fast to store in its entirety. The second reason listed above is certainly applicable when dealing with a patient's medical data. Doctors will often need immediate access to data, users of PHM devices will need to interact with the data in real-time, and the data may very well be needed to make split second life or death decisions. Medical situations are never uniform, which means that the data collected is used in real-time and usually analyzed at a later time. "'Streaming processing' is the ideal platform to process data streams or sensor data (usually a high ratio of event throughput versus numbers of queries)" [66]. Whether someone is out for a run using their FitBit or at home taking a their blood oxygen level, they will be transmitting data. PHM ranges from data collected by device sensors to streams of data from mobile devices. Streaming processing not only helps account for the variety of data, but may also make the data flow from PHM more usable and accessible to all.

> Essential to stream processing is Streaming Analytics, or the ability to continuously calculate mathematical or statistical analytics on the fly within the stream. Stream processing solutions are designed to handle high volume in real time with a scalable, highly available and fault tolerant architecture. This enables analysis of data in motion.
>
> In contrast to the traditional database model where data is first stored and indexed and then subsequently processed by queries, stream processing takes the inbound data while it is in flight, as it streams through the server. Stream processing also connects to external data sources, enabling applications to incorporate selected data into the application flow, or to update an external database with processed information. [66]

Streaming processing is also an effective way to create value from the data in real-time. Doctors, specialists, and patients will be able to get more useful and usable data faster, and that is the core goal of PHM. "Stream processing has a great future and will become very important for most companies. Big Data and Internet of Things are huge drivers of change," says Kai Wähner, *InfoQ* [66]. In an evolving world, with PHM becoming a modern form of health-care, new methods of processing data could be the key to taking the next step forward and accounting for velocity and other issues caused by big data.

The final topic in the alliteration of big data issues, veracity, is no less important than the other three. The veracity, or accuracy, of data collected from PHM is not an issue to be taken lightly. The systems of the EMR will be forced to accept large quantities of data. This data will be both structured and unstructured, and it will be coming into the system at speeds which are too high for the system to be able to account for these issues completely. Additionally, unstructured data can often be imprecise, incomplete, and inaccurate. These uncertainties need to be accounted for to ensure the best results when using or applying the attained data. The following are a list of some of the best practices to help account for big data veracity [55]:

- Check data against multiple sources when possible
- Explore the data
- Document the process

Within all of the data collected by PHM there will be specific sets of data that doctors and patients want to use most. Data sets like these can be compared to previously collected data in similar sets. This allows doctors and other health care professionals notice inconsistencies in the data. If readings or data sets are drastically different, the data could be inaccurate or it could be an indication that something

is wrong with the patient's health. This data could then be recollected in an attempt to gain a more accurate representation of the information in question. Exploration of the data collected is also a great way to discover inconsistencies and errors. Plotting data points and using data visualizations can help professionals find inconsistencies thrown by the veracity of the data. A final best practice is to create a clear and precisely documented process of the manner in which the data was collected. With PHM, the patient is often in an environment that is less controlled than a hospital, so inconsistencies are likely. By documenting the process the patient goes through to obtain the data about their health, it will be easier to discover any places that the data could have been faked or corrupted. By following these methods it is possible to minimize the veracity of PHM data.

4.4 Security and Privacy

When used in the context of patient health information, the definition of Privacy must be clarified. Confidentiality can nearly be used in place of the word privacy. Confidentiality itself is a very similar expectation in that a healthcare institution should closely guard both it's patient's and employee's information. Security is yet another word that can be used ambiguously but when combined with confidentiality gains greater meaning. Security refers to the technical safeguards that are in place to defend a person's private information.

Confidentiality refers to an inherent understanding between a healthcare professional and their patient that the knowledge gained during a visit to the doctor will be kept secret to anyone that is not essential to the patient's care. Privacy is the combination of both confidentiality and security. Privacy develops a clarified understanding of how patient's information should be handled in practice. Privacy in terms of healthcare encompasses both an expectation of confidentiality from a healthcare professional but also an expectations that the institution has properly secured the systems storing patient's information.

A modern healthcare institution has a responsibility to proactively secure its systems. In the past it could have been considered sufficient to protect only payment information and personal identification information. Today a variety of new threats combined with an expanding market of raw data sales have driven both international law and best practice standards to pay a greater attention to privacy. Without proper security safeguards in place thieves can be the least of an individual's worries. When a person's health information is available to a government, employer, family, friend or insurer it can lead to distress. Whether being denied for an insurance plan or personal embarrassment the effects of poor privacy cannot be overlooked.

In a healthcare environment the need to share a patient's information can cause confusion when understanding privacy. In other words, how can a person's healthcare information be private when many people have instant access? Mostly patients enjoy the benefits of their data being shared amongst healthcare professionals more so than they worry about how this takes place. Also portability can be attributed to laws encouraging strong practices of security and confidentiality. Although a law may clearly state the measures to be taken by an institution simply complying with these measures is far from proactive. Security threats are changing every day and the technologies to stop them evolve just as rapidly. There is also a constant need to train employees to observe strong confidentiality when dealing with a person's healthcare information. If the institution can both regularly update security measures and consistently certify and train its employees the sharing of information becomes simple, so simple that in fact most patients never notice that their entire health portfolio is regularly transferred. The reason why they do not notice is because of the effort of healthcare institutions to ensure the best care is given while observing strong practices.

Security and privacy are of utmost importance to the patient home monitoring system. If patients do not

feel safe and secure, they most likely will not use the system and it will be rendered useless. There are currently many threats to the security of patient home monitoring systems. These threats can be related to the software, the hardware, or the people using the system. Threats can come from all angles and each is important to understand and to mitigate in order to reduce the risk of patient home monitoring. According to Infosec Institute for Information Security Training and IT Bootcamp, approximately 29.3 million patient records have been compromised since 2009 [15]. Improving security and privacy of PHM systems will attract more users in the form of patients and providers, and it will encourage adoption from all parties which will help patients receive better, cheaper, and faster healthcare all from the convenience of their own home.

One of the most important currently unmitigated risks comes from the inside. Trusted staff on the inside of the systems may have ulterior motives and may sell data to interested parties. Some examples of interested parties include hackers trying to steal identities and commit fraud or insurance providers trying to raise rates based on current health data [17]. What makes the risk of data selling so high is the current value of data. These stolen records can fetch as much as $363 per record, according to data from the Ponemon Institute,"patient health which is more than any other piece of data from any other industry" [15]. These insiders already have access to the data so it makes it exceedingly easy for them to make cash by selling the data that they work with. This risk is extremely hard to mitigate, but it is very important to limit as much as possible.

One way to mitigate this risk would be to remove personally identifying information and any unnecessary information from the PHM system. The more information that is stored on these PHM systems, the more information insiders have to sell. Removing personally identifying and unnecessary information would reduce the insiders' ability to sell protected information about the patients and reduce the risk overall [15]. While this may not completely eradicate the threat of insiders selling data to potential parties, this is a good start and is one of the only things we can do to reduce the threat.

Another one of the factors threatening patient home monitoring systems is software defects or configuration errors. While this does not directly relate to security regarding hackers, it heavily affects reliability of patient home monitoring system, making it relevant to security. Software defects or configuration changes or errors can cause PHM systems to become unresponsive [17]. If these PHM systems are unresponsive, they are unable to perform their job of monitoring patients. There are a couple of ways we can lessen this threat. One of the first steps to preventing messed up configurations and unresponsive software is to set write permissions [17]. Removing permissions from people who may accidentally change something is a key. Workers who have access to the software but are not familiar with it may unknowingly make changes and this can easily be prevented by creating correct write permissions in the right places. Another key to preventing software defects is to perform a validation check on the software after it is installed and after it is updated [17]. These simple checks can prevent problems and can catch easy to fix bugs before they affect client usage. The last preventative measure that could also help with software defects is performing a software security assessment of the modules, components, and functions of the software. These assessments are usually performed by professionals that can find specific weak spots in the software. All of these ideas are good ways to reduce the threat of software defects that could potentially cause harm to patients. While this threat is not as high as insiders leaking data, it is still a relevant threat and should be looked into by healthcare facilities that employ patient home monitoring systems.

Hardware defects are also a threat to the security of patient home monitoring systems. This threat is similar to software defects because both types of defects can cause unresponsiveness from the patient home monitoring systems, and both can compromise the level of care the systems are able to provide [17]. For this threat, system checks should be run on the hardware periodically, and hardware should be replaced every few years when old systems are declared to be out of date. If healthcare providers are notified when a system is out of date or the system fails a system check, medical professionals can be

sent to repair the current system or replace it with more modern technology. These suggestions help can ensure the PHM systems are always providing the highest level of care possible and being reliable at the same time.

The last threat to discuss is perhaps the most famous. Outside sources may try to hack into patient networks or hospital networks and try to steal data, modify data, or simply disrupt operation of patient home monitoring systems [17]. This actually is one of the least probable threats, but still needs to be discussed because many patients think of hackers when they think of threats to their data. Hacking is not as probable because patient home monitoring systems are not widely used yet, but as PHM systems grow in popularity, the threat of hacking will grow as well. As with the threat from insiders, removing unnecessary information from the patient home monitoring system will also help with this threat [17]. Also, encrypting data and sending messages through secure channels are recommended by security professionals to increase security from outside sources. Lastly, configuring communication systems to validate and discard invalid messages can improve security by getting rid of possible malicious messages [17]. Some of these solutions would require more technical knowledge, but all would help to improve overall security of PHM systems and keep them secure for the future.

