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DEVELOPING A FRAMEWORK FOR CREATING mHEALTH SURVEYS

by

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Marquette University,
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ABSTRACT

DEVELOPING A FRAMEWORK FOR CREATING mHEALTH SURVEYS

Veli Melih Bilen, B.S.

Marquette University, 2016

Various issues in the design of surveys for mobile health (mHealth) research projects still exist. As mHealth solutions become more popular, new issues have been brought into consideration. Researchers need to collect some critical information from participants in these mHealth studies. These mHealth studies require a specialized framework to create surveys, track progress and analyze user data. In these procedures, mHealth's needs differ from other studies. Therefore, there has to be a new framework that satisfies needs of mHealth research studies. Although there are studies for creating efficient, robust and user-friendly surveys, there is no solution or study, which is specialized in mHealth area, and solves specific problems of mHealth research studies. mHealth research studies sometimes require real-time access to user data. Reward systems may play a key role in their study. Most importantly, storing user information securely plays a key role in these studies. There is no such solution or study, which covers all these areas.

In this thesis, we present guidelines for developing a framework for creating mHealth surveys. By doing this, we hope to propose a solution for problems encountered in creating and using surveys in mHealth studies.

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LIST OF ACRONYMS

| | |
|--------|--|
| ERB | Ethical Review Board |
| HIPAA | Health Insurance Portability and Accountability Act |
| HITECH | Health Information Technology for Economic and Clinical Health Act |
| HTTPS | Hypertext Transport Protocol Secure |
| IEC | Independent Ethics Committee |
| IRB | Institutional Review Boards |
| LAMP | Linux, Apache, MySQL, PHP |
| PHI | Protected Health Information |
| REB | Research Ethics Board |
| SSL | Secure Socket Layer |

CHAPTER 1: INTRODUCTION

Medical science has rolled out progressive improvements in the last few decades. However, the healthcare system couldn't achieve a similar level of improvement in the mean time. This situation can be changed with the increasing usage of e-health technologies. E-health has been described as, "The combined use in the health sector of electronic communication and information technology (digital data transmitted, stored and retrieved electronically) for clinical, educational and administrative purposes, both at the local site and at a distance" [9]. It has also been explained as: "An emerging field in the intersection of medical informatics, public health, and business, referring to health services and information delivered or enhanced through the internet and related technologies. In a broader sense, the term characterizes not only a technical development, but also a state-of-mind, a way of thinking, attitude, and commitment for networked, global thinking, to improve healthcare locally, regionally, and worldwide by using information and communication technology" [9].

There are several problems in healthcare which prevent it from catching up today's progress. The most important problems are inefficiency and ineffectiveness of the methods that are being used in healthcare delivery. Healthcare organizations and researchers can solve this issues by concentrating on three major aspects; 1. Access - caring for anyone, anytime, anywhere, 2. Quality – offering world class care and establishing integrated information repositories, and 3. Value – providing effective and efficient healthcare delivery [12]. In order to solve these problems, researchers should come up with new solutions to overcome limitations with traditional approaches.

The internet is playing a key role in transforming healthcare in spite of the various concerns associated with it. While there are still many questions about the internet, especially in terms of privacy and confidentiality, it provides solid solutions to improve health-related research and healthcare solutions [2]. Unique features of the internet make possible to come up with more contemporary ideas in this fast changing world. The internet can be used to improve communication between patient and healthcare providers or researchers. It also makes it really easy to access any information user wants to have. It provides a new way of interaction between patients and healthcare system [2]. Increasing usage of internet in healthcare area brings new concepts into consideration. Even terms like eHealth are becoming obsolete. At this point, new notions like mHealth come into consideration. Since mHealth is still in its infancy in terms of proving itself and establishing a solid foundation, it still has multiple definitions. It is considered as the branch of eHealth and broadly defined as following “The use of mobile computing and communication technologies in healthcare and public health” [5]. It is also defined as “Using wireless mobile communication technology to aid health services delivery” [8].

In 2008, Mary Meeker, an analyst at Kleiner Perkins Caufield Byers who reviews technology trends annually in May, made a significant prediction indicating that "Mobile to overtake fixed Internet access by 2014". She was right. In 2014, the number of mobile device users surpassed the number of desktop device users. Figure 1-1 shows that in 2014 one era ended, and a new era has begun. This change has been affecting and will continue to affect more healthcare studies in terms of using new methodologies which engage more mobile devices.

