

InfantCare: A Personal Health Record System Prototype for the Next Generation

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Abstract

We observed that commonly available personal health record (PHR) applications usually focus on handling general health information instead of special conditions. To address this issue, we designed and developed a PHR application with features targeted toward one specific user base, caretakers of infants. We utilized Google Health APIs and Java for the development of this application. We also carried out preliminary usability testing with actual users.

Executive Summary

In recent years, electronic personal health records (PHRs) have started to become a wide spread and relevant technology. To aid in acceptance of PHRs, we worked to develop an application targeted for a specific user group that would help those users store their health records online. We restricted the groups that we considered to those which had a large amount of health data. We chose caretakers of infants as our target group since they have to manage a large amount of health data about their babies.

The generation that is currently coming into this world will be the first generation who will spend their entire lives with electronic PHRs. They are the ones that will have the greatest access to them as they grow up. By starting the PHR of an infant early, we allow the child to have a fuller record in the future. We also hope to acclimate the child to keeping medical records online. From the cradle, the health of the child will be logged in electronic databases. As the infant grows up he or she will accept all records being electronic as the modern and correct way to do this. Our application serves to start up this goal.

To develop our application, we followed a rapid application development process, and more specifically a prototyping-based methodology. This approach allowed us to implement a significant subset of our requirements while keeping to a very tight time frame. Our life cycle went through a few major phases. The first was requirements gathering. It was followed by an application and system design. We then worked on developing the application in several major iterations. Finally, we had our target audience evaluate our application to see if it fulfilled their expectations.

To gather our requirements, we created a survey that was distributed to personal acquaintances who had new born children as well as participants of the REACH program. The survey was composed of 23 questions about the acceptability of electronic health records and how records were currently being kept. The questions were conceived as a way to understand the needs of the users so that we could develop an application that would address them. We received four responses to our survey. The most important non-functional requirements were usability, security, and portability. The most common types of records to be stored were height, weight, head circumference, immunizations, and feeding information. The basic functional requirements were the ability to store and retrieve records as well as free-form text notes and the ability to represent them in some way that is easy to interpret and manipulate.

In the design phase we had two major tasks. One was to come up with a solid system design that would be able to handle the needs of our application and the data that it would be using. The other major task was to choose the basic details of our application such as programming language and major screens. In this phase, we dealt with concerns like data security and application portability. At the end of this phase, we had a solid design of what the application would look like and the basic flow of operation. The design we settled on was to use Java as the programming language and used Google Health to store records. Our application would provide an interface to enter, view, edit, and delete data stored in tables. The data would be stored as a series of entries on the Google Health notice board of the user. The record types that we focused on were: growth data, immunization records, feeding and sleeping times, numbers of diapers consumed, and free form notes on each of the subjects.

The development phase focused on turning the design of the previous phase into a real program. This phase was broken up into several iterations. The first iteration focused on creating

the basic application and a subset of requirements that we felt were the most important to the functioning and usability of the program. This iteration had the ability to store and retrieve records of all the types listed. The records were stored in static tables. The second iteration added the ability to edit and delete records. We also changed the growth tables to no longer accept age values for the child and instead had them calculated based on the date. By the third and final iteration, we included the ability to chart feeding and sleeping times over the course of a day. We also included a large number of bug fixes in the third iteration. The largest problems of the development phase were caused by the design omitting or improperly implementing features.

Our final phase was the evaluation phase. In this phase, we concerned ourselves with acquiring a measure by our target audience of the usability of our software. Like the requirements analysis phase, we created a survey. The new survey contained a number of questions focused on getting a quantitative measurement of the application and its functionality. For the most part, those surveyed responded positively to the application. They praised the application's ease of use and complimented the application for having all the basic functionality that the user wanted. On a System Usability Scale, we scored 69.167 out of 100 with no question on the survey upon which we did particularly bad. User suggestions focused mostly on getting more aggregate data such a total sleeping times over the course of a day and a summary of daily activities over the course of a week or month.

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Appendix B: Informed Consent Form For Survey Participants: Erik Archambault

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1 Introduction

Our project focuses on systems storing Personal Health Records (PHR). These are systems for users to manage their health records and share them with their doctors. The main purpose of PHRs is to empower healthcare consumers, allowing them to easily and efficiently manage their own health and health records [1]. This is different from most information technologies concerned with health records, which are designed for use by clinicians [2]. PHR systems create a great opportunity for the patient to be in control of his/her own medical records [3]. Because they are a new technology, they are open for growth and improvement [4].

The importance of PHRs has become ever more widely recognized in recent years [5]. It may be the case that at this point in time the advancement of PHRs is and has been driven by the healthcare industry rather than those who would most benefit from the technology, consumers [4]. Regardless, this advancement has been ongoing and will certainly continue into the future, especially in the current political environment [6]. However, because PHR technology is still largely in its infancy, with even a set of standards yet to be fully developed and adopted, there is, again, wide room for progress and improvement [7].

Consequently, within the topic of electronic PHRs and their impact, there seems to be a persistent problem, observed from various sources about PHRs [8, 9]. Based on sources like these, most applications seem to be very general in terms of the type of information and records they accommodate. These applications tend to record basic information such as physical attributes, current medical conditions, and prescription information for an individual, but there is

a lack of specific, targeted applications or application features that would be desirable to some particular set of potential users, such as those with particular medical conditions.

The scope of this problem is quite considerable, as it appears to be common among widely available PHR applications. As our background research indicates (see Chapter 2), one of the most important characteristics that affect the impact of a PHR application is the set of features it offers [10]. An application that offers features that increase its appeal in the eyes of certain potential users is more likely to be deemed useful and actually used by these people than an application lacking those features [1]. Thus, the potential impact of a PHR application could seemingly be increased with respect to this important criterion by giving it features that appeal to diverse sets of users or that appeal strongly to a specific, preferably large, set of users.

Due to this lack of targeted PHR applications, we have decided to create a prototype of such a targeted application for our project. There are many possible target user bases for such an application, but we have chosen parents/caretakers of infants as our targets. We have chosen this group of people because they need to maintain important records associated with the healthcare of their infants, a need which a PHR application, by nature, is well suited to satisfy [11]. This is also a large target group, with the U.S. birth rate being well over 4 million per year [12]. This means that the potential for impact of an application made specifically for this group should be high, and it should also be conducive to our recruitment of research participants belonging to the group.

Ideally, our goal in this project is to create an application that is as good as, if not better than, any paper based alternatives for record keeping. Our application will help new parents keep

better records more efficiently. Since the amount of records that need to be kept about a newborn can be quite large, a common electronic repository for the records will help keep them together and organized. Our application will also serve to help our target audience become acclimated to using a PHR system. It will allow users to first make use of PHRs with an application that models familiar objects or constructs in its interface (e.g. a chart or table) to maximize ease of use. The users then will not have to use a larger, more complex PHR system until they are prepared for it and may want to take advantage of other features that such a system may offer.

In the next chapter, we present the background information relevant to this project. This includes discussion of health informatics, definition and principles of electronic health records and personal health records, and review of some available PHR applications. Chapter 3 describes our methodology, including overall planning and decision-making processes, for this project. Chapter 4 is a presentation and discussion of our results, that is, the outcome we achieved in carrying out our methodology. Finally, chapter 5 contains our conclusions based on our results in this project as well as recommendations for future work.

2 Background

The focus of this project is the impact of personal health records (PHRs), or, more specifically, electronic, software-based or web-based PHR systems. In order to understand these systems and study their impact, it is first necessary to understand some of the basic concepts of health informatics, electronic health records (EHRs), PHRs in general, and electronic PHRs. One can then begin to examine the actual potential for impact of electronic PHRs. After the presentation of the basic concepts, this examination will begin by looking at a study on how willing patients are to use electronic personal health records. It will continue with a review of some currently available examples of electronic PHR systems for analysis and comparison.

2.1 Health Informatics

According to answers from Zeger [13] to questions about the nature of health informatics, health informatics, in general, is “the science that deals with health information, its structure, acquisition and use”. Zeger goes on to describe how the field can be divided into three major branches, which differ conceptually in their scale: bioinformatics, medical informatics, and public health informatics. Bioinformatics deals with using information technology and computing to gain understanding of biomolecular and cellular processes. Medical informatics, the branch with which this project is primarily concerned, deals largely with usage and handling of patient information. Public health informatics is a more statistical branch dealing with monitoring and measuring the health of populations rather than individuals.

Medical informatics, according to Bansal [14], can be considered to encompass a wide array of subfields, including such uses of information technology as telemedicine, computer-

assisted surgery technology, medical simulations and virtual environments, and physician and patient education. Also discussed by Bansal, in accordance with the previously mentioned focus of medical informatics on patient information, a major area of medical informatics is that of computer-based patient records. Electronic patient records, also known as electronic health records (EHRs), are partially the focus of this project, and will be discussed in more detail in following sections.

2.2 Electronic Health Record (EHR)

The term electronic health record (EHR) is a generic term that can refer to a number of distinct but similar types of electronic patient care systems [15]. In general, EHRs are electronic record systems used by medical professionals to maintain and process patient records, as well as to facilitate access to these records by those that need them [16]. One formal definition given is “a secure, real-time, point-of-care, patient-centric information resource for clinicians” [17]. The important point is that EHRs are designed for use by clinicians rather than patients themselves, which is a major difference between EHRs and PHRs [18].

As for the intended function and purpose of an EHR, there have been multiple attempts by different healthcare standards organizations to produce a set of requirements that EHRs should meet. For example, a committee from the Institute of Medicine of the National Academies produced this set of criteria that an EHR’s core functionalities should satisfy: Improve patient safety; Support the delivery of effective patient care; Facilitate management of chronic conditions; Improve efficiency; Feasibility of implementation [19].

