## Assisted Lows: Collaboratively Finding Ways to Support T1D Patients During Hypoglycemia Episodes

Lisa M. Semidey Capriles

Submitted to the faculty of Herron School of Art and Design in partial fulfillment of the requirements for the degree Master of Fine Arts in Visual Communication Design Herron School of Art and Design Indiana University

May 2017

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## Thank you! / ¡Gracias!

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This thesis is dedicated in loving memory of Kaytee Torres. We lost you too soon my friend. Thank you for inspiring me.

# Contents

| Abstract 8                               |
|--|
| FRAMING                                  |
| Question + Sub-Questions12               |
| Justification14                          |
| Research Limitations23                   |
| CONNECTING                               |
| I. Understanding Needs27                 |
| II. Understanding Users31                |
| III. Co-Designing with Users35           |
| IV. Developing the Mobile Application 44 |
| I. Evaluating Answers66                  |
| DECODING                                 |
| In Conclusion                            |
| Bibliography80                           |
| APPENDIX                                 |
| Glossary84                               |

## Abstract

This research focuses on how hypoglycemia episodes

—low blood sugar events spark specific communication **needs** in Type 1 Diabetes (T1D) patients. As a 22 year T<sub>1</sub>D veteran, I've personally faced challenges when needing, requesting and receiving an adequate response to help me overcome an episode. This research is born out of the knowledge that other people want to genuinely help, and aims to close the gap between a failure of knowing 'what to do' and effective actions.

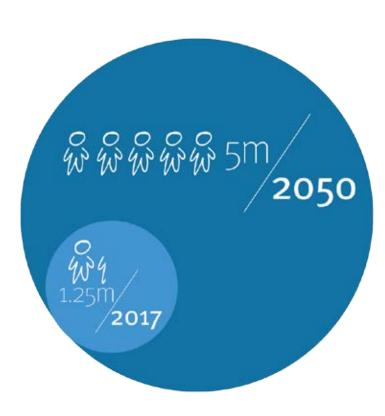


Figure 1 presents JDRF
Statistics projecting the growth
of Type 1 diabetes diagnosis
from present day to 2050.

The Center for Disease Control (CDC) said "Diabetes is becoming more common in the United States. From 1980 through 2014, the number of Americans with diagnosed diabetes has increased fourfold (from 5.5 million to 22.0 million)." While diabetes (types 1 and 2) incidence is growing, non-diabetics are not necessarily equipped with the correct knowledge to aid a patient in need. Small key steps can aid in the facilitation of effective communication. Even though T1D diabetes has a common diagnosis, the experience and solution to the problem is unique for every patient. There is space to explore the impact of visual and gesture-based communication as an alternate means of creating effective, responsive, and helpful communication. This research plans to test this out.

On the one side, different T1D patients will be involved and evaluated using a people-centered methodology. Then, participants who have already aided T1D patients in the past will be brought into the conversation to serve as contrast. Common experience will serve as the starting point and dissonance in understanding will serve as context for possible explorations.



# Framing

# Question + Sub-Questions

How might mobile applications facilitate effective communication between responders & T1D patients during hypoglycemia episodes?

**MOBILE APPLICATIONS** emerged as the simplest way to facilitate the experience since the use of Smartphones is prevalent among T<sub>1</sub>Ds and Responders alike.

**EFFECTIVE COMMUNICATION** within the context of this thesis refers to the patient successfully requesting help, and an appropriate response from the responder.

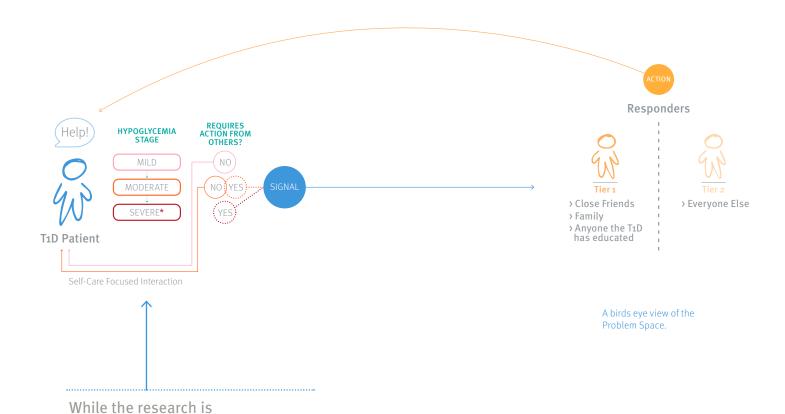
**RESPONDERS** can refer to anyone the T1D patient is in contact with who could respond to the call for help. While professionals with medical training will know what to do, they are not available to the patient 24/7. The research will consider other people the patient can be in contact with, such as co-workers, classmates or passers by on the street. Although family members and close acquaintances might not have medical training, it can be assumed that they have received instructions from the patient or medical staff on the proper course of action.

**T1D PATIENTS** are distinguished from Type 2 Diabetes patients because they experience hypoglycemia (lows) more often than Type 2's. Type 1 Diabetes, an autoimmune disease that prevents the pancreas from producing insulin. The lack of production of insulin requires patients to follow care regimens that balances nutrition, exercise, glucose testing and insulin therapy. The constant flux of these 4 pillars can lead to hypoglycemia episodes.

**HYPOGLYCEMIA EPISODES** also knows as "lows", are when blood glucose levels (BGL) drop below 70 mg/dl.

The research is framed through exploration of the varying needs in the three stages of hypoglycemia, **Mild**, **Moderate**, and **Severe** Episodes.

- 1. What are the needs of a T1D patient during the three stages of hypoglycemia episodes?
- 2. What are the needs of an untrained responder in order to provide effective aid during each type of hypoglycemia episode?
- 3. What interactions with the tool will enable communication between the T<sub>1</sub>D patient in need of help and the responder?



framed through all stages of

in this thesis project.

hypoglycemia, the findings in the

research point to **Moderate**, and **Severe** Episodes as the key areas of focus for the solution developed

# Justification

"The average patient suffers untold numbers of asymptomatic episodes, two episodes of symptomatic hypoglycemia per week (thousands of such episodes over a lifetime of diabetes), and one episode of severe, temporarily disabling hypoglycemia, often with seizure or coma, per year"

The Clinical Problem of Hypoglycemia in Diabet

The experience of every T<sub>1</sub>D patient is unique. Many factors can affect their experience including length of time with the condition, the support network they have around them and how rigorously they care for their condition. While all these may provide a positive or negative outlook on the condition, the experience of hypoglycemia itself can be a scary complication. While some patients may experience it more often than others, hypoglycemia can occur as frequently as twice a week for T<sub>1</sub>D patients'<sub>1</sub>. This was reported initially in the Diabetes Control and Complications Trial (DCCT) back in 1993 and the data reflecting the incidence of severe hypoglycemia episodes has remain mostly unchanged since. Mild and moderate episodes are harder to report because they would require studies that utilize more constant monitoring technology to truly detect the episodes instead of self-reporting from patients<sup>2</sup>. The fact that the numbers of episodes hasn't shifted, supports the need for the research.

Understanding that the numbers have not shifted, points to a problem that has yet to be solved. Bringing in patients as participants through participatory design allows for solution exploration that is aimed at solving the problem that science alone has yet to resolve fully.

## Yearly, 298,000 T1D patients

visit the Emergency Department due to Hypoglycemia (CDC, 2014)

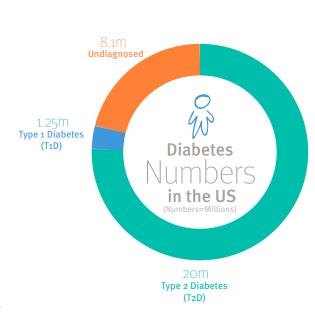
Some technology such as Continuous Glucose Monitors (CGMs) has emerged in the past few years but has yet to meet universal adoption. In the March 2015 meeting of the American Association of Diabetes Educators, the group pointed out many positive features of CGMs but also highlighted some challenges such as, unrealistic expectations from the patients, alarm fatigue or obsession, skin issues and cost<sup>3</sup>. Understanding the pros and cons of CGM technology helps position possible solution and might inform criteria for evaluating said solutions.

## Diabetes & Hypoglycemia

According to the American Diabetes Association (ADA) website, a 2012 survey showed 29.1 million Americans had diabetes. Of those 29.1 million, 1.25 million Americans have type 1 diabetes (T1D), 20 million have type 2 diabetes (T2D), and 8.1 are undiagnosed<sup>4</sup>. The projected growth for T1D in the United States is 5 million patients by 2050. T1D, previously known as juvenile diabetes, is a chronic autoimmune disease in which the pancreas produces little or no insulin, preventing glucose to be used by cells in energy production<sup>5</sup>. T2D, previously known as adult onset diabetes, is a chronic metabolic disease where the body has trouble producing enough insulin to handle food intake. The lack of insulin in T1D patients requires a care regimen designed by health team, usually comprised of an endocrinologist, a nutritionist, and diabetes educators (among others); that emphasizes a careful balance of nutrition, exercise, glucose testing and insulin therapy.

The focus of this research will be looking at the life and contexts of adults with T1D, especially focused on the hypoglycemia episodes they experience. Because of the complexity and required rigor of their care regimens, T1D patients experience hypoglycemia episodes more frequently than T2D in the pursuit of achieving strong glycemic control. Not only is it frequent and frightening, it is considered a fact of life for all T1D patients<sup>6</sup>.

Hypoglycemia, which is when blood sugar levels drop below 70mg/dl, is seen as a true medical emergency requiring immediate corrective action. There are many causes for hypoglycemia, some are patient triggered, but the most common are delayed meal times or too little food consumption, an excessive insulin dose or more physical activity than normal.



Statistics taken from the American Diabetes Association. www.diabetes.org

Cryer, Philip E. Hypoglycemia in Diabetes. n.p.: American Diabetes Association, 2016.

<sup>2</sup> Ibid

<sup>3 &</sup>quot;Continuous Glucose Monitoring Summit." CGM Thought Leader Summit. n.p.: Americal Association of Diabetes Educators, 2015.

<sup>4 &</sup>quot;Diabetes Statistics." American Diabetes Association. Sept 16, 2016. <a href="http://www.diabetes.org">http://www.diabetes.org</a> diabetes-basics/diabetes-statistics

<sup>5 &</sup>quot;Type 1 Diabetes Definition," Mayo Clinic, August 2, 2014, accessed September 23, 2016, http www.mayoclinic.org/diseases-conditions/type-1-diabetes/basics/definition/con-20019573.

<sup>6</sup> Shafiee, Gita, Mohammadreza Mohajeri-Tehrani, Mohammad Pajouhi, and Bagher Larijani. "Ti importance of hypoglycemia in diabetic patients." Journal of Diabetes & Metabolic Disorders:

<sup>7</sup> Ibid

<sup>8 &</sup>quot;What Can I Do to Prevent Serious Hypoglycemic Episodes When I Am Hypoglycemic Unaware Joslin Diabetes Center, September 23, 2016, accessed September 23, 2016, http://www.joslin.org/info/what\_can\_i\_do\_to\_prevent\_serious\_hypoglycemic\_episodes\_when\_I\_am\_hypoglycemic\_unaware.html.





**PHYSICAL** 

- Nervousness or anxiety • Irritability or impatience
  - Confusion, including delirium
  - Anger, stubbornness, or sadness
  - Speech impairment
  - Shakiness • Sweating, chills and
  - Rapid/fast heartbeat · Lightheadedness or dizziness
  - Hunger and nausea Sleepiness Blurred/impaired
  - Sweating, chills and
- Tingling or numbness in the lips or tongue
- Weakness or fatigue Lack of coordination

Headaches

- Nightmares or crying out during sleep
- Seizures Unconsciousness
- Coma Death

Symptom information referenced from the American **Diabetes Association** www.diabetes.org

There are varying levels of hypoglycemia severity and each level is accompanied by different symptoms. Mild and moderate hypoglycemia can show varying levels of physical and mental symptoms such as shakiness, dizziness, (cold) sweating, hunger, moodiness or irritability. Severe hypoglycemia requires support and action from others in order to correct because of the corresponding cognitive and physical impairment. While a patient of 5 years might still feel the symptoms, patients spanning over 20 years with the disease may not perceive the symptoms or recognize them before the point that the patients' are too low to self-treat9.

Hypoglycemia, although common, can be complex and unpleasant to handle as a T1D patient. Additional factors of the disease may add unexpected challenges. For example, T1D can be talked about as an invisible condition. Although there is growing acceptance and knowledge within the general public about the condition because of it's accelerated growth and prevalence in the past few years, patients could be challenged with stigmas associated with the condition. Public perception and knowledge, or lack thereof, is a big source of stress and reflection of stigma for T1D patients. Adam Brown from DiaTribe recently discussed the stigmas related to diabetes patients at the 2016 Annual Meeting of the American Association of Diabetes Educators (AADE).

"Diabetes stigma is related to visibility – the more intensive one's therapy, the more stigma was reported. People with type 2 diabetes reported the least stigma if they were only on pills and the most stigma if they were on intensive insulin therapy. Parents of children with type 1 diabetes reported the most stigma.10"

#### Communication

T<sub>1</sub>D patients might not reveal their condition openly for fear of being judged or scrutinized. As Gloria Joachim and Sonia Acorn mention in their Journal of Advanced Nursing article, "The management of information is critical in the lives of people with chronic illnesses and conditions." <sup>11</sup> This is especially critical in a T1D patients life. Lack of disclosure could procure deadly consequences in terms of uninformed medical response or lack of response in the face of erratic behavior, especially in the case of hypoglycemia episodes. Non-disclosure could even have negative consequences in terms of the discovery of diabetes care supplies a patient might carry during social activities, leading to additional stress. It's interesting to consider the difference between the act of disclosure and the act on informing. Joachim and Acorn point to informing as a way to have greater control over the emotions of who shares the information and the responses from the recipients of the information. Disclosure is seen as almost an act triggered by shame and fear, not control<sup>12</sup>. It is important to consider intent in communication by T1D patients during a hypoglycemic episode. Although intent might be present, there are other barriers to consider in communication, providing a possible opportunity space for a tool to aid this exchange.

Non-disclosure of a condition might have negative impact of the patient, but it is interesting to consider the possibility that the condition renders them unable to disclose information in a clear manner. How is the public at large supposed to handle erratic behaviors of an unknown person for unknown reasons? In a crosscontextual example, Japan has taken a step towards the idea of handling unknown people, their unknown behaviors and how the community can help. The city of Matsudo has established Matsudo's Orange Patrol<sup>13</sup>, whose responsibility is to engage with city elders in an effort to make sure that their behaviors are not a

consequence of dementia. Training offered by the Orange Patrol to community members enables them to engage, recognize and react accordingly if they suspect dementia is at fault. A growing aging population is in direct correlation to the amount of Alzheimer's and dementia cases. The brief sessions used to train civilians in how to engage these elders with dementia prevents them from getting lost or finding themselves in dangerous situations. This presents an opportunity that leverages community education and training as a way to aid patients with invisible conditions in a way that is not demeaning or disrespectful, but accepting and understanding of their current state and knowledgeable of how to engage and react. This aspect could be a complement to an overall solution, understanding that main solution touchpoints should be within more direct patient control.

People exist as part of a community and interact with different people, known and unknown on a daily basis. It is important to understand and consider these interactions as possible barriers and opportunities for aiding treatment of hypoglycemia in T<sub>1</sub>D patients. Different daily environments—work, school or social engagements—present different relationships and interactions. Some environments and communities can be supportive to the patient, in contrast some T1D patients have faced challenges and negative consequences because of hypoglycemia in the workplace. It is important to provide them with the proper tools and support to help communicate and manage these episodes<sup>14</sup>. Hypoglycemia sadly does not discriminate by time or place if the contributing factors for the episode align. This variability in daily opens a space for questioning what possible solutions could break down the perceived barrier within the communication loop between T1D patients and the community at large.