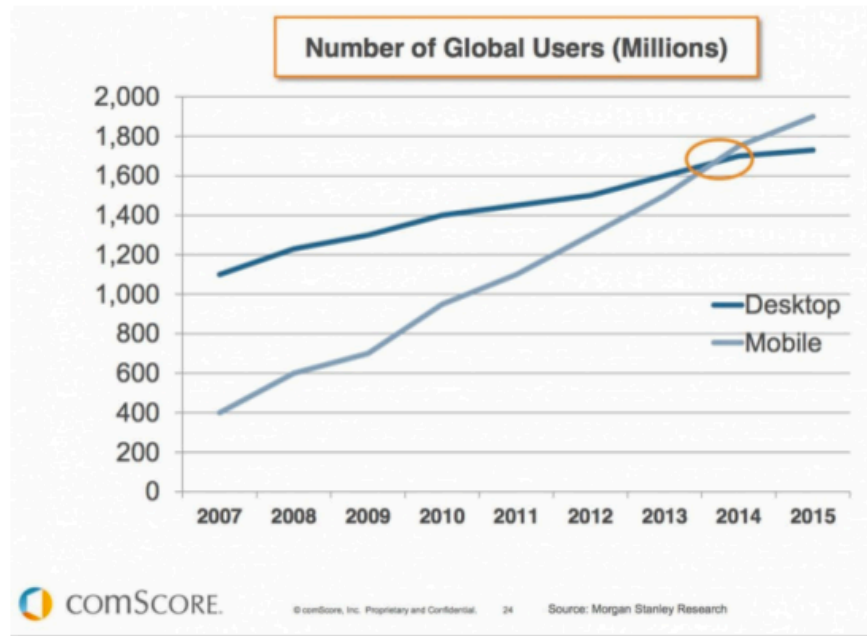


Figure 1-1: Number of Mobile and Desktop users [7]

Recent studies show that people who have access to the internet, and have smartphones are using their devices for health-related issues as well. Gunther Eysenbach states in his article “*Understanding Determinants of Consumer Mobile Health Usage Intentions*” as following, “According to a recent healthcare market research study, 31% of US adults have used their mobile phones for accessing health information. In addition, 19% of US adults who own a smartphone have at least 1 health application on their phone, with exercise, diet, and weight apps among the most popular.” In addition to increasing usage of mobile devices in health related issues, people are willing to engage more in mHealth solutions since they believe that mHealth can increase their ability to control their healthcare. Nearly half of the surveyed participants wanted to have more mHealth solutions using their phones [8].

As mHealth solutions become more popular, new issues are brought into consideration. Researchers need to collect some critical information from participants in these mHealth studies. Since surveys generally require participants to remember a past activity to complete it, their reputation has not been very good [1]. Although surveys are not the best tools to collect data from participants, they are also the most common way to gather important information in behavioral sciences and health related studies. There are three different ways of conducting surveys. These are via e-mail, mail, and online surveys.

mHealth studies require specialized framework to create surveys, track progress, and analyze user data. In these procedures, mHealth's needs differ from other studies. Therefore, there has to be a novel framework that satisfies needs of mHealth research studies.

CHAPTER 2: BACKGROUND

In recent years, mHealth has continually extended as a branch of eHealth. Increasing mobile device usage has helped this exponential growth. Mobile and web applications have potential to solve specific problems of healthcare and health related studies by being able to reach all sort of participants [5]. The area of mHealth is evolving so quickly with the help of technology. Therefore, researchers should adopt their methodology into this fast pace environment so that mHealth studies, and applications can together reduce the cost of current healthcare, and improve the current health research and their outcomes. One of the most important methodologies they should consider is data collection procedures. With the help of widespread usage of devices with all different type of sensors (e.g. smartphones), data can be collected automatically from patients or participants. However, researchers still need to ask specific questions about the, participants about behavioral data. In their article Weber and Bradley clearly states that “Surveys have been and remain a popular method for data collection in the social, behavioral and consumer sciences” [11].

