

## Final Narrative Report

### Title

LIVING PROFILES: Transmedia Personal Health Record Systems for Young Adults

### Program

Project HealthDesign: Rethinking the Power and Potential of Personal Health Records

### RWJF Grant Identification Number

59889

### Dates of Grant

December 1, 2006- May 31, 2009

### Amount of Grant

\$300,000

## Overview

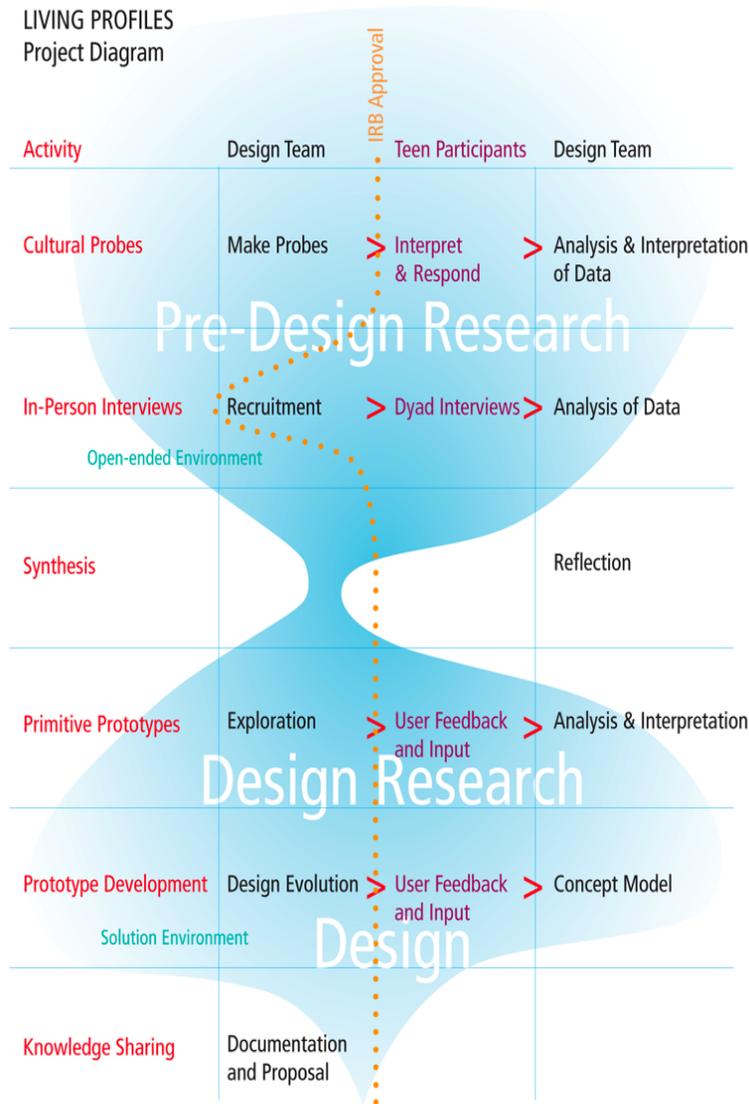
Art Center College of Design's Graduate Media Design Program, along with its multiple partners proposed the design and development of *Living Profiles*, an innovative personal health application for teens. The specific concept of *Living Profiles* is to vitalize family and personal health histories through new technologies and interaction design to engage the teen population in issues of their health and healthcare. An important focus is to help teens *bridge the transition process* from a pediatric to an adult health care model, and in so doing motivate and empower them in their own healthcare as they gain independence. The proposed project seeks to accomplish these goals through the development of a *transmedia system* enabling and encouraging teenagers to create and maintain personal health records. A transmedia system is one that works with different media types to fulfill a strategic goal (e.g. iTunes and iPod are a transmedia system to legally sell individual songs).

