

FETAL ALCOHOL SPECTRUM DISORDERS IN ADULTS: HEALTH AND NEUROBEHAVIOR

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in collaboration with Joanne Weinberg, PhD

The problem:

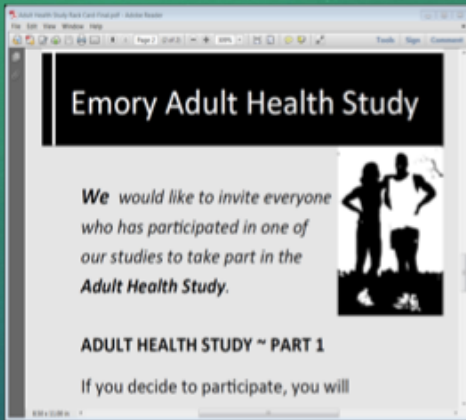
- Despite the prevalence of FASD and its life-long course, there is no empirical research about adult health, physical characteristics, neurobehavior or adaptive functioning in Middle Adulthood.
- The Developmental Origins of Health and Disease (DOHoD) hypothesis suggests that fetal programming by PAE should result in vulnerable organisms with increased sensitivity to stress, adverse health and functional outcomes.

THE STUDY

- Multisite Collaborative Study (part of the Collaborative Initiative on Fetal Alcohol Spectrum Disorders (CIFASD))
- Sites include Atlanta, GA and Seattle, WA, with a parallel study in Vancouver, BC.
- Two “Tier” Assessment
 - Tier 1. Demographic and Health Survey
 - Tier 2. In-Depth Assessment of medical records, physical characteristics, immune function, mental health, cognitive functioning, social/adaptive functioning



- Tier 1



Example of the recruitment materials.

Adult Health Survey (N=500) of access to health care, chronic medical problems in midlife, ages 25-45.

(Another 120 will be tested in Vancouver using the same form.)

Health Issues to be assessed:

- Access to health care
- Sleep
- Vision/Health/Dental
- Allergies and Asthma
- Cardiovascular
- GI
- Diabetes
- Autoimmune disorders
- Arthritis
- Seizures
- Depression/Anxiety
- Other Medical problems

TIER 2 ASSESSMENT

- This is intended to be an in-depth assessment of the Adults' current status. There will be several areas assessed:
 - Physical Characteristics
 - Psychological factors
 - Environmental
 - Substance Use
 - Health, including Immune Function
 - Medical records
- *120 individuals at each site (240 total) will be invited to complete this comprehensive assessment. They will be invited to the study site and will spend about 4 hours being evaluated and completing questionnaires.*
- *We will draw blood and take urine samples to confirm substance use reports and to allow assessment of metabolic status (A1C), liver function (GGT) and immune status.*

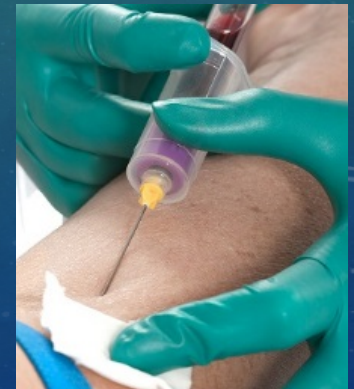
TIER 2 ASSESSMENT-PSYCHOLOGICAL MEASURES

- Cognitive Functioning- “fluid intelligence” → • NIH Tool Box
- Adaptive Functioning → • Adaptive Behavior Assessment System, 3rd Ed
- Psychiatric Problems → • Psychiatric Diagnostic Screening Questionnaire (PDSQ)
- Substance Use → • AUDIT, Drug Grid, Lab tests
- Life Stressors and Resources (Moos) → • LISRES-2



TIER 2- PHYSICAL ASSESSMENT

- Dysmorphology assessment → • Evaluation by Ken Jones
- 2-D Photography taken on site → • In collaboration with Peter Hammond
- Urine Toxicology for 7 drugs → • Sampled in Lab
- GGT → • Sampled in Lab
- A1C → • Sampled in Lab
- Immune Measures → • Samples sent to Joanne Weinberg, PhD
- Health History → • Abstracted from current medical records



PROGRESS

- All the Administrative hassles
 - Co-ordination among three sites to develop materials.
 - Materials Transfer Agreements
 - IRB
 - Review assessment protocol and purchase materials
 - Develop Assessment tools and database in REDCap
 - Search databases for previous participants



DEVELOPED HEALTH QUESTIONNAIRE

Based on the Centers For Disease Control's Behavioral Risk Factor Surveillance System (BRFSS) Questionnaires

Modified to include modules on vision, hearing, dental problems, seizures, immune disorders, etc.