Another key aspect of EHRs is interoperability. According to the National Alliance for Health Information Technology, an electronic medical record (EMR) is a patient health record maintained and used by a single healthcare organization, while an EHR is the aggregate health record for a patient, accumulating data from multiple organizations; essentially, an EHR is a larger scale EMR with interoperability [20]. Some would even go so far as to say that widespread adoption of stand-alone EMR systems with no interoperability would set a detrimental precedent for the treatment of health information [21].

Much of the literature and discussion of health informatics, especially its benefits and costs, concerns the adoption of EHR systems. According to a presentation by Catz [22], adoption of EHRs is supposed to bring about improved quality of healthcare delivery and enhanced healthcare management. In this presentation they are cited as key to modernizing healthcare, and it is stated that their implementation should be a priority. However, it is also stated that one of the most tangible potential benefits of an EHR system is reduction of medical error rates. For example, it is stated that medication errors account for many of the deaths attributed to medical mistakes, while studies have shown that many, even most, medication errors can be eliminated through the use of information technology.

However, as seems to often be the issue with healthcare, actually implementing the system(s) is costly [23]. Though it does seem potentially that bearing this cost could serve as an investment which will allow great saving in the long term [24]. Some estimates for nationwide EHR implementation in the U.S. range as high as \$150 billion [25]. However, others say that this may lead to the country saving \$500 billion per year [26]. At any rate, the recent American

Recovery and Reinvestment Act of 2009 includes provisions promoting adoption of health information technology by healthcare providers, with cost estimates that include anticipated future savings to offset near-term expenses to some degree [27].

Such grand machinations as the global adoption of EHRs are beyond the scope of this project. The focus is instead on something on a smaller scale, more available and tangible to actual healthcare patients; this being PHRs, which are addressed in detail in following sections. Consideration must also be given to determining which group of people health informatics would be most likely to impact throughout their lives. Given that health informatics have yet to be widely adopted, especially in any ways visible to patients, obviously the population most likely to be impacted the most by these technologies are today's children, especially the recently born. Even now, information technology is being used to benefit children's health through the use of interactive multimedia applications for educating children [28].

Unfortunately, newborns and infants are unable to make use of information technology themselves. However, in an age where there are concerns over ensuring children, now and in the future, have adequate healthcare coverage, and over the present and future costs of this coverage, any sort of head start could prove beneficial [29, 30]. Therefore, one potential path of progress is to create technology for use by parents in relation to their young children, in the hope that such technologies and others could go on to follow and benefit a child throughout their life. One such potential technology is that of PHRs.

If we consider our target users to be parents of young children, and our chosen technology to be PHRs, we can attempt to determine the size of our potential user population.

According to the National Center for Health Statistics, there were 4.27 million births in the U.S. in 2006, with preliminary estimates for the 2007 birthrate at 4.32 million [12]. This means that if our primary user population is to be parents of children from 0-3 years old, then the population size may be on the order of up to 12-13 million potential users in the U.S. (with a strict cutoff at exactly 3 years of age). These statistics also indicate that approximately half of these births are to parents 20-29 years old. So a distinct majority of new parents, taking into account younger parents as well, are young enough that they have a high likelihood of being familiar with computers, allowing them to benefit from computer-based PHR applications [31].

2.3 Personal Health Record (PHR)

In contrast to all of the formal definitions and specifications produced for EHRs, the concept of PHRs in general is more varied. A PHR can take various forms, including written notes or digital files, or some combination thereof. It may contain any set of health-related information that the creator or maintainer of the record desires to keep. It may also be used for any of various purposes, such as helping an individual keep track of their own healthcare history, or manage an ongoing condition, or keep records on another individual in their care [32].

However, the focus of this project is on electronic PHRs, which can be classified somewhat more formally. There are three overall types of electronic PHR [33]: (1) the free-standing PHR, which is not linked to any outside data sources and functions only as a private record populated with data provided by the record's maintainer (all written record PHRs are inherently free-standing); (2) the interconnected PHR, which is linked to (such as by some web protocol) and populated by data from multiple sources, such as the individual's health care

provider's own EHR system, pharmacy data, or home diagnostic equipment; (3) the tethered or provider system PHR, which is essentially an extension (often in the form of a web-based portal application) of the individual's health care provider's EHR that allows the individual some level of access to their own records within the provider's system. Depending on the provider, a tethered PHR may present data in a read-only format, not allowing the user to modify any data, or it may provide some capabilities for data manipulation; however, tethered PHRs may tend to offer more restricted capabilities to the user than other types [18].

Given this background information, we can begin to address the actual impact of personal health records, beginning with an examination of how willing people are to actually use an electronic PHR. Here is a summary of a study on the matter [34]: A retiring doctor offered 1,000 patients copies of a free-standing electronic PHR program, along with copies of their own records exported from the practice's EHR, to be imported to the PHR program. There were 330 patients who accepted the offer. Ten months later, the doctor surveyed those who had accepted. There were 136 who responded to the survey, and here are some pertinent results [34]:

- 50 had made use of the PHR, while 52 stated they had not

- 49 of those who had used the PHR said that it was easy to use

- 11 of those who had not used the PHR said that they did not understand the software or that it seemed too difficult

- of the nonusers, 46 planned to use it "when the time comes"

- 113 stated they felt that people should maintain personal health records

-63 stated they would not prefer to keep their records on the Internet rather than on their own computer, while 4 stated they would prefer the Internet

-61 stated they would not keep their complete personal records in an Internet-based record, while 43 said that they would

-those who would not keep Internet-based records generally cited privacy concerns

If, for the sake of argument, we take these results to be representative of widespread attitudes toward electronic PHRs, we can make some conclusions as to the possible impact of electronic PHRs. While many people choose not to avail themselves of the capabilities of electronic PHRs, there are obviously those who do. Even among those who do not make use of such applications there seems to be the understanding that these applications could be useful in certain situations and to certain people. This is revealed by the fact that most of the respondents in this survey, including nonusers, felt that people should maintain their own personal health records, and that most of the nonusers planned to use the application if/when the situation called for it. In addition, an important factor in determining whether or not an individual is likely to use such an application appears to be how easy it is to use for that individual. Another important inference is that people were reluctant to store their records in some form on the Internet, mainly because of privacy concerns. It is important to note at this point that the survey was conducted in 1999-2000, and current attitudes toward the safety of information on the Internet may be different. However, even though many more people trust their confidential information to Internet data stores today, privacy and information security are still major concerns, and problematic information leaks still occur.

It can be inferred from this survey that certain characteristics of an electronic PHR increase its appeal to potential users and thus its potential impact. The importance of these characteristics is also supported by numerous other sources. It seems that the presence of a variety of features and capabilities that would make a PHR appealing to a diverse set of users is important [1, 8, 10, 35, 36]. Also, ease of use is important, to make a PHR accessible and useful to a large audience [8, 36-39]. Perhaps the most important issue is the overall issue of information security and user privacy. This issue appears to be addressed more often than any of the others; it is of the greatest importance that a PHR application offer adequate security and that users can be confident in their privacy, especially with web-based applications [1, 8, 35, 36, 39-42].

In addition to those important factors indicated by the study, some other possible issues for PHR applications to address are accuracy and error handling. The improvement of the accuracy of information entered by the use of guided data entry and the detection of likely errors by a clinical rules engine can improve acceptance of a PHR application by addressing these issues [35, 43].

Another survey [44] focused on user satisfaction of a tethered PHR. It was conducted at a Fortune 500 company using a major third-party PHR solution. Out of the 368 invited participants, 132 responded to the survey. When asked about overall satisfaction, 45% were satisfied with the software while 32% were not. On the question of concerns, the two biggest were outside intrusion (34%) and the employer misusing the information (22%); 36% of responders chose not to voice any concerns. On the questions of expectations of the system, 55%

had none, 23% wanted privacy and security, 14% wanted up to date and accurate information, and 8% wanted a usable and user friendly interface. When asked if they would use the PHR in the case of an emergency, 45% chose not to answer, 27% said they would with 11% saying that it would be especially useful in they are unable to communicate, and 17% said that they would not want to use it, many preferring to speak for themselves. When asked if they wanted the PHR available to emergency responders, 40% were not sure, 29% voiced concern about giving the information to a third party, 7% questioned whether the PHR was reliable enough for such a situation, and 5% were not even sure if the emergency responders would be able to use the PHR system; only 19% said that they wanted the information to be available. The expectations of ease of use were easy to find information (31%), private and secure application (5%) and a standard UI (2%) with 62% not voicing an opinion. When the responders were asked to evaluate the UI 21% found it hard to navigate while 22% praised the format and layout and 30% praised the navigation.

Now we have discovered some of the most important potential criteria to determine the usefulness and possible impact of an electronic PHR. In moving forward, we will now analyze and compare some currently available, web-based PHR systems.

2.4 Analysis of PHR Applications

For our project, we need to select a PHR application for which we will write our tool. At the current time, there are three major online applications that offer online PHR. These are Google Health¹, Microsoft HealthVault², and Indivo³. Indivo is backed by a consortium of

¹ <https://www.google.com/health/>

industry leaders including Wal-Mart Stores Inc., Intel Corp., AT&T Inc. and five other large companies, collectively referred to as Dossia [45]. Out of the three, Indivo is clearly the weakest candidate for our purposes.