Not always, but generally speaking, patients are at fault from progressing from one stage of hypoglycemia to the next. For example, they may be in a meeting, sense the symptoms, but might put off treating because they believe the meeting will be over soon. They might even negotiate with themselves and blame their sleepiness on not sleeping well the night before or might attribute their shakiness to having finished a tough gym session and believe their muscles are feeling the burn. All these delays in action will push the severity of their hypoglycemia episode from mild to moderate. At the point of being in a moderate hypoglycemia episode, short-term and working memory can be affected, therefore posing a barrier in self-treating. Patients might stutter, or find it difficult to recall and parse words or instructions

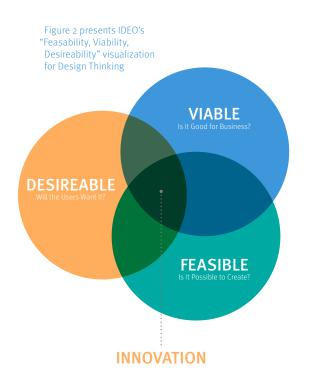
to give to whomever can help<sup>15</sup>. This can bring frustration to the patient and also whomever is available to help if they don't know the proper course of action. The impact of hypoglycemia on cognitive function for the patient is a barrier that cannot be corrected internally by the patient but could potentially be assisted externally through the use of tools—technological or analog in nature—in order to provide the information needed for action from an external helper. The tool itself and trigger steps must be simplified enough for the patient to be able to carry them out in their potential state of impairment<sup>16</sup>, but should provide robust information for the recipient of the message to act in a timely and effective manner.

If looked at as a communication exchange, and understanding there might be limits in the verbal expression during it, visual and gesture based communication could be considered the best alternative forms of transmitting the urgent message. Visual communication surrounds us in daily life in sometimes simple forms such as watches, to more complex forms such as mobile phones<sup>17</sup>. If used simply and precisely, it can potentially have a great impact in a communication experience when other forms of communication might be impaired. In conjunction with visual design, gesture based communication should be considered as well, acknowledging that it is one of the most primal forms of communicating and could be the simplest for T1D patients to use. Common gesture based communications are as simple, and universally recognized, as waving to say hello, or effective in signaling for help as the universal sign of chocking. Leveraging a combination of both visual and gesture based communication presents an opportunity for design to be at the forefront of the solution to this problem exploration. Visual communication and interaction design are key factors to leverage when trying to make a solution that is desirable, feasible and viable 18.

On a daily basis, mobile devices receive visual alerts about many topics. Users are able to see the latest news and score from our favorite teams, alerts from social media platforms such as Facebook, Instagram and Twitter and on more serious occasions, emergency weather alerts (WEA) that are accompanied with a



<sup>6</sup> Ihid



<sup>14</sup> Reid, Brad. "The Hypoglycemic Employee and the Law." Huffington Post (The Huffington Post), July 31, 2014. http://www.huffingtonpost.com/brad-reid/the-hypoglycemic-employee\_b\_5638371.html.

<sup>17</sup> Workshop notes written by Keith Tam. Understanding Visual Arts Work with Functions from Various Perspectives. The Hong Kong Polytechnic University, 2008. http://www.edb.gov.hattachment/tc/curriculum-development/kla/arts-edu/pd/visual%20communication.pdf.

<sup>18</sup> IDEO. "About." 2016. Accessed September 26, 2016. https://www.ideo.com/abou

particular visual and audible cue that allows users identify it<sup>19</sup>. The capacity to be able to send out alerts such as Severe Weather alerts provide an opportunity because it responds to some of the needs of T1D patients during hypoglycemia episodes. The technology and capacity should be used in an appropriate manner relative to the need, but it is interesting to consider this as a possibility to model solutions thinking of the appropriate scale and use for the specific problem the research trying to address.

Although wearable and mobile medical alerts exist, for example bracelets or the Health app on iOS, and are widely used by patients, the information these provide is not necessarily helpful to responders that are not medically trained and can also be complicated to access when needed. These types of alerts are also more geared towards severe cases of hypoglycemia and other medical episodes when the patient is not responsive. Although simple, the steps needed to retrieve the information from the Health App are not as commonly known as desired and might be challenging to perform if unknown to the user. Additionally, some of the medical alert services require sending a call to a call center which dispatches medical help to the patient location, thus adding time and cost to the experience in addition to distance and device limitations that might facilitate the service. Hypoglycemia episodes are time sensitive and shouldn't be treated in the manner as an "I've fallen and I can't get up" 20 situation.

## **People-Centered Design**

Understanding the fuzziness and complexity surrounding hypoglycemia episodes and the possible solutions to aid them is why a Design Thinking methodology is a good fit to address the problem. The methodology can facilitate developing an understanding and appropriate solutions in collaboration with the people affected by the problem space this research intends to study. These are key factors which Design Thinking values and thrives on. Collabo Creative's People-Centered Design Approach<sup>21</sup> will serve as the methodology to guide the research, focusing on framing and solution development. This methodology was selected because at a higher level presents all the necessary steps and components to substantiate design processes following Dorst and Lawson's abstracted "Analysis, Synthesis, Evaluation" model<sup>22</sup>. Collabo's process is divided into 6 main phases: Sensing, Understanding, Framing, Ideating, Iterating and Implementing. Within this thesis project the projection is to reach the Iterating step of the design process, understanding that this is dependent on the results generated in the earlier phases.

## People-Centered Design Approach

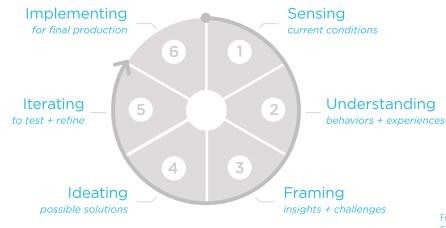
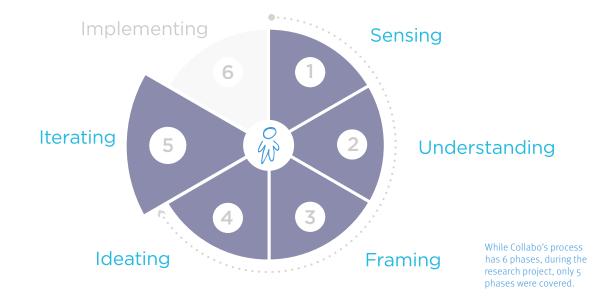


Figure 3 presents Collabo Creative's People-Centered Design Approach.

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## **Phases Addressed During Research**



<sup>19 &</sup>quot;Wireless Emergency Alerts: Weather Warnings on the Go!" Accessed September 24, 2016. http://www.nws.

# Limitations

## **Design Thinking & Diabetes**

This project will not be the first time that Design Thinking and diabetes have met. As far back as 2006, the UK Design Council used Design Thinking processes and methods for their Bolton Design Notes project, targeted at the epidemic growth of T2D in the town of Bolton. According to the Bolton report, 29 new cases of diabetes were diagnosed weekly. In light of the growing numbers, design researchers and designers in the areas of product, service and interaction design were brought in to research within the community and develop and iterate the end-product known today as the Bolton Design Notes<sup>23</sup>.

These cards were designed as a way to enable patients to take their care into their own hands and guide conversations with their care providers about topics they felt were important and necessary to learn about, not just the physicians' agenda. IDEO, a known heavy hitter in the design innovation and design thinking world, has also jumped into using design thinking to help problem solve issues around diabetes. They developed Prevent, now Omada. Prevent was developed as a 16-week personalized program that supported T2D patients in reshaping their behaviors in order to achieve their diet and exercise goals<sup>24</sup>. Observing the landscape, most of the efforts surrounding diabetes and Design Thinking are solely focused on T2D and not T1D. Although it's understandable that T1D has more variables at play that add complexity to possible solutions, it is important to understand that because of this, the patient population might need more help in facilitating their day to day.

It is useful to note that feeling supported within a network can have positive effects on the T<sub>1</sub>D patient. If this feeling of support in conjunction with technology can be leveraged, it can provide a useful and powerful solution for T1D patients experiencing hypoglycemia episodes. This concept of a support network was highlighted in an article in the Journal of Diabetes Science and Technology, reviewing the use of User-Centered Design for Diabetes-Related Consumer Health Informatics Technology, known as CHIT. The study found other positive outcomes from user inclusion in solution development were better adherence to care regimens and expanded knowledge about T<sub>1</sub>D<sup>25</sup>. Developing user informed CHIT for diabetes management presents as a great opportunity space that can address a variety of pain points in T1D patient experience such as hypoglycemia, medication adherence and glucose testing. One of the main goals of user-centered design for diabetes related CHIT is to empower the patient in the chronic disease management<sup>26</sup>. This proves most compelling if it's possible to do so in a moment of critical need.

While this research is focused around a T1D patient population, it is not approaching the condition and challenges from a medical standpoint, but more so from the patient experience standpoint. Care regimens, dosing and response plans are not within the scope of the research. These are established with the medical professionals within the patient's care team and should remain unaffected by the research or outcomes of this thesis project. The solution is focused on solving the communication challenges faced by the patient and those who may help during a hypoglycemia episode. It is also important to understand that the research does not intent to develop a new device, but to leverage existing devices to serve T1D's needs during hypoglycemia episodes. It is important for this research to leverage design, especially a co-design approach, because T1D patients rich personal experience serves as their expertise.

The complexity of T1D also offers a possibility to explore other challenges in patient experiences such as hyperglycemia, or high-blood sugar, but considering the deadline constraints on the thesis project it will only focus on hypoglycemia, acknowledging its inherent complexity. Further research or solution development could extend the scope of the designed solution not only to hyperglycemia episodes, but to other medical conditions that face similar communication challenges.

It is important to note that while some expert validation on the solution outcome, the ideal process would have included a more active working relationship between the interaction subject matter expert and the designer in order to address certain technological limitations and future development opportunities.

<sup>23</sup> UK Design Council. Design Notes o2 the Diabetes Agenda 1 Design Council RED Health Report. The RED Health Report: UK Design Council, 2006. http://www.corposem.org/sinc/boltondesignnotes.pdf.

<sup>24</sup> Komeya, Remi. "Back to Basics: Behavior Change Networks." Decembe 13, 2012. Accessed September 24, 2016. https://designthinking.ideo. com/?tag=diabetes.

<sup>25</sup> LeRouge, C. and N. Wickramasinghe. "A Review of User-Centered Design for Diabetes-Related Consumer Health Informatics Technologies." Journal of Diabetes Science and Technology 7, no. 4 (2013): 1039–56. Accessed September 24, 2016. doi:10.1177/193229683300700429. http://jdst.org/ https://dxidos/1/01.74.085/3. LEROUGE pdf



# Connecting

# CONNECTING

In order to develop a solution to respond to the thesis question, various research engagements were developed as ways to integrate the two main stakeholder groups into the development process. It was essential to bring both the T1D patients as well as Responders into the process in order to understand expectations and needs from both sides of the problem. Both sets of stakeholders were asked to participate in the following phases of the research:

- I. Understanding Needs
- II. Understanding the Users
- III. Co-Designing with the Users
- IV. Developing the Mobile Application
- **V.** Evaluating the Answers

# I. Understanding Needs

#### Methods and Tools Used

The first step to respond to the thesis question was to understand both the needs of T1D's and the Responders that assist them during hypoglycemia episodes, or "lows" as T1D's colloquially identify hypoglycemia episodes. In order to be able to understand the needs, two different research methods were employed. A digital cultural probe¹ was used to engage with T1D's. A probe method was used for this group of participants because it allowed them to reflect on their experiences, past and present, with more time to provide insightful answers and the opportunity to provide photos to support their story. The probe was sent to three T1D participants through an application called Cluster, which allowed each participant to have their own channel with the researcher in order to protect their identity during the 5 day engagement.

Through the application, each participant received the following prompts per day:

#### DAY 1

How long have you had diabetes?

What system do you to treat it (glucose tester, insulin pump, CGM, multiple daily injections...)

## DAY 2

In a typical week, how often do you (physically or via your CGM) notice you're experiencing a low?

How do you treat your lows? Do you have a kit or something for it? If you do, what it contain?

#### DAY 3

Now think back a little, remember a particularly memorable/ extreme/difficult/severe hypoglycemia episode you've experienced. What was that like and how long ago was it?

<sup>1</sup> Hannington, Bruce, Bella Martin, and Bruce M. Hanington. 2012. Universal Methods Of Design 100 Ways To Research Complex Problems, Develop Innovative Ideas, And Design Effective Solutions. Gloucester, MA, United States: Rockport Publishers.



A digital Cultural Probe screen from Patient 2's responses.

Tell me how did you notice, what you did to correct it, did anything/anyone aggravate you, did you need help from anyone around you, what was difficult for you?

#### DAY 4

What do you need others to know when you're experiencing a hypoglycemia episode? It could be anything. You could talk about what to give you during the episode. How to approach you (or not. What to say. What's OK and not OK to do...)

During a hypoglycemia episodes, what needs do you have that are currently not being met? Even if it seems far fetched, it's OK to imagine outside the box here.

These questions were prepared following a scaffolding structure that began with understanding the condition history and context per participant in more general terms, then moved into more specifically talking about lows and their experiences and systems for handling them. After understanding the condition context, questions focused more on understanding the needs of each T1D when they experienced lows and what ideal solutions could respond to the needs they shared. Following this scaffolding progression allowed participants to ease-in to the activity as well as develop more focused responses.

While this digital variation of the Cultural Probe proved useful in terms of collecting data and being able to prompt participants remotely (while providing them some time to think over each prompt), it proved to be a difficult method to set up and initiate. Initially, 6 participants had shown an interest in engaging in this research activity, but, in the end only 3 actually completed the necessary set up steps to go through the process. A possible explanation for the lower follow through is the way that the set up ask was handled. The complex set up instructions was provided via email. In the future, researchers might consider a phone conversation or in person meet up to go over set up details. This way the researcher could coach or assist the participants during the set up, removing some of the workload on the participants end. Also, the fact that it was a digital engagement put some distance between the participants and the researcher, adding to the sense of disconnection and allowing the participants to feel less obligated to complete the steps to be able to participate.

For the responders, in-person interviews were set up. During the interviews, the researcher recorded the responses to questions on a worksheet (include image of worksheet with call out of the main categories on the sheet) as a way to keep the responses organized for the post-interview analysis phase. Scaffolding was also used to set up the questions in a framework similar to the Cultural Probe prompts. The first step was to establish the context of how they

knew the T1D they helped through a (or many) low. After understanding the history, the conversation pivoted towards understanding the details of a memorable low they helped out in and then understanding their feelings and needs as responders.

Four responders participated in the interview engagement. Because one of the responders was married to a T1D, a hybrid method evolved where both the T1D and responder were present at the same time. While the hybrid method was not originally part of the planned research activities, the ability to have both stakeholders present during the interview enriched the responses for the interview and the probe. Since the T1D participant had agreed to participate in the Cultural Probe, the sequence of probe prompts was asked during the in-person meeting. Just like the T1D added comments about their side of the low experience during the responder interview, the responder also filled in any gaps or added additional insights into the cultural probe responses. It could be recommended to researchers that are trying to understand complex experiences from two perspectives bring the different stakeholders together to gain more detailed responses as a way to enrich the understanding to be gained from the interviews.

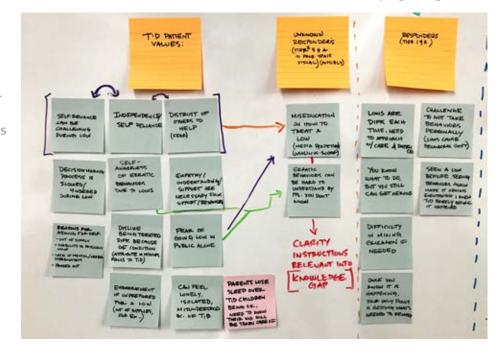
## **Collected Data & Analysis**

In reading the data collected from the cultural probes, certain themes started to surface in the participant responses. The data was transcribed to Post-it notes in order to aid theme-based sorting and clustering. The affinity diagramming<sup>2</sup> method used facilitates moving

individual pieces of data around to find groups that allow building intuitive relationships around a common theme. Relationships can also be established among the different thematic clusters. While affinity diagramming was done after each individual research method, it was also used to compare responses from different methods.

For the probe method, the most prevalent themes that came up were fear, distrust, self-awareness and a deep sense of independence and self-reliance on the part of the type 1 participants. The complex relationship between all of these

Analysis process of collected data through affinity diagramming.