Developed by three sites.

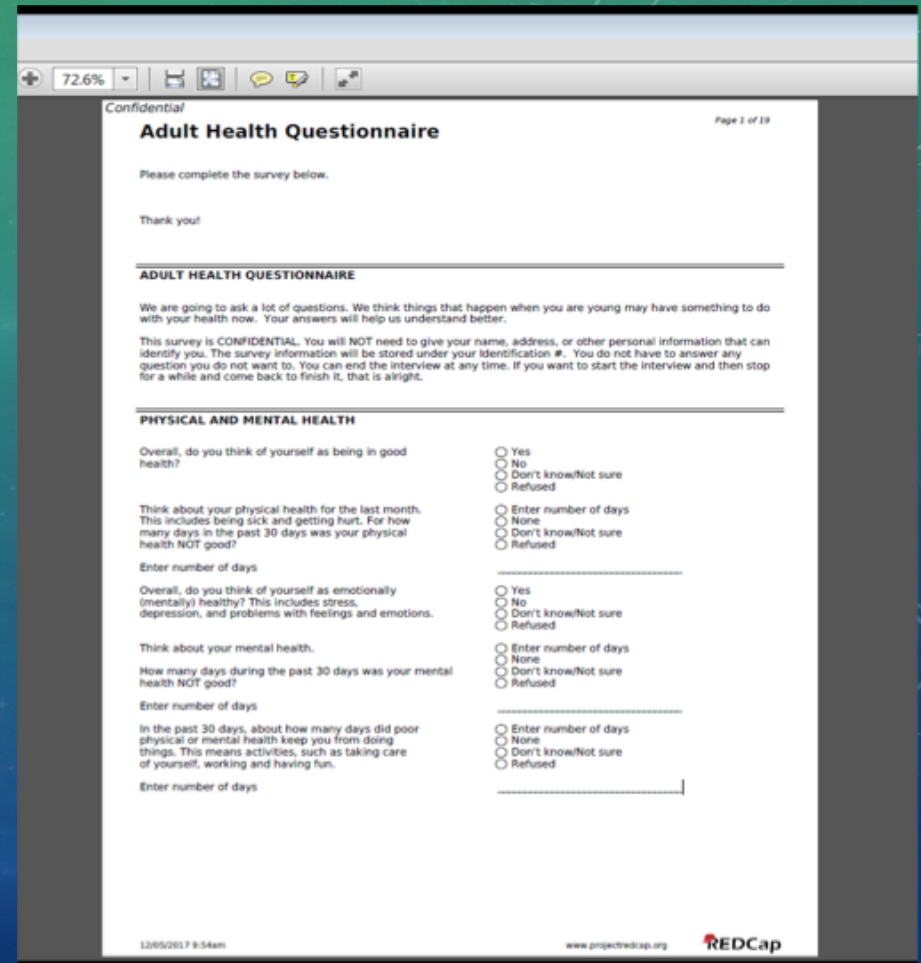
Using REDCap system, created data entry forms that can be accessed on computer or smart phone. Can be completed by participant directly or through interview.

System is confidential and HIPAA-compliant.

Converts directly to interactive database. Can be exported in Excel or SPSS.

Multisite access.