Overall, there are threats to patient home monitoring systems that currently exist. These solutions listed above are great steps to keep up with security and help patients to feel comfortable using the patient home monitoring systems. If healthcare providers can implement some of these solutions to reduce the risk, patients would feel much better and more comfortable with using PHM systems.

4.4.1 How Banks Handle Personal Information

A big challenge in implementing patient home monitoring is how to transfer and handle the personal data that is sent to the medical professionals in a secure way (4.1). The banks in Sweden have managed to do this successfully with a security mechanism called E-identification [51]. E-identification is an electronic ID for use on the internet. With the help of an e-ID you can identify, sign in and sign contracts and authorize transactions on the different authorities, banks and corporate websites. The states are the ones that issue the e-IDs. Countries in which the state issues the e-ID includes Belgium, Bulgaria, Germany, Israel, Italy, Luxembourg, the Netherlands, Mexico, Morocco, Pakistan, Portugal, Romania, Estonia, Latvia, Spain, Slovakia, Malta, and Mauritius. Countries that accept e-ID for identification for the authorities, often called BankID, are Finland, Norway and Sweden [51].

In some countries, such as Germany, they use a physical entity that can also be used as an electronic ID card (EIC), that works both online and offline. In Finland, they too have electronic ID, but the experiment was terminated due to of limited demand. A Swedish EIC is under development by the e-ID Board. An EIC usually has the format of a regular bank card, with printed identity information on the surface and an embedded microchip.

E-identification is usually based on a digital certificate, a data file containing information about the user and a code called public key cryptography. The public key corresponds to a private cryptographic key. It generally requires many years' computer calculations to figure out the private key even if one knows the public key. Cryptographic keys can be partly used for encrypting communications to make eavesdropping more difficult. Both for authentication when logging in and confirming transactions, and also to provide files and emails with a digital signature so as to ensure the identity of the sender that the message has not been tampered with during transmission. In Sweden, the eID is given to individuals by the banks through different variants of a system called BankID, and by Telia. Earlier, Nordbanken had a system called Nordbanken e-ID, but Nordbanken is now connected to the BankID collaboration. EID Board is an agency under the Swedish Ministry of Industry launched 1 January, 2011 and has plans in 2016 to introduce an electronic identity card (e-IC) to be known as Swedish e-ID. Examples of

Swedish authorities who accept eID are Tax Board, Employment Office, Social Insurance and the Swedish government authority that administers the Swedish student financial support system, which consists of loans and grants [58]. Digital signatures that are created with an e-ID under Swedish law in most contexts are equivalent to ordinary signatures on paper.

BankID is by far the largest e-ID system in Sweden and managed by the company Financial ID-Teknik BID AB, owned by several Swedish banks. In October 2012, there were approximately 5.6 million active BankID users in Sweden and more than 600 Web services that supported BankID [31][59]. BankID is available in several variants, but the most popular is Mobile BankID that is an electronic ID for modern smartphones from certain providers, combined with a mobile application [31]. This has become popular because people always have their smartphones with them. BankID can be used both for logging and signing via the web on any standard PC with the phone working as a separate security token, and for login via the bank or the authority's mobile application. The bank or the authority that the customer must identify themselves to has a validation server.

If a fraudster manages remotely to listen to your computer or mobile phone, for example with a Trojan horse, the person can break the link between what users think they approve and what ID is used to approve. A controlled computer can be used to intercept and reuse passwords and codes, in some cases, even if the secret key is safely stored on a smart card or a token. By installing security software on the phone ,such as an antivirus software, you are protected against malware, virus and people who want to steal your data [33]. Most people are sufficiently aware of having firewall, antivirus, and all sorts of other security software installed on their computer, but not on the phone. This is despite the fact that the phone is actually a computer and a more powerful one than most computers were just a few years ago. Until awareness of this has settled, the phones will be less secure. People who currently use their smartphones to store and send personal information and will in the future must take into consideration to have a security software installed. But unfortunately, many people do not even protect it with a password, even though the size makes it easily stolen and easy to lose. By installing a security software on the phone, using BankID is safe [33].

4.4.2 Privacy by Design

Privacy by Design is a set of principles for creating secure systems and ensure privacy by thinking about data security and integrity issues through every stage of software development. The most important tenet is to not collect more sensitive data than is needed, and to not store it longer than necessary [5].

This framework of principles was developed by the Information and Privacy Commissioner of Ontario, Canada. According to them, "Privacy by Design advances the view that the future of privacy cannot be assured solely by compliance with legislation and regulatory frameworks; rather, privacy assurance must become an organization's default mode of operation". In October 2010, Privacy by Design was recognized as the global privacy standard in a resolution by the International Conference of Data Protection and Privacy Commissioners [8].

There are seven fundamental principles in Privacy by Design: [2]

1 Proactive not reactive; preventative not remedial

Anticipate and prevent privacy-invasive events before they occur.

2 Privacy as the default setting

No action must be required on the part of the individual to protect their privacy – it should be built into the system, by default.

3 Privacy embedded into design

Privacy is embedded into the design and architecture of IT systems and business practices when they are created, not added on later.

4 Full functionality – positive-sum, not zero-sum

Privacy by Design states that there is no trade-off needed between positive objectives like privacy and security. It is possible, and even advantageous, to aim for achieving all of them.

5 End-to-end security – full lifecycle protection

All information must be securely managed during the entire lifecycle of the data involved, and data is to be destroyed when it is no longer needed.

6 Visibility and transparency – keep it open

The system must be subject to independent verification. Its component parts and operations must remain visible and transparent, to users and providers alike.

7 Respect for user privacy – keep it user-centric

Ensure the integrity and empowerment of the individual by measures as strong privacy defaults, appropriate notices, and user-friendliness.

Following these principles from beginning to end of system design can help ensure privacy and security. It can also let you avoid the unnecessary work and costs that come from having to fix integrity related issues once the system is already built. The Swedish Data Inspection Board (Datainspektionen) mentions Privacy by Design on their website, and they have compiled advice on how to implement it in practice in a Swedish setting [5].

4.4.3 Legal Restrictions on Patient Home Monitoring Data

The legal landscape around PHM and healthcare is complex, as there are both national and EU regulations that apply [9]. IT is still a relatively young field, evolving very quickly, lawmakers all over the world have to work hard to catch up to the technology. New laws are currently being written in the EU, and it is likely the laws will need to be updated again regularly for the foreseeable future [11].

In recent news, the Swedish Medical Products Agency (Läkemedelsverket) called attention to the fact that there are many health related phone apps on the Swedish market that do not have the proper certification that medical products need to have. This is mostly due to developers being unaware of the regulations, and the problem of determining whether an app counts as a medical product or not [10].

For this reason, anyone who plans to build a PHM device or any other healthcare related IT system will need to be careful to see they are following the current regulations. It is also best to be prepared for future changes in legislation and plan your systems to be versatile enough to accommodate these changes.

The Swedish Personal Data Act (PuL) is meant to protect the privacy of individuals whenever personal data is stored. It is based on EU regulations, and it involves things related to giving proper information to the people whose personal information is stored, as well as getting their consent. It also recommends that organizations appoint someone responsible for the proper handling of personal data. Application of the law depends on the way the information is stored. If the data is "structured" - as in a database - the law is more strict than in cases where the data is "unstructured". Any large system that regularly registers health-related data from individuals would fall into this first category [18].

Some healthcare related laws, like the Swedish Patient Data Act, only apply within the hospitals (to the journal systems), and thus do not directly apply to PHM devices like those we are looking at. There are a large group of international regulations that do relate to PHM devices, however. The EU even has some guidelines for defining and classifying medical devices [12]. To be legal, all medical devices need to have a special certification saying that they adhere to these regulations.

The CE certification is required for products to be sold in the EU and is given to products that adhere to the EU's regulations regarding health, safety, environment, and function [3]. It is the responsibility of the producers to follow the regulations, but for certain safety critical products (like medical products), an independent agency controls that all rules are met.

There are CE certifications for products in a number of areas. It is needed for all products that can be potentially dangerous, which is everything from machinery and electrical appliances to children's toys. Generally, the producer is responsible for any damage caused by a certified product, given that the user has followed all instructions.

In Sweden, Läkemedelsverket (the Medical Products Agency) is responsible for controlling that medical products follow these EU regulations. They are currently working on guidelines to clarify where this line between phone app and medical product is drawn - in general, if an app claims to give medical information, it needs to be CE certified. They are also planning to start banning apps that are not certified, to force developers to adhere to the rules, and to prevent harm to consumers [10].

There are several reasons the certification is important. If an app claims to give a diagnosis, or give any kind of health-related information to the user, this information could be incorrect for a number of reasons. Such misleading information can cause real damage to the user if it would, for example, give the user a sense of false safety in a situation where they should have consulted a doctor, or gives an erroneous diagnosis that can lead to an incorrect treatment.

Regulations relating to the safety and performance of medical devices in the EU were harmonized in the 1990s, following the New Approach legislative principles. The core legal framework consists of three directives: [11]

- Council Directive 90/385/EEC on Active Implantable Medical Devices (AIMDD) (1990)
- Council Directive 93/42/EEC on Medical Devices (MDD) (1993)
- Council Directive 98/79/EC on In Vitro Diagnostic Medical Devices (IVDMD) (1998)

The aim of these Directives is "to ensure a high level of protection for human health and safety and a good functioning of the Single Market" [11]. These three main directives have been supplemented and amended several times. There are also a number of legally non-binding guidance documents to help ensure uniform application of the directives within the EU.