***What measurable goals did you set for this project and what indicators did you use to measure your performance? To what extent has your project achieved these goals and levels of performance?***

### LIVING PROFILES: Synopsis of phase 1 goals

1. To design a PHR that helps teens manage their health and transition from pediatric care to adult care successfully
2. To define the exact questions we would like to address with a teen PHR by qualitative research (using a design research methodology) by
  - a. Developing cultural probes to evoke teens perceptions on health
  - b. Interviewing teens to enhance expand the information elicited by the probes.
  - c. Continually returning to teen users to help affirm and refine our interpretations
3. To propose a concept prototype based on analysis of above measurements, with refinements based on teen and other stakeholder input.
4. To create a visualization of the experience using the concept prototype through a video scenario.
5. To build a working functional prototype, based initially on the concept prototype and transformed by using iterative design and user testing, with one focus on being able to integrate into a common platform (shared data repository).

Human-centered design research methodology in which users are engaged to help define the problem(s) was used to begin the process of prototype design and development. This pre-design stage incorporated design research techniques that have been rarely used in traditional health services or medical research, including the use of “cultural probes”– self-reflective activities that provide teens alternative strategies to share their unique perspective. Our research team used the information gathered from the activity returns to evoke and uncover areas warranting further exploration. The cultural probes were supplemented with in-home dyad interviews to bring in teens’ voices in interpreting concepts such as health, wellness, and social interaction. (Figure 1)



**Figure 1**  
**Human-Centered Design Research Methodology**

To uncover the exact question or problem our prototype would address, cultural probes and in-person interviews were used to define our concept (note: the pre-design research area). In turn, the prototype was defined (e.g. our Quality of Life Timeline), and it underwent further iterations and refinements using patient input and user testing (design research/ design area).

The cultural probes included various online and offline behaviors to evaluate what teens might use such as journaling (i.e. blogging), texting, and photo-documenting in a PHR. Some activities assessed the capability of teens to follow directions, which could influence how we designed and built our prototype. For instance, one probe directed the teen to interview a parent and ask him or her, “what animal do you think you most

resemble?”. Other activities were open-ended to allow self-exploration and interpretation into a topic or theme being put forward by an activity or probe. These probes often were introspective and focused on evoking ideas and concepts that teens would want to share with others. Examples of tasks include listing life goals or mapping out their future by the time they turned 21. (Figure 2: assortment of probes)



**Figure 2 Assortment of Cultural Probes**

Cultural probes were activities to help evoke ideas to help define the concepts we would pursue regarding teens and personal health records. Each teen performed at least 3 activities from a total of 7 available. (From center and then working clockwise from 12 o'clock) What did you feed yourself today?, Map your social tree, Map your road to the future, Make your mix, 5 tips on wellness, Where's my info, and Mojournal. For a full description of each, see LIVING PROFILES, Project HealthDesign website.

The patient population studied were teens with potentially severe chronic genetic hematologic disease (e.g., hemophilia) and chronic rheumatic disease (e.g., juvenile arthritis, systemic lupus erythematosus). Use of these two patient populations allowed assessment of whether onset or type of disease (hereditary and acquired disease) resulted in differences and whether prototype direction needed to be altered by disease onset. Probe information and interviews were qualitatively analyzed and interpreted to define the problem that the prototype should address.