Piloted in Atlanta (N=10)



The image shows a screenshot of a web browser displaying a confidential adult health questionnaire. The browser's address bar shows a zoom level of 72.6%. The page is titled "Confidential" and "Adult Health Questionnaire" (Page 1 of 19). The form includes instructions to complete the survey, a "Thank you!" message, and a section titled "ADULT HEALTH QUESTIONNAIRE". Below this, there is a confidentiality notice and a section titled "PHYSICAL AND MENTAL HEALTH". The form contains several questions with radio button options and input fields for the number of days. The questions are:

- Overall, do you think of yourself as being in good health? (Yes, No, Don't know/Not sure, Refused)
- Think about your physical health for the last month. This includes being sick and getting hurt. For how many days in the past 30 days was your physical health NOT good? (Enter number of days, None, Don't know/Not sure, Refused)
- Overall, do you think of yourself as emotionally (mentally) healthy? This includes stress, depression, and problems with feelings and emotions. (Yes, No, Don't know/Not sure, Refused)
- Think about your mental health. How many days during the past 30 days was your mental health NOT good? (Enter number of days, None, Don't know/Not sure, Refused)
- In the past 30 days, about how many days did poor physical or mental health keep you from doing things. This means activities, such as taking care of yourself, working and having fun. (Enter number of days, None, Don't know/Not sure, Refused)

The footer of the page includes the date and time "12/05/2017 9:54am", the website "www.projectredcap.org", and the REDCap logo.

IDENTIFICATION OF POTENTIAL PARTICIPANTS

Goal: Tier 1-500
Tier 2-240

- Atlanta
- (Tier 1= 250, Tier 2=120)
 - Accessed databases from previous study waves and accumulated names, addresses, SS #; names of collaterals, Total potential subjects identified =
 - Contracted with Accurinet to allow computerized search for participants' current address, phone numbers.
 - Currently have located 60 previous participants who will be contacted when IRB completes review of recruitment materials.

Potential problems for recruitment process:

Participant mobility. May have moved out of area.

No longer in "phone book". Cell phones don't have white pages.

Privacy concerns. People are much more worried about privacy than they were previously and may not answer phones.

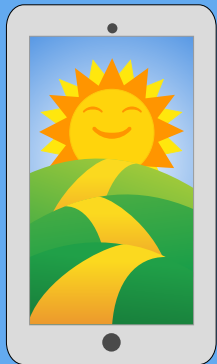
Not interested in participating

Seattle

- (Tier 1= 250, Tier 2=120)
 - Accessed databases from previous study waves and accumulated names, addresses, SS #; names of collaterals, Total potential subjects identified = 433
 - Contracted with TransUnion (TLO) to allow computerized search for participants' current address, phone numbers.
 - Currently have located 125 previous participants; so far 65 are interested in being in this new study. All will be contacted after IRB completes review of recruitment materials.

TIME LINE

- Tier 1- Years 1-4
 - December 2017: Complete Administrative Requirements/ Develop Forms and Questionnaires/Recruitment Materials
 - January 2018: Initiate recruitment, Health Surveys, Registry
- Tier 2- Year 2-5
 - January - May, 2018: Obtain all materials, permissions, identify initial sample
 - July 2018: Begin Tier 2 Assessments



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FMF Connect Team



Christie Petrenko, Ph.D.
MHFC / U. of Rochester



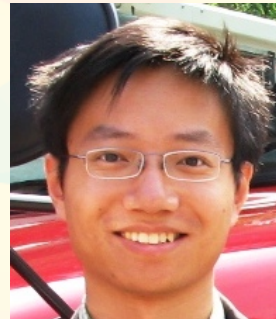
Cristiano Tapparello, Ph.D.
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Wendi Heinzelman, Ph.D.
U. of Rochester



Zhiyao Duan, Ph.D.
U. of Rochester



Jenn Parr
MHFC / U. of Rochester



Rebecca Van Dyke
U. of Rochester



FMF Connect Components

Learning Modules

- 12 core modules, 3 levels
- Educational text/audio
- Exercises to practice content
- Animation and video

Notebook

- User builds personalized section for later reference
- Exercises about child, selected content, tools, notes

