INDEPENDENT HEROES

Supporting type 1 diabetic young adults' transition to independent living

Kunal Gupta

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ABSTRACT

This Master of Design Thesis project focuses on the condition of severe hypoglycemia (low blood sugar) in young adults living with type 1 diabetes by carefully understanding the unique challenges they face in transitioning to adult care. This research surfaces the needs that often get blurred in the transition process and offers a design for an appropriate solution to support the identified issues.

Canadian young adults living with type 1 diabetes often find themselves at the risk of hypoglycemia during emerging adulthood. The concept of emerging adulthood has not been considered extensively in managing chronic illness and transition from pediatric to adult care. Yet, this is a critical time when a person may first assume full responsibility for their diabetes self-care while simultaneously facing all the usual challenges young adults face. Additionally, the fear of hypoglycemia is strongest in this group.

A review of the literature informs us about previous work done in this field. However, most current interventions are in the form of bulky printed materials. Another critical issue with the development of most recent tools is the absence of user involvement in the creative process leading to unmet user needs.

In this project, participatory design methodologies were introduced in a human-centered approach, collaborating with young adults to understand and address the transition process gap. It included actively listening to user narratives and co-creating the solution.

The synthesis of primary and secondary research resulted in the designed outcome of a smart wearable device that will work in conjunction with the Continuous glucose monitor (CGM) and alerts the bystander and emergency contacts by turning them into potential lifesavers. It will inform them of a diabetic emergency and guide them through the life-saving instructions. Additionally, it will alert the medical emergency services for prompt assistance if needed.

The solution attempts to provide early intervention during emergency and could also alleviate the fear of hypoglycemia in young adults. This in turn will reduce the load on the already burdened healthcare system.

KEYWORDS

Young adults
Type 1 diabetes
T1D
Transition
Hypoglycemia
Glucagon
Medical emergency
CGM
Blood sugar
Participatory
Human centered
Co-creation
Cultural probe
Affinity diagramming
Early intervention
Smart wearable

1 INTRODUCTION

1.1 Thesis Statement

1.2 Project Objective

1.3 Project Rationale

1.1 THESIS STATEMENT

Facilitating type 1 diabetic young adults' transition to adult care through a design intervention that helps them navigate hypoglycemia.

1.2 PROJECT OBJECTIVES

The objectives of this project include:

1. **Understanding and identifying the needs of type 1 diabetic young adults as they transition fully into adult self-care.**
2. **Employ participatory design methods that empower young adults to have a voice in the design process.**
3. **Integrate research findings to develop a solution.**

1.3 Project Rationale

The transition of young adults living with type 1 diabetes from pediatric to adult care is fraught with challenges. Current gaps in this process pose some serious health challenges and add to the cost of diabetes, which was estimated to be $15.36 billion for 1.2 million Canadian living with diabetes (Bilandzic & Rosella, 2017). Ensuring care and support for people with diabetes will safeguard the patient's well-being and reduce the systemic cost associated with diabetes care.

Young adults experience gaps in the care transfer procedure and have additional transitional issues and challenges apart from diabetic-related complications. Many of these transitional challenges have been identified; however, very few interventions exist to assist them through the process. The healthcare system in Canada acknowledges the challenges young adults face in transition and is facilitated through transitional programs; however, research indicated that healthcare professionals may not always conduct a detailed needs assessment and generally tend to lack user participation in these solutions' design processes, leading to unmet user needs (Shah, Robinson, & AlShawi, 2009).

My primary research identifies that the incidence of hypoglycemia (low blood sugar) is prevalent among the targeted group. At this age, young adults are often moving out of their parents' home to start university or join work—a new environment with people who might be unfamiliar with diabetes. Glucagon, an emergency medication commonly used to treat severe hypoglycemia, only works if someone knows **when** to use it, **where** it is, **how** to use it and is motivated to do so. After reviewing precedent literature and work done in this field, I identified a gap that no treatment plan exists in the market that addresses the above and provides life-saving assistance to people with diabetes.

There is a need to provide young adults with such a life-saving tool that they can utilize in emergencies. A secondary outcome would be the confidence this tool might give young adults and reduce their stress during diabetic situations. My thesis project seeks to address this gap by developing a solution that aims to provide early assistance by alerting people when to use it, notifying their location and guiding them to the life-saving process.

2 SECONDARY RESEARCH

2 SECONDARY RESEARCH

To ground the design firmly in its context, secondary research was initiated to understand the existing knowledge base of the problem space.

2.1 Understanding Type 1 Diabetes

Roughly 10% of people living with diabetes in Canada have type 1 diabetes ("Type 1 diabetes," 2020). The increase in diabetes is expected to grow by 30% from 2020 to 2030 (Diabetes in Canada: Backgrounder. Ottawa: Diabetes Canada; 2020).

Type 1 Diabetes (TID) is neither preventable nor curable. Living with T1D requires constant attention to avoid acute, life-threatening **hypoglycemia** (low blood sugar) or the long- term damage done by **hyperglycemia** (high blood sugar). People with diabetes check their blood sugar levels either with **blood glucose testing devices** or with a **Continuous glucose monitor (CGM)**. One must carefully calculate insulin doses based upon activity and stress levels, food intake, illness, and additional factors. These calculations are rarely perfect; both patients and caregivers experience a tremendous emotional and mental burden. Blood sugar regulation is necessary because, over a long period, high glucose levels in your blood can seriously damage the heart, eyes, feet, and kidneys ("What is Type 1 diabetes?" 2020).

Prevalence (1)	2020	2030
Diabetes (type 1 and type 2 diagnosed)	3,772,000 / 10%	4,891,000 / 12%
Diabetes (type 1)	5-10% of diabetes prevalence	
Diabetes (type 1 + type 2 diagnosed + type 2 undiagnosed) and prediabetes combined	11,232,000 / 29%	13,559,000 / 32%
Increase in diabetes (type 1 and type 2 diagnosed), 2020-2030	30%	
Direct cost to the health care system	$3.8 billion	$4.9 billion
Out -of -pocket cost per year (2)		
Type 1 diabetes on multiple daily insulin injections	$1,100-$2,600	
Type 1 diabetes on insulin pump therapy	$1,400-$4,900	
Type 2 diabetes on oral medication	$1,200-$1,900	

Figure 1: Estimated prevalence and cost of diabetes (Source: Diabetes Canada)

2.2 Managing type 1 diabetes

Managing and treating T1D is a two-part process: measuring blood glucose and delivering insulin. There are many ways in which glucose monitoring processes can be performed.

BLOOD GLUCOSE MONITORING

Glucose monitoring is a vital process for glycemic control. Regular monitoring makes it easier for patients to make daily management decisions related to food intake, insulin dose, and physical exercise. It enables patients to avoid potentially dangerous hypoglycemia and hyperglycemia episodes. There are different ways in which one can execute this task ("My Site - Chapter 9: Monitoring Glycemic Control," 2018).

Figure 2: Blood glucose monitor (Source: Pixabay)

Blood glucose monitors are the most commonly used and traditional glucose monitoring methods, including a test strip that inserts into a meter. A special needle called a lancet is used to prick the finger and touch the drop of blood to the test strip, which the meter starts processing and gives a blood glucose reading (Center for Devices and Radiological Health, 2019).

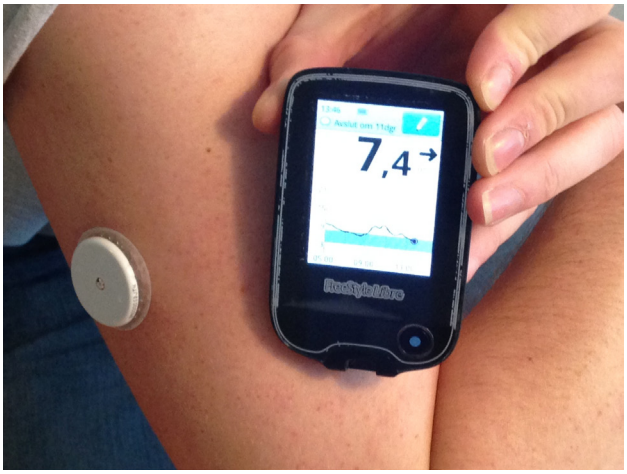


Figure 3: Continuous glucose monitor. 2016. Wikimedia commons, licensed under CC BY-SA 4.0

A **continuous glucose monitor (CGM)** is a small wearable device that tracks the person's glucose throughout the day and night. While not as common as the glucose monitors, it is becoming the new norm. It notifies the user of any highs or lows to give individuals a clearer picture of fluctuating blood sugar levels in real-time. The continuous glucose monitor automatically checks your blood sugar at regular intervals and displays the blood glucose reading on a screen (Diabetes Daily Staff, 2019).

2.3 Hypoglycemia

Hypoglycemia is the state of low blood sugar caused by **too much insulin** or **too little** sugar in the body. It is defined as blood sugar below 70 milligrams per deciliter (mg/dL), or 3.9 millimoles per litre (mmol/L). **If left untreated, it may result in seizures, unconsciousness and sometimes death**, so it is not surprising that fear of hypoglycemia is common among adults and children with T1D (Seaquist & Clark, 2013, as cited in Peters & Laffel, 2013, p. 348).

Symptoms of hypoglycemia include anxiety, behaviour changes that seem similar to being intoxicated, confusion, difficulty in concentrating, drowsiness, fast heartbeat, shakiness, slurred speech, unusual tiredness, or weakness.

There are two situations in which hypoglycemic reactions can be treated—awake or unconscious (Hamdy, 2020).

Treatment

If a person is awake, they should be ingested simple carbohydrates (15 grams*) such as glucose tabs, glucose gel, regular soda or juice or sugar.

If a person is unconscious, they should be treated with a glucagon and emergency services should be called.

2.4 Glucagon

Glucagon is a hormone produced naturally within the body. It is also an **emergency medication** used when a person with diabetes is experiencing **hypoglycemia,** and sugar cannot be taken orally.

It comes in powder form and is usually added to a solution to administer it. Once glucagon is injected, it raises the blood sugar by sending a signal to the muscles and liver (where glucose is stored in the body). The effect of glucagon is the opposite of insulin, raising blood glucose instead of lowering it. As well as the injectable glucagon, Nasal glucagon called BAQSIMI is also used to treat hypoglycemia. This powder form of glucagon is administered into the nose and comes in a single-use dispenser.

When a person is conscious but cannot consume sugar orally, then glucagon can be self-administered. If the person is unconscious or has an altered level of consciousness, someone else will need to inject the glucagon into the muscle or administer BAQSIMI (nasal glucagon) to the nostril. If hospitalized, an injection may be given intravenously ("Glucagon," 2020).

The standard glucagon (injectable) requires cumbersome reconstitution and could be intimidating for caregivers during an emergency (Suico et al., 2020). The nasal glucagon offers a promising alternative to the transitional ones as it is needle-free, easy to use, as effective as the standard one (Sherr et al., 2016). This option provides a more reliable opportunity for treating diabetic emergencies.

2.5 Young Adults in Transition

Health care transition is defined as the "purposeful, planned movement of young adults with chronic medical conditions from pediatric care to the adult health care system" (Kaufman & Pinzon, 2007). The change is often a challenging process and becomes a significant challenge for healthcare providers. The transition for young people with diabetes means increasing their diabetes knowledge and enhancing their self-management skills. However, this is influenced by multiple parallel changes in holistic personal development during emerging adulthood. Several studies claim that ineffective or broken healthcare transitions may increase diabetic-related complications.

The period of emerging adulthood is focused on exploring one's identity and experiencing many social, emotional, educational, occupational, and financial concerns during this stage. With new responsibilities and reduced parental management, young adults may struggle, and their glycemic control may suffer (Nakhla M, Daneman D, Frank M, Guttmann A, 2016; Insabella, Grey, Knafl, & Tamborlane, 2007). Maintaining a near-normal glycemic level is essential in reducing future complications from diabetes. A study states that suboptimal glycemic levels established during this age group may be challenging to change later (Rausch et al., 2012).

Along with regular developmental changes that the age transition offers, youth are loaded with tangled daily necessities of diabetes care, such as monitoring blood glucose levels, administering insulin, regulating food and exercise, and have appropriate access to medical care and diabetes supplies (Weissberg-Benchell, Wolpert, & Anderson, 2007). At this stage, they often struggle with these demands and may feel unsupported and vulnerable.

Several barriers are reported to self-care and standard glycemic control in the targeted demographic. In a small survey, irregular schedules, diet, hypoglycemia, and finances were also reported as barriers to glycemic control, along with peer pressure and lack of parental involvement (Ramchandani et al., 2000).

Young adults have unique needs that usually do not fit into the typical pediatric or adult diabetes care agenda. These needs must be woven into the transition process to ensure a connected and sophisticated health care transition.

2.6 Technological Precedents

In order to develop a potential solution to address hypoglycemia, several existing technology precedents were explored, which acts as the base for the design.

VOICE ACTIVATION

Voice activation technology has evolved for years but is relatively new in this area. Several health apps, including Covert Alert and Safe, use this technology to alert SOS contacts through a chosen phrase ("The #1 voice-activated personal safety app is now available on both Android and iOS.," 2019) (MobileSoftware AS. 2020). These are personal safety apps intended for the general public, including children, family members, employees etc. As well, a voice-activated medical alert system like a medical guardian allows seniors who want to send medical alerts and summons for help ("The Best Voice Activated Medical Alert Devices - Caring.com," 2021).

However, there are ongoing issues, not least of which is the challenge of slurred patient speech in an emergency. This technology provides practical support for this current app but necessitates a fallback plan. It is believed that A.I. could better handle these challenges and provide a robust experience.

AUTOMATIC 911 CALLS

The upcoming next-generation 911 service in Canada allows people to interact with 9-1-1 call centers using innovative services and capabilities such as text messaging and the transmission of photos and videos (Government of Canada, Canadian Radio-television, and Telecommunications Commission (CRTC, 2017). Companies like Apple and Google have started utilizing this feature in their SOS systems to request emergency responders' help (Dhara Singh, 2019) (Apple, 2020). Apps such as Lifeguard employ this feature to alert emergency medical services of a drug overdose incident and provide all the required information such as location, number, etc. ("New Lifeguard app launched to help prevent overdoses," 2020). This feature facilitates prompt action and saves time in an emergency.

FALL DETECTION

Fall detection has been an invaluable addition to medical alert systems. The automatic fall detection feature uses an accelerometer to detect hard falls by detecting the abrupt changes of body movements and provides alerts for assistance to the chosen contacts. Apple has included this in their Apple Watch, where it alerts the emergency services in an emergency incident (Apple, 2020).

Similarly, Lifeline from Philips is a medical alert system for seniors with fall detection and allows quick access to help ("Medical Alert Systems for Seniors with Fall Detection | Fall Detection Device," 2020). This technology equips the alert systems with an added feature and ensures to provide early assistance.

GPS LOCATION

In case of an emergency, the most important factor in providing care is the person's accurate location. The majority of cell phone apps use GPS to track the person. However, it does not tell us about the building elevation, which can pose a challenge to first responders helping in an emergency. A Sensory App developed by Columbia University could identify the caller's exact location by detecting elevation and translating it to a floor number. If this feature integrates with the current smartphone, this would be a game-changer for emergency services, who often have difficulty locating the incident (Baraniuk, 2017).

MASS NOTIFICATION & TURNING BYSTANDER TO LIFESAVERS

Mass alert notification leverages technology to send critical messages to reach a larger population during emergencies such as COVID-19 outbreak, natural disaster, biological hazard etc. Emergency alert systems such as Alert Ready is a Canada wide program used by government officials to issue emergency alerts. The alert helps the public respond as directed in emergencies and stay safe ("BC Emergency Alerting System Test," 2019).

Every minute is crucial in an emergency, and bystanders, such as family, friends, and good Samaritans, play a vital role in increasing the likelihood of survival until professional medical responders arrive. Many apps such as Pulse Point, Unity Philly understand the community's power and prepare bystanders ready to help save lives (French, 2020) ("Inform and engage your community," 2020). However, these require an additional app that the citizen needs to download to get the information and provide assistance that may be restrictive for some people. Providing alternate options to downloading an app could motivate more citizens to help others in need.

DETECTING HYPOGLYCEMIA BASED ON ECG

A recent Pilot Study on deep learning for hypoglycemic events detection based on ECG uses personalized medicine and artificial intelligence (A.I.) to detect nocturnal (nighttime) hypoglycemia automatically (Porumb, Stranges, Pescapè, & Pecchia, 2020). The results show that hypoglycemic events can be automatically detected using a few ECG heartbeats recorded with wearable devices in free-living conditions using personalized classifiers based on deep-learning artificial intelligence algorithms.

Combining the CGM glucose readings with this data could help reliably detect early hypoglycemia and proactively alert the user of any impending incident.

ACTIVITY RECOGNITION

An individual's activity dramatically affects the blood sugars, and it would be helpful to know about the person's physical activity when he/she has diabetes to avoid low blood sugar ("Blood Sugar and Exercise | ADA," 2021). Accelerometer-based activity monitors are capable of quantifying human motion. A study proves this by using a single tri-axial accelerometer (the same for fall detection) to recognize different activities and classify them into four categories, i.e. ambulation, cycling, and sedentary activities (Mannini, Rosenberger, Haskell, & Intille, 2017).
This reliable recognition will assist the person in having a greater understanding of their activity effect on blood sugar, in turn, better manage diabetes.

3 CONTEXT AND FRAMING

3.1 Situating Research

3.2 Scope of Intervention

3 CONTEXT AND FRAMING

3.1 Situating Research

Diabetes research and health care generally have been divided into two distinct phases for receiving medical care: pediatric and adult. The transition period between pediatric and adult care occurs in late adolescence. The next developmental stage of life is emerging adulthood, and the population in this bracket are emerging adults[1]. This stage of emerging adulthood has not been considered extensively in managing chronic illness (Paone & Whitehouse, 2011). Yet, this is a critical time when a person not only assumes responsibility for their diabetes self-care and interactions with the health care system but when they become more independent, potentially moving out of their parents' home to attend college or to join the workforce (Peters & Laffel, 2011).