Over the years, paper-based surveys have been used primarily in all type of research. Although this traditional way of conducting surveys is very intuitive and easy to develop and adopt, it is now slowing down many aspects of research. Nowadays, researchers want to see and analyze participant data immediately, since it is really important to understand and intervene (if necessary) during the study. Therefore, data collection time is playing a very significant role in mHealth research. In a study using both Web-based and pencil-and-paper surveys, researchers discovered a mean response

speed of 5.97 days for the Web-based surveys compared to 16.46 days for mailed surveys. [11] Besides increasing speed of collecting data, there are other important issues which need to be taken into consideration. Andrews, et al., from 2003 suggest that “Survey design, subject privacy and confidentiality, sampling and subject solicitation, distribution methods and response rates and survey piloting are critical methodological components that must be addressed in order to conduct sound online research” [1]. Although there are studies and tools for creating and conducting online surveys, most of them are failing when it is specific to mHealth applications because designing for mHealth requires some specific attention.

2.1 Survey Methods

It is really crucial to choose the most fitting technique for your research. When researchers want to collect quantitative data from participants or users, they generally decide to use questionnaires. Surveys provide a large number of views on a specified topic. Thus, we can define surveys in research as following; “Surveys systematically collect information on a topic by asking individuals questions to generate statistics on the group or groups that those individuals represent.” [7]

Nowadays, there are three different and unique ways to conduct surveys; paper-based or mail-based surveys, email surveys and online web-based surveys. When we consider today’s technological development and extensive usage of mHealth solutions, online surveys are the most appropriate solutions for studies because of several reasons including scalability, cost, and time effectiveness. Kumar, et al., from 2013, states that “mHealth can facilitate remote research recruitment and potentially reduce the frequency,

and consequently, the burden of face-to-face interactions. The mobility of mHealth allows research to take place in a participant's home, workplace, and community, rather than during trips to an academic research center" [6]. Since using online surveys make it easy to collect data from remote participants, it perfectly fits into the area of mHealth research studies. When you consider paper-based or mail-based surveys, their costs increase linearly when researchers want to scale their study into bigger participant sizes. However, in online surveys, costs do not change dramatically, while the number of participants in the study is changing.

In addition to all advantages of online surveys mentioned above, it also supports self-reporting inherently. When a participant answers survey questions online, his/her answers are automatically being saved into a database. This feature eliminates the problem of having human errors when translating participant answers since all the manual work of a researcher is replaced with an automatic process. Having this important aspect also provides real-time data analysis available to researchers, because saving participant answers into a centralized data store takes only seconds.

2.2 Mobile Device Usage and mHealth studies

People are using the internet for healthcare purposes more and more every day. Recent studies show that at least more than half and as much as 80% of adults who have access to the internet uses the internet for healthcare purposes [2]. In today's world, people are using the internet for their health related issues. Therefore, we can not think about collecting data from participants in a way other than a system utilizes mobile devices and the internet. In a study, researchers found that only 37.99% of the

participants have started to use mHealth. However, they found that 66.96% of the participants favor using mHealth as a complement to traditional methods of healthcare [8]. Researchers can achieve this high percentage of participants in thesis studies by only considering and following contemporary trends of technology such as mHealth.

Researchers in mHealth area have to design their study in a way that people who have a different type of mobile devices should be able to use it. Nonetheless, people may want to use their desktop devices for inputting data into study. Therefore, researchers should use a new methodology called responsive design. In responsive design, applications adapt themselves into the device. This means that applications are aware of the device on which they are running, and they fit their components into the device's screen. Although implementing responsive applications requires more effort in the beginning, it eliminates effort of designing for each type of device individually. This will definitely help when scaling out the study. We will talk about this in some later sections, when we propose a framework for designing mHealth surveys.

2.3 Our Framework and Design Considerations

Despite the fact that mobile devices are being used in all different type of studies including smoking cessation, weight loss, diet and physical activity, treatment adherence, and disease management, there is not a study which addresses specific requirements of mHealth studies when designing and conducting surveys and utilizes mobile devices in data collection process. Although, there are paid tools all over the internet for conducting questionnaire purposes, there are only a few studies which evaluate these tools in the light of mHealth's specific and special requirements.

mHealth studies mostly require special attention to privacy and security areas since working with human subjects and sensitive personal data are generally regulated by Institutional Review Boards (IRB) and some specific issues regulated by U.S. Health Insurance Portability and Accountability Act (HIPAA) or Health Information Technology for Economic and Clinical Health Act (HITECH).

Another consideration is that incentives, interventions and reminders are playing a key role in mHealth studies. Hence, researchers should take all these issues into considerations when designing questionnaires for mHealth studies. We will try to provide guidelines in the following chapters for a framework which covers all the issues mentioned above.