Dashboard

- Summary of progress
- Badges earned, child behavior ratings, usage metrics



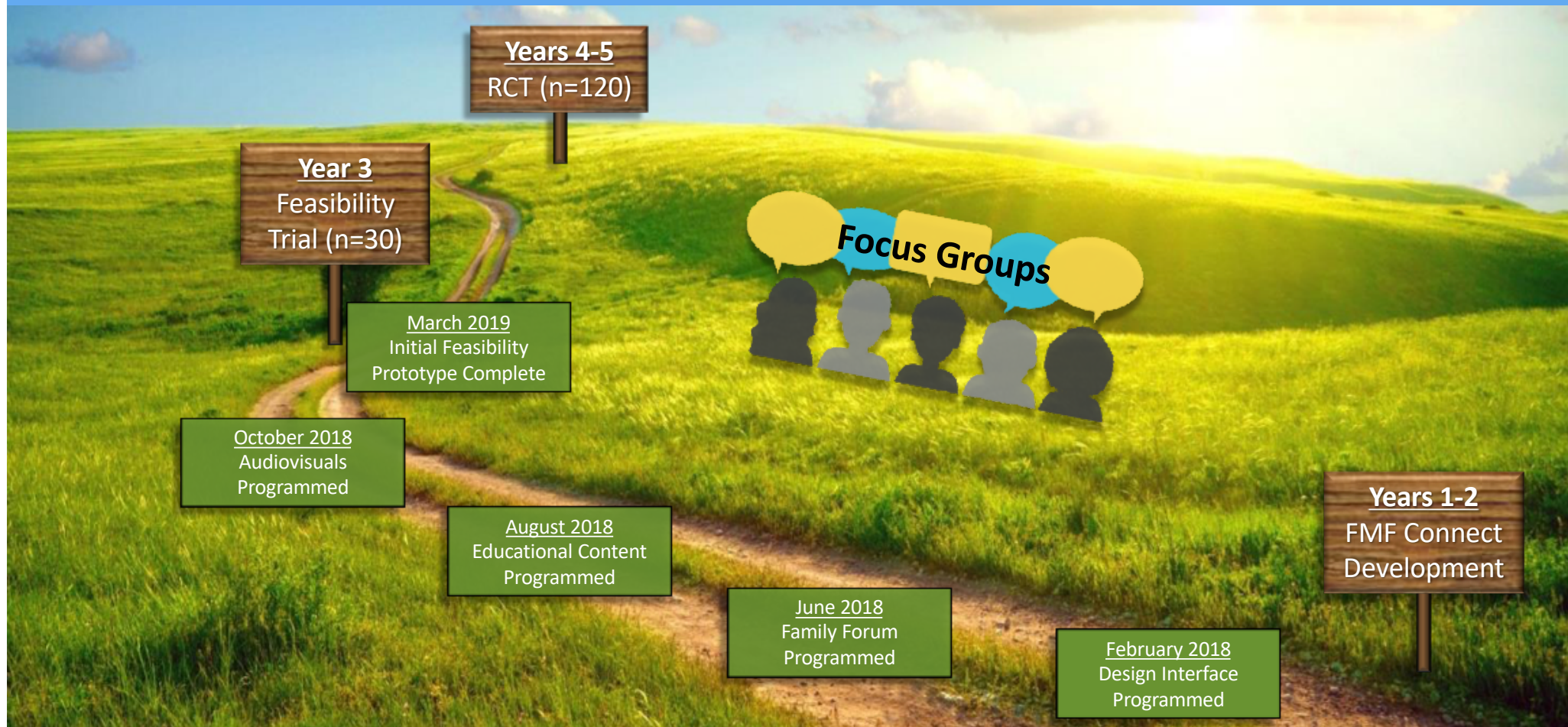
Family Forum

- Users share ideas, ask questions, get support
- Organized in sub-forums
- Moderated by trained peers