The regulatory framework is currently being revised, following a decision in 2012. The new regulations, once adopted, will replace the existing three medical devices directives. The European Commission has also called attention to the issue of so-called "borderline products", for which it's not clear whether they fall under the medical devices legislation or another piece of legislation, which "are of great concern to EU countries, the European Commission and other stakeholders since they can lead to different interpretations within the EU". On their website, it is described as one of the "Specific areas of development", and they have published a manual with guidelines to ensure a uniform approach for this particular problem [11].

4.5 Previously Implemented Patient Home Monitoring Systems

Some medical professionals said in the interviews that they were doubtful whether implementing patient home monitoring will be cost effective (4.1). They also doubted whether it is possible to restructure the hospitals so that someone actually will have time to look at and study all the data sent from patient home monitoring devices. Patients were worried about whether patient home monitoring devices will be secure for their personal information. We have found previously implemented PHM systems that has helped the doctors in providing better healthcare.

4.5.1 Diabetes in the Visiting Nursing Association of Western New York

Many medical professionals in the interviews addressed diabetes as a disease that would benefit a lot from home monitoring (4.1). In New York, there is a home health agency that has been really successful with implementing it. The Visiting Nursing Association (VNA) of western New York is a home health agency that has successfully used patient home monitoring systems for chronic disease monitoring since 2005 and has an average of 400 to 600 PHM patients and 420,000 home visits per year [41][46][35]. Many nurses say that having PHM has been such an advantage for their patients, and thanks to the additional information that comes from PHM devices, the patients feel more connected and that they have more control of their disease [41][35][46].

On a daily basis, the patients weigh themselves and check blood pressure, pulse, blood sugar levels and oxygen saturation. In addition, the patients need to answer a series of questions related to possible diabetes complications. They are performed on an easy-to-use, small store-and-record unit in their home, which securely transmits the data to nurses at a central location. If the data sent and analyzed by the nurses shows something that is abnormal, nurses intervene with a follow-up telephone consultation and/or a home visit. The patient's primary care provider is also contacted, either through the patient's electronic health record or by direct contact if the issue needs more urgent attention.

Patients are introduced to patient home monitoring by their primary care physicians, who customizes monitoring and reporting to the individual patient's needs. Before starting with home monitoring, the patient receives instructions on how performing the daily assessments and must also demonstrate that they are able to do it. However, patient home monitoring does not replace appointments with doctors or home visits. It extends rural providers' capabilities, as one centralized nurse can observe and respond to numerous patients in a timely manner. Patients feel better because their physicians can configure medications and diet regimens based on the monitored daily data [41][35][46].

VNA's patient home monitoring system has had a lot of success within diabetes because patient home monitoring for diabetes gives tighter glucose control, improved clinical outcomes, reduced hospitalizations, and closer screening that prevent development of serious complications. In nine western New York counties, diabetes is among the top five diagnoses for patients served by the Visiting Nursing Association (VNA) of Western New York. In Sweden almost 4.5 % of the population is suffering the disease [41][34]. To improve reimbursements for diabetes care, VNA demonstrated that, in the last year, 80 % of the patients considerably improved their A1C levels. [41][35][46].

A1C is glucose attached to hemoglobin, a protein found in red blood cells that transports oxygen from the lungs to other parts of the body. The normal level of A1C in people without diabetes is approximately between 4 and 6 points. You need to be cautious having between 6.5 and 10 points and it is dangerous having above 10 points. Diabetes has a lot of complications because every individual reacts differently to it. With the help of PHM, it is possible to help the patients on a daily basis by observing how the patients react to different types of diets and medications. Some of the VNA's patients had 13 in A1C level or higher, but after being monitored come down to normal ranges. In the study above, some of the

80 % of patients lowered their levels as much as 6.9 points [41][35][46]. One study also showed a 50 % drop in mortality with patient home monitoring intervention [41].

4.5.2 SHL Telemedicine Chronic Obstructive Pulmonary Disease Monitoring Program

In our interviews with medical professionals, an interest in PHM devices for patients with COPD was addressed. The medical professionals saw a lot of possibilities with implementing home monitoring to COPD patients and that they could benefit a lot from being monitored and provided regular feedback from their doctor (4.1). One company that has entered this market of PHM for COPD is SHL telemedicine [49] as mentioned earlier in the report (4.2.3). Since 2006 they have had a COPD monitoring program that helps patients to monitor their progress and health, particularly during the rehabilitation process. The results of a study done on monitoring after hospital release were documented in Fierce Mobile Healthcare, a mobile telehealth news provider. It was found there were obvious successes when using monitoring devices on patients with COPD. The average hospital readmittance is 20 % of patients within the first 30 days after being released to rehab when they have been diagnosed with COPD. In this study, 14 people were tracked while they were using monitoring devices to assist them in compliance with their rehabilitation program, and none of them needed to be readmitted in 30 days [49]. This shows that these kinds of technology solutions for assisting people in compliance with their care plan can work. The learning curve for using new hardware and software is not insurmountable. With time, some training, and the will to adopt a new strategy, this could become useful to the patient, and then their care personnel. In the end, both patients and medical professionals benefit. Medical professionals are given the data from their patients with more information than previously, which leads to better healthcare for the patient and a healthier life.

4.5.3 Time Sensitive Health Risks in The University of Pittsburgh Medical Center

The University of Pittsburgh Medical Center (UPMC) is an excellent example of a hospital that has successfully integrated PHM into the way it diagnoses and treats patients. UPMC began their patient home monitoring system with just two services, telestroke and telepsych, which were highly specialized and for high-need situations in stroke control and psychiatry, respectively. They have expanded their use of patient home monitoring to apply it to a broad range of medical purposes [63]. Patients take routine measurements of disease specific data and use home monitoring for very time sensitive health risks like heart attacks. This expansion has been gradual, and includes both outpatient services for a patient who is hospitalized for less than 24 hours and inpatient services for a patient admitted to the hospital and stays overnight or for an indeterminate time [44]. UPMC's example showed that they successfully incorporate PHM and worked carefully to ensure the systems are making the experience easier for everyone involved. UPMC developed their systems over many years, instead of implementing them all at once [44]. A gradual approach to integrating PHM may work better, and be easier for patients and doctors alike to get used to. Rather than giving patients access to all their information at once or giving doctors access to all of a patient's vitals tracked every day. This way, no party is overwhelmed with new information and the hospital is able to better monitor the success of these programs, allowing the hospital to gradually tweak/improve them before adding more features or systems.

4.5.4 Sleep Apnea in Finland

In Finland, some clinics are using patient home monitoring to help people with sleep apnea or sleep-disordered breathing [56]. Sleep apnea is a chronic disease that disrupts sleep in the form of pauses in

normal breathing. Clinics in these countries are using patient home monitoring to double the number of patients they can take care of in a given time period and reduce the number of early-dropouts from their programs by 90 % [56]. Demand for treatment of sleep apnea is growing as more people learn about the disease and as the obesity rate climbs, since obesity is directly connected to sleep apnea. In Finland, the clinics were receiving many more patients, whereas their budgets were remaining the same and waiting-times for the clinic were rising quickly [56]. To solve this problem, they began using patient home monitoring.

The clinics recognized that 70 % of patients using PHM systems had no problems with their treatment and thus, did not need to come in for a follow-up checkup [56]. Clinics started to use patient home monitoring to check if patients had any trouble, and if not, patients were not scheduled for a follow-up appointment. This saved both doctors and patients time. The general public has positive feelings about PHM as well. The majority of respondents to a poll (74 %) were open to PHM if they had a cardiovascular disease. 92 % of those who actually have a cardiovascular disease that were using PHM said they were satisfied [56]. Overall, patient home monitoring seemed like a very positive change. While using patient home monitoring, clinics had reduced waiting times, improved treatment quality, and reduced patient travel time. The only barriers to adoption for Finland were fixed budgets regardless of number of patients. There could be similar positive effects and barriers to adoption for Sweden. The only other barrier to adoption specifically for Sweden would be reimbursements for physical visits in some regions, since the hospitals in Sweden have a limited budget.

5 The Future for Patient Home Monitoring Users

Until recently, patient home monitoring has been nothing more than a vision for better quality of care. In just a few years, numerous devices have been invented and patented that measure vitals and monitor patients in the comfort of their homes. It is important to think about what can be done in the next years to come when so much has been accomplished with today's technology. Group discussion and reflection proved to be very helpful with the analysis of possible futures for PHM. The method used was Vision Seminars[39], which was supplemented with structured interviews.

Our vision seminars were structured to allow time to be strictly allocated for group discussion. This was both to enable and encourage productive discussion, but also to respect the time of the participants. A standard seminar involved a short writing exercise followed by a discussion about what was written in the exercise to expand on ideas as much as possible. The scope of the meetings were planned several days in advance and communicated to the participants.

A vision seminar meeting always began with a small discussion about the topic, and explained the goal of the seminar to the participants. Following the initial discussion, the first exercise was handed out, which would describe a PHM situation for the participants to reflect on. The goal from this exercise was to listen for and record the positive and negative parts of this situation and get the participants to have a discussion about these parts, resulting in a synthesis of the ideas developed. Figure 3 presents a fragment of initial idea synthesis from seminar participants, and how they would be grouped for future reference and use.