<sup>2</sup> Martin, Bella, and Bruce M Hanington. 2012. Universal Methods Of Design. 1st ed. Beverly, N Rockport Publishers. 12-13

Visualization of analysis result from the Cultural Probe and Interview data.

emerging themes can complicate the relationship they have with the disease, and can also establish barriers to responders. The T<sub>1</sub>Ds also provided some insights that fell more onto the responder side of the equation that theirs. For example, the awareness that not everyone knows the correct way to remedy a low or that lows can be hard to identify from an outsider's perspective unless the responder is knowledgeable. Both of these insights point to a knowledge gap from responders. For the interviews, some of the most common themes that emerged were how lows can be different each time, T1D's range of behaviors and how they may affect the responder, and how anxiety can affect responders even if they have helped a T1D through lows before. It is important to note, that the responders that participated were Tier 1 responders, or responders that have someone in their lives with type 1 diabetes and know what to do. Their responses to the interviews reflect some sense of prior knowledge and experience. Tier 2 responders are the type of responders that may fall into the role of responder not because of the knowledge they have, but because they were accessible at the moment of need. Tier 2 responders are those the T<sub>1</sub>Ds are worried have a knowledge gap, and would need guidance in order for the call for help to be handled appropriately.

# II. Understanding the Users

#### Methods and Tools Used

While the previous methods helped develop an understanding of the user's past experiences and perceived needs, it is important to develop personas<sup>3</sup> as a tool that facilitates framing a generalized understanding of experiences, motivations and needs to help evaluate proposed solutions. Personas of the patient and the responders will serve as a tool to show the solution in action, presenting both sides of the interaction surrounding the low, the communication exchange and the solution in action. This type of method falls into the convergent thinking side of the modes of inquiry. Although persona development was scheduled to be done earlier during the research phase, it happened after the co-design session instead of before. While no specific data from the session was used in the context of developing the personas, researcher observations from the participants' behavior during the session provided some additional depth that enriched the three personas developed.

While the most clear segments of personas within this research are T1D and Responders, it was not essential to develop all types of Responder personas. As mentioned previously, within the context of this research, responders have been categorized into two tiers. Tier 1 represents the type of responder that either has a close relationship with a T1D, or has been educated on what to do in response to a low. Tier 2 represents the type of responders that may fall into the role of responder not because of the knowledge they have, but because they were accessible at the moment of need. Tier 2 responders also represent the group that T1Ds are most preoccupied about because they said they feared going low in public alone because of an overwhelming knowledge gap they identified during the cultural probe method.

The framework used to build the personas featured 3 main categories: background information, care regimen details (if a T1D) and lifestyle or daily routine. It was important to define these three categories for each persona because they help paint an archetype that can help identify the reasons behind why they might need the solution developed and how they might interact with not only the solution, but the responder.

<sup>3</sup> Hannington, Bruce, Bella Martin, and Bruce M. Hanington. 2012. Universal Methods Of Design: 100 Ways To Research Complex Problems, Develop Innovative Ideas, And Design Effective Solutions. Gloucester, MA, United States: Rockport Publishers.



Kaytee, 32 F T<sub>1</sub>D for 20 yrs

## Background

- Has experienced many Severe Lows, especially while pregnant. Glucagon had to be used twice during those severe lows.
- Married, mom to six year old Mia, who also has T<sub>1</sub>D

T<sub>1</sub>D Care • Medtronic Insulin pump, Dexcom CGM, Bayer Meter, iPhone, Family.

- Lifestyle Is always on the go! Constantly runs errands independently and values her freedom.
  - Fears going Low while alone in public, "Not everyone understands what to do." Wants to make sure she'll be OK.



Alicia, 46 F T<sub>1</sub>D for 12 yrs

- Works at a diabetes related company.
- Experiences lows daily. More often when the weather is nice out.
- Has handled T<sub>1</sub>D as a single person since her diagnosis, was previously married.
- Affrezza Inhaled Insulin, Dexcom CGM, AccuCheck Meter.
- Likes to keep active and be outdoors. Has experienced lows frequently while bike riding or hiking.
- Is proud to be an independent woman, sometimes to a fault, especially when she goes low and is resistant to treating.



Rich, 22 M No connection to T<sub>1</sub>D

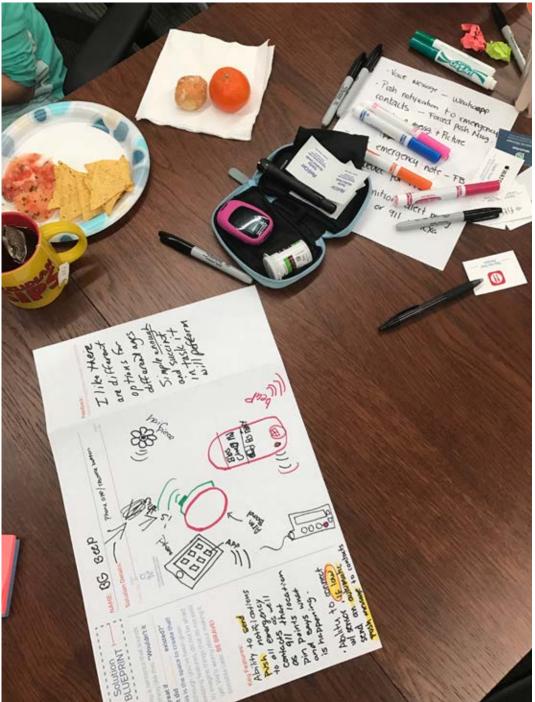
## Background

- University Student, about to graduate from his bachelors degree.
- Works at the local mall
- Only knowledge of diabetes comes from things heard on TV

- Lifestyle Sometimes jogs around the White River State Park or along the Canal. Always carries his smartphone with him to listen to music while he runs.
  - Service oriented. Volunteers occasionally with local organizations, including Riley Hospital.



T1D and Responders working together during the Solution Modeling activity within the co-design session.



# III. Co-Designing Users

### Methods and Tools Used

The ability to conduct a co-design workshop<sup>4</sup> with both T<sub>1</sub>Ds and responders provided a unique opportunity to have both stakeholders within the problem space working together. The work session was developed taking into consideration feedback and findings gathered from the cultural probe and interviews. Scaffolding was also used in order to develop the progression of the session activities so that each activity served as a primer for the following one. This not only allows easing-in to the activities, but begins to focus participant mindsets towards the intended objective of the session. For this session specifically, the desired outcomes were a few different solutions that responded to the thesis question.

Seven participants (two responders and five T<sub>1</sub>Ds) came together for the co-design workshop. The session can be broken down into three main activities: Brainstorming, Solution Modeling and Prototyping. Before getting into the brainstorming, participants were prompted to storyboard the last time they called or contacted someone to get together as an initial warm up exercise. While the content of the activity did not contribute any valuable content or data to the research, it served as a priming activity for having participants think of events in a sequential format. This type of thinking is beneficial when they are thinking through solution development. After the warm-up, the session progressed into brainstorming<sup>5</sup>. This type of activity is typically used in the beginning of co-design sessions as a way to generate thoughts and ideas that could be used in more refined solution development. It is also a low-risk type of activity where the free flow of ideas can generate simple, sometimes funny, sometimes serious ideas. Facilitators should be cognizant of prompting and promoting a "safe-space" where all ideas are welcome in order to reduce participant angst about providing perfect ideas. The first two brainstorming prompts asked participants to identify what

<sup>4</sup> Hannington, Bruce, Bella Martin, and Bruce M. Hannington. 2012. Universal Methods of Design 100 Ways To Research Complex Problems, Develop Innovative Ideas, And Design Effective Solutions. Gloucester, MA, United States: Rockport Publishers.

<sup>5</sup> ibi



Close up of the worksheet and the Feature Cards used by participants during Solution Modeling.

ways do they receive and send messages daily. The third prompt was more pointed and asked participants to think of ways they could alert someone they didn't know that they needed help. These prompts were presented in this sequence to get the participant's thinking more focused as the session progressed.

The next activity planned for the session was Solution Modeling or Diagramming<sup>6</sup> as a way to help participants think through essential components and action sequences for a solution. Prompts asked participants to engage with feature cards that were presented on the tables. These cards had examples of different applications, websites and technology that could be used and re-purposed to present a solution that would allow a T1D to call for help during a severe low. For this activity specifically, participants were segmented into groups and given a worksheet to help them collect their solution details. While the ideal group division would have been 1 responder to 1 or more T1D it was not possible because of the make up of the session attendees. In this specific case, the participants were broken down into two groups that included a responder and a T<sub>1</sub>D and one team that included two T1Ds. They used the first 10-minute time segment of the solution modeling activity to discuss and develop their idea within their teams. They also had a prompt that would allow them to pass their idea over to another team to get feedback, praise, or questions related to the solution they were proposing. This provides the opportunity to validate details before moving into the prototyping<sup>7</sup> phase of the session.

For the prototyping part of the session, participants were then prompted to use different materials to try and bring their ideas to life. As seen in the d.school bootcamp bootleg8, there are many reasons for prototyping including: Empathy gaining, Exploration, Testing and Inspiration. For the case of this thesis, the main reason was "Exploration: Building to Think"9. Some of the materials available included Legos®, pipe cleaners, modeling clay, construction paper and markers. This activity helps in adding some refinement to the idea developed through the solution modeling

activity, but also helps bring them to a physical form so that other users can get a clearer picture of how the idea works and how some of the features work. Through the activity of prototyping, participants are encouraged to think with their hands, not their head. This physical act of making also seems connect the makers with the idea which in turn solidifies the sales pitch the were asked to provide after the prototyping time was finished.

The final step of the session involved each team using their selling skills to present their idea to the rest of the teams. Each group selected a representative that would provide a 1-2 minute overview of their product, and highlighting some of the key features. After all of the team presentations, all of the solutions were put up and the participants were asked to vote on the solution they thought best responded to prompt they were presented with at the beginning of the Solution Modeling phase. Initially, participants were prompted to vote on the finalized solution but one of the participants mentioned that while she understood the process, she felt that all of the solutions had components they thought were beneficial in order to respond to the prompt so she asked on behalf of the other participants to make the voting feature-based rather than whole-solution based. As a researcher, it was important to remain flexible in light of this request because it presented an opportunity to see frequency in the liked features. This activity was the end of the co-design session per se. A more formalized prototype development phase will be discussed in the following section, but it is essential to indicate that the results of the codesign session, especially the solution modeling and prototype development were key as drivers for the final prototype.

## **Collected Data & Analysis**

While the co-design session had many activities on the agenda, the most important results to analyze from the data were the solutions developed during the solution modeling and prototyping activities and the voting results. Nonetheless, the brainstorming activities were analyzed to see if any emergent patterns that support emerged in the process. In order to analyze the brainstorming results, each prompt was separated, and then affinity diagramming was used to find underlying and recurrent themes. An overarching theme that emerged through this process was a high frequency of technology-reliant forms of communication. While some of the messages either sent or received were text based, some of the data points also showed sound and light as possible ways of getting a message across. These emergent themes started to point to technology as a viable component of the solution to be developed in the researcher/ designer phase of prototype development.

Affinity grouping results from the 3 brainstorming activities within the co-design session.







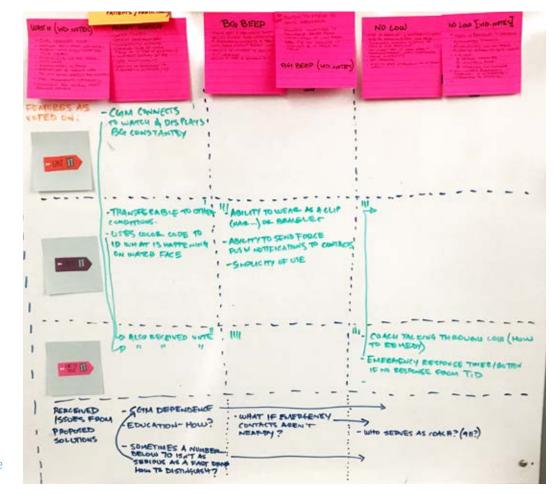
<sup>6</sup> Kumar, Vijay. 2013. 101 Design Methods. 1st ed. Hoboken, N.J.: Wiley

<sup>7</sup> Hannington, Bruce, Bella Martin, and Bruce M. Hanington. 2012. *Universal Methods Of Design:* 100 Ways To Research Complex Problems, Develop Innovative Ideas, And Design Effective Solutions. Gloucester. MA. United States: Rockbort Publishers.

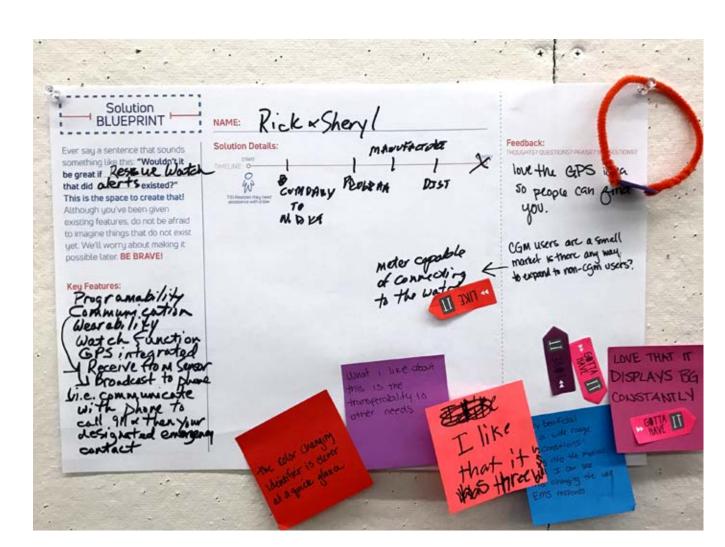
<sup>8</sup> The Bootcamp Bootleg. 2012. 1st ed.

<sup>9</sup> Ibio

As a second step, the different solutions that resulted from the codesign session were analyzed in order to provide a more focused starting point that could lead to developing a more refined and relevant solution. It is important to consider that some design criteria emerged from earlier research activities such as the digital cultural probe and the interviews. The first key to the analysis of the solutions was to look closely at the voting results from the session itself. While the initial parameters of voting on complete solutions would have made analyzing the results an easier task, the feature-forward voting provided deeper insights into what specific features the participants valued most because it presented an opportunity to see frequency. As an additional form of gathering insights, participants were asked to write why they liked the features they voted on with Post-it notes. This allowed the researcher to be able to validate results and voting patterns without depending on the participants being present during the analysis process.



Analysis process of the solutions developed during the co-design session.



# Alert Watch

## 1. CGM pairing, constant BG display

This solution constantly displays blood glucose levels on the watch face read from a paired CGM system.

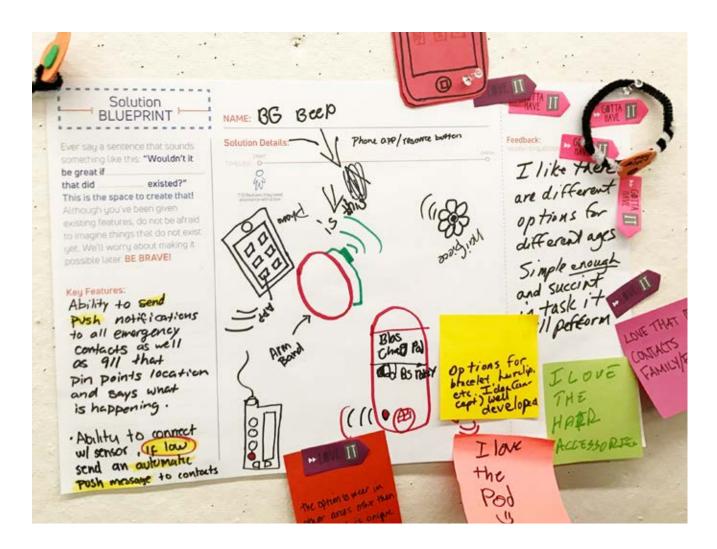
# 2. Watch face changes color when an "event" happens

To indicate what type of "event" is happening, the watch face will change color. Hypoglycemia, like other conditions, will have an identifying color.

## 3. GPS + Smart Phone connectivity

This solution connects via Bluetooth with smart phones and also provides GPS data if a call is triggered by the watch to 911 and emergency contacts.

## 4. Ability to call/alert 911 service



# BG Beep

1. Watch/Wristband, Hair Clip, Phone App

This solution presented the wearer options of how to interact and wear it

2. Send Push Notification to Emergency Contacts

Once the BG Beep was triggered to call 911, it would send people on the emergency contact list a force push notification to alert them that the T1D was experiencing a low.

