

Development of a Mobile App for the FRAXA Research Foundation

An Interactive Qualifying Project to be submitted to the faculty of Worcester Polytechnic
Institute in partial fulfillment of the requirements for the Degree of Bachelor of Science

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Abstract

Fragile X Syndrome (FXS) is a mental retardation and autism spectrum disorder that currently has no cure. The purpose of this project was to work with the FRAXA Research Foundation to increase participation in clinical trials for new FXS therapies. We surveyed FXS families and utilized literature resources to design an app that would allow users to locate nearby clinical trials for new FXS treatments using GPS services. The app also includes a discussion board designed to increase communication between members of the FRAXA community. The mobile app design was implemented using XCode. The result of this project is a storyboard that details how a user would navigate through the app, thus making the actual creation of the app as quick and cost-effective as possible.

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Introduction

While there has been an overwhelming rise in popularity of smart phones and other mobile devices, many organizations are finding it difficult to take full advantage of what these new technologies have to offer. In particular, some medical non-profit organizations are struggling to appeal to a larger and ever changing audience. The goal of this IQP is to help a single non-profit organization, The FRAXA Research Foundation (FRAXA), develop an app to allow them to reach a wider audience. The app will ultimately appeal to smart phone users within the Fragile X Syndrome community; however, the content presented in the app, as well as some of its dynamic features, will appeal to a younger generation of parents or people who are looking for support or basic information regarding Fragile X Syndrome. In addition, the app will use modern GPS tracking technologies to connect users, if they so choose, with each other and with events held on behalf of FRAXA.

In order to achieve this, several aspects of mobile application development were researched. Because mobile apps fulfill a need of their users, our team surveyed our target audience to discover the needs of the FRAXA community. These findings were then incorporated into our design of the app. In addition, our team researched the use of the built in “location services” on most smart phones and this proved to be invaluable to some of the goals we hoped to achieve with the app. For example, the location services of the app will be used to filter the list of clinical trials presented to users of the app to show the closest trials to them at the top of the list.

It was also important to research the success of other industries in using some of the features we incorporated into the design of our app. For example, we researched statistics on how often people use GPS location services on their smart phones and the ways in which they

do. Based on that, as well as on the results of personally conducted surveys, we decided that a clinical trial locator section of the app would have a significant impact on FRAXA's goals. Likewise, because our team believed adding a discussion board would help to connect the community, we researched how useful they have been with other organizations over a wide range of media. After compiling this research, we finalized the design of our app to include three sections that will all fill some need of the FRAXA community.

The mission of FRAXA is "to accelerate progress toward effective treatments and ultimately a cure for Fragile X" (fraxa.org). In achieving the goals we laid out, we hope to see a rise in internet traffic towards FRAXA as well as an increase in clinical trial participation which will help FRAXA to achieve their mission. We hope to not only widen the community around FRAXA, but to also bring their members closer together through the discussion board. With a larger community, the hope is that there will be more support towards families participating in the clinical trials. To this end, we hope to also make it more convenient for time-constrained parents to find information on relevant clinical trials near them. More families participating in the clinical trials will help to bring medication into the market to treat symptoms of Fragile X Syndrome and change lives. The measure of success for this project is the designing of the app itself.

This paper serves not only as documentation of our app designing process, but also as a presentation of our survey results and statistics. Success of the app we design will offer a framework for other similar organizations to help broaden their respective communities and promote their causes.

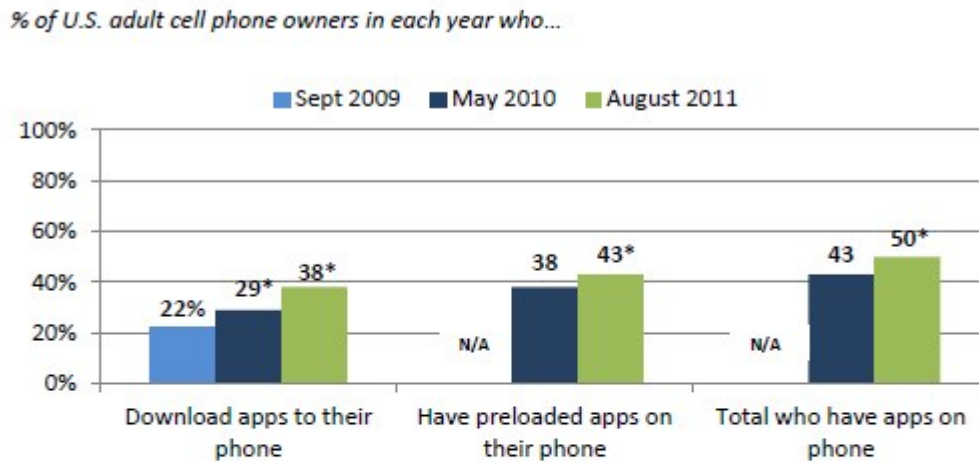
Background

Fragile X Syndrome (FXS) is the leading cause of intellectual disability and inherited autism in the world (fraxa.org). It is caused by a mutation in the FMR1 gene, but does not always present with symptoms, so it is possible to be a carrier without knowing it (fraxa.org). A mother who is a carrier has a 50% chance of passing the mutated gene onto her children, who may then present with symptoms. These symptoms range from mild to life-altering (fraxa.org). Some children may only present with altered physical features while others may present with severe autism, attention disorders, and seizures (fraxa.org).

