I, Ricardo Elizondo Costa, hereby submit this original work as part of the requirements for the degree of Master of Design in Design.

It is entitled:
Lost In Transition: A Patient-Provider Service Framework to Improve Transitional Care

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Lost In Transition:
A Patient-Provider Service Framework to Improve Transitional Care

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Abstract

The transition into adult care is considered a major problem for young adults with chronic diseases. There is a greater expectation of independence from family members, and the style of care they receive from adult health services changes drastically from the pediatric level. Not achieving successful management of their disease and lack of personal goal setting has translated into increased mortality in chronic disease patients after transitioning to adult care.

This thesis presents the ethnographic research and design synthesis methods applied to the development of a custom service framework for pediatric health care providers caring for sickle cell disease patients in the process of transitioning into adult care. The framework focuses efforts of pediatric hospitals to increase patients’ independence in the areas of self-management, disease knowledge, education and vocation, social aspects of the illness and health insurance, in order to achieve successful control of their disease after their transfer to adult health services.

The project also describes conceptualization, evaluation and refinement of analogue and digital artifacts which provide a shared understanding of the transition process between sickle cell disease patients and care providers. These tools provide a space for care providers to share gathered qualitative information about patients which enables better decision-making in transitional care and helps co-relate clinical interventions to the patient’s specific needs.
Acknowledgements

Special thanks to my thesis committee Steve Doehler, Craig Vogel and Heekyoung Jung, for their advice and support in the completion of this thesis, and providing much valuable experience.

To Linda Dunseath from the Live Well Collaborative, Lori Crosbi, Naomi Joffee and the rest of the Cincinnati Children’s staff for allowing me to pursue this project and providing their continuous support and expertise.

Special thanks to Ashley Walton for leading the summer project and for being so passionate about the subject. Also, to my other two Live Well co-workers, Alexandria Wolfe and Rachel Lee for being so talented and making this project possible.

To my classmates and friends from the master of design program, I could not have done this without all of you and I will miss all of you.

Finally to my family for all their love and encouragement and to Tefy, the love of my life, for believing in me, supporting my dreams and enduring with me these two years.
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Introduction

This project is a result of a nine month interaction with health care providers and young adult patients (17-22 years old) with sickle-cell disease, with the purpose of developing solutions to increase the success of transitioning from pediatric to adult care in young adults with sickle-cell disease. It started as a collaborative project between the Live Well Collaborative (LWC), a non-profit specializing in research and development, and Cincinnati Children’s Hospital (CCH), a pediatric and research healthcare institution. The LWC set up a team of two designers and two student designers, with backgrounds in graphic, digital, product and psychology, in order to develop three patient-provider tools that addressed the current existing problems during transition.

The design team went through a process of exploration and conceptualization involving secondary research around the subject. Primary research was conducted, consisting of interactions with patients with sickle-cell disease, and care providers and researchers from CCH, in order to understand the problem, the actors and its context. The team also worked with the researchers in co-creation activities to find solutions around the different problems observed. This process resulted in the re-framing of the projected objective from three tangible tools, to a personalize-able service framework, a co-creation tool to build the service with stakeholders using the new framework, and the design of a patient–provider touch point where
they could have a common understanding and management of the transition process at their respective comprehension levels.

Concepts were developed using the new objective and at the end of the project were presented to CCH. The concepts included: a the service framework, a set of cards used as a co-creation tool to build the service, and two analogue patient-provider tools used to interface with the service. This thesis continued the project by going through a process of refinement where the co-creation tool was implemented with care providers, developing the service under the proposed framework. With that information the patient-provider touch point was made into a digital interface and developed further through many iterations.

The results of this project present a systemic solution which can enable successful outcomes in sickle-cell disease patients transitioning into adult health care. However, the same framework is scalable into any kind of transitional health care services, or even other kinds of developmental changes, not necessarily related to health care. It also shows the impact that design can have in intangible products such as health care services through the way designers synthesize information, use abduction to generate ideas, follow a non-linear process and rapidly prototype and evaluate complex solutions.
Chapter 1
The Issue

Transitioning from Pediatric to Adult Health Care

The transition from pediatric to adult health care is a major problem for chronic disease patients. There is currently no standard of care in the United States, which states the service requirements for transitioning, even though there are studies which claim that, knowledge of their illness, communication with providers, ability to set life goals and navigate the medical system, are essential for a successful transition (Dickerson et al., 2011). From a health provider’s perspective, a successful transition is a planned process which begins long before the actual transfer to adult care. Pai (2011) mentions that due to “the dynamic nature and complexities” of transitioning, it is very hard to pinpoint an exact age where this process should begin.

Children’s hospitals in general use age instead of considering the proficiency in the previously mentioned areas and transfer patients between the ages of 18 and 21 (Dickerson et al, 2011).
This transition occurs at the same age range when they are becoming adults and gaining personal independence in managing their health care responsibilities (Annunziato et al., 2007).

![Diagram showing percentage of deaths due to SCD vs. Age at death by age group in 2006.](image)

*Figure 1 – Percentage of deaths due to SCD vs. Age at death by age group in 2006. Age range when health care transitioning occurs is shown in red. Constructed by cross referencing data from Hassell (2010) and Annunziato et al. (2007).*

It has been observed among different chronic disease populations that during this stage there is a substantial decline in their adherence to treatment (Pai & Ostendorf, 2011). It is after this transition that mortality rates in sickle-cell disease begin to climb as shown in Figure 2, where the transfer age range mentioned by Annunziato et al (2007) is overlaid on a graph published by Hassell (2010), which compares SCD death rates vs. age group. This graph shows that even though the highest mortality in 2006 occurred between 35 and 44 year-olds, the transfer age range corresponds with a drastic rise in SCD deaths.
Sickle Cell Disease

Sickle-cell disease (SCD) is a genetic blood disorder where red blood cells deform into a sickle-like shape and their flexibility is reduced, resulting in a series of complications and shortened life expectancy (Chen & Zieve, 2012). There are approximately 50,000 people with sickle-cell disease in the US, primarily of African descent, and they experience acute pain crises and infections on a general basis, as well as other symptoms caused by cardiac, pulmonary, and renal complications as shown in Figure 1. SCD causes pain crises that require using synthetic opioids, like Oxycodone, and often need hospitalization. Treatment includes pain relief, antibiotics, and lots of fluids (Steiner & Miller, 2006). Some patients can experience small strokes, which result in slight cognitive delay and confusion. These issues affecting the brain may be so subtle that they are not easily perceived by family and require a diagnosis from a specialist (Chen & Zieve, 2012).

Figure 2 - Complications and effects of sickle cell disease in the body. Created by Alexandria Wolfe
Chapter 2
Exploratory Phase

During the data gathering phase of the design process, the team progressively acquired data from medical and psychology journals, contextual interviews with SCD patients, group interviews with care-providers, and from additional seemingly unrelated sources and topics. The team became completely engaged, both cognitively and affectively, with the world of sickle cell disease, transitioning to adult clinics, the patients and the hospital staff caring for them.

Research Scope

During a span of 8 weeks the research team targeted fifteen Sickle-Cell Disease (SCD) patients, between the ages of 17 and 22, in the process of transitioning to adult health care, from Cincinnati Children’s Hospital in Cincinnati, Ohio. Due to inconsistency in attendance to their appointments, only eight could be engaged. The care-provider team from the hematology department was also approached, which included hematologists, social workers, case manager, school interventionists, psychologists and nurse practitioners. There were also multiple
interactions with the Innovations in Community Research and Program Evaluation team (INNOVATIONS team) from the children’s hospital. Most of the interaction with patients and care-providers occurred at the Cincinnati Children’s Hospital, University of Cincinnati Medical Center, and with the INNOVATIONS team in the offices of the Live Well Collaborative. Different qualitative research methods were applied in order to gather data from the patients’ perspectives, care-providers’ perspectives and from literary sources.

