Type 1 Diabetes (T1D) Ecology Model

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Prepared in partnership with

Collaborative Chronic Care Network (C3N)
at Cincinnati Children’s Hospital Medical Center

T1D Exchange

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EXECUTIVE SUMMARY

As a key part of a “Goal Directed Design” process adopted for the larger C3N T1D project, the authors conducted ethnographic interviews of patients with Type 1 Diabetes, family caregivers and professional care teams of such patients, and healthcare administrators with an interest in T1D. All participants were affiliated with either Cincinnati Children’s Hospital or University of Michigan Hospital.

The patient/family interviews focused on those people’s experiences living with T1D, the context of their overall lives, and their interactions with the healthcare system. The care team interviews focused on their interactions with T1D patients/families, and how that fits in with their overall professional work. Interviews with administrators focused on the place of T1D care within the organization’s overall services, and perceptions of the value of a C3N for T1D. We interviewed 12 patients, 12 family caregivers, 10 professional care team members, and 5 healthcare administrators. We also observed 3 patients in clinic visits. Interviews we conducted primarily in person, at home (patients/families) or office (health professionals); a few were done by phone.

The interview findings were used to create a set of “personas”, representative of important types of people and issues in T1D. The report includes 5 personas of different types of patients, with differences in key variables including age, socio-economic context, life circumstances, and health management approach and success. We also created 2 family caregiver personas, and 3 care team personas. In addition, the report also highlights several important themes heard in the interviews.

The report also describes a model of a person’s health journey — Continuous Cycle of Health Self Management — that seems especially relevant to the T1D experience, shows how the personas are reflected in the model, and highlights helpful and unhelpful care team activities within the model.

The report concludes with recommendations on how the C3N T1D team can use the personas, themes, and model as they begin to think about creating this network and the interventions that can be tested within it, as they strive to develop innovations to improve the lives of people living with T1D as well as those caring for them.
**Introduction**

“Every system is uniquely and perfectly designed to produce the results it is currently producing.”
Peter Senge, MIT, Author of The Fifth Discipline

Every part of the healthcare system that we experience was designed, consciously or unconsciously, through a myriad of both small and large decisions and actions. Every form, every waiting room, every workflow, and even every treatment plan were all designed at some point. In fact, each of these has been redesigned again and again, over the course of years.

All of these things that people interact with during their healthcare experience have changed over time.

Though our current system of healthcare is too often frustrating, inaccessible, too expensive, and inadequate for the people it is intended to serve, there is great hope. If our current system is the product of its design, then it can be improved with better design. That is, we can change the system, we can effect more positive outcomes for people who receive care, by designing better plans, better decisions, better workflows, better applications of technology, and better tools.

It is in this spirit that the Collaborative Chronic Care Network (C3N) at Cincinnati Children’s Hospital Medical Center (CCHMC) and T1D Exchange have partnered to create a new T1D learning health network.

We hope that the work detailed in this document — a small but useful set of personas of patients, family caregivers, and health professionals dealing with T1D, and a model of a person’s health journey — will be useful to the people and organizations participating in this effort in helping them make better decisions, take better actions, and create better experiences and outcomes for people living with T1D, the family members and care givers who support them, and the physicians, care team members, and researchers who work every day to improve their lives.
Our process

This section contains information about our approach to this project. We detail the design philosophy and methodology called Goal Directed Design that guided our work. We also provide the particulars of our research process, including information about the interviewing activities that we completed, and details about the synthesis process that was used to generate the personas that were created as a product of our research.

The primary objective of our work was to create models that will be useful to the members of the various committees as they envision, consider, design, develop, deploy and evaluate innovations within the T1D learning health network. Our models took two primary forms: personas and the Continuous Cycle of Health Self-Management model, each of which is described in subsequent sections of this document.

Goal Directed Design

Goal Directed Design (GDD) is a methodological approach to product, service, and experience design that was developed by Alan Cooper, which is now practiced and taught by his consulting group (cooper.com) and used by design teams all over the world.

The fundamental premise of GDD is that the best way to achieve a successful process, product, or service is to focus on helping members of the particular ecosystem (e.g., people, customers, organizations, businesses, etc.) achieve their goals. The intent of GDD process is to ensure that the process of design is centered on human context and need.

The GDD process begins with research that borrows concepts from ethnography and focuses on understanding goals, the tasks undertaken to achieve goals, the current use of tools by various members of the ecosystem, and obstacles that stand in their way of success. This research also explores the range of skills, attitudes, behaviors, and knowledge of the actors in the ecosystem.

The synthesis of data gathered during the research phase can produce various kinds of models that can be used to represent aspects of the ecosystem. In particular, the GDD methodology is used to generate personas, which are representative of the people found during the research process. Personas and the process used to generate them are described in more detail below.¹

¹ Although a complete description of the GDD process is beyond the scope of this report, interested readers can learn more about the entire GDD process in Designing for the Digital Age: How to Create Human-Centered Products and Services (Goodwin, 2009).
Research and Design Team

The research and design team for this project consisted of John Chaffins and Rajiv Mehta, who worked in close partnership with Dr. Joyce Lee, a practicing endocrinologist and associate professor at the University of Michigan.

IRB Approval

Since our work involved contact with human subjects, our plan for recruitment and interviews with T1D patients, families, and care team members was submitted to and approved by CCHMC’s Institutional Review Board (IRB). When the opportunity became available to expand the location of our interviews to the University of Michigan, Dr. Joyce Lee was able to amend an existing IRB-approved study to include our work plan.

As a condition of IRB approval, each member of the team successfully completed an human-subjects research educational and certification program offered online by the Collaborative Institutional Training Initiative (CITI). The CITI program was devised by the University of Miami to provide educational content and training materials to “...promote the public's trust in the research enterprise by providing high quality, peer reviewed, web based, research education materials to enhance the integrity and professionalism of investigators and staff conducting research.”

Participation in T1D Design Conference

The research and design team also participated in a 2-day network design meeting, which was hosted by the T1D Exchange and the Collaborative Chronic Care Network team at CCHMC.

The meeting brought together a diverse group of collaborators, including:

- Leadership from the T1D Exchange
- Members of the James M. Anderson Center for Health Systems Excellence at CCHMC
- Information systems experts from CCHMC
- Endocrinologists from CCHMC and UM
- Patients and family members with T1D

During the course of the meeting, participants were asked to take part in a number of design-related exercises in order to forge a sense of common purpose, spark cross-disciplinary conversations, and raise awareness of issues and concerns.

The meeting provided a foundation for various work groups to begin generating a starting set of ideas for interventions that can be tested by the emergent T1D network. This list of ideas will be
filtered through a variety of mechanisms, including the personas presented in this document, to determine the desirability and value for members of the T1D ecosystem.

**Ethnographic interviews**

To gain a better understanding of people living with T1D, their goals, daily routines, challenges, thoughts, and feelings, we conducted interviews and observations as a part of a rapid ethnography process.

Just as importantly, we also wanted to recognize the role that family caregivers, physicians, and other members of the overall care team play in terms of decision making, the identification and implementation of care strategies and processes, and the monitoring of success in management of T1D.

Whenever possible, we visited people in their homes or places of business so that we might get a better sense of their overall environment, the challenges they face, and the impact of T1D on their daily lives. We visited care team members in both clinical and research settings.

During our interviews, we invited people to show us the tools and techniques they use to help manage their condition, including log books and sheets, continuous glucose monitors (CGMs), insulin pumps, smartphone applications, and the like. We were also able to inquire about and observe how people cope with issues around meal planning, management of medications and medical supplies, and communication with peers, teachers, and co-workers.

**Clinical Encounter Observations**

We were also invited to participate in observations of T1D patient visits at both Cincinnati Children’s Hospital Medical Center and at CS Mott’s Children’s Hospital at University of Michigan. We did not interact directly with patients, family, physicians, or care team members during these observations, but our presence was obvious to all (two, large men with notebooks in small examination rooms). We did have a limited opportunity after each visit to ask care team members brief follow-up questions about the clinical encounters we observed.

Each of the encounters we observed was a quarterly check-in appointment conducted in an outpatient clinic setting. Each visit lasted between 2 and 4 hours and consisted of the patient and his or her family caregiver(s) meeting with a physician, diabetes nurse educator, dietitian, and social worker.
Interviewee recruitment and screening

Interviews were arranged by clinical team members at Cincinnati Children's and University of Michigan. They selected interview subjects based on the project stakeholders’ hypothesis of an appropriate variety of clinical, patent and family caregiver perspectives, while also being limited by the accessibility, availability and willingness of interviewees. These included:

- People with Type 1 Diabetes with a range of ages and situations
- Parents and other caregivers of people with Type 1 Diabetes
- T1D Professionals:
  - Physicians (primarily Endocrinologists)
  - Researchers
  - Nurse Educators
  - Social Workers
  - Dietitians

In addition, the team was asked to include in our interview process various kinds of facility executives in order to gain an understanding of their perspective on the potential benefits and the required conditions for a learning health network for T1D.
Interviewee & Observation Demographics

Here are the basic demographics of the people interviewed and observed for the project. Note that some of those listed as health professionals also had T1D themselves or have cared for a family member with T1D. Likewise some of those listed as administrators also care for patients with T1D.

16 People with Type 1 Diabetes
• interviews: 13; observations: 3
• ages: 2 - 87
• gender: 10 female, 6 male
• ethnicity: 13 caucasian, 1 african american, 2 other/unknown
• time since diagnosis: 2 months – 46 years
• location: 7 at Cincinnati Children’s Hospital Medical Center, 9 at University of Michigan
• use of insulin pump: 10 with, 6 without
• use of continuous glucose monitor: 7 with, 9 without

13 Caregivers of People with Type 1 Diabetes
• gender: 9 female, 4 male
• ethnicity: 10 caucasian, 1 african american, 2 other/unknown
• location: 5 at Cincinnati Children’s Hospital Medical Center, 8 at University of Michigan

11 Care Team Members
• 6 Physicians / Researchers (4 CCHMC, 2 UM)
• 1 Nurse Educator (CCHMC)
• 2 Social Workers ( 1 CCHMC, 1UM)
• 2 Dietitians (1 CCHMC, 1UM)

5 Healthcare Administrators
Interview Structure and Conversation Topics

The interviews we conducted were focused on understanding the experiences and needs of each participant. We asked questions that would help reveal each person's motivations, behaviors, use of tools, and goals. Each interview session lasted between 60 and 90 minutes.