Despite the prevalence of FXS, information and awareness about this genetic disorder have been severely lacking. The FRAXA Research Foundation (FRAXA) started in 1994 to address the extremely small amount of federal funding being directed towards research about FXS (fraxa.org). To that end, the goal of FRAXA is to sponsor researchers and clinical trials in the hopes of finding a cure.

Many people are hesitant to participate in clinical trials for a number of reasons (fraxa.org). For example, people feel as though they are “human guinea pigs” in clinical trials, or that they are jeopardizing their health by participating in them (“Participate in a Study”, 2004) and therefore ignore the potential benefits of participating in clinical trials. According to the U.S. National Library of Medicine, some of these benefits include having access to treatments that are not made available to the general public and helping to contribute to medical research. Our app will be designed to not only bring people information about clinical trials near them (which will be done through the use of GPS location services), but to also connect people with each other so that they may discuss their experiences with clinical trials in order to better understand the process and the importance of clinical trials.

FRAXA’s primary means of reaching parents and other interested parties is their website. However, they recently branched into social media with limited success compared to other non-profit organizations and even other organizations that share the same goal of raising awareness of Fragile X. Our research on the rise of popularity in mobile apps has led us to believe that an app would allow FRAXA to target (and ultimately reach out to) a wider audience. Figure 1 shows this increase in popularity in mobile phone apps over a three-year period. It is important to note that the bars in the graph that are marked with asterisks show differences at a 95% confidence level.



Source: Pew Research Center’s Internet & American Life Project, July 25-August 26, 2011 Tracking Survey. N=1,948 cell phone owners, margin of error is plus or minus 2.6 percentage points. Interviews conducted in English and in Spanish. May 2010 figures from April 29-May 30, 2010 Tracking Survey. N=1,917 cell phone owners, margin of error is plus or minus 2.7 percentage points. Interviews conducted in English only. September 2009 figures from August 18–September 14, 2009 Tracking Survey. N=1,868 cell phone owners, margin of error is plus or minus 2.7 percentage points. Interviews conducted in English only. An asterisk (*) indicates a significant difference across years at the 95% confidence level.

Figure 1. Increase in Cell Phone App Downloading (over a three-year period)

These statistics indicate a favorable projection of success for our app in that they show an increase in app users in a general sense (i.e., not specific to medical apps). Luckily, there have

already been many attempts to integrate mobile apps into the medical industry, so a means of increasing FRAXA’s popularity has never been more attainable.

Figure 2 shows a breakdown by several demographic populations of app downloads over a two-year period from Figure 1.

% of cell phone owners in each group who download apps to their phone...

	August 2011 (n=1,948)	May 2010 (n=1,917)
Gender		
Male	40	34
Female	36	24
Age		
18-29	60	52
30-49	46	31
50+	15	11
Education		
Less than high school	20	21
High school graduate	30	23
Some college	45	32
College graduate	48	35
Annual Household Income		
Less than \$50,000	33	27
\$50,000-\$74,999	38	29
\$75,000+	55	38
Community type		
Urban	40	29
Suburban	40	31
Rural	28	20

Source: Pew Research Center’s Internet & American Life Project, July 25-August 26, 2011 Tracking Survey. N=1,948 cell phone owners, margin of error is plus or minus 2.6 percentage points. Interviews conducted in English and in Spanish. May 2010 figures from April 29-May 30, 2010 Tracking Survey. N=1,917 cell phone owners, margin of error is plus or minus 2.7 percentage points. Interviews conducted in English only.

Figure 2. Increase in App Downloading Rate among Different Demographics over One Year

From May 2010 to August 2011, the percentage of people who downloaded mobile apps increased steadily. This table gives us a variety of information that helps us better understand our target audience. Though the app targets younger generations with the use of mobile phone apps,

it will also be indirectly targeting other age groups that exist across a variety of income brackets, education levels, community types, etc. For example, the two largest classes of users are between the ages of 18 and 49. Our target audience - parents of children with new FXS diagnoses - fall within these brackets. Over the course of a year, there was an increase in the percentage of cell phone owners that downloaded apps between the ages of 18 and 29 of 8% and between the ages of 30-49 of 15%. This shows us that an app is useful in order to reach a varied audience on a somewhat large scale, much like a social media presence would be; however, it is important to look at what exactly makes an app a successful tool.

Literature Review

The sources gathered cover a range of topics about the use and prevalence of mobile apps both in the medical field and in general. The goal was to gauge whether designing an app is a viable solution to increasing participation in clinical trials and bringing attention to FRAXA and Fragile X. It is also important to make sure that patients and their families would be willing to look for and take advantage of information presented to them in an app.

PREVALENCE OF SMART PHONES

Certain aspects of smart phones make them appealing to a wide audience. For example, Boulos (2011) mentions their “Geo-positioning systems” and “Internet access” as parts of a modern way of communicating. This increases the popularity of smart phones, and as a result, people are more prone to turning to their mobile devices as their primary means of gathering information. In order to explore what people look for in an app, one study gathered information on the top 200 apps to determine the most common types of apps bought (Garg, 2013). The findings of this study show that medical apps are actually one of the least popular on the app market.