Research Methods

**Secondary Research:** Consisted of a literary review of academic papers, articles and books directly related to the subject of the design problem and which could be used to corroborate primary research data. It included topics like: transitioning to adult hospitals, symptoms of sickle-cell disease, and self-management in patients with chronic disease.

**Indirect Secondary Research:** This consisted of a literature review of books and articles unrelated to the problem, but which could create new connections during the synthesis phase and provide a new perspective on the issue. Topics in the indirect secondary research included using games in order to motivate behavior and how humans create understanding through narrative.

**Ethnographic Interviews:** Consisted of understanding patients’ actions and experiences from their own perspective and in the context where they are realizing the activities.

An interview guide was created based on the information gathered from the secondary research and initial stakeholder feedback. The topics for observation and interviewing in the guide included: Sickle-Cell Disease patients’ (1) Everyday lives with the disease. (2) Experience with
pediatric care and adult care. (3) Health management skills. (4) Goals and aspirations. (5) Attitudes towards transitioning into adult care. (6) Care-providers’ roles and activities with the patients. (7) Affective relationships developed between patients and providers.

The questionnaire in the interview guide was designed to be open-ended and exploratory. It served more as a loose guide than a rigid structure since many follow-up questions were asked as a direct result of answers and comments made by the interviewees. Two members of the design team took part in the ethnographic interviews, one as the interviewer and the other as a documenter. They were accompanied by a staff member from the children’s hospital that was familiar with the patients and would introduce them. The interviewers would explain to the patient, care-providers and people involved the purpose of the interview. The interaction was structured as a conversation with initial questions unrelated to their disease in order to create a sense of comfort and familiarity for the patient. Audio recordings of the interactions were made and transcribed, with the knowledge of the participants.

Two of the younger male patients (17 and 18 years old) were interviewed and shadowed together with their mothers at their routine appointments at the children’s hospital. A male patient (21) was interviewed and shadowed together with his wife and two children during his transfusion appointment. One female patient (21 years old) was shadowed and interviewed during her first appointment with her new hematologist at the adult hospital. The care-providers and INNOVATIONS team members that the patients interacted with during their appointments were also engaged and observed.

After each interaction, the research team would debrief to discuss what was learned, what information was missing and how it was going to be acquired.

Interviews: The information that could not be acquired from the ethnographic interviews was later covered in follow-up interviews. Three older patients (21, 21 and 22 years old) who had
already transferred into adult care did not participate in the ethnographic interviews; however, the same questionnaire developed was also used to interview them. They were conducted in a private room at Cincinnati Children’s hospital without intervention from care-providers and outside of the medical appointment’s context. Two members of the design research team took part in the interviews, one as the interviewer and the other as a documenter. Audio recordings of the interactions were made and transcribed, with knowledge of all participants. After each interview the research team would debrief to discuss on what was learned.

**Group Interviews:** There were six group interviews with the INNOVATIONS team in between the patient interviews. These interactions were conducted in the offices of the Live Well Collaborative. The participants included eight members of the psychology department and research assistants who had interacted with patients and had knowledge of sickle-cell disease (SCD) and transitioning to adult care. The psychologists had treated and interacted with the care-providers involved and with some of the patients and had the technical expertise on things like medication, treatment and management of the disease. The group interview dynamic consisted of the research team presenting findings from the patient interviews and asking questions about them. The INNOVATIONS team would provide additional technical information on the subject to corroborate the findings or provide a care-provider’s particular perspective on anecdotes from the patients.

One group interview was conducted with the members of the *Sickle-Cell Disease Transition Team* from the children’s hospital, which included hematologists, social workers, school interventionists, psychologists and nurse practitioners from both the children’s and adult hospital. Interaction occurred in the SCD Transition Team’s conference room in the hospital. An interview guide was created for these interactions based on the information obtained from the secondary research and interactions with patients.
The topics of the interview included: (1) *Clinical experience of having SCD.* (2) *Role of providers in care-management* (3) *Nature of patients’ relationship with the care-providers.* (4) *Relationship and communication between teams within the hospital, and between hospitals.* (5) *Perceptions and attitudes about transitioning.*

After each group interview the research team would debrief to discuss what was learned.
Research activities obtain large amounts of useful data, which seems unrelated, overwhelming, and difficult to understand. Jon Kolko (2010) mentions that through synthesis designers “attempt to organize, manipulate, prune and filter gathered data into a cohesive structure” which will translate into design principles to guide ideation. Designers scrutinize the data gathered, look for relationships, classify them into themes, and abstract specifics into generalities; all this while relating it to the problem at hand. (Kolko, 2007, 2010)

It is important to mention that due to the non-linear nature of the design process used in the project, the synthesis phase directed the exploration phase as much as the research obtained fed synthesis; and both started almost simultaneously. For example, themes were created from the data gathered in the initial literary review and through conversations with the INNOVATIONS team, by finding relationships and prioritizing the important data. These themes were used as a basis to develop the interview guides used during the exploratory phase. Visualizations of the data obtained during the exploratory phase were presented to the INNOVATIONS team in order to obtain their perspective and fill in information gaps, achieving another cycle of analysis and synthesis.
Sense-making

The design team, working on developing tools to help SCD patients transition, needed to create new connections, filter and organize the data into themes and design objectives; however, the amount of data gathered was too large to be able to mentally visualize all at once, and the team needed to create a common understanding of the problem and the information being generated. This required the data to be visualized through diagrams and pictures which allowed for better comprehension of the ideas gathered. The designers who created this imagery were able to better understand the data and communicate it to the rest of the team. Thanks to these, the design team needed less mental effort to create connections between seemingly unlinked pieces of data and produce knowledge. They also served as an objectivized reference that would provide a common direction for the team.

Examples of visualizations created during synthesis activities, included a sketch of a kid in the middle of crossing a bridge (shown in figure 3), where one side had a lot of structural beams, and the other side had very little, and the weakest point of the bridge was the middle where the kid was trying to cross. This visualization became a metaphor which summed up the design problem. The side of the bridge with structural beams represented the children’s hospital, where Sickle Cell Disease patients have a lot of support from care-providers. The side of the bridge with no structural beams represented the adult hospital with less support from the system and with a different style of care. The weakest link in the bridge depicted as falling apart symbolized the transition point between pediatric and adult care, where the death rate among SCD patients begins to increase dramatically.
The kid is shown preoccupied and hesitant to cross to the less supported side, representing SCD patient’s negative attitudes towards transitioning. This diagram was a way to sum up the data gathered to that point; it zoomed out and showed the design problem through a lens of simplicity and storytelling and gave the design team a common understanding of the problem.