The current literature does identify a wide range of issues regarding transitioning. A document generated by the BC Children's hospital titled "Developing a transition initiative for youth and young adults with chronic conditions and special needs in British Columbia" addresses specific diabetic challenges (Paone & Whitehouse, 2011). Within the context of this transition, the lacunas in diabetes care can lead to substandard health care utilization, deteriorating glycemic control, increased occurrence of acute complications, the emergence of chronic complications of diabetes that may go undetected or untreated. These gaps include poor glycemic control, working with new healthcare providers, assuming independent care for diabetes, etc. (Iyengar, Thomas, & Soleimanpour, 2019; Monaghan, Helgeson, & Wiebe, 2015). Moreover, there are risks associated with psycho-social, behavioural, and emotional challenges (Peters & Laffel, 2011). Young adults' challenges include maintaining control of diabetes, finding a good team of health professionals, drugs, and alcohol, leaving school/starting work or university, moving out of home, relationships, and many more (Buschur, Glick, & Kamboj, 2017).

With the increasing incidence of both type 1 and type 2 diabetes in childhood, adolescence, and young adulthood, there is a surge in the total numbers of young adults with diabetes in this transition period. Emerging adults with diabetes face even more complicated decisions in their life than their healthy peers. T The daily requirements of diabetes care include coordinating daily care, finding an appropriate care provider, and accessing proper supplies and medical care. All of this must be woven into all the normative choices regarding relationships, occupations, living arrangements, financial management, etc. The developmental period after high school represents a definite stretch with unique demands which are separate from adolescence (Peters & Laffel, 2011; Ford, 2015; Palladino et al., 2013; Weissberg-Benchell, Wolpert, & Anderson, 2007).

1 Emerging adult is the age group in late teens through the twenties, focusing on ages 18 to 25 (APA Dictionary of Psychology, 2014).

Figure 4: Affinity map of challenges faced by young adults in transition: Secondary research (Mapping by author)

Each year, in British Columbia, around 1,700 youth with chronic diseases reach 17 years of age and transition into the adult care system (Paone & Whitehouse, 2011). This process often occurs in an unplanned manner, can be poorly coordinated, and threatens care continuity.

Inadequate planning for transition demonstrates significant negative consequences that include a deterioration in health status and increased morbidity and mortality.

To gain a deeper understanding of the user, the primary and secondary research collection seeks to answer the following research questions:

1. **How can design support young adults in providing immediate life-saving assistance in extreme hypoglycemia conditions?**
2. **How can design support young adults in alleviating the stress associated with hypoglycemia?**
3. **How can we engage young adults with type 1 diabetes in the creative process and make sure we hear their voices?**
4. **How can we empower young adults so that they have control over their medical emergency?**

3.2 Scope of Intervention

Young adults with diabetes face additional challenges with diabetes-specific psychosocial stressors linked to adherence to regular medical regimens, which require frequent blood glucose monitoring, insulin administration, and dietary restrain. Not all young adults want their peers to know about their medical condition. Young adults with diabetes report fewer friendships, resulting from a drop in intimate friendships and a reduction in the level of intimacy and trust in relationships. Additionally, alcohol and tobacco exposure could result in short- and long-term complications for diabetes, including death (Monaghan, Helgeson, & Wiebe, 2015).

Even though new diabetes technologies such as continuous glucose monitoring or closed-loop systems (system that automatically adjusts and deliver insulin based on CGM blood glucose reading) continue to revolutionize this field, they may not be accessible because they are either expensive, not covered under medical insurance, or still in early development stages.
While much research continues in the area, few tools are being designed directly for young adults to navigate this change. A program titled "ON TRAC 2" has been designed to support youth transition with chronic conditions from pediatric to adult care (Paone & Whitehouse, 2011). However, most of the interventions are combined in the form of bulky guidebooks and workbooks. Another critical issue with the development of most current tools is the absence of user involvement in the creative process leading to unmet user needs.

Additionally, fear of hypoglycemia is prevalent among the targeted demographic (Driscoll, Raymond, Naranjo, & Patton, 2016). According to Diabetes Canada, a person with type 1 or type 2 diabetes needs to have a rescue plan if their blood sugar level becomes so low that they are unable to help themselves. It recommends a plan in place, so those around the diabetic will be prepared for unexpected lows. During a hypoglycemic event, actions range from drinking a beverage containing sugar to paramedic/emergency assistance, with about 1 in 5 taken to hospital (Severe Hypoglycemia in Canada, n.d.).

Severe hypoglycemic episodes require the assistance of another person to treat. The diabetics may show some or all the symptoms of mild and moderate hypoglycemia, and in rare cases, they may also lose consciousness or have seizures. If a person cannot eat or drink, a glucagon emergency kit may be used to treat the severe hypoglycemia episode, and emergency services must be contacted. Various causal factors have been identified, yet very few interventions exist to avoid it or provide aid in an emergency. Glucagon is a medicine used to treat severe hypoglycemia, but it only works if there is someone around who knows where it is, when to use it, how to use it, and eventually do it (Kedia, 2011; Freeborn, Dyches, Roper, & Mandleco, 2013).

Emily Perrins is a Paramedic and an Emergency Medical Call-Taker with British Columbia Emergency Health Services. In an interview regarding hypoglycemic emergency calls, she stated that "*I am quite surprised the family members and friends who spend a lot of time with these people that have diabetes don't know enough about it, that does need prioritizing*" (E.Perrins, Personal Communication, November 27, 2020).
Another primary care paramedic, Nic Hume, states that "*most people are not aware of the protocols and what to do with their partner or that close person is becoming unconscious or having a low.*" He adds to this saying, "*For someone who's severely hypoglycemic, things can go bad quickly*" (N. Hume, Personal Communication, November 30, 2020).

4 PRIMARY RESEARCH

4 PRIMARY RESEARCH

Secondary research has identified various challenges and gaps faced by young adults living with type 1 diabetes. These challenges necessitated human-centered research to gather a deeper understanding of the user (young adults) and various perspectives from experts in surrounding fields.

4.1 Methodology

The research methodology focuses on human-centered design research practices, an assortment of tools and methods that create a space where we acquire a profound empathy with the stakeholders in a particular situation by putting them at the core of the research process and ensuring they have a voice. This user engagement brings about more inventive results, a superior "fit," and higher acknowledgment rate of intended solutions than traditional design methodologies (Health Design Lab, 2016).

IDEO, one of the world's leaders in **human-centered design**, posts the following definition on its website:

> Embracing human-centered design means believing that all problems, even the seemingly intractable ones like poverty, gender equality, and clean water, are solvable. It means that the people who face those everyday problems are the ones who have the power to answer them. Human-centered design renders a chance to design with communities, deeply understand the people we are looking to serve, dream up scores of ideas, and create innovative new solutions rooted in people's actual needs.
>
> (IDEO, 2015)

To further reveal the stakeholder's knowledge various HCD[2] methodologies were used. These included collaboration with young adults living with type 1 diabetes through surveys, interviews, cultural probes and co-creation workshops.

The global pandemic posed some severe challenges restricting mobility, gathering people, and face-to-face meetings for interviews. To conduct research using the virtual world, I used internet research methods to conduct digital ground research.

2 HCD refers to Human-centered design.

4.1.1 RESEARCH METHODS

SURVEYS

It was first essential to find the young adult diabetic community and gather general information. To break the initial barrier, I circulated an online survey on various Reddit diabetic blogs, Juvenile Diabetes Research Foundation (JDRF) blogs etc. This survey was completed by thirty-four respondents and built a basic understanding of some of the real challenges faced by type 1 diabetic young adults and gave them an opportunity to be further involved in the research study. Participants who do not use modern diabetic devices such as continuous glucose monitor (cgm) and insulin were excluded from this study. This survey is shown in Appendix 9.3.1.

BLOGS & PODCAST

The growing Coronavirus pandemic posed some severe challenges in connecting directly with participants. The normal channels of group meetings and networking opportunities became increasingly difficult. An alternative to personal meetings proved to be blogs and podcasts run by the diabetic community (see appendix 9.3.2). M. Jones & I. Alony talk about the potential of blogs in the paper "Blogs – the new source of data analysis." This media proved to be a rich resource for insights into diabetic young adults' lived experiences and the hurdles they encountered.

SEMI-STRUCTURED INTERVIEWS

Survey participants who signed up for further engagement were asked to participate in a semi-structured interview. Six participants aged 19 years to 25 years were consulted. To better understand their lived experiences, the semi-structured approach allowed the interviews to become enlightening conversations, and some of their unique challenges surfaced.

Additionally, semi-structured interviews were conducted with five experts in diabetic care to acquire multiple perspectives on the topic. Conversations with paramedics, emergency call takers and dispatchers associated with **British Columbia Emergency Health Services (BCEHS)** helped understand the challenges in diabetic-related emergencies. These dialogues helped build an understanding of the healthcare system as it connected with the diabetic community as well as the unique challenges faced by professionals in administering care. The interview questions are shown in appendix 9.3.2.

CULTURAL PROBES

COVID-19 made it challenging to conduct an ethnographic study and observe participants directly in their environment, necessitating the use of digital cultural probes, which five young adults completed. Three activities were created specifically for living with type 1 diabetes, which allowed them to record events and their feelings or interactions. The purpose of utilizing this research tool was to gather a deeper understanding of participants' emotional space and daily lives. The probe (see appendix 9.3.3) was made available to five participants through an online collaborative platform called MIRO. One participant excluded herself from further research activities due to her busy schedule.

CO-CREATION

Co-creation is a design research method that empowers individuals for whom we are designing to participate in the creative design process. It taps into the co-creators' latent and tacit knowledge and provides insights into their needs, hopes, and desires ("Design Kit," 2021). The primary purpose of utilizing this methodology was to acquire a greater understanding from young adults living with type 1 diabetes on how they would like to be helped during a hypoglycemic episode. Four young adults participated in Co-creation discussion centered around scenarios related to hypoglycemia and how we could improve outcomes.

These research activities provided rich data collection from different sources. They added to the understanding of TID in young adults, which helped direct the project.

4.2 Ethical Consideration

Young adults with type 1 diabetes who are transitioning/transitioned to adult care were invited via third party mechanisms (i.e., public postings) to participate in this project. Due to persisting social distancing measures necessitated by COVID-19, all human-human interactions were suspended. All research activities took place online: survey forms were web-based; interviews were by phone or video; cultural probes were distributed, and co-creation activities took place on a collaborative online platform called Miro. Young adults aged 19 years to 25 years were involved in this research. Only one participant older than 25 years was included in the research because of her rich experience of living with type 1 diabetes and also owns a diabetic podcast. The expert interviewees had a variety of professional experience, practicing in different health settings.

Before conducting the research, it was necessary to obtain a participant's informed consent. This project's documentation received full Research Ethics Approval from Emily Carr University Research Ethics Board (May 6, 2020, **ECU-REB #100379**) (see appendix 1). From an ethical standpoint, this documentation explained the research's intentions and an understanding that the activities were a minimal risk.

It was considered that there might be minimal risks associated with participation. Participants could encounter sensitive subjects and would likely have privacy concerns. It was also identified that there could be emotional or psychological risks to the participant due to the sensitive subject matter.

To mitigate the psychological risks participants were reminded of their right to withdraw from research or limit their participation if they become uncomfortable. Participants were thoroughly debriefed after research sessions were completed and appropriate resources were provided beforehand in case someone experienced distress. To mitigate social risk, all the data collected was confidential.

Anonymity was maintained throughout all the participatory research sessions to reduce social risk.

4.3 Analysis and Findings

The subsequent section reveals the analysis and insights from the primary research collection and how this information was brought forward in the brainstorming process.

SURVEYS

The research began with an online survey completed by thirty-four Canadian young adults living with type 1 diabetes. While caution needs to be exhibited with a small sample size, the results are based on the responses provided by thirty-four participants. It was found that 97% of young adults experience hypoglycemic events when alone, and one third of this population had experienced a severe hypoglycemic episode where they have lost consciousness in public and needed third-party assistance. Approximately 85% could realize that they had low blood sugar. When asked about the challenges faced during the transition to the adult service, specific responses were identified.

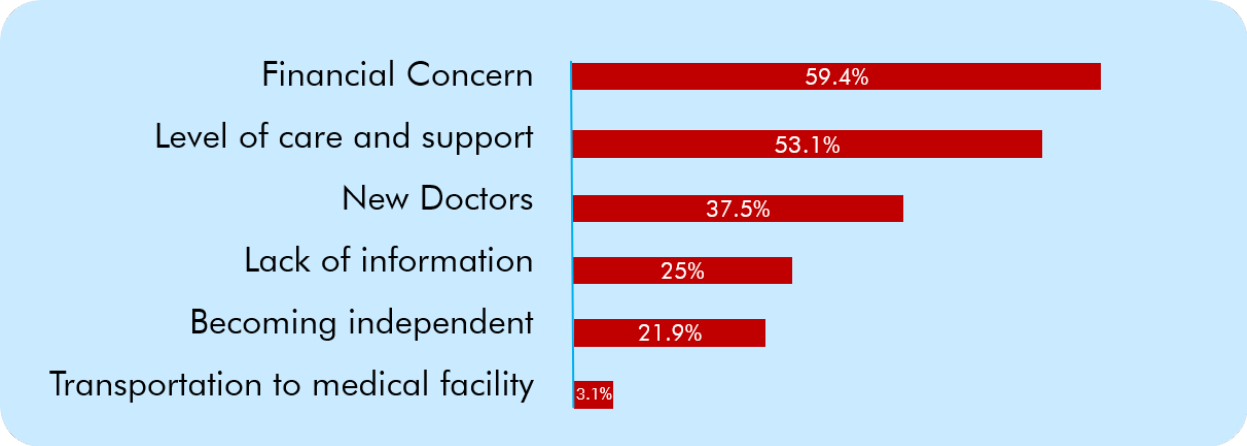


Figure 5: Challenges faced during the transition to the adult service

SEMI-STRUCTURED INTERVIEWS

It was evident that hypoglycemia is prevalent among this age group; so, to proceed forward, semi-structured interviews were conducted with participants who signed up for further engagement. The interview questions were oriented towards hypoglycemia yet open enough to tap into other challenges. Interviews with six participants took place, and the dialogues have been divided into four categories: metaphorical expression, improving an existing product, new design opportunities and other concerns of the user.

During the conversations, specific challenges surfaced. They include the need to connect with fellow type 1 diabetics of similar age to interact and share their success and failures with them. Some participants face challenges when calculating carbohydrates in particular food and often stick to guessing games for doing this task because sometimes they under or over bolus (a single dose) for the food consumed. The majority demanded more affordable technologies and the need for better insurance coverage for continuous glucose monitors and insulin pumps. Some of the participants use a closed looping system[3] and need it to be more sound and smoother. They feel that there should be more resources available at the university to assist the transition. One issue that stood out was the unexpectedness of low blood sugar. They require someone to help them during hypoglycemia. They fear that in case of a diabetic emergency, most people around individuals with diabetes are unaware of what to do.

When asked to discuss the fear of hypoglycemia, some interviewees responded by saying:

> *"Then someone else who knows me, who knows where the glucagon is, who knows how to mix it, It's a complicated process. You have to know how to mix the medicine and feel comfortable enough to inject it in a muscle, which is a big deal".*
>
> *(Interview Participant,2020)*

> *"I would want them to know what is happening, not make a huge deal out of it (a big enough deal to get me the help I need, but not so big that I'm ridiculously embarrassed after). Call 91, preferably administer glucagon or oral gel - solve problem to get one of those things or something like it".*
>
> *(Interview Participant,2020)*

3 Close looping system is a combination of CGM (continuous glucose monitor) and an insulin pump to regulate the persons' insulin with minimum interaction required. It is also referred to as artificial pancreas (Lovett, 2019).

CULTURAL PROBES

The cultural probe was vital for understanding the users' emotions, feelings, and reflection. The insights above were important and helped to inform the cultural probe methods. When analyzing the results of the probes, existing challenges were confirmed, and new ones identified. Some of the insulin pumps available in the market are not well designed. Participants pointed out specific problems with their current diabetic technology, such as a reusable cgm sensor applicator, better clips for the insulin pump, better adhesive which is strong enough and does not leave a scar behind. However, another common challenge highlighted was the condition of hypoglycemia. It illuminated that there is a need for a solution that addresses hypoglycemia. Users are interested in a solution that makes someone aware of what is happening to the person with diabetes, acts promptly, alerts 911, knows how to help and helps quickly.

PROBE FINDINGS

Postcard

BGM / PROS & CONS Diabetic Tech

PARTICIPANT 1

- Freestyle Libre **CGM has changed my T1D management significantly** over the past few years
- use a blood glucose meter very infrequently, mostly **trusting my CGM readings** (as advised by my nurse)
- **it's expensive** without coverage, but **completely worth it**
- allows to adjust insulin pump settings without excessive blood sugar testing, which is a **major bonus**
- **more confidence** being 'low' overall
- **amazing** for producing simple reports with averages, trends, etc.

Need for low cost tech

PARTICIPANT 2

- Dexcom (CGM) has made monitoring **super easy** and conveinent in comparison to normal finger pokes with a glucometer.

Need for sys which wakes you up

- One of my **biggest issues was hypoglycaemia/hyperglycemia through the night**. Considering you sleep 7-9 hours, that's a long time to be out of range (mine being 4.4-8 mmol/L).
- Obviously sleep is important and because I feel like **I can't catch up on missed sleep due to diabetes**, it's easier to try to prevent bad nights than fix them after the fact. Also makes it much easier for training at the gym etc.

PARTICIPANT 3

Dexcom G6

PROS: easy insertion, accurate numbers, available on multiple platforms (I get numbers on my phone, pump and smartwatch). Trustworthy, have experienced very few errors, good customer service, subscription program makes getting supplies easy

CONS: so much **waste from inserters**. Can't they be reusable?! 10-day hard stop, can be tricky to restart

Need for a reusable sensor applicator

PARTICIPANT 4

I use a dexcom. Pros I can see in real time what my blood levels are and it lets me know if I'm high or low.