The idea synthesis exercise was managed using affinity diagrams [45]. The resulting affinity diagrams were then discussed and each participant was asked to think about the three most important categories for the next meeting. These categories, synthesized from the participants discussion, are a major outcome of the process. Figure 4a and figure 4b show the synthesis of 'data issues' and 'legal issues' from a broader set of issues from one vision seminar. In the last exercise, each participant wrote a short essay, describing how a normal day for the participant could look like in the respective situation. The essays were usually around one page of length.

Each vision seminar had its own digital documentation of results, which would be used later to structure the next meeting with the participants as well as the interview with the doctor.

Overall, several PHM stakeholder work groups were developed in Uppsala, including patients and medical IT specialists. Each of these are summarized in the sections that follow. The potential benefits of PHM from the perspective of each work group is summarized in the section. This is followed by a section summarizing the interviews about the future of PHM with medical doctors using the themes developed from the vision seminars.

5.1 Work Group: Patients

We met the patient group during two vision seminars, both having a duration of two hours. The participants of this work group have a connection to healthcare having the role as a patient. We chose this work group since the end users of the patient home monitoring devices will be patients and their thoughts are therefore very important to consider. During the first vision seminar session, four patients were present. During the second vision seminar two patients were present.

The First Meeting

The goal of the first vision seminar was to understand the participants' general thought on PHM. To achieve this, we did an exercise called "What are the benefits and problems with PHM?" and used affinity

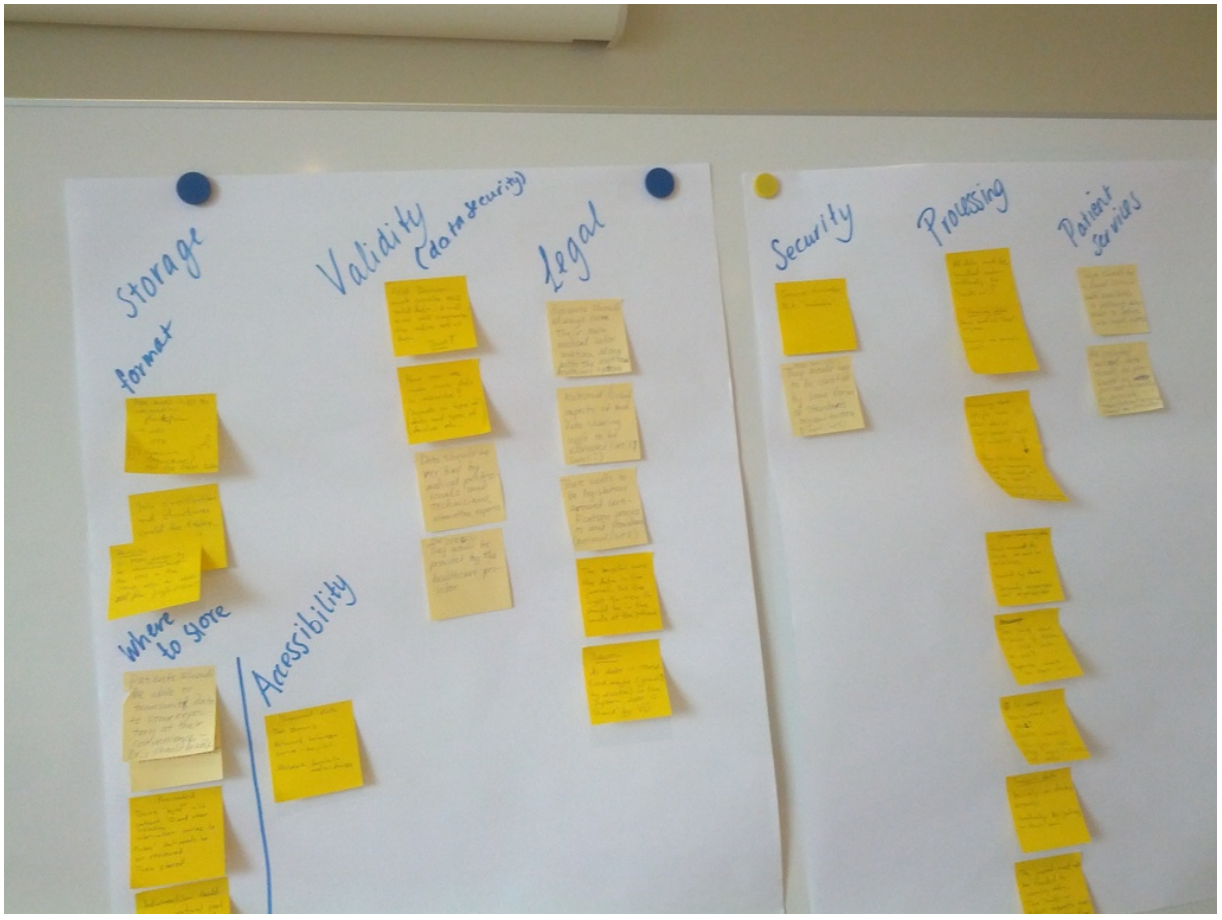


Figure 3: Idea synthesis from the first vision seminar

diagram [45] to execute this exercise.

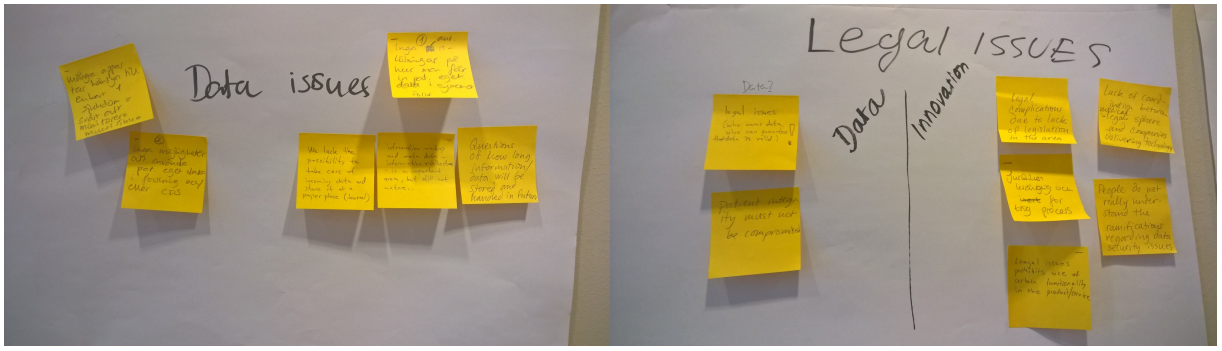
We asked each participant to write a short essay called "A normal day 2015", which should be about how a normal day is for the participant as a patient. The patients were given 15 minutes to complete this essay at the very end of the seminar and they were a helpful tool for planning the second vision seminar.

The Second Meeting

The goal of the second vision seminar was to understand the participants' vision of PHM in the future and to understand what their vision for healthcare in 5-10 years looks like. We did an exercise called "The future of healthcare" using the above mentioned affinity diagram method. The participants were asked to describe their dream and nightmare scenario of the structure of healthcare in the future and how this dream/nightmare could be achieved/prevented.

The second and last exercise for this meeting was that each participant should write a short essay called "A normal day 2020", which should be about how a normal day for the participant in five years as a patient.

The exercises resulted in several interesting discussions regarding PHM which are described below:



(a) Data issues (b) Legal issues

Figure 4: Synthesis of issues from individual vision seminar comments

Integrity

The patients describe that they do not want to feel that everything they do affecting their health condition will trigger an alarm in a medical center that monitors their health. They do not want to feel that it is an "electronic policeman" that is ever present judging their decisions.

It is also important, says the patients, that their health information is not used for other purposes than originally stated. The participants explain that patients want to know that they can be sure that the data sent will not be shared to companies.

The participants see great possibilities for medical research to make use of the gathered medical data as long as there is a good system implemented for anonymization of the data so the patients cannot be identified. It was hence very important for the patients that the integrity of the handled data is taken into account.

Safety Risks

There are some safety risks to consider before implementing PHM devices. The participants explained that some patients potentially could try to fake the medical information that they send, which would lead to research on data that would not reflect reality.

The participants also said that patients might draw hasty conclusions when using their PHM devices and that it is, therefore, very important to receive good feedback directly after using the device. The patient should not only have to rely on the device but should also be able to book a meeting with the doctor if the patient feels that it is necessary.

The participants saw a problem that some patients do not use technological devices in their everyday life. They said that this might not motivate the patients to use PHM devices and it is therefore important that the patients should be educated in how to use them as intended. The patients should also be able to contact a support for any questions regarding their device.

Benefits for the Patients

The patients think that PHM can give you quick answers on your medical condition and it is less likely that you have to go to the hospital as frequently. More personal freedom can therefore be achieved for the patients, where patient does not have to rely on regular meetings and fixed appointments.

The patients said that with the constant flow of health information from the patient and from the provided research of the data, it will be easier to catch health problems early on. This could lead to

earlier treatment when it is needed, which could be life-saving.

One of the participants explained that as patient it can be stressful to meet a doctor because of the time-limit. The participant explained that a lot of the meeting time is spent on doing different tests on the patient's health. If PHM information is integrated into the healthcare system, a doctor could access the patient's information and in this manner, the doctors would have more time for the patient. The participant said that this could change the structure of these meetings to be more focused on questions rather than doing testing, which could result in more optimal time consumption of the meeting time. The other participants discussed this scenario and also added that this would probably result in less stress for the doctor because the doctor can read up on the health information of the patient before the meeting. This could make the meeting more structured with a focus on talking with the patient and less time for doing tests.