Chapter 3: RELATED WORK

In this chapter, first, we will explain and compare different methods of conducting surveys. These methods are paper-based- mail-based surveys, email surveys, and online surveys. After comparing distinctive ways of questionnaires, we will compare different tools for online surveys. The demand for online surveys is ever increasing, so the industry is creating different solutions for this. Ladner et al., from 2002, reports that “a simple Internet query of ‘Web-based surveys’ produce[s] over 18,500 matches” [11]. Same query, ‘Web-based surveys’ currently creates 3,410,000 matches when you use Yahoo search engine. As you can imagine, it is impossible to evaluate all those results so we have picked two post popular online survey services SurveyMonkey and Qualtrics. We will evaluate these two instances in the light of specific requirements of the mHealth area.

3.1. Comparison of different methodologies

As we mentioned earlier, there are three main different methodologies; paper-based-mail surveys, email surveys, and online surveys. Paper-based surveys are the oldest way of collecting data from participants, so it is the traditional way. However, it is still being used by researchers because of several reasons including proven methods of creating surveys and ease creating them. There are two types of paper-based surveys. The first one is face-to-face, and the second one is mail surveys. We can easily say that face-to-face surveys bring more disadvantages than advantages.

Online surveys are better than paper-based surveys in couple ways. First of all, paper-based surveys need to be printed and be posted to participant or participant should visit the research center to complete it. Later participant needs to send completed back. Then a researcher should manually analyze and enter data into a centralized data collection system. After all these procedures, researchers can start to analyze data which is the main reason behind performing the alone listed time-consuming tasks. Besides, it is really hard to protect anonymity, if it is necessary, when researchers are using paper-based surveys. In her article, Weber et al., summarizes advantages of web-based surveys as following “Collecting data online, in general, takes comparatively less timely and is a less expensive avenue for tapping into basic human attitudes, opinions and behaviors. This capability of reaching thousands, even hundreds of thousands, of individuals in one click is a survey researcher’s dream come true.” [11].

Another common method is email surveys. In this method, researchers create surveys in a word document or another editable format and send it to the participant. When the participant gets it, he/she needs to first download it to their computer. This method generally doesn’t allow using mobile devices since the survey needs to be edited using an editor program. However, nowadays there are some smartphones which enable to run those editors, and they have big enough screens to work on those. Although today’s technology makes it easy to conduct email surveys, it doesn’t eliminate basic problems of email surveys such as lack of anonymity, creating conditional questions, answer validation, etc. In their article Andrews, Nonnecke and Preece summarize comparison of email vs. online surveys so you can find their findings in table 3.1 [1]. As you can easily interpret from the table, web-based surveys are superior to email based

surveys in multiple ways including but not limited to providing feedback with completion, preventing multiple submissions automatically, adaptive questions and providing animation, sound, graphics options.

| Design Items | Email | Web-based |
|--|--------------|------------------|
| Supports multiple platforms and browsers | Yes | Yes |
| Controls for browser settings | No | No |
| Prevents multiple submissions automatically | No | Yes |
| Presents questions in a logical or adaptive manner, e.g., provides control of when and how questions displayed | No | Yes |
| Allows saving responses before completion | No | Yes |
| Collects open-ended or quantified-option responses | Yes | Yes |
| Provides automatic feedback with completion | No | Yes |
| Can apply paper questionnaire design principles | Yes | Yes |
| Provide automatic transfer of responses to database | No | Yes |
| Prevents survey alteration | No | Yes |
| Provides response control and economical displays | No | Yes |
| Provides researcher control over question presentation | No | Some |
| Provides for animation, sound, graphics options, etc. | No | Yes |
| Does not requires familiarity with survey software | No | Yes |
| Rapid display to respondent | Yes | Depends |
| Technical ability to track response source | Yes | No |
| Technically easy to design and implement | Yes | No |

Table 3-1: Electronic Survey Design Evaluation

Online surveys provide multiple advantages over both paper-based surveys and email surveys. These advantages include but not limited to time, cost efficacy, ease of

editing, reaching a huge number of participants and having endless options while creating surveys. The next couple of sections analyze two popular online survey tools; SurveyMonkey and Qualtrics.