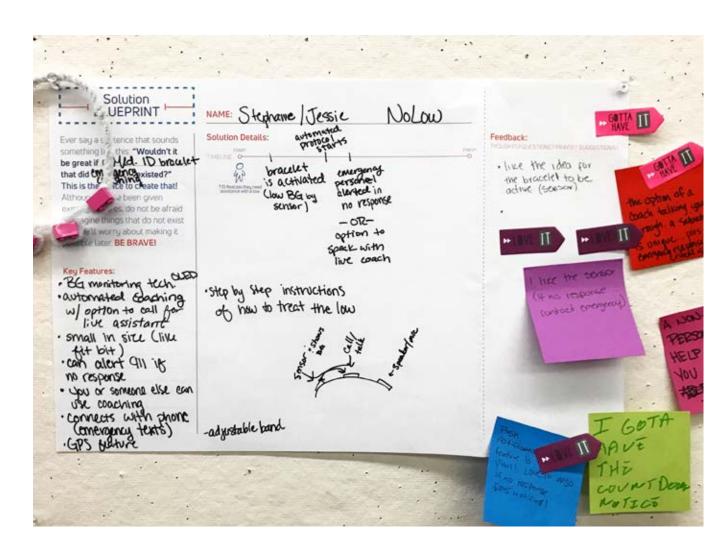
3. Provide GPS location of patient

It provides a pinpointed location for emergency services to find the person who triggered the call.

4. Ability to connect with CGM for sensor data

Connectivity via Bluetooth to send pre-emptive push message to emergency contacts if a low reading is present.

5. Ability to call/alert 911 service



## NoLow

1. Watch/Wristband with screen + Call button + Speaker

This solution is a wearable device that facilitates all interactions through the Screen, Call Button and Speaker.

2. Automated Help Protocol + Ability to contact live Coach to support patient or responder

Protocol is activated when wristband received a "low" reading from the sensor it is paired with. Provides step by step instructions that can support either the T<sub>1</sub>D or the responder.

Ability to connect with CGM for sensor data + BG Monitoring through OLED

Provides the ability to connect via Bluetooth with CGM for data or uses OLED technology for measuring blood glucose levels.

4. Ability to call/alert 911 service if unresponsive



An initial observation was that all of the solutions manifested as wearable technology or devices. The solutions presented within the co-design session were the Alert Watch, BG Beep and NoLow. While all three might have had different features, ones that came up across all three were the ability to connect to a Continuous Glucose Monitor (CGMs)or having a way to read glucose constantly, the capacity to provide a GPS location of the person suffering the low, some form of visual identification or instructions to tell the responders what is happening or what should be done, and the ability to connect or call a 911 service for help if the T1D was unresponsive or needed professional emergency care. These repeated features point to these three main insights:



- 1. Wearables and technology were prevalent results during the entire co-design session. This is possibly due to the fact that diabetes care is heavily reliant on technology like insulin pumps, CGMs and Bluetooth enabled glucose meters. It was an easy next step for the T1Ds to imagine.
- 2. The solution needs to be simple for the T1D to use during the low and should provide responders with clarity on what to do.
  - 3. Reliance on 911 as a way to ensure proper care will be provided if the situation were to escalate to that point.



In looking back and connecting previous insights from the research process, these line up directly with those that emerged from the cultural probe and interview saying that the T1Ds need empathy, patience and responders that know what they should do in order to correct the situation. This can now be looked at as design criteria to take into consideration for the more focused phase of solution development that will be carried out by the researcher. The more formalized prototype will be evaluated later with both types of stakeholders in order to validate the concept and the design.

# It's prototype time!

# IV. Developing the Mobile Application

#### **Process**

After conducting all of the other research methods and prototype development, the researcher will take on a more expert mindset during the prototype development. It is important to consider that while a people-centered process greatly benefits from including the stakeholders in the process, it is not necessary to include the stakeholders in every step of the process. Participant input will be sourced later through evaluative method engagements. The reason to bring in an expert mindset to solution development is because there is more specialized knowledge that is necessary for successful solution development. While co-design workshops are incredibly powerful in bringing stakeholders into the process in a generative phase, technical expertise can be lacking and could lead to challenges for successful solution implementation. The expertise of the researcher was not limited to design, but also included a 22 year relationship with type one diabetes. While a designer or developer can read about the symptoms of hypoglycemia, first-hand experience is key for insightful prototype development.

The key source of information for this step was the analysis of the solutions that were generated in the co-design session. While some key features were more or less directly translated into the final solution, some of the most important features came from questions that emerged through the analysis process. Having spoken to T1Ds and Responders throughout the entire research phase, it was now time to develop a solution that responded to the original research question. While the original thesis question used the word 'tool' as a placeholder until further research was completed, the more concrete 'mobile application' came to replace it. It is important to note that while all solutions presented were presented as wearable technology, some form of software application must be developed in order to drive the solution. While T1Ds might not think twice about purchasing a piece of wearable technology, it cannot be expected that responders will be as likely to invest in an additional piece; these are some

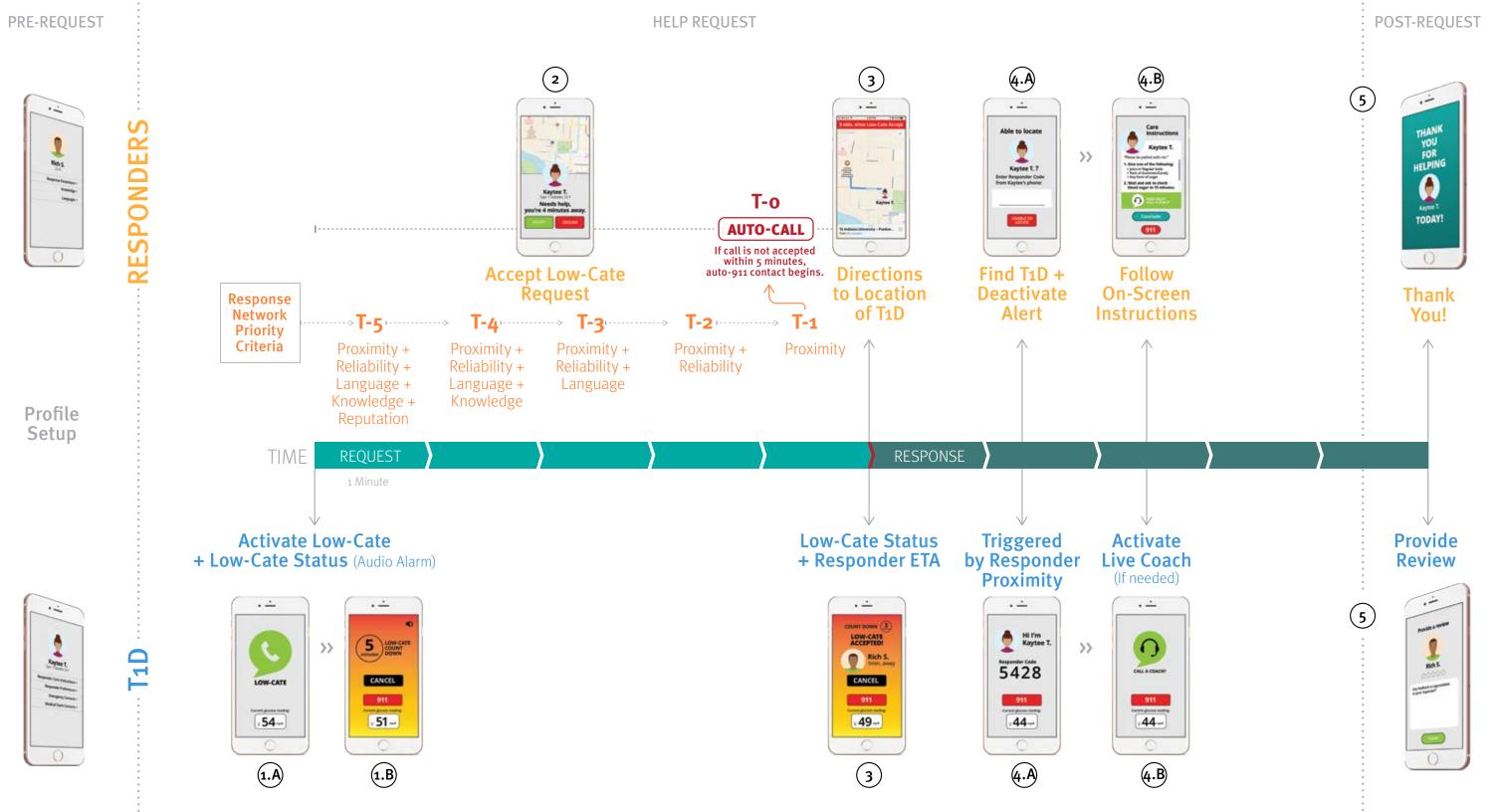
of the main reasons why the solution is presented as a mobile application. In future research, the solution can be expanded into a wearable form, but understanding the time limitations for this research, the mobile application was the best format to test out.

The hypothesis driving the design of the mobile application is that this mobile application will aid T1Ds to call for help when experiencing a severe low, and the Responder will be able to successfully provide the needed aid without much effort on behalf of the T1D. This way, key components that need to be kept in mind are easier to outline:

- 1. Easy for the T1D to use while experiencing a "low"
- 2. Provides Responders with key details such as location and care instructions for them to be able to take appropriate action to respond
- 3. Requires little interaction from the T<sub>1</sub>D in order to communicate needs during the "low" episode

# Overall Solution Flow Map To see an expanded

Solution Flow map with additional screens, please see Appendix.



# REQUEST RESPONSE

T-o

AUTO-CALL

If call is not accepted within 5 minutes, auto-911 contact begins.

### **Solution Features**

#### **TIMELINE**

Keeping these details in mind, the best way to develop the NoLow<sup>10</sup> prototype was to determine a feasible timeline that took into account the fact that the two stakeholders were experiencing different screens. This also established a key cause-and-effect relationship within a time frame for action. The formation of the network that the T<sub>1</sub>Ds will call upon for help will be discussed at a later time in the paper. While the details of who would be recruited evolved later in the evaluation process, an assumption can be made that there would be a network of responders who had opted-in to participate. The next parameter that needed to be established within the solution would be time. In a reflective process looking back at previous hypoglycemia episodes, I determined that a 5 minute window between asking for help and getting help would seem manageable on the part of the T1D and would not cause any major problems. This time frame has been arbitrarily designated and would need validation from medical professionals and additional testing in controlled environments to ensure it is acceptable. Related to this is the question of distance relative to the response. The 5 minute time frame is manageable for the T<sub>1</sub>D, but also does not allow for a long distance to travel. Being conscious of this, it would be hard for responders that are too far away or even caught in traffic to be able to participate in a help request without it being too much of a burden, or adding too much time to T1Ds wait time, knowing that this might also put the T<sub>1</sub>D in danger.

#### **AUTO-CALL 911**

As the findings in the previous methods and prototypes from the co-design session showed, a 911 contingency should be a key component of the solution. To try and integrate it as simply as possible, a 911-auto call feature was integrated. The feature will get triggered if no response to the request is received within the 5 minute timeline, as indicated by the T-o.

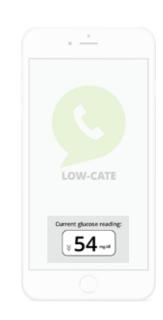
#### 10. The name Nollow was taken from one of the prototypes developed in the co-design session

### PERSISTENT CGM DATA DISPLAY

Another feature that was present in all three user solutions was the ability to constantly see CGM readings within the application. A simple integration was done where the data of the paired CGM is displayed in the same place so the T1D is aware of how the situation is progressing. While some of the design teams had their solutions triggered by a reading from the CGM, the solution should not be solely driven by a CGM. Some of the reasons for this is that CGM adoption is not universal, and, while CGMs are getting better every day, they are not entirely reliable and can present numbers drastically different from finger stick glucose monitor readings. As technology improves moving towards CGMs that can reliably drive insulin pumps by themselves, it might be possible to have a more direct reliance on them, but for now, the solution will remain user activated.

### **INFORMATION PROVIDED**

One of the most important functions of NoLow is to facilitate a call for help. The second most important feature is to provide the right information at the right time. After the help request is made, various pieces of information are shared to the users involved in the exchange. As soon as the call is accepted by the responder, he/she receives the T1D's location information, and the T1D, in turn receives a confirmation of who accepted the call and their estimated time of arrival (ETA). The next exchange of information occurs when the responder encounters the T<sub>1</sub>D. As a way to validate each others identity, a code triggered by the proximity of the responder to the T<sub>1</sub>D appears on the T<sub>1</sub>D's phone screen. Once the responder enters this code on their phone, the care instructions that the T<sub>1</sub>D prepared in their profile will appear on the responders phone. After the low has been taken care of and the T1D can confirm that they are OK to continue on their own, the responder confirms the conclusion of the call. The final exchange of information occurs when the T1D provides a review of the experience with the responder. While this is not a direct exchange with the responder, this data gets tagged to the Responder's profile and will be taken into consideration in the future when a new help request is sorting through the 5 minute timeline driven by the Network Priority Criteria.







#### **NETWORK PRIORITY CRITERIA**

While timing and distance have been considered, there is a need to address the possibility of T1Ds preferences for responders. Lows can be unpredictable and might cause different behaviors in the T<sub>1</sub>D, therefore the T<sub>1</sub>D should have the opportunity to provide responder preferences when setting up their profile as a safeguard for them and the responders because of the close interaction that will occur if the application is used. While different parameters can be considered, in this prototype the main considerations that could be pre-determined by the T1D are: language preferences, in case the T<sub>1</sub>D is bilingual; **gender**, considering that lows can put T<sub>1</sub>Ds in a vulnerable position, it might be worth considering that selecting the gender of the responder is something that could put the T<sub>1</sub>D at ease. Aside from addressing vulnerability, cultural and religious factors could play in to why responders should be from one gender and the other; **prior knowledge of the condition**, acknowledging that someone that understands the condition would be more likely to respond and more likely to respond appropriately without much guidance. The other two parameters established in this prototype are more data driven, considering the reliability of the responder, taking into consideration how many calls in their surroundings they respond to and the **reputation**, determined from the reviews provided by the T1Ds after the interaction is over. The only criteria that is out of the control of either the T1D or the responder is proximity. At this moment, acceptable proximity parameters have not been established, but they should conform with the 5 minute time frame previously established. This parameter can be further explored at a later time through testing and could be validated through existing navigation services with an API, like Google Maps for example.

These established parameters will be programmed in relation to the 5 minute timing sequence prior to activating the automated 911 call if no response is received from the network. In the initial minutes, all five parameters will be taken into consideration when the help request is sent out. As 1 minute increments of time elapse, the priority criteria start falling off in an effort to broaden the call radius until either someone responds to the call or it gets to the end of the sequence and initiates the automated 911 protocol.

While the essential criteria is established on the side of the T<sub>1</sub>D within the application, responders also have the opportunity of

establishing some criteria on their end. They can set a schedule for when they are available to take help calls and how far they are willing to go. This network and application depend heavily on the goodness and willingness of responders to participate. There need to be boundaries established that do not exhaust the participation of the willing responders.

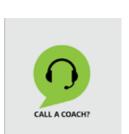
#### **INTERFACE**

As complex algorithms and criteria drive NoLow on the back end, the interface that T1Ds and responders interact with must be kept simple for a variety of reasons. First, the T1D is experiencing a low and is challenged by cognitive decline. The interface needs to offer the T1Ds easy trigger points in order to successfully fulfill the help request. As the request progresses, the T1D gets updated information on their side of the interaction while most of the burden falls on the responder to get to the T1D and follow through on the actions. There are also possibilities for the T1D to trigger other actions such as calling 911 if the T1D feels the situation getting worse. Validation points have been added in between making the call to 911 just in case it was an accidental trigger due to the deteriorating cognitive motor function. The interface is not only simple for the T1D to use, but is simple for the responder to follow and engage with.



#### **CALL A COACH**

This feature was presented in the NoLow prototype version from the co-design session and because it received many votes it was integrated into the formalized prototype. This feature is available to both the T1D and the responder. Knowing that lows can be erratic and can take a turn for the worse quickly, the ability to call a coach might help provide support to the responder while providing assistance. It might not be the most used feature in the prototype, but it provides the opportunity to get support before having to resort to calling 911. While all of the research participants acknowledged that 911 would be OK to use, there is an awareness that the service does come with steep costs. If using 911 is absolutely necessary, the system supports this, but it is important to also offer alternatives until calling 911 is the most appropriate course of action.



### The Solution in Action

A useful way to understand how all the features work within the solution is to experience what both the T1D and responder experience through a scenario<sup>11</sup> method. This method calls for building a believable narrative that will present how and why the stakeholders would engage with a solution, in this case NoLow. Personas were developed earlier in the research and will be used during the scenario presentation to gain insights into how the solution would realistically be used. For this scenario, we will assume that both stakeholders have downloaded and installed NoLow onto their phones, have successfully completed their profiles and are within an acceptable distance for interaction through the app. In the following pages, the solution is presented sequentially, but first meet the two personas who will be using the solution.