Cons, I am allergic to the adhesive used and the **scarring** it leaves behind a hard.

Need for a better adhesive that doesnt leave scar behind

PARTICIPANT 5

- I think the **technology behind basic glucometers is extremely outdated**, other than continuous glucose monitors such as the Dexcom, there hasn't been much growth in the development of glucose strips, glucometer, and lancet.
- In my experience people struggle to understand **how to check someone else's sugars**, this includes medical care workers at walk in clinics and people in my personal life. *Need for a whare to learn how to check signs*
- As well, my Dexcom is great for alerting lows and their sensor insertion has become incredibly easy **I wish it was better at detecting patterns** and **I wish it could communicate with my pump to deliver** more insulin when tracking highs.

Need for a consistent sys patterns *Desire for keeping*

INSULIN

PARTICIPANT 1

- Medtronic insulin pump- I'm **very comfortable with my pump**... perhaps too comfortable if anything should happen to it!
- Not perfect (neither is the CGM), but most days it allows me to **move through my T1D management pretty easily.**
- The changes I've made recently, which are simple but significant, include pre-bolusing before meals, adjusting to arrow trends as shown on my CGM, and inputting my blood sugar readings before meals.

PARTICIPANT 2

- I'm using an older medtronic pump, so the pump is technically "**only as good as the user**".
- If my BGs are out of range I have to manually correct them through my pump. **The lack of communication between the two systems is sometimes inconvenient**, however I much prefer having the pump than being on MDI so I feel like I can't complain :)

Perfect keeping system

PARTICIPANT 3

Tandem t:slim x2 insulin pump

Need for better site for pump

PROS: slim design, touch screen, easy to use. Basal-IQ technology prevents lows a lot of the time. **Clip is acceptable in terms of holding on to clothing**

Need for better insurance coverage *Need for better insulin cartridge*

CONS: **expensive**, not covered by Pharmacare (UGHHH), **cartridges (to hold insulin) are finicky and occlude more often than with other pumps**. **Less types of infusion sets** available than with medtronic brand, **insulin seems to stop working sometimes (believe it is a cartrdige/insulin interaction)**

Need for low cost affordable pump *Need for better designed infusion sets*

PARTICIPANT 4

I use an insulin pump. Pros are that I have **more freedom** and **control** in how I mange my blood sugar and what I eat.

The con is that I have something that is always on my body and I have to live with the pump on my clothing so it affects how I dress.

Need for a better designed pump that doesnt affect clothing

PARTICIPANT 5

Insulin injections are a pain when you're on the pen because you always have to find an available, uncovered piece of skin which can be difficult in winter months, **sometimes it is difficult to inject by yourself**, insulin burns, and the smallest amount you can deliver is half a unit. Having an insulin pump is great because you can get down to .05 of a unit of insulin and having a constant stream of insulin stables sugars out immensely! However, **I wish changing your insulin site didn't produce as much garbage** and the pump itself is very bulky and out there which makes certain wardrobe choices hard. I hope one day there's a way that **you can control your insulin dosing from your phone** and **get the luxury of no tubing without the bulkiness of an Omnipod**. Another con about todays insulin administration is how sensitive the insulin is out of the fridge and in the pump... I think pumps should have some sort of built in cooler to keep the insulin at an optimal temperature, and then maybe we wouldn't have to change our pump sites as often!

Need for a reusable pump site *Need for a functioning insulin from phone* *Need for a lighter pump with no tubing and insulin cooler* *Need for a tubeless pump which doesnt interfere with direct*

External help in extreme hypoglycemia

PARTICIPANT 1

Discretely, with **patience**, and by a **professional healthcare** worker who understands T1D.

Need for a expert external help

PARTICIPANT 2

I haven't personally experienced this so I'm kind of unsure based on situation, ex. at the gym vs in public vs at home. Most of my roommates are kind of aware of **low protocols**. The best I'd say is to just **call 911 and not freak out**. If they **know to massage honey in my gums** (and **are willing to do so** lol) or **administer the glucagon**, that's also alright too. I think after the fact too, is just courteous to privacy to **not go about telling people about my "diabetic attack"**.

What to do in an emergency situation

PARTICIPANT 3

I would **want them to know what is happening**, not make a blood-sugar out of it (**a big enough deal to get me the help I need**, but not so big that I'm ridiculously embarrassed after).
Call 911 *Need for a solution which make someone aware of what's happening, auto weakly alert ??? Know what to how, how to do and actually do*
Preferably **administer glucagon or gel** - problem **solve enough to get one of those things or something like it**
Follow-up would be most important for me; if they're going to constantly worry and helicopter over me, that is not going to be a sustainable relationship.

PARTICIPANT 4

I would want the **third party** to **hand me food and drink if I was still conscious** and **just keep an eye on me**. If I was not then to put me in **recovery position** and **call 911**. Never try to give food to an unconscious diabetic

Need for a solution where third party knows how to help diabetic person and call 911

PARTICIPANT 5

Ideally the third party wouldn't have to jab a needle in me (aka administer the glucagon that I am most familiar with) but in all honesty I am having trouble coming up with an answer to this question because I genuinely think any third party, **even those closest to me, would not know what to do in a situation where I was unable to self treat hypoglycemia**. From our interview I liked the sound of a nasal spray version of glucagon , I think that is much less invasive and much more self explanatory (if it was known that I was experiencing a severe low blood sugar)!

Need for education - what to do in an emergency situation

Advice to younger slef

PARTICIPANT 1

Reach out to the **T1D community** for **support.**

need for platform to find diabetic community

PARTICIPANT 2

Diabetes care is far from a perfect science and it sucks but as long as your body continues to change so will your diabetes. Just be mindful of what food choices you're making and what kind of activities you enjoy and if possible track patterns around eating/training and learn to adjust. You also **need to be over prepared for a lot of things** (trips, working, going out, etc.) **than the average person** and **having emergency kits prepped beforehand to just grab-and-go are super handy.** (emergency kits for me would include, spare site changes, insulin, glucose tabs, a snack of some sort, granola bar/ protein bar likely, AAA batteries for my pump, and standard syringes) if it's a far destination or overnight/ trip of some sort, extra dexcom supplies, and a glucometer as a backup.

need for handy emergency kit

PARTICIPANT 3

YOU CAN'T BE PERFECT. Don't even try. Try for good, and healthy, but never touch perfect because it will not happen. (I was quite a perfectionist when I was younger and that made it hard to accept that numbers were not always what I wanted them to be).

Also, find **diabuddies**, and a diabetes community. They're the best resources you'll ever have.

need for place to find diabetic community

PARTICIPANT 4

Stop hiding it and let other people help. Hiding it brings nothing but trouble and it's not worth the energy it takes. **Also look into other adhesive you are not allergic to.**

Need for a thing that keeps tensor on skin without adhesive/ need for a adhesive that doesnt cause allergy

PARTICIPANT 5

Try everything - it takes a lot of work and a lot of patience but what works for others isn't going to necessarily work for you but taking the time to figure what exactly does work for you is worth it!

Part of that is **investing in technology** that does make your diabetes management much easier.

Type 1 diabetes it a constant battle that continues to change day by day so take the opportunities you are presented with to make that battle easier, even if it's by ever so slightly.

Change to diabetic care

PARTICIPANT 1

I'd love to 'LOOP' one day soon... from what I understand it requires quite a bit of trial and error, but once certain elements are sorted, it's fantastic.

Desire for keeping

PARTICIPANT 2

I wish the registered dieticians in the diabetic education centre of the clinics had more **individualistic advice**. I find their knowledge is catered to Type 2s or old standards of care. Ex. eat 3 times a day at the same time and you must eat 60 carbs, 80 carbs, and a source of protein at each meal... snacks have to be low carb to not affect BG patterns etc. Especially as an athlete in a weight-divided sport, they frown upon a lot of the high protein, water cutting and such for sport.

personalized diet plan

PARTICIPANT 3

I would **like to have less high blood sugars** (problem solving with a new insulin pump), be **less stressed about the finances around it all**, and not have to constantly think about it. (This is getting better with the dexcom-tandem working together and I hope will get even better when they come out with control-IQ which will prevent high blood sugars as well as lows).

need for more affordable supplies and tech

PARTICIPANT 4

I would like to **change the amount of scaring left behind by everything**. **Invest something that is for diabetics** that can help with it. Also look for more **young adult support.**

need for find more young adult support

PARTICIPANT 5

Right now I am pretty content with my diabetes care, as I mentioned above I do **hope for a better, and more affordable system** one day that **connects insulin administration and glucose monitoring much smoother.**

Need for affordable, better and smoother keeping technology

I think one of the hardest things about having type 1 diabetes is pushing through day in and day out, and finding a care team and technology that makes that easier is always the goal!

SOS Contact list

PARTICIPANT 2

1. My mom
2. My aunt (mom's sister)
3. If needed my endocrinologist

PARTICIPANT 3

1. My parents
2. My partner
3. That's probably it; I will tell others as it becomes relevant

PARTICIPANT 4

1. Parents
2. Sister
3. My work

PARTICIPANT 5

1. People around me
2. Mother
3. Sister

Rave & Rant

Love

My 20 year dia-anniversary is fast approaching. Looking back, there have been so many ups and downs of living with this disease. But it's hard for me to imagine a different life, especially when my diabetes has led to so many unique opportunities.

Love and hate are strong words. I don't think I can truly associate either with a T1D device or service. But when I think about the word **love**, I **think about being comfortable and feeling safe**. For the most part, my CGM offers that dependability. And it **offers hope**. Only a few years ago this technology was inaccessible.

What I truly love about T1D is the **community of people** I have come to know and love over the past few years.

I appreciate the increasing technological advances for diabetics and how much more robotic it is becoming. The time and effort for simply trying to eat and go about your day is **incredible** and when advances such as the dexcom come out, **it can give you some peace of mind** because (when it works lol) if something is imminently wrong, it should alarm you to fix it.

To Dexcom (G6),

Thank you for providing a service that makes many people breathe easier. I love having my blood sugar available all the time, I love how **accurate** it is, and I love how **painless** the sensor insertion is - much better than the G4.
You made my **diabetes anxiety go away**, and I **feel better and safer** having you with me.
A few points of contention, because nothing is perfect:

need for more affordable tech

- **the hard stop on sensors and transmitters feels like a money grab**
- the **single-use sensor inserters**? Are you kidding me??? It's 2020. Make them recyclable, make them reusable, sell me one to keep for all the sensors I ever insert. Just stop being so **wasteful**! This disease creates enough garbage, we need to work past that!! *need for more reusable tensor applicator*
- Your **app is pretty bad**. If people with very limited experience can make something as great as xdrip, your team of paid people can figure something out. *need for a better app*

Thanks for existing, you make my life a heck of a lot easier. Please work on yourselves, we all have to.

I've been on the insulin pump for decades and I would not give it up for the world. **When I forget to put it on or it's off for whatever reason it feels like you are missing a limb because it's always attached to you and your body adapts around it.** It brings me freedom and security that I feel I don't have with needles. I also see it as a badge and a calling card for other diabetics. People who see it can ask questions about it and diabetics who know what it is can start a conversation with me or at least have the sense they are not alone. I love it and would not change it.

Dear Dexcom,

If it wasn't for you I would have many more hours not slept, many more times woken by the beat of my heart racing and sweat dripping down my face instead of a little alarm to remind me to drink my juice box. If it wasn't for you I'm sure I would spend many more hours in bed due to highs I am unaware of and I'm sure I would have lashed out at more people but instead you remind me to take my insulin to keep my sugars in level (and my mood)! I love that you hold me accountable, and I love that you act as **security blanket**. I never have to worry if I'm too high or too low because I know you'll let me know. You don't just take away four finger pricks a day but you give me upto **298 phone glances**, making sure I'm okay. I love that you're connected to my phone! I love how easy you are to use. I also love that you come with Clarity, an easy to use, in depth blood sugar level collector. Not only do you help me track patterns but you give me in depth ananlysis, you give me statistics, you let me share my sugars with my doctor and those closest to my heart with one simple feature. If it weren't for you Dexcom I don't know how I'd live!

Hate

It's certainly **very frustrating** using technology that often feels **antiquated**. In one hand, I hold my iPhone, with capabilities beyond comprehension. In the other hand, I hold my insulin pump, which is similar in size and shape and function to the very first pump I ever owned, back in 2002.

Need for a compact pump and modern tech

Custom incorrect

This may not be directly associated with any company in particular but **I personally have struggled with it** (my parents pay for everything out of pocket and I acknowledge that many diabetics do not have this luxury, but that's the problem) **Medical devices and medication shouldn't be designed to profit off of**. Dr. Banting sold the patent of insulin for $1 and the 3 main pharmaceutical companies, Novo nordisk, Eli Lilly, and Sanofi profit billions of dollars off of insulin sales.
I am not covered under any private insurance, and use the OHIP25 (I'm 22 so it's running out too) and my insulin still costs 60% of its market value. **A full-time student, who pays their rent and requires specific nutrition for medical conditions is expensive to begin with.** In one month I estimate I spend $700 on diabetic supplies. On the more political side, as tech advances are being made, government parties are trying to remove diabetes as a disability to claim. Excuse me, but regardless of if it's more technologically advanced, **I still lose an hour of sleep every night making adjustments**. **I get harassed by the MTO to make sure I'm still road safe.** I PAY upwards of $10 000 every year for medication I didn't choose to be on. There's decades worth of research on debilitating consequences of diabetes and that 1 in 3 diabetics will end up with mental health problems. There's also research on comorbic autoimmune disorders such as T1D and Celiac disease, as well as T1D and Crohn's, and T1D and Rheumatoid arthritis. The pharmaceutical companies profit off of diabetes' physiologic necessities and the government backs it up although it is known that these are life-saving advances.

diabetes and drugs

To Medtronic in general but the 600 series pump specifically,

I have never loved anything less. **You're the worst.**

I'm really not sure how such a successful pump company for so many years came out with a product so shitty? And still managed to sell it to thousands and thousands of people???

need for a better INTEGRATED PUMP which is worn

It feels **cheap and nasty**. **Plastic**? For real? This shit is **$7000**, at least give me **something nice**.
The clip is SHIT. I've gone through tons of pump clips and never have I seen one this bad. **It falls off everything**, it's **SO BULKY**, **and I hate wearing it in ever possible iteration.** *need for a better CLIP which holds properly, strong , light weight, and easy to wear*
TOO MANY BUTTONS to press. When I have to confirm a bolus FOUR TIMES for a high blood sugar, you know what **gets missed**? **Doses for high blood sugar**. You know how vital those are? Very. *Make tubeless easy to pump*
There are so many safety workarounds. Stop. I've had training, I know what I'm doing, I don't need you to check up on me every goddamn time I want to do something! **You make managing diabetes even harder**, I didn't think that was possible, AND your whole thing should be making diabetes easier shouldn't it?

Your sites are awful. I had so many leaks. I don't know why, because the sites are made the same as the ones I used before, but your bad energy just rankles it. *need for leak proof sites*

I never used the 670G, but it just sounds bad. Plus your **sensors are shitty, need way too much calibration,** and I just don't trust them. And if I'm being corrected to 6.7 all the time, that is just too high for me! So it's not "great for everyone" is it!

The one good thing you do is your **reusable inserters and round pump sites**. That's the only good thing I will take forward from this experience.

Also, your salespeople are assholes. In summary, I hate you, I'm glad I've left you behind, and good riddance.

I **hate blood sugar testing kits**. I understand that they are needed but at the same time after using them for years my fingers have so many scars on them that they became calloused to the point that doing certain things hurt. **It also forces me to carry around this ugly and bulky object that I don't want.** It's easier now being on a Continuous Blood Sugar monitoring system but I still sometimes have to use it and I hate it. I also dislike how at **my hospital they don't have many transition tools for young adults going to adult clinic or tools for college and other things.**

need for a lighter and attractive blood sugar testing kits *need for more transition tools for adult care, college, etc*

Dexcom, I **hate that you don't connect to my pump yet**. I hate that **you don't come with little cards that explain what you do and why it is important so that I could just hand them out whenever someone asked "what is that on your arm"**.

need for educating after expanding diabetic base

I really hate that you cost so much. I also hate that you **only last 10 days per sensor when I pay so much for you.**

need for long lasting and affordable tensor

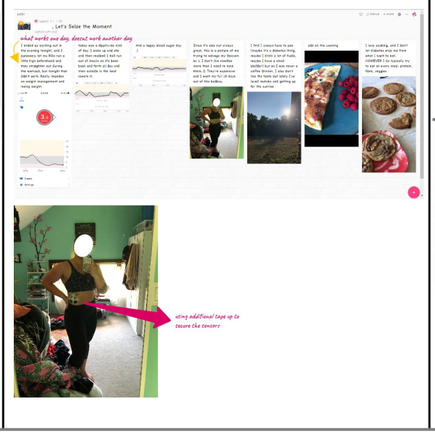
I hate that such an amaxing technological addvance isn't available to everyone who would benefit from it but rather its owned and run as a corporation so even though I'd like to believe your main goal is meaningful, dexcom youre just a company trying to make as much money as possible.

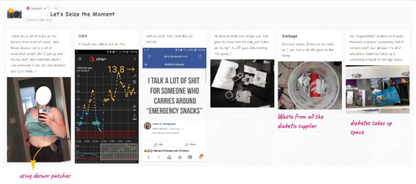
need for overtreated alarm notifs *need for option in alarm to input what you have eaten*

I hate that you **can't customize the alarm noises** more or that you can't set a timer to alarm you when your sugars have been too low or high for too long. I also hate that you **can't input what exactly you've eaten.** The last thing I need at 3am when my sugars are low and im putting all my energy into surving is alarms going off over and over again - **I wish I could input that I've drank my juice** and then the app would recognize that I'm trying to raise my sugars and only alarm in 15 to 20 minutes if my sugars still haven't improved! *need for sys to recognize that bsugr has been consumed*

I also hate that I can never exit the app on my phone and that the bluetooth is pretty spotty sometimes. But most of all I hate that I need you.