In theory, Indivo should be the front-runner in our search. It is being developed as a collaboration between Dossia and Children's Hospital Boston, which offers it a unique ability to include both medical professionals and a large pool of volunteers in the development process. It is also the only product of the three that is open source, allowing us to develop a tool that would better interface with the system. The developers go as far as to encourage third parties to create their own clients to fit specialized needs [46]. Unfortunately, Indivo loses out because it is yet to become available to the general populace. Though it has been in internal testing at Dossia companies for well over a year and used by Children's Hospital since 1998, it has yet to get a major public release [47]. As it stands right now, the only way to use Indivo is to download the source code and set up the complex data storage center required to keep records secure.

Microsoft HealthVault was also a promising candidate that we passed over. Unlike Indivo, which is not yet widely available, HealthVault has been available for public use since October 2007. It supports the largest set of applications from which it can pull health records with 40 available at launch and more added since then [48]. Records that are not available from one of the partners can be added manually by uploading them if they are available in a digital format or, if it is one of a selected list of types, including allergies, immunizations, and medications, you can enter it by completing a form. HealthVault also includes a specialized

² <http://www.healthvault.com/>

³ <http://indivohealth.org/>

search engine for medical questions. The search engine includes targeted advertisements based on the search criteria though, according to Microsoft, no personal information from the health records is used for advertisement purposes [49]. The largest reason for why HealthVault is a bad candidate is that it lacks a documented interface for third-party applications to add records to it. This presents a very large hurdle that would limit our efficiency if we were to choose it as our platform.

The third and best candidate for our project is Google Health. It is the newcomer to the field, having been launched in May of 2008. It is also the one with the fewest third party repositories from which to get user records. They started with eight partners, with the majority providing prescription records, and have only attracted a few new partners in the short time that the product has been available for the public. At the current time, the user needs to enter many records in manually. Google makes up for it by making the process easy. Like HealthVault, Google Health offers preset forms for conditions, medications, allergies, procedures, test results, and immunizations, but unlike the competition, Google Health offers users a list from which to choose the condition or treatment and the user is only asked to fill in details. This style of user interaction is typical of Google Health, which, in general, offers a better and easier user experience, with features like directories of medical professionals and a reference library of medical conditions. Google also includes many third party applications that can use the records in the profile [50]. Overall, the Google strategy is to offer a product that is easier to use and to include an open and easily accessible API [51]. This API sets Google up to be a very good platform for our work. The API is very thoroughly documented and available in a couple

different programming languages. It also has a news group and forum hosted by Google with developers present to answer questions.

As shown in Table 1, Google Health was the strong choice for our back end. They have an open and public API. They have public availability. They have a growing number of third party partners. All three are major factors that pushed us to decide on Google Health as our PHR application of choice for this project.

Table 1: Comparison of PHR Applications

	Indivo	HealthVault	Google Health
Backing company(s)	Wal-Mart Stores Inc., Intel Corp., AT&T Inc., Children's Hospital Boston	Microsoft	Google
Public Availability	Not yet widely available	Public beta since October 2007	Public beta since May 2008
Third party data sources and applications	Children's Hospital Boston, corporate health plans	23 applications to import records and analyze risks	9 applications to import medical and prescription records, 17 applications that use data for other purposes
Openness to independent additions	Open source	No obvious methods	Open API and support for some standard protocols

3 Methodology

In the previous chapter, we researched health informatics and PHR technology, and analyzed some currently available PHR applications. Having considered the three candidate applications, Google Health is the best choice to work with. It is both easiest to code for and will provide users the best experience with other records. It also supports Google data formats and Continuity of Care Record data standards [52], potentially allowing records that we create to be used by any other tools that could arise in the future.

Our plan was to further study the impact of personal health records by developing a PHR application targeted for use by a specific community. In our research, we discovered no available electronic PHR applications that are specifically intended to handle records for infants. Such an application would appear to be very useful to many people, given the amount and importance of records necessary to keep for infants, and could thus have a considerable impact [11]. Therefore, we planned to produce an application designed to serve this purpose.

To develop this application, we first had to decide on what type of software development life cycle (SDLC) to use. Ideally, to create a fully functional application, an iterative SDLC would be desirable, allowing the application to, after initial development, be repeatedly evaluated and refined [53]. However, given that in our limited time frame for the project we would not have time for repeated development iterations, this process was ruled out.

Another SDLC we considered was the traditional waterfall development model, as this model is somewhat like a single iteration of the iterative development process [53]. However, in

the waterfall model, the developmental phases are supposed to be rigidly divided and sequential, and each phase should thoroughly accomplish all that is necessary before beginning the next phase [54]. This may not have allowed us the flexibility we would need in our development process, as well as still requiring more time than was available to us. Also, the waterfall SDLC is supposed to rely on users exclusively for the purposes of requirements gathering, whereas we wanted to conduct some form of user evaluation of our final product [55].

Ultimately, we decided to use a rapid application development process. Specifically, we chose a prototyping-based methodology. This process would give us the needed flexibility by making multiple traditionally sequential development phases concurrent [54]. It would be well suited to allow us to implement a reasonable proportion of our functionality goals in our limited time frame [56]. Additionally, this SDLC includes the desired user assessment/evaluation of the prototype [53]. Thus, while in our development process the implementation depended on the application design and the design depended on the requirements analysis, the phases did largely overlap.

3.1 Requirements Analysis

To develop our prototype, we first would have to gather information to determine the desired requirements to fulfill. We planned to invite members of the intended user base (parents or caretakers of infants) to participate in a research study for this purpose. Specifically, we planned to approach members of the REACH Program for child development as the primary base of potential users we would invite to participate. Members of the REACH Program are families with children who range in age from newborn to 3 years old, which means they fit our target

demographic of caregivers of infants [57]. In addition to these program members, participants in our research would potentially include personal contacts that fit the demographic and accepted our invitation (see Appendix A) to participate.

Given our information gathering needs (i.e. minimal cost to all parties involved in terms of time and effort, as well as the ability to potentially accommodate any number of participants, large or small), we decided it would be best to use a simple questionnaire survey format [58, 59]. Because this research was both exploratory, in that we were looking for fresh input from potential users, as well as confirmatory, in that we hoped research participants would also confirm some results of our background literature review, we decided we would use both quantitative and qualitative questions in our survey (see Appendix C) [60].

3.2 Design of the InfantCare PHR Application

With the requirements we would derive from our survey results, we would go on to produce a general design for our application prototype. Since we chose to make use of Google Health as a result of our research, we chose to use Java to code our application, as there is an available Java interface to use with Google Health. This also addresses the issue of portability, as Java is designed for maximum portability and cross-platform compatibility [61]. We also decided to make our application a simple stand-alone program, requiring no installation itself. It would be usable in any environment with Java installed and an available internet connection.

The application interface was to be simple, intuitive, and easy to use. Data was to be represented using tables, charts, and text boxes, with tabs used to navigate between screens for different types of data. As for security and data protection, our application would not

permanently store any information locally. All information would be stored in the user's Google Health account, protected by Google's password authentication. Any user comfortable with storing personal information with Google Health should be just as comfortable using our application to store information using their Google Health account.

As for features, our application was to implement the basic, necessary features of storing and retrieving the most common and useful types of records kept for infants. It would also be able to store notes associated with the different types of data, as well as miscellaneous notes to keep track of any additional information desired by the user. We also planned to implement extra features such as data aggregation and visual representations such as graphs and calendars if time allowed.

The architecture of the system would consist of two parts. One handled the GUI and user interaction. The other dealt with Google Health API and storing events to it. The separated design insulated the GUI from the details of the data storage and allowed the two parts to be developed separately around a common interface. The separation allows the GUI and database not to depend on one another to implement functionality since the single interface is reasonably simple to implement on both sides.

We also wanted to have an abstraction between the GUI and Google Health API. The GUI deals in data structures such as a set of measurements for a growth table. In contrast, Google Health does not have these data structures. Our architecture had to include a layer of abstraction to pass data between the components.

3.3 System Development

In developing the application, we accomplished it in three iterations. The first was to create the core functionality of the application. The second two iterations were bug fixes and improving on the functionality.

The first release was completed on December 17th. It had a four-tab design. The first tab is a record tab. It contains a table of the age, height, weight, and head circumference of a child as a function of time. The second is a daily chart to track the number of wet and soiled diapers as well as the child's feeding and sleeping times. The third tab is for daily notes. The parent can keep four types of notes: diaper notes, feeding notes, sleeping notes, and miscellaneous notes. The final tab is an immunization tab to record immunization dates. Each of the tabs was able to pull data from and post new data into Google Health. We also had support for the daily charts and daily notes tabs to pop up new windows to give the user a summary of all entries of a certain type (wet diaper count, sleeping notes, etc).

Despite the fact that Google Health does have a public API, it is not very well documented. Although Javadoc is available, methods often lack meaningful comments or have comments imported from a general Google Data interface [62]. The problem is further increased by the fact that the Google tutorial on API usage is very minimal and targeted towards developers of web applications rather than applets [63]. Finally, Google Health does not have specific fields to store data such as infant feeding and sleeping times. To get around all these problems, we built a solution using the Google Health notice board. The Google Health notice

board is a well-documented and accessible feature. It allows us to store our data as discrete objects on the Google Health server.

The second iteration of the application was done by March 16th. It featured several bug fixes and added the ability to edit and delete data out of the data store. On the GUI end, it involved creating new data boxes and buttons to handle the enhanced functionality. On the data storage side, the ability to edit the data was not straightforward. In order to be able to delete an entry (so a replacement can be inserted), we needed to be able to uniquely identify it in the raw notice board stream. The logical place to store such a unique identifier would be the version ID field of the feed entry. The field is defined as a unique identifier that should be edited whenever the entry is modified. It is also a field that Google Health will edit when it is processing the data internally [62]. Unfortunately, it turned out that it also not stored on the server. The next field that we tried to use to store the identifier was the id field of the entry, which is meant to uniquely identify it [62]. We rewrote the system to store the unique key in that and it still did not work. Upon a careful inspection, it became very evident that the value that we were submitting to the API was not the value it was giving back to us. Luckily it seemed that the value that it returned was unique for each entry and stayed the same every time you pulled it off Google Health. With the unique identifier set up, deleting and replacing data points was plausible.