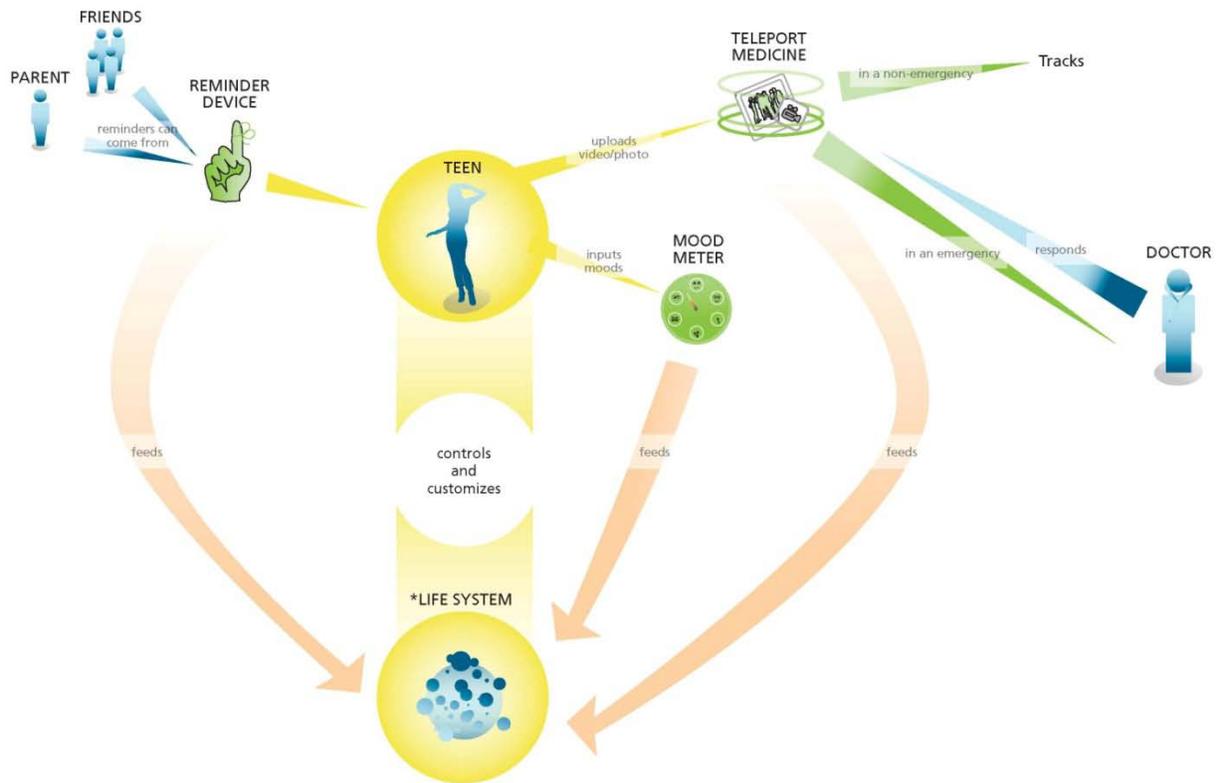
Our initial cohort consisted of a total of 31 teens who underwent assessment with the cultural probes. Of these, 11 underwent interviews, and 8 brought a “healthy” friend to help encourage discussion during the interview process. Through analysis of the cultural probes, key findings were identified that lay the foundation for concepts of our PHR prototype. For instance, teens were capable of collecting and documenting their emotional state through drawing, texting, blogging and photo-capture (see figure 3); they

focused on their futures in spite of their condition; often not including their medical condition when they were inquired about concepts surrounding health and wellness; and lastly, they articulated their appreciation of the assistance, guidance and love caregivers (especially parents) have provided, including helpful reminders about their care and their health (although teens did not want someone nagging them). Teens find that social and peer interaction are crucial to how they identify themselves, and it is this sharing of information— whether they be stories, ideas, pictures, or music— that enriches their experiences with their friends and family and helps create and define their identity.



**Figure 3**  
**Cultural Probes**  
**Examples**  
 Future map to age 21 (above) reflects this teen's perceived goals, obstacles, and life events including college, temptations, and travel. Personalize your health record (below) shows this teen placing his activities and achievements as the 5 important pieces of information to share with his doctor regarding health and wellness (note- no mention of his chronic condition in his images).

In culling through these ideas and data abstracted from the teens, we defined our main prototype concept for Living Profiles: the Quality of Life Timeline (QLT). The QLT will comprise many elements that make up a teen's life, incorporating not only health and medical issues but also the teen's important social and life goal elements. In addition, teens had expressed the importance of incorporating into their PHR more features and unique characteristics of themselves that they cannot always talk about with words or questions during clinic settings. The teen becomes the focal point of the PHR and has the control of the information that is being shared with anyone who may want to review it (Figure 4).