This information gives us an idea of how best to market our app when it is completed. Because medical apps cater to a niche audience, trying to market the app to anyone but that audience will most likely be a waste of time. For this very reason, trying to measure the success of the project based entirely on app downloads may also be problematic. The focus of our conducted research was directed more towards specific medical fields, how they have incorporated mobile devices into patient care, and the success of incorporation. However, while this information was not used directly, it was useful to the actual creation of our app as it is important to know the potential of the media being used to achieve our ultimate goals. It was important to look at how other medical fields make complex information easily available and understandable for their patients in order to successfully incorporate the same practice within the design of our own app.

USE OF LOCATION SERVICES AND DISCUSSION FORUMS

According to a survey conducted by PewInternet, 75% of Americans are active in at least one online community; of those communities, 40% host discussion boards. If a community has younger members, the number jumps up to 50%. While this information may provide enough of a basis for the inclusion of a discussion board, it would still be pointless to include if no members of the community would use it. However, the PewInternet survey also points out that 24% of online members use discussion forums with younger members being twice as likely to participate as older members. Because this app is aimed more towards younger parents of children with Fragile X, this confirms that a discussion forum should be included in the app.

One other interesting statistic to note about the PewInternet survey was that people whose groups had a Facebook or Twitter account were more likely to be active in the group than those whose groups did not have a social media presence. It can be inferred that this is because people

regularly check their own Facebook or Twitter accounts, so there is no added inconvenience of going to another site to stay active in their groups. The inclusion of a discussion forum may then have the added benefit of making people more likely to look up nearby clinical trials on our app because they already have the app open to check the discussion forum.

After researching the use of location services we found that the use of these services is fairly commonplace. 74% of adult smartphone users say that they use their smartphones for “directions or other information based on their current location.” However, there is a drop in users who “check in” using their smartphones. That is, fewer people (now at 12% from an 18% reported in 2012) are using location services to share their locations with friends. In addition, security concerns are turning people away from keeping their location-tracking features on their smartphones. 46% of teen app users (as of September 2012) say that they have turned off this feature on their smartphones because they were “worried about other people or companies being able to access that information”. Though this may be a cause for concern for the design of this app, an adult demographic suggests that 35% of adult app users turn off their location-tracking services on their phones (as of April 2012). While this means that a majority of adults are willing to have their location services turned on, it suggests the app should be flexible enough to be able to function even with location services turned off, if at a loss of some convenience to the user.

POSITIVE ASPECTS OF HEALTH-RELATED APPS

In her research study, Zvornicanin, an associate of the Institute of Public Health Tuzla Canton, points out the success of mobile devices and how they have been incorporated into the ophthalmology field. In many elements of patient care, mobile devices have seen some kind of success, whether from tools to educate patients to actual vision tests. For example, the “Eye Handbook” is an app that serves as an encyclopedia containing testing tools and other important

information (Zvornicanin, et al., 2014). It has seen great success as an app that contains mostly information and not anything related to diagnosis, like some of the other ophthalmology apps on the market. This app shows that patients are willing to use smart phone apps in order to gather information about their condition, which in turn validates our desire to work with FRAXA to include information about Fragile X Syndrome in our own app in order to better educate the public about the disease.

Boulos looks at how smart phones can be used to assist those living independently and with disabilities (Boulos, 2011). Boulos highlights how the GPS functionality of smart phones has been deemed useful, which is important to the design of our app as it will use the GPS on smart phones to connect parents to clinical trials near them. The article also offers a helpful piece of advice to app developers by telling them they “need to look ‘at the margin’, i.e., how the latest group of adopters are using smart phones and how the next group of new users may use it” (Boulos, 2011). Because the app is using GPS services, it was important to look at how and why other medical apps have used the technology to their advantage. Articles like this one allow us to see that GPS services are useful and are actually taken advantage of in apps, which gives us confidence to implement them in our own app and to expect good results from them in terms of bringing people closer to clinical trials.

PITFALLS OF HEALTH-RELATED APPS

While the literature did not specify the failures of health-related apps, it has certainly claimed that there is no evidence to suggest their effectiveness. In fact, one article claimed that “information alone is insufficient to change behavior” (Bender, et al., 2013). The main problems cited with medical apps were the lack of regulation in the app market and the sheer volume of apps available. While many of the complaints were directed towards diagnostic apps, which is

not the type of app that was designed, it was still useful to look at where other companies have failed so as not to make the same mistakes. Thinking of ways to work around this and increase the popularity of the app was one of the biggest challenges faced.

Methodology

Our primary means of gathering data for the design of the app was through a survey consisting of fifteen questions, half of which come from our partner group working to improve the FRAXA website. The survey was, with the head of FRAXA's permission, linked to the FRAXA Facebook page and was distributed via email to the recipients of the FRAXA newsletter. The most important group we hoped to gather information from was the parents of children with Fragile X; however, since the survey was a combination of the questions of the two groups of this IQP, some of the responses we received to our questions came from family friends and employees of FRAXA. We did ask the survey participants to specify their relation to FRAXA, so we were able to separate the responses by these relations.

We chose to do an online survey over other means of gathering information because of time constraints. More specifically, mailing out a survey would have taken a lot of time and postage would have been costly. In addition, the intended target for the survey was parents with children who have FXS. An online survey was most convenient for both parties involved as we didn't have time to conduct more formal methods of gathering information, and the parents we surveyed could fill out an online survey at their convenience.