Photo Diary





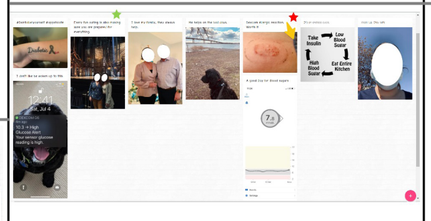


Figure 6: Cultural probe analysis

MAKING CONNECTIONS - KEY FINDINGS

After collecting and careful analysis of the primary research, an affinity diagramming technique was used to cluster the qualitative information into key research insights.

Figure 7: Affinity mapping, Primary research: Qualitative information clusters formed from primary research insights (Illustration by author)

These insights were paired into themes, which translated into a list of **key findings** that included a need for:

1. Low-cost diabetic technology.
2. Improved insulin pump.
3. Improved continuous glucose monitor (CGM) sensor and applicator.
4. Improved closed loop system (a system that automatically adjusts and deliver insulin based on CGM blood glucose reading).
5. Helping T1D's during extreme hypoglycemia.
6. Carbohydrate counting device.
7. Platform for diabetics to find each other and exchange supplies.

4.4 Design Direction

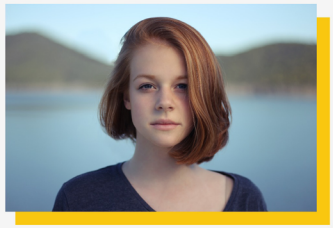
This exploratory research yielded much useful information. To further proceed with one design direction, I decided to work on the incidence of hypoglycemia and helping T1D young adults during extreme hypoglycemia. In an article published in the Healio Journal regarding fear of hypoglycemia in young adults, Phil Neuffer states that caring for young adults should include minimizing their worries about diabetes, including reducing fear of hypoglycemia. It also talks about how this fear damages the quality of life for young adults, and the goal should be to achieve a high quality of life while minimizing worries about diabetes ("Hypoglycemia fear damages quality of life for young adults with type 1 diabetes," 2018).

An online brainstorming session was held with fellow MDes cohort members to frame the design problem. The session took place in the form of HOW-MIGHT-WE QUESTIONS, and each of them posted ideas around "How might we help type 1 diabetics during an extreme hypoglycemia emergency"? The question prompts people to offer specific ideas and, at the same time, is broad enough to explore wild ideas.

PERSONAS AND SCENARIOS

The two personas represent the user profiles, which have been inspired by the research insights. The construction of these personas allowed for a deeper understanding of a young adult's thoughts. Throughout this process, it was recognized that young adults share similar ideas and emotions.

Persona 1
ALICE
Deeply Commited user



Age 24

Martial Status Single

Occupation University Student

T1D Since 20years

Alice is a university student who lives alone in a studio apartment. She is always on top of her diabetes management and keeps an eye on her numbers. She perfectly balances her part-time job and studies but sometimes experiences hypoglycemia in her studio or public places. She does need people to help her out in such a condition. She carries an emergency kit with her, and most of her close contacts have a general idea about it. She doesn't hang out with people often. Recently she made a new friend, jack, who knows she has diabetes. She uses a cgm and insulin pump to manage her blood sugar.

Goals & Tasks :
- Strive to keep her diabetes under control since she is juggling university and a part-time job.
- Eager to better manage her diabetes and avoid hypoglycemia episodes.
- She wants to be helped as soon as possible when she is not in a position to self-help.

Frustrations:
- She might run out of diabetic supplies,
- Sometimes experiences hypoglycemia when alone in the studio.

Barriers to goal
- She doesn't like asking for help.
- Not many people know she has diabetes because it doesn't interact with many people.
- She lives alone in the studio and sometimes experiences mild hypoglycemia that could turn to severe if not treated in time.
- When she experiences hypoglycemia, people wanted to help but are unaware as to what is happening with her and why is she behaving weirdly.

Persona 2
RIZZI
Casual user

Age 23

Martial Status Single

Occupation University Student

T1D Since 8years

Rizzi is a university student who lives in student housing with five other boys. He has recently moved out of his parent's house and sometimes becomes careless about his diabetes management. He is not great at balancing his part-time job and studies and often experiences hypoglycemia in lectures, public spaces and housing. His friends are aware of the basic protocol for treating lows but not everything. He carries an emergency kit with him, and most of his close contacts have a general idea about it. He has many friends and likes to party and hang out with them. All of his friends know he has diabetes.

Goals & Tasks :
- Strive to avoid low blood sugars and better manage diabetes with this new university lifestyle.
- He wants to be helped as soon as possible when he is not in a position to self-help.
- Focus and not become unconscious when blood sugar starts dripping.
- Someone will help him during a diabetic emergency.

Frustrations:
- He might run out of diabetic supplies.
- People don't know how to help him even if he is carrying supplies.
- Need people to keep an eye on him during low blood sugar.

Barrier to goal
- Communicating needs to people around him as he cannot focus appropriately during hypoglycemia.
- When he experiences hypoglycemia, people wanted to help but are unaware as to what is happening with him and why is he behaving weirdly.
- Friends don't know how to administer glucagon in case of emergency.

Figure 8: Personas

After persona development, I did scenario mapping, representing the different scenarios where hypoglycemic condition arises and its treatment. This helped in building a better understanding of the user's current experience and identified opportunities for improvement. Based on the scenario maps generated (see appendix 9.4), detailed scenarios have been developed, representing the user's action, feeling, and thinking in each case. This helped in revealing pain points and design opportunities at each step of the scenario allowing a comprehensive needs assessment.

Figure 9: Scenario Development with pain points and design opportunity

Following persona and scenario development, a Co-creation session took place with four participants through MIRO (online collaborative whiteboard).

CO- CREATION

Co-creation sessions were valuable in communicating and gathering individual perspectives directly from users and it was about developing the solution collaboratively. Four participants came together in a digital space (MIRO), where two scenarios were presented. Each scenario showed multiple situations through sketches. Scenarios were discussed with the group, and participants voted on the preferred ideas along with suggesting more ideas and giving more detailed responses on sticky notes.

In this session, the users made several choices concerned with being helped during hypoglycemia. Participants discussed how others could handle hypoglycemia's different situations moving from a minor to a severe incident. They provided ideas that could be implemented and listed some concerns. They all noted that they need more than one option/choice for a particular task.

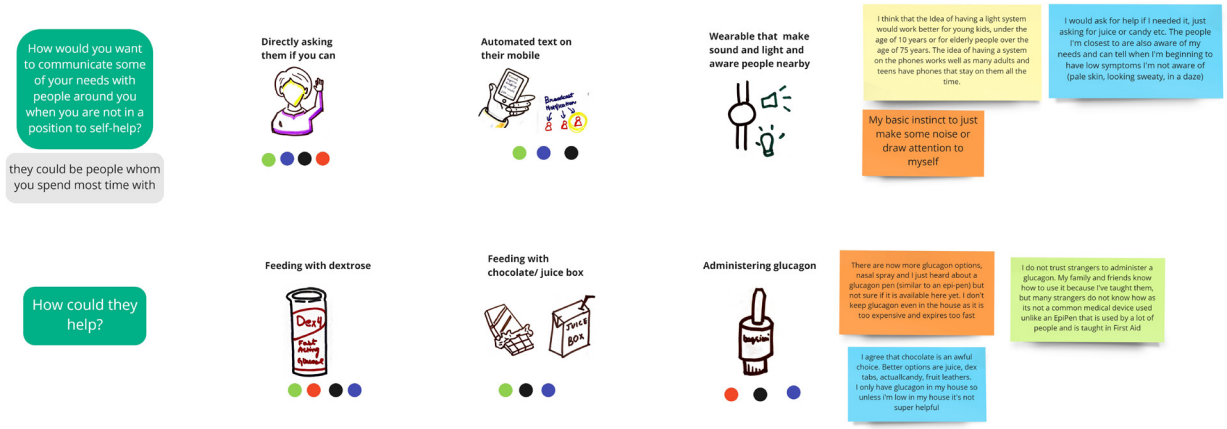


Figure 10: Co-creation activity 1- Partial Consciousness

The 1st scenario presented described a situation when the blood sugar starts dropping, and the person is at a slightly altered level of consciousness. When asked about communicating their needs with people around them when they are not in a position to self-help, most participants prefer to request help if they can directly. Additionally, they liked the idea of an automated text on the cell phone through a broadcast notification with people nearby. The basic instinct is to draw attention to them.
All of them prefer to be treated with fast-acting glucose tablets if they can swallow. However, they are open to treatment with glucagon.

One participant wrote, "*I do not trust strangers to administer glucagon. My family and friends know how to use it because I've taught them, but many strangers do not know since it's not a common medical device used, unlike an EpiPen that is used by many people and is taught in First Aid*". They said that glucagon is super expensive, and since it is not used frequently, hence it expires. Other participants stated, "*I only have glucagon in my house, so unless I'm low in my house, it's not super helpful*."

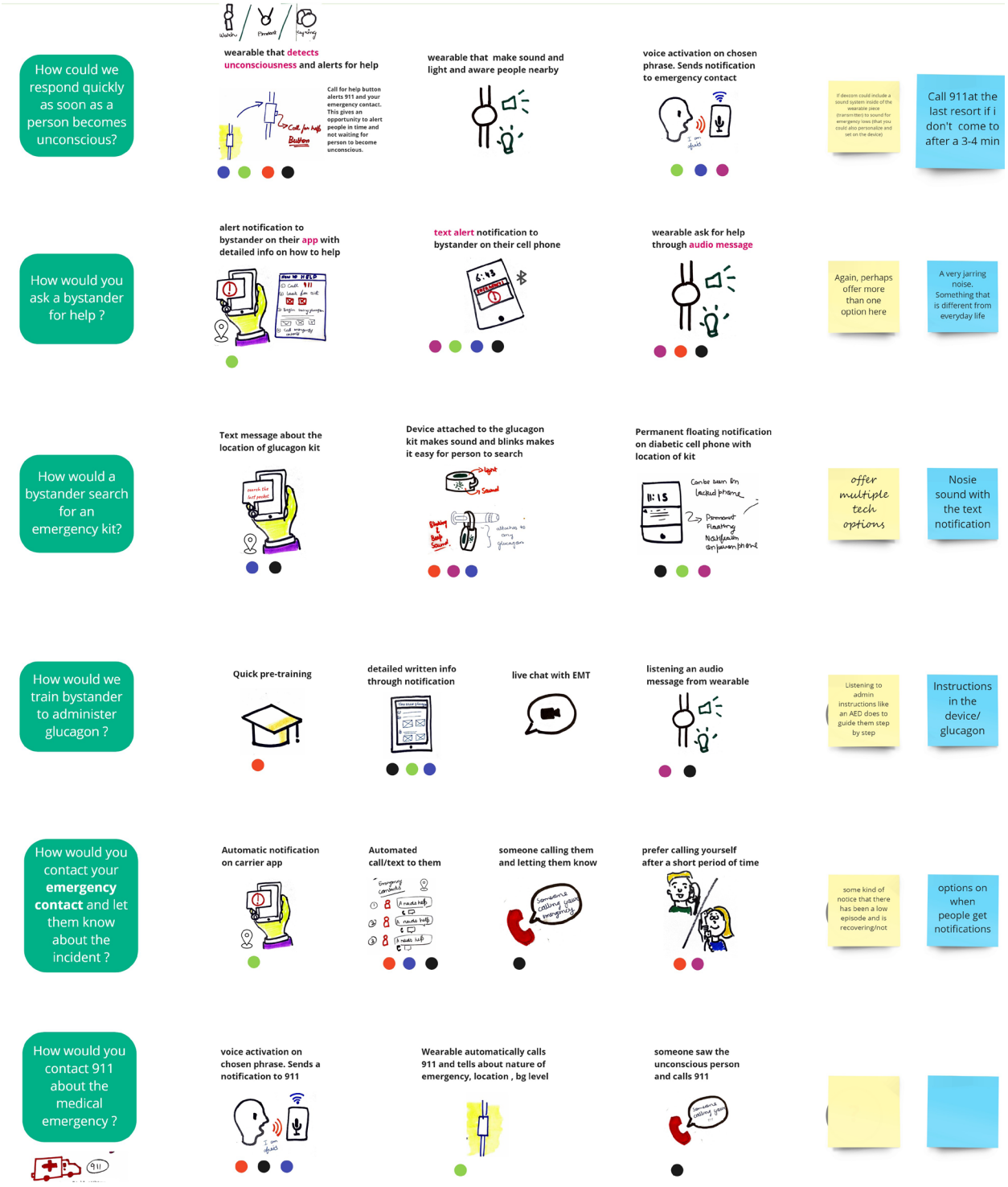


Figure 11: Co-creation activity 2- Unconsciousness

The second scenario is severe hypoglycemia where a person has become unconscious because of extremely low blood sugar. When discussing this, the group indicated a preference for a wearable device that detects falls and alerts for help. They were equally interested in voice-activated alert notifications to an emergency contact or medical services.

This situation requires prompt action, and the idea is to turn bystanders into potential lifesavers. While discussing how to ask for help in this condition, they mostly preferred a text alert to the cell phone and, at the same time, a wearable that will ask for help through an audio message. The alarm noise should be jarring in order to capture attention from bystanders.

In discussing how bystanders might search for an emergency kit, they liked the idea of a permanent floating notification on the diabetic's cell phone with the kit's location. Additionally, they loved having a small alert device attached to the glucagon kit that makes sound and blinks, making it easy for a person to find.

In this severe situation, for the diabetic to recover from hypoglycemia, someone else needs to administer glucagon, which requires some training. There are many options for glucagon available in the market, and each one has a different delivery mechanism. Participants suggested sending detailed written instructions through the same notification, which is also calling for help. They also selected the option of an audio message from a wearable.

Most current continuous glucose monitors (CGM) allow the person with diabetes to share data with their close contacts and some participants prefer to contact their emergency contacts if an emergency incident takes place. They prefer an automated call or text message, letting them know of the incident. They also choose to call the loved ones personally afterwards.

When a hypoglycemic emergency takes place, it is essential to contact the medical emergency services. Participants correspond to the idea of a voice-activated phrase that will alert 911 and connect with medical emergency service.

Working with young adults in this session reaffirmed what was uncovered during the primary and secondary research phases. To further understand this condition, expert interviews were conducted with personnel from British Columbia Emergency Health Services (BCEHS).

EXPERT INTERVIEW

Interviews with paramedics, emergency call-takers and dispatchers yielded specific field insights. Ryan Ackerman (Interim Senior Leader, Practice Education BC Emergency Health Services) said hypoglycemia is a reasonably typical emergency to which paramedics are called. The majority of hypoglycemic emergency calls come from family members/ close contacts of the diabetic. Sometimes callers are not aware of treatment protocols, or they are calling 911 for safety. He added that most of the calls occur in indoor settings and predominantly in the late afternoon, evening, and midnight. He explained that when the blood glucose levels fall below a magic threshold, which is individual to every person, they can quickly move from confusion to coma. Once paramedics determine that hypoglycemia is the cause, it is like a ticking clock. "*Now, we are looking at how we can get sugar back to their brain as quickly as possible*." He added that "*It's one of the most common misconceptions is that people mistake hypoglycemia for intoxication*" (R. Ackerman, Personal Communication, November 25, 2020).

Emily Perrins is a call-taker and paramedic with British Columbia emergency health services (BCEHS). She explains that family members and friends who spend much time with diabetics do not know enough about it and need help prioritizing. BCEHS uses a system to colour code the calls based on their severity so that resources could be directed appropriately (E.Perrins, Personal Communication, November 27, 2020).

Nic Hume is a Primary Care paramedic with BCEHS. He states that "*most people are not aware of the protocols and what to do with their partner or that close person is becoming unconscious or having a low*" (N.Hume, Personal Communication, November 30, 2020).

For medical emergency services, knowing the exact location is the most important factor. If the paramedic team also knows that it is a diabetic emergency, it helps prepare them for the call. If the person is intoxicated, that knowledge also helps in their decision-making.

When discussing the design outcome, paramedics liked the idea of an early notification assisted with an automated voice call, to help them respond quickly. The discussion around emergency medication (glucagon) led to the paramedics indicating a preference for nasal glucagon over standard injection delivery, which is less frightening and easier to administer by a layperson.

INTERVIEWEES

RYAN ACKERMAN
Interim Senior Leader, Practice Education

EMILY PERRINS
Call-taker and Paramedic

NIC HUME
Primary Care Paramedic

DAVID BROWN
Call-taker, Dispatcher, Paramedic

SCOTT KOZOL
Paramedic

5 DESIGN OUTCOME

5 DESIGN OUTCOME

After developing a deep understanding of the user's needs and wants through the research activities, several concepts were developed to assist the young adults during hypoglycemic episodes. The proposed solution builds on the existing diabetic devices being used by young adults, CGM.

5.1 Design Criteria

Following the collection of primary research from the experts and users through discussions, cultural probes and a co-creation workshop, the data was analyzed through an affinity mapping process. This led to the development of key findings (see section 4.3), which informed the development of design criteria for the wearable device and digital application. These acted as a translational tool, informing the generation of ideas and prototypes that needed to be tested further. The design goal here is to achieve the user's unmet demands to create a solution that proactively addresses hypoglycemia and provides the necessary assistance required by turning bystanders and emergency contacts into lifesavers. They are as follows:

The Wearable

Technical requirements

- Speaker for an alarm system to attract attention.
- Emitting light for people to find it easily.
- SOS button to alert the medical emergency services system.
- Fall detection sensor.
- Voice-activation, which makes it easy for the user to call for assistance.
- Haptic feedback to the user.
- Guide the person (bystander and emergency contacts) step-by-step.
- Also request assistance through an audio message.

Aesthetics

- Fashionable, modern, and easy to carry.
- Seamlessly merge with all types of clothing or complement their style.
- Compact and easy to wear.
- Offer flexible options in terms of wearability.