We had an interview guide, a set of questions to ask, but by design we allowed the conversations to flow to topics that were important and top-of-mind to the interviewees in order to discover important issues that might otherwise have been overlooked.

As much as possible, we interviewed people with T1D and their family members in their homes. A small number of patient interviews were conducted remotely via telephone or Skype. Patient and care giver interviewees that were recruited by CCHMC were compensated for their time with a $20 stipend.

Interviews with physicians and care team members were conducted in their offices or in clinical settings.

The order and range of interview topics varied by interviewees’ roles, context, and areas of expertise. The following is a list of typical interview topics for each role:

**Patients and Family Caregivers**
- Understand the context of their overall life, both separate from and relative to their condition
  - Story of diagnosis
  - History of treatments and symptoms
  - Perception of past/present/future health condition
  - Relationships/communication with clinical care team (data sharing/privacy)
  - Understand health management tools, efforts, and obstacles
  - Understand their personal care ecosystem & associated care giver support
  - Involvement in communities
  - Transition to adult care
  - Use of offline and online tools/media to learn about T1D

**Physicians/Care Team Members**
- Areas of expertise and research interest
  - Career history
  - Interaction with care teams
  - Challenges in patient care
Limitations and Bias in Clinician Researchers

Due to time and budget constraints, there were several dimensions of T1D care we were unable to explore adequately. We did not directly interview any physicians who provide T1D inpatient care, though we heard several stories from both clinicians and patients about inpatient care experiences. Similarly, we did not speak with any pediatricians, general practitioners, or emergency room physicians, but heard stories from other clinicians and patients about these clinicians’ roles in diagnosing and treating T1D.

We would also like to recognize bias related to the location of our research. Both CCHMC and UM are large, well-funded, teaching and research institutions in or nearby areas with relatively large urban populations. CCHMC is also among the top 10 facilities in the country for pediatric diabetes and endocrinology, according to the U.S. News and World Report. As a result, our research and the models that we have produced generally represent the experiences and practice patterns of patients and practitioners connected with large teaching institutions.
Synthesis process

Synthesizing data gathered during research into patient, care-giver, physician, and care team personas was a multistep process. The following sections briefly outline the activities undertaken during this phase of our work.

Data Organization

During each interview, our team took notes and (with permission) made audio recordings of the conversation for later review. A log of each interview session was maintained, and each interviewee was assigned a code for use in communication and documentation. We also noted important demographic data on the log, such as the interview date and each person’s role or title.

Contextual and behavioral variables

The team spent numerous hours discussing each interviewee, both immediately after the interview took place and in subsequent follow up sessions. These discussions iteratively became the basis for a set of themes and common factors we identified. Based on these discussions, we developed a list of demographic, contextual, and behavioral variables to be used as the basis for mapping out each interviewee.

The variables that we identified included the following:

- Sex
- Age
- Role: person with T1D, family caregiver, physician, care team member
- Time since diagnosis
- Level of complexity
  - Stability (day-to-day life variations)
  - Stress (socio-economic challenges)
  - Co-morbidities
- Degree of support from family caregivers (for patients)
- Care responsibilities (self care versus care provided by family)
- Degree of executive ability (to deal with logistics, math, access to care, etc.)
- Degree of attachment to physician and/or care team members
- Use of technology
- Degree to which interaction with T1D community (other patients and families) is sought out and valued
At the conclusion of our interviews, we again reviewed our notes and recordings and then mapped each individual interviewee to these variables. During this process, we openly debated the relative positioning of each person to all other interviewees on each of the variables.

Next, we used the mapping of each interview to identify individuals who clustered together across multiple characteristics. Each of the clusters we identified, along with their associated attitudes, skills, and behaviors, became the basis for one of the personas.

The figure below illustrates several key factors that were used during the mapping and analysis of data for patient and family caregiver personas. Each of the dots on the chart describes the characteristics for one of the personas we created which, in turn, represents the interviewee groupings we identified.

With these patterns identified, we created detailed narratives for each persona based on the common goals, attitudes, skills, and behaviors. Each of the personas was then iteratively reviewed and revised by the team.
Personas

This section provides some background for the design models that were created as a product of our research process.

The section titled “Making Use of Personas and the Continuous Cycle Model” offers further insight into how to make use of the personas presented here.

What are personas?
A persona is a type of model that can be used to help guide decisions about which product or service ideas to pursue, what features and interactions should be present, and even what kind of content and visual elements would be most useful and desirable.

The personas that were generated for this project are archetypes who represent the people living with T1D, as well as the family caregivers, physicians, and care team members who provide support, assistance and guidance to them. As described earlier, these personas were created through a process of analyzing and synthesizing the results of ethnographic interviews and research activities.

Each of the personas represent a set of experiences, behavior patterns, skills, attitudes, obstacles, and goals of a group of similar (real) people found during our research in the T1D ecosystem. Because each persona represents groups of real people, they become an effective and efficient way of communicating and remembering the details of the research.

Each persona is described as a short narrative that includes these factors, as well as a few fictional elements to help make each character more realistic. The majority of the details in each of the persona narratives are taken from or inspired by stories that were shared with us during our research process.

Why design solutions for personas?
Designing solutions for a particular persona prioritizes functionality, content, and the overall form of a product or service for that particular persona, as well as all of the people they represent. As a result, personas provide clear design targets that can help ensure that the end result will be useful, usable, and desirable for its intended audience.

Because personas use elements of storytelling, they are a more effective and memorable way of sharing research findings. Each narrative helps to contextualize and bring to life the kinds of details that help to situate proposed solutions or services alongside important factors that are likely to influence their success. As a result, designers and teams can explore and discuss the personas as a means of making more informed and effective design decisions.
Personas can also act as a means of improving communication and collaboration among members of a product or project team. Often, individual designers and teams approach problems with their own preconceived ideas about how the intended audience for a product or service thinks, feels, and acts. By providing concrete characterizations of these factors, personas can help teams develop a shared language when it comes to envisioning and empathizing with the behaviors, feelings, and motivations of audience members.

Personas may also help unearth and clarify differences of perspectives amongst the team members. Personas are just a sketch; readers will imagine the “rest of the story.” In the process, team members may come to different perspectives on the persona’s needs and appropriate interventions, based on their own assumptions. Discovering and addressing these differences is a key part of the design process.
Life wasn’t easy for Kayla before, but she’s had an even tougher time of it since being diagnosed with T1D two years ago. Her mom (Norma) and dad (Gerald) split up about a year ago and, as a result, Kayla was forced to move with her father from North Carolina to Florida. For the time being, Kayla and her dad are staying with her aunt Gloria. Since Kayla’s dad, a carpenter, is trying to establish a new life for them in Florida, he’s working a lot of long hours. Kayla’s aunt also works long hours in a local super store. As a consequence, Kayla spends most days after school by herself at her aunt’s house. Kayla’s T1D is just another annoyance on top of the normal challenges of life as a teenager, her messy home life, and having to start all over again in a place she doesn’t like all that much.

Kayla’s diagnosis of T1D came after she passed out one day at school. The school nurse called Kayla’s mom (Norma) to let her know, and recommended that she get Kayla checked out by her pediatrician. Norma hadn’t noticed anything unusual about Kayla around this time, other than losing some weight, which she chalked up to a growth spurt. Still, Norma thought, Kayla hadn’t been to see a doctor in a couple of years, so she called and made an appointment.

During Kayla’s visit to the pediatrician, a urinalysis revealed that she was in a state of diabetic ketoacidosis (DKA). As a result, the pediatrician sent Norma and Kayla straight to the emergency room. Since then, Kayla has been through one other round of DKA, which required her to spend a week in the hospital.

Kayla hasn’t shared anything about her condition with anyone at school in Florida. It’s hard enough to be the “new kid” without having something weird that everyone knows about you. She does okay in school, but most days she’s worried more about trying to fit in than getting good grades.
Gerald makes sure that Kayla gets to the quarterly visits to the endocrinologist. Kayla listens when they meet with the doctor and nurse educator, but most of the time it feels like one more thing that she’s not good at. She already knows most of what they tell her, and it feels like no one listens to her or understands how hard everything is. She usually does a little better with “sticking to the plan” for a couple of weeks after a clinic visit, but then school gets stressful and she finds herself overwhelmed again.

Kayla doesn’t test her blood sugar on a regular basis because it hurts her fingers and she finds it depressing to be reminded of her problems. She also avoids testing at school so that she doesn’t stand out from the crowd any more than she already does.

Mealtimes for Kayla are also tough. She dislikes the food at school, and at home she’s on her own for breakfast and dinner most days. Sometimes, when she gets tired of what Gloria has in the house, Kayla will walk down the block to one of the fast food restaurants or she’ll just skip the meal altogether.

Kayla feels that her life is so hard that it’s just not fair that she’s supposed to deal with T1D as well.
Carlos Perez

Age: 12  
Middle School Student  
Time since diagnosis: 5 years

Goals
- Be a better soccer player  
- Feel smart and in control  
- Be trusted

Carlos has become confident in his ability to manage T1D. He was diagnosed with T1D 5 years ago, after he started wetting the bed at night. He lives with his mom (Maria) and dad (David) in Houston.

More than anything, Carlos likes to play soccer. He has played on an elite local team in the competitive league for the past three years. The team practices four times a week, plays matches most weekends, and sometimes travels to other cities, which require overnight stays. The coaches on the team recognized that Carlos has a special talent for the game, and have worked closely with him to develop his skills. This year, Carlos is the starting center forward on the team, and he couldn’t be more proud of this achievement. At home, Carlos likes to spend his free time playing FIFA against his friends on Xbox or outside practicing his ball-handling skills.