It could be easier for patients to understand how their choice of lifestyle actually affects the disease, according to the patient group. An example is when patients with diabetes measure their blood glucose. One of the participant is a diabetes patient and explained that it could be very useful to see a graph over a short time interval, which would give diabetes patients a good view on how food and sleep affects their blood glucose. It could also be useful to have a graph over a longer time to see how their medical condition changes over time. Examples like this can result in patients being more included in healthcare, which can be a great motivation for the patients.

5.2 Work Group: IT Specialists

We met the IT Specialists work group during three separate vision seminars, which all had a duration of two hours. The participants of this work group have a connection to healthcare as IT specialists. We chose this work group because of their knowledge on how IT processes in healthcare work in reality; therefore, their input was very valuable for us. During the first and second vision seminar, four IT specialists were present and on the third vision seminar, there were three IT specialists present.

The First Meeting

The goal of the first vision seminar was to understand the participants general thought on patient home monitoring and to understand what work process an IT specialist in healthcare will have during a normal day. To achieve this, we did an exercise called "What are the benefits and problems today?" and used the management and planning tool affinity diagram [45] to execute this exercise.

After this exercise, we asked each participant to write a short essay called "A normal day at work", which should be about how a normal day is for the participant as an IT specialist. The essays were written in between the first and second vision seminar and were a helpful tool for planning the second vision seminar.

The Second Meeting

The goal of the second vision seminar was to understand the participants vision of PHM in the future, to understand how their vision for working in healthcare as an IT specialist in 5-10 years. We did an exercise called "Information from PHM Devices", to understand their vision on how information sent from PHM devices can be handled in the future, using the above mentioned affinity diagram method.

The participants were asked to write a short essay similar to the first vision seminar called "A normal day at work 2020", which should be about how a normal day at work will look for the participant in five years.

The Third Meeting

During the third vision seminar, we went through the work from previous vision seminars and also presented the results from the patients' vision seminars. Our goal with this meeting was to see what similarities or differences there were between both groups.

Results

The exercises resulted in several interesting discussions regarding PHM, which are described below:

Data from PHM devices

The participants thought that PHM data should be a natural part of a standard journal in the future. But they said before that will be reality, there are a lot of things to consider, such as how the structure of data from PHM devices would work, how data will be transferred, who the owner of the data should be and how data would be stored.

The participants explained that today there is no structure implemented to use the patient's own personal data gathered from mobile applications in a doctor's appointment. They said that they see a great potential in using such data and PHM data in research, because of the massive amounts of possible data that is possible to receive. They also said if PHM devices would be a part of healthcare, it is important that there will be automated IT solutions that will receive the data into the systems, because it will be too much data to work with otherwise.

The participants said that it has to be a good IT solution for how the data transfer should work. They discussed whether the data should be transmitted or sent and identified important things to consider: should it be sent on a doctor's request or should it be transmitted at all times? If that is the case, how do you avoid being overflooded by massive amounts of data? They also said that it is very important that there is a secure data transfer, which is not hackable.

The participants discussed how an alarm system could work, which would analyze the incoming data. They said that the system should match the incoming data to different alarm levels where a high alarm level would mean that it is an emergency and that the patient should go to the hospital. A lower level to send out an automatic message to the patient's device that would recommend the patient what to do. The participants said that they would like to see that when an alarm has been triggered, it should be noted automatically in the medical journal with the medical data that triggered it.

Storage

The participants explained that today they lack the possibility to take care of incoming data and store it all at a proper place. They said that it is important that a storage solution will have to be implemented before PHM devices can transfer data to them.

The participants explained that it is very important that only valid data is stored, because the doctors might give a faulty diagnosis otherwise and it would not be possible to research the stored data if it is not valid. They said that to make it possible to only have valid data, it has to be verified by medical professionals, technicians and information experts.

Regarding the owners of the data that is stored, the participants said that it should be the patients themselves that should be the owners of their data. One of the participants suggested that each patient should have a personal repository where the patient can send data at their own convenience. The doctors should then be able to request certain data at their convenience in conjunction to treatment. The other participants liked this idea of storing data, since the patients themselves would be responsible of sending data to this repository, because they are the owners of their own data. The participants said that patient integrity is very important for any solution for storing the data and it should not be compromised.

Devices

Regarding the devices, the participants said that the devices should all be certified by some form of standards organization on a national and international level. They thought that it would be most fair if PHM devices would be provided by the healthcare provider since otherwise they may only be affordable by some people. They also said that the devices should be stable, which they found more important than advanced functionality.

Legal issues

The participants explained that before introducing PHM devices, a lot of legal complications will have to be solved. They said that this is because of lack of legislation in the area and that these processes are very slow. The participants said that often, legal issues occur because of lack of coordination between the medical sphere and companies delivering technology, which would most likely be the case for PHM devices as well.

5.3 Interview: Medical Doctor

After having the patients and IT specialists vision seminars, we finished this process with having an interview with a medical doctor, which lasted for an hour. We chose to finish our vision seminar process with an interview with a doctor because the doctors will be working a lot with the information that is sent from PHM devices if it is a part of healthcare.

The Interview

The goal from this interview was to listen to the doctor's point of view on PHM and on the other work groups' results. We chose to focus on the results we found most relevant for a doctor, which were the results that the work groups' found was most relevant for healthcare professionals during the vision seminars.

We started the interview and talked about the technological part of the vision seminars. We asked how doctors would want to work with data collected from PHM devices. The doctor told us that they do not want to work with all the data collected from the devices because it would be too much. But they do want to work with some of the data that is relevant for a meeting with a patient.

The doctor explained that data is a difficult thing to rely on, an example is patients weighing themselves: A patient that is supposed to monitor their weight has to do it right. The patient has to stand correctly on the scale and make sure that the right setting is on.

The doctor continued to explain that designing easy to use systems for patients is very important. The patient should not have any difficulties to use the device that the patient is supposed to use and it is important that the patient will receive instant feedback so the patient knows the patient has done it correctly.

Regarding the patient's integrity, the doctor explained that it is not so important for all data. The doctor explained that data, like weight or blood sugar or other data that is monitorable, is not important to have secure. Monitorable data is not seen as sensitive data for the doctors because they only see this data as numbers. Sensitive data that is not monitorable, like traumas and relationships is, on the other hand, important to have secure and should only be accessible for doctors that need to know that information. The doctor explained that today doctors are able to access almost all medical data about the patients.

The doctor said when data comes in from PHM devices, it is possible to evaluate the data for research purposes. The doctor said that the medical professionals could learn a lot from analyzing the patient's data.

The doctor also explained that the patients should be responsible for their own health and make sure that they know how to use their devices. Everyone should own their own data and have the option to send personal data to a large data bank where companies or hospitals have the opportunity to work with it. If something useful, such as a medicine, comes out of the research of that data available on the market, the patients should receive a share of the money since it is their data which led to the discovery of this medicine.

The doctor said that the doctors could save a lot of time if data could be presented in graphs showing any deviations. It is important that the doctors should not spend time to go through a lot of raw data, but rather see if something is out of the ordinary, which can trigger an alert. The device can help the patient with advice about patient's disease.

The doctor explained that with PHM devices in healthcare, there would be less patients that will need to go to the hospital. The doctor said that 75-80 % of the patients probably do not need to go to the doctor for their disease, the patients know what to do. If this group of people would have a PHM device which could help them, they would rarely have to go to the hospital. 10-15 % of people may need to go to a doctor to for advice on their disease. 5-10 % will need to go to the doctors often for help with their health. The doctor summarized that it will probably have to be a restructure of healthcare when PHM devices are integrated in healthcare. The new structure, according to the doctor, would probably be more focused on primary care and less on the medical specialists, because patients will not have to the medical specialists as often.

Since a patient is the one with a disease, data gathered from the patient's PHM device should be owned by the patient. Therefore, the patient should decide what data the patient wants to share and not to share, according to the doctor. In the future, the doctor suggested that there should be a medical database implemented for medical research purposes which contains anonymized medical data, including PHM data. The doctor continued explaining that doctors are only interested in the medical data.

The doctor explained that it is less than one percent of the patients that worry about their integrity and that they are the ones who are very "loud" compared to the other group of patients. Integrity is a bigger question than it should be and the doctor thinks that the solution for this is to have journals which cannot be identified as belonging to a certain person.

The doctor explained that it could be possible to implement a structure where the doctors would use some of their work day reviewing alarms triggered by PHM devices. For alarms that are on a level such that the patient does not have to go to the hospital, the doctors diagnosis the patient and can send out a notification similar to an email or text message to the patient with recommendations. When doctors are going to handle alarms from PHM devices, they can, in this structure, work with fully anonymous data, because it does not matter for them who has the alarm. Everything the doctor wants to do is to analyze the data and to diagnose the alarm, the doctor does not need to know who it is.

5.4 Summary

Overall, the vision seminars, supplemented with structured interviews provided a realistic snapshot of a vision for the future of PHM. Significantly, this research suggests that PHM data can be realistically integrated into everyday life. This integration comes by way of user-friendly devices that do not burden the patient by taking up large amounts of time or through a complex interface. Similarly, with appropriate security, interfaces and IT support, it can help healthcare professionals focus their attention on their patient, and connect with them about the critical and important changes and medical events in their health, supported by real (or even real-time) information.

To highlight a future vision for PHM and to illustrate the benefits uncovered by this research, the team undertook the development of a film [13]. In the film, Maria, a student with Type 1 diabetes, goes about her day fluently from her commute to school to a jog through the park all while constantly being monitored. The film shows the everyday benefits of PHM coupled with it's simplicity. This also illustrates how this process can simplify and focus the efforts of the doctor in managing her care.