**Figure 4 Systems Diagram for Living Profiles**

Living Profiles, with its various modules for the Quality of Life Timeline (QLT) that includes the Mood Meter, Teleport Medicine, and Reminder Device, places the Teen as the central figure in charge of this information. By providing these data streams to the patient and incorporating items found in a conventional electronic medical record, this allows the teens to learn more about themselves and how to track their health and wellness, opening new opportunities of discussion with health providers.

To address how this QLT would function, we are developing a secure, online calendar-based timeline application aggregating multiple data streams, including personal interests, goals, journaling, images, and events, as well as elements of a traditional electronic medical records existent in doctor's offices or hospitals. An essential aspect of this application will be that teens are able to modify and change the appearance of their QLT and control sharing of information with different individuals. This prototype incorporates data collected from a mobile device such as a cell phone, as our research and others have shown its importance in teens' lives. In assessing what would be most useful and wanted by teens in the QLT, we proposed the development of 3 initial applications to pursue: a mood meter, teleport medicine, and a reminder device. Each of the proposed data flows we envision can be a "stand-alone" module designed to require minimal effort for the teen to increase the ease and usability.

The **Mood Meter** is a tool for teens who would like to see their mood trends in the context of their life goals and daily activities as a way to understand how to better manage their health and wellness. At this time, the mood meter is our first focus of development for our working prototype. So much of teens' behaviors reflect their mood, which in turn, may provide a glimpse about their health state. Using a typical teen activity such as text messaging, we will determine if frequency of texting and the frequency of individual word use in text

communications can be a catalyst for making mood/event associations and over time establish a mood pattern of how teens are feeling (i.e. anger, stress, happiness). The results are displayed using an interactive tool, allowing teens to explore and reflect how their mood and condition interplay with other elements of their lives and may alter their behaviors such as adherence with medications, fatigue, resilience and coping.

### ***Mood Meter System Characteristics***

#### **Capture A**

- Volunteer capture of teen's texting messages that are sent by mobile phone.
- Only sender's messages are captured in a database located on a secure server.
- An application that has algorithmic capability to visualize words in cloud formations that illustrate frequency over time. Clouds provide a quick look at what nouns, verbs, and adjectives the user is using whereby giving clues to the relationship between moods and activities.
- Word clouds populate the QLT.
- The QLT provides context of teen milestones and goals, health events, and medication.
- Viewable on browser on any web-enabled device.

#### **Capture B**

- Publish mood for public/friends through API (Facebook or other social page)
- Additional intentional change mood through phone using emoticon or words to publish mood
- Ability to create custom emoticons
- Viewable on browser on any web-enabled device
- Archived historic view possible
- On/off sharing feature (for example friend can automatically receive shared mood)
- The same application as Capture A has capability to visualize words in cloud formations that illustrate frequency over time whereby giving clues to the relationship between moods and activities.
- Word clouds populate the QLT.
- The QLT provides context of teen milestones and goals, health events, and medication

The **Reminder Device** is conceived to be a small object that resides in the teen living space and is represented in our scenario video created as part of this project. The actual creation of this module is planned for future development. In direct response to our qualitative research that teens want a reminder to take their medication from their mom or from someone who cares, the reminder device provides the means for a reminder to be sent to the object thus changing the color of the light emitted from the object. For example, mom can set up a discreet reminder system to take medication by sending the color orange. Once the teen acknowledges the reminder by waving a hand over the object, it returns to its calm state – the color blue. There is a memory feature to the device that when turned on the colors (sent by friends, family, and care givers) will rotate through a day, week or month to create a light show representing social interactions for that time period. We do foresee that the same features of the reminder system potentially could be a component added to a teen's existing mobile phone such that it functions in the same manner as the object as described above. In this instance, when mom sends an orange reminder the message is

automatically sent to both the object and the teen's phone. The phone receives color as photo or may glow a color depending on technology.