Being diagnosed with T1D wasn’t fun, but Carlos had a friend in school (Jacob) with diabetes, so that made it a little less scary. From being around Jacob, Carlos already knew a little about testing blood glucose, taking insulin, and being careful about what you eat. Still, watching someone else and learning to do it for yourself were two different things. There was a lot for Carlos to learn, but his mom kept track of everything, especially at the beginning.

After Carlos was diagnosed, he and Jacob became closer friends. Before lunch each day, they would go to the school nurse together to test their blood sugar. On the days when the school nurse wasn’t there, they would test in the classroom with the teaching assistant while the rest of the kids went to the lunchroom.

Through careful attention to testing and diet, Carlos’s T1D was pretty stable for the first couple of years. All that changed once he joined the competitive soccer team, which was more physically demanding. Maria would test his blood sugar before and after practice, and was always there with energy bars and sugary drinks when his levels started dropping. Game days, and especially tournaments (4-5 matches in a weekend), were a different story, and Carlos struggled to perform well. Over time, after much trial and error with different amounts and timing of food and drink and
paying close attention to Carlos’s performance, Maria and David have developed a game-day routine that allows Carlos to excel.

Carlos’s teammates quickly got used to the sight of his testing and shots. Now they pay no attention. They just cheer when he scores, and groan when he misses.

During his first year on the team, Carlos’ mom and dad didn’t let him go on the weekend trips. They weren’t sure how they would be able to deal with multiple matches, overnight stays, and everything that went with this. Now that he’s allowed to travel, Carlos knows that they are counting on him to tell them how he’s feeling and to help them take good care of his T1D so that he continue to play well.

(See below for more about Maria.)
Samantha Lewis

Age: 21  
College Student  
Time since diagnosis: 15 years  

Goals  
- Live without limits, but know when to ask for help  
- Make the right choices  
- Help others with T1D

Samantha is just starting her second year of college at University of Wisconsin in Madison, where she’s studying to be a social worker. She chose UW-Madison for their excellent program, and because it was far enough from her home in Pittsburgh to be adventurous (but not too far). After many years of increasing confidence and success in managing T1D, the transition to college has proved to be far more challenging than expected, and now Samantha is really struggling.

Samantha was diagnosed with T1D after a series of illnesses and trips to see her pediatrician. At first, her doctor just thought that she was fighting a “bug” that she couldn’t get rid of, but when her mom noticed that she started losing weight, she started Googling to find some answers.

Over the next few years, Samantha and her mom gradually learned all of the details about how to manage the highs and lows of her T1D. Looking back, the thing that made the biggest difference was the year that Samantha decided she wanted to go to a JDRF diabetes camp. Samantha was 9 at the time, and by then her T1D was fairly stable. That stability came at a price though, since their regimen had become so strict that Samantha wasn’t doing much other than going to school every day. Samantha’s mom was always worried about trying out sports, going to sleepovers, or basically anything else that strayed from “the plan”. Samantha’s mom worried a lot, so Samantha worried, too.

About this time, Samantha got a new classmate (Rhonda) who also had T1D. Rhonda told Samantha about how she had gone to camp the previous summer, and how much fun she had there. All of the kids were just like them, Rhonda said. Samantha had to ask her mom to let her go to camp for most of the rest of that year, and she finally said “yes”.

At camp, Samantha went hiking, climbed on the ropes course, and went swimming every day. More than that though, she found out that she didn’t have to be afraid to try new things. The counselors at camp helped her with testing and figuring out how much insulin to use depending on what they were doing that day. She even ate cake and ice cream. Samantha went to camp every year after that.
After that first trip to camp, things changed for Samantha and for her mom. They both started to feel more comfortable getting away from “the plan”. Samantha started taking dance classes. They went hiking together in the woods near home a couple of times a month. Samantha went to her friends’ birthday parties. As they did these things, Samantha’s mom began to feel more comfortable with anticipating and making the adjustments that were necessary for different food and activities. As time went on, they both started feeling like there were very few things that they couldn’t do, as long as they planned accordingly.

As Samantha went through her high school years, her mom started focusing more on getting her ready to care for herself when she moved out on her own for college. Samantha felt a little nervous about that sometimes, but she liked that her mom trusted her to be independent. Her sophomore year, Samantha got an insulin pump.

Her success with managing T1D while also having a busy social life and academic success, gave Samantha the confidence to go to an out-of-state college. But it turns out she was unprepared for the many big changes caused by the high school–college transition.

Even though she thought she was ready, the first year of college was tough for Samantha. There were so many new things to learn all at once. Class schedules changed every quarter, which made it tough to get into a regular routine. The food at the dining hall wasn’t what she was used to eating, and some of it was just downright gross. Sometimes, things like lack of sleep, finals week, or going out with friends just got in the way of taking care of T1D. To her dismay, Samantha discovered that her old regimens, habits, and adjustment instincts, no longer sufficed.

Samantha also missed her mom, especially when she got a cold. She drove the 9 hours home during holidays and breaks, but her mom as busy at work and only visited her at school once that first year.

To top it all off, Samantha also had to adjust to new medical professionals, not just those in Madison but also back home in Pittsburgh, where she was transitioned to adult care once she turned 18.

During that first year at college, her A1C went up nearly 3 points, which was the difference between being classified as “good control” and “poor control”. The summer after her first year of college, Samantha volunteered to help at the diabetes camp in Pennsylvania. While this temporarily buoyed her spirits, once she was back at college her health and confidence deteriorated further.

Samantha and her mom agonized all summer break, and are now considering whether she should move back home and perhaps switch to a less demanding community college.
Eric Clark is a high school social studies teacher. He lives with his wife Alice and their two German shepherd dogs in a suburb outside of Detroit, Michigan. Alice is a legal consultant who travels for work a couple of times a month. Both Eric's and Alice's parents passed away when they were relatively young, and neither of them have brothers or sisters.

Even though Eric now spends most of his work time in a classroom, he stays pretty active. When the weather is decent, he runs 3-4 times per week. He often participates in 5K and 10K runs, and has even completed a half-marathon. Eric started running as a way to keep in shape, but he's now really into the competitive aspect of the races. He has started recording the times and distances of his runs on his Nike FuelBand. In addition, Eric usually takes the dogs for walks or to a nearby park to stretch their legs twice a day.

Eric has lived with T1D since he was 16, and he has become very skilled and self-confident in his ability to “figure out” whatever is going on. He tends to stick pretty closely to his daily regimen, making small adjustments as necessary. In his teenage years and early 20’s, Eric kept a careful log of his diet, blood sugar readings, activities, and anything else that seemed relevant. He used the log to help him remember what he did and to figure out what might have caused changes to his blood sugar readings. Similarly, he used to weigh his food portions and carefully count carbs, which drove Alice crazy, but now he is comfortable making intuitive decisions and being more flexible.

Eric is not bothered to maintain a consistent, detailed log for many years now, as he doesn’t feel there’s a good reason to do so. He can usually feel it when he’s “off”, and he most often has a good guess about what has caused him to feel that way. But on occasion, usually spurred by an unexpected problem, he’ll return to his tracking and analysis skills to recover his health and confidence.

Despite Eric’s skills and self-sufficiency, Alice worries. Not long after they moved to Michigan 5 years ago, Eric had an incident while he was out for an afternoon run. During his run, Eric collapsed as a
result of low blood sugar. It was sudden and strange to him, as he didn’t feel weird at all any time before or during his run that day. Fortunately, another jogger in the park saw Eric collapse and came over to assist him right away. Eric only had a few scrapes to show from this incident, but it shook his confidence a little. Another time, while walking the dogs, Eric got a little disoriented after having another low. Thankfully, the dogs led Eric back to the house, though he didn’t remember later how he got there. For Alice, these episodes were alarming. What if there was nobody there to help him the next time? Dealing with T1D has always been Eric’s thing, but she worries about him, especially when she’s traveling for work.
Linda has learned to take things a day at a time. Her husband passed away 3 years ago after a lengthy battle with cancer. Her two sons live with their families back East, so she’s on her own for the most part now. Linda now lives in a retirement community in Phoenix, Arizona called Sunny Oaks, where she and her husband had planned to spend their golden years together.

Linda was diagnosed with T1D in her early 30’s. She had a hard time understanding how she could contract a childhood disease as an adult. She even visited two other doctors for second opinions before she came to accept the diagnosis. Nobody in her family had T1D, or any other chronic illness for that matter.

Linda has lived a long time with T1D, and for many years her day-to-day routine of testing and adjusting insulin dosages became relatively commonplace for her.

There have been other health complications for Linda. She is a breast cancer survivor of five years, and she had a bad car accident about 10 years ago in which she broke both legs and shattered her right shoulder. Recovery from the accident is still very much an ongoing process. Linda eventually had both knees replaced, and has endured 3 operations so far on her damaged shoulder. As a result, there are a multitude of lingering effects that limit her mobility and send her back for another round of physical therapy about twice a year. During the times when she’s battling one or more of these ongoing effects, it’s hard for Linda to focus on managing her T1D. She has also found it frustrating and discouraging that many of her doctors have not understood what she has to do to manage T1D. There are many days when she finds herself too exhausted to worry about it.

Once her husband got sick, everything became much more difficult. Long days in chemotherapy and radiation treatment, along with several hospital stays, made things that were usually easy for Linda, like eating well, much more of a challenge. During the time of her husband’s illness, Linda’s blood sugar was frequently out of control, sometimes for months at a time.
After her husband passed away, Linda decided to get a continuous glucose monitor (CGM). She had experienced seizures in the middle of the night several years ago, and the alarm feature on the CGM made her feel a little more comfortable that she wouldn’t accidentally miss it if her blood sugar started going low.

Linda and her husband had long planned to move to Phoenix when he retired, and had settled on Sunny Oaks after much consideration. After his death, in spite of the challenges, she decided to stick with their plan and is making the most of her “new” life at Sunny Oaks. She has developed a close circle of friends who visit with each other daily and travel around together on numerous outings. Between her card club, shopping trips, movies, and volunteering, Linda stays pretty busy.
Anna Smith is a mother of three kids, aged 3, 9, and 12, living in upstate New York. Penelope is Anna’s youngest and the most headstrong personality of the family, used to getting her way as the baby of the family. Penelope spends the majority of her time at home during the day, but she does attend a preschool at least 2 times a week during the morning. Anna’s husband (Anthony) has a full time job running his own small business as a plumber, and Anna works part time as a speech therapist the days that Penelope attends preschool. The family is intact and supportive, but most of the household and childrearing duties fall on Anna because she is home at least 3 days a week.