The third iteration was worked on for April 5th. In it, we focused on adding additional displaying capabilities to the user interface. We created the ability to chart sleeping and feeding schedules in a table with the date on one axis and whether the infant slept during that time on the other. In the data store, we stopped storing the age of the child as data. Instead, we calculate it as

a function of the date of birth and the entry date. In order to accomplish this, the user profile had to be pulled from the Google Health server. This would not be by any means be an easy task because the profile is kept in the footer of the Continuity of Care Records of the user and the date of birth is buried in the profile. Normally the profile can be pulled from the same feed URL as the notice board and read using an XML parser. Unfortunately, many of the URLs that one can use to edit it do not work. [64] When we did get one that did work, it could not be parsed by the XML parser. It is currently being parsed using the `String.indexOf()` method.

After the third iteration, we decided that our application was feature complete enough to be useful to the general public and sent it off to be evaluated.

3.4 Evaluation

To evaluate our application, we developed a survey and invited (see Appendix D) the same subjects that participated in the requirements gathering survey. This survey (see Appendix F) consists of a standard System Usability Scale set of questions [65]. These allow us to gauge the overall ease of use of the application. We also included several questions to give the user a space to add additional comments that they may have. Included with the survey and application was an informed consent waiver similar to the one that was used with the initial requirement gathering survey (see Appendix E) and a users' manual (see Appendix G). Participants were given 10 days to evaluate the application and provide feedback.

4 Results

The previous chapter outlined our planned methodology for this project. In this chapter we present the results of carrying out that plan.

4.1 Requirements Analysis

4.1.1 Research Participants

In order to create our application prototype, we approached members of the intended user group and gathered their input as to what features would be desirable in such an application. As discussed in the previous chapter, members of the REACH Program for child development were the primary base of potential users we invited to participate, as well as suitable personal contacts. The invitation letter given to potential survey participants is presented in Appendix A. We distributed our survey (Appendix C) to those who responded to our invitation and agreed to participate.

All research participants were required to give their formal consent to be surveyed, in accordance with regulations of the WPI Institutional Review Board (IRB). The IRB-approved informed consent form is presented in Appendix B. Measures were taken to protect identifying information of our human subjects. Those participating in our survey were instructed to return completed surveys to us in print form, either in person or by mail, to ensure that these documents would be directly transferred to us or protected by those laws which protect the confidentiality of mail until they reach us. Upon receipt of completed surveys, the documents were to be kept

secured. In accordance with regulations, upon completion of this project, these documents are to remain secured or, if necessary, be destroyed.

4.1.2 Requirements Gathering

We created a self-administered questionnaire including both discrete, quantitative questions and open-response, qualitative questions to be given to our participants. Ultimately, four subjects agreed to participate in our survey. The subjects were three females and one male, averaging 30 years old, each a parent of a single young child. This group included one member of the REACH program. Our survey was made available to the participants in print form and via e-mail, with appropriate instructions. Our full survey is presented in Appendix C.

4.1.3 Determining Requirements

Results from our survey provided us with some of the most common types of information recorded about infants, as well as input about desirable qualities for our application and data representation methods. The survey results agreed with our literature research results in that the potential users stressed the importance of ease of use as well as privacy and information security. Other desirable qualities mentioned were that use of the application not be time consuming, which could be considered a part of ease of use, and portability, or the ability to access records from anywhere. As far as the most common types of records to be stored, those mentioned were height, weight, head circumference, immunizations, and feeding information.

From survey questions about what type of records and information representation methods the subjects were familiar with, it appears that our potential users most often use simple notes or a notebook to keep track of records, sometimes only keeping mental notes, and the most

common structuring of data was in the form of basic tables, charts, or spreadsheets. In some cases, the importance of the flexibility of keeping free-form notes was stressed, indicating that a rigid structuring of records should not be enforced in all cases. It has also been noted that some potential application features that would be an improvement over conventional note and record taking are the ability to aggregate certain types of data and display their change over time as well as some type of checking for data that is abnormal or likely to be erroneous.

To summarize the survey results, the most important non-functional requirements to aim for in our implementation are usability, security, and portability. The most important and basic functional requirements to meet are the ability to store and retrieve records of the previously given types, as well as free-form text notes, and to be able to represent them in some way that is easy to interpret and manipulate. Of course, additional nonessential features are also available for consideration.

4.2 System Design

We made several major decisions in this phase. One was to decide how the data was going to be stored. Another was what level of abstraction about the storage details would be used when developing the GUI. The third decision was the way to figure out the detail of the data storage.

In order to make our system more secure, the application is created so that no data is permanently stored on the user's computer. Because of this, our application is simply a GUI, which converts data between a user readable format and a format used by Google Health, which stored the actual data. A user story illustrating this is shown in Figure 1. It depicts the user

editing a Health Record. When the user starts up the software, she enters her account information. The application establishes a connection with the Google Health server. The login credentials are then passed onto Google Health. Once the server verifies them, the software starts up the main menu to interface with the user. The user can then look up the records that they want to edit. The application requests the data that should go into the view from Google Health. Google Health returns the data and the application then presents the data in the interface for a user to view. To edit data, the user tells the application the revised data. The application accomplishes the edit in two actions: first the original record is deleted from the server, and then a corrected record is added. Finally, when the application exits, the connection to Google Health is automatically severed.

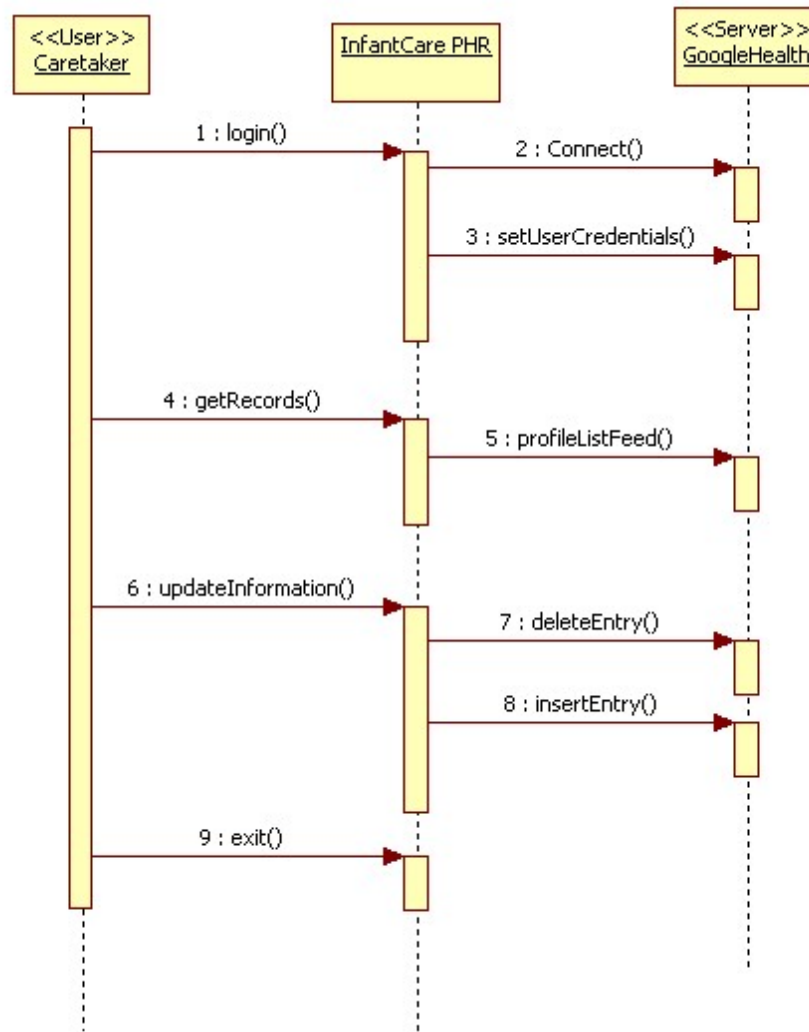


Figure 1: Sequence of Communication within the InfantCare PHR Application

In order to work easily with the data, we made another major decision. We decided that the GUI would be able to deal in a different set of abstractions from those used when storing the data on the Google Health server. To make this work, the system has to be able to convert between different levels of abstractions about the nature of the data (see Figure 2). Any data sent to the GUI by the user is first wrapped into a Datum by the GUI, the GUI then sends the Datum

to the Connector. The Connector then converts the Datum into a notice that can be stored by Google Health and sends it off. Data is retrieved in the opposite order. The notice is retrieved from the Google Health API. It is then converted into a datum by Connector. The Datum is then sent up to the GUI, which then unpacks the Datum to get the useful data.