Figure 3 – Visual metaphor of the design problem

Figure 4 shows a visualization of the transfer process that all SCD patients at Cincinnati Children’s Hospital go through in order to transition into adult care. This was made in order to dissect the steps and see which care providers were involved in which steps of the process. The design team was able to better understand the patient’s journey through the current transition process thanks to this, and it helped to visualize which additional data needed to be obtained through further research. This representation gave comprehension of the process’ complexity due to the involvement of so many different stakeholders.
Another visualization used to sum up the data gathered and which aided in design synthesis is Figure 5 which shows the effects of sickle-cell disease in the body of one of the patients, the different complications that SCD brings, as well as the location and intensity of pain. It also showed which management strategies the patient was doing and medication used. This representation was created for each one of the patients that interacted with the design team.
Another example of a visualization created to help with synthesis were the individual patient concept maps, where the data obtained through contextual interviews was classified into different themes (shown in figure 6). These diagrams allowed designers to find semantic relationships in the data gathered from each patient and between patients. In this case, information was classified into the themes of: family, envisioning the future, self-management, attitudes towards transitioning, daily life, interactions with care-providers and social aspects of SCD.
Audio Visual Storytelling with Personas

Through diagrammatic reasoning, the design team was able to make sense of the data gathered and find semantic relationships. These were very useful from a practical perspective; however, they were missing the emotional part of the patient’s experience, and did not provide an easy way to communicate empathy with them. This is where Audio Visual Storytelling and Persona Definition came into place with the purpose of building empathy, defining direction, structuring the knowledge generated during synthesis and inspiring future ideation. (Kumar, 2012)
A profile was built for each patient using the themes from the concept maps and information from the SCD Effects on the Body and Pain Management Diagram. Common attributes were clustered into the three different personas, shown in table 1.

Table 1 – Attributes used to generate Personas

<table>
<thead>
<tr>
<th></th>
<th>Persona 1</th>
<th>Persona 2</th>
<th>Persona 3</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Quote</strong></td>
<td>“I'll be fine... and I don’t really have a choice.”</td>
<td>“They want me to be ready, but I'm not ready.”</td>
<td>“I wish my nurse could have transitioned with me.”</td>
</tr>
<tr>
<td><strong>Attitude toward</strong></td>
<td>Negative (because of stories about Emergency Room)</td>
<td>Negative</td>
<td>Negative (Attachment to care-providers at children’s hospital)</td>
</tr>
<tr>
<td><strong>Transitioning</strong></td>
<td>Motivated by managing his disease the best he can. “I’m on my game.”</td>
<td>Plans to go to college and own his own business.</td>
<td>Wants to be a nurse and works at the children’s hospital.</td>
</tr>
<tr>
<td><strong>Envisioning the Future</strong></td>
<td>High</td>
<td>Low (because of parent)</td>
<td>Low</td>
</tr>
<tr>
<td><strong>Self-Management</strong></td>
<td>4-6 (Pain and seizures make him feel weak)</td>
<td>1-3 (No short-term feedback as incentive to take medications)</td>
<td>7-10 (Has to take many medications)</td>
</tr>
<tr>
<td><strong>Pain Rating</strong></td>
<td>High (Positively affects self-management)</td>
<td>High (Negatively affects self-management)</td>
<td>Low (Goes alone to appointments)</td>
</tr>
<tr>
<td><strong>Family Support</strong></td>
<td>None</td>
<td>None</td>
<td>Affection to nurse (Replaces family support)</td>
</tr>
<tr>
<td><strong>Attachment to</strong></td>
<td>None</td>
<td>None</td>
<td></td>
</tr>
<tr>
<td><strong>Care Providers</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Personas were a helpful tool in order to create cognitive empathy, however in order to communicate affective empathy, designers used Audio Visual Storytelling (Appendix 1) to externalize the design problem in an emotional way. The personas were turned into the
characters and used imagery, music, and audio quotes with an expressive voice tone recorded from the patients to tell a story. It shows a day in the life of the patients, when they have to go their first appointment at the adult clinic. Each persona is at a different stage of the journey and forming the whole story.

The purpose of combining Persona Definition with Audio Visual Storytelling was to humanize the issue by making it about the experience and life of the patient, rather than focusing just on individual problems. It created a lens of the patients’ experience to use while ideating solutions.

Important Findings

Based on the exploratory and synthesis phases, the design team found that every sickle cell disease patient is different; not only in their personal lives, aspirations and motivations, but also in the way the disease affects them and the pain that they feel. For example, some patients may have cognitive problems that affect their management skills, while others do not.

Pediatric care’s environment and style of care is very different from adult clinics. Patients are afraid of the adult ER due to stories they’ve heard and personal experience, but this system is not something that can be easily changed. Therefore, patients need to be independent in how they manage their disease, instead of relying on the system changing to accommodate them.

There are other aspects that affect a SCD patient’s health after transitioning, besides self-management skills and knowledge of their disease. They require good personal and professional goal setting, managing their insurance, and dealing with their disease on a social level. These are things that may affect a patient’s health in the long term.
If patients stop doing essential things to manage their disease, like taking medication or special precautions, they will not feel the effects of this until months later. A result of this is the lack of short term feedback to create motivation. There is a lack of short term motivation in many patients to comply with their health management.

Some patients have high expectations of their future, but they do not see a connection between good self-management and being able to achieve this future, while other patients that do see this connection have good self-management skills. This led to possibly helping patients create a link between the futures they envision for themselves and their self-management skills.

Parents are essential for patients to learn to deal with their disease, but too much parental involvement is just as negative as too little involvement. Parents need to slowly phase out of their children’s management in order to empower them.

Some patients have affective relationships with care-providers since they have known each other since the patients were children. This created a bond that makes many patients not want to transfer to the adult clinic where they will not interact with the people they care about. What if these relationships could be used positively for motivation?
Chapter 4: Generative Phase

The generative phase was divided into two sections: In the first one, ideation was done with stakeholders through co-creation sessions. In the second one, the design team built upon the results of the co-creation session and clustered concepts into solutions.

Besides being part of the generative phase, the co-creation sessions were also used to observe the Innovations in Community Research and Program Evaluation team (INNOVATIONS team) from Cincinnati Children’s Hospital interact and generate ideas as a team, which led to new insights. Also, new problems were extracted from the ideas they generated which had not been observed during the exploratory phase.

Co-creation Sessions

Two distinctive activities were planned for in order to generate concepts through co-creation sessions. Both activities involved the members of the INNOVATIONS team. The purpose of having these co-creation sessions was to combine people involved in the project from different
backgrounds; the INNOVATIONS team had graduate students, research assistants and fellows with backgrounds in psychology and community medicine while the design team had backgrounds in digital, graphic and industrial design. Both teams had interacted with the patients and care-providers, and were aware of the research done during the exploratory phase, and the INNOVATIONS team had previous experience with the patients and knew the capabilities of Cincinnati Children’s Hospital.

**Focused Ideation Session based on Findings:** The first co-creation session consisted of ideation structured around the findings generated during synthesis. The purpose of this session was to generate as many concepts as possible and not to evaluate the ideas. A member of the design team acted as moderator and would choose one of the opportunity areas, and describe the insights that led to create that opportunity area and included examples of quotes and anecdotes that supported that insight. The team, which consisted of twelve people in total, was split into six groups of two who would ideate upon the opportunity area presented for seven minutes, trying to generate as many ideas as possible. Each pair had post-it notes to write on.

After the seven minutes were over, each team presented their ideas while the rest of the teams would build unto them using a “yes and…” statement as a starting point. Another member of the design team acted as a recorder registering the ideas presented. The session lasted an hour and a half.

**Systematic Inventive Thinking Session on the Original Transition Process:** The second co-creation session consisted of applying Systematic Inventive Thinking (SIT) tools to the process that was being used at Cincinnati Children’s Hospital to transition to adult care. SIT is a thinking method used for generation of new ideas. It works by creating a hypothetical solution first and then finding the problem which this solution may solve, this is opposite to the first co-creation session which started with opportunity areas derived from observed problems.
SIT was developed by analyzing creative ideas (products, services, strategies or communication activities) and finding patterns in them. Those patterns then became the thinking tools used to generate new ideas. The process consists of breaking down the current idea into its components, which in case of a service is broken down into its steps. Then one of the thinking tools is applied to the dissected idea (Goldenberg & Mazursky, 2002).