#### **KAYTEE**

Kaytee is the epitome of a mom on the go. She's always trying to get as many things solved during the day as possible so that she can enjoy time with her family at home in the evenings. Aside from being a stellar mom, she's also a type 1 diabetic. She's had the condition for over 20 years and while she has had some pretty severe highs and lows during her life, it doesn't stop her from getting things done. Some of the most severe lows she has experienced happened while she was pregnant and another occurred while she was getting some back-to-school shopping done for her daughter Mia.



Today, for the sake of convenience, Kaytee parked somewhere in downtown Indianapolis and decided to walk to most of the errands she had to complete that day. Nothing like getting your steps in! By 1:30p.m. she had already gone to a doctor's appointment, stopped by FedEx to get something copied and shipped and was on her way to the Government Center to get Mia's paperwork for her passport validated. As soon as she left the Government Center and was walking towards her car, her vision was blurring and she felt like the world around her was going in a million directions. She sat down on one of the benches and began to fumble through her purse to find her phone to read her CGM. It was reading 54mg/dl and had been beeping for a while, but was ignored because she was talking with the employee who was processing her paperwork. As soon as she realized this, she began to look for some sugar in her bag, and after searching through all the usual spots where she has things she realized she had blown through all of the supplies during the week. Her next reaction was to launch NoLow and hit the Low-Cate button to trigger the help request.

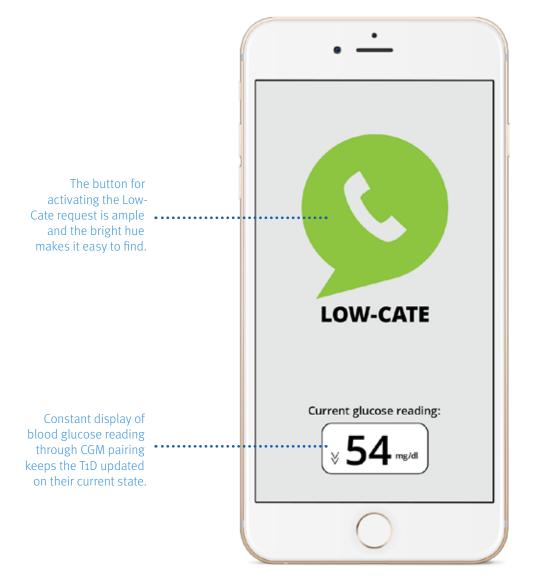
#### **RICH**

Rich is currently in his last semester of school at IUPUI. To offset some of his school costs, he works at the Circle Center Mall a few times a week. As is the case with most millennials, he carries his phone everywhere he goes—be it jogging around the White River State Park, or during his lunch breaks.

On this day, Rich was just finishing his lunch at the mall food court after his shift when received the NoLow notification on his phone. His service-minded and empathy-driven upbringing show as he immediately accepts the request.



<sup>11</sup> Martin, Bella, and Bruce M Hanington. 2012. *Universal Methods Of Design*. 1st ed. Beverly, MA: Rockport Publishers.



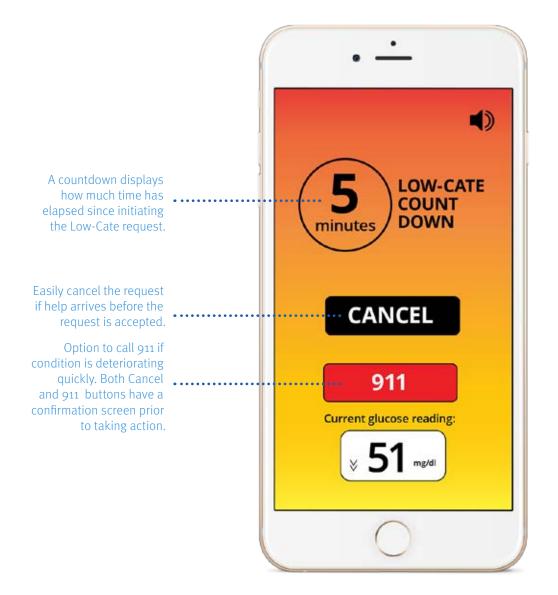


# **Activates Low-Cate Request**

After activating the Low-Cate request, Kaytee's energy should be devoted to keeping herself safe and making sure she's conscious of her condition. Very few interactions will be required on her part from now on.



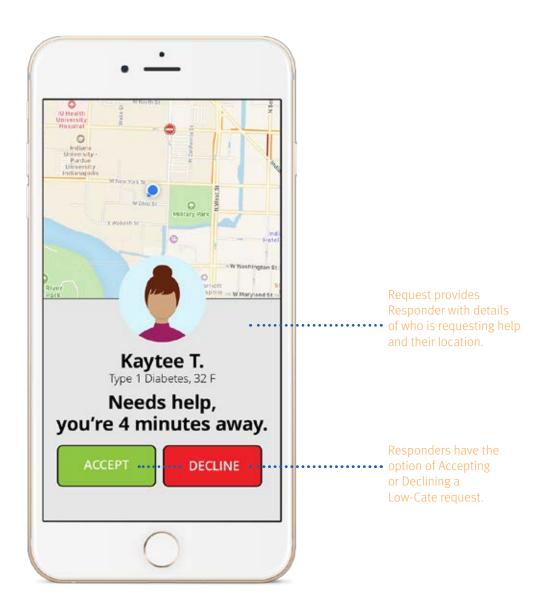






# **Request Status Screen**

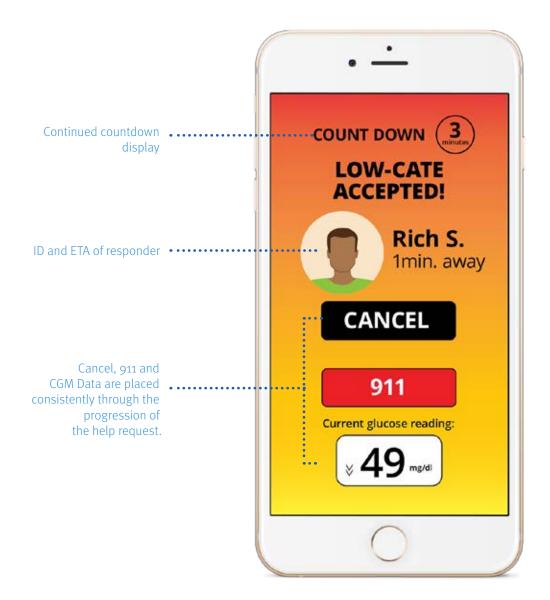
Once the request is sent, Kaytee is kept updated during the 5-minute timeline of how much time has elapsed. This screen also presents her with the opportunity to cancel the request if she gets help before the request is accepted, or the opportunity to call 911 if she feels her condition deteriorating quickly.



# **Receive Low-Cate Request**



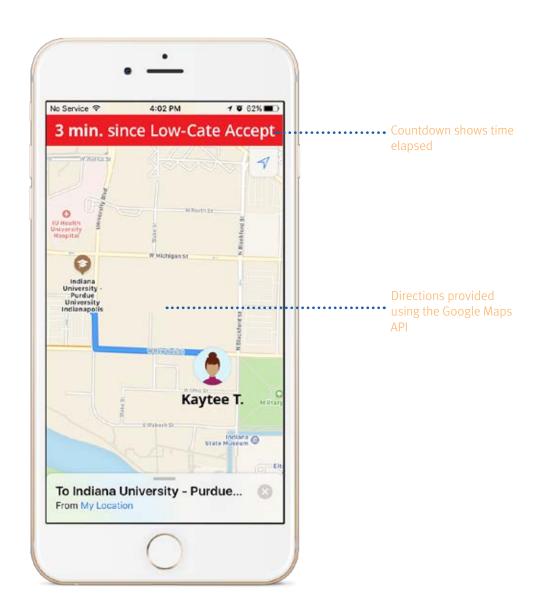
Closely following the model established by Uber and Lyft, responders within the deistance range receiving the Low-Cate request can **Accept** or **Decline** the request. They are provided with some basic details of the T1D such as name, a photo, and a location. In this case, Rich accepts Kaytee's request.





# **Request Status-ACCEPTED**

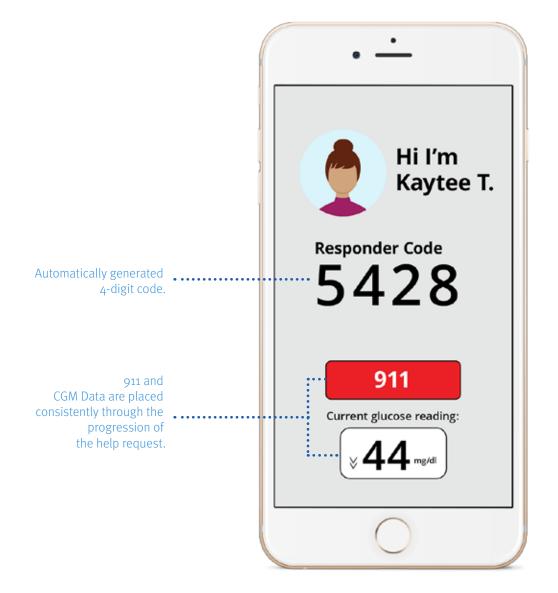
As soon as Rich accepted the request, Kaytee receives an updated status of the request, responder ID and their ETA to Kaytee's location. The option to either Cancel or Call 911 are still available, and her CGM reading is still visible.



# Request ACCEPTED > Directions



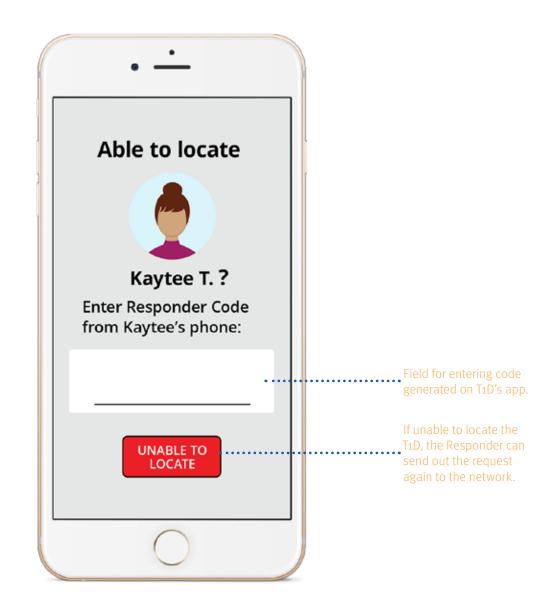
At this time, Rich is provided with the directions needed to find Kaytee and help her out. There is also a count down so that he's aware of the time elapsed since accepting the call.





# **Proximity Triggered Code**

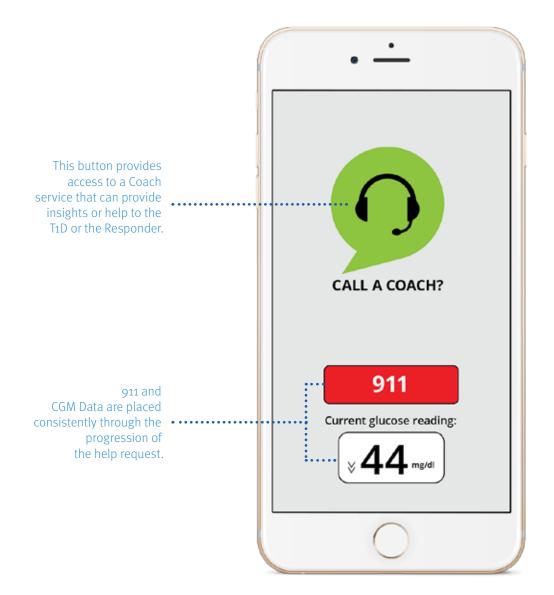
As Rich is getting closer, a code is triggered on Kaytee's phone. This code is used as a safety validation for the T1D to know that the person approaching them is actually the responder who accepted the call.



# Low-Cate'ed > Enter Code



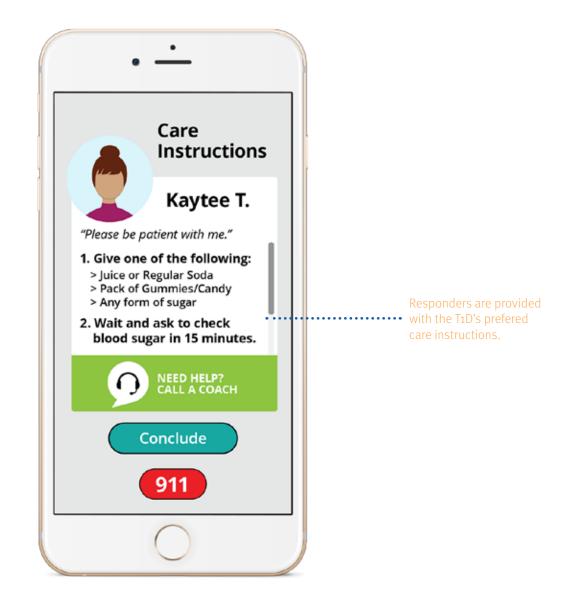
To validate on the Rich's phone, the code that appared on Kaytee's phone needs to be entered in order to reveal the detailed care instructions she set up in her profile.





## Call A Coach

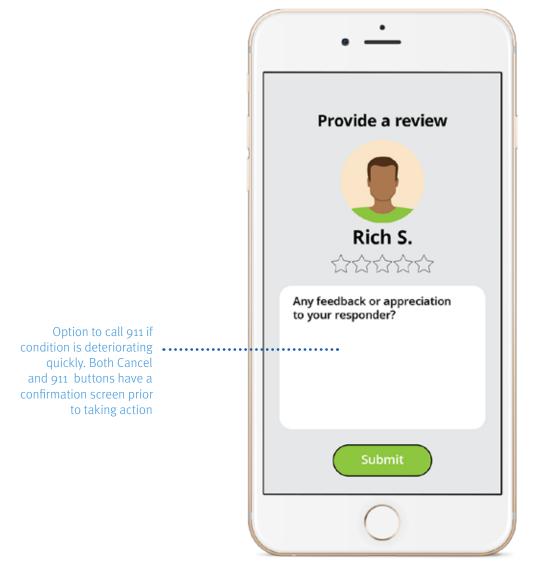
At this point of the interaction, Kaytee shouldn't be concerned with much other than receiving help. However, if she perceives that the responder might need additional support she can trigger the "Call a Coach" feature on her phone. Rich also has access to this feature on his screen.



## **Care Instructions**



As soon as the code is validated, Rich receives the care instructions provided by Kaytee in her profile. It is completely custom per user, so Rich needs to make sure to read the instructions and





# **Responder Review**

After the help request has been successfully taken care of, the Kaytee is able to leave a review for Rich. This information is vital because it informs the Reputation criteria from the Network Priority Criteria used during the intial 5-minute call timeline before lauching the auto-911 protocol.





Rich receives a Thank You from Kaytee after the request has been taken care of.

# V. Evaluating Answers

## Is the solution...

## Useful

Does it solve the problem?

## **Usable**

Is it intuitive & easy to use?

## Desirable

Do you want or need to use it?

### **Metrics**

After conducting all of the other research methods and prototype development, it was essential to evaluate the prototype in order to understand how the solution stacks up in the eyes of the stakeholders. The Trinity of Good UX<sup>12</sup> was key in driving the evaluation because it measures three important criteria in successful UX design. The first tenet is **Useful**. If a solution is useful, it successfully solves the problem that was defined in the beginning of the design process. The second tenet is **Usable**. The solution might solve the problem, but most importantly in the case of this solution, is it intuitive and easy to use. As mentioned previously, this solution is getting used in an emergency basis, so it needs to be usable in a time where users can be nervous or have limited cognitive function. The final tenet of the evaluation framework is **Desirable**. While the solution might satisfy usability and usefulness, users should also want to use it. A great product might exist, but if the users do not want to use it, then it might as well not exist.