Penelope had just turned 3 years old when she was diagnosed with diabetes. The diagnosis was a total shock to the family, as there was no family history of T1D. Penelope had been potty trained by 2 ½ years of age, but Anna noticed that she had been wetting the bed for the weeks leading to the diagnosis. She thought that this was strange since she had been dry for at least 6 months, so she decided to take her to their pediatrician. The doctor performed a urinalysis and found high glucose levels, so they were sent to Golisano Children’s Hospital which is about an hour away from home. They learned about diabetes, were sent home in a few days, and now are trying to adjust to the realities of their life with diabetes.

It has been a whirlwind of events for Anna, Penelope and the whole family. When Penelope was diagnosed with diabetes it was early June, which was the end of the school year. At that time, they had a lot of school related year-end activities (sports, school concerts) which they had hoped to attend as a family. Instead, Anna, Anthony, and Anna’s mom and dad, who live 15 minutes away, had to take turns attending the events to support the older children.

Anna relied on her mom and dad for childcare and support before the diagnosis, but now she’s unsure of relying on them for support as she feels like they haven’t learned enough about the
diabetes for her to feel comfortable leaving Penelope alone with them. She is also trying to figure out how to deal with diabetes management at the preschool while maintaining her focus at work.

Anna prepares all of the meals for Penelope so that carbs are correctly counted when she is at daycare or with grandma. Penelope is having her blood sugars checked 4x a day and is on insulin shots right now. She is in diabetes “honeymoon”, so she is not having a lot of high blood sugars. In fact, they dropped the breakfast dose for now because her lunch blood sugars were low.

When Penelope was first diagnosed, Anna was on the phone with the diabetes team on a daily basis, but she is unsure of when she should call or contact them now. Anna also isn’t sure whether or not she should be logging everyday now that Penelope’s blood sugars are doing better. Anna knows that the diabetes and insulin doses will change over time, but isn’t sure if she should call, especially if she has her endocrinology visit coming up in the next 2 months.

Anna also understands that there aren’t a lot of pediatric diabetes specialists locally and that it’s important for Penelope to see one because of her very young age, but the distance to the hospital is inconvenient. It’s a one hour drive each way, which takes up nearly the entire day and she also has to find someone to pick up the older kids from school if she isn’t back in time.

Anna has yet to seek out diabetes specific support for herself and for the family. She has just been too busy to deal with this emotionally since she has been so focused on learning the mechanics of everything she needs to know about diabetes. She has read the entire “Pink Panther” book that they gave them in the hospital, but has found it simultaneously helpful and overwhelming. There is another child in the neighborhood who has T1D, but that child is in high school. Their neighbors have been over with offers to help in any way, but Anna’s not ready yet to deal with all of the questions.
Maria Perez is a 40-year-old stay-at-home mom. She lives with her husband David, and her son Carlos in Houston, Texas. David works as a manager of a software development team at a large company on the other side of the city. His job requires him to spend a lot of time at work, including some nights and weekends, so Maria and Carlos are on their own a good bit of the time.

When Carlos was diagnosed with T1D, Maria was working as an elementary school teacher. A few months afterward, though, she decided to quit her job to stay at home full time with Carlos. In those first few months at home, Maria tried to learn everything she could about T1D. She found that there was no shortage of information, between organizations like JDRF and personal websites and blogs, but it was also hard to know exactly which sources of information were best for them. She would call the nurse practitioner at Texas Children’s 2 or 3 times a week with questions at the beginning. Now, the online stuff is a lot less useful to her, though she still talks a couple of times a month with a nurse practitioner who gave her a direct phone number. She does this whenever she wants some validation of changes that she’s making for Carlos.

At first, Maria looked forward to their appointments with the endocrinologist and the rest of the care team, as it presented another opportunity to learn how to deal with T1D from people who had experience. As time goes on, though, she’s finding less and less value in these visits. She knows that the check-ins are important, but they take so much time (3-4 hours each), and she can’t help feeling that they have “graduated” beyond what the team has to offer.

Maria has spent a good deal of her time focusing on how to make sure that Carlos gets the care that he needs, even when she’s not with him. At the beginning of each school year, she meets with the school nurse and the principal to make sure that they’re up to speed on testing, administering insulin, and what to do in an emergency. She does the same with Carlos’ soccer coaches, but worries that they’ll be too focused on the team to notice if there’s something off with Carlos.
Maria keeps David informed about whatever she learns about T1D and Carlos’s condition, and they discuss all major decisions. They’re both comfortable with David caring for Carlos whenever he can or must.

David also helps out with the team as much as he can, and makes the weekend trips to help keep an eye on Carlos. Game days are filled with lots of extra testing and constant adjustments, snacks and juice drinks. It took

Maria and David some time to figure out how Carlos’ blood sugar fluctuated on game days. At first, they worried that because of all the running, that Carlos’ sugar would go too low. But what they found was that his blood sugar readings actually went up during the match, so they figured out how to start game days a little on the low side to even things out.

(See above for more about Carlos.)
Provisional Personas

A note about provisional personas
Provisional personas are used as a placeholder for an important situation that was identified, but for which insufficient data was available to create a full persona. Such situations include:
• A parent of a teen with T1D who finds it difficult to be involved in his child’s care (see example below)
• A woman with T1D preparing for and going through pregnancy
• A young adult navigating the transition from school/college life to independence, including managing one’s own healthcare interactions and insurance
• A spouse of an adult struggling with T1D (possibly along with other health issues)

The provisional persona provides an intermediate design target and is a good opportunity for follow-up research.

Jeffrey

• Trying to let teenaged son handle T1D independently
• Inconsistent pattern of son’s success with self-management
• Regimen is a source of friction, and frustration
• Reviews data infrequently
• Son does not seek extra care assistance

Goals
• Have his son be independent with T1D
• Avoid feeling guilty
• Keep the peace
Dr. Amit Singh

Endocrinologist and Researcher
7 years in practice

Goals
• Help patients avoid the consequences of T1D
• Work with others to advance the care of people with T1D
• Find a balance in his busy schedule

Dr. Singh is an endocrinologist who practices at major academic health care center on the east coast. He also serves as the co-chair of the endocrinology department at the nearby medical school. During a typical week, he spends about 2.5 days seeing patients, and the remainder of his time split among administrative and research activities at the school. Balancing all of these responsibilities is tricky, and most weeks Dr. Singh feels like he works three full time jobs.

On any given day, Dr. Singh’s attention is divided between seeing patients at the hospital clinic and any number of projects running simultaneously. When he’s seeing patients, Dr. Singh finds the 15 minutes or so that he gets to spend with each person inadequate to address more than the urgent issues and the basic requirements for visits. Easily half of the time with patients is spent reviewing their recorded blood sugar measurements and the A1C score. He knows that reviewing the numbers can be an uncomfortable conversation for many patients but, really, what else is there to tell him what’s been going on in the 3 months since they last met?

Dr. Singh appreciates all of the hard work the rest of the care team puts towards getting a deeper understanding of each patient’s situation and helping them make adjustments to improve their health. He does his best to coordinate with the team on the treatment plan, but with the volume of patients they’re seeing most days it can really feel like an assembly line. He ordinarily only gets a few minutes to review the patient’s chart before entering the exam room, and only a few minutes in their “bullpen” with some of the other care team before it’s on to the next patient.

It’s frustrating to Dr. Singh that there aren’t more treatment options he could offer his patients. In spite of the tremendous advancements in T1D care over the past 20 years, he sees that so much of the success for individuals lies in their ability to learn how to understand their condition and make the necessary adjustments. He wishes all his patients were like his 10% “star performers”, but he doesn’t know what he can do to help them get there. Other than encouraging them to “do the best
you can”, he doesn’t have anything to offer. He’s been at practicing for seven years now, and he worries that he’s falling victim to diabetes burn out, like some of his patients.
Jennifer Allen is a diabetes social worker who practices at major academic children’s health care center on the east coast. She decided to specialize in diabetes because several members of her family have T1D, and she also really likes working with kids and their families.

When she first started 5 years ago, it was a full year before Jennifer started to feel comfortable in her role. In addition to everything there was to learn about the condition itself, Jennifer quickly realized that there was so much more to learn about patient and family experiences, and how much more each of them knew about their own, individual circumstances of living with T1D than the care team could possibly understand.

In any given week, Jennifer sees anywhere between 50 to 100 patients and families. Due to the high volume of patients being seen each day, everything in clinic is geared toward speedy visits. This presents challenges for Jennifer, who plans to spend 15 minutes in each visit but occasionally ends up meeting for 45 minutes or more. To top it all off, insurance company rules sometimes require her to spend time with patients that she doesn’t really need to visit.

Jennifer’s biggest challenge is keeping track of all of the cases that she’s following. There are so many ways that things can fall through the cracks. For instance, for a variety of reasons, some patients simply stop coming to visits. Sometimes this happens when patients move away or start following up with different physicians. But just as often, patients just don’t show up for their appointments. Jennifer has started spending her own time to try to track down some of the patients that fall off of the radar. She’s started double checking schedules to find the no-shows, and she logs these in a spreadsheet that she keeps on her laptop. Whenever she has some time, she calls these patients to see if she can touch base with them and encourage them to make a new appointment. Sometimes she has to do a little detective work to track them down.

Recently, Jennifer has been working with the director of her department to change the way that they handle the transition from adolescent to adult care. As of now, kids get referred to adult care at the nearby university medical center as soon as they turn 18. Through her own follow-up, she’s seen far too many cases where people are not doing well after the transition. Between graduation, going off
to college or starting a new job, moving out of the house, and, on top of it all, switching care providers, it’s no wonder. She’s been proposing that they find ways to take a more individualized approach to assessing when patients are ready to transition, but progress is slow.
Kimberly Henry works in a teaching hospital in the midwest. She has been working long enough to feel like she can really see the big picture of T1D. She has also come to understand that her job is less about taking care of patients, and more about helping people learn how to take care of themselves.