Goldenberg and Mazursky (2002) mention the five SIT tools as:

1. Subtraction: This tool consists of removing an essential component and find uses for the new envisioned arrangement of components. If the new arrangement does not work, then the subtracted element can be replaced by something else, normally using the closed world principle. This principle refers to the elements that already exist in the product, system or process, or in the immediate environment.

2. Multiplication: One of the components is repeated one or more times and relocated in the process, but the new components must be changed in some way.

3. Division: In this tool one of the components is taken out and repositioned in the process, or one of the components is physically divided and its new part is also repositioned.

4. Task Unification: A new task is added to an existing component in addition to the one that it is already doing. The task can be concrete and related to one of the components in the process, or can be a desired abstract task external from the component list.

5. Attribute Dependency: Is about creating connections between attribute variables of the process or product. Variables such as color, size, material, gender, time, etc. A matrix of these variables is created where they are paired against each other; each cell in the matrix represents a possible connection between variables or a possible disconnection if there is already an existing link.
In the co-creation session using Systematic Inventive Thinking tools, the design team and INNOVATIONS team used the information obtained from the Visualization of the Current Transition Process created during the synthesis phase (figure 7), which had already divided Cincinnati Children’s current transition process into its components. Both teams, which consisted of twelve people in total, were split into groups of two. One of the members of the design team, who played the role of moderator, would explain the steps needed to apply a particular SIT tool to the process. Each pair would apply the tool to a randomly chosen component, and for seven minutes try to generate as many ideas as possible.

After the seven minutes were over, each team presented their ideas while the rest of the teams would build unto them using a “yes and…” statement as a starting point. Another member of the design team acted as a recorder registering the ideas presented. The session lasted an hour and a half.

Figure 8 shows an example of the division tool, used by one of the pairs during the session. In this figure, the last step of “patient is tracked for one year” was moved to the beginning of the transition and a new “virtual” process was created where patients are tracked for one year at the beginning of the process, instead of post-transition.
Based on this the pair started to come up with the following idea: *The care-providers would be able to modify the transition process based on the results from the initial tracking and offer a personalized service.* This idea was later used and built on, and had great repercussions in the project.

**Results**

Both co-creation sessions resulted in dozens of focused/specific solutions which could be developed further. Examples of these were:

- **A Transition Mentor Program:** Where patients shadow another patient’s first appointment at the adult clinic, they are also in charge of passing their knowledge and expertise down to their pupils.

- **Insurance Board Game:** Create a board game that would facilitate learning all the nuances related to patient’s health insurance. Patients would be able to see the repercussions of their financial choices through the game.
• Develop a series of steps for phasing out the presence of parents during appointments: Where Nurse Practitioners would set up boundaries for parents, and set up time frames for parent-less time with patients.

• Parent Tool-kit: A kit with tools for parent’s to teach their children with SCD about self-management and being independent.

Some of the focused solutions were similar to initiatives already being developed within the hospital or which were being already implemented by another department, but could be transferred to patients with SCD. All of the ideas were important and had a deep impact in the patient’s health and were relatively easy to implement.

The co-creation sessions also resulted in high level solutions, like the idea used as an example in Figure 8 where each patient is tracked and the transition process is redefined for each patient’s needs, or the concept of incorporating developmental milestones or goals, into the existing transition process. These would later be taken into account into the final solution.

Besides obtaining these solutions from the staff, the design team was able to observe the researchers from INNOVATIONS interact to come up with solutions. This led to the insight that through focused ideation sessions they could develop high impact specific solutions to specific problems, because they had a deep understanding of the patient’s lives, the disease, and the workings of the hospital; they possessed more knowledge than the design team could acquire during the project.

Due to the nature of Cincinnati Children’s as a research institution, there was a plethora of interventions already developed at other departments that could easily be translated or implemented by the hematology department dealing with transitioning patients.
This realization led to the question: How can we hone the creative capacity of a “wiser” staff to develop interventions and gather existing interventions and help CCH target them on individual patient’s needs? This question would re-direct the original objective of the project.
Chapter 5:  
Re-framing the Objective

A Service Framework

Based on the new insights after the co-creation sessions, the team started to conceptualize a solution that would take them into account. The team clustered several of the high-level ideas to conceptualize a new service framework for transitional care given to SCD patients. The service framework consisted of adding developmental milestones common across patients to their current transition process and extending so that it started at age 14. These milestones would be around the key areas identified during the exploratory phase; consisting of: 

*independence in health management,* *knowledge of the disease,* *education and vocation,* *social aspects of living with sickle cell,* and *insurance.* Personalization would be added through patient specific milestones and by having a menu of interventions which could be assigned if needed. Interventions would have the role of helping the patients achieve their milestones. These interventions would be gathered from applicable solutions already existing at CCH and from the ideas generated during the design project.
This new system would also use patient-provider affective relationships, in order to assign champions to the patients, who would serve as expert role models to motivate and guide them in the milestones. Cziszentmihalyi (1998) and McGonigal (2010) mention the importance of the challenge level of a task matching the skill level of the person performing the task, to achieve motivation. The interventions are a way to help patients so that their skill level matches the challenge level of the milestones he has to achieve.

The proposed framework led to the following design requirements. The design team now needed to solve how to populate the service framework with the necessary milestones for a successful transition and also with interventions which could enhance the patient’s ability to achieve the milestones. The addition of developmental milestones and interventions added a new level of complexity to the transition process, which care-providers had to be able to manage for individual patients during the eight years of the process. The information from the framework provided to patients had to be released to them only when applicable, otherwise it would be too overwhelming. Language also had to be modified to the patients’ comprehension level without affecting communication between providers. Based on this, the new objective was visualized in the diagram shown in figure 9.
A Co-creation Tool

A co-creation tool was conceived which would allow the care providers with the required expertise to populate the service framework with the required milestones, interventions and identify the staff responsible for the identified areas of independence in health management, knowledge of the disease, education and vocation, social aspects of living with sickle cell, and insurance.

The tool was proposed as a set of cards (shown in figure 10) where the care providers could write on and lay out to sketch different transition processes around individual patients’ problems, using their personal knowledge of the patients and hospital workings and the synthesis from the research conducted by the design team.
Three types of cards were conceived; first the Milestone cards which represented the developmental milestones required for a more successful transition. These cards had different sets of colors, which the design team and providers could assign to the individual areas of independence in health management, knowledge of the disease, education and vocation, social aspects of living with sickle cell, and insurance.

The next type of card was the Transition Step cards, which represented the current transition process which SCD patients at Cincinnati Children’s were following. The idea behind these cards was to enable the providers to play around with the current process using the Systematic Inventive Tools they learned during the previous co-creation session, in order to make the system better, or generate new interventions if needed.
The next type of card was the *Power-Up* cards, which represented the interventions being tried at CCH and the applicable solutions generated during the previous co-creation sessions. The name of intervention was changed to *Power-Up*, thinking into its application into the patient side where it could have negative connotations as “interposition or interference of one state in the affairs of another”, while a *Power-Up* is “an object that instantly benefits or adds extra abilities to the game character in a videogame as a game dynamic”. This type of card also had a space to write which providers were in charge of implementing a specific *Power-Up* when necessary, the language was changed from *Provider* into *Allies*, to also provide a more positive connotation. This change in language was incorporated in order to change patient perceptions of the different activities in the service. The use of this language would trickle down into the patient tool.