The alert notification

- To people (bystander and emergency contacts) should be optional.
- Be sent via text to bystanders.
- Could also be a permanent floating notification (placement of glucagon, how to help) on the diabetic's cell phone.

The alert device (for finding glucagon)

- Should have a blinking light and beeping sound.

The alarm sounds

- Could be personalized.
- Should be a jarring noise that is different from everyday life.

The solution should instantly guide bystanders and emergency contacts to administer glucagon (this should be done through audio message or/and detailed information through text notification).

5.2 Ideation

WEARABLE DEVICE

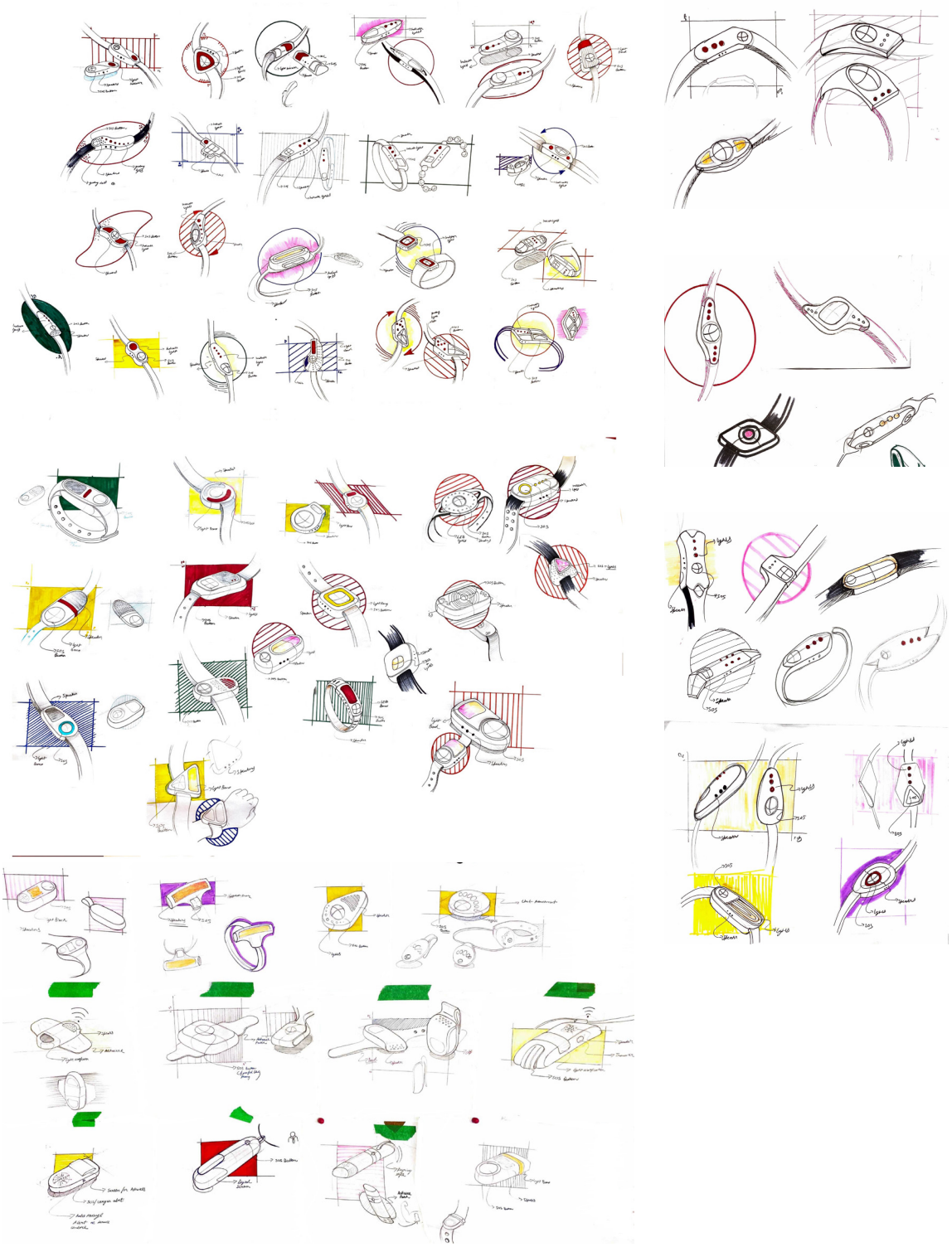


Figure 12: Concept Diagram wearable(Illustration by author)

ALERT DEVICE

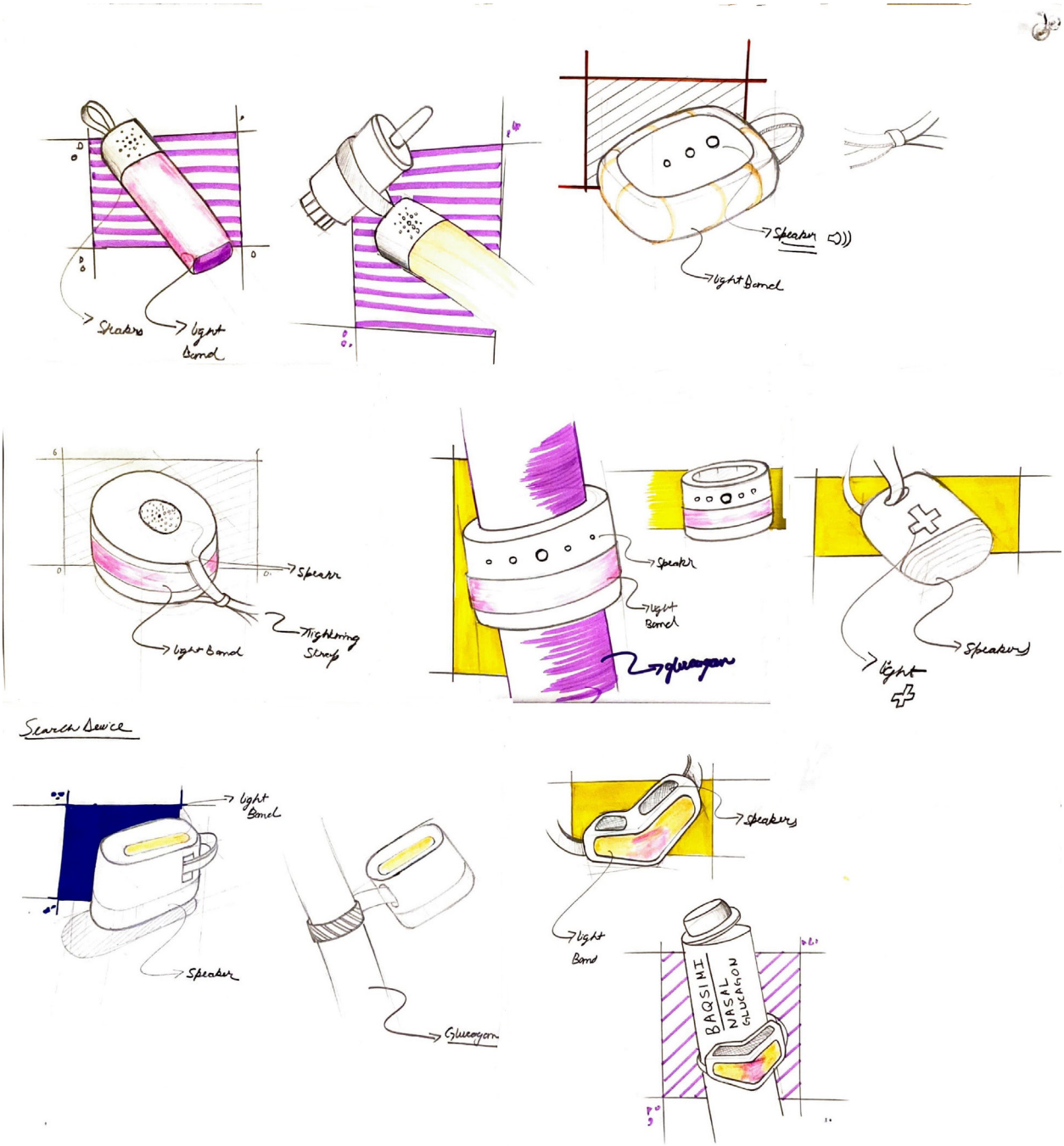


Figure 13: Concept Diagram alert device (Illustration by author)

5.3 The Concept

The basic concept includes three components: a smart wearable device, a digital phone-based application, and an alert device.

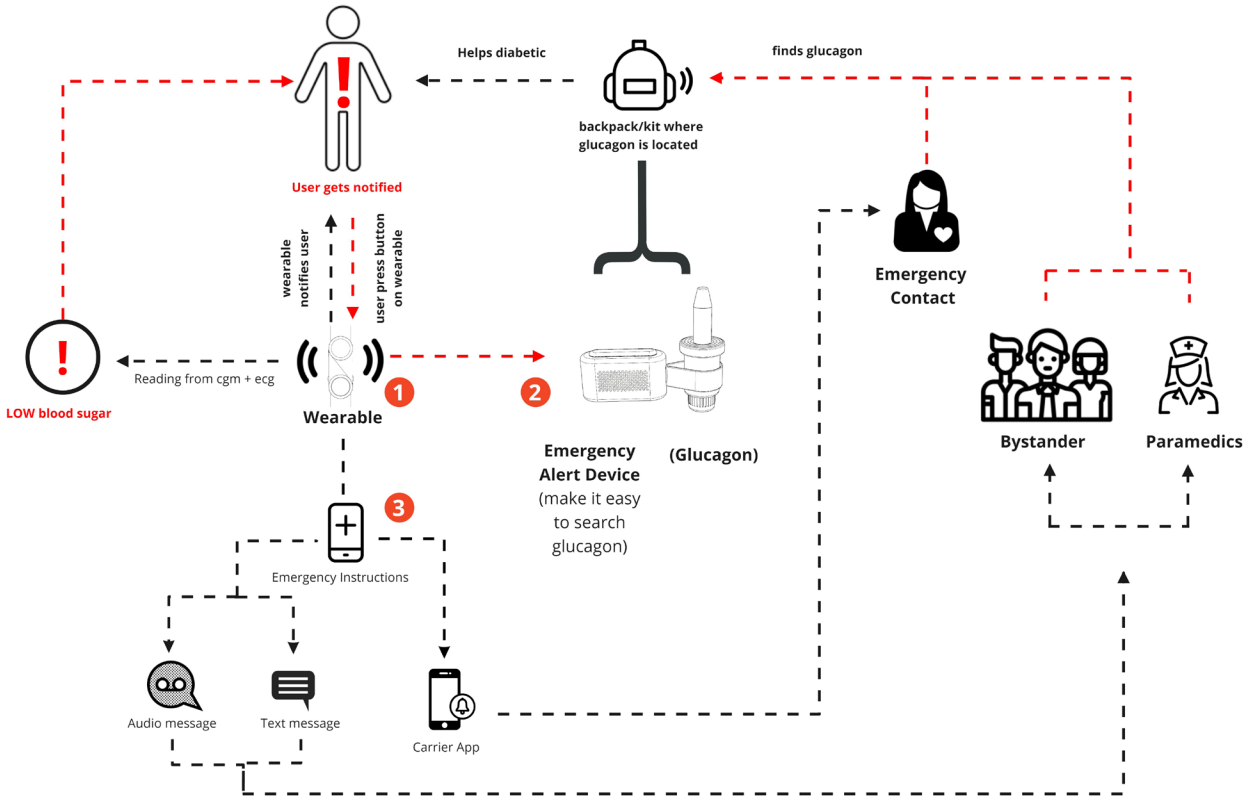


Figure 14: Concept Diagram (Illustration by author)

The **wearable device (1)** acts as a personal alarm device to alert people and guide them through the life-saving process in emergencies. It works in conjunction with an existing CGM and is based on the CGM readings. The wearable connects to the user's cell phone through Bluetooth. It will come as a band that fits the wrist—this decision was dictated by the need for accurate blood glucose readings, which will be achieved by combining heart rate monitors. It also has a tri-axial accelerometer, which consumes low power, has a small dimension and is lightweight, making it easy to wear. The accelerometer serves two purposes: one used for reliable activity detection, and the other is utilized to detect hard falls. It also has a vibration motor, which provides haptic feedback stimulus based on different actions. The audio sensor embedded is a standard microphone that is used for voice activation.

The wearable has an SOS button to report a possible emergency condition, which activates by long-pressing two times. It has an alarm system accompanied by an embedded LED and speaker, which provides the wearer with additional intuitive audio-visual feedback, i.e., it blinks and produces sound when low blood sugar is detected.

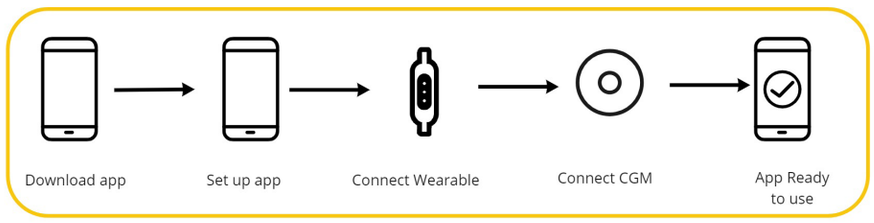
The **alert device (2)** attached to the emergency glucagon kit has a signal LED and a speaker representing the alerting system. As soon as the button is pressed on the wearable or through the app to locate the emergency medication, it starts blinking and beeping, making it easy for the attendant to search and administer the medication based on the app or text instruction notification. The solution is based on nasal glucagon which is commercially available in the market and is easy to use as opposed to injectable glucagon.

The smart wearable integrates with any CGM device through a **digital application (3)** using Bluetooth technology. It alerts emergency contacts through a carrier app and bystanders through mass text notification which doesn't require an embedded app. This is done through wireless emergency alerts (WEA), which disseminate emergency alerts to mobile devices in a designated geographic area (Wilson, 2018). The app initiates an automatic voice call to medical emergency service if required and also offers customization options such as choosing alarm sounds, contact lists, voice activation phrases etc.

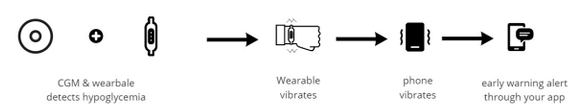
As soon as the blood sugar starts dropping, the wearable follows a four-tier system where the user only is alerted at level one through a discreet vibration and app alert. At the second tier, the user's nearby emergency contacts are alerted through a carrier app. At the third level, bystanders are alerted and given detailed instructions for assisting the person with diabetes via simple text messages. At the fourth level, medical emergency services are notified of the emergency and location.

SYSTEM MAP

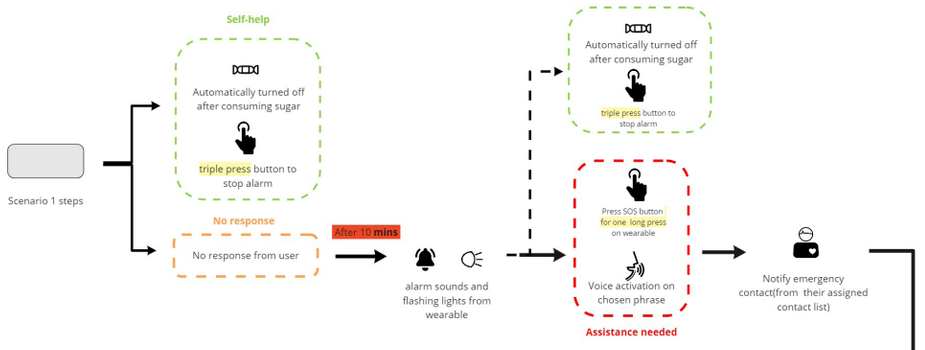
The system map represents how the wearable device system works in various scenarios. It also shows all the components of the environment which are structured and helps better communicate the results.



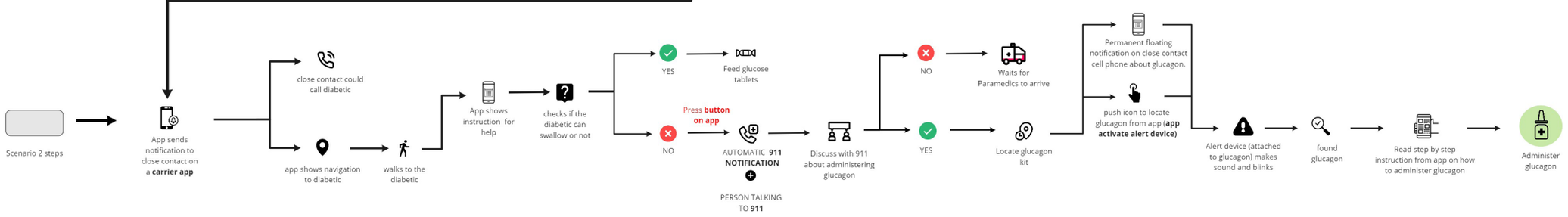
Scenario 1 - Early warning alert



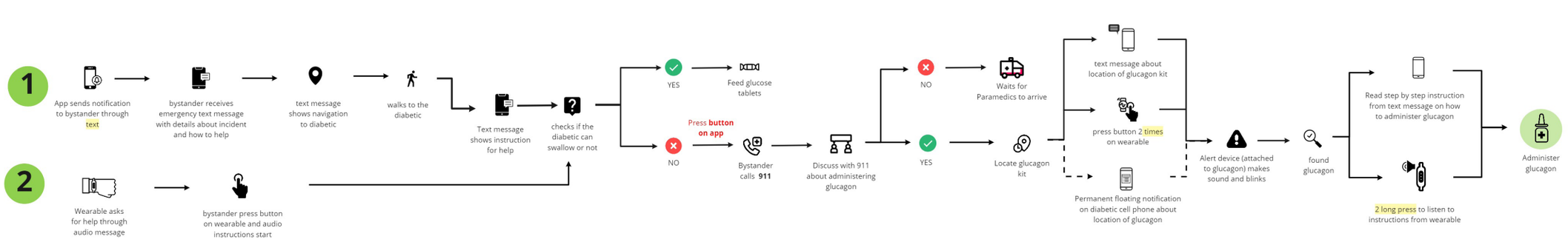
Scenario 2 - Experiencing hypoglycemia 70mg/dl)



Scenario 3 - Experiencing hypoglycemia (60mg/dl)



Scenario 3(2)- No close contact nearby



Scenario 4- extreme hypoglycemia (unconscious

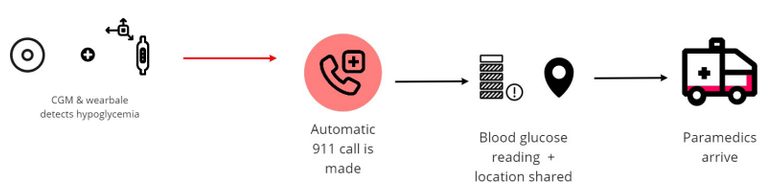


Figure 15: System Map (Illustration by author)

UNDERSTANDING CONCEPT THROUGH SCENARIOS

The next section explains the concept through different scenarios. Amy is a hypothetical character who is a university student and often finds herself in hypoglycemic conditions. Scenarios below will walk-through different situations and how the design will assist her in each case.