3.2 SurveyMonkey

One of the most popular online survey tools which is used by both researchers and other people is SurveyMonkey. SurveyMonkey provides very nice and clean user interface to create surveys. It has different plans for users. Most basic plan is free, but it lacks almost any feature you need. If a researcher wants to use SurveyMonkey for his/her research, he/she should pay at least \$300 annually in order to have some basic features like having an unlimited number of questions in a survey and having unlimited responses from participants.

In addition to features mentioned above, some fundamental features like being able to export participant data and reports, randomizing the order of questions, and creating custom paths according to answers of participants is not included any plan below the “Gold plan” which is \$300 per/year. However, even this plan doesn’t include some fundamental features which are a must for mHealth studies. If you want to store participant’s answers in an HIPAA compliant environment, you have to pay \$1020 yearly per user. You have to pay additional \$1020 for each researcher who wants to have access to study. This plan is called “Platinum” and comes with some other important features such as advanced logic in your survey, including advanced branching, block randomization, quotas, and more to enhance your data.

As you can infer from the analysis above, you have to pay at least \$1020 per user annually in order to have important features like HIPAA compliant environment. Even when you have a platinum plan, you will not be able to have features like distributing incentives or having interventions during study.

3.3 Qualtrics

Qualtrics is one of the most advanced and easy to use online service for creating and distributing surveys. Qualtrics basically has 3 different plans. The free version has very limited features including having only one active survey with 100 responses only. In this plan, you will not have an export option for participant data. There is a “Q Lite” plan which provides more features than basic plan for \$300 annually per user. This one provides 10 active surveys with 300 responses and gives you the option to export participant data. If you want to have real-time report option and advanced type of questions you should consider “Q Enterprise” plan. Although Qualtrics does not explicitly reveal a price for enterprise plan, several reports show that it starts \$2500 yearly per user.

Qualtrics gives you HIPAA and HITECH compliant environment even starting from the basic free plan. You can not find this feature even in paid versions of some other tools. However, Qualtrics has limited responsive design when it comes to the customization of surveys. You may need to code yourself to have what you want. Besides, it does not have a built-in incentive system, but it supports some 3rd party tools for this purpose. It is obvious that Qualtrics aims enterprise users with this price.

In table 3-2, we have summarized and compared some key features of online surveys. As you can see, UbiSurvey provides all those key features without requiring too much money and time.

| Design item | SurveyMonkey | Qualtrics | UbiSurvey |
|---|--|--|------------------|
| Responsive design, mobile survey | Yes | Yes (but very limited requires coding) | Yes |
| Incentives (built in) | No | No (only via 3 rd party) | Yes |
| Interventions (reminders and interventions during study) | Limited | Limited | Yes |
| HIPAA compliant environment | Platinum plan (\$1020 annually per user) | Yes | Yes |
| Live report | Limited | Yes (Enterprise plan) | Yes |

Table 3-2: Comparison of SurveyMonkey, Qualtrics, and Our Framework UbiSurvey

All of the tools analyzed above have very clear user interface design and are used by a great number of people. In spite of this, either they do not satisfy some basic requirements of mHealth area. They support in a limited way with a high cost. Since they are not designed for mHealth studies, mHealth area is still missing one such low-cost option for online survey tool. Our framework (UbiSurvey) will have all necessary features with easy deployment and use. Cost can be decreased by having an open source tool, and deploying it into an HIPAA-compliant cloud server. We will talk about our framework in the following sections.

Chapter 4: CONSIDERATIONS WHEN DESIGNING FOR MHEALTH

mHealth studies differ from other research studies since they involve human subjects. Therefore, there are some aspects, that need to be considered when you are doing mHealth research. Designing a survey framework for mHealth should also follow a set of guidelines. Firstly, and most importantly, there are some laws and regulations you need to follow when you are working with sensitive personal data. In the US, these are regulated by HIPAA and HITECH law. In addition to this, most of the research studies which involves humans in biomedical and behavioral research need to be approved by institutional review board (IRB), also known as an independent ethics committee (IEC), ethical review board (ERB), or research ethics board (REB). The purpose of IRB is to be sure that researchers are following regulations from beginning to end of study. This control mechanism is used to protect human subjects throughout the study.

Secondly, there are some issues like response rates and biased/unbiased studies. Since using mobile devices and the internet is inherent to mHealth, the concerns mentioned above arise. We will talk about some other considerations in Chapter 5 when we are explaining some features of our survey framework (UbiSurvey).