**A Care Provider Tool**

Next part of the new objective was a tool that allowed providers to manage the transition process for individual patients, by personalizing milestones and assigning interventions. Thinking that the providers would become familiarized with the card system of the co-creation tool, the care provider tool was conceived similar to the previous concept, as shown in *figure 11*. The same card types, colors and language were used to designate the *Milestones, Power-Ups, Transition Steps* and *Allies*. This tool would be used after the service has been defined through the co-creation tool, and would be used to collaboratively lay out each patient’s transition process based on their individual needs. The size of the cards was increased in order to enable discussions between providers from different areas.
Allies, Providers which have a stake in the area that the milestone belongs to, who are backing a specific Power-up, or who a part of a Transition Step, are represented in smaller Ally cards under the card they are supporting. An Ally who has an affective relationship with a patient, may be assigned as their champion. For example, if a nurse practitioner has known a patient since he was 5 years old, and the patient looks up positively to her, the nurse practitioner would be assigned as the patient’s supporter in the areas of health management and disease knowledge which are related to her job. If a researcher is testing the effectiveness of a new intervention, she would be assigned as a champion of that Power-Up card.

The Milestone cards most relevant to a patient’s needs would be located first and Power-Up cards would be if a patient had difficult achieving a milestone. Once a milestone, Power-Up or Transition Step has been completed by the patient, the care providers would turn the card as a signifier. A visual profile of each patient, using a format similar to what was done during the
synthesis phase by the design team, would become the starting point of the process. This visual profile would help inform each transition process creation, and represents the importance of gathering qualitative information of each individual patient in order to plan a successful personalized transitional service.

**A Patient Tool**

The last part of the new objective was a tool that enabled patients to comprehend their personal transition process and give them a sense of achievement when completing the established goals. This was designed as the patient tool shown in figure 12, which is a binder/tool-kit serving as an extension of the care provider tool. Like in its care provider counterpart, the patient tool has *Ally cards* in its *myAllies* section, these cards represent providers that the patient has interacted with and bonded. There are different *Allies* championing different areas, and it informs the patient who they can go for help when they have a problem in a particular mission.

The *Milestone*, *Power-Up* and *Transition Step* cards are represented in the binder as the *myMission* cards, which are distributed to the patient depending on the planning on the provider side, and only after he or she has finished his previous *myMissions* cards. Once the patient completes a mission, the cards are returned to the providers and he or she receive a *myTool* card as a signifier of completion. These cards describe techniques, tools and abilities that they learned while completing a milestone or intervention, and serve as a badge, giving them “bragging rights” among other SCD patients and providers.
The binder also includes a section to keep physical tools which were identified during the research as important in self-management. Tools such as a thermometer, a pain diary to keep track of pain crises, a color coded folder to keep all important documents related to the hospital and disease, and also a pill dispenser to keep track of medicine intake. Appendix 2 - 4 show storyboards created in order to explain to patients and providers how sections of the patient binder worked.

Both the provider and the patient tools would enable common understanding across stakeholders and would serve as the key patient-provider touch point which would allow the service to work.

\[\text{Figure 12 – Visualization of patient tool}\]
Chapter 6:
Refinement Phase

First Evaluation – From Analogue to Digital

The system of a co-creation card deck, a provider transition planning tool and a patient binder/tool-kit were presented to a group of care providers, researchers and management staff from Cincinnati Children’s Hospital signifying the end of the LWC+CCH section of the project. The presentation stemmed feedback from the stakeholders attending.

CCH staff showed interest in the use of developmental milestones as part of the transition process, since it was generally understood that in pediatric transitional care that patients need to have knowledge of their disease, good communication with providers, ability to set life goals and navigate the medical system, in order to successfully transition to adult care. They agreed on the importance of the qualitative data gathered by the design team during the exploratory phase in order to inform their decisions around the transition process, and also how visualizing it as it was done during the synthesis phase could facilitate the understanding of all the data. However they expressed how they did not have a dedicated staff that could continuously do the
qualitative research and commented about finding a way for patients to gather the data by including patients and parents in the planning of the transition process.

Providers commented positively on the change to a more colloquial and optimistic language, because of the negative connotations that the word intervention may have. Some providers were worried about being assigned extra responsibility as champions, but others commented that it was something which was already being done implicitly.

Regarding the provider tool, CCH staff commented that they did not have a defined space where they could use and permanently leave the tool for discussion and tracking. There were also problems with privacy by having confidential patient information being displayed in a room where someone could glance inside. They mentioned the possibility of making the provider tool a digital interface where it would be protected and which could accessed by staff any time.

Based on this stakeholder feedback, the next phase of this thesis was to turn the provider tool into a digital interface. This change would have repercussions on the other parts of the system due to the possibilities that a digital interface could bring. For example information could be compartmentalized for easier understanding, due to the complexity of an eight year long transition process. Space did not become a limit and multiple patients could be tracked, and their information would be protected.

The patient tool could also be turned into a digital interface which would share the back-end with the provider’s interface. This would allow instant assignment of milestones and interventions to patients in their smartphones, and have instant feedback whenever a patient achieved the milestone or had trouble with one. This would make the patient side more portable and perhaps better accepted by the patients who belong to a generation constantly connected through technology.
Interface Concept Development

An initial concept of a patient interface was created in order to explore the possibilities of using digital technology. Based on the development of the analogue tools and the feedback received by Cincinnati Children’s Hospital a set of design requirements was created for both a patient interface and a provider interface shown in *appendix 5* and *appendix 6*, respectively. Each requirement was linked to a finding that supported it. They were also prioritized as Needs, Wants and Nice-to-Haves. The components of the provider interface were visualized in a task flow diagram shown in *appendix 7* displaying the different decision paths that could be taken. If a patient had just turned 14 and was starting the transition process, the providers would create a new custom transition process by placing individual Milestones, Interventions and Process Steps, or the user could automatically place a generic process and then arrange it according to the patient’s needs. Once a process has been created, providers could track the progress of patients, or visualize the general progress of several patients at once. Providers also had the option of inputting custom milestones for patients and create new interventions.

Initial concept studies, shown in *appendix 8*, involved exploring different ways to display and interact with the transition process. One example used a *skeumorphic* approach, where the transition process is visualized as a deck of cards. The premise for this was that because providers would have used the deck of cards of the co-creation tool, they would feel familiar with this approach and would be easier to learn. The digital cards would be laid out horizontally and sequentially in a timeline fashion. Users could arrange the digital cards, add new ones or flip them in order to represent their completion.
Another approach shown in figure 13 consisted in visualizing the process as a complete timeline, and dividing the developmental areas into different parallel color-coded rows as Health Management, Disease Knowledge, Education & Vocation, Social and Insurance.

Each milestone would be represented as circles which the users could click in order to add a developmental milestone, intervention or process step, in each area. A vertical figure moving through the timeline would represent where the patient was in the transition process. Once the patient completed all the milestones (represented as circles) the vertical figure would slide to the next milestone column and the provider would send it to the patient.

Figure 13 – Visualization of Transition Process

Appendix 9 - 10 shows the exploration between a sequential and concurrent interface. The sequential interface would compartmentalize information and show it one step at a time; it would be up to the user to choose which information to display. Through this method, information becomes easier to comprehend. On the other hand a concurrent interface would show all the information at once, which would make the learning curve steeper, but after this would allow a more efficient use.
In the end a hybrid method was chosen, shown in figure 14 (more screens are displayed in appendix 11), which would allow the user to pick which sections to show. This concept visualized the transition process as a whole like in figure 13. It included a patient profile built around the semantic themes done during the synthesis phase of the design process. The profile allowed providers to gather and input the qualitative information relevant to plan a custom transition process.