Case 1

Amy is in her home and about to experience mild hypoglycemia. Her wearable detects early low blood glucose and vibrates. At the same time, her application also sends her an early warning alert through the app notification.

She notices the alert notifications and consumes a glucose tablet, after which the vibration alerts are automatically turned off (as her glucose level rises). She could also press the button on wearable thrice to stop the warnings.

If she has missed the alert notification as she was busy, after 10 minutes, the wearable will start an alarm sound and flashing light to attract her attention. She might notice and consume sugars and repeat the steps above, or she could long-press the SOS button on the wearable to request assistance. She could also ask for help through a voice-activated phrase.

Case 2

Amy experiences occasional hypoglycemia and has requested her new friends to become her emergency contacts. The emergency contacts here are the people who are close to Amy and are nearby such as partners, friends, roommates, colleagues etc. While setting up the app, Amy chooses a list of these contacts. She sends them an invite to download a carrier app called “Connect app,” which will be used by emergency contacts to help Amy in a diabetic emergency.

Amy’s partner (an emergency contact) receives an alert notification on his dedicated app that Amy is experiencing a low and might need assistance. He has two options: to call or navigate to her. Since he is close to her, he walks to Amy, and the app shows him the step-by-step instructions for help. Amy is in an altered level of consciousness at this point, and he checks if she can swallow or not.

(1) If she can swallow, he feeds her with glucose tablets, and her blood glucose reaches back to normal range after some time.

(2) If she cannot swallow, and he presses a button on his app to make an automated 911 call which connects to a medical dispatcher afterwards. He discusses with the medical dispatcher if he can administer glucagon (emergency medication) or not.

The dispatcher recommends him to administer the medication, but first, he needs to find the kit, for which he presses a button on his app to locate it. An alert device attached to the glucagon kit sounds an alarm and flashing lights, making it easy for him to find inside Amy's backpack. He then reads detailed instructions from the app on how to administer it and save Amy's life.

Case 3

Amy is at a grocery store and experiences a severe hypoglycemic episode. Her app sends a mass alert text notification to bystanders asking for help in a 50m radius (customizable radius).

The bystander receives an emergency text message which explains the incident and states that this person needs your help. The text message has a link that opens a web page and gives instructions on how to help, starting from showing navigation to Amy and then checking if she can swallow or not. In case she cannot, they are advised to call 911, narrate the incident and discuss administering the glucagon. All of this is guided through the web page that is linked to the text message. They can then locate the glucagon kit either by pressing the button twice on Amy's wearable or read about the glucagon's location. They are then guided through the administering instruction to complete the life-saving assistance. The wearable that she is wearing also asks for help through an audio message. All above procedure is happening but with the audio message and requires a bystander to interact with the wearable.

Case 4

Amy is out for a long run and experiences severe hypoglycemia in a park where she is alone. Her blood glucose is severely low, and she has passed out. The wearable detects the fall and alerts the emergency medical services (through an automated call) of the incident and shares her blood glucose reading and live location. The paramedics reach her in no time and save her life.

CONCEPT SKETCH

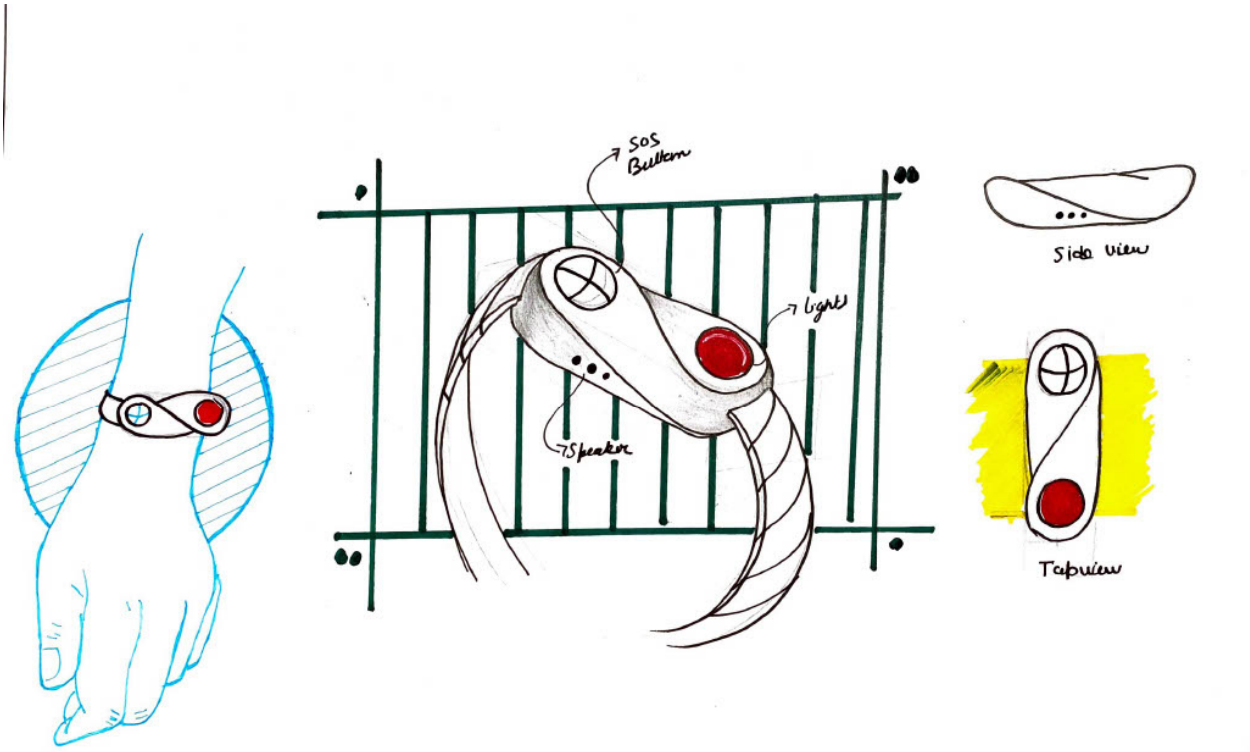


Figure 16: Wearable device concept sketch

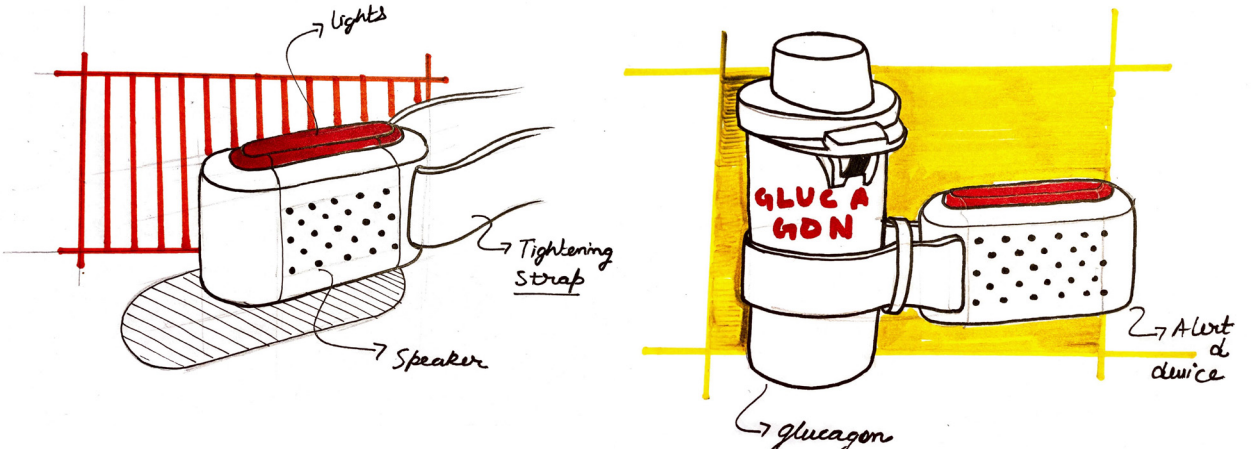


Figure 17: Alert device concept sketches

APPLICATION USER FLOW & WIREFRAMES

The accompanying app prototype has been designed based on the wearable features and allows for customization of the wearable functionality. Moreover, this application communicates between CGM and the wearable and enables the user to perform specific actions simultaneously. The app makes it easy to alert and notify emergency contacts (through a carrier app), bystanders (through text messages) and emergency services (through an automatic voice call). The app is visualized below as a user flow.

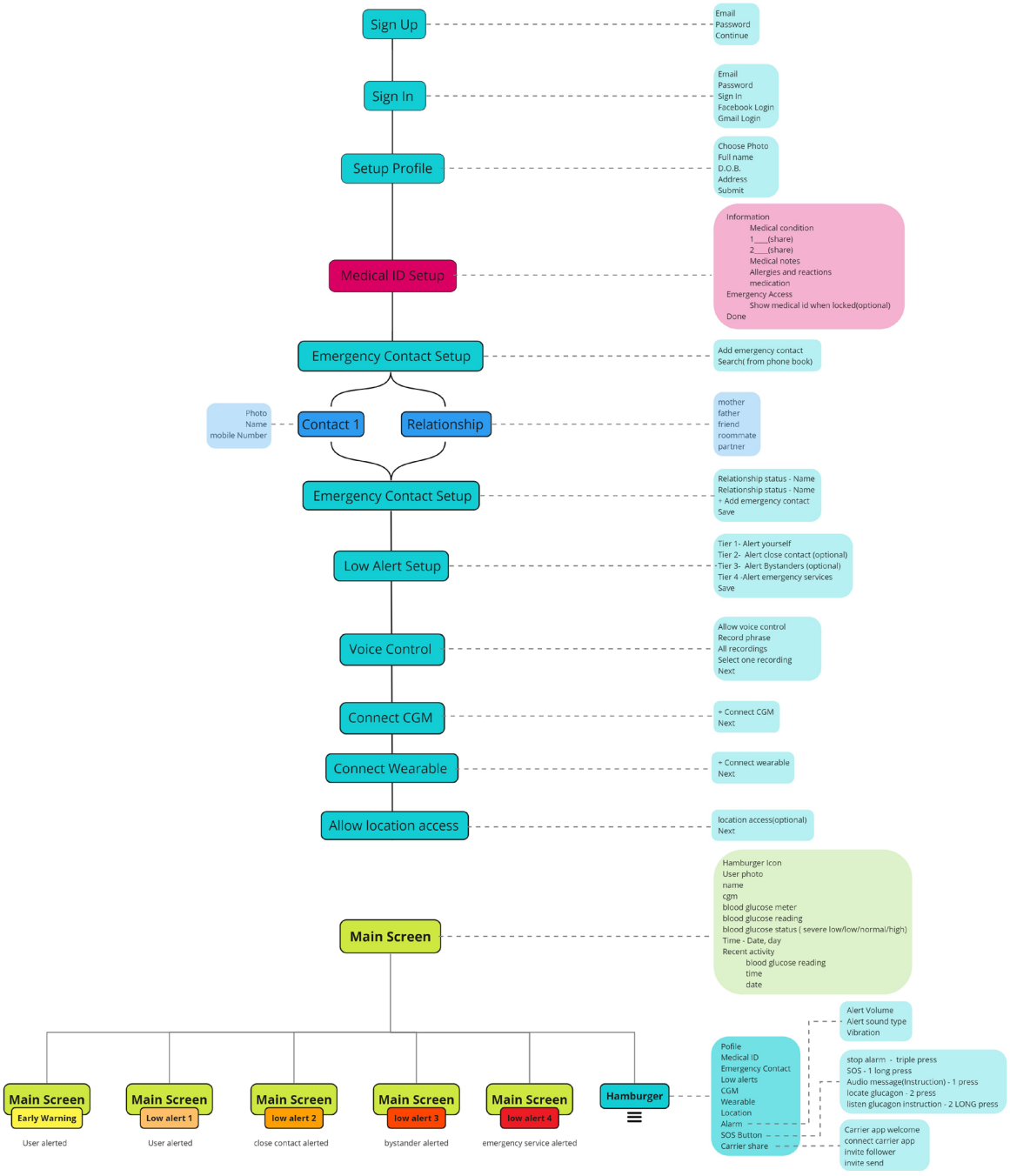


Figure 18: Information architecture showing the user flow for the App (illustration by the author)

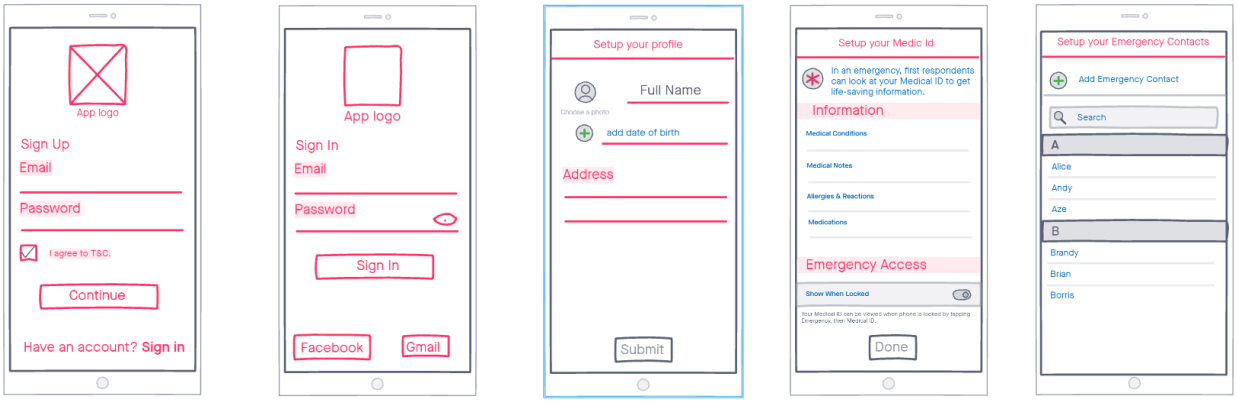


Figure 19: App wireframe

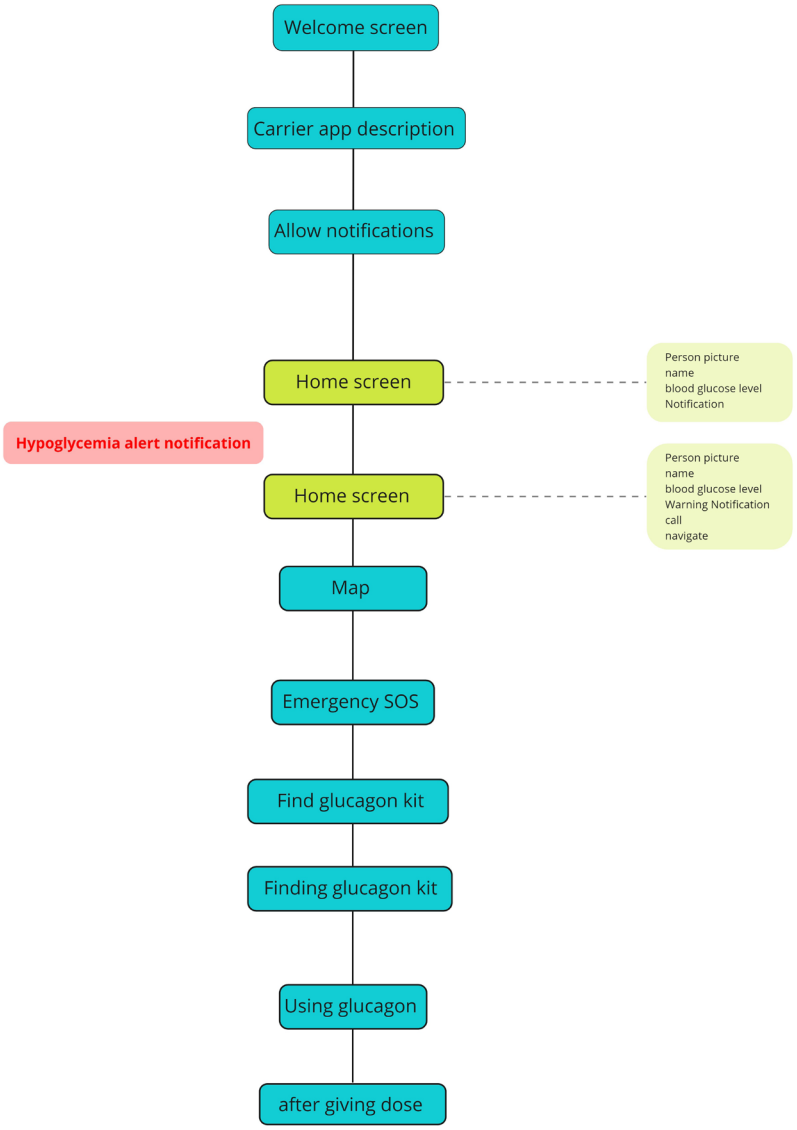


Figure 20: Information architecture showing the user flow for the Carrier app (illustration by the author)