4.1 HIPAA and HITECH

The Health Insurance Portability and Accountability Act (HIPAA) was passed in 1996. The aim of this legislation was to protect workers so that they are able to retain their health insurance coverage when they lose or change their jobs. However, another

important purpose of this legislation was to improve efficiency and quality of healthcare system using improved information technologies. Increased usage of electronically collected medical records required to have a law which protects security and privacy of Protected Health Information (PHI). PHI includes a very wide set of health-related data including but not limited to lab results, billing information, and diagnosis data. These rules apply not only to hospitals, healthcare providers but also researchers who are working with human subjects.

HIPAA was expanded by the Health Information Technology for Economic and Clinical Health Act in 2009 (HITECH). HIPAA and HITECH together, establish a set of rules for healthcare providers and researchers working with PHI. If a researcher wants to collect data which needs to comply with HIPAA, all transactions between systems and user, the place where researcher keep this PHI also have to comply with HIPAA. We will explain HIPAA requirements in details, in the following chapters. In the US, HIPAA focuses on three significant elements as following; security, privacy and standards for transactions of healthcare information [4] This can be visualized as a triangle of HIPAA as shown in Figure 4-1.

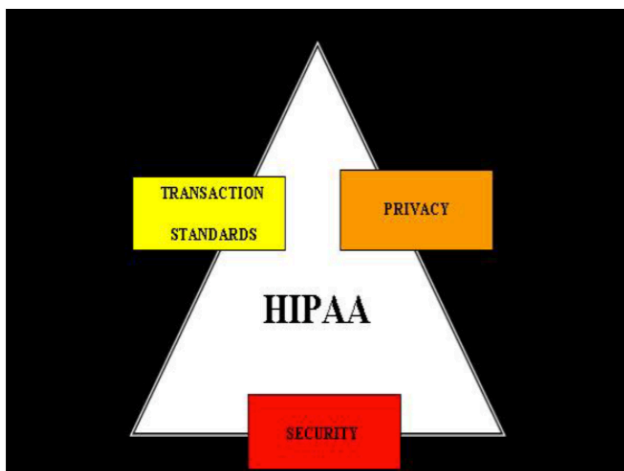


Figure 4-2: HIPAA triangle

4.1.1 Security and Transactions

Wickramasinghe and Bali explain security portion of HIPAA in their article an Integrative Framework for Achieving HIPAA-Compliance for Healthcare Information Systems as following “According to HIPAA, a number of security criteria must be met by all electronic healthcare transactions. Some of these criteria directly affect how healthcare systems can be accessed and interact with by the users of healthcare information systems. Essentially, these security criteria fall into 3 main categories; namely administrative, physical and technical”. [4] When it comes to the online surveys in mHealth area all the data transaction between participant and online system should be secure and encrypted. This can be achieved by using some secure protocols like HTTPS (Hypertext Transport Protocol Secure) which utilizes SSL (Secure Socket Layer) over HTTP in general. Another aspect is storing sensitive user information in a secure place. When researchers use web-based surveys, generally data is stored with the server which online surveys are hosted on. Although any server which is in HIPAA compliant environment can be used, nowadays cloud servers are cheap, easy to use and HIPAA compliant options for these purposes. In Table 4-1, Fadlalla and Wickramasinghe summarize major issues in HIPAA security requirements. One of the key elements of this procedure is maintaining security configuration throughout the study.

| |
|--|
| Extracts from HIPAA Concerning Security Requirements |
| Establishment of trust partnership agreements with all business partners. |
| Formal mechanisms for accessing electronic health records. |
| Procedures and policies to control access to information. |
| Maintaining records of authorizing access to the system. |
| Assuring that system users receive security awareness training and the training procedures are periodically reviewed and updated. |
| Maintaining security configuration including complete documentation of security plans and procedures, security incident reporting procedures, and incident recovery procedures. |
| Communication and network control including maintaining message integrity, authenticity, and privacy. Encryption of messages is also advocated for the open network transmission portion of the message. |

Table 4-1 HIPAA Security Requirements (Fadlalla and Wickramasinghe, 2004) (1)

4.1.2 Privacy

The second element of HIPAA triangle is dealing with providing privacy in healthcare information systems. Wickramasinghe summarizes the purpose of this aspect as following “The purpose of these rules is to maintain strong protections for the privacy of individually identifiable health information, addressing the unintended negative effects of the privacy requirements on healthcare quality or access to healthcare, and relieving unintended administrative burdens created by the privacy requirements”. [12]