The concept also included a visualization of the severity of the patient’s disease through time, as shown on figure 15. This would allow for CCH staff to make connections between a patient’s completion of health management and disease knowledge milestones and interventions, and the state of the patient’s disease. This would help to introduce new milestones to help that patient, and also help make a case to implement successful interventions into the hospital’s standard of care.
This initial interface concept also included a messages section where patients could request suggestions from providers about problems they were having completing different milestones or interventions.

This interface was developed in order to explore the possibilities that a digital interface could bring to the system, but was working on many suppositions of the service, and required for the service to be co-created.

Second Evaluation – No Objective Reference in Disease Severity

The initial concept was evaluated by the co-director and a research fellow of the Innovations in Community Research and Program Evaluation team (INNOVATIONS team). Both evaluators had been involved with the project since its LWC + CCH stage and were part of the psychology department where they interacted with patients and parents. The method consisted in using
evaluators, experts on the subject matter, knowledgeable of SCD patients, and experienced on existing interventions in the hospital and care provider roles.

Comments from this evaluation included removing the messages section, because systems like it are already implemented at Cincinnati Children’s and it could confuse the patients. There was also worry about patients asking questions regarding medication, which should be done in person with their Primary Care Provider (PCP). This feature could be restricted to transition specific interactions, so that it did not overlap with existing systems, or also included in institutions without the system if implemented outside CCH.

Another issue was gathering the qualitative information for the patient profile. They agreed that this information was essential to plan a custom transition process, and that care providers possessed some of this data through their interactions with the patients, but staff was not doing this systematically and are normally too busy to do so. However, they mentioned that they were in the process of hiring a Transition Coordinator who could take the role of gathering this information from providers and patients.

Regarding graphing the severity of a patient’s disease, the evaluators commented that due to the nature of sickle cell disease which affects patients differently there is no single indicator which providers could quantify which would show an objective measurement of a patient’s disease severity. Other measurements like pain are subjective in nature and can fail to provide useful clinical data.

In order for this interface to be developed further, the service had to be co-created with the providers under the proposed framework. It was important to know the number of milestones each area would have, which Power-Ups would be implemented and which developmental areas would be used.
Prototyping the Service

A series of three sessions were planned with care providers in order to build the service. Thirty minutes were scheduled per session during their regular weekly meetings. The co-creation card deck previously developed was used. Different color Milestone cards were given to different providers. Nurse Practitioners and Doctors were given the areas of health management and disease knowledge. Social workers were given the areas of Social Aspects of SCD and Insurance. School interventionists were given the area of Education and Vocation. Researchers and psychologists were given Power-Up cards. Psychologists only intervene when there is a problem with a patient, and their role is related to behaviors which would belong in any of the previous developmental areas. Therefore psychology interactions were considered Power-Ups instead of having their own area.

Care providers were asked to imagine one of the transitioning patients interviewed as if he was 14 years old again. They were asked to ask themselves question: What activities, goals or knowledge could I have given the patient back then that could have made him more independent, capable of managing his disease and with a brighter future after leaving Cincinnati Children’s? The answers to these questions would become the milestones. Providers were asked to write down the necessary steps or actions the patient would need to do in order to achieve such milestones. They were also asked to write down any intervention existing in CCH that could help the patient in case they had trouble completing the milestone. As shown in Figure 16, the milestone cards with the providers’ written input were laid out in order to sketch and discuss that patient’s transition process.
This method was repeated for the next two sessions, but became too demanding of the patient’s time, which they could not take out of their daily activities in the hospital. After this, a top-down approach was tried which required less time from them, where they would write more general milestones that all patients had in common. This led to a common transition process. Personalization would be achieved on a per patient basis in the interface through individual input.

Besides serving as a way for staff to create the service, the co-creation meetings were used to observation of provider – provider interaction. Because the sessions were scheduled during their weekly meetings, it was possible to observe their planning and discussions about patients, and the importance they gave to their use of time. Through this it was possible to conceive how the interface could be implemented into their weekly meetings.
Final Concept

Using the information gathered during the co-creation sessions a service blueprint was created as shown in figure 17. The blueprint describes the initial interaction between care providers from different areas in order to plan the transition process, as well as the key role that the transition coordinator would play in enabling this service. It also shows how Power-Ups would be implemented in order to help the patient accomplish challenging milestones, and how independence in different areas would be achieved by patients upon completion of their goals.

Figure 17 – Service Blueprint
Based on the feedback from the second evaluation and through the observation of provider meetings a new iteration of the provider interface was created. Interface is meant to be projected during meetings to discuss transitional care of individual patients between the care provider team. It can also be used during appointments with patients in a tablet version, in order to input qualitative information which may be important to plan and tweak the patient’s custom transition process. The interface would reside their existing encrypted portal which complies with HIPAA regulations. Providers would be able to access it with their personal passwords in order to add or review information regarding the developmental areas of health management, disease knowledge, educational/vocational and social.

Figure 18 – Patient Profile Section of Provider Interface
The interface shown in figure 18, displays a timeline between 14 and 21 years of age, the patient’s current age shown in red. Users are able to move through this timeline and review how the patient’s information has changed through the years. The first section is the patient profile which contains information relevant to plan their transition process. It also contains a visualization of where the patient feels pain and the effects of the disease in their bodies. When inputting these symptoms into the visualization, providers are able to leave comments to put the patient’s pain in context of the patient’s lives. For example, a nurse practitioner would be able to leave a comment on how the patient mentioned that the extreme pain in his legs is causing him trouble in paying attention during class, and when he has too much pain he will skip class. This is information which would be relevant for a school interventionist in charge of education and vocation would want to know.

Figure 19 – Milestones Section of Provider Interface
Figure 19 shows the Milestones section of the interface as cards. The card analogy approach was re-introduced because it facilitated the reorganization of the milestones in order to customize the process. Customization also occurs by adding Power-Ups which make the milestone easier to accomplish, and also by adding personalized milestone cards. Each card can be sent to a patient interface shown in figure 20 or printed to be used in the analogue patient binder from figure 12. Language on the patient side would change for better comprehension by patients and to add more positive connotation for motivation, for example milestones would be called missions, which connotes a call to action.

Figure 20 – Patient Interface showing a milestone as a mission
The last section called Health (figure 21) displays a visualization of different data inputs which would serve as a representation of the change of the patient’s health during the transition process. It would be a way to track the success of milestones and interventions directly related to health, in order to influence the standard of care in the hospital. Due to the variability of sickle cell disease and there not being an objective way to measure disease severity, a number of measurable variables, that could be co-related with each other, were proposed. It included Pain on a 1-10 scale, number of visits to the emergency room, number of hospital overnight stays and the patient’s overall feeling. Important measurements would be accompanied by qualitative information gathered from patients, which would put the measurements in context.

Figure 21 – Measuring Health Section of Provider Interface
Overall feeling or mood would be gathered from the patients through the patient interface (figure 22) or during appointments at CCH. The idea behind this measurement is that it is so general and its causes can be so varied that one measurement by itself is meaningless, but when several measurements of it are viewed through time and/or co-related to the other variables of pain, ER visits, overnight hospital stays and qualitative information from the patients, connections are made which give insight into the patient’s health. This insight would inform if tweaking of the transition process is required or the milestones and interventions which the patient has accomplished have helped.