Far too often, Kimberly sees how the focus on “the numbers” leads her patients to feel embarrassed, defensive, and even angry. She's seen firsthand how some clinicians can blame patients for not following their directions. She understands how hard T1D can be, and how unique each patient’s situation is in terms of dealing with their condition. Still, even as a more senior member of the team, it’s not easy for Kimberly to find a way to give feedback to other members of the care team about not being judgmental. They’re all under the same pressure, and everyone is doing the best that they can.

Kimberly has also been practicing long enough now to realize that the time she spends with patients is only a tiny fraction of their lives. She has seen time and again that the patients who become most successful at T1D self-management are the ones who find or create their own systems for doing so. In this regard, she sees herself as a resource for information and practical knowledge about how she has seen others succeed. She’d like to be able to do more to connect patients and families to one another, but HIPAA gets in the way.
Themes in the Type 1 Diabetes Ecology

During our research, we interviewed and, in some cases, observed patients, family caregivers, physicians, and care team members at Cincinnati Children’s Hospital Medical Center (CCHMC) Endocrinology Department and at the University of Michigan (UM) C.S. Mott Children’s Hospital.

Through these interviews and observations, we collected a great deal of interesting information about the current state of T1D care taking place in and around these facilities. Several of the most common themes that we heard from patients, family caregivers, physicians, and care team members were incorporated into the personas presented above. We expand on some of those and note a few more below.

The patient experience

There are no vacations from T1D

Even those who are able to manage their T1D with the least daily effort — people with stable lives and health, wearing a CGM and an insulin pump — still have to prick their fingers two-three times a day and look at their CGM readings several times a day. There is no day in which this minimum can be avoided, no day off. For many, the daily care regimen requires much more.

Some children are able to take a “vacation” for a few days or weeks, meaning that the parent(s) take over complete management of the care regimen — remembering, administering, tracking, and decision making for glucose testing, insulin intake, and food. In this case the adult is taking on the full cognitive load, but the child must still participate physically, and presumably can’t completely detach emotionally.

These “vacations” are not possible for those who are primarily responsible for their own care, and ignoring the minimum management requirements can very quickly lead to serious illness and hospitalization. Several interviewees, patients, family caregivers and clinicians, mentioned this as one of the most fundamental challenges of T1D management.

In order to master self care, people with T1D need to learn to “rake the sand”

Dr Arno Kumagai, one of our interviewees at University of Michigan, tells a story\(^2\) of an adherent, engaged patient who nevertheless had elevated A1C levels which caused the patient great concern. Dr Kumagai tells the patient about monks who every day rake sand in their gardens into beautiful patterns which are then always disturbed by breezes, squirrels and leaves. The monks take

satisfaction from the act of raking, accepting that squirrels and breezes, and therefore the outcome (clean, beautiful sand), is beyond their control. Adopting a similar outlook, but otherwise making no changes to his regimen, over the next several months the patient's A1C levels came down significantly.

Several patient and clinician interviewees raised the same point, that patients should focus on developing and performing routines rather than the A1C results or BG log, and especially not view the A1C measure or any particular glucose reading as a judgement on the patient's motivation or engagement. All the patients interviewed who had good control of their health had this sense of equanimity, of not reacting emotionally to any particular number.

However, interviewees also stressed that clinician encounters can give the opposite impression. Clinical encounters often begin with the clinician reviewing the patient's numbers (A1C, logs, etc.). If the numbers are good, patients are congratulated on what a good job they are doing. If the numbers are bad, sometimes clinicians convey an impression, without necessarily intending to, that the patient is not doing enough.

Clinicians too can fail to adopt a Zen attitude of “raking the sand”. They can feel frustrated at their limited ability to improve their patient’s health, to increase their patient’s attention to self-management, or to address underlying problems preventing better health (such as poverty or lack of social support).

**Carefully done small changes can lead to the biggest insights in self care of T1D**

“Diabetes is all about n of 1 trials everyday” Dr Sarah Corathers.

Almost all of the patients who seemed most comfortable with managing their T1D had done a lot of tinkering with their care regimens as well as their manner of living.

One adult patient (diagnosed in his 40's) explained that with his background in computer engineering, to be experimental is second nature to him. At times, after any major changes, he will carefully track his health and treatment and make small changes to achieve a new state of stable health. Like others he stressed the importance of small steps (no more than changes of 10%).

Another adult patient (diagnosed in his 30’s) adopted a very strict regimen soon after diagnosis, and then slowly and methodically “loosened up” (for example, allowing more variety in his diet). He wanted to know exactly what impacts these adjustment had on his body, to know what he could and could not do.

Another young adult we spoke to is a college athlete who has experimented extensively to find the optimal ways to monitor and treat her T1D before, during, and after competition to ensure that her
performance and health are not negatively impacted. Eventually, this led her to also call on her teammates to assist in the administration of insulin.

One family, with two children with T1D, had developed a wide range of practical solutions for living with T1D. They had a “lunch basket” with pre-made forms, charts and tools that made it easy for the children to count carbs as they prepared their lunch bags for school. A nightstand next to each child’s bed had a small light and all needed supplies for middle-of-the-night BG testing (done by the parents). A small refrigerator near the play area was stocked with juices, appropriate snacks, and emergency supplies. These are just a few of the many things the family has done to make T1D management easier. They continue to discuss current and future challenges and experiment with system solutions.

Active management of T1D in this way is a lot of work, requiring high degree of time, discipline, experimental and analytical skills, and creativity.

**T1D does not preclude significant physical activity, but it’s complicated**

Managing T1D can be especially challenging for those doing demanding physical activities. The impacts of adrenaline, exhaustion, cold, etc. from physical labor or athletics on blood glucose can be rapid and significant. They can also be countervailing — the physical activity lowers BG level while the adrenaline raises it. Which makes determining the “right” insulin-and-Smarties intake strategy difficult. A simple rule of “begin the activity with a high (or low) glucose level” is not adequate.

Despite this, several of the patients interviewed were far more active than the average person.

We met a college aged student who was active as a competitive swimmer. To discover a regimen appropriate for race days, she had to experiment by testing her glucose level as often as 25 times over a two-hour period.

Several patients were avid bicycle riders, participating in rides lasting from 50-300 miles. One had ridden over 2,600 miles in 2014. All have had to discover regimens that allow them to manage T1D. On the other hand, one patient had changed from bicycle riding to exercising in a fitness center after a low caused a bicycle accident.

One patient’s work often involves field science, and she manages to cope with multi-week assignments on a ship. However, there’s a limit, and she has to avoid assignments that would require her to spend too many hours standing in cold streams and lakes.
Patients can manage T1D with limited clinician involvement; clinicians cannot manage T1D without active patient involvement

From a practical perspective, except during inpatient care, given that managing T1D requires numerous actions throughout a day, no clinician can actually manage a patient’s care. We recognized this theme in various ways for essentially all of the patients we interviewed.

One patient told us of the major realization he came to when, after being unsatisfied with his previous doctor, moved to a new doctor who helped him to understand that “I [patient] had to treat my diabetes; he [doctor] couldn’t do it. The patient has so much more information.”

The understanding that patients often have more and better information to make decisions about fine-tuning their treatment plan can also be a double-edge sword. Some patients expressed that some physicians fail or refuse to recognize the patient’s life circumstances and degree of experience and expertise in self-management, which leads to feelings of being judged and of mistrust.

However, clinicians do help patients understand and adjust regimens to best fit each patient’s unique life and changing situations. One patient mentioned that her doctor had advised on her on how to change her normal regimen for an upcoming long bicycle trip.

We also observed two separate instances of reviewing logs and discussing appropriate regimen changes with parents of young children. However, we heard from many that clinicians simply lack the time to interact frequently and intensively enough with patients to help them make the kind of rapid, fine-tuned regimen changes that patients, at least those who are very good at self-management, can and do make. As a result, if patients rely upon clinician-approved regimen adjustments, they may only achieve sub-par disease management.
The parent/caregiver experience

T1D has consequences for everyone in the family
Some adults we interviewed insist on being completely self-reliant for T1D self-management, not accepting assistance even from their spouses. Others mentioned benefiting a lot from their spouse’s support. We hypothesize that one possible difference between these situations is whether the patient was diagnosed before or after marriage. Spouses and other family members have a measure of their own in terms of vigilance and worry, even in cases where their active participation is not required or welcomed.

In the case of parents of children and teens with T1D, we observed a range of situations. In cases involving younger children, we saw parents who in effect become a kind of surrogate patient, performing all treatment activities and making all decisions on behalf of the patient. As children become older, we noted that the parent’s role relative to T1D care and decision making often shifts from one of surrogate to mentor. In these cases, parents begin to actively let go of their T1D responsibilities in order to prepare their children to become self-sufficient.

We also observed cases where parents’ attempts to allow their children self-manage T1D ends up backfiring. In these cases, families struggle with both the regimens to control T1D and the interpersonal dynamics to create healthy collaborative relationships.

Patient (and family) interaction with others with T1D varies widely
Some of the children/parents interviewed had friendships with and strong support from others with T1D. They had family members or school mates with T1D, so they regularly interact with others who really understand what they have to cope with to learn from and get support from.

Other children were more isolated, either by circumstances or by choice, and so did not seek out or enjoy support of friends.

Among the interviewees who did have interaction with others with T1D, one of the most common cited experiences was JDRF camp. Several patients and care team members mentioned, in enthusiastic terms, positive involvement with camps.

All of the adult patients interviewed had limited-to-no regular interaction with other adults with T1D, though two mentioned participation in JDRF activities.