There are several concerns regarding privacy and confidentiality in mHealth area because mHealth studies have highly sensitive and personal data such as social interactions, location, emotion, and other potentially sensitive health conditions. [6] Kumar, et al., from 2013, clearly explains the pressure on researchers as “Nonetheless, the mHealth research community is now challenged to develop methods to preserve participant privacy and confidentiality while satisfying research needs.” [6]. This can be

done by using a framework like our framework which addresses confidentiality, authenticity, and integrity in all steps of collecting data from online surveys in the mHealth area. As we mentioned above, secure transactions can be achieved by utilizing encryption methods.

4.2. Response Rates

Response rates can be easily calculated in traditional survey methods like paper-based surveys. However, when it comes to the online surveys, it is complicated to calculate response rates. Eysenbach in his article “*Improving the Quality of Web Surveys: The Checklist for Reporting Results of Internet E-Surveys (CHERRIES)*” explains this as following “In traditional surveys investigators usually report a response rate (number of people presented with a questionnaire divided by the number of people who completed the questionnaire) to allow some estimation of the degree of representativeness and bias. Surveys with response rates lower than 70% or so (an arbitrary cut- off point!) are usually viewed with skepticism. In online surveys, there is no single response rate. Rather, there are multiple potential methods for calculating a response rate, depending on what are chosen as the numerator and denominator. As there is no standard methodology, we suggest avoiding the term “response rate” and have defined how, at least in this journal, response metrics such as, what we call, the view rate, participation rate, and completion rate should be calculated.” [3]. This is true especially when a researcher is conducting online open surveys. When you open your online survey to the public, it is really hard to determine what to use as a denominator of response rate.

4.3 Biased/Unbiased studies

Another challenge in conducting online mHealth surveys is having the biased set of people to collect data from. Mostly online surveys used in an uncontrolled environment are less reliable than the ones used in a controlled environment. [3]

Eysenbach explains this in a very good way “Every biased sample is an unbiased sample of another target population, and it is sometimes just a question of defining for which subset of a population the conclusions drawn are assumed to be valid. For example, the polling results on the CNN Web site are certainly highly biased and not representative of the US population. But it is legitimate to assume that they are “representative” for visitors to the CNN Web site who choose to participate in the online survey.” [3]

Chapter 5: OUR FRAMEWORK

This research focuses on developing a modern and generic framework for creating surveys in mHealth area. It will identify and solve specific problems in different stages of mHealth studies. These stages are creating a survey, collecting data from participants and analyzing user data. Further, it will integrate different components for different needs. These components are notification system and reward system. First, we will explain what needs to be done for conducting online surveys in the mHealth area. Secondly, we will explain some technical details in order to create a web-based tool that integrates the features mentioned in first part of this chapter.

5.1 UbiSurvey features

In this chapter, we will give step by step guidelines for creating online surveys, and we will try to explain how you can utilize them when you are designing surveys.

The purpose of the survey: Researcher should start with deciding what is your research question and what will be your target population. In online surveys, choosing target population is playing key a role because of the risk of having a biased population.

IRB approval: IRB approval is very crucial when you are working with human subjects. Be sure to have necessary approvals and you should mention about this at the beginning of the survey.

Informed consent: In most of the cases you need to take consent of participants if you will collect personal data, and you will store it. You should include this consent page in the beginning.

Data protection: As we mentioned in earlier chapters, data protection is key to mHealth studies. Data has to be stored in an HIPAA compliant environment, and all the transactions have to occur in a secure and encrypted way.

Survey type: An “open survey” is a survey open for each visitor of a site while a closed survey is only open to a sample which the investigator knows (password-protected survey). [3]

Responsive Design: One of the most important things researchers need to consider is target population’s mobile device usage preference. If researcher’s study utilizes smartphones, tablets etc., they should also use these devices in their data collection process. Responsive design methodology can be used to make data collection easier from different mobile devices. As we explained earlier, responsive design enables online survey to adapt itself to participant’s mobile device screen.