Figure 22 – Patient Interface showing how “mood” is obtained from patients
Final Evaluation

This last iteration of the provider interface and how it relates to a patient interface were evaluated with the care-providers who would be using it. A focus group method was used for this evaluation; participants included the transition coordinator, social worker, psychologist, case manager, and two research fellows. A second session was done with the co-director and a research fellow of the Innovations in Community Research and Program Evaluation team.

Both sessions consisted in giving a demonstration of the workflow in the interface and explaining its different sections and their purpose. Then asking open-ended questions and follow-ups which would help to obtain comments about the interface and also spark conversation between them to see their attitudes and talk about anecdotes where the proposed service framework would have helped if it had existed.

Providers commented on how the ability to add personal milestones for individual patients would make it their creation and would make take ownership on some part of the process.

CCH is always piloting new interventions, trying to improve its standard of care, which takes a lot of the provider’s time. Therefore, a lot of emphasis was put in the transition coordinator as the “owner” of the system. She would input new patients into the system and would gather the required information from providers and patients and create the transition process for each patient. They saw other providers as taking more of a passive role, where they would access it to learn about the patient more than input their own information.

They also saw the system as a way of tracking interventions that were successful. They mentioned how they used an intervention available in the hospital and then just forgot that it
existed, a couple of years later they remembered that it had had positive results, but they had just forgot about it.

Staff liked the idea of making the interface accessible to the transition coordinator in clinic, during appointments with patients in order to gather the required information. Adding the ability to download that information into their current electronic health record system would help reduce double documentation.

Providers also saw the provider interface as making their internal communication better. Even though they already have an electronic health records system where they write notes, these notes are so extensive and on many different topics that no one really goes through all of them. The information in the provider interface is visual and synthesized which allows for easier understanding.

The focus group also mentioned about the possibility of granting patients access to the information in the patient profile. This information would be helpful for them to see, but done in a way that they could control exactly what to show.

Regarding the health measuring section of the profile, the staff said that the variables of mood, ER visits, pain and hospital overnight stays, were already informing their decisions, but the visualization of the information through time gave them an overall view of the whole picture. They also mentioned about the importance of how the pain number was gather from the patient, since it is subjective and it influences all of the other variables. There was also worry about measuring the variable of mood. It is something that they do already, but there is no consistency and portrays whimsical results.
From the provider interface side, staff wanted more emphasis on a complete milestone to serve as reinforcement. Also incorporate a signifier for milestones that the patient has not been able to finish.

Overall, they see the system as being implementable in the hospital and it is something that does not duplicate any of their current systems or interventions.
Chapter 7: Conclusions

Next Steps

To further investigate whether the service proposed in this thesis would be beneficial to patients and providers, a long term study is required. This would call for the programming of the provider and patient interfaces and for IRB approval in order to include patients in the evaluations. This pilot would test whether their independence in self-management and other areas, necessary for a successful transition, increase. From the provider side it would test whether it would be a more effective management tool than their current practices and systems. This test would also be useful to evaluate whether combining the variables of mood, pain scale, ER visits and overnight stays at the hospital, are successful in measuring disease severity in sickle cell disease patients.

Some features of the concept were removed or not explored further due to time, however they could be implemented and tested in further iterations. One of these features is a system which helps providers gather relevant qualitative information from the patients, either during their
interactions or directly from the patients without directly involving providers. The whole service could put more emphasis in the role of key providers as role models and motivators of patients with which they have an affective relationship.

At the moment the planning of the transition process involves care providers discussing patients and gathering information from patients, but the system could include more active involvement from patients and their parents in order to plan their custom transition process. The service could also benefit from a way to measure the success of milestones and interventions related to education and social aspects of the disease. These areas affect overall health indirectly, so they are more difficult to measure.

Application of this service framework to other areas of transitional care could be explored. Examples of other areas would be the transfer to adult care in other chronic diseases where transitioning is affecting the outcomes of patients such as diabetes. It could also grow to encompass the transition of adults into geriatric care, or other types of developmental transition not necessarily related to health care.

Observations & Personal Findings

This project was the first time I combined Systematic Inventive Thinking (SIT) tools with user centered design techniques. These two ways of concept generation have different perspectives; SIT has a systematic, solution first, approach, while user centered design is based on detecting needs and then generating solutions around them. In this project I was able to show how both can work together, by using the SIT session as a way to gather more insights. The findings from
the session were related to the research, this led to a more high level solution than the individual focused solutions obtained during the SIT session.

I interviewed the members of the INNOVATIONS team after the project had ended. We discussed the different ways in which design adds value to a health care project. An example of this is how designers have the ability to iterate fast, and create different levels of prototypes that can be used to test concepts early. This is something that they did not do at the moment, but which they believe adds value.

Another way that we believed that design added value was through focused ideation, which is something that they do not do regularly. Also, user centered design was helpful in giving the patient a voice in the project. This was a new concept to them, since they normally work with populations instead of individuals.

How design was able to consolidate the research data very quickly through diagrammatic reasoning was also seen as valuable. In health care projects they normally take a long time to code all the data gathered from the research, while in this project we sacrificed precision for a more general understanding in order to drive the project quickly.

In user centered design we normally work with qualitative research where we prioritize depth over breadth of the data gathered. We normally work with extreme cases of the population under the assumption that if we are able to solve the problems of people at the extremes, then you will also encompass the rest of the group. This was a new perspective to them, since they normally do not prioritize the extreme cases, since they see them as outliers.

The difference between a design approach and the approach in health care is exemplified in the following quote by one of the members of the INNOVATIONS team from Cincinnati Children’s:
“From the science researcher perspective I am always a critical thinker, which in these situations makes me a Debbie Downer all the time… but in design, their job is to figure out what is important and seek it. There may be lots of things that may get in the way, but if it’s important, how are we going to make it happen, and what’s the best way to make sense of it. There is always something we had not thought of, which is why we felt like Debbie Downers in the first place”.

— Naomi Joffee
Bibliography


Appendix 1

Screen captures of Audio Visual Storytelling
Appendix 2

Using myStory (Analogue Patient Tool)

Care-providers give patients cameras and Photovoice booklet with instructions of photos to take.

Patient takes the photos.

Patient discusses photos with care-providers.

Care-providers formats photos in myStory panel.
Appendix 3

Using myAllies (Analogue Patient Tool)
Appendix 4

Using myMission (Analogue Patient Tool)
# Appendix 5

Patient Interface / toolkit (analogue or digital)