Parents have to prepare and coordinate care at school
Parents we interviewed described a wide variety of situations with respect to the availability and degree of preparedness of care for their children with T1D at school. In some cases, school nurses are shared among different facilities, and are not always available to provide or monitor care. In other
cases, schools had more regimented rules regarding the procedures for blood testing and administration of insulin. Even in cases where school nurses are present and familiar with T1D care, teachers are often unfamiliar with patient regimens or warning signs. As a result, we noted that to a large degree parents are required to evaluate the preparedness of schools and to orchestrate much of the care that takes place there.
The physician experience

Physicians who treat T1D are frequently dealing with issues related to time
Many of the practitioners that we spoke with expressed the challenges of balancing teaching and research responsibilities with those of caring for patients. For physicians we interviewed at the teaching institutions that we visited, it was common for patient care to represent only 50% or less of their time during a typical work week. Physicians also spoke of the conflict between the “academic life style” and the value of long-term patient-provider relationships that might be developed in other care settings.

During a patient’s quarterly check-in appointment, we observed that individual consultations take place with each member of the care team. As a result, 15 minutes or less of their total time of 3 to 4 hours in clinic were spent in direct consultation with the physician. Physicians also cited the lack of time with patients leads to the need to focus on urgent issues as opposed to the “small stuff” that might have a great impact on day-to-day self management.

Both physicians and other care team members mentioned the concern of “diabetes burn-out” not only as a phenomenon that can impact their patients, but also for themselves. Clinicians mentioned they feel a conflict between their performance being judged by population-level metrics, as opposed to what’s necessarily best for each individual patient. This, along with the high volume of patients, relative lack of time with each patient, and the need to balance multiple professional responsibilities can all add up to the feeling for physicians that they are not working at the top of their craft.

Physicians face serious issues in terms of continuity of care
Since T1D patients typically have “check up” visits once every 3 months, physicians have very short, infrequent opportunities to interact with their patients. This situation contributes to what is often a disjointed relationship between people with T1D and their physicians. Physicians expressed concerns about the lack of visibility into the 99% of patient life that takes place outside of the clinical setting.

Continuity of care is also disrupted by lack of visibility into referrals to other specialties and by patients who are unable or unwilling to follow up on a regular schedule. In these cases, we noted that physicians and care team members often had to seek out their own solutions to help address these deficiencies in the care system.

The overall lack of time together for patients and physicians also factors into their ability to develop a good collaborative relationship that is based on trust. Lack of familiarity and established collaborative history together may contribute to patients feeling judged and on guard during their time in clinic.
Anecdotally, several of the patients who were best at self-management also had very close relationships with their physicians. Some of these close relationships seemed to be based on unconventional interactions between patients and physicians, including social visits (at the gym), email exchanges, and shared spreadsheets. However, the opposite was also true. Some of the best self-managers we interviewed had almost no relationship with their physicians. A close patient-provider relationship is nice, but apparently not necessary.

Physicians have relatively few treatment options for their T1D patients

There have been tremendous advancements in the tools, treatment, and delivery mechanisms available for T1D over the past couple of decades, with even more promising innovations on the horizon. Still, the effective use of the available tools and treatments is still largely dependent on patients and family caregivers ability to develop effective self-management knowledge and routines.

Because of this, we heard physicians express frustration with their ability to meet the full range of actual patient and family needs. Physicians also indicated that T1D is not viewed as a money-maker for the hospital facility and, as a result, T1D care programs enjoy relatively lower support and priority compared to other conditions.

Adding to this frustration, physicians also mentioned that the bureaucratic structure of insurance provider processes, rules and regulations often make it difficult to assure that patients will receive all appropriate devices and supplies that can help them succeed at self-management.
The care team experience

The care team members that we interviewed included nurse educators, dietitians, and social workers. These care team members, like their physician counterparts, practice at relatively well-resourced research and teaching institutions. As a result, our interviews with and observations of the care team members are subject to the same biases as the physician group.

The care environment and incentives can be discouraging

Though each member of the care team spends more individual time with patients and family caregivers than physicians, they struggle with many of the same issues.

Most care team members that we spoke with identified the volume of patients and the lack of continuity as major challenges. We also heard their concerns about the conflict they perceive between delivering good quality of care as opposed to satisfying checklists of items to be completed during the visit to satisfy reimbursement requirements or research protocols.

Like physicians, care team members also cited a lack of adequate mental health and other psycho-social resources as a source of frustration and concern.

There are many challenges in patient education

There are a myriad of things that T1D patients must learn, and eventually master, in order to become successful at self-managing their condition. Just the basics of the processes and techniques of testing blood sugar, calculating and administering insulin dosages, managing diet and exercise, and knowing what to do in an emergency is more than newly diagnosed patients are typically able to absorb during their first few weeks living with T1D. Even the “Pink Panther” T1D primer (A First Book for Understanding Diabetes, by H Peter Chase and David M Maahs) is 116 pages long.

It is the responsibility of diabetes nurse educators, dietitians, and social workers to teach patients, and their family caregivers what they need to know in order to successfully manage T1D. Through our interviews, we learned that patients receive information and training in a variety of ways, including one-on-one sessions, formal classroom seminars, books, pamphlets, videos, websites, and through materials produced and distributed by foundations and other supporting organizations.

In spite of the number and variety of ways that information and training is provided, patient education remains a challenging endeavor. Care team members we interviewed told us of the difficulties presented not only by the sheer number of basic instructions and guidelines that must be communicated, but also by the higher level functions such as understanding graphed data and recognizing data patterns as they emerge. Some mentioned that they found it difficult to find high-quality education and training materials.
In our review of the educational materials shared with us, we found the overall design quality of many of the resources to be poor. We found that care teams are often left to invent their own educational materials in order to suit the need for customized resources or make up for a lack of available components.

Care team members also mentioned that HIPAA regulations are often a barrier to patient education. In particular, opportunities for peer-to-peer learning are challenging, since clinicians feel they are prohibited from connecting patients or families.

Care team members often have to improvise solutions
Social workers, in particular, often mentioned the need to improvise solutions that fit within each person’s unique life circumstances as a critical success factor in improving self-management abilities. As one social worker told us “everyone makes it up as they go”. In a sense, care team members are called upon to teach people with T1D how to learn and adapt more than providing them with procedures to follow.

Care team members are also to a large degree improvising their approach to solving important problems. For instance, in order to address the issue of T1D patients who “fall through the cracks” of the system, social workers were creating their own tracking spreadsheets and devising ways to find and reconnect with patients who were no longer showing up for appointments. Functions to support these kinds of continuity of care related activities are nor present in the electronic medical record systems in use in the facilities we visited.

Care team members would like opportunities to connect and learn
Care team members have limited opportunities to interact with and learn from their counterparts at other healthcare facilities. When we asked interviewees about their perceptions of potential benefits of a T1D learning health network, they often cited the possibility of sharing methods, data, and lessons learned as the most promising aspects.

Healthcare administrator themes

Administrators want to participate in learning health networks…
All of the healthcare administrators we spoke to expressed knowledge of and enthusiasm for the concept of learning health networks. The anticipated benefit most often cited by our interviewees was the value of sharing and learning from best practices in use at other healthcare facilities. The longer-term benefits most often mentioned were more rapid dissemination of care models that are known to result in better outcomes.
…but they also worry about various aspects of these emerging networks

Despite the general eagerness to engage in learning health networks, the healthcare administrators we interviewed also expressed some worries about various aspects of implementing and working with these networks.

One issue was cost, both in terms of fees to participate and the time required of individual clinicians. Since the costs associated with participation are not tied to reimbursement mechanisms or revenue streams for health facilities, they tend to be scrutinized alongside many other potential investments. Related to this, we also heard that administrators are struggling with quantifying the benefits of participation in learning health networks in traditional return-on-investment terms.

Along these same lines, administrators worry about the potential for conflict between competition and cooperation among the facilities that participate in a learning health network. Data related to facility performance and patient outcomes has already been positioned in competitive terms by the publication of the U.S. News and World Report rankings, where it was noted that much gamesmanship takes place.

Another concern was whether a formal information-sharing mechanism might lead to a reduction in information sharing, either because formal approval processes might filter out or deter “non-standard” innovations, or because people might think that because “someone else” is taking responsibility to share information that they themselves can apply their energies elsewhere.

The challenge of achieving agreement among the participating network clinics as to the definition and consistent collection of a common set of data was also a common concern. Management of T1D is already heavily informed by the inspection of data, but our interviewees stressed that less obvious factors, such as staffing models and measures of interactions with patients, must also be taken into consideration to ensure apples-to-apples comparisons.

Administrators also expressed concerns that their facilities would be properly committed to using the data and lessons learned to drive changes that would ultimately aim to improve the overall quality of care. As one interviewee put it, without this commitment, participation in the network would be a waste of money.
Continuous Cycle of Health Self-Management

Unlike many small, acute health issues, like the healing of a cut, managing a chronic health condition is a lifetime activity. It is often difficult, and the journey from diagnosis to stable health is never a simple, unidirectional path. The model Continuous Cycle of Health Self-Management (CCHSM) [figure 1] depicts key stages on the spectrum of unstable to stable health, key requirements for progress, and major causes of retrogression. Most importantly it highlights the dynamic nature of managing chronic illnesses.

The Continuous Cycle model was first developed by Rajiv Mehta and Priya Kamani in 2008, and initially published in “Reframing Health to Embrace Design of Our Own Well-being”³.

Like any model, or any map, the CCHSM is a simplification of real life, but as shown in this report it seems to be a very useful model, especially in constantly reminding us that chronic care management is a dynamic system.

About the CCHSM model
The model applies to all kinds of chronic health issues, but we describe it here with a focus on T1D.

Stage 0: Unstable health
As the model describes a continuous system, there is no specific “starting point”. However, by convention, we begin at “Stage 0, Unstable health”. Here, the health of the person (patient) is off from his norm (e.g. frequent urination, strong thirst, lethargy, weight loss). The person may be in this stage for a long time if he (or his parents/caregivers) has not noticed or chooses to ignore his condition. Eventually, his condition is diagnosed as T1D, and the patient learns from clinicians how he must learn to manage his condition

Transition: Stage 0 to Stage 1
The patient may or may not emotionally accept the diagnosis of T1D and the attendant self-management demands. Such emotional acceptance may be difficult if the patient is already overwhelmed by other, major life challenges (e.g. poverty, abuse, loneliness, etc.); if there is a lack of support; or if there is fear and confusion. On the other hand, emotional acceptance may be easier if the patient has pre-existing familiarity with T1D, especially if a relative or friend with T1D is living a full life; if the patient has had previous experience reconciling himself to some other health condition or life-setback; or if the person is just generally emotionally resilient. Just the passage of time may also help with acceptance.