Before the survey was released, a notice was sent to all potential participants informing them of the upcoming survey and its importance to FRAXA. In addition, a reminder was sent some weeks after the survey in case there were some members of the community who missed the previous notices or had changed their mind about answering the survey. Based on the results of

the survey, it was anticipated that certain aspects of the app design would need to be changed to fit with the wants and needs of the community it is aimed at. To more easily look at the data, we used MATLAB to create visual representations of the gathered responses.

Once the scope of the design of the app was refined and modified to fit with what the parents of the FRAXA community were looking for, we implemented our plans into XCode, an app development software. More specifically, we used XCode to create a storyboard of our app which is a way to design the user interface of the app with minimal coding. This will not only allow users to navigate through the app as if they were doing it on a smart phone, but it will also make for easier app development by future teams since it can be done using the same software.

Results

After gathering the results from our survey, we looked to these results to confirm three main aspects of our intended project. First, the survey results were used to determine the overall interest in a FRAXA app of regular app users. Next, we wanted to confirm the creation of a clinical trial locator in the app based on its appeal to parents of clinical trial participants and those of non-participants. Finally, we wanted to justify the inclusion of a discussion forum to promote conversation between parents of clinical trial participants and non-participants.

In order to confirm these three aspects, we analyzed the responses to the questions we created based on relationships we made between questions. In other words, we would use the responses from one question as a "filter" to another question. For example, we used responses to the question "How many hours per week do you spend using apps?"¹ to see if regular app users

1 See question 12 in Appendix A

(i.e, those who use apps one hour per week or more) would be interested in a FRAXA app.²

Figure 3 below shows these results.

#	Answer	Response	%
1	Yes	61	54%
2	No	20	18%
3	Maybe	33	29%
	Total	114	100%

Figure 3. Interest in FRAXA app of regular app users

It can be concluded that a majority of regular app users (54% yes, 29% maybe) in the FRAXA community would at least consider using a FRAXA app incorporating a clinical trial locator.

Next, we looked for validation for the implementation of a clinical trial locator. We used the question "Has your child participated in a Fragile-X clinical trial?"³ to see if parents of both clinical trial participants and non-participants would be interested in an app that uses GPS to locate nearby clinical trials ("Would you be interested in a Fragile-X related app that uses GPS services to locate nearby clinical trials or events?"⁴). The results can be seen below:

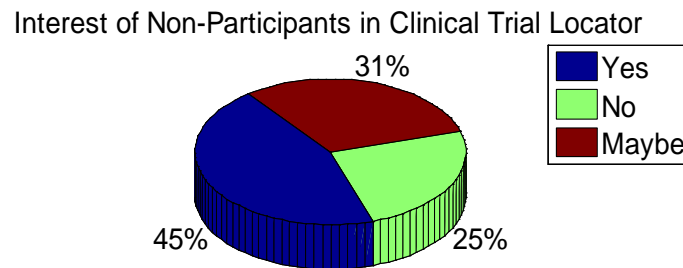


Figure 4. Interest of Non-participants in Clinical Trial locator

² See question 14 in Appendix A

³ See question 6 in Appendix A

⁴ See question 14 in Appendix A

Figure 4 shows that 76% (45% yes and 31% maybe) of parents whose children have never participated in a clinical trial would have some interest in an app that uses GPS services to locate nearby clinical trials.

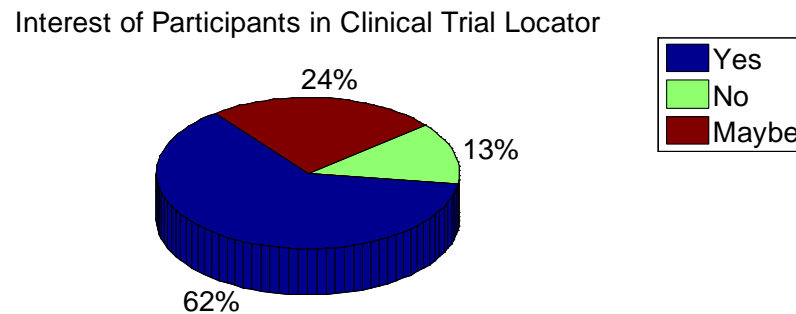


Figure 5. Interest of Participants in Clinical Trial locator

Figure 5 shows similar information to that found in Figure 4; however, Figure 5 shows an analysis of parents of clinical trial participants. Here, we see that a significant majority (62% yes and 24% maybe) of parents of clinical trial participants would be interested in the clinical trial locating feature of the app. We found the results displayed in Figures 4 and 5 to be of high importance to the design of our app because they confirmed that the use of GPS services to locate nearby clinical trials would be appealing to both parents of clinical trial participants and non-participants. These statistics support the team's decision to include this feature in the app design because they show that both parents of participants and non-participants would use the app in order to find a clinical trial, thereby increasing the overall number of clinical trial participants and, ultimately, helping FRAXA attain one of its goals towards finding a cure for Fragile X Syndrome.