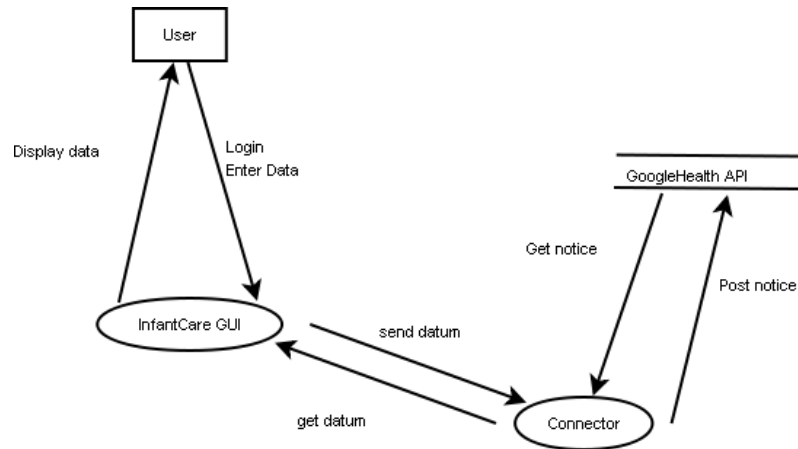


Figure 2: Information Flow of the InfantCare PHR Application

Our third major decision was the format used to store the data on Google Health. Because Google Health does not have an area to store many of the records that we create, we depend on the Google Health notification board to store our data. This lack of structure in our data storage backend causes us to create the Datum abstract class as an interface between the GUI and Connector. The Datum is, in some ways, a design compromise in terms of complexity. The Datum has to be very simple to store data to and load data from Google Health. At the same time, it wants to be complex to be easy to use for different fields such as tables of sleeping times and immunization records. As a compromise between the two, there is an abstract Datum class that is stored in the database. The developer can then derive any number of children that will handle their own packing into a string and unpacking. In our application, we had the abstract

parent Datum and four children; they are Note, Immunization, Measurement, and FeedAndSleep. (see Figure 3). The Datum itself has three fields: the date that the data relates to, a unique id string, and a type that corresponds to the child class that it belongs to. The Note child is used in the Daily Notes tab and stores all the data for it. The Immunization child class stores a list of immunizations for the immunizations tab. The Growth Chart tab uses the Measurement child class. FeedAndSleep child class stores the data of the Daily Activity tab.

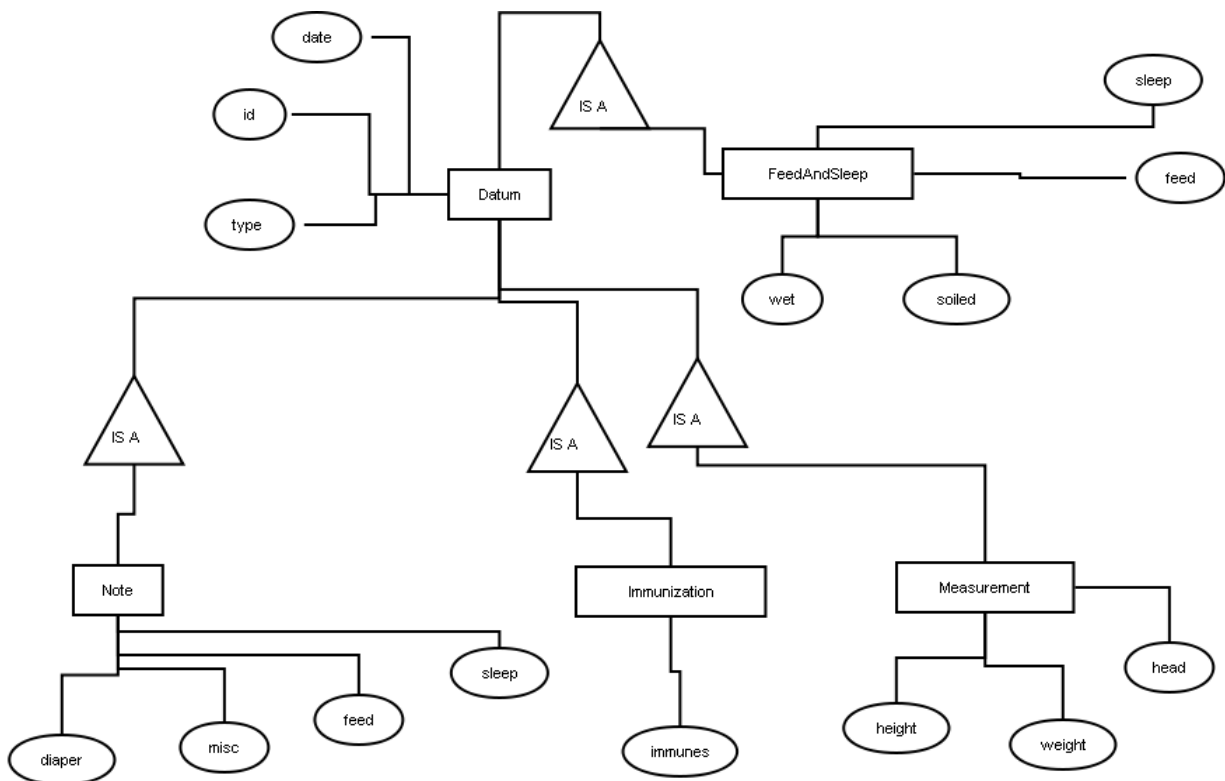


Figure 3: Data Model of the Datum

4.3 System Development

Our development was done using the Eclipse IDE and Java 1.6 JDK. This limits our audience to people who have Java 6 installed, but since it was released a few years ago, we

assume that the users will have it. We used the Standard Widget Toolkit to develop the GUI. We used Google Data API version 2.0 to get communicate with Google Health. Our application was tested on Windows XP and Windows Vista, both running Java 6. When testing with earlier versions of Java, we found that the class loader is not compatible with our code and stops our application from starting.

At the end of the development phase, we created a prototype that implements a sufficient subset of features that we felt our application should provide to the end user. Our final prototype is an application that can

- authenticate users using Google Health,
- connect to Google Health and store data on the server,
- store and chart the height, weight, and head circumference as the child develops,
- store and chart daily sleeping and chart daily eating patterns,
- keep track of how many times a child produced bodily waste each day,
- store immunizations the child had, and
- keep miscellaneous notes about the child.

4.4 Evaluation

By our deadline, we received a completed survey from all but one of our subjects. The surveys were mostly positive. Most users praised the application. Only one major defect was

reported: One user had encountered difficulty saving data using the application. The defect had not previously been reported and is not yet reproducible.

The first part of the survey was a System Usability Scale. Using an unweighted scoring formula from Serco Ltd [65], we were able to assign each response a grade from 0 to 100 which reflects the respondent's satisfaction with the usability of our application. When averaged together, the three surveys give us a combined score of 69.17. For most of the questions, the respondents gave favorable scores and no question had a score that was critical of the application. The only question that received a neutral score was one asking if the application was cumbersome to use.

The second part of the survey consisted of open-ended questions to allow the subject to express her opinion. Out of the three respondents, two praised the application for ease of use. One user reported difficulty saving data that very drastically hindered her ability to use the application. Several suggestions were made to improve the existing functionality of the application. One was to allow the application to store partial records. Another one was to increase the granularity in sleeping time records. A third was to add in a visible confirmation when data is sent to the Google Server. Respondents also made some suggestions about new functionality that we could add. A common suggestion from respondents was a function to calculate the total time a child sleeps over the course of a day. Another was the ability to compare the child's size and growth rate with average values. An additional one was that we should display aggregate data over the course of a week or month about daily activities. A final

suggestion was that we should add in a field to store the total amount of food that the child consumed over the course of a day.

5 Conclusions and Recommendations

Based on our observations gained in completing this project and the results of our application evaluation, we can attempt to draw some conclusions. First, we will consider usability, the characteristic determined to be one of the most important from our literature review in Chapter 2. From the part of our evaluation (Appendix F) based on the System Usability Scale [65], our application received a calculated score of 69 out of 100. Furthermore, multiple evaluation participants commented that the application was generally good in terms of its usability, such as allowing the user to easily view and manipulate information. From this, we can conclude that while there may certainly be room for improvement, our application's user interface style seems to be a step in the right direction for such applications in terms of satisfying core usability requirements. It would appear that, in regard to our observation from Chapter 2 that usability strongly influences the potential impact of such applications, a more fully developed application like ours could certainly have a considerable potential impact in this respect.

Criticisms and recommended modifications to our application by and large were concerned with its limited functionality. As discussed in Chapter 3, we planned on implementing as many potentially useful features as time permitted. Ultimately we were only able to implement core storage and retrieval functionality for the most important types of records, as well as some rudimentary charting capabilities for certain record types. The conclusion to be made here, and the overall impression seeming to come from the application evaluations, is that the idea behind the application is a good one and that further developing it and fleshing out its

functionality could make it very useful. Referring again to the discussion in Chapter 2 about what attributes affect the impact of PHR applications, while usability is highly important, an application must also have features that make it worth using. Thus, fully developed functionality must be implemented to maximize an application's potential impact.

As for recommendations, there is much future work that could be done just in terms of building from our example, i.e. taking our application or one similar to it and exploring the possibilities of taking it further, expanding and adding onto it. This is largely in the vein of additional or refined functionality such as that we had considered implementing or that which our evaluation participants brought to our attention. There are indeed many more features that could be implemented in an application like ours to be evaluated. These include better capabilities for representing data visually, using charts, graphs, and calendar-style interfaces for example. This would be especially useful in conjunction with the ability to analyze the data aggregated over time. This could be further enhanced with the ability to compare trends in the data to a data set representing what is considered to be average or normal. On a similar note, there could be implemented some sort of "sanity checks" which notify the user of abnormalities in the data.

Another way of making our application or a similar application that interacts with Google Health more useful is to provide deeper integration with Google Health's inherent functionality. Our application was designed mainly as a standalone application that made use of Google Health primarily for secure storage of data. At least one of our evaluation participants seemed to be anticipating, or at least recommending, some fuller integration with Google Health in the respect

that the records they stored would be visible in some meaningful way and perhaps also modifiable through Google Health's own web interface. This level of communication and interaction with Google Health would greatly increase the complexity of such an application, as well as not being possible with regard to some of the records our application deals with, given the current state of Google Health.