Library

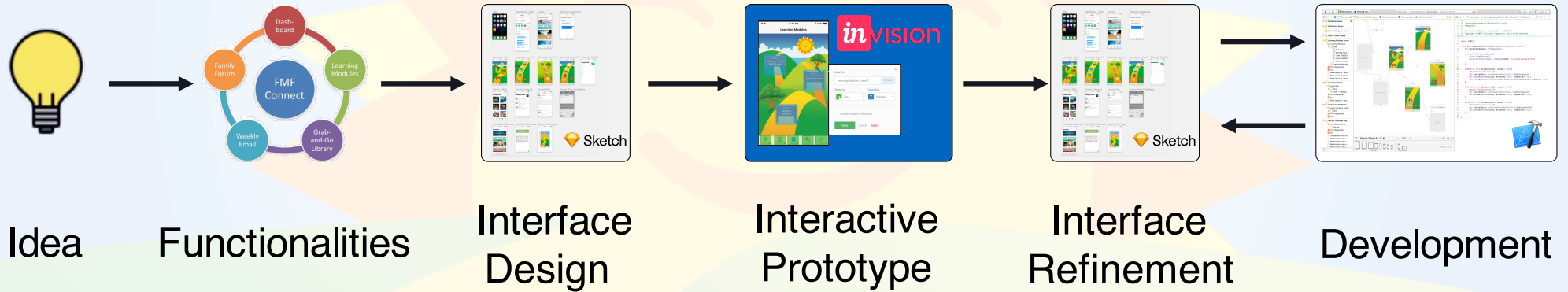
- Lists of books, websites, other resources
- Optional fact sheets

Project Timeline Overview



- Families Moving Forward Program – content, principles, methods
 - FMF developed by Heather Carmichael Olson and team at UW/SCRI
 - Funded by CDC
- FMF Connect is a derivative product with unique features
- Informed by multiple fields:
 - Translating content and principles across methods of delivery
 - Education/online learning: Backward design process
 - Implementation science: Behavior change techniques
 - Ethical considerations

- Update on content development progress:
 - 12 core modules – all drafted (~ 100 pgs), 1st round intense editing complete (> 64 hrs), revisions in process
 - Drafting optional content, compiling materials for library
- What's next?
 - 2nd round editing review core content, 1st review of optional materials
 - Programming content and exercises in app
 - Elicit feedback on content in focus groups
 - Scripting and producing audiovisual content



- App idea consolidated during grant writing/submission



App idea

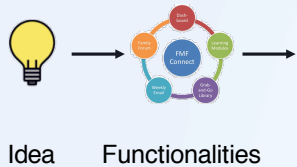


Idea

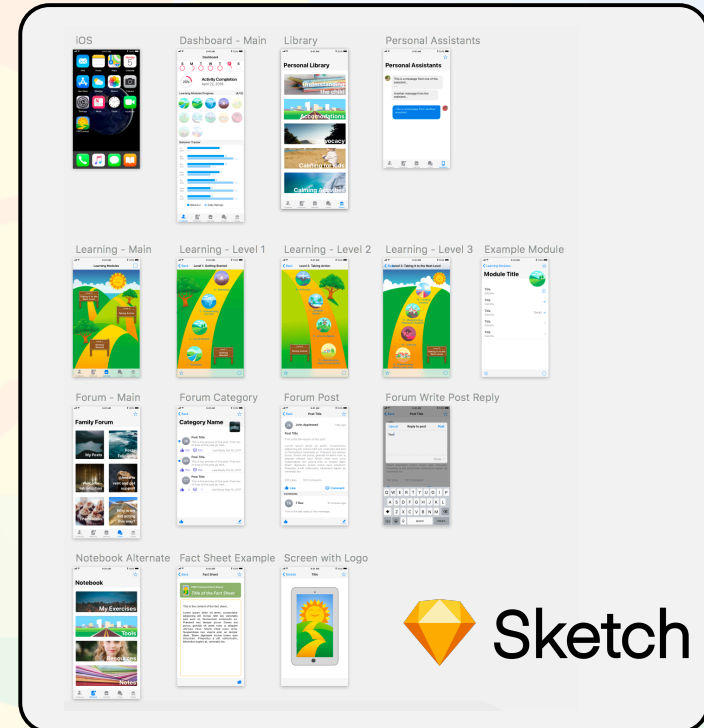
- App functionalities identified during grant writing
- Refined while working on the app content