In order to determine whether a discussion board would be a suitable feature in the app, a similar analysis was performed with the survey results. We first wanted to determine whether

communicating with parents of clinical trial participants would have any impact on the decision making process of parents of non-participants. The inclusion of a discussion board in the app would not serve its purpose if families from both groups would not be willing to participate. We used the results from the question “Would interacting with other parents who have undergone the clinical trial process be helpful for making a decision to participate in a clinical trial?”⁵ to ascertain this information. According to Figure 6, an overwhelming majority of parents of non-participants would find communication with parents of participants helpful in making a decision to have their child participate in a clinical trial.

#	Answer	Response	%
1	Yes	50	77%
2	No	15	23%
	Total	65	100%

Figure 6. Influence of communication with clinical trial participants on non-participants

Knowing that communication would help in the decision-making process is only half of the validation of the inclusion of a discussion board in the app. We also need to know if parents on both sides would be willing to communicate using a discussion board specifically, since our intention was to include one in the app. In order to do so, we used the results from the question "Has your child participated in a Fragile-X clinical trial?"⁶ to filter the question "How likely are you to participate in a discussion board/forum with other parents of children with Fragile-X?"⁷ (Note: Survey responses to this question ranged from 1-7, 1 being "Very Unlikely" and 7 being "Very Likely"). The results are displayed below:

5 See question 16 in Appendix A

6 See question 6 in Appendix A

7 See question 15 in Appendix A

Clinical Trial Participants' Willingness to Use Discussion Board

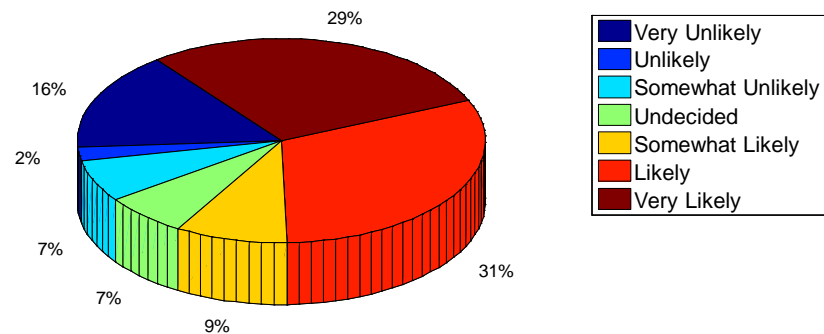


Figure 7. Willingness of Clinical Trial Participants to Use Discussion Board

Figure 7 shows that 69% of parents whose children have participated in a clinical trial (29% very likely, 31% likely, and 9% somewhat likely) are at least somewhat likely to participate in a discussion forum. A large percentage like this is important for supporting the development of the discussion forum because it is a clear indication that parents who have undergone the clinical trial process would be willing to participate in a discussion forum. This means that parents who have experiences with clinical trials can share their stories and ideas with those who have not had such an experience.

Likewise, it is important for parents whose children have not participated in clinical trial to also show interest in participating in a discussion forum. Figure 8 below shows the willingness of parents of non-participants to participate in a discussion forum.

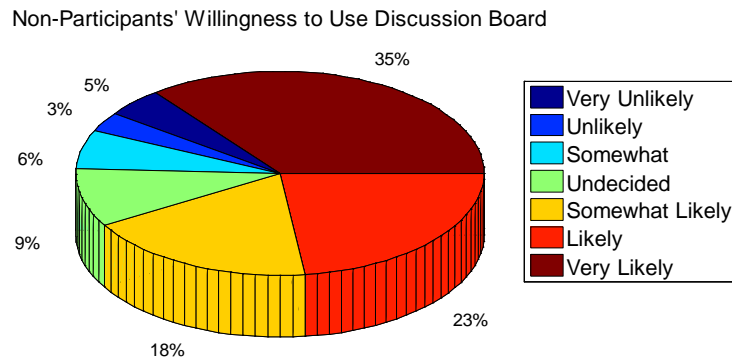


Figure 8. Willingness of Non-Participants to Use Discussion Board

According to Figure 8, 76% of parents (35% very likely, 23% likely, and 18% somewhat likely) within this population would be at least somewhat likely to participate in a discussion forum. This data, along with the data presented in Figure 7, are important to take into consideration when we were deciding whether the discussion board would be suitable to include in the design of the app. In fact, the results from this particular analysis support our decision to include a discussion board in the app because parents of both clinical trial participants and non-participants would be willing to use it. Our hope is that in seeing shared experiences about the clinical trial process, parents of non-participants and parents of newly-diagnosed children may be more likely to have their child participate in clinical trials, or at least have some of their questions answered (or fears alleviated) by parents of participants.

NAVIGATING THROUGH THE APP STORYBOARD

Ideally, the app can be divided into four separate sections: the "Clinical Trial Locator" section, the "Engaging a Child with Fragile X" section, the "Fragile X Discussion Forum" section, and the "Events" section. Each section was designed to be similar in look and feel to allow for users to quickly learn how to use the app.