In addition, those of us involved with this project made note of the ubiquity of portable devices such as smart phones and PDAs and the way in which people use them for scheduling purposes and handling information on a daily basis. As a result, it seems that one possible avenue for greatly increasing the impact of a PHR application like ours would be to implement it in a portable form so that it could be used in conjunction with these portable devices that people tend to carry with them at all times.

Ultimately, our results look promising. It appears that PHR applications certainly do have at least the potential to have some significant impact on their user populations, especially those which cater specifically to the needs of particular populations. While our work attempts to confirm this and explore the area of PHR applications with targeted functionality, there remains a wide field of future work to build upon it, reinforce it, and examine targeted applications much more deeply than we could hope to in a project of this scale and scope.

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Appendix A: Invitation to potential Survey Participants

Invitation to Participate in a Research Project

We are Erik Archambault and Konstantin Naryshkin, computer science students currently working on our Interactive Qualifying Project (IQP) at WPIⁱ. The IQP is a project all students must complete, and its purpose is to relate science and technology to societal and human needs.

The topic of our IQP is the Impact of Personal Health Records (PHR). PHR systems in general enable individuals to electronically manage an integrated and comprehensive view of their health information, including individual and family medications, medical conditions, immunizations, allergies, and other personal health informationⁱⁱ. In researching the area, we have discovered that there seem to be no widely available electronic personal health record applications that facilitate health information management for infants. We found this quite surprising given how useful such an application could be for so many people. Therefore, in our IQP we decided to develop an application that will help parents of infants manage information about daily activities such as sleep patterns, feeding patterns, wet and soiled diapers, vaccinations, etc. This application will work with a web-based personal health record system (Google Health) that is already freely available.

We are currently working to create a set of requirements for our application and would like to invite you to take a survey and, if you wish, be interviewed as part of the research activities for our IQP, because we value your input as the caretaker of an infant. In order to create this application, we want to get an understanding of how records are currently kept and what information is recorded. Our questions will be on the topics of how you manage health information, maintain records, what records need to be maintained, and what difficulties or frustrations you had doing so. The survey will be designed so as to not take up much of your time, and it may be completed at your leisure and returned to us. Interviews will not exceed half an hour and they will be conducted on the phone or in-person. We will try to model our system as closely as possible to the traditional methods so that our system is intuitive. We also hope to build upon the traditional methods to improve them. The resulting application will be available to you for testing purposes once this project is completed.

The survey will be available online, via email, or on paper by October 28, 2008 for two weeks. The interviews will be conducted between October 28, 2008 and November 8, 2008. If you would like to participate in our survey or interview, or get more information, please contact us or our advisors with our information below. We look forward to your participation.

Sincerely,

Erik Archambault

archer10@wpi.edu

Konstantin Naryshkin

konary@wpi.edu

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ⁱFor more information about Worcester Polytechnic Institute please visit <http://www.wpi.edu>.

ⁱⁱ("The Transformative Potential of Integrated Personal Health Records.")

Appendix B: Informed Consent Form For Survey Participants

Informed Consent Agreement for Participation in a Research Study

Investigators: Erik Archambault, Konstantin Naryshkin

Contact Information: Erik Archambault: archer10@wpi.edu

Konstantin Naryshkin: konary@wpi.edu

Title of Research Study: Requirements Analysis Survey for Infant-care PHR Prototype

Introduction:

You are being asked to participate in a research study. Before you agree, however, you must be fully informed about the purpose of the study, the procedures to be followed, and any benefits, risks or discomfort that you may experience as a result of your participation. This form presents information about the study so that you may make a fully informed decision regarding your participation.

Purpose of the study: The purpose of this study is to gather demographic information and other input from caretakers of infants to be used in determining desirable features and characteristics of a software application for managing health records for infants.

Procedures to be followed: We will provide you with a survey either in print form, by email, or on the web. The anticipated starting date for this study, when the survey will become available, is October 28. The survey will last for two weeks following the start date, during which time you may complete the survey and return your responses to us. Completing the survey should not take more than 30 minutes. To avoid concerns about the security of digital information, we request that you return your responses to the survey in print form, so as to ensure the confidentiality of your personal identifying information.

Risks to study participants: There are no apparent risks associated with this study. The only foreseeable cause for your discomfort in this study would be answering a question that makes you uncomfortable. You may choose not to answer any question that makes you uncomfortable.

Benefits to research participants and others: There is no direct benefit to you as a result of this study.

Record keeping and confidentiality: Records of your participation in this study will be held confidential so far as permitted by law. However, the study investigators and, under certain circumstances, the Worcester Polytechnic Institute Institutional Review Board (WPI IRB) will be able to inspect and have access to confidential data that identify you by name. Any publication or presentation of the data will not identify you.

Compensation or treatment in the event of injury: This study involves no apparent risk of injury or harm to you. Thus, there is no need for compensation or medical treatment in the event of injury. It is required to inform you that you do not give up any of your legal rights by signing this statement.

For more information about this research or about the rights of research participants, or in case of research-related injury, contact:

Erik Archambault
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Konstantin Naryshkin
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You may also contact the chair of the WPI Institutional Review Board (Prof. Kent Rissmiller, Tel. 508-831-5019, Email: kjr@wpi.edu) or WPI's University Compliance Officer (Michael J. Curley, Tel. 508-831-6919, Email: mjcurley@wpi.edu).

Your participation in this research is voluntary. Your refusal to participate will not result in any penalty to you or any loss of benefits to which you may otherwise be entitled. You may decide to stop participating in the research at any time without penalty or loss of other benefits. The project investigators retain the right to cancel or postpone the experimental procedures at any time they see fit.

By signing below, you acknowledge that you have been informed about and consent to be a participant in the study described above. Make sure that your questions are answered to your satisfaction before signing. You are entitled to retain a copy of this consent agreement.

Study Participant Signature

Date: _____

Study Participant Name (Please print)

Signature of Person who explained this study

Date: _____

Appendix C: Requirements Gathering Survey

Part 1: Demographic Data

1. Name
2. Gender
3. Age
4. Occupation
5. Highest level of Education
 - a. Less than high school
 - b. High school
 - c. Some undergraduate education
 - d. Bachelor's Degree
 - e. Some post graduate education
 - f. Master's degree or higher
6. How many children do you have?
 - a. Please tell us the ages of your children:

Part 2: General Survey:

1. I feel very comfortable with using a computer.
Strongly Disagree _____ Strongly Agree
1 2 3 4 5
2. I feel very comfortable with using the internet.
Strongly Disagree _____ Strongly Agree
1 2 3 4 5
3. Do you have an internet connection at home and if so, what is the approximate speed of it?
 - a. I have a high speed connection (cable, DSL, or better)
 - b. I have a dial up connection
 - c. I do not have an internet connection at home
4. Would you trust a third party company (such as Google or Microsoft) with your medical records?
 - a. Yes
 - b. No
5. Do you know if your healthcare provider offers the ability to view your medical records online?
 - a. Yes
If so, have you ever used this system?

9. Are there any other suggestions that you want to offer?

Appendix D: Invitation to Second Round of Survey Participation

Invitation to Participate in the Second Phase of a Research Project

We are Erik Archambault and Konstantin Naryshkin, computer science students currently finishing our Interactive Qualifying Project (IQP) at WPI⁴. The IQP is a project all students must complete, and its purpose is to relate science and technology to societal and human needs.

The topic of our IQP is the Impact of Personal Health Records (PHR). PHR systems in general enable individuals to electronically manage an integrated and comprehensive view of their health information, including individual and family medications, medical conditions, immunizations, allergies, and other personal health information⁵. In researching the area, we have discovered that there seem to be no widely available electronic personal health record applications that facilitate health information management for infants. We found this quite surprising given how useful such an application could be for so many people. Therefore, in our IQP we decided to develop an application that will help parents of infants manage information about daily activities such as sleep patterns, feeding patterns, wet and soiled diapers, vaccinations, etc. This application works with a web-based personal health record system (Google Health) that is already freely available.

In November, you participated in the 1st phase of this study and provided requirements for our system. We have recently completed development on our application, InfantCare PHR, and we would like to get feedback on it. In order to evaluate our application better, invite you to the second phase of the study where we will ask you to try the system and provide feedback. Since you participated in the first phase that we did to gather requirements for our application, we feel that your input would be especially helpful.

Attached is a short list of questions for you to answer about the application, please consider them in that context. The questions are intended to give us an objective overview of your experience. We have also attached the application, the installation instructions, and the user manual. We would appreciate it if you could fill this survey out in the next ten days and return it to us by April 15th. We look forward to your participation. Thank you for your time.

Sincerely,

⁴ For more information about Worcester Polytechnic Institute please visit <http://www.wpi.edu>.

⁵ ("The Transformative Potential of Integrated Personal Health Records.")

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Appendix E: Informed Consent Form For Evaluation Participants

Informed Consent Agreement for Participation in a Research Study

Investigators: Erik Archambault, Konstantin Naryshkin

Contact Information: Erik Archambault: archer10@wpi.edu

Konstantin Naryshkin: konary@wpi.edu

Title of Research Study: Infant-care PHR Prototype Evaluation

Introduction:

You are being asked to participate in a research study. Before you agree, however, you must be fully informed about the purpose of the study, the procedures to be followed, and any benefits, risks or discomfort that you may experience as a result of your participation. This form presents information about the study so that you may make a fully informed decision regarding your participation.

Purpose of the study: The purpose of this study is to gather evaluation information and feedback on an infant care PHR application prototype from caretakers of infants to be used in determining how well the prototype implements desirable features and characteristics of a software application for managing health records for infants.