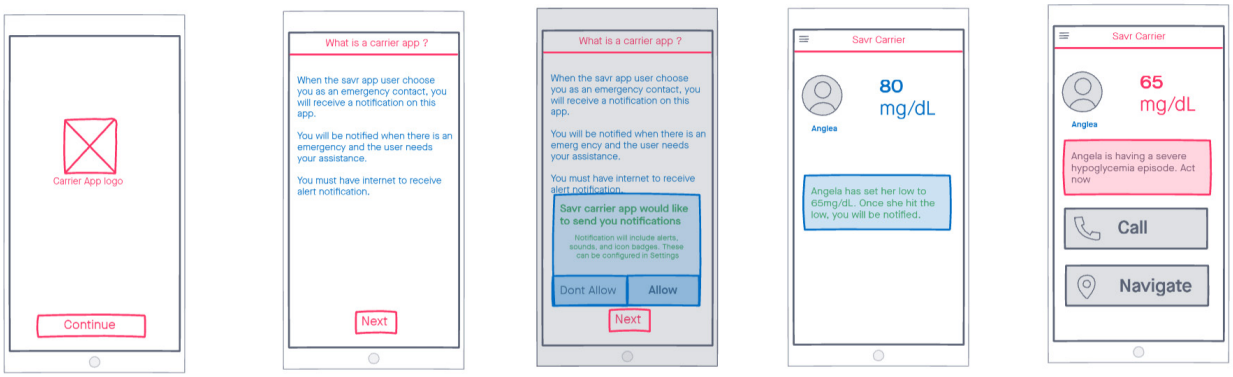


Figure 21: Connect App wireframe

5.4 Mockups

Figure 22: Smart wearable mockups

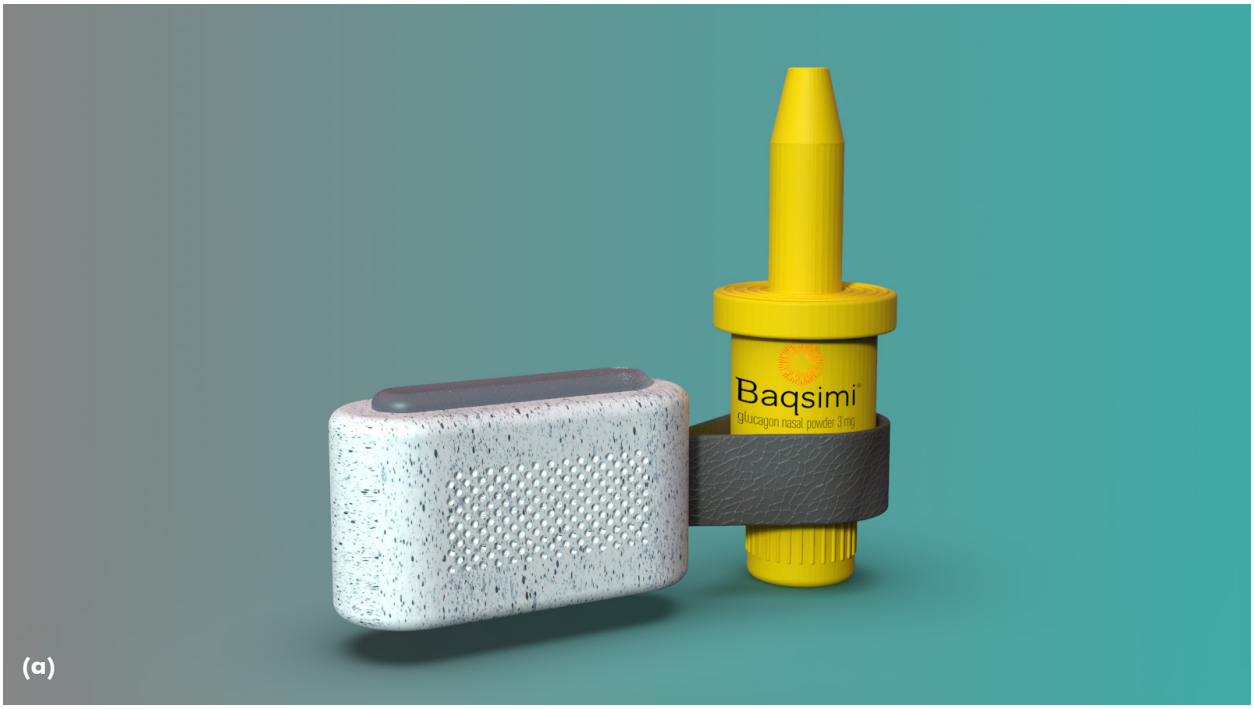
Figure 23: Alert device mockups

5.5 Digital model and rendering

WEARABLE DEVICE CAD MODEL AND RENDER

Figure 24: (a) Wearable device turned off; (b) Wearable device when activated

ALERT DEVICE CAD MODEL AND RENDER



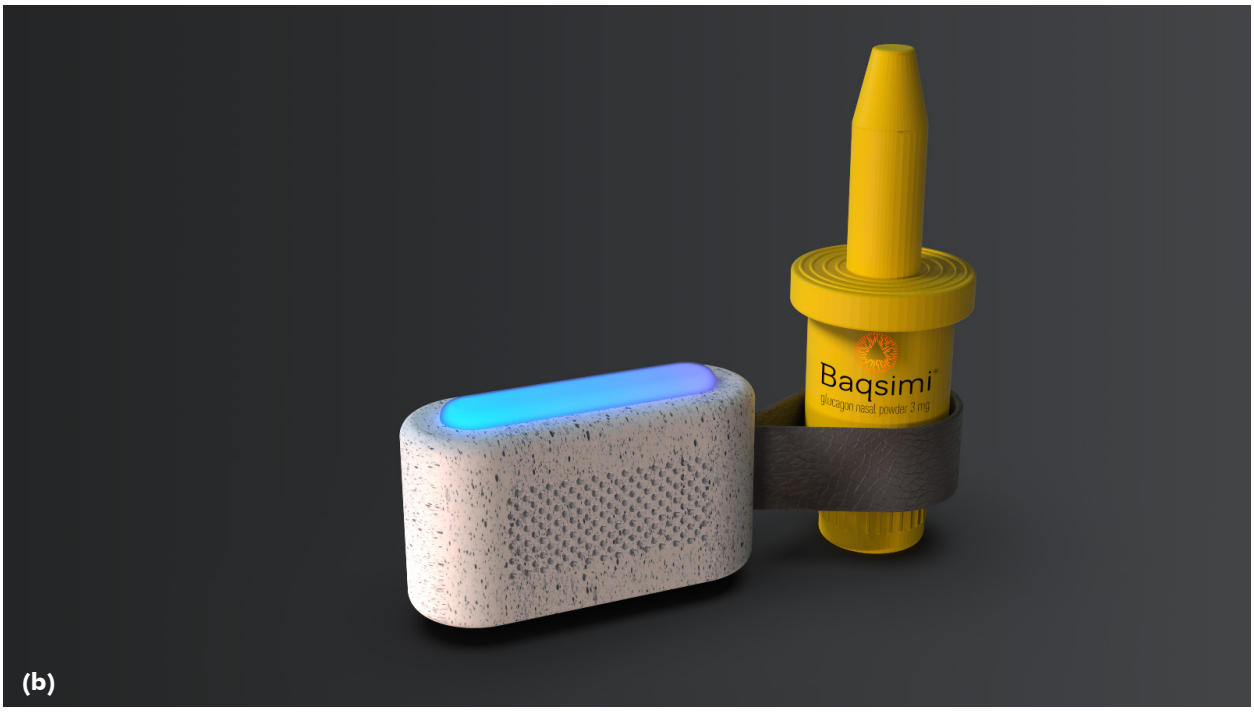


Figure 25: (a) Alert device turned off; (b) Alert device when activated

5.6 Prototype

WEARABLE DEVICE PROTOTYPE

Figure 26: Wearable device prototype

ALERT DEVICE PROTOTYPE

Figure 27: Alert device prototype

Figure 28: Wearable and alert device prototype

Figure 29: Wearable device prototype on hand

Figure 30: Alert device prototype placements

APP PROTOTYPE SCREEN

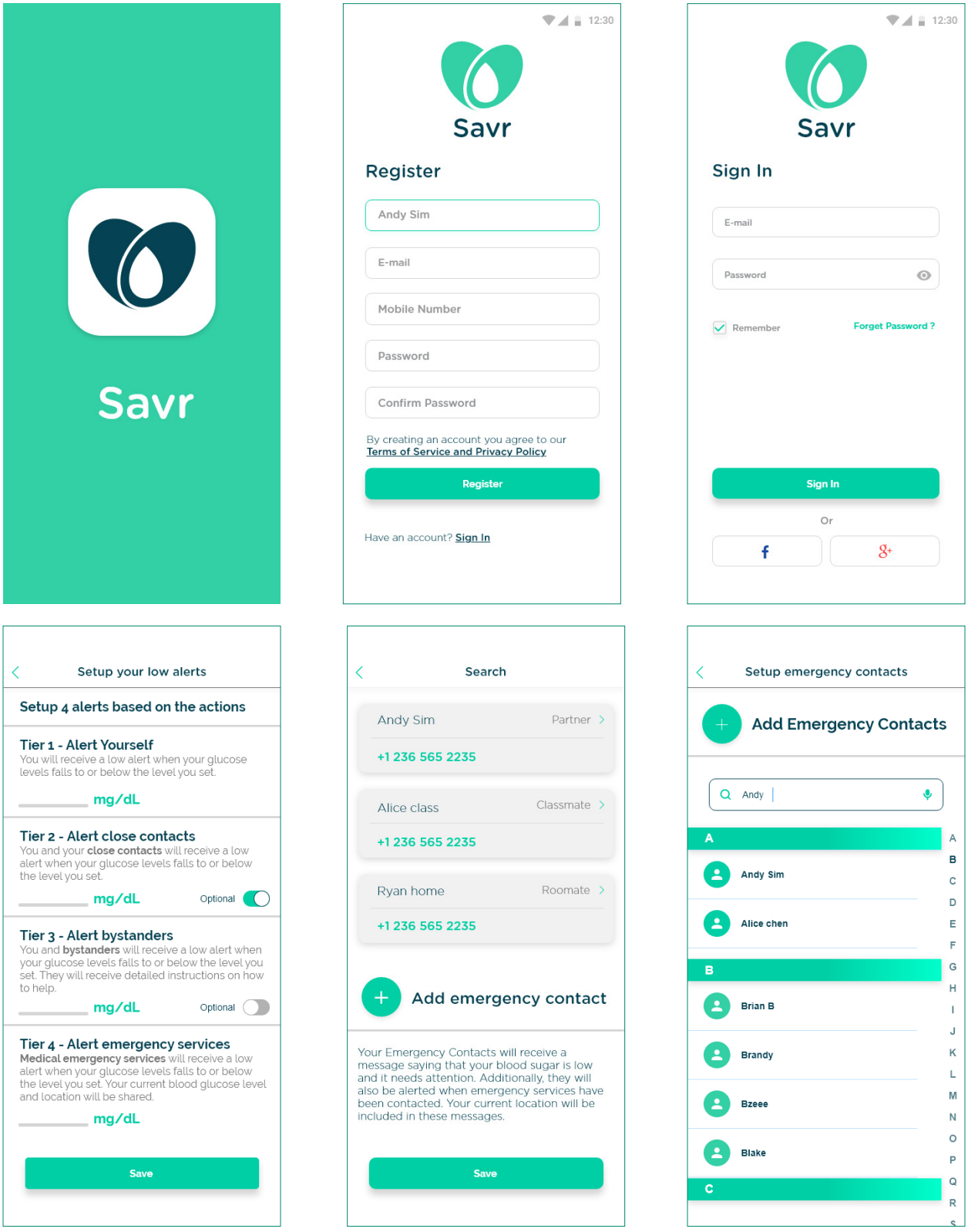


Figure 31: App prototype

CONNECT APP PROTOTYPE SCREEN

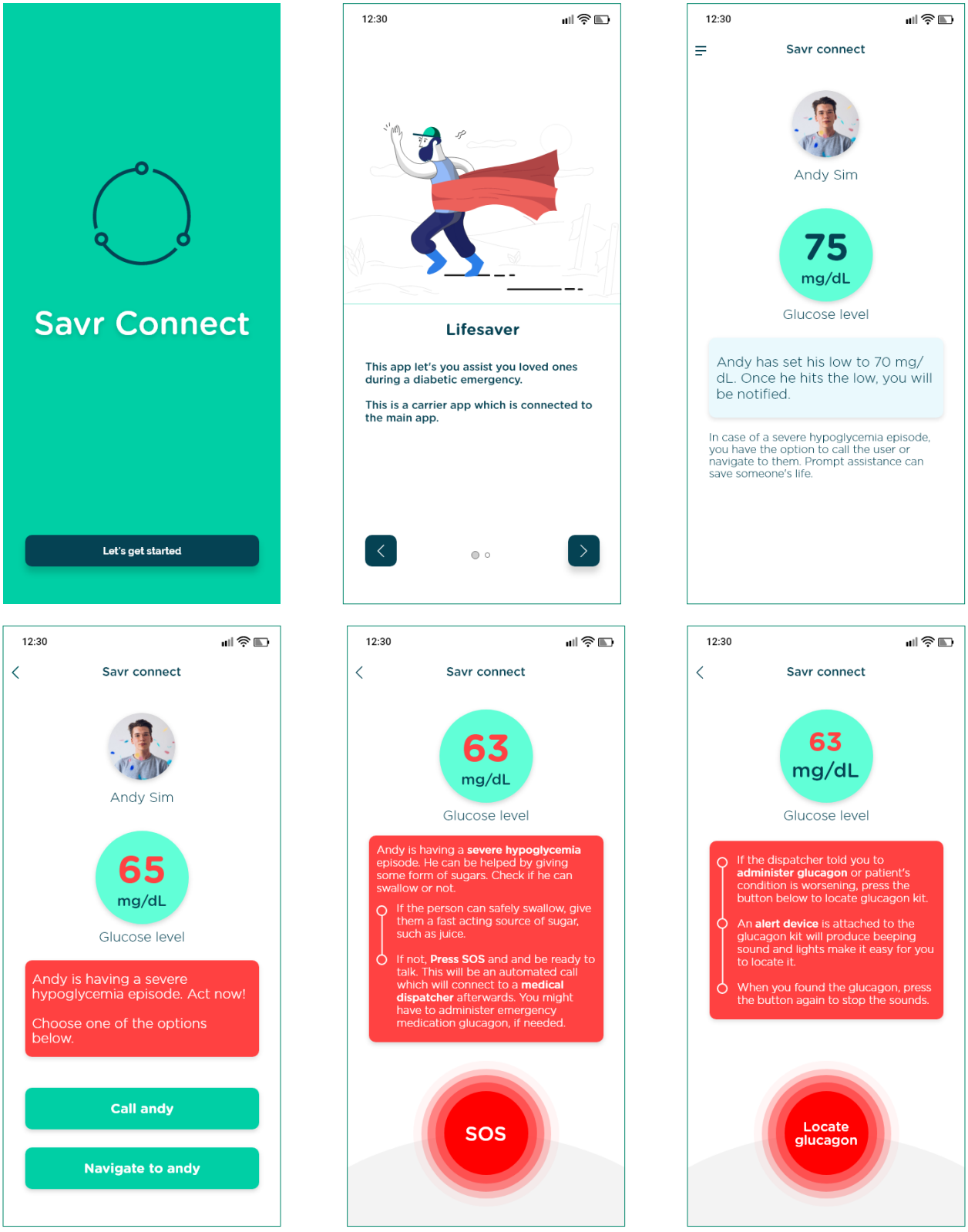


Figure 32: Connect app prototype

5.7 User Feedback

Following the concept development phase, I presented the ideation sketches to the three participants in an individual online session. The sessions started with explaining to them about the system map (see appendix 9.5) of the concept and how it will work in different scenarios. There were some questions listed for which the participants provided answers and suggested more promising solutions.

The next part of it was selecting the shape and form of the wearable (see appendix 9.5). Participants were provided three dots to vote on the concepts: one is the primary choice, and the third being the last. The sketches consist of ideas that have been divided into unique or generic shapes. The participants preferred a unique shape that may not be mistaken for a regular watch/fitness tracker. However, the form should be sleek and slim and should not represent the medical reason for wearing it.

When asked about the strap/band design, they all prefer silicone as it is easy to wear and clean simultaneously, but they also liked swappable bands for a change. On asking about the colour preferences, they prefer neutral colours but would love to have some colourful covers for some occasions. They also prefer a pin and tuck band closure instead of no buckles for adjustability and secure grip.

6 REFLECTION AND FUTURE DIRECTION

6 REFLECTION AND FUTURE DIRECTION

6.1 Insights and learning

The research started with the question, "How could we support young adults living with type1 diabetes transition to independent living?"

The proposed design is based on the needs of young adults who may need more support than an older and presumably more independent adult. During this transitional age, young adults tend to become more independent, possibly leaving their parents' home to start university or join a workplace with new people around who are unfamiliar with their medical condition. In diabetic emergencies, new friends may be unaware of the protocol for helping, leading to life-threatening situations. The developed solution caters to those needs and makes sure that young adults are facilitated with immediate assistance and avoid those severe episodes. It provides a stepping stone to complete independence. However, the resulting solution may also prove to be beneficial to older adults as well. All diabetics share ongoing concerns with hypoglycemia and this tool may prove helpful to a range of ages.

I believe that human-centered design is more important than ever and becomes an effective means of targeting limited resources towards building empathy. With rapid and continuously changing behaviors and expectations, understanding the human perspective is fundamental, influencing us to think differently and implement innovative solutions for shifting realities. The user's mindset is essential for successful design, and here it is rapidly evolving. With the changes necessitated by COVID-19, I quickly learned how promptly designers have to adapt to emerging situations and devise new methodologies when we are not able to meet users in their own environment. COVID-19 also allowed me to rethink how often overlooked resources such as online blogs and podcasts could prove useful in gathering qualitative information.