THE CLINICAL TRIAL LOCATOR

Upon entering the Clinical Trial Locator section of the app, the user will be sent to a sub-page where all the clinical trials that are currently recruiting participants can be seen (for the purposes of the design, we limited this to three sample trials). On this page, there is a blue "FAQ" button that, when pressed, leads to a page of frequently asked questions regarding clinical trials (the questions and their answers are taken from fraxa.org for demonstration purposes). The user can navigate back to the sub-page containing the names of all the clinical trials currently recruiting participants. After the user selects from the available clinical trials, the app will move on to another sub-page that will display the locations in which the clinical trial is being held. Based on the user's location, he will be able to select the clinical trial site closest to him. After making a selection, the user will be sent to another sub-page where the lead investigator's name will be displayed. In addition, this sub-page will also include a contact's (or contacts') name, phone number, and email address in case the user has any follow-up questions on the clinical trial. An example of this navigation can be seen in Figure 9 below.

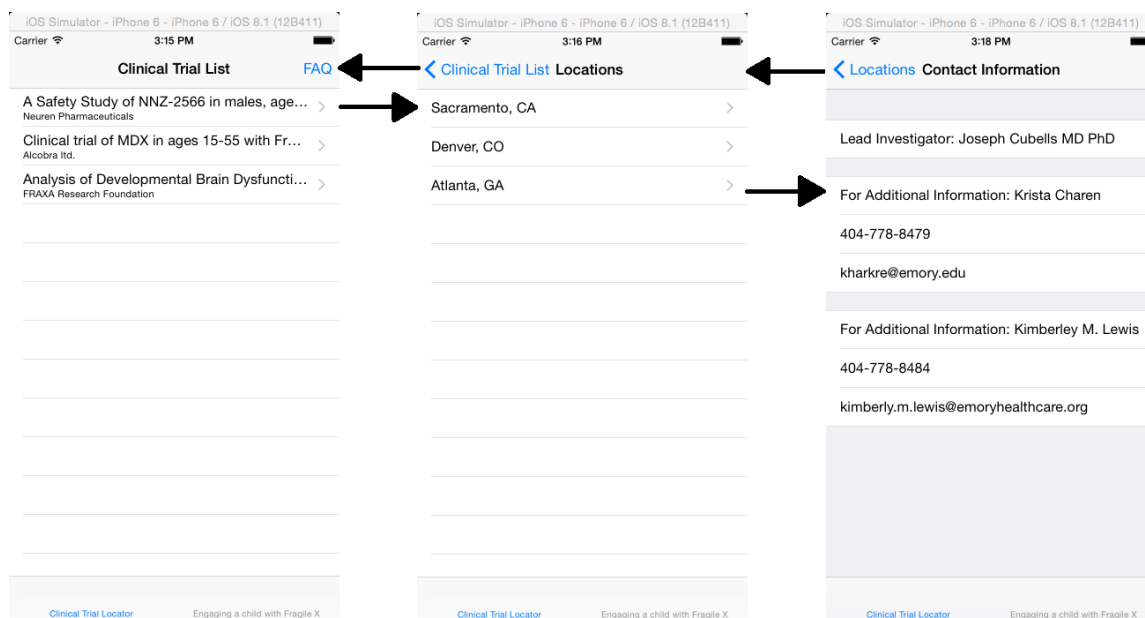


Figure 9. Navigating Through the Clinical Trial Locator

Examples of how the data hierarchy of the clinical trial locator works can be found in Figure A and Figure B of Appendix B. Essentially, data that is stored in the current view controller object is passed to the immediate next view controller. Based on which clinical trial was picked, the different locations for each one will then be displayed onto the next screen. This is the same for the next level of the hierarchy. The view object containing information about the locations will pass on the contact information of the selected location to the next view object. A sample data file has been included for reference (see Figure C in Appendix B). All of the data for the app is loaded in from separate files so that no code needs to be changed if another clinical trial is added. This also allows for the possibility of loading in information from a database into a data file that can then be displayed in the app.

ENGAGING A CHILD WITH FRAGILE X

The inspiration for this section of the app came from a survey participant's request for a pamphlet style information page with tips for interacting with a child with Fragile X. This section of the app is aimed more towards family friends of the FRAXA community (like the survey participant who suggested this). The second largest number of respondents of the survey were family friends or extended family members, so the aim of this section of the app is to increase the app's appeal to all members of the FRAXA community. As there is far too much information to reasonably fit into an app, this section will also link certain pages on the FRAXA website. This will avoid redundancy of information as well as keep the app's tips more compact and user-friendly on mobile devices.

EVENTS

This section serves a similar purpose to the clinical trial locator except that instead of informing users of nearby clinical trials, users are informed of nearby FRAXA-sponsored events. For demonstration purposes within the storyboard, several events, including some that had already taken place, were used to populate the various table views within this section. Because clinical trials are able to offer travel expenses for families that needed assistance, we made the highest level of the data hierarchy of the clinical trial locator the individual trials themselves. As travel expenses are not covered for events, this section of the app starts with the location of the events, so users can easily find events that are closest to them in order to engage with the FRAXA and its community.

FRAGILE X DISCUSSION FORUM

Due to time and technical constraints, we were not able to build a mock-up of this section of the app. However, our idea for the format of the discussion board was something similar to both the clinical trial locator and the events locator. Keeping a consistent look and format to all sections of the app will allow users to quickly learn how to use every section of it. A sample layout from an already existing app can be seen in Figure 10.