Incentives: Researchers should consider about giving incentives when participants complete necessary surveys. The use of incentives increases response rate in a significant amount. If researchers have built-in reward system in their online survey tool, that would be a lot easier

Reminders: Reminders are an important part of conducting online surveys. Many studies suggest that use of reminder increases completing rate of the survey. [11]

Adaptive questions: Researchers should utilize adaptive question feature when it possible to use. This feature allows you to have more clean design, and it make easier to complete surveys for participants.

Randomization of questions: In order to prevent bias, a researcher might use randomization that displays questions in different order for each participant.

Survey length: Participants should have information about how much is done and how much is left. This will increase the engagement of participants in the survey.

Completeness check: Researchers should have an option to make questions required or optional. Survey tool needs to check participant answers accordingly and, if necessary, the tool should inform participants about incomplete required questions.

Validation check: Researchers should be able to put some validation rules for participant answers.

Preventing multiple entries from the same participant: In closed surveys, having multiple entries from the same participant is not an issue since it requires having username and password for completing the survey. However, in open surveys, there should be a mechanism to prevent multiple entries from the same participant. This can be achieved by utilizing some technical features like IP address control and using cookies.

Interventions during study: Interventions during study, is also really important if a researcher is running a study which is longer than just collecting data from a survey.

Analysis: Real-time data reports help researchers to be able to verify and analyze participant data on the go.

5.2. Creating an online survey tool

In the previous section, we have explained some unique steps to conduct an online survey. This procedure is the foundation of our proposed framework. Although most of

the items are straightforward and there is no need for explanation, there are some steps need little bit more explanation. As we explained in Chapter 3, there is no online tool which satisfies all the necessary requirements of creating online surveys for mHealth research studies. In this section, we will explain how can a researcher implement an online tool so that all the steps mentioned above can be followed.

For responsive design there are many open source, free to use frameworks which can be used in implementing an online survey tool. Bootstrap can be used as frontend framework. Improved technology in the development area help us to have more power while developing web applications. JavaScript can be used in completion check and validation purposes. Enabling cookies might help to prevent multiple entries from same user, if survey is open to public and it does not require username and password to complete it.

Chapter 6: CONCLUSIONS

Although there are studies for creating efficient, robust and user-friendly surveys, there is no solution or study, which is specialized in mHealth area and solves specific problems of mHealth research studies. mHealth research studies sometimes require real-time access to user data. Reward systems may play a key role in their study. Most importantly, storing user information securely plays a key role in these studies. There is no such solution or study, which covers all these areas.

In this thesis, first, we explained how surveys are being used in research studies and what type of different ways there are to conduct surveys. We compared these methods, and we found that online surveys are the best for mHealth studies. It has multiple advantages such as time and cost effectiveness. Another advantage is more precise data entry since it eliminates any human error while entering data into a centralized data store system. [11]

In the preceding chapters, we analyzed and compared online tools with our proposed survey framework. We understood that although there are great tools in the market, none of them are designed for mHealth studies, and sometimes they miss some really important must features of conducting surveys in mHealth area. We found that some tools have really great features, and they are easy to use. However, they cost a lot more than a researcher can afford it when he/she wants to use it in his/her study.

In Chapter 5, we proposed a full guideline to create and deliver online surveys. This guideline will help to any researcher from beginning to end. Then we explained how an online tool can be implemented to be used to create and deliver online surveys.

UbiSurvey is the solution for researchers who want to have unique features like built-in incentive system, customizable reminders, being HIPAA compliant in every step of research.

6.1 Future Work

It is very obvious that online surveys in the mHealth area have been and will continue to be a crucial component of research in terms of data collection. [10] It will be used by healthcare providers and researchers. Innovative techniques and improving technology will help to conduct these surveys in a more robust way. We will try to implement a web-based tool for creating and distributing surveys. This tool will be used by Ubicomp Lab at Marquette University. Besides, we are planning to create a repository online and publicly so that any researcher wants to have his/her own instance of tool to deploy, he/she can use it. It will be in a way that it supports easy deployment to any LAMP (Linux, Apache, MySQL, PHP) stack installed server. Researchers will be able to use their own machines to use as a server, or they will be able to use their own choice of a cloud server.

In addition to the future works above, incorporating sensor data while conducting surveys might be a good idea to research on. Mobile devices provide us unlimited data from different components including but not limited to camera, temperature, heart rate etc. We should think about that how we can use this data which is collected while participant answering the questions. Therefore, incorporating with sensor data and using our framework and online tool can be main topic of another research.

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