6 Future Work

The vision for an ideal implementation of PHM has been explained but it is important to point out that the results of the research done do not cover all aspects of successful implementation. While this report has covered multiple aspects of advancing PHM, there are issues that impact the overall success of this vision. These problems surfaced mainly while interviewing both medical and IT professionals. They are not solved in this report, but summarized here as areas that would very much need to be considered while planning for implementation. Each implementation would be different, and it would be up to the authorities to determine what is the best solution in their particular case. Substantial issues include:

- Where will all the data these devices collect be stored and who will govern or manage that storage? Hospitals, third-party data companies, government entity or some variation or combination?
- Will hospitals store local copies of PHM data on-site, replicating third-party systems, or will the patient's data be stored off-site, creating an additional step to work through the data company's storage?
- Will the patient, hospital, or other entity (i.e. insurance company) pay for patient home monitoring devices?
- Would the devices and data management systems considered be cost effective?
- What legal considerations will affect implementation of these solutions?
- Are people going to embrace or reject the proposed changes in their care?

Insurance: Another aspect to consider would be insurance. Different countries have very different systems for handling insurance, which is normally heavily regulated by governments. Who will be paying for these devices and systems goes right along with who owns the data coming out of them. It is important to know the specific types of devices that potentially will be covered by a patient's insurance. Depending on the necessity of a system, patients may be less reluctant to use certain systems if the patient has to pay out of pocket. Payment and insurance coverage would be pivotal to the success or failure of utilization.

Cost: All of the research carried out so far ignores costs as well. A total cost analysis of a large-scale implementation of PHM will need to be analyzed. While many of the ideas covered in this report would be beneficial to the public, there is the possibility that they are simply too expensive and therefore unrealistic. There is also the possibility that some applications of the devices will be fairly inexpensive yet very efficient. The best outcome will have a limited cost with unlimited possibility for integration and applicability. The final way to categorize the approach of implementing these ideas will be to compare effective and efficiency to the additional costs associated with expanding PHM. Software and hardware will be organized based off their ability to integrate together and with other existing systems to limit changes that could cost a lot of money. Simply put, the goal should be to maximize efficiency while minimizing total costs.

Legal Issues: One of the problems could be legalities around these devices and transfer of data. Those will need to be investigated and addressed, which could mean pushing for a change in existing laws or making new ones. Data ownership and data accessibility will each receive specific laws and guidelines to avoid any negative interactions. The interaction of large medical and technological companies would create a large influx of necessary laws to regulate everything smoothly. Also, laws that protect patients from exploitation by companies or others must follow so the patient feels safe enough to use these services. As data becomes tangible property, ownership will come into question and the extent of rights that medical and/or technological companies have over the data will need to be justified. Additionally, accessibility to this data becomes very relevant. Laws will need to be reviewed or implemented that regulate who is

able to access a patient's data and to what extent are they allowed to see and use it. The application of PHM devices into a daily routine may necessitate significant changes in regulations and laws. Future work will need to lay out a rough idea of each of those laws so that the privacy and security of the patient is reserved while still connecting them with the medical help they need through PHM.

Addressed in the subsection Legal Restrictions on Patient Home Monitoring Data (4.4.3), there is also legal issues involved with software and devices. The section goes more in depth about current legality with PHM. The issue of regulation in healthcare can throttle PHM as new technologies get produced faster than regulation are adjusted to allow the technologies. Future legislation needs to be versatile and ready for these chances. With new phone apps emerging, legislation also needs handle the apps in ensuring they are certified. If not, this could possibly pose a health risk for patients using and trusting non-certified apps. Not only the usage of the certifications, but monitoring and making sure the public is aware to get the certification and look for them with phone apps.

Public acceptance: Finally, it is imperative that more interviews and research be carried out to catalog the reactions received from the public. Specifically, are people comfortable with this type of monitoring? The public may feel it is a breach of personal space or a loss of privacy, and could completely ignore the application of PHM devices to the medical field. It is important to connect research to the public and collect reactions received from each application idea. Feedback from the patients, public, and doctors will make it easier for those developing PHM systems and devices to ensure that they are as successful as possible.

7 Conclusion

The medical professionals who want PHM to be a part of healthcare do not want to monitor all PHM data, because it would take too long to analyze and would not be useful for neither them nor the patients (4.1). The medical professionals we talked to could see PHM systems most useful for monitoring chronic diseases (4.1). If it proves to be profitable and effective, then the doctors could imagine implementing PHM in a larger scale. A great initial focus could be devices for patients with diabetes because there are already several successful systems in the US and it is a disease that is increasing constantly in Sweden (4.5, 4.1). This report describes previously implemented PHM systems that show that it is possible to reduce the number of patient visits and give more time to patients who really need to be hospitalized, such as the clinics in Finland where 70 % of the patients did not need to come in for a follow-up checkup (4.5, 4.1, 5). It is also important that nurses are given time to teach patients how to use the devices, because a nurse will then be able to assist a patient experiencing difficulties with a device. (4.5, 4.1, 5). A correlation between success stories is the common theme of offering a "test drive". Patients are given a driving test to see if they can use the device correctly. Depending on their interactions, providers could change the device to a more suitable one for the patient if the current one is not working (4.5, 4.1, 5).

To ensure usability and to ensure automatic data analysis, the devices should be provided from the hospitals since it will make it easier for the medical professionals that handle the data to analyze everything in a standardized format (4.5, 4.1, 5). A number of different devices with many different standards would make users and medical professionals confused and by having the option to switch between the different standards would increase the chance that users and medical professionals will not learn any standard well enough (4.5, 4.1, 5).

The vision seminars and interviews showed that patients do not seem to be as concerned about security as medical professionals seem to think (5, 4.1). However, patients are using BankID for many personal issues and are dealing with sending sensitive data when using the BankID application (4.4.1). If people are using applications for sending other sensitive data, why would they have a problem doing it with PHM (4.1)?

This lack of concern does not remove the need for data security. When data is stored it is important that it is anonymous since users do not want to be identified, and this anonymity has multiple benefits. One benefit is that companies will not be able to go through medical data for sending offers to people with a certain disease such as a diabetes patient (5). Another benefit is the potential to use the data to support epidemiological and other research.

While there will always be people who are critical of developments in society like this, but our research suggests that the majority of people seem to be optimistic (5, 4.1)? If it helps the society to become healthier, should we let a minority hinder us (4.5, 4.1, 5)? Feedback from the interviews showed it is necessary to integrate technological solutions such as PHM in healthcare. (4.5, 4.1, 5). It will be important because there will be more patients going to the hospitals and to handle this increasing number of patients medical professionals thought that PHM would be a good tool (4.1). Patients also want to be able to call a support for their device if they feel the need for advice or something unexpected occurs with the device (5). For PHM to be possible, some certain criteria must be met. As we have seen in the vision seminars it turns out that it is important to consider the thoughts of everyone involved in PHM to understand each other's needs (5). Patients must have a chance to use devices that are user-friendly and it should be their choice to use it. Doctors want a good overview of the submitted data and should also convince the patients to use the devices because it can lead to better health (4.1). IT specialists should be concerned with providing user-friendly devices that are cost effective for hospitals to buy. In Sweden hospitals have a strict budget to follow (5, 4.1). In short time maybe the county council must expand their budget if it proves that PHM leads to a healthier society, but in a long run it can even save money with less people

going to the hospitals and more effective patient visits (5). In the United States hospitals are funded through private health insurance, which means that they do not have the same economical problems as in Sweden and therefore has already had several successfully implemented PHM systems (4.5).

The technology that is needed to implement PHM exists and there are success stories with PHM that have shown patients benefiting from it (4.5). This report has explained that there are challenges such as restructuring of healthcare, privacy and security and how to overcome them. Convincing every doctor of the benefits of patient home monitoring implementation will take much more than just speculation and research. Success stories and proof that PHM will benefit the very definition of healthcare is essential. This proof can be obtained through implementations of PHM on a smaller scale. Why should we not take advantage of the technology and knowledge that we already have access to for what is most important in our life, our health? A potentially healthier future is in reach, and we should take advantage of that opportunity.

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Appendices

A Interview Questions

Data Group Questions:

1. Do you in your daily life have to type in data in many different kinds of systems in different format? → Follow up question: → How would you react if more systems were added to your daily working procedure?
2. What are your problems with the devices now, if any? Do things just simply not work? Do things work, but just not how you want them to?
3. If you avoid using some of the software, what do you try to avoid and why do you not like to use it?
4. Do you hear about or see problems that patients are having with using these systems/ current IT systems? (myPatientTracker, signing up for healthcare, seeing test results, etc)

Devices Group Questions:

1. What home monitoring devices do you use / are you aware of, and

   What is your experience with those devices? – Which devices do you prefer (the really technical ones, the fitbits/ iphone info), which do you see as most useful to you?
2. What symptoms / statistics do you monitor with these devices? Which are the most useful?
3. What kind of data do you get from these devices and how do you use the information you receive?
4. What kind of data would you like to have that you currently don't have? How do you see obtaining that data?
5. As technology improves, do you see home monitoring devices reducing the amount of time patients will need to spend in a doctor's care?

Usability Group Questions:

1. We have found in our research that the devices today are useful, although many patients would like better feedback from the devices. Do you think it is possible, and how?
2. As more and more people will start using patient home monitoring devices the medical professionals will get more data to handle, how would you like it to be visualized?
3. As medical professionals gets more data to handle and will need to give feedback to the patients, that will take a lot of time from their work. What changes will need to be made in the organisations in the hospitals to make this possible?
4. Do you know if these organisations changes have tried to be made before, if so, why have the changes not gone through?