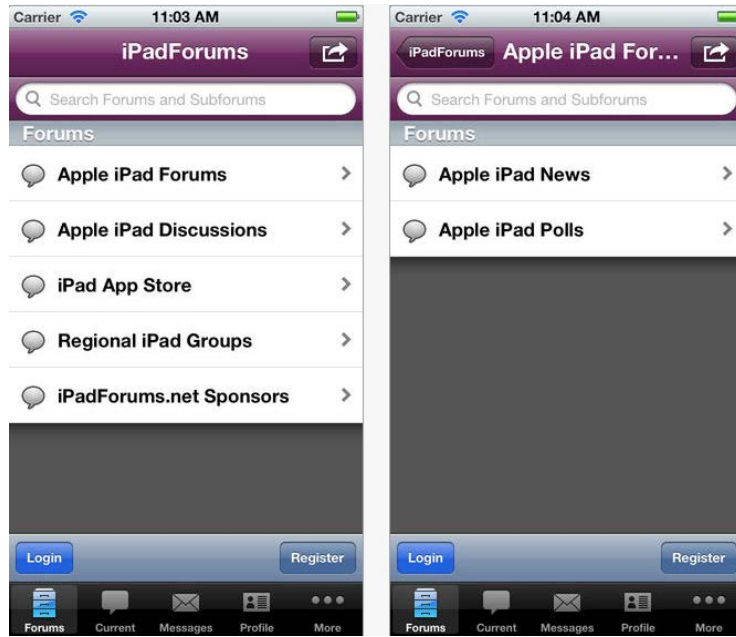


Figure 10. Sample layout of Discussion Board

Recommendations

From our time spent researching and developing the storyboard of this app, our team came up with the following recommendations on how best to use the resources we have found or created.

DEVELOPING THE APP

In order to sufficiently meet our goal of increasing the number of clinical trial participants, this team recommends this app design be given to a software developer with experience in building applications for the mobile market. Because the design this team worked on was built using the storyboard feature in XCode, the software developer will be able to begin building the app without the need to design most of it. This will hopefully serve to save both

time and money for the FRAXA research foundation, so the app can be put into the hands of the FRAXA community as quickly and cheaply as possible.

A decision must still be made on the method by which updates to the list of clinical trials available in the app will be made. A conscious effort has been made to design the app such that the list of clinical trials is not hard-coded into the source code for the app. Instead the list is read in from a separate file, which opens up the possibility of querying a database for information about active clinical trials. The decision, then, is whether to create this database of clinical trial information or to simply have an employee of FRAXA update the pre-existing list when necessary. As the list of clinical trials seemingly does not change very often, either choice seems equally valid.

MODERATING THE DISCUSSION BOARD

The discussion board, although not implemented in our storyboard due to time constraints, was researched thoroughly to make the addition of one as easy as possible. When looking up information about discussion boards, the topic of moderation was our top priority as we believed that being able to control what is posted in a forum (i.e, removing negative comments) is important in terms of letting participants have productive conversations regarding their questions and concerns. We also wanted to avoid placing the burden of moderating an app on one person alone. Therefore, we are proposing that the responsibilities of moderating a discussion board be distributed amongst a hierarchy of individuals. Each individual would be assigned a role in moderating the board with varying responsibilities. These individuals would be recruited from current FRAXA employees to particularly active and trustworthy members of the FRAXA community. Figure 10 below shows roles and hierarchy.

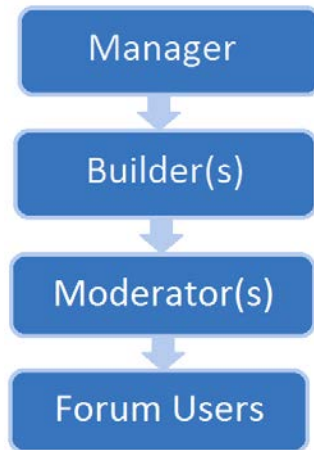


Figure 11. Proposed Hierarchy for Discussion Board Moderating

The manager occupies the most important role and has full control and authority over the discussion board. The specific powers of the manager include changing forum settings, moderating posts, and assigning roles to other members of the community in order to more effectively manage the discussion board. A builder's typical responsibilities include editing and deleting forums in the discussion board, and creating new threads in a forum. A moderator's responsibilities include editing, locking, and deleting individual posts inside a forum or thread. The roles designated to the builders and moderators are subject to change based on the manager's preferences.

Conclusions

In an attempt to adhere to FRAXA's mission statement, we designed an app that would not only allow the FRAXA community to more easily access information on nearby clinical trials, but also give people within the community the opportunity to communicate with one another. After sending out a survey and getting over 200 responses, we were able to successfully validate the inclusion of these features into our app as well as another suggested feature to provide tips on interacting with a child with Fragile X.

In order to implement this design, we used an app development software called XCode to build a visual layout of the user interface of the app called a storyboard. All planned features of the app were included in the storyboard with the exception of the discussion board due to time; however, we have provided tips on how to moderate a discussion board as well as a potential layout that is consistent with the other sections of the app. The hope for this storyboard is that it will be given to a software developer with mobile development experience to be made into a completed app.

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Appendix A

IQP Survey Questions

This is an anonymous and confidential survey. No specific identifying information will be collected. Information gathered will solely be used for academic research and will not be shared with any third parties.

Participation in this research survey is voluntary. You may end your participation at any time. You do not need to answer every question in this survey.