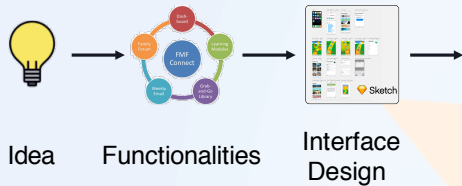
Functionalities



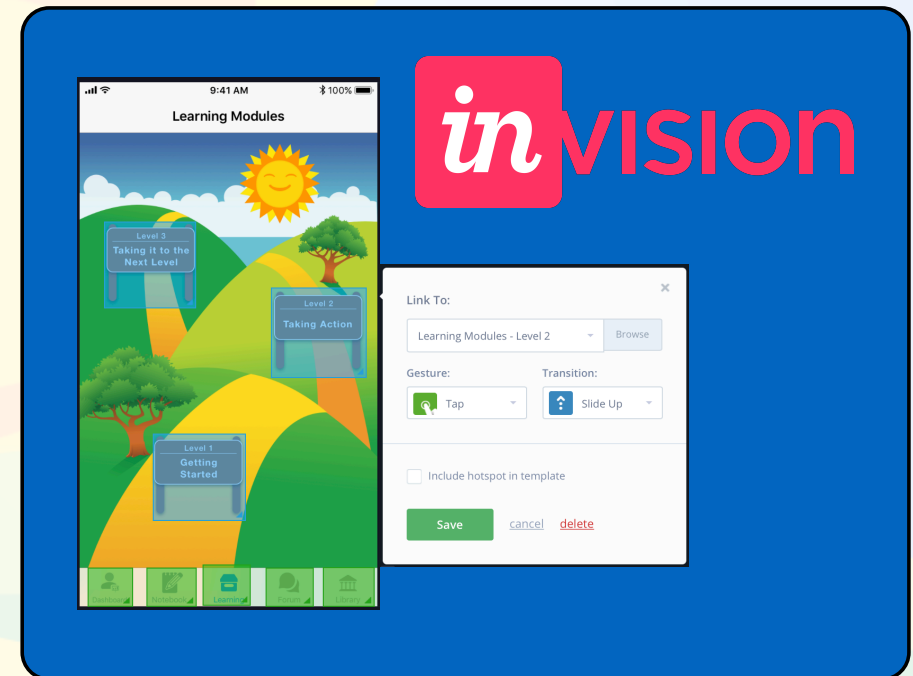
- Mockup app idea and functionalities into a set of screen images
- Facilitate feedback and discussion across team



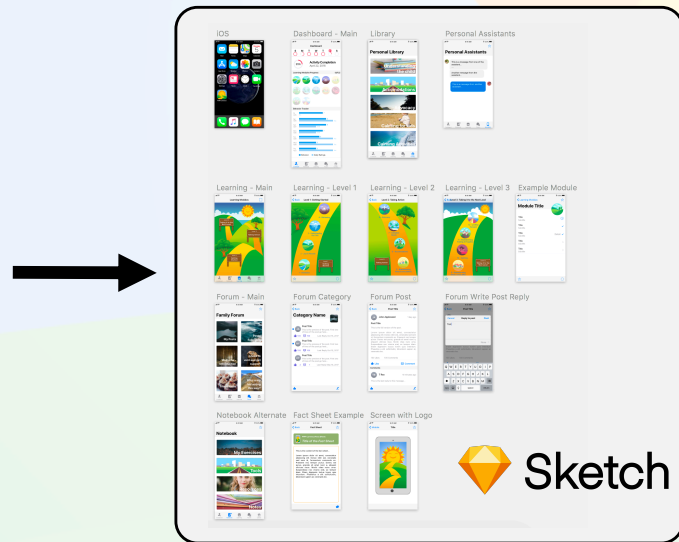
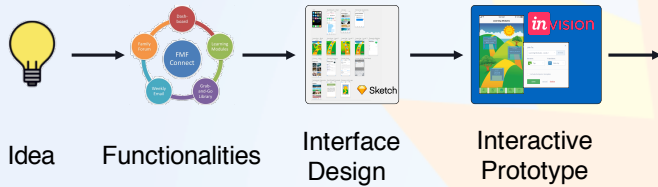
Interface Design