### ***Reminder Device System characteristics***

Functionality provided to end users:

- Ambient object glows a color (e.g. blue) in its clam state.
- Light-emitting diodes enable the device to glow a full spectrum of colors.
- Parent or someone in close social network can send reminder via mobile phone or email and change the color (e.g. orange). The teen user may assign a unique color to each person with the network.
- Teen acknowledges reminder through gesture (e.g. wave hand over device) and triggers the device to return to its clam state
- In the future reminders may expand beyond colored light and include text and music
- Teens make create "reminders to self" by texting to system – the reminder will display on device as a color and on the phone as color and text.
- Teen may also sync any daily reminders from QLT calendar (e.g doctors appointments) to mobile phone via Bluetooth
- All reminders are captured in a PHR secure database that populates the QLT UI.
- All reminders on the ambient device can replay by day, week, or month and create a personalized light show of the teen's social network. Color patterns will reveal who is reminding most and when.

**Teleport Medicine** is a methodology whereby teens with chronic conditions can post and communicate via mobile phone (text, photos, video) health events that occur in the field in real time to their caregivers. This actual application will be built in future development. The scenario video, created as part of this project, demonstrates how teleport medicine would facilitate communications between patients and practitioners who are miles apart from each other and are allow for troubleshooting without needing an actual encounter. We believe it is inevitable that video streaming (likely from mobile phone technologies but may also be from web cameras) will provide a critical interface for emergency situations as well as a more immediate monitoring for symptoms such as rashes or swelling. We envision that teens will be able to send video or still images to the clinic in the case of a health event or accident. Doctors will be able to respond via text and/or voice. All communication will be archived in the patient's PHR and EMR.

### ***Teleport Medicine: Video Blogging and Text Messaging characteristics.***

Functionality provided to end users:

- Secure blog environment for easy posting of mobile phone content: photos and video
- Trauma/event occurs and teen sends video/photo via mobile phone (time stamped and automatically is archived in EMR)
- Doctor/liaison responds via texting to teen's mobile phone (time stamped and archived in EMR)
- All is captured in a private blog space that sends data to secure PHR database server. From the server data populates the QLT UI.
- Teen blog input is viewable on a browser on any web-enabled device. Images/text also viewable on teen's mobile phone
- Zone for notations is available in QLT for physician and teen.

Through this aggregation of different information flows, the QLT should facilitate better communication between teens and providers. In addition, teens may use it to self-reflect about information they have collected and see various connections they would not otherwise visualize without the assistance of the QLT. For example, they may evaluate how their mood on a given day relates to their activity level, medication intake, or personal activities. The QLT packages important information in a compact, streamlined way, which can be used to share with their providers even when they transfer to a new practitioner. Through this process, we hypothesize that teens will be more successful with transition and the transfer to an adult provider as they will have gained insight about their lives, not only from a health standpoint, but also by learning to be more independent and skilled at integrating all of life's goals and barriers. To convey this experience, a video was developed as part of this phase to demonstrate the potential uses of the QLT in a teen's interaction with her physician.

### **Working prototype and CP**

We did not do an actual build of the working prototype during phase 1. Issues arose with changes of the principal investigator role at ACCD and the ability to provide continued future commitment to the project was jeopardized. We did find the opportunity to transfer the project to one of our other sites, allowing us to sustain the project but resulted in some delay in the design and development beyond the concept prototype we proposed. No programming was done for the working prototype during phase 1, and so we did not integrate into the CP. Regardless, we did outline ideas for the integration and identified potential areas we would be using the core components.

#### ***Did the project encounter internal or external challenges? How were they addressed? Was there something RWJF could have done to assist you?***

The gap between the cultures of design and medical research led to both challenges as well as creating an intensely fertile interactive space for cross-fertilization of ideas. Key challenges included:

- Getting designers acclimated to rules surrounding research with human subjects.
- Getting medical researchers acclimated to design methodology and accepting of its difference in approach from traditional health research techniques.
- Getting software engineers to learn to be more creative in their approach and understand how the nature of the project was to be open-ended and future thinking.
- The main IRB used for the study was an external IRB which placed unusual demands on ACCD. In addition, the subcontracting institutional IRBs at Stanford and CHOC were involved, each with its own expectations and guidelines for research with teen human subjects, technology, and qualitative research.
- Variability in involvement of the different partners depending on the stage of the project, where some needed to take lesser roles and eventually having contracts with some original partners terminated once we understood better the project direction.
- Original PI leaving ACCD, requiring replacement with another PI from ACCD. Inability for project continuation at ACCD, resulting in eventual project transfer to the PI at Stanford (Christy Sandborg) around phase 1 completion.
- Long distance collaborations were handled well but still represented some level of complexity and challenge.