1. Which describes you best?
 - a. I am a parent of a child with Fragile X
 - b. I am a Fragile X researcher
 - c. I am an employee of the FRAXA Foundation
 - d. Other (please specify) _____ ----

2. How frequently do you visit the FRAXA website?
 - a. Rarely
 - b. Once a month
 - c. 2-3 times a month
 - d. Once a week
 - e. 2-3 times a week
 - f. Daily

3. What page do you visit most frequently on the FRAXA website?
 - a. Clinical Trials
 - b. Ongoing Research / Towards a Cure
 - c. About FRAXA
 - d. FRAXA home page
 - e. FRAXA events
 - f. Other: _____

4. What do you think is the most helpful part of the FRAXA website?
 - a . Clinical Trials
 - b . Ongoing Research / Towards a Cure
 - c . About FRAXA
 - d . FFRAXA home page
 - e . FRAXA events
 - f . Other: ____

5. Are you aware that there are clinical trials for the treatment of Fragile-X syndrome?
 - a . Yes.
 - b . No.

6. Has your child participated in a Fragile-X clinical trial?
 - a . Yes.
 - b . No.
 - c . No, I was not aware of clinical trials.

7. Would interacting with other parents who have undergone the clinical trial process influence your decision to participate in a clinical trial?
 - a . Yes, positively.
 - b . Yes, negatively.
 - c . No

8. Is there any information you would like to see added to the website?
 - a . Clinical Trial Information
 - b . Research Information
 - c . Parent & Family Resources
 - d . Events
 - e . Latest News
 - f . Other: _____

9. Please rate the following aspects of the FRAXA website (poor, fair, no opinion, good, excellent)

- a. Layout
- b. Navigation
- c. Lack of Information
- d. Images and Videos
- e. Patient Stories
- f. Clinical Trials Page
- g. Ongoing Research / Towards a Cure Page
- h. About FRAXA Page
- i. FRAXA home Page
- j. FRAXA events Page
- k. Other: _____

10. What about the layout / design would you like to be changed?

- a. _____

11. Do you own a smart phone or tablet?

- a. Yes, an Apple device.
- b. Yes, an Android device.
- c. No.
- d. Yes, other: _____

12. How many hours per week do you spend using apps?

- a. Less than 1.
- b. 1-3.
- c. 3-5.
- d. 5-7.

e. More than 7.

13. Are any of the apps you use health related?

a. Yes.

b. No.

c. Unsure.

d. If unsure, specify name of app(s): _____

14. Would you be interested in a Fragile-X related app that uses GPS services to locate nearby clinical trials or events?

a. Yes

b. No

c. Maybe.

d. Comment: _____

15. How likely are you to participate in a discussion board/forum with other parents of children with Fragile-X?

a. 1 – 10. (least likely – most likely)

b. I am not a parent of a child with Fragile X.

16. Would interacting with other parents who have undergone the clinical trial process be helpful for making a decision to participate in a clinical trial?

a. Yes

b. No

Appendix B

Sample source code for storyboard

```
// In a storyboard-based application, you will often want to do a little preparation before navigation
override func prepareForSegue(segue: UIStoryboardSegue, sender: AnyObject?) {
    // Get the new view controller using [segue destinationViewController].
    // Pass the selected object to the new view controller.
    var indexPath : NSIndexPath = self.tableView.indexPathForSelectedRow()!

    var DestViewController = segue.destinationViewController as ContactInfoViewController

    var passInfo : ContactInfo

    passInfo = trialContacts[indexPath.row]

    DestViewController.leadInvest = passInfo.leadInvestigator
    DestViewController.names = passInfo.contactNames
    DestViewController.emails = passInfo.contactEmails
    DestViewController.phones = passInfo.contactNumbers
}
```

Figure A. TrialInfoViewController.swift

```
// In a storyboard-based application, you will often want to do a little preparation before navigation
override func prepareForSegue(segue: UIStoryboardSegue, sender: AnyObject?) {
    // Get the new view controller using [segue destinationViewController].
    // Pass the selected object to the new view controller.

    if(segue.identifier == "FAQ")
    {
        return;
    }

    var indexPath : NSIndexPath = self.tableView.indexPathForSelectedRow()!

    var DestViewController = segue.destinationViewController as TrialInfoViewController

    var passInfo : TrialLocation

    passInfo = trialCities[indexPath.row]

    DestViewController.trialsCities = passInfo.cities

    DestViewController.trialContacts = passInfo.contacts
}
```

Figure B. TrialViewController.swift

```
//  
// SampleTrials.swift  
// Mock-Up  
//  
// Created by Christopher Gillig and Krishna Nazareth on 2/20/15.  
// Copyright (c) 2015 IQP. All rights reserved.  
//  
  
import Foundation  
  
// Setting up sample data that will be read into the app.  
let trialsData = [ Trial(name: "A Safety Study of NNZ-2566 in males, aged 14-40 years with Fragile X", company: "Neuren Pharmaceuticals"),  
                  Trial(name: "Clinical trial of MDX in ages 15-55 with Fragile X", company: "Alcobra Ltd."),  
                  Trial(name: "Analysis of Developmental Brain Dysfunction (DBD) in Families with Fragile X Syndrome", company: "FRAXA Research Foundation") ]
```

Figure C. SampleTrials.swift