Procedures to be followed: We will provide you with a copy of our application, with any appropriate usage instructions, and an evaluation form. The anticipated starting date for this study, when the evaluation materials will be made available, is March 30. The study will last for a maximum of eight weeks following the start date, during which time you may test the application and complete the evaluation before returning your responses to us. Completing the evaluation should not take more than 30 minutes once you have taken as much time as you feel appropriate to test the application. To avoid concerns about the security of digital information, we request that you return your evaluations in print form, so as to ensure the confidentiality of your personal identifying information.

Risks to study participants: There are no apparent risks associated with this study. The only foreseeable cause for your discomfort in this study would be answering a question that makes you uncomfortable. You may choose not to answer any question that makes you uncomfortable.

Benefits to research participants and others: There is no direct benefit to you as a result of this study.

Record keeping and confidentiality: Records of your participation in this study will be held confidential so far as permitted by law. However, the study investigators and, under certain circumstances, the Worcester Polytechnic Institute Institutional Review Board (WPI IRB) will be able to inspect and have access to confidential data that identify you by name. Any publication or presentation of the data will not identify you.

Compensation or treatment in the event of injury: This study involves no apparent risk of injury or harm to you. Thus, there is no need for compensation or medical treatment in the event of injury. It is required to inform you that you do not give up any of your legal rights by signing this statement.

For more information about this research or about the rights of research participants, or in case of research-related injury, contact:

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You may also contact the chair of the WPI Institutional Review Board (Prof. Kent Rissmiller, Tel. 508-831-5019, Email: kjr@wpi.edu) or WPI's University Compliance Officer (Michael J. Curley, Tel. 508-831-6919, Email: mjcurley@wpi.edu).

Your participation in this research is voluntary. Your refusal to participate will not result in any penalty to you or any loss of benefits to which you may otherwise be entitled. You may decide to stop participating in the research at any time without penalty or loss of other benefits. The project investigators retain the right to cancel or postpone the experimental procedures at any time they see fit.

By signing below, you acknowledge that you have been informed about and consent to be a participant in the study described above. Make sure that your questions are answered to your satisfaction before signing. You are entitled to retain a copy of this consent agreement.

Study Participant Signature

Date: _____

Study Participant Name (Please print)

Signature of Person who explained this study

Date: _____

Appendix F: Application Evaluation Survey

Part 1: System Usability

Please circle the number that best represents your opinion on a 1-5 scale.

1. I think that I would like to use this system frequently
Strongly Disagree _____ Strongly Agree
1 2 3 4 5

2. I found the system unnecessarily complex
Strongly Disagree _____ Strongly Agree
1 2 3 4 5

3. I thought the system was easy to use
Strongly Disagree _____ Strongly Agree
1 2 3 4 5

4. I think that I would need the support of a technical person to be able to use this system
Strongly Disagree _____ Strongly Agree
1 2 3 4 5

5. I found the various functions in this system were well integrated
Strongly Disagree _____ Strongly Agree
1 2 3 4 5

6. I thought there was too much inconsistency in this system
Strongly Disagree _____ Strongly Agree
1 2 3 4 5

7. I would imagine that most people would learn to use this system very quickly
Strongly Disagree _____ Strongly Agree

1 2 3 4 5

8. I found the system very cumbersome to use
Strongly Disagree _____ Strongly Agree

1 2 3 4 5

9. I felt very confident using the system
Strongly Disagree _____ Strongly Agree

1 2 3 4 5

10. I needed to learn a lot of things before I could get going with this system
Strongly Disagree _____ Strongly Agree

1 2 3 4 5

4. Did you encounter any errors while using the application?

5. What other features would you like to see in the application?

Appendix G: InfantCare PHR Users' Manual

Introduction

Though we hope that the InfantCare PHR will be straightforward and easy to use, we have created this manual to give you a reference containing all the functionality and a step-by-step guide to using it.

Prerequisites

In order to use the program, you need Java 6 or newer. Java can be downloaded at <http://www.java.com/en/>. Select the button labeled "Free Java Download" and follow the instructions on the page.

You will need to have a Google Health account for your infant (used to store records and for profile information such as the birth date). You can learn more about Google Health and create an account at <https://www.google.com/health/>. Follow the link labeled " Create a new account now" and fill in the form.

Starting the program



1. Double click InfantCare.jar to start the program
2. Enter your infant's Google Health user name and password into the pop-up box
3. Click the login button

Daily Activities

The daily activities screen is used to track the number of wet and soiled diapers and the sleeping and eating schedule of your infant.

The screen is the first one you come to when you start the application. You can return to it at any time by selecting the leftmost tab, labeled Daily Activities, at the top of the window.

Posting a New Daily Activity

The screenshot shows a software window titled "Main Screen" with four tabs: "Daily Activities", "Daily Notes", "Growth Table", and "Immunizations". The "Daily Activities" tab is active. It contains the following elements:

- "Wet diaper count:" followed by a text input field (labeled 1) and a "Clear all fields" button.
- "Soiled diaper count:" followed by a text input field (labeled 2) and a "Chart activity data over time" button.
- Two columns of checkboxes for "Feeding Times" and "Sleeping Times". Each column has sub-columns for "Day" and "Night". The "Feeding Times" sub-column "Day" is labeled 3. The "Sleeping Times" sub-column "Day" is labeled 4. Each sub-column lists hours from 6 AM to 5 PM.
- A "Save new chart under this date:" section with three dropdown menus (month, date, year) and a "Save" button (labeled 6). The date dropdown is labeled 5.
- A "Display chart for this date:" section with a date dropdown and a "Display" button.
- Buttons for "Edit currently displayed chart" and "Delete currently displayed chart".
- A "Show all data of this type:" section with a dropdown menu and a "Show" button.

1. Enter the number of wet diapers that your child had in the box labeled "Wet diaper count"
2. Enter the number of soiled diapers that your child had in the box labeled "Soiled diaper count"
3. In the "Feeding Times" columns, check off the boxes next to the hours during which your child was fed.
4. In the Sleeping times, check off the times next to the times during which your child slept.
5. In the "Save new Chart under This Date" area, select the date for which this data applies. The fields going left to right are month, date, and year.
6. Press the "Save" button to have the data recorded

Viewing an Existing Daily Activity

The screenshot shows a software window titled "Main Screen" with a tabbed interface. The "Daily Activities" tab is active. It contains input fields for "Wet diaper count" and "Soiled diaper count", a "Clear all fields" button, and a "Chart activity data over time" button. Below these are sections for "Feeding Times" and "Sleeping Times", each with a grid of checkboxes for "Day" and "Night" from 6 AM to 5 PM. At the bottom, there are controls for saving and displaying charts, including a date dropdown menu with a list of dates (11/2/2006, 3/2/2012, 3/2/2012) and buttons for "Save", "Display", "Edit currently displayed chart", and "Show".

1. Select the date of the record in the "Display chart for this date" drop down
2. Press the "Display" button to load the data into the screen

Editing an Existing Daily Activity

Main Screen

Daily Activities | Daily Notes | Growth Table | Immunizations

Wet diaper count:

Soiled diaper count:

Feeding Times: Sleeping Times:

Feeding Times		Sleeping Times	
Day	Night	Day	Night
<input type="checkbox"/> 6 AM	<input type="checkbox"/> 6 PM	<input type="checkbox"/> 6 AM	<input type="checkbox"/> 6 PM
<input type="checkbox"/> 7 AM	<input type="checkbox"/> 7 PM	<input type="checkbox"/> 7 AM	<input type="checkbox"/> 7 PM
<input checked="" type="checkbox"/> 8 AM	<input type="checkbox"/> 8 PM	<input type="checkbox"/> 8 AM	<input type="checkbox"/> 8 PM
<input type="checkbox"/> 9 AM	<input type="checkbox"/> 9 PM	<input type="checkbox"/> 9 AM	<input type="checkbox"/> 9 PM
<input type="checkbox"/> 10 AM	<input type="checkbox"/> 10 PM	<input type="checkbox"/> 10 AM	<input type="checkbox"/> 10 PM
<input checked="" type="checkbox"/> 11 AM	<input checked="" type="checkbox"/> 11 PM	<input type="checkbox"/> 11 AM	<input type="checkbox"/> 11 PM
<input type="checkbox"/> 12 PM	<input type="checkbox"/> 12 AM	<input type="checkbox"/> 12 PM	<input checked="" type="checkbox"/> 12 AM
<input type="checkbox"/> 1 PM	<input type="checkbox"/> 1 AM	<input type="checkbox"/> 1 PM	<input type="checkbox"/> 1 AM
<input type="checkbox"/> 2 PM	<input type="checkbox"/> 2 AM	<input type="checkbox"/> 2 PM	<input type="checkbox"/> 2 AM
<input type="checkbox"/> 3 PM	<input type="checkbox"/> 3 AM	<input type="checkbox"/> 3 PM	<input type="checkbox"/> 3 AM
<input type="checkbox"/> 4 PM	<input type="checkbox"/> 4 AM	<input type="checkbox"/> 4 PM	<input type="checkbox"/> 4 AM
<input type="checkbox"/> 5 PM	<input type="checkbox"/> 5 AM	<input type="checkbox"/> 5 PM	<input type="checkbox"/> 5 AM

Save new chart under this date:

Display chart for this date:

Show all data of this type:

1. Select the date of the record in the "Display chart for this date" drop down
2. Press the "Display" button to load the data into the screen
3. Edit the data on feeding times, sleeping times, and diapers as you did when you first entered the data
4. Press "Edit currently displayed chart" to save the data