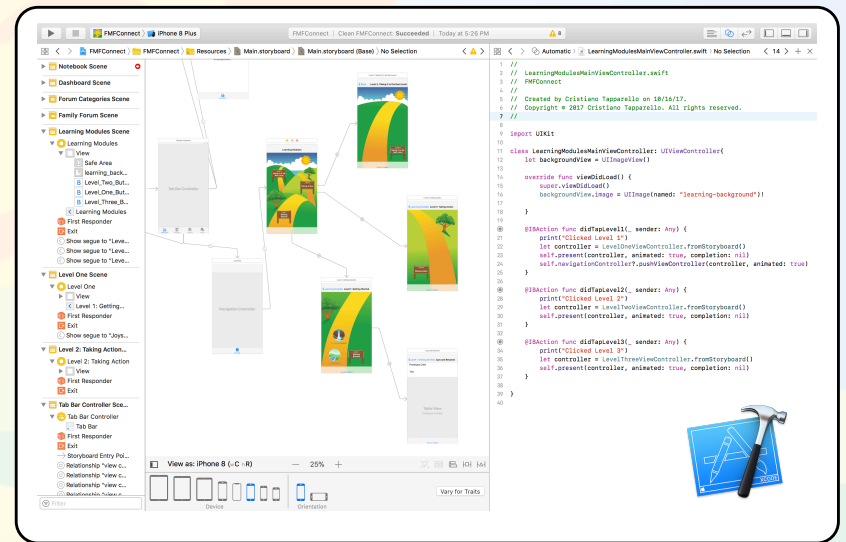
- Combined the different screens into an interactive prototype
- Demonstration in focus groups



Interactive Prototype



Interface Refinement



Programming

- App requirements:
 - Cross-platform (iOS, Android, web?)
 - Authentication, security, modular structure, cloud functionalities, real time synchronization, push notifications, analytics, etc.
- Open source products
 - Google Firebase
 - ResearchKit and Carekit
 - ResearchStack and ManageMyCondition



- Initial implementation of the InVision prototype on iOS
- Forum development:
 - Cloud database structure
 - Authentication
 - Read and write operations from app
 - Real time synchronization
- Current work in progress:
 - Interface to fully match prototype
 - Forum: messages organized in thread (replies), avatar

- Diverse perspectives: family structure, comfort with technology, location, child age, etc.
- Initiated focus groups in Rochester 12/6 and 12/8
- Planning additional groups in:
 - Rochester (periodically) *including with and without prior FMF exposure
 - Washington DC (Mitchell) ? – emphasis on birth parent perspective
 - Atlanta (Coles) ~ March
 - Minnesota (Wozniak) ~ April
 - San Diego - coincide with RSA in June

- Components
 - Felt strongly users should be able to use app indefinitely to return to helpful content and engage with forum
 - Liked that app content of interest could be saved to Notebook for later reference
 - Positive about tools in Notebook; suggested additional tools
 - Trust, confidentiality, and protections were major themes for Family Forum
 - Suggested access to specific sub-forums be introduced as users complete relevant learning modules
 - Liked idea of having sub-forums available based on geographic location (sharing resources/advocacy tips)
 - Want easy way to aggregate and find tips/resources suggested by other users

- **App & Interface Design**
 - Strong, positive reaction to learning module interface design
 - Less enthusiasm for logo/icon, but generally neutral to positive
 - Prefer graphics to photos
- **Facilitators to use**
 - Content/Features: When child is struggling; connecting to other users
 - Technology: Voice-to-text; transition across platforms (e.g., phone, computer)
- **Barriers to use**
 - Content/Features: poorly moderated Family Forum, concerns of trust/safety
 - Technology: difficulty to navigate; lots of scrolling; slow loading



Questions

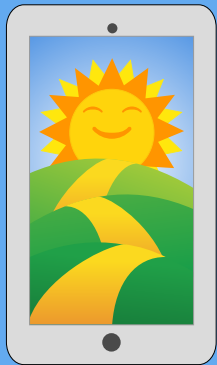


Comments



Feedback





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