In order to test the NoLow prototype, two versions of the screens were uploaded into the InVision platform. This tool allows for aninteractive prototype to be built with interaction triggers in order have users experience the product as closely as possible to reality without going through the entire design and development phase. When using NoLow, T1Ds and responders experience different screens due to the different tasks each is completing. In light of this, two prototypes were built so that each type of stakeholder could evaluate what they would experience. To supplement the evaluation, a side-by-side PDF presentation was shown to the users with the corresponding screen sequence for each user as a way to supplement the simulated experience. While the PDF presented the sequence, it was essential for participants to get a sense of scale and interaction from the InVision prototypes. This prototyping platform can help inform the feedback in terms of design revisions to make down the line

during the iterative prototyping cycle, especially considering the cognitive challenges the T<sub>1</sub>Ds face and the stress levels the responders might experience.

Prototype testing was done with 4 T1Ds and 3 responders. While the solution should be tested further with a larger group of stakeholders, the current test group provided a good range in terms of age (participants ages ranged from 9-65) and knowledge of the condition (tested with responders from both Tier 1 and Tier 2). As participants clicked on the phone to test the InVision prototype, the researcher clicked through the PDF presentation to show what was happening on the other screen. After having the participants experience the prototype, they were asked if they found the solution useful, if they felt the solution was usable and if they felt the solution was desirable. Their responses were recorded using an evaluation worksheet.

#### The Verdict is In

After reading through the seven evaluation worksheets, the overall response to NoLow was very positive. Participants from both types of stakeholders felt at ease with what they were seeing on the screen and felt it was easy to understand and intuitive to use. An interesting comment that was shared by one of the T1D's:

"I feel like my family would feel more at ease with letting me travel and go further from home because they could have some reassurance that help would not be far away."

Patient 3, as discussed during solution evaluatio

Another participant shared that he thought the solution would address the self-imposed barrier for requesting help. Some of the insights gathered during the Understanding Needs phase of

<sup>12</sup> Schmidt, Aaron, and Amanda Etches. 2014. *Useful, Usable, Desirable*. Chicago, Ill.: American library Association.

research supports this. Some participants mentioned that they can be stubborn and self-reliant as much as possible during lows, but this solution might present an opportunity to lower the barrier that could impede them to ask for help openly.

While the comments were overwhelmingly positive, participants from both stakeholder groups started to bring up interesting considerations for the overall solution development. The first observation was relative to the network. While the network sourcing was still not fully addressed through the research, participants suggested to bring in the Diabetes Online Community (DOC) as the key partner to begin populating the network. By inviting the DOC into the network first, two issues can be resolved simultaneously. First, the DOC would be more likely to participate because they can empathize with the problem from personal experience and would be more willing to step up and help. The second issue this addresses is the knowledge gap that was indicated in the earlier phases of research as a source of fear. Since the T<sub>1</sub>Ds live with the condition, they will know exactly what to do and could resolve the issue with little to no guidance, indirectly providing some sense of reassurance to the T<sub>1</sub>D who called for help. The organic expansion of the network after the initial recruitment phase with the DOC could then bring in some of the Tier 1 Responders into the network, eventually recruiting the Tier 2 Responders. The Tier 1 Responders would hopefully respond to calls made by others, not just the T<sub>1</sub>Ds they are familiar with.

Another point of reflection brought up by the participants was the possibility to expand the use of the application to other conditions. This feature was also presented in some of the solutions presented during the co-design session. While hypoglycemia was used as a contextual focus of this thesis research, it would be ideal to be able to expand to other conditions that might benefit from responder support. Which conditions could be supported would need to be researched further, but some of the examples offered by participants included heart conditions, stroke, and arthritis. Expanding to other conditions might provide an opportunity for a more robust network of responders.

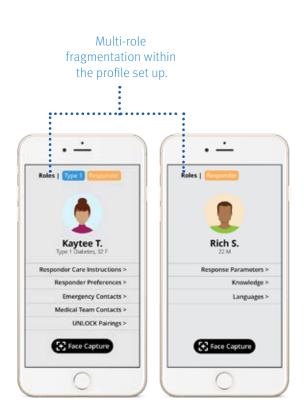
A concern that was brought up was cost. Would buying and using this application this application cost money? The question came mostly from the T1Ds engaged in the evaluation process because they are conscious of the high cost of disease management and thought that an additional cost for something that could be lifesaving, though not out of the question, might challenge solution adoption. At the moment of the evaluation, details on costs were not considered within the scope of the thesis project, but if the solution development were to move forward, it is an important point to consider when developing a business model to support the application.

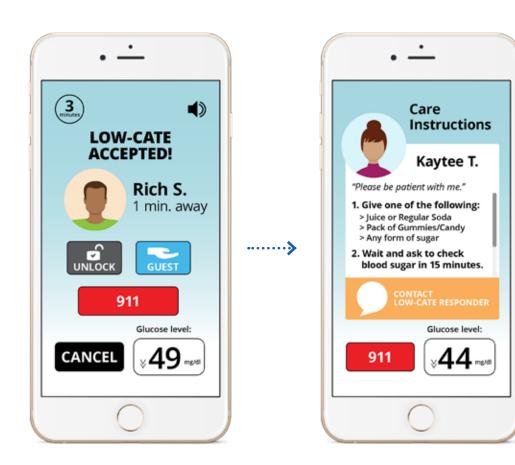
## **A Second Prototype**

After participants evaluated the NoLow prototype, a second iteration of NoLow was created after discussions with a subject matter expert. This expert was very insightful because aside from having expertise in the area of Interaction Design, he is also a T1D. This double expertise allows for critical evaluation and feedback from an insider perspective relative to the condition. The ability to find experts that have such a deep connection to the condition adds valuable opprotunities for feedback while taking real challenges brought on by the "low" experience into consideration.

While the second iteration of NoLow did not alter the flow and sequence of the actions taken by either stakeholder, certain details were revisited to include more robust features. The first feature that was revised was the addition of fragmented user groups in the profile set up page. This would allow for users from one group, such as the T1D group to participate within the network as a Responder. This allows for an expanded network even if there are not as many participants enrolled in the network because the same person can fulfill both roles, obviously not during the same help request.

The second significant revision to the prototype was including an pathway to get to the T<sub>1</sub>D's Care Instructions in case someone aside from the responder had arrived and wanted to jump in and help. The reveal of the Care Instructions for the Responder who

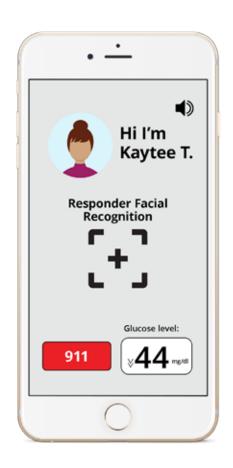




accepted the help request depends on the validation of their identity during the "handshake". If another Responder emerges and needs the information to help, the T1D can show the Guest Responder the phone, have them click on the "Guest" button to reveal the Care Instructions. On the Care Instructions screen, there is also an opportunity for the Guest Responder to contact the Responder who originally accepted the Low-Cate request to notify them and discuss if they need to arrive and help or if they are free to go. This feature needs to be developed further to understand the relationship between the Guest Responder and the reputation criteria that feeds into the Responder's profile thanks to the reviews provided at the end of the interaction.

Another detail that was revisited in the second iteration was color palette. Although a secondary detail, it is important to consider how color psychology plays into the emergency situation. Previously, the color palette used on the side of the T1D's interface was red and closely related to the emergency feel. On the other hand, the palette on the Responder's interface was light grey, almost conveying a sense of serenity. These palettes have been swapped, providing the T1Ds a more serene, calming blue palette versus the red colors, now prominently featured on the Responder's interface. It was important to change this relationship to communicate a larger sense of urgency on the Responder rather than the T1D.





For a Solution Flow map of the second iteration of NoLow, please see Appendix.

More futuristic features were also included in the second NoLow prototype, including the opportunity to use Facial Recognition as the security validation between the T1D and the Responder, and the ability to connect to Smart Home features and services to facilitate unlocking doors in case the T1D is severely "low". While both features are becoming more ubiquitous as mobile technology improves, there is still a low adoption rate for both. It is important to evaluate these features, and others like them in order to facilitate the experience for both the T1D and the Responder.

Although these new features were designed with the discussion of the subject matter expert, none of the participants that evaluated the initial prototype have interacted with the newer features. It will be important to re-evaluate the solution with the participants from the first round of evaluation to see if these revisions still successfully hold up to the Trinity of Good UX. The evolution of the solution is proof of the need for iteration in successful solution design and development. While the initial solution presented was well received, feedback from both stakeholder groups as well as more experienced subject matter experts yielded feedback the pushed the solution forward and brought up new considerations that would have been ignored if the solution was completely developed without external input.

#### **Future Considerations**

If a third iteration of NoLow were to be developed, there are some key factors that should be revised and discussed in more detail because they were not considered within the scope of research at this time.

#### **SECURITY**

One of the first questions that came up from the thesis committee was, *How are you going to address security?* It is an important issue to consider, because other applications that provide GPS location have been used for wrong rather than good. A recent example of this was through the PokémonGO application, where thieves would lure players to isolated locations to rob them. While one can remain optimistic that members of the network will keep the application use to it's true altruistic nature, there is a possibility that T1Ds could find themselves a target group for crime, especially considering the vulnerable state that they find themselves in during the low. This component needs to be explored further and better integrated into the solution to avoid negative experiences and results.

#### THE NETWORK

The T1Ds suggested that the Diabetes Online Community would be the ideal partner to begin populating the network of Responders. They cited the inherent supportive nature of the online forum members as well as the pre-existing knowledge of T1D as key reasons why it would be the ideal first partner. While the suggestion is well received, there has been no way of validating interest from key online forums such as Beyond Type 1, the Juvenile Diabetes Research Foundation (JDRF) and the American Diabetes Association (ADA) among a long list of others as it was not defined within the scope of the research project. An initial contact needs to be made in order to validate interest and to coordinate logistics if NoLow were to get developed further.

#### **SIMULATIONS**

While the NoLow prototype was tested using InVision, there should be additional testing done within a controlled environment that would allow T1Ds to experience a real low in order to validate usability. It is important to consider that positive comments made about the prototype could be invalidated if during an actual low, T1Ds aren't able to really use the mobile application. Other important details to test during a controlled simulation is the acceptable time and distance where the solution is still valuable to respond to the T1D's needs. Hypothetical time frames were used to model the solution, but being able to test time frames with a real low will be important to help delineate the acceptable radius for emitting the Low-Cate requests and defining the proximity criteria for the Network Priority Criteria algorithm.

#### 911

As a key feature present in every prototype in the co-design session, and a key element in the final prototype, the use of the 911 system needs to be studied more so that it can be included as a functional element. It is important to note that 911 services are currently getting modernized because their initial service model relied on land lines for accurate location information. As mobile phones have become ubiquitous and land lines have fallen into disuse, the previous infrastructure cannot accurately support mobile 911 calls. As E-911 services become more readily available, they might provide the right channel for the partnered use with the NoLow application.

#### **CGM DRIVEN APPLICATION**

While CGM data reliability and user adoption is not universal at this point, industry trends point to more reliable systems in the near future. Some of the newer systems are so reliable that they're trusted to auto-control newer insulin pumps. As these systems become available, it is possible to envision a version of NoLow that could be automatically triggered by the CGM data. Time thresholds for sensor calibration need to be added into the applications programming, but it could come as a relief to patients who tend to ignoring warning alarms from their sensors. It is important to note that they application was not initially conceived as a sensor triggered application because it is a well-documented fact that sensors are not adopted by all T1Ds. The ability to have a user-triggered application provides a more inclusive platform.



# In Conclusion

#### Results

After going through the entire research process, it is important to look back at the driving research question (sub-questions included) and its accompanying hypothesis in order to understand if the findings were successful in answering the question. It is also important to look at the appropriateness of the research methods used in order to arrive at the final solution.

How might mobile applications facilitate effective communication between Responders & T1D patients during hypoglycemia episodes?

- 1. What are the needs of a T1D patient during the three stages of hypoglycemia episodes?
- 2. What are the needs of an untrained responder in order to provide effective aid during each type of hypoglycemia episode?
- 3. What interactions with the tool will enable communication between the T1D patient in need of help and the responder?

Through the course of this research project, a mobile application was developed that bridged the communication gap between T<sub>1</sub>Ds that were experiencing a "low" and Responders that were trying to help. The solution developed went further than telling responders what to do, by aiding T<sub>1</sub>Ds in calling for help from a network if they were unable to seek out help themselves. Through some secondary research, the researchers direct experience with T<sub>1</sub>D and the responses sourced during the *Understanding Needs* phase of research, insights, needs and criteria were identified in order to focus the solution development.

While initially, the research set out to understand all three stages of "lows", the ones that demonstrated a need for external help

were the Moderate and Severe stages. The Mild stage, although listed in the problem space, can be addressed through mostly self-care actions. The stages where communication and self-care are jeopardized are Moderate and Severe. When discussing past experiences in the Cultural Probes, the T1Ds always mentioned episodes that were reliant on Glucagon or help from others. T1Ds and Responders commonly noted words like "fumbling", "mumbling" and blurred vision as descriptors of the events they experienced or witnessed. This was a clue to understand that whatever solution was developed, it had to be easy enough to use when these types of challenges were present.

Although there were many research methods used during the people-centered process, the most valuable results for solution development emerged from the Cultural Probe/Interview phase and the co-design session. As mentioned earlier, the needs and insights from the *Understanding Needs* phase helped develop the prompts that lead to a successful *Co-designing with Users* phase. The ability compare the results from both methods and to be able to validate certain trends and needs in the solution modeling and prototyping activities provided criteria that could be referenced.

After understanding the T1D experience with "lows" and what "tools" they thought would be ideal to call for help through codesign, three main criteria were used for solution development:

- 1. Easy for the T<sub>1</sub>D to use while experiencing a "low"
- 2. Provides Responders with key details such as location and care instructions for them to be able to take appropriate action to respond
- 3. Requires little interaction from the T1D in order to communicate needs during the "low"

As evaluated by the participants, the solution design presented during the *Evaluating the Answer* phase satisfied the criteria collected throughout the research. Participants noted that they perceived the solution as easy to use (satisfying criteria number 1 and 3), and that it is equipped with the right information to provide any responder, no matter how knowledgeable they are about T<sub>1</sub>D (*satisfying criteria number 2*). In other words, it facilitates communication during a moment where the physical act of communicating can be challenged. It also provides the opportunity to call an additional source of support (the Call a Coach feature) if needed during the interaction. While the solution was simple and easy to use, it provided access to additional features which many participants found helpful and reassuring, such as access to calling 911. It was satisfying to see that a solution that was conceived after analyzing and synthesizing the participants contributions was well received, even if it was not a direct translation of one of the proposed solutions from the co-design session. This success can be attributed to reseacher/designer's expertise with T1D, but also to the power of insightful analysis and synthesis. The ability to look across the solutions and not focus on just one allowed for a more robust solution that attended to latent needs and desires rather than just an amalgamation of features.