Security and Privacy Group Questions:

1. Do you think the data from these devices is secure and do you worry about data breaches or breaches of privacy?
2. Who has access to this data or who can see it?
3. How should the data be structured to be usable for YOU?

4. Do patients ask about IT privacy/security and if so, what do they say?
5. What information about security or privacy would help you feel better about doing your job?

Future Questions:

1. How is today's work carried out with these diseases?
2. What are identified threats for the future? Why?
3. What would be the best scenario for you with PHM?
4. What procedures would be worth keeping that PHM could hinder?
5. What goals do you have today - how do you see it changing in the future
6. How do you see future work will be carried out in practice?

Job Specific Questions:

Doctor/General Practitioner:

1. What about patient data is hard to analyze?
2. Too much text, too much data, poorly displayed?
3. What do you think about PHM systems also analyzing the data? (examples: let the patient know if they should contact a doctor, or diagnose an illness before seeing a doctor)
4. As a doctor, how do you view/receive the data that patients collect using their home monitoring devices? (Do you need a special device for that or web dashboard?)
5. How do you use patient home monitoring devices (i.e. heart rate, blood pressure, fitness bands) to help you do your job right now?
6. Regarding a scientific standard: What data is accurate enough?

IT Department:

1. Does your hospital have an IT security policy and if so does it talk about PHM?
2. Have you heard about any mishaps where PHM was involved? (For example, faulty information, leaked information..)

Patient:

1. How often do you think about IT privacy/security in your everyday life? Why?
2. Do you find it beneficial to monitor your own health?
3. What would motivate you to use home monitoring devices? If none, what discourages you?

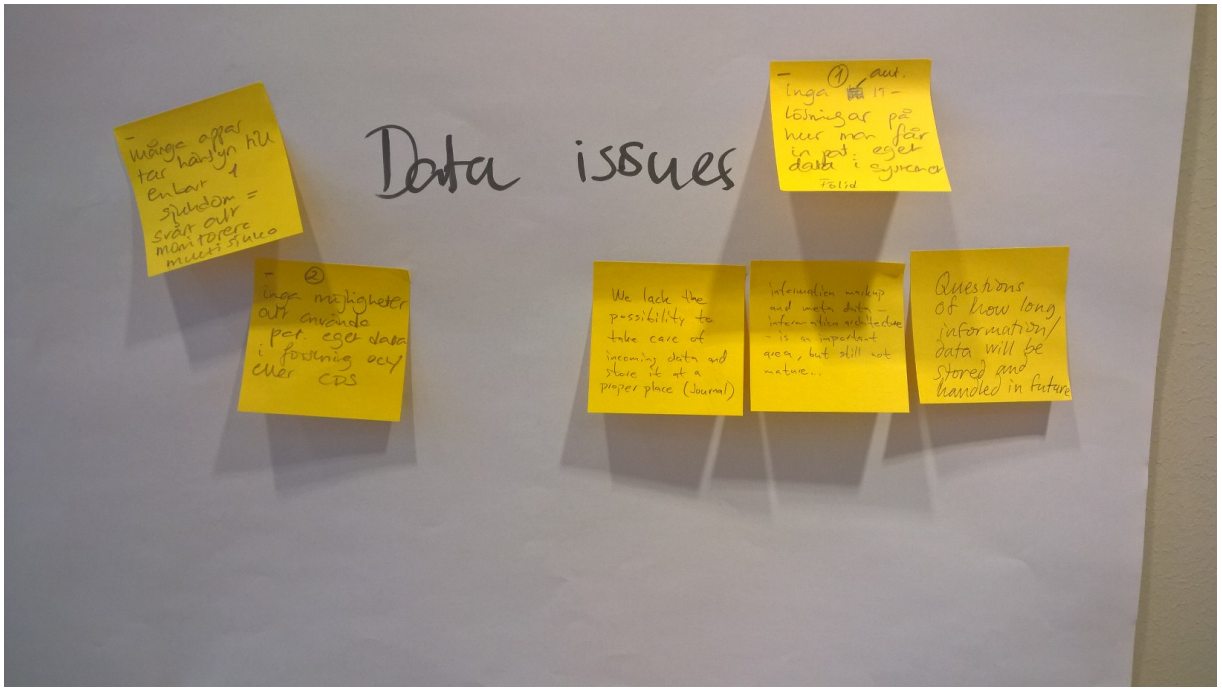
B Video Links

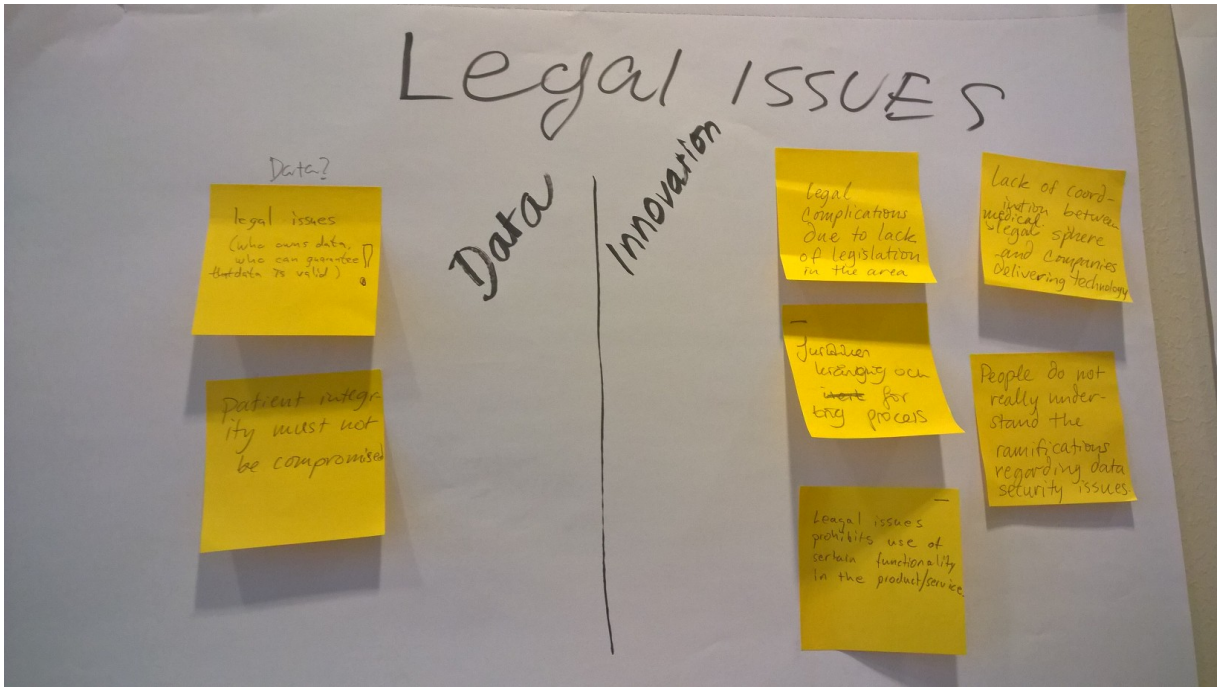
Below are links to a Youtube video [13] made by this research team. This film captures a future day in the life of a diabetic patient. Also, a video of the the full presentation of this research effort on PHM as given by this research team in December, 2015.

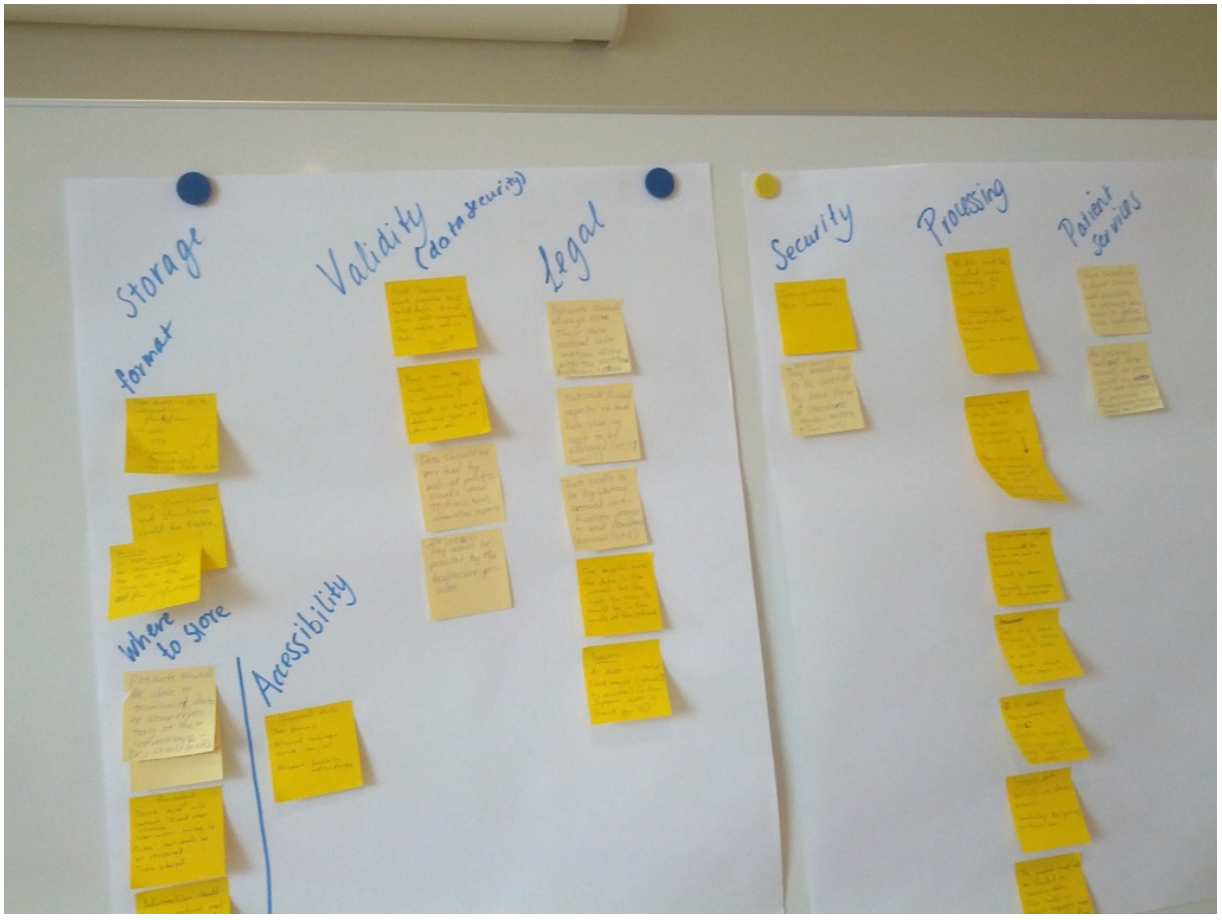
Patient Home Monitoring Video: http://tinyurl.com/phmmovie