Figure 1: Mehta-Kamani model of Continuous Cycle of Health Self-Management

Stage 0: Unstable health: conditions may often be ignored, regimen erratic

Stage 1: Reconciliation: acceptance of conditions & regimen

Stage 2: Habituation: new regimen becomes routine

Stage 3: Understanding: mental model of issues, possible actions, and likely effects

Stage 4: Stable health: feeling well; self-management becomes routine

Unstable health may lead to emotional acceptance, which leads to adherence to regimen, which enables experimentation & pattern recognition. This leads to habituation of new regimen, which leads to understanding. Understanding makes possible stable health, which supports context change and may be disturbed by condition change. Condition change may lead to regimen change, which may lead to emotional acceptance.

Continuous Cycle of Health Self-Management
Stage 1: Reconciliation
At this stage, the patient has accepted that he has T1D, and that he must be take various actions to manage the condition.

Transition: Stage 1 to Stage 2
Wanting to adhere to a regimen (Stage 1) and actually doing so consistently (Stage 2), are two different things. For T1D “adherence” requires more than the unthinking following of a doctor’s prescription. It requires active management — checking glucose levels, tracking diet, and making necessary insulin intake adjustments. To do this the patient must understand the basics of T1D management, the kind of information in the “Pink Panther” book (A First Book for Understanding Diabetes), and have adequate math skills.

A turbulent life, with other urgent and conflicting priorities, can make adherence difficult. There are many other things that also make adherence difficult, such as if there are practical/logistical problems, including insufficient supplies and tools; if co-morbidities complicate self-care management; if caregivers are needed but unavailable (such as schools that aren’t prepared to help children with T1D); or embarrassment when self-care activities (e.g. checking BG levels or administering injections) are not socially accepted.

On the other hand, consistent, routine adherence is easier if the regimen itself is easy; if the patient has all the needed supplies and tools; and if he is supported (by parents, spouses, school nurses, etc.). Patients may also have other life goals that support their intrinsic motivation to manage T1D well, such athletic performance or a desire for a successful pregnancy.

Stage 2: Habituation
At this stage, the patient, possibly with the active support of family caregivers, has been able to achieve good adherence to the basics of T1D management, and made this management a routine part of normal life.

Transition: Stage 2 directly to Stage 4
Good, basic T1D management enables good health, and may lead to stable health (Stage 4). However, T1D can be strongly influenced by so many life issues, that good basic habits may be insufficient.

Transition: Stage 2 to Stage 3
Often the basics of checking BG before/after each meal and sleeping, and making appropriate insulin adjustments, is only a starting point. The patient needs to pay deeper attention to his life — activities, moods, travel, work demands, etc. etc. — to discover how and how much these things impact his health. The patient needs to vary his T1D management routines to discover management practices best suited to his life. Much observation, experimentation, and analysis of the resulting
patterns is required to achieve Stage 3, to achieve a deep understanding of his unique situation, to reach a point where a better, personalized regimen has been identified.

Note that “observation, experimentation and analysis” encompasses the full range of formality and rigor. Paying attention to one’s moods upon waking; trying different exercise routines; varying breakfast cereals; testing BG every 5 minutes;… it all counts. It’s the process that is important: making considered decisions to try something, observing its impact, and learning from the experience.

**Stage 3: Understanding**

At this stage, the patient has developed a deep enough understanding of his own health within his own context of living that he can make appropriate small and large adjustments to his health management activities to match changing circumstances. The patient now has a deeper expertise about managing his own T1D than do his clinicians. The clinicians may still have much broader knowledge about T1D in general, but the patient has greater expertise in day-to-day, moment-to-moment management of his condition in the specific context of his own life. The patient has developed a rich mental model of his life, of appropriate ways to respond to tribulations, and the likely effects of interventions.

Note that for the patient to achieve such deep understanding of his condition he must be actively involved in the experimentation and analysis. Automatic tools and/or experimentation by someone else (e.g. a clinician) is not good enough. Similarly, patients who are too passive or cautious, who depend on direction and approval by health professionals may not be able to develop the deep understanding required to gain mastery.

**Transition: Stage 3 to Stage 4**

Mastery of T1D management based on a rich, personal, mental model developed in Stage 3 enables good health, and may lead to stable health (Stage 4).

**Stage 4: Stable health**

At this stage, the patient enjoys stable health. Feeling well is the normal state, and everyday self-management is routine. Especially for complex conditions like T1D, this is not a passive existence. The patient is actively involved, continuously making small adjustments (consciously or instinctively) to maintain stable health within the normal variations of life. Those who have achieved Stage 3 level understanding are more resilient than those who have only mastered Stage 2 level T1D management; they are able to maintain stable health through much greater life turmoil.

Many things can cause the patient to retrogress, to move back to earlier stages. Three major causes are highlighted in the model. For simplicity, the CCHSM model shows these changes occurring after Stage 4; in reality they can happen at any time.
Context change
Context change refers to changes to the person’s environment (home, work, society, geographic, financial, etc.). Such changes can directly destabilize health or cause changes to the patient’s condition. Sometimes small changes in context snowball into major problems (a loss of a babysitter leading to a job loss leading to loss of healthcare coverage leading to …). Some people enjoy very stable lives, but for others significant and ongoing context changes outside their control are a fact of life. Even changes that are overall positive can cause some ill-health in the short term, until the patient adjusts to the changes.

Condition change
Condition change means changes to the body itself including life phases (e.g. puberty, pregnancy, aging), significant changes to the underlying illness, new illnesses and disabilities, and the consequences of accidents. Certain medical treatments, such as surgeries (transplants, ectomies, etc.) and devices (insulin pumps, defibrillators, etc.), can also be considered condition changes. Condition changes may lead to unstable health and/or prompt changes to the patient’s regimen.

Regimen change
Regimen change means any change to the day-to-day routine. This includes changes to medications (new drugs, dosage, timings), technologies (glucometers, CGMs, etc.), but also changes to any aspect of living (diet, exercise, therapies, sleep, etc.). The patient needs to accept this new pattern to again reach Stage 1. While many regimen changes are easily accepted and make a positive impact on the patient’s health, sometimes even seemingly minor changes can have significant and challenging impacts. Regimen changes can sometimes destabilize health significantly, leading back to Stage 0.
Personas and the *Continuous Cycles of Health Self-Management model*

Key aspects of the personas can be highlighted using the CCHSM model.

**Samantha Lewis**

Samantha’s life with T1D has been a journey from unstable health at initial diagnosis, through a long period of increasing mastery of T1D management, and then back to unstable health due to a dramatic change in circumstances. Figure 2 depicts Samantha’s journey on the CCHSM model:

1. The onset of T1D
2. Initial achievement of stable health through very regimented and circumscribed living
3. Discovery that a fuller life is possible
4. Cautious experimentation leading to greater mastery and confidence in self-management
5. Transition to college impose context and regimen changes too much for Samantha
6. Leading back to unstable health and highlighting the limits of her mastery
Samantha and her mom seemed to have been doing so well. Samantha had a stable, supportive home and community. She had learned how to manage T1D while enjoying a full life. Presumably her clinicians had supported and been pleased with her progress. And yet she now finds herself in deep trouble, because of changes that many others cope with much better. Looking at the model, looking at Samantha’s journey, we can ask ourselves what, if anything, might have been done differently and these different stages, so that Samantha wouldn’t find herself in trouble now?
Kayla Robinson

Figure 3 highlights the challenges that Kayla faces in coming to grips with T1D, including her difficult life, with major, recent context changes and constant flux in day-to-day living. The advice of Kayla’s clinicians is having little impact, as Kayla feels she’s not being heard.

Given Kayla’s very real psycho-social challenges, what can Kayla’s clinicians do to improve her health, to support her life?
Carlos Perez
Carlos is well-cared for by his mother Maria (mainly) and father David. As highlighted in Fig 4, soccer has played a big role in Carlos’s life, including his management of T1D. Soccer has provided motivation to master T1D but also imposed significant practical challenges. It has taught the skills and value of discipline, while also requiring disciplined experimentation and observation. Carlos and his family's initial response to T1D was aided by having familiarity with T1D through a friend, and by Maria being able to leave her job and stay at home.

Carlos may be a “poster child” for pediatric T1D. This persona also raises interesting questions. What, if anything, could or should clinicians do to further support the family? Also, what could clinicians learn from this family? Can the family’s hard won knowledge and expertise help other families, or even help clinicians better understand T1D?

Figure 4

Type 1 Diabetes Ecology Model
Eric Clark

Eric Clark is a capable, experiment-savvy, self-reliant adult. As highlighted in Fig 5, he has a deep understanding of managing his life with T1D, mastered over 26 years of careful observation and experimentation. Mastery does not imply perfect control however, and health setbacks have occurred. His self-sufficiency is also a source of worry for his wife.

Similar to persona Carlos Perez, Eric is an exemplary person with T1D. What can be learned by professionals from such expert patients? How could such learning be done?
**Linda Martin**

Linda is a widowed, older adult with multiple significant health issues in addition to T1D. As highlighted in Fig 6, Linda has managed to cope well with many, major changes. She’s a “good patient” in the sense that she is willing and able to follow her care team’s advice as well as possible. But, unlike persona Eric Clark, doesn’t look too deeply into managing health. Her energies are devoted to the social activities she enjoys.

Linda has several major but unrelated health issues, and unfortunately her care team is no “team”. Many of them have little understanding of T1D. How could the health system be more of a team, and would that lead to significantly better health and life for Linda?

Figure 6
Anna Smith
Anna’s young daughter Penelope has only recently been diagnosed with T1D. As shown in Fig 7, Anna, her family, and others important in Penelope’s life are only starting to learn how to adjust to the new demands on their lives.