The design workshops held by RWJF at Vanderbilt Center for Better Health were very helpful in coalescing the concepts and principles of the project by the key members of the team at specific intervals. They helped us open up the dialogue with other grantees as well as within our team as we did not always have many opportunities for face-to-face interactions otherwise. Additionally, RWJF and the NPO were extremely helpful and understanding about the issues including the PI changes, assisting in dealing with terminating subcontracted collaborators, and providing support systems such as the ELSI team to help deal with IRB questions.

***Has your organization received funding from other foundations, corporations or government bodies for the project RWJF has been supporting?***

None during phase 1.

***When considering the design and implementation of this project, what lessons did you learn that might help other grantees implement similar work in this field?***

Preconceived notions held by the medical providers about the important components for a personal health for teens (and probably also any other group) were consistently distorted or completely wrong. For instance, we had originally focused on using family health histories as the entry point for our teens to deal with building a PHR and none of our teens felt this was pertinent. Using the non-judgmental, open-ended, creative and engaging approach to eliciting core beliefs and expectations using design methodology was essential to the success of this project. Doing so allowed us to uncover the importance of social interaction and connectivity to friends and family in teens' lives, which was also important to what they wanted to show and share with their health providers. Designing the applications around the end-user and iteratively test/retest the application with the end-users will allow the best (and most usable) product to be developed.

***What impact do you think the project has had to date? Who can be contacted a few years from now to follow up on the project?***

Please see transition phase final report for more details. We were able to meet with liaisons from Congress to open up the discussion about PHRs and their importance in concepts such as self-management and transition care for patients with chronic childhood-onset diseases. Through the facilitation by PHD, new opportunities have arisen with possible collaborators (industry) and working with other grantees.

The teen participants have wanted to learn more about the eventual follow-up regarding their participation and how they may have influenced the new age of health tracking for young people through technology. They are keenly interested in further participation and the results and findings of all the activities in which they have participated.

LIVING PROFILES transferred over to Stanford after completion of this phase. Contact Christy Sandborg, MD [sandborg@stanford.edu](mailto:sandborg@stanford.edu) and Peter Chira MD MS, [pchira@stanford.edu](mailto:pchira@stanford.edu) for any future questions.

***What are the post-grant plans for the project if it does not conclude with the grant?***

Through the funding from the RWJF Transition fund (\$50,000), the CHCF grant (\$25,000) and a generous gift from Johnson and Johnson International (\$95,000), we have been able to continue the creation of the prototypes that were designed in phase 1. Please see the Transition Funds Final Report for details.

***With a perspective on the entire project, what have been its key publications and national/regional communications activities? Did the project meet its communications goals?***

2 team members participated in the communications training sponsored by RWJF, opening up the concept of needing to have a clear message regarding the project and its goals. One of the goals of our communication plan was to open up the idea of using this type of multidisciplinary collaboration for other future health services research, as it generated new concepts and ideas for all of our own team.

Exposure from RWJF sponsored activities as well as poster presentations during national meetings have sparked interest in others learning more about our project, including contacts by industry and non-profit agencies.

## **BIBLIOGRAPHY**

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### Presentations

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Lisa Nugent, Sean Donahue, "Cultural Probes: Design and/or Science?" Design Research Roundtable, Art Center College of Design, Pasadena, moderated by Anne Burdick. November 2007.

Sean Donahue, Tina Park, "Cultures of Inquiry: Context", People-Centered Design Symposium, Humanities & Design Sciences, Art Center College of Design, Pasadena. March 2008.

### Reports

LP design report, May 2007

LP Executive Summary, May 2007

LP Prototype Documentation, September 2007

### Audiovisual

Video scenario (see accompanying CD)