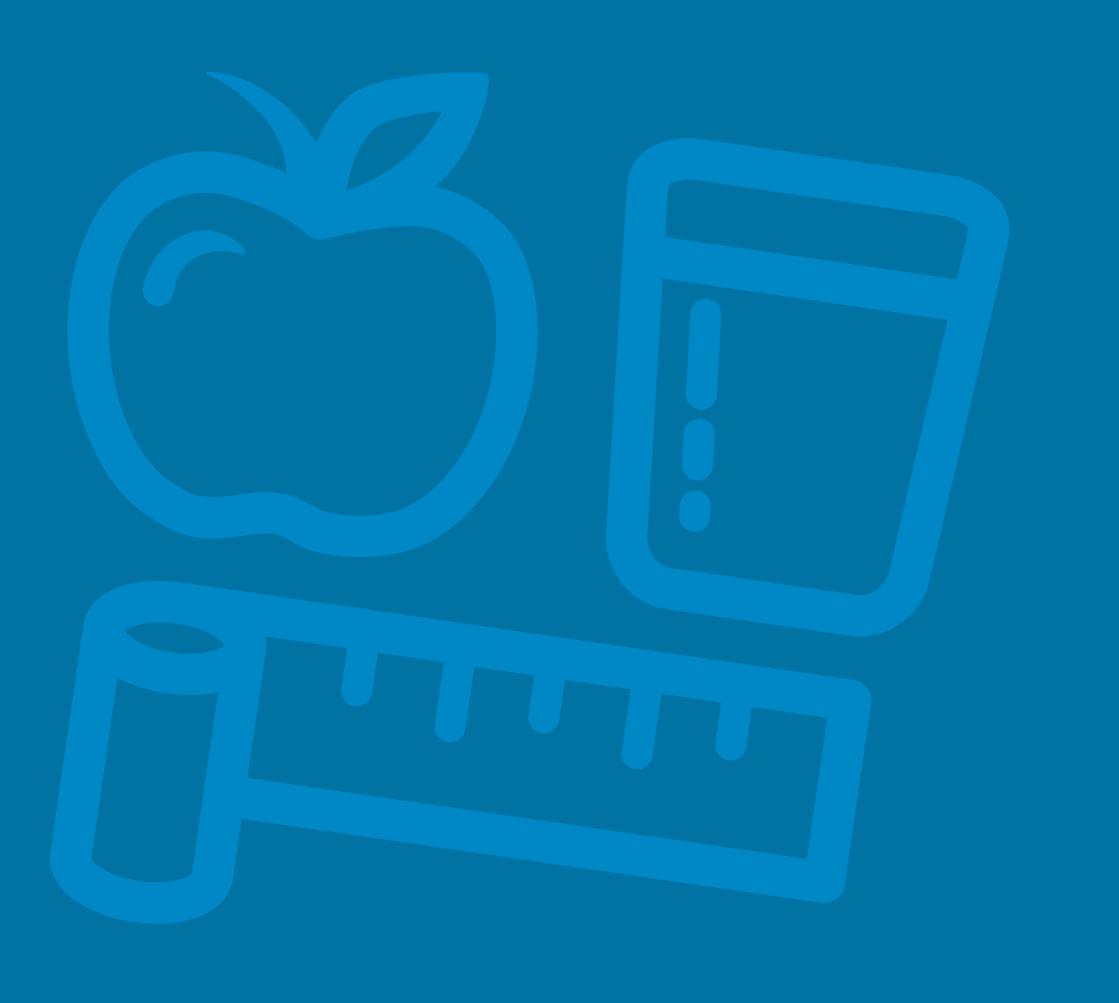
Another contributing factor to the overall success of the research project was the ability to have some of the participants engage through the entire process. Most of the participants engaged in the Cultural Probe/Interviews, the Co-design session and the Evaluation activity. While it can be argued that the limited range of participants might provide a limited range of needs and solution designs, the ability to have the participants be familiar with the focus of the project allowed more time to be focused on the work and less time focused on brining every participant up to speed on what happened in previous phases of the research. It also established a sense of camaraderie during the co-design session which allowed for an easy integration when teams were split up for solution modeling.

If a similar project were to be developed in the future, researchers might consider the ability to integrate new users into the *Evaluating the Answer* phase in order to gain perspective from fresh eyes. There is a possibility that because participants were somewhat familiar with the co-design solutions, that they might have been positively primed for the solution they evaluated. That being said, it can also be a positive experience to evaluate the result with both new and prior participants alike in order to validate progress with the prior participants.

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# Appendix

# Glossary

**Care regimen:** Defined as the combination of protocols provided by the doctor or coordinated care team in order to maintain type 1 diabetes under control. Can involve steps such as eating a balanced diet, maintaining an active lifestyle, checking blood glucose and doing calculations for insulin dosing.

**Co-Design Workshop (or Facilitation Session):** Specific workshop focused on facilitating activities that enable and empower people to express, make, evaluate and collaborate, in order to creatively solve problems. Can involve different smaller methods and activities to arrive at output that is aimed at answering or responding to the needs of the planned session. (Definition taken from P. Napier and T.Wada *Defining Design Facilitation: Examining new roles for designers and what it means for design education*)

**Continuous Glucose Monitoring (CGM):** a sensor device paired with either a reader or insulin pump that provides real-time reading of glucose levels and can demonstrate patterns in order to provide the patient information on the actions needed.

**Cultural Probe:** A tool provided to research participants to elicit reflection in day to day activities as a way of collecting their daily experience without being present. Can involve a variety of tools for collecting information such as notebooks with prompts, cameras, or recording devices. (Definition taken from Universal Methods of Design)

**Fear of Hypoglycemia:** Phobia developed by T1D patients as a result of having experienced many hypoglycemia episodes, or an especially challenging one. This Fear leads patients to rely on measures to maintain blood sugar levels high in order to not experience hypoglycemia which is acceptable in certain moments where it would be wise to do so, but results counterproductive in the longterm care of diabetes possibly leading to complications.

**HbA1c:** (also referred to as A1c) Blood test used by endocrinologists to determine average glycemic control over a span of 3 months. Recommended range for adults with T1D is between 6.5 and 7%. A person without diabetes shows results of 5.7% on average.

**Type 1 diabetes (T1D):** Previously known as juvenile diabetes, is a chronic autoimmune disease in which the pancreas produces little or no insulin, preventing glucose to be used by cells in energy production

**Type 2 diabetes (T2D):** Previously known as adult onset diabetes, is a chronic metabolic disease where the body has trouble producing enough insulin to manage food intake.

**Insulin:** Injectable hormone used by diabetes patients to regulate the use of glucose by cells in energy production. Non-diabetic people produce this naturally in their pancreas.

**InVision:** An online and mobile platform that allows for prototyping and testing of web and mobile applications before going through a full development cycle.

**Hyperglycemia:** Moment when a diabetes patient's glucose reading is 24omg/dl or above. Much like hypoglycemia, can be patient triggered and sometimes reflects similar symptoms to hypoglycemia.

**Hypoglycemia:** Also known as low blood sugar or lows. Moment when a diabetes patient glucose is equal or lower to 70mg/dl in a reading. This can be caused by a variety of factors or combination of them including delayed meals, excess insulin dosing, and unexpected or increased physical activity. Depending on the glucose reading, patients experience different symptoms and will need to treat each case differently independently or with the assistance of another person. Many times, this other person may not be a medically trained professional. In this document, hypoglycemia and lows is used interchangeably.

Low

Moderate

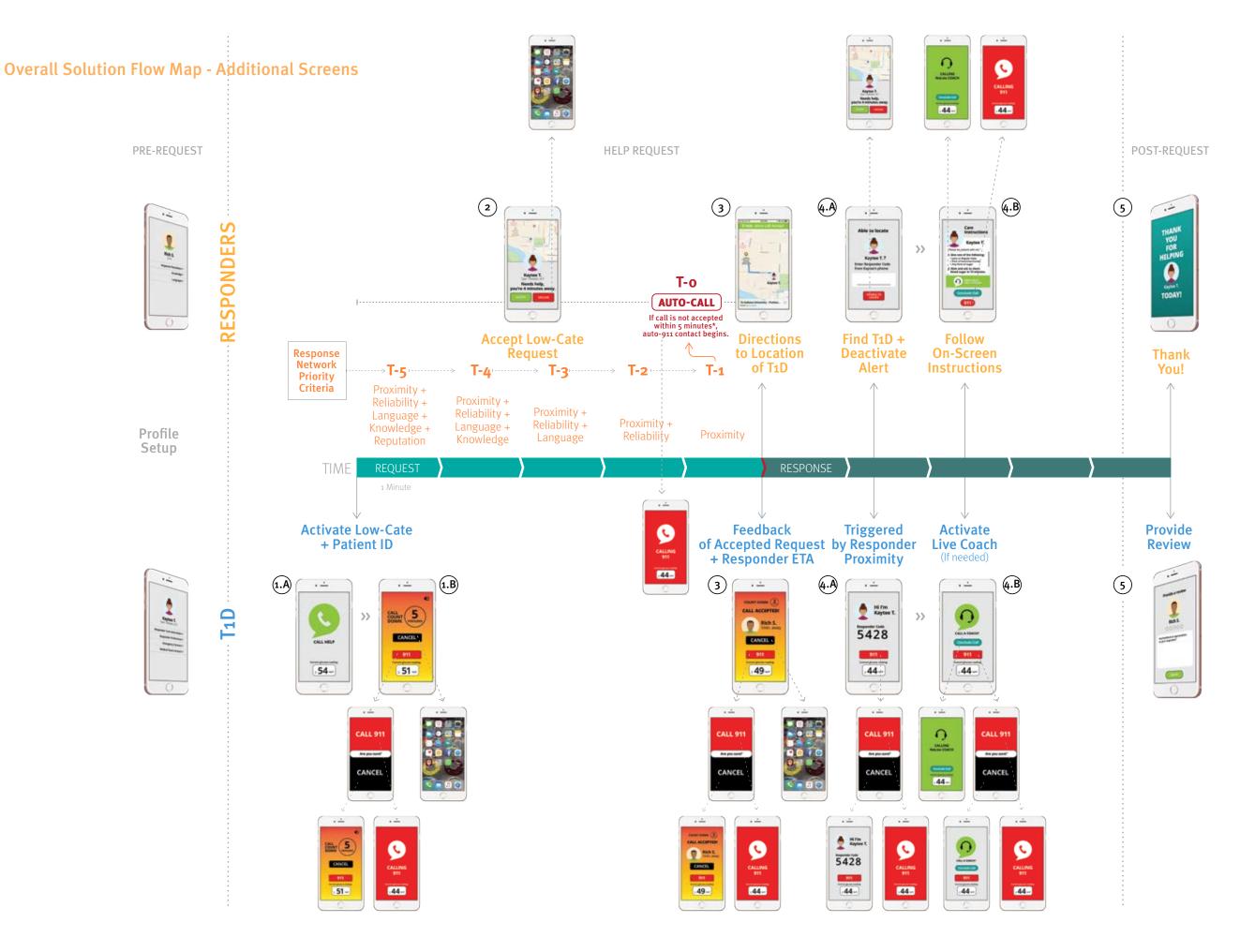
Severe

**People-Centered Design:** Methodology that strives to understand and present peoplecentered solutions to fuzzy and complex problems. As opposed to other design methodologies, it relies heavily on interacting with the problem owners or stakeholders in order to source their experiences, frustrations and solutions to the problem from their perspective.

**Persona:** Tool that consolidates archetypal descriptions of user behavior patterns into representative profiles of the user segment, to humanize design focus, test scenarios and aid design communication. (Definition taken from Universal Methods of Design)

**Patient singularity:** Every T1D patient has very unique and singular experiences. Although a general definition of the disease may be made, it's effects and reactions are individual per patient.

**Self-treat:** When a patient is functional enough to treat the hypoglycemia episode by themselves without help.



### **Cultural Probe Transcripts**

#### **LISA SEMIDEY**

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#### **LISA SEMIDEY**

Day 1: How long have you had diabetes? What system do you to treat it (glucose tester, insulin pump, CGM, multiple daily injections...)

#### PATIENT 1

I was diagnosed with type 1 diabetes January 25, 2005. I have been living with diabetes for 12 years. I treat with a tandem t:slim insulin pump, humalog insulin, dexcom G4 cgm, and use a one touch glucometer to test. I went on an insulin pump 4 months after diagnosis and have been rocking one since then. I started on an animas pump but switched to tandem 3 years ago. I started on novolog insulin but had to switch due to insurance. (I prefer novolog) I use the G4 cgm so that my parents and husband get alerts if I go low as I lost my hypo awareness during and following my first pregnancy. So I guess my iPhone and family should be included in how I treat as well!

#### **LISA SEMIDEY**

Thanks for sharing! I would definitely count them in your care system.

Day 2: In a typical week, how often do you (physically or via your CGM) notice you're experiencing a low? How do you treat your lows? Do you have a kit or something for it? If you do, what it contain?

#### LISA SEMIDEY

Day 3: Now think back a little, remember a particularly memorable/extreme/difficult/severe hypoglycemia episode you've experienced. What was that like and how long ago was it? Tell me how did you notice, what you did to correct it, did anything/anyone aggravate you, did you need help from anyone around you, what was difficult for you?

#### PATIENT 1

Day 2: probably about 5 times a week I experience lows. I keep a variety of things to treat a low stashed throughout my car, house, office, purse, and parents house. I keep fruit snacks and juice boxes in my glove compartment of my car in addition to a glucagon. I keep a glucagon and snacks, such as fruit snacks, in my purse. I also keep glucose tabs in my purse. We have juice in the fridge at home and at my parents home. I keep smarties and glucose tabs at home too and sleep with juice boxes in my night stand. I have glucose tabs and juice boxes at the office. I keep a glucagon at the office and at home as well.

#### PATIENT 1

Day 3:I had several extremely bad lows while pregnant. (5 glucagon used because I was unresponsive) the worst one happened while I was driving, which was extremely scary. I was close to home and tried to pull off the road and skimmed a guard rail (which wrecked my car) I was transported to the hospital via ambulance and treated that way. This particular hypo came on extremely quick and because I was unresponsive I am not sure how long it lasted. During my severe hypos I get very very cold and it takes about an hour for me to warm up. I often refuse to acknowledge that I am low when I go too low and fight my husband on whether or not to treat. I get very silly when I am low and often act "tipsy."

#### **LISA SEMIDEY**

Here are your final prompts for this Cultural Probe. Day 4: What do you need others to know when you're experiencing a hypoglycemia episode? It could be anything. You could talk about what to give you during the episode. How to approach you (or not. What to say. What's ok and not ok to do...

During a hypoglycemia episodes, what needs do you have that are currently not being met? Even if it seems far fetched, it's ok to imagine outside the box here.

#### PATIENT 1

I always make sure that someone around knows I have type 1 if possible. I have my husbands contact info under the emergency info on my phone, on a paper in my wallet, and posted by my desk. My coworkers and friends know what my. Cgm beeps mean and when to bug me about getting a juice box. My husband knows how to use a glucagon, as do my parents and brother. My family also knows how to use my glucometer to check my BG if I seem off. They are also familiar with instant glucose and I give them a refresher "low course" every year. Most people know to bug me until I treat because I can sometimes be resistant.

I would love something that takes me out of the equation because as I mentioned I am not always quick to treat and when I get low I sometimes don't think clearly and don't want to treat. I would love a pump that automatically suspends or could give glucagon to raise BG without me needing to do anything. It would be great to have something that could pop up and instruct those around me with exactly what I need. One of my biggest fears is going low when in public alone.

#### **LISA SEMIDEY**

Patient 1, thank you!! Your responses have been incredibly insightful. I appreciate your participation in this.

#### **LISA SEMIDEY**

If you want to participate in any other part of the research please let me know!

#### **PATIENT 1**

Lisa, I'd love to participate more but I actually live in PA now and I thought I saw the other parts were face to face

#### **LISA SEMIDEY**

Aww! Well my deepest appreciation for your contributions!

#### **LISA SEMIDEY**

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#### **LISA SEMIDEY**

Day 1: How long have you had diabetes? What system do you to treat it (glucose tester, insulin pump, CGM, multiple daily injections...)

#### LISA SEMIDEY

Day 2: In a typical week, how often do you (physically or via your CGM) notice you're experiencing a low? How do you treat your lows? Do you have a kit or something for it? If you do, what it contain?

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#### PATIENT 2

Q1. I have had diabetes for 16.5 years. After using a pump for 13 years I'm currently taking a break. I am now using tresiba long acting insulin, afrezza inhaled insulin, a dexcom CGM and Accu-chek BGM.

Daily. The last few days with nice weather multiple x due to exercise. I don't have a kit. I keep juice or soda in house all the time, have two movie theatre boxes of dots in car (one of the few candies I won't

eat unless necessary) and carry misc supplies in purse. Often s can of coke and currently starburst. At work The same.... Soda, juice, candy. I'm not against glucose tabs but not my fav. I don't have a glucagon kit.

#### **PATIENT 2**

Q3. Most memorable involve others. Ones on own blur together (never had a comma....). Today I had to end a bike ride with friend as it was stuck in 50s. I'll remember that one above other 5 over weekend as it involved other person. Most memorable is my boyfriend leaving me in car to find coke after I had blown thru supplies. When he left I was normal. When he came back I was screaming about how long he took and dying. Second was at work. I dropped so quickly during 1:1 meeting the other person finally went to get help. That person helped but also called security. I yelled at 4 colleagues helping me in 30 minutes till sugar came up and I figured out what was going on. Most of that was blur.

#### **PATIENT 2**

I'm lucky that I work at a company dedicated to diabetes. I'm never too embarrassed to treat a low but it's taken years to get to this place. It's with others I get aggravated. Like on weekends with college girlfriends. One tries to help and I'm so used to doing it on own when dexcom is waking others up and they try to help I get defensive. And maybe a bit angry that they only want to help when it's in their face, when I could have used some help ALOT the last 16 years.

#### PATIENT 2

I should mention I'm 55, diagnosed at 37 and have been single the entire time I've managed my diabetes.

#### **LISA SEMIDEY**

Wow Patient 2! I remember you mentioning you were diagnosed as an adult. Do you think being diagnosed as an adult made your experience adjusting to caring for T<sub>1</sub>D easier? Harder? What was that experience like?