<table>
<thead>
<tr>
<th><strong>Design Requirement</strong></th>
<th><strong>Justification</strong> (Observations &amp; Insights)</th>
<th><strong>Priority</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Interface should use colloquial language easily comprehended by patients.</td>
<td>Excessive use of acronyms by care providers. Certain terminology may have negative connotations.</td>
<td>Want</td>
</tr>
<tr>
<td>Interface should be usable by patients with an age range of 14 to 21.</td>
<td>Secondary research suggests that the transition process should start at an early age.</td>
<td>Need</td>
</tr>
<tr>
<td>Interface should be appealing to patients with an age range of 14 to 21.</td>
<td>CCH wants to use 14 as the starting age for the transition process; this is backed up by secondary research.</td>
<td>Need</td>
</tr>
<tr>
<td>Interface should be usable by patients younger than 14.</td>
<td></td>
<td>Nice-to-have</td>
</tr>
<tr>
<td>Interface should receive transition steps, milestones and interventions to patients, as defined in the Provider Interface.</td>
<td></td>
<td>Need</td>
</tr>
<tr>
<td>Interface should notice providers when a transition step, milestone or intervention has been completed.</td>
<td></td>
<td>Want</td>
</tr>
<tr>
<td>Interface should section/segment the information communicated to patients.</td>
<td>Transition process and other information given to patient may be too complicated and overwhelming for teenager patients to comprehend.</td>
<td>Need</td>
</tr>
<tr>
<td>Interface should show information to patient sequentially.</td>
<td>Sometimes silent strokes affect cognitive and planning abilities in SCD patients. The whole transition process may be too overwhelming.</td>
<td>Need</td>
</tr>
<tr>
<td>Interface should give patient</td>
<td>Patients do not feel an instant negative</td>
<td>Want</td>
</tr>
<tr>
<td>Feature</td>
<td>Description</td>
<td>Desirability</td>
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<tr>
<td>Positive short-term feedback for completion of steps and milestones defined by care-providers for the patient to transition into adult care.</td>
<td>Physical response when they do not manage their disease correctly and stop taking their medication, so there is no short-term incentive to do so.</td>
<td>Nice-to-have</td>
</tr>
<tr>
<td>Interface should give patients information of the care-provider staff they are in contact with during the transition process.</td>
<td>Patients sometimes develop affective relationships with providers, and would see them as expert role models for guidance and motivation.</td>
<td>Nice-to-have</td>
</tr>
<tr>
<td>Interface should communicate to patients which care-provider is in charge of a particular milestone category, a transition process step and/or an intervention.</td>
<td>Patients sometimes develop affective relationships with providers, and would see them as expert role models for guidance and motivation.</td>
<td>Want</td>
</tr>
<tr>
<td>Interface should visualize the patients’ progress in their transition process.</td>
<td>Could serve as motivation.</td>
<td>Want</td>
</tr>
<tr>
<td>Interface should provide space to organize documentation given to patients related to their disease, insurance and interactions with hospital.</td>
<td></td>
<td>Nice-to-have</td>
</tr>
<tr>
<td>Interface should provide space to keep medication and track intake.</td>
<td></td>
<td>Nice-to-have</td>
</tr>
<tr>
<td>Interface should provide space to keep health insurance card.</td>
<td>When asked what things they would take on a trip, patients failed to mention important things like their insurance card, which would give them faster access to healthcare in case of an SCD crisis.</td>
<td>Nice-to-have</td>
</tr>
<tr>
<td>Interface should provide space to keep a self-management journal.</td>
<td>Care-providers suggest patients to keep a notebook where they keep track of their pain crises, what triggers pain, and their medication.</td>
<td>Nice-to-have</td>
</tr>
</tbody>
</table>
## Appendix 6

### Care Provider Interface

<table>
<thead>
<tr>
<th>Design Requirement</th>
<th>Justification (Observations &amp; Insights)</th>
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<tbody>
<tr>
<td>Interface should allow customizability (order of transition steps/milestones/interventions, quantity of milestones/interventions, and type of milestone/interventions) of the transition process for individual patients.</td>
<td>Every patient is different, not only in their personal lives, goals and aspirations, but also how disease affects their body and causes pain.</td>
<td>Need</td>
</tr>
<tr>
<td>Interface should include predefined transition process steps.</td>
<td></td>
<td>Need</td>
</tr>
<tr>
<td>Interface should include predetermined milestones.</td>
<td>There is a standard of care in the hospital which applies to every patient.</td>
<td>Need</td>
</tr>
<tr>
<td>Interface should include customizable milestone spaces for different developmental areas.</td>
<td>Every patient is different, not only in their personal lives, goals and aspirations, but also how disease affects their body and causes pain.</td>
<td>Want</td>
</tr>
<tr>
<td>Interface should include interventions (power-ups).</td>
<td>The hospital already has existing interventions for sickle cell disease patients, or has applicable interventions in other departments. A portfolio of interventions was created during co-creation sessions during generative phase.</td>
<td>Need</td>
</tr>
<tr>
<td>Interface should include customizable interventions.</td>
<td>Because every patient is different some milestones</td>
<td>Want</td>
</tr>
<tr>
<td>Interface should show additional tools that can help in completing process steps.</td>
<td>Would serve as a link for the myTools section in the analogue patient tool (binder).</td>
<td>Nice-to-have</td>
</tr>
<tr>
<td>Requirement</td>
<td>Description</td>
<td>Type</td>
</tr>
<tr>
<td>----------------------------------------------------------------------------</td>
<td>-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td>------------</td>
</tr>
<tr>
<td>Achieving milestones and when doing interventions.</td>
<td>Providers need to be able to measure the success of interventions in order to make the case to incorporate it into the standard of care.</td>
<td>Need</td>
</tr>
<tr>
<td>Interface should measure success of interventions on the patient’s health and abilities.</td>
<td>Interface should measure success of interventions on the patient’s health and abilities. Providers need to be able to measure the success of interventions in order to make the case to incorporate it into the standard of care.</td>
<td>Need</td>
</tr>
<tr>
<td>Interface should visualize progress of patients with their personal transition process.</td>
<td>Interface should visualize progress of patients with their personal transition process. Providers have different pieces of information around the patient’s lives which could influence decision making around transition process creation.</td>
<td>Need</td>
</tr>
<tr>
<td>Interface should allow for patient transition processes to be determined collaboratively.</td>
<td>Interface should allow for patient transition processes to be determined collaboratively. Providers have different pieces of information around the patient’s lives which could influence decision making around transition process creation.</td>
<td>Nice-to-have</td>
</tr>
<tr>
<td>Interface should show individual care-providers in charge of each process step, milestone and intervention.</td>
<td>Interface should show individual care-providers in charge of each process step, milestone and intervention. Patients sometimes develop affective relationships with providers, and would see them as expert role models for guidance and motivation.</td>
<td>Want</td>
</tr>
<tr>
<td>Interface should transmit the necessary steps to achieve milestones to both an analogue and a digital patient interface.</td>
<td>Interface should transmit the necessary steps to achieve milestones to both an analogue and a digital patient interface. 6 out of 8 patients had smartphones. Analogue version would take into account patients without access to technology or internet.</td>
<td>Need</td>
</tr>
<tr>
<td>Interface should only provide patient information permitted by HIPAA regulations.</td>
<td>Interface should only provide patient information permitted by HIPAA regulations. HIPAA regulates security of access to information. (CCH already has a safe portal where the interface could exist in.)</td>
<td>Need</td>
</tr>
<tr>
<td>Interface should include a visualization of how much they have been involved (helped) each individual patient.</td>
<td>Interface should include a visualization of how much they have been involved (helped) each individual patient. Could provide motivation for providers when championing a specific patient.</td>
<td>Nice-to-have</td>
</tr>
<tr>
<td>Interface should not be accessed by unauthorized users.</td>
<td>Interface should not be accessed by unauthorized users. HIPPA regulates security of access to information.</td>
<td>Need</td>
</tr>
<tr>
<td>Interface should allow providers to visualize overall progress of all patients on the different developmental areas.</td>
<td>Interface should allow providers to visualize overall progress of all patients on the different developmental areas. To influence standard of care and future decision making.</td>
<td>Nice-to-have</td>
</tr>
</tbody>
</table>
Appendix 7

Initial Task Flow Analysis
Appendix 8
Exploring Visualization of Transition Process
Appendix 9
Sequential Interface Sketch
Appendix 10

Concurrent Interface Sketch
Appendix 11

Initial Provider Interface Wireframe