Full Presentation: http://tinyurl.com/phmpresentation

C Pictures from Vision Seminars






Storage
format
Where to store
Accessibility
Validity
(data security)
Legal
Security
Processing
Patient services

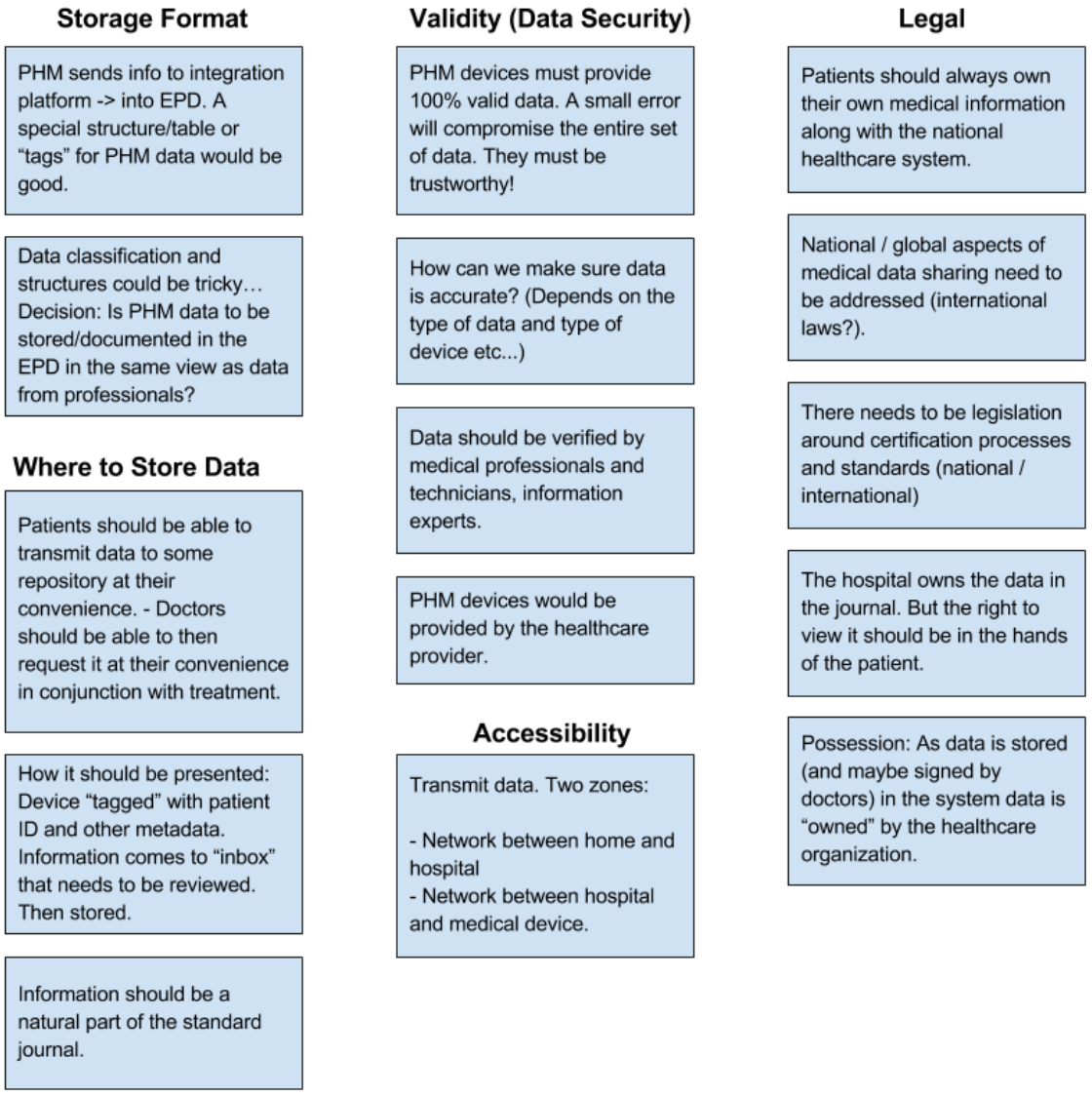


Figure 5: Idea synthesis from the first vision seminar

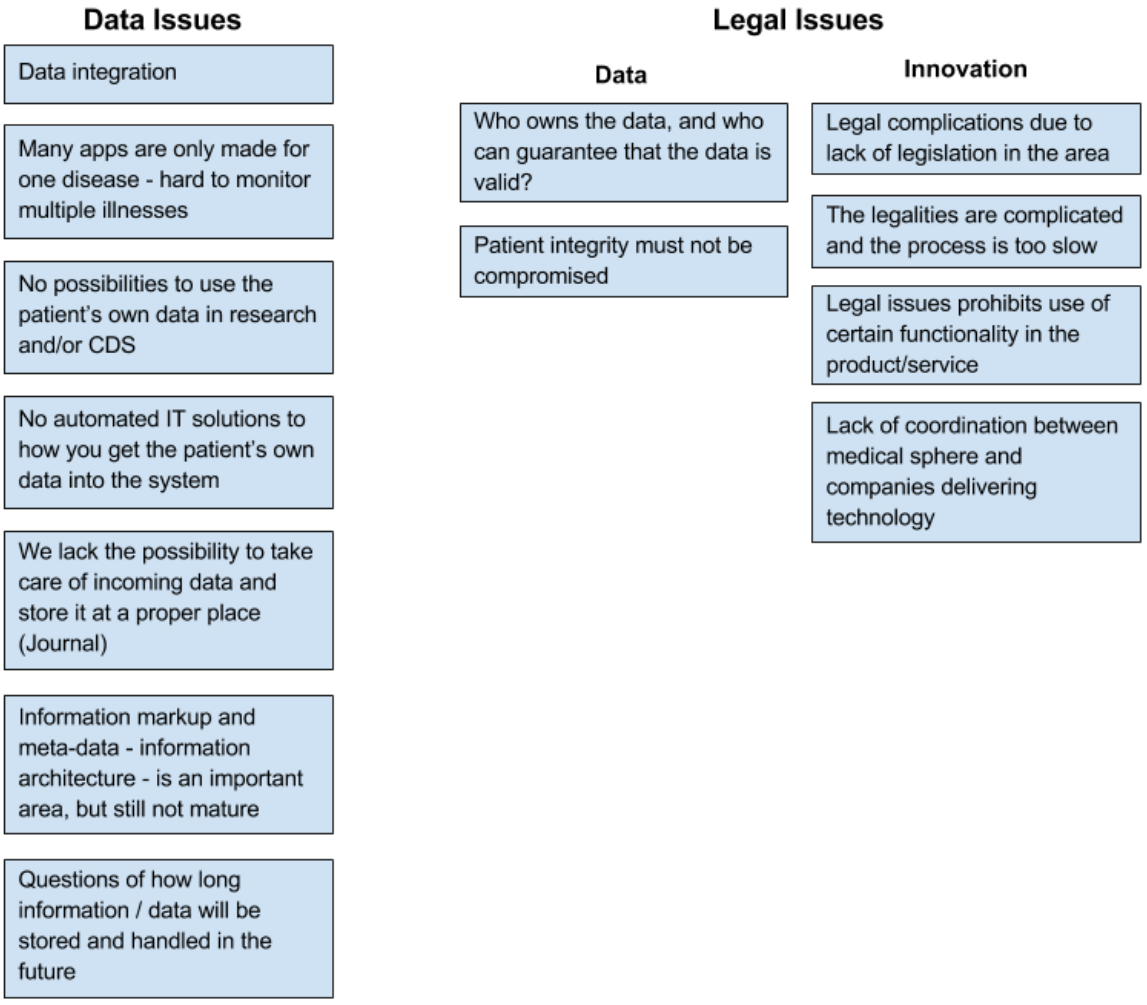


Figure 6: Synthesis of issues from individual vision seminar comments