#### **LISA SEMIDEY**

This is the last set of questions for the Cultural Probe. Since you responded to three days in a row, take your time in responding to these.

Day 4: What do you need others to know when you're experiencing a hypoglycemia episode? It could be anything. You could talk about what to give you during the episode. How to approach you (or not. What to say. What's ok and not ok to do...

During a hypoglycemia episodes, what needs do you have that are currently not being met? Even if it seems far fetched, it's ok to imagine outside the box here.

#### PATIENT 2

I am ok with persons asking me if I need to test or are you low if they sense I am going low. I am more sensitive to this from people who are not around me much and ask if I trip or something. I hike with a group of ladies from church and after a backpacking trip, on the drive home, I went to answer a question and realized I could not speak. I treated, recovered but scared them. Later, when the story was retold I was literally described as going bonkers. After that, if I did anything "wrong" on a hiking trip, like trip, I would be asked if low. That gets on your nerves after awhile. But people I work with, family etc don't bother me.

#### PATIENT 2

I'm embarrass if low and don't have something handy to treat so being proactive to just solve that is good. Just find me a f----ng coke . Recently at work I was sharing my story and tested for them and was low. Before you knew it a coke was handed to me, actually passed to me from the back of the room. What great service!! Much better than being infuriated with a "do we need to stop so u can treat."

I meant interrupted not infuriated. Spell check

As far as unmet needs. Different alarm choices for CGM. You get immune after awhile and don't always notice. Same amount (I'm trained that 3 mean low and 4 mean danger) but new tones. For Share to connect or have a way for the follower to see emergency contacts. That way if I don't respond you could find a number and check with a neighbor, etc before calling 911. Or tracker to see where I am. (google wearsafe for example)

#### **PATIENT 2**

One last thing.... In response to inquiry about me being diagnosed as adult. EASD reported last year 50% of t1s diagnosed are 30+ years old. Just misdiagnosed so data skewed. I'm guessing most of us get minimal education. Thank goodness I'm independent or I may have not survived suddenly handling this on my own. I'm so fortunate to have started working at Roche soon after diagnosis. I can't imagine working in an atmosphere that is not empathetic. I had an attitude it would not stop me and it hasn't. But I'm scared for my future on my own .. Especially complications like dementia.

#### **LISA SEMIDEY**

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Day 1: How long have you had diabetes? What system do you to treat it (glucose tester, insulin pump, CGM, multiple daily injections...)

#### PATIENT 3

For 17 years (almost to the day) and I use a TSlim insulin pump

#### **LISA SEMIDEY**

Thanks for responding! New questions will be sent tomorrow

Day 2: In a typical week, how often do you (physically or via CGM) notice you're experiencing a low? How do you treat your lows? Do you have a kit or something for it? If you do, what does it contain?

#### PATIENT 3

Maybe once a week, sometimes not at all. I normally take 4 glucose tablets and then have a snack, and by snack a lot of times it turns into a small meal because all I want to do is eat when I'm low.

#### **LISA SEMIDEY**

Day 3: Now think back a little, remember a particularly memorable/extreme/difficult/severe hypoglycemia episode you've experienced. What was that like and how long ago was it? Tell me how did you notice, what you did to correct it, did anything/anyone aggravate you, did you need help from anyone around you, what was difficult for you?

#### PATIENT 3

I was in elementary school (I don't remember what

year, but maybe 3rd or 4th) and it was the first and only time I've passed out from a low. My blood sugar was 47 once someone checked it. One second I was fine and the next my stomach hurt and I remember my mom taking me to the office (It was right before lunch and thankfully my mom had come to have lunch with me that day) and next thing I know I woke up on the floor. I remember my art teacher and the school secretary also helped with getting supplies and getting me up off the floor. I had to be forced to drink juicy juice because I still felt sick. It was such an extreme episode that I really couldn't do anything besides try not to panic and let my mom take care of me.

#### **LISA SEMIDEY**

Wow! I'm glad that you had your mom close by to help you out!

Here are your final prompts for the Cultural Probe.

Day 4: What do you need others to know when you're experiencing a hypoglycemia episode? It could be anything. You could talk about what to give you during the episode. How to approach you (or not. What to say. What's ok and not ok to do...

During a hypoglycemia episodes, what needs do you have that are currently not being met? Even if it seems far fetched, it's ok to imagine outside the box here.

#### PATIENT 3

I guess the biggest thing I need them to know is to don't freak out or hover. The more other people stress out the more I panic. I have panic attacks when I go low because my brain can't figure things out fast enough. I just need someone to sit with me in case I do pass out or need anything, but to not say/do anything unless I ask them to.

It's also super important that people realize that a low will affect me long after my numbers have returned to normal. I need time to recover from the symptoms and then I'll probably go really high from over treating, but that's a whole other story.

It'd be nice to have a way to avoid panicking when I go low. I'm not sure if there's anything out there that helps. I mean I know how to treat a low, but when I'm actually low it's likel can't do anything besides panic and shove food in my face

#### LISA SEMIDEY

Patient 3, thanks for sharing the amazingly honest and insightful responses!

| Responder Interview Worksheet |       |
|-------------------------------|-------|
| Context:                      |       |
|                               |       |
|                               |       |
|                               |       |
| Event:                        |       |
|                               |       |
|                               |       |
|                               | Start |
|                               |       |
| Feelings:                     |       |
|                               |       |
|                               |       |
|                               |       |
| Needs:                        |       |
|                               |       |
|                               |       |
|                               |       |
|                               |       |
|                               |       |
|                               |       |

# **Responder Interview Worksheet**

#### Context:

42 YEAVS (DIAGNOSED C IT)

PUMP + EGM + LANTUS

J DEXOM (SYEARS)

LAG INDICATOR (IS MINS BEHIND)

MON WAS TID /+ COMPLICATIONS

SEVEREY IS DIFFERENT

- MATRIED 39

ENOUN 44

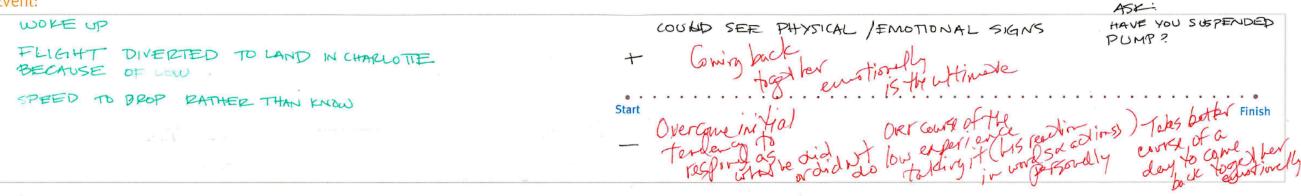
- HE INITIATEN TID CONVO

- PESPECT

- CAREFULLY MEASURED IMPACT OF

TID ON LOVED ONES/ RELATIONS HIPS

#### Event:



#### Feelings:

- FRIGHTENINAR I KEEP YOUR HEAD ABOUT YOU

TEMPER YOUR REACTION

- MIGHT GAUGE FOR

- NERVERACKING

- NERVERACKING

- HAPPENS MIDDLE ON NIGHT

- AFTER 40-SIME YEARS,

- CANT HELP HIMSELF IF HE CALLS

- PEACTION FROM ME MIGHT MAKE HIM FIGHT BACK NATURALLY

- TOUGH NOT TO TAKE THINKS PERSONALLY (REACTIONS FROM RATOR)

- FEAR OF NEEDLES (GBUCAGON)

#### Needs:

PRE-MIXED HLUKAGON

UNKNOWN

- TOUGH MUST PESPECT
- ABILITY TO STEP THROUGH & KNOW HOW TO HELP (CONFIDENCE)

STRAIGHT FORWARD & DIRECT RESPONSE

| Solution<br>BLUEPRINT  | NAME:  |  |
|--|--|--|
| Ever say a sentence that sounds something like this: "Wouldn't it be great if existed?"  This is the space to create that!  Although you've been given | START TIMELINE:  T1D Realizes they need assistance with a low. | Feedback: THOUGHTS? QUESTIONS? PRAISE? SUGGESTIONS |
| existing features, do not be afraid to imagine things that do not exist yet. We'll worry about making it possible later. <b>BE BRAVE!</b>              |  |  |
| Key Features:  |  |  |
|  |  |  |
|  |  |  |
|  |  |  |
|  |  |  |
|  |  |  |
|  |  |  |

## **Evaluation Worksheet**

# **Evaluation Worksheet**

Based on a co-design session with Type 1 Diabetes patients and untrained responders, we have come up with this soultion I'm presenting to you today.

Imagine that you were faced with a hypoglycemia episode, as the patient or responder, what do you think about the solution?

# Is it...

## **Useful?**

Does it solve the problem we set out to solve? Does it respond to the need?

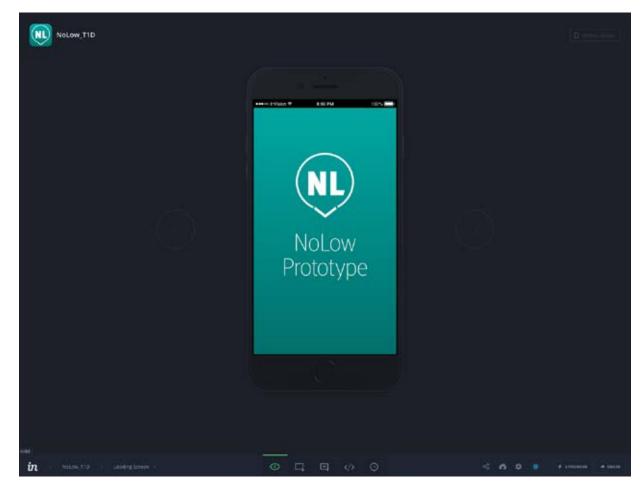
#### **Usable?**

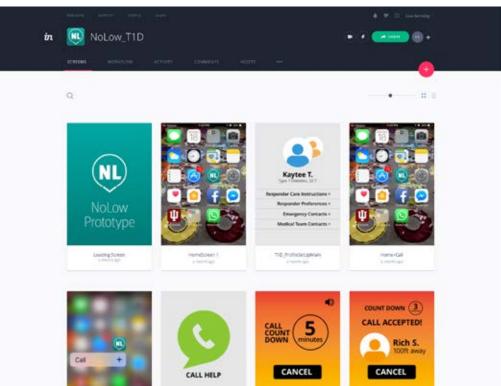
Is it intuitive and easy to use?

#### Desirable?

Lastly, do you **need** it or **want** to use it?

#### **InVision Platform**





## **Evaluation Worksheet**

Based on a co-design session with Type 1 Diabetes patients and responders, I have come up with this soultion based on the solutions they developed during the session.

Imagine that you were faced with a hypoglycemia episode, as the patient or responder, what do you think about the solution?

Is it...

INTEGRATE TO EXISTING APS TIDE POOL MY SUGAR

Useful? YES.

Does it solve the problem we have defined? Does it respond to your needs?

GIVES TID COMM. OPPORTUNITY TO INTERACT AT CRITICAL POINT.

ACCESS TO THIS WOULD TRIGGER NEARBY PPL.

ACCESS TO 911

LIKE ACCESS POR RESPONDER TO 911.

#### Usable?

Is it intuitive and easy to use?

RELIES ON ABILITY TO ATTRACT RESPONDERS TO SYSTEM.

DIABETES ONLINE COMMUNITY WOULD BE WILLING TO SIGN UP.

4CTIVE, ENGAGED, LARGE

EASY TO DEACTIVATE IF CGM TRIGGERS HASTILY

#### Desirable?

Lastly, do you need it or want to use it?

DEFINITELY SIGN UP

USED MAINLY BY TIDS

LIMITATION, HAVE TO ACTIVATE IT.

DEXCOM 4 NOT TO ENLITE SENSORS

# **Evaluation Worksheet**

Based on a co-design session with Type 1 Diabetes patients and responders, I have come up with this soultion based on the solutions they developed during the session.

Imagine that you were faced with a hypoglycemia episode, as the patient or responder, what do you think about the solution?

# Is it...

#### Useful?

Does it solve the problem we have defined? Does it respond to your needs?

LIKE INFO FROM TID /INSTRUCTIONS

FLOW FROM CODE

PESPECTS DIGINITY

CHOICE IS GREAT

CLATZIFY

SIMPLE

(LEAR / SIMPLE INTERACTIONS

#### Usable?

Is it intuitive and easy to use?

IMPORTANCE OF SOCIAL ASPECT.

#### Desirable?

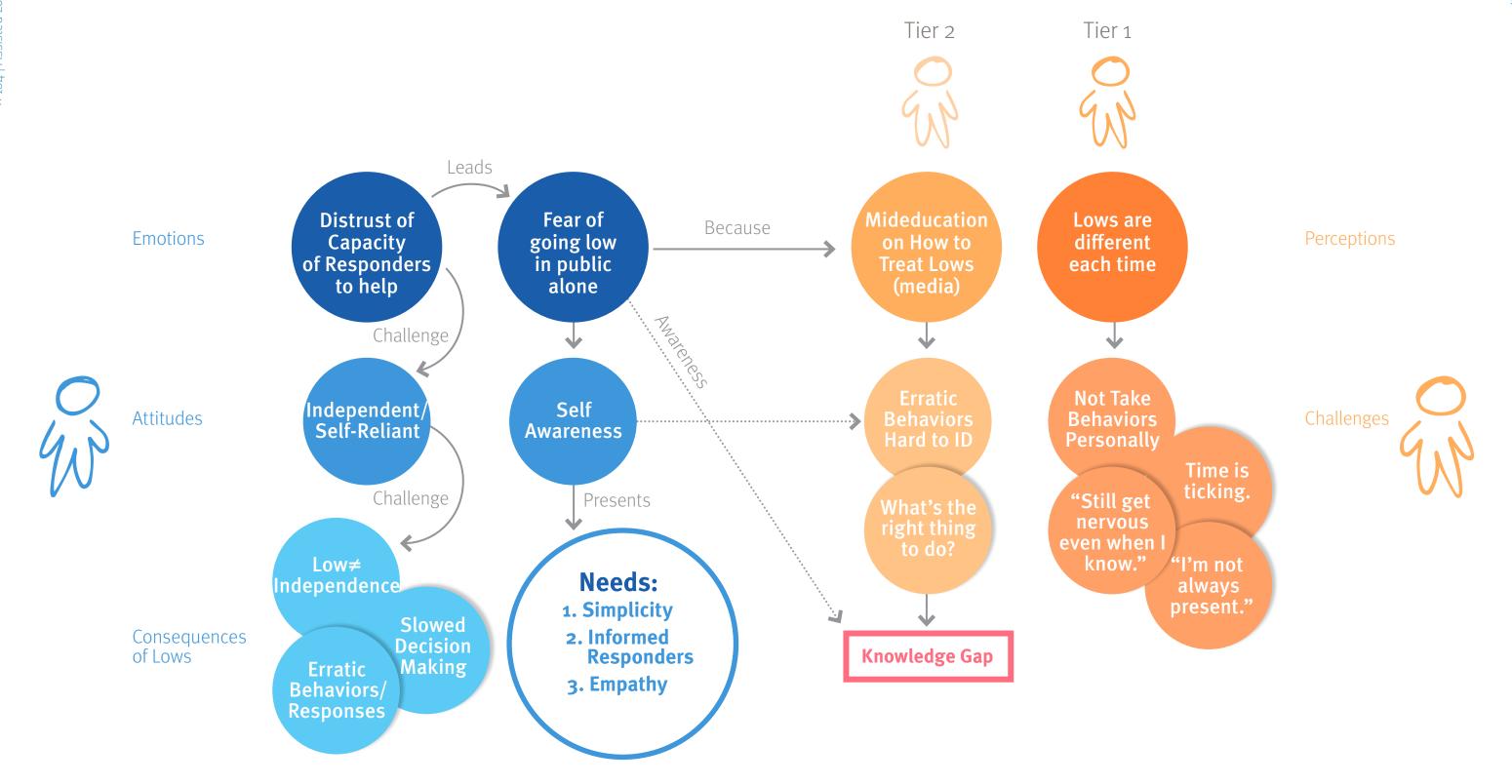
Lastly, do you need it or want to use it?

WOULD THINK ABOUT IT:

USEPUL TOOL.

PEMOVES BOUNDARRY OF ASKING "ARE YOU OK" — PESPECT

MUTUAL UNDERSTANDING OF TID & RESPONDERS



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by Pedrovisc