Figure 7
Helpful and unhelpful professional caregiver interventions

Healthcare professionals and institutions can have a huge impact, positive or negative, on the lives of their patients. Key themes raised by patients, family caregivers, and clinicians are here placed in the context of the CCHSM model.

Stage 0: Unstable health

<table>
<thead>
<tr>
<th>Helpful</th>
<th>Unhelpful</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Access to health professionals</td>
<td>• Lack of knowledge of T1D by non-specialists (pediatricians, GPs, etc.)</td>
</tr>
<tr>
<td>• Rapid, accurate diagnosis</td>
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</table>

Transition: Stage 0 to Stage 1

<table>
<thead>
<tr>
<th>Helpful</th>
<th>Unhelpful</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Empathy</td>
<td>• Confusing environment: rushed; too many people</td>
</tr>
<tr>
<td>• Clear explanation &amp; training</td>
<td>• Lack of empathy; blame; condescension</td>
</tr>
<tr>
<td>• Support (practical; emotional)</td>
<td>• Financial burdens</td>
</tr>
<tr>
<td>• Financial assistance</td>
<td>• Poor explanation and/or training</td>
</tr>
<tr>
<td>• Introduction to others like the patient</td>
<td>• Kafkaesque healthcare systems</td>
</tr>
</tbody>
</table>

Transition: Stage 1 to Stage 2

<table>
<thead>
<tr>
<th>Helpful</th>
<th>Unhelpful</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Treatment tailored to patient’s unique condition(s), context and capabilities</td>
<td>• Complex, difficult regimens</td>
</tr>
<tr>
<td>• Clear and easy-to-do regimens</td>
<td>• Ignoring patient’s other chronic or temporary health issues</td>
</tr>
<tr>
<td>• Easy access to affordable supplies (medications, devices, …)</td>
<td>• Ignoring patient’s practical challenges</td>
</tr>
<tr>
<td>• Easy and timely access by patients to the right care team members</td>
<td>• Lack of time to help patients with “small things”</td>
</tr>
<tr>
<td></td>
<td>• Special case for in-patient situations for patients with T1D in for non-T1D issues: improper management of T1D regimen and diet by nurses and doctors, combined with not allowing patients to self-manage</td>
</tr>
</tbody>
</table>
### Transition: Stage 2 to Stage 3

<table>
<thead>
<tr>
<th>Helpful</th>
<th>Unhelpful</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Support and encouragement of patient’s self-learning activities; respect for patient’s perspectives, ideas and initiative</td>
<td>• Paternalism; overemphasis on “consult your doctor first”; making patient too fearful to make own adjustments</td>
</tr>
<tr>
<td>• Easy and timely response to patient questions</td>
<td>• Ridicule of patient’s ideas; lack of interest in and support of patient’s own experiments and learning</td>
</tr>
<tr>
<td>• Teaching self-experimentation skills</td>
<td></td>
</tr>
<tr>
<td>• Support/encourage peer-to-peer learning (patients talking with and learning from each other)</td>
<td></td>
</tr>
</tbody>
</table>

### Stage 3

<table>
<thead>
<tr>
<th>Helpful</th>
<th>Unhelpful</th>
</tr>
</thead>
<tbody>
<tr>
<td>• True collaborative partnership with patient/caregiver</td>
<td>• Lack of acknowledgement of patient’s (or family caregiver’s) expertise; unwillingness to actively engage in shared decision-making</td>
</tr>
<tr>
<td>• Willingness to learn from patient</td>
<td></td>
</tr>
</tbody>
</table>

### Context change

<table>
<thead>
<tr>
<th>Helpful</th>
<th>Unhelpful</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Continuity in patient–provider relationships</td>
<td>• Dramatic changes in institution, staff, procedures, etc.</td>
</tr>
<tr>
<td>• Smooth, personalized transitions (such as pediatric-to-adult, or clinic-to-clinic)</td>
<td>• Rushed, inflexible transitions</td>
</tr>
</tbody>
</table>

### Condition change

<table>
<thead>
<tr>
<th>Helpful</th>
<th>Unhelpful</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Cures</td>
<td>• Medical mistakes</td>
</tr>
<tr>
<td></td>
<td>• Over-treatment</td>
</tr>
<tr>
<td></td>
<td>• Negative drug interactions</td>
</tr>
<tr>
<td></td>
<td>• Infections (due to presence in clinic)</td>
</tr>
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</table>

### Regimen change

<table>
<thead>
<tr>
<th>Helpful</th>
<th>Unhelpful</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Easier regimens</td>
<td>• inflexibility of a new clinic to work with patient’s existing regimen based on his previous clinic’s practices</td>
</tr>
<tr>
<td>• Easy, rapid access to required medications and supplies</td>
<td></td>
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</table>
Making Use of Personas, Themes, and the Continuous Cycle Model

Our goal for the work we conducted as a part of this project was to create a set of tools that would be useful to the members of the teams who are designing and building the T1D learning health network.

Very often, a design process begins with a specific idea for a product or service. In this case, the design research and persona generation is done in order to explore in detail the specific problems to be solved or improvements to be made. In the case of the emerging T1D network, though, our personas, and models were created to help the team explore various possible kinds of interventions that might be tested for their effectiveness in improving the lives of people with T1D.

The personas, themes, and Continuous Cycle Model presented above should be useful starting points as the team begins to think about creating this network and the interventions that can be tested within it. These design tools can be useful during any kind of design methodology or activity, as they help to ensure that people living with T1D are represented within the creative process. The design process itself is iterative and organic, and these tools can be used at any stage in the process.

Though not comprehensive, the following sections provide some additional guidance on making use of the design tools included in this document.

Starting with Personas

The personas can be used to generate ideas for innovation. One can start by envisioning the persona’s goals, both those explicitly described in the persona and further insights generated by the design team. What might the persona himself say he wants? (Think specifically about one of the personas — Kayla, Carlos, Samantha, et al — and not just about some generic person.) How could these goals and wants be acknowledged (so the persona knows he is understood)? What can be done to address these wants? How should the care team respond to goals and wants that are well beyond the team’s ability to satisfy? One can also consider what the clinical team believes is important for this persona? How can the team help the persona understand that this is important, and get their buy-in? What innovations does this inspire, does this close examination lead to?

Assuming we make progress with these innovations, how do we envision the future unfolding for this persona (using the Continuous Cycle model)? What new challenges, goals, wants will arise? What could be done now to prepare for that? What innovations are needed now to address these future issues?
While our personas do not represent every possible context and circumstance in the T1D ecosystem, the range of differences across individual personas along various factors should provide good opportunities to examine the range of obstacles, skills, attitudes, behaviors, and situations that exist.

Starting with Themes
The themes may also be good starting points for brainstorming innovation concepts. What new products, services, processes, etc. might address the needs described, or alleviate the challenges presented, in the themes?

Starting with the Continuous Cycle of Health Self Management Model
The different stages and transitions in the model can also be used to generate innovation concepts. New ideas to help in “Stage 0: Unstable health” may be very different than those for assisting in “Stage 3: Understanding”, for example. The ideas noted in the “Helpful and unhelpful professional caregiver interventions” section are a good starting point. What can be done to encourage, support and strengthen the helpful interventions? What can be done to minimize, mitigate or overcome the unhelpful actions and situations?

Staring with Concepts
When innovation concepts are generated through other means, the personas and the model can be used to evaluate and expand them: Which persona(s) would this idea help, either now or in their envisioned futures? For which personas, if any, is this idea something that they would say “I really want that!” — for whom would this be obviously and immediately compelling? How much of a difference would this innovation make to the personas’ lives right now, or in the very near future? How clear is the cost-benefit ratio, to the patient, to the care team? How could the idea be improved to make it more compelling? If the idea doesn’t seem relevant to any of the personas, is there some other group of people (some other persona) for whom it is?

In evaluating concepts against the personas, imagine them as real people and consider fine-grained questions, such as: Why would this (concept) help ‘Kayla’ achieve her goals? How would ‘Carlos’s mom’ want this to work? How would ‘Eric’ react differently to this than ‘Linda’? How and when would ‘Samantha’ use/do this? How will this help the care team be confident that ‘Carlos’ is fully prepared for transition out of pediatric care?
Further Model Development

As noted earlier under “Provisional Personas”, there are several patient/family situations that were not included in this ethnographic study but are felt to be important by the larger project team. If these are indeed important, then we would strongly recommend interviewing several such people to generate appropriate personas.

Similarly, the range of clinicians interviewed may be far from representative of the range of interests, needs, and challenges of the larger T1D clinical community. And hence the personas may be too limited. If so, a continued study with a much wider group of participants would lead to a much improved set of clinician personas.

Finally, once the list of innovation concepts has been filtered down to a selected few with high-promise, then a more focused ethnographic study would prove to be very important. Such a study would focus on specifically the types of people, and the specific tasks, that a selected concept is targeted towards. For example, if a decision was made to pursue the “Try Anyway Club” (one of the ideas generated during the first Design Meeting), one would interview high schoolers to deeply understand their needs, interests, desires and challenges around peer-to-peer, chronic illness-related support and learning, and their responses to this specific idea.
About the Authors

John Chaffins is an independent health innovation and design consultant, working in collaboration with Wondros, where he leads teams that define, design, and create custom online environments that forge meaningful, creative, and healthy relationships. He leads Wondro’s design efforts with the Collaborative Chronic Care Network (C3N) at Cincinnati Children’s Hospital, where ethnographic based behavior design is creating digital tools that allow a nationwide network of patients, family members, physicians, and researchers to collaborate and improve the care of children with Crohn’s Disease. Prior to joining Wondros, John applied his extensive background in medical records administration and technology to design, develop, and implement systems that allowed physicians to receive real-time data about their patients in a network of more than 320 acute care hospitals across the country. He has also held directorships at Cross Country Healthcare and JFK Medical Center, among other prominent healthcare organizations. At Cross Country Healthcare, he led a team of designers and developers that built an enterprise-grade online career management system, including mobile applications for traveling nurses. John has a degree in Health Information Management from The Ohio State University. (jchaffins@gmail.com, 305/323-3260)

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