Deleting an Existing Daily Activity

Main Screen

Daily Activities | Daily Notes | Growth Table | Immunizations

Wet diaper count:

Soiled diaper count:

Feeding Times: Sleeping Times:

Feeding Times		Sleeping Times	
Day	Night	Day	Night
<input type="checkbox"/> 6 AM	<input type="checkbox"/> 6 PM	<input type="checkbox"/> 6 AM	<input type="checkbox"/> 6 PM
<input type="checkbox"/> 7 AM	<input type="checkbox"/> 7 PM	<input type="checkbox"/> 7 AM	<input type="checkbox"/> 7 PM
<input checked="" type="checkbox"/> 8 AM	<input type="checkbox"/> 8 PM	<input type="checkbox"/> 8 AM	<input type="checkbox"/> 8 PM
<input type="checkbox"/> 9 AM	<input type="checkbox"/> 9 PM	<input type="checkbox"/> 9 AM	<input type="checkbox"/> 9 PM
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<input checked="" type="checkbox"/> 11 AM	<input checked="" type="checkbox"/> 11 PM	<input type="checkbox"/> 11 AM	<input type="checkbox"/> 11 PM
<input type="checkbox"/> 12 PM	<input type="checkbox"/> 12 AM	<input type="checkbox"/> 12 PM	<input checked="" type="checkbox"/> 12 AM
<input type="checkbox"/> 1 PM	<input type="checkbox"/> 1 AM	<input type="checkbox"/> 1 PM	<input type="checkbox"/> 1 AM
<input type="checkbox"/> 2 PM	<input type="checkbox"/> 2 AM	<input type="checkbox"/> 2 PM	<input type="checkbox"/> 2 AM
<input type="checkbox"/> 3 PM	<input type="checkbox"/> 3 AM	<input type="checkbox"/> 3 PM	<input type="checkbox"/> 3 AM
<input type="checkbox"/> 4 PM	<input type="checkbox"/> 4 AM	<input type="checkbox"/> 4 PM	<input type="checkbox"/> 4 AM
<input type="checkbox"/> 5 PM	<input type="checkbox"/> 5 AM	<input type="checkbox"/> 5 PM	<input type="checkbox"/> 5 AM

Save new chart under this date:

Display chart for this date:

Show all data of this type:

1. Select the date of the record in the "Display chart for this date" drop down
2. Press the "Display" button to bring up the data and confirm that this is the data that you wish to delete.
3. Press the "Delete currently displayed chart" button to delete the data.

Examining all Daily Activity Data by Type

The screenshot shows a software window titled "Main Screen" with several tabs: "Daily Activities", "Daily Notes", "Growth Table", and "Immunizations". The "Daily Activities" tab is active. It contains input fields for "Wet diaper count" (value: 4) and "Soiled diaper count" (value: 3). A "Clear all fields" button is next to the wet diaper count, and a "Chart activity data over time" button is next to the soiled diaper count. Below these are sections for "Feeding Times" and "Sleeping Times", each with a "Day" and "Night" column. Each column lists times from 6 AM to 5 PM with checkboxes. In the "Feeding Times" section, 8 AM and 11 AM are checked. In the "Sleeping Times" section, 11 PM and 12 AM are checked. At the bottom, there are controls for saving and displaying charts. A "Save new chart under this date:" section has three dropdown menus and a "Save" button. A "Display chart for this date:" section has a date dropdown set to "3/2/2012" and a "Display" button. Below these are "Edit currently displayed chart" and "Delete currently displayed chart" buttons. At the very bottom, a "Show all data of this type:" section has a dropdown menu (labeled with a red "1") and a "Show" button (labeled with a red "2"). The dropdown menu is currently open, showing "Diapers".

1. Select the data type in the "Show all data of this type" dropdown
2. Press "Show" to have the data pop up in a new window

Daily Notes

The daily notes screen is used to store notes about diapers, feeding, sleeping, and miscellaneous other notes. To open it, select the "Daily Notes" tab at the top of the screen.

For technical reasons notes cannot contain the symbols ~ and |. Also, any indents, new lines, and multiple spaces between any two words are converted to a single space when saved.

Posting a New Set of Daily Notes

The screenshot shows a software window titled "Main Screen" with four tabs: "Daily Activities", "Daily Notes", "Growth Table", and "Immunizations". The "Daily Notes" tab is active. It contains four text input fields for notes: "Diaper Notes" (containing the number 1), "Feeding Notes" (containing the number 2), "Sleeping Notes" (containing the number 3), and "Miscellaneous Notes" (containing the number 4). Below these fields are several controls: a "Save new notes under this date:" section with three dropdown menus (the middle one contains the number 5) and a "Save" button (containing the number 6); a "Display notes stored for this date:" section with a dropdown menu and a "Display" button; two buttons: "Edit currently displayed notes" and "Delete currently displayed notes"; and a "Show all notes of this type:" section with a dropdown menu and a "Show" button.

1. Enter any diaper notes into the "Diaper Notes".
2. Enter any feeding notes into the "Feeding Notes".
3. Enter any sleeping notes into the "Sleeping Notes".
4. Enter any miscellaneous notes into the "Miscellaneous Notes".
5. In the "Save new Notes under This Date" area, select the date for which this data applies. The fields going left to right are month, date, and year.
6. Press the "Save" button

Viewing an Existing Set of Daily Notes

The screenshot shows a software window titled "Main Screen" with a tabbed interface. The "Daily Notes" tab is active. Below the tabs are four sections for notes: "Diaper Notes", "Feeding Notes", "Sleeping Notes", and "Miscellaneous Notes". Each section has a large text area with vertical scroll bars. At the bottom of the window, there are several controls: "Save new notes under this date:" followed by three date pickers and a "Save" button; "Display notes stored for this date:" followed by a date picker (marked with a red '1') and a "Display" button (marked with a red '2'); "Edit currently displayed notes" and "Delete currently displayed notes" buttons; and "Show all notes of this type:" followed by a type selector and a "Show" button.

1. Select the date of the record in the "Display notes stored for this date" drop down
2. Press the "Display" button to load the data into the screen

Editing an Existing Set of Daily Notes

The screenshot shows a software window titled "Main Screen" with a tabbed interface. The "Daily Notes" tab is active. It contains four sections for notes: "Diaper Notes" (text: "DIAPER NOTE HERE"), "Feeding Notes" (text: "FEEDING NOTE HERE"), "Sleeping Notes" (text: "SLEEPING NOTE?"), and "Miscellaneous Notes" (text: "A MISC NOTE!"). Below these sections are controls for saving and displaying notes. The "Save new notes under this date:" section has three empty dropdown menus and a "Save" button. The "Display notes stored for this date:" section has a dropdown menu showing "2/2/2008" and a "Display" button. Below that are two buttons: "Edit currently displayed notes" and "Delete currently displayed notes". At the bottom, there is a "Show all notes of this type:" section with an empty dropdown menu and a "Show" button. Red numbers 1, 2, 3, and 4 are overlaid on the interface to indicate the steps for editing an existing set of notes.

1. Select the date of the record in the "Display notes stored for this date" drop down
2. Press the "Display" button to load the data into the screen
3. Edit the data in the notes as you did when entering it
4. Press "Edit currently displayed notes" to save the data

Deleting an Existing Set of Daily Notes

The screenshot shows a software window titled "Main Screen" with a tabbed interface. The "Daily Notes" tab is selected. It contains four sections for notes: "Diaper Notes" (text: "DIAPER NOTE HERE"), "Feeding Notes" (text: "FEEDING NOTE HERE"), "Sleeping Notes" (text: "SLEEPING NOTE?"), and "Miscellaneous Notes" (text: "A MISC NOTE!"). Below these sections are controls for saving, displaying, and deleting notes. The "Save new notes under this date:" section has three dropdown menus and a "Save" button. The "Display notes stored for this date:" section has a date dropdown menu (set to "2/2/2008"), a "Display" button, and a "Delete currently displayed notes" button. The "Show all notes of this type:" section has a dropdown menu and a "Show" button. Red numbers 1, 2, and 3 are placed next to the date dropdown, the "Display" button, and the "Delete currently displayed notes" button respectively.

1. Select the date of the record in the "Display notes stored for this date" drop down
2. Press the "Display" button to bring up the data and confirm that this is the data that you wish to delete.
3. Press the "Delete currently displayed notes" button to delete the data.

Examining all Daily Notes Data by Type

The screenshot shows a software window titled "Main Screen" with four tabs: "Daily Activities", "Daily Notes", "Growth Table", and "Immunizations". The "Daily Notes" tab is active. It contains four sections, each with a text area and scrollbars:

- Diaper Notes:** Text area containing "DIAPER NOTE HERE".
- Feeding Notes:** Text area containing "FEEDING NOTE HERE".
- Sleeping Notes:** Text area containing "SLEEPING NOTE?".
- Miscellaneous Notes:** Text area containing "A MISC NOTE!".

Below the note sections are several controls:

- "Save new notes under this date:" followed by three empty date dropdown menus and a "Save" button.
- "Display notes stored for this date:" followed by a dropdown menu showing "2/2/2008" and a "Display" button.
- Two buttons: "Edit currently displayed notes" and "Delete currently displayed notes".
- "Show all notes of this type:" followed by an empty dropdown menu with a red "1" next to it, and a "Show" button with a red "2" next to it.

1. Select the data type in the "Show all data of this type" dropdown
2. Press "Show" to have the data pop up in a new window

Immunizations

The immunizations table is a quick list of all the immunizations that the child received and the date administered.

For technical reasons immunization names cannot contain the symbols ~ and |. Also, multiple spaces between any two words are converted to a single space when saved.