The most striking aspect was the co-design part of the research, where young adults meaningfully partnered to create more inclusive solutions. Co-design made it possible for the user and the designer to share power; co-designers and individuals built a cooperative relationship and moved together as active partners who were also involved in surveys, interviews, cultural probes and user feedback sessions. However, if I had more time, co-creation would involve more users, and the research would benefit from sharing multiple perspectives and generating numerous ideas.

6.2 Barriers and limitations

It becomes essential to identify this research's constraints, including conducting human-centered research during the global pandemic. The radical shift from physical to digital human engagement made it extremely difficult to do much of the design research originally proposed. "If there is one thing that one can say about ethnography, it is that social intimacy, and not social distancing, is crucial" ("Fine, Johnson, & Abramson, 2020). Social distancing conditions made it cumbersome to observe and interact with the participants in their real-life environment. The question which arises here is how we can better understand and meet these young adults' needs and aspirations in the new reality?

The proposed concept is based on the diabetic patient wearing a continuous glucose monitor (cgm), and it relies on everyone having a smartphone and internet access. Participants who do not have access to them were excluded from the participation and would not benefit from this research outcome. The first step to better manage glucose levels and have fewer low blood sugar emergencies is access to cgm (National Institute of Diabetes and Digestive and Kidney Diseases, 2021). Persons of lower socioeconomic status would not value from this study. Also, the system works on the internet; hence it may have difficulty working in poor coverage areas. The solution has been built on the needs of specific participants who have access to the technology.

Due to limited mobility and exposure risk, I learned the working of the British Columbia Emergency Health Services (BCEHS) through semi-structured interviews with call-takers, medical dispatchers, and paramedics. It otherwise would have been a visit to their physical spaces and perceiving things in greater depth.

This new normal delayed the research, forcing me to quickly pivot to alternative methods. Additionally, the global pandemic directly affected the participants' original condition by burdening them with one more challenge.

The shift necessitated the use of digital media and the internet for primary and secondary research while suspending all physical in-person research activities. This restricted the gathering of many participants for the research, and to some extent limited the knowledge creation to be based on fewer narratives and viewpoints.

However, to further refine the design outcome, it would greatly benefit from an in-depth ethnographic study and more users involved in each research method to gather multiple perspectives. The use of "shadowing" for qualitative research involving young adults with type 1 diabetes would also help me get more familiar with their lifestyle and better understand their challenges. Additionally, physically meeting the participants would have established a trustful relationship and allow more knowledge sharing. Having the participants do the user testing of the wearable and application in a physical space would fetch better results than doing it virtually and relying on anecdotal evidence.

6.3 Contributions and implications for design practice

Current research has identified a wide range of transition issues; however, few actual interventions exist to cope with those challenges. After conducting primary research, I formulated a list of critical findings from the research activities, and many opportunities beyond the scope of this project emerged such as designing improved insulin pump and CGM, sound looping system, carbohydrate counting device etc. This list demonstrates opportunities for other researchers in the design and medical domain to work towards.

Another striking feature was online blogs and podcasts in this research, which provided rich information. Their use is comparatively new in research yet offers a unique and inspiring frontier. During COVID-19, it became difficult to hear from the participants because of social distancing, Instead I looked at various blogs and social media groups run by the diabetic community. By examining bloggers and commenter's interactivity in different entries, comments, and threads, I found evidence of the many challenges. The addition of this methodology allowed for a reliable and accessible examination of human behavior.

6.4 Future implications

IMMEDIATE STEPS

The proposed design is aimed at young adults living with type 1 diabetes. A wearable working prototype could be developed to validate its functionality to move forward with this concept. Testing it with the user to check its feasibility and reliability in emergency conditions would be helpful. Also, analyzing the prototype in different scenarios will help to illuminate any problems and provide opportunities for improvements.

The proposed solution is a 24/7 medical wearable; hence it should be subtle enough so that wearers forget that it's on their wrist. A comprehensive trial for the device's comfort and wearability would be valuable, which could be done by making the user wear a lookalike prototype and recording their feedback.

Working closely with emergency contacts and bystanders to understand their perspectives on receiving alert notifications and acting promptly would be important. It is crucial to observe bystander response in the persisting COVID-19 situation. Additionally, measuring the success rate of a broadcast text notification to bystanders would also be beneficial. This will help us develop a cohesive product that is more realistic.

A part of this system involves automatic emergency calls to 911; testing the feature with the BCEHS would help acknowledge its practicality and ensure it is not burdening the existing 911 systems. This will also help us ensure that calls are colour-coded correctly and not ignored, as the case with automated voice calls.

LONG TERM DIRECTION

Tracking blood glucose fluctuations is crucial for patients living with diabetes. Researchers are trying to create less invasive procedures for hypoglycemia detection. Future development might include more sophisticated use of artificial intelligence (i.e., deep learning) and other biometrics to predict hypoglycemic episodes before they happen. It also opens the opportunity to include other physiological indicators that might influence the glucose imbalance, such as activity levels, temperature, skin conductivity or nutrition information that might enhance the A.I. system's performance.

As the health wearable industry grows exponentially with new smart wearables launching in the market, stakeholders' and designers are trying to perfect various devices in this ecosystem.

Alarming systems such as this project could be incorporated within more extensive emerging interconnected networks. Such a system could link lifestyle wearables (fitness trackers), location sensors (tracking activities), and insulin pumps to allow blood sugar levels to become more automated as to approach non-diabetic biological systems.

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8 GLOSSARY

Young adults: A person ranging in age from their early twenties to their thirties. Statistics Canada defines the age range from 20-24 years.

Transition: It refers to health care transition (HCT), a purposeful and unplanned movement of young adults with chronic medical conditions child-centered to adult-oriented health care systems.

Blood Sugar: Blood Sugar or blood glucose is a sugar that is transported through the bloodstream to supply energy to all the cells in the body. This sugar is made from the food an individual consumes.

CGM: It stands for Continuous glucose monitor and is a device that tracks blood sugar throughout the day and night. It takes glucose measurements at regular intervals and translates readings into data on a screen.

T1D: It is an acronym that stands for Type 1 Diabetes.

Hypoglycemia & Hyperglycemia: When a type 1 diabetic's blood sugar is too high or too low, he or she feels very unwell. Hyperglycemia or high blood sugar symptoms include frequent thirst and urination, blurred vision, fatigue and nausea. Hypoglycemia or low blood sugar symptoms include sweating, fatigue, nausea, shakiness and severe moodiness.

Glucagon: It is a hormone that raises an individual's blood sugar (glucose). It is also an emergency medication which is used to treat severe hypoglycemia. It is available in two forms: an injectable solution and a nasal powder.

Human-centered design: It stands for Human-centered design (HCD) that is an approach to problem- solving where the user is the heart of the process. It starts with people we are designing for ends with innovative tailor-made solutions.

Co-creation: It refers to a collaborative effort of designer, stakeholders, and users in the design process. It ensured that we received significant inputs while working with communities for whom we are designing.

6 APPENDIX

9 APPENDIX

9.1 REB Application

Emily Carr University Research Ethics Board (ECU-REB)
Research + Industry Office
520 East 1st Avenue
Vancouver, BC V5T0H2

+1 604 844 3800 ext 2848
ethics@ecuad.ca

CERTIFICATE OF RESEARCH ETHICS APPROVAL

The Emily Carr University Research Ethics Board approves the following project:

File #	Title	Principal Investigator:	Other Investigators
100379	Independent Heroes: Supporting young adults with type 1 diabetes transitioning to independent living	Jonathan Aitken	Kunal Gupta

The current approval dates are:

Approval Date	Expiration Date
May 6, 2020	May 6, 2021

The nature of the approval is as follows:

Type of Event	Type of Review	Approved Documents
New Approval Process	Delegated Review	Consent questionnaire and agreement/co-creation agenda/ Cultural probe/Interview questions

It is the researchers' responsibility to meet all research ethics requirements in the jurisdictions in which the research takes place. The procedures and protocols described in this certification must be followed closely. Note the following conditions associated with this approval:

- Delegated review completed and the committee has given approval once conditions regarding Covid-19 issues have been resolved and we are able to resume research activities as normal.
- For multi-site or partnered research, researchers are required to comply with all research ethics requirements that apply. Researchers are expected to share notice of this approval with partners, sites of research, or other research ethics review boards, as applicable.
- If changes to the approved application and documents are required by new partners, sites of research or other research ethics boards, researchers are required to inform the ECU-REB of these changes.

Researchers are required to report anticipated changes, adverse incidents, and project completion for further research ethics review. All reporting is managed through the research portal on the Research Management System Process Pathways Romeo - https://ecuad.researchservicesoffice.com/. Login and complete "event" reports for changes, adverse conditions, renewals, and the completion of this research ethics file.

This research ethics approval is in compliance with Tri-Council guidelines (TCSP2 2018) and Emily Carr University policies and procedures.

Dr. Cameron Cartiere
Chair, Emily Carr University Research Ethics Board
Emily Carr University of Art + Design

Cc. Research Finance Office, Emily Carr University

Figure 33: REB Application

9.2 Nasal glucagon

https://www.baqsimi.com/what-is-baqsimi

Figure 34: Nasal Glucagon

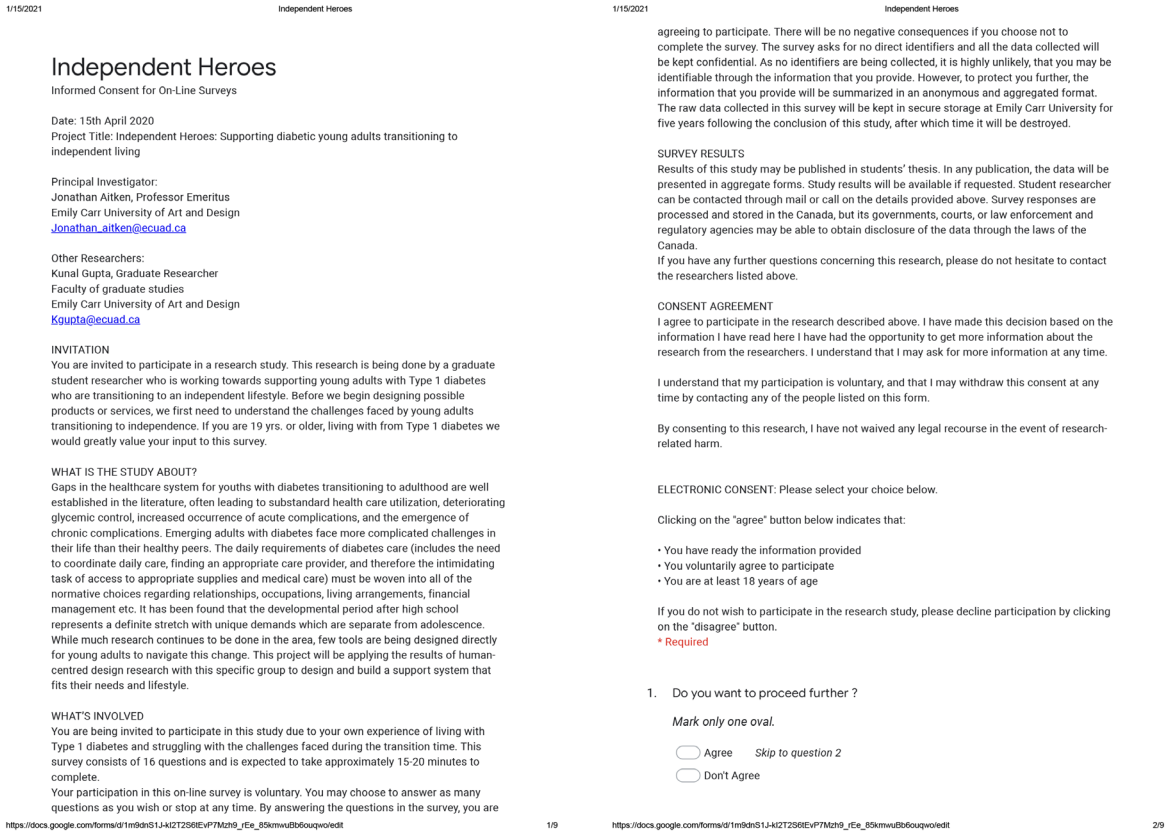
https://www.baqsimi.com/how-to-use-baqsimi

Figure 35: Nasal glucagon delivery (Source BAQSIMI)

9.3 Research Activities

9.3.1 SURVEY

Survey posted on various blogs run by diabetic community. This was done to invite participants for the research and gather information from those sources.



1/15/2021 Independent Heroes

Independent Heroes

Informed Consent for On-Line Surveys

Date: 15th April 2020
Project Title: Independent Heroes: Supporting diabetic young adults transitioning to independent living

Principal Investigator:
Jonathan Aitken, Professor Emeritus
Emily Carr University of Art and Design
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Other Researchers:
Kunal Gupta, Graduate Researcher
Faculty of graduate studies
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INVITATION
You are invited to participate in a research study. This research is being done by a graduate student researcher who is working towards supporting young adults with Type 1 diabetes who are transitioning to an independent lifestyle. Before we begin designing possible products or services, we first need to understand the challenges faced by young adults transitioning to independence. If you are 19 yrs. or older, living with from Type 1 diabetes we would greatly value your input to this survey.

WHAT IS THE STUDY ABOUT?
Gaps in the healthcare system for youths with diabetes transitioning to adulthood are well established in the literature, often leading to substandard health care utilization, deteriorating glycemic control, increased occurrence of acute complications, and the emergence of chronic complications. Emerging adults with diabetes face more complicated challenges in their life than their healthy peers. The daily requirements of diabetes care (includes the need to coordinate daily care, finding an appropriate care provider, and therefore the intimidating task of access to appropriate supplies and medical care) must be woven into all of the normative choices regarding relationships, occupations, living arrangements, financial management etc. It has been found that the developmental period after high school represents a definite stretch with unique demands which are separate from adolescence. While much research continues to be done in the area, few tools are being designed directly for young adults to navigate this change. This project will be applying the results of human-centred design research with this specific group to design and build a support system that fits their needs and lifestyle.

WHAT'S INVOLVED
You are being invited to participate in this study due to your own experience of living with Type 1 diabetes and struggling with the challenges faced during the transition time. This survey consists of 16 questions and is expected to take approximately 15-20 minutes to complete.
Your participation in this on-line survey is voluntary. You may choose to answer as many questions as you wish or stop at any time. By answering the questions in the survey, you are

https://docs.google.com/forms/d/1m9dnS1J-kI2T2S6tEvP7Mzh9_rEe_85kmwuBb6ouqwo/edit 1/9

1/15/2021 Independent Heroes

agreeing to participate. There will be no negative consequences if you choose not to complete the survey. The survey asks for no direct identifiers and all the data collected will be kept confidential. As no identifiers are being collected, it is highly unlikely, that you may be identifiable through the information that you provide. However, to protect you further, the information that you provide will be summarized in an anonymous and aggregated format. The raw data collected in this survey will be kept in secure storage at Emily Carr University for five years following the conclusion of this study, after which time it will be destroyed.

SURVEY RESULTS
Results of this study may be published in students' thesis. In any publication, the data will be presented in aggregate forms. Study results will be available if requested. Student researcher can be contacted through mail or call on the details provided above. Survey responses are processed and stored in the Canada, but its governments, courts, or law enforcement and regulatory agencies may be able to obtain disclosure of the data through the laws of the Canada.
If you have any further questions concerning this research, please do not hesitate to contact the researchers listed above.

CONSENT AGREEMENT
I agree to participate in the research described above. I have made this decision based on the information I have read here I have had the opportunity to get more information about the research from the researchers. I understand that I may ask for more information at any time.

I understand that my participation is voluntary, and that I may withdraw this consent at any time by contacting any of the people listed on this form.

By consenting to this research, I have not waived any legal recourse in the event of research-related harm.

ELECTRONIC CONSENT: Please select your choice below.

Clicking on the "agree" button below indicates that:

- You have ready the information provided
- You voluntarily agree to participate
- You are at least 18 years of age

If you do not wish to participate in the research study, please decline participation by clicking on the "disagree" button.
* Required

1. Do you want to proceed further ?

Mark only one oval.

Agree *Skip to question 2*
Don't Agree

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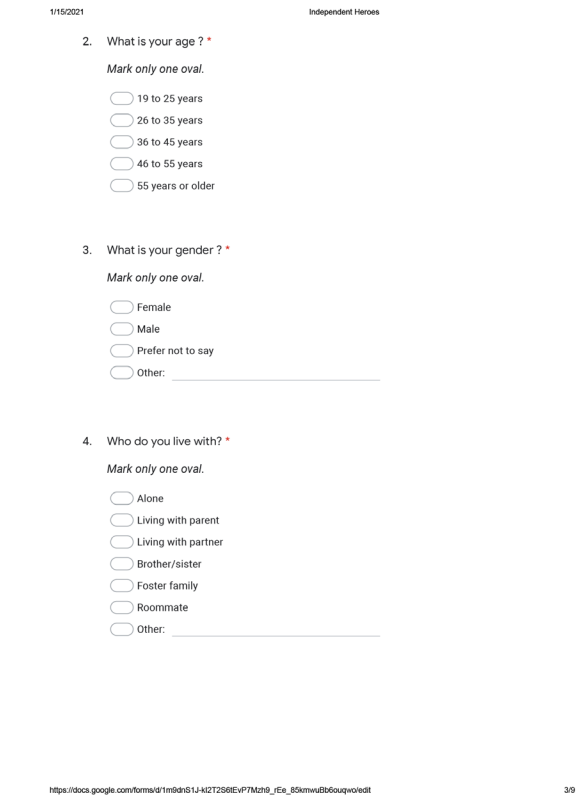
Figure 36: User survey form(1/5)



1/15/2021 Independent Heroes

2. What is your age ? *

Mark only one oval.

- 19 to 25 years
- 26 to 35 years
- 36 to 45 years
- 46 to 55 years
- 55 years or older

3. What is your gender ? *

Mark only one oval.

- Female
- Male
- Prefer not to say
- Other:

4. Who do you live with? *

Mark only one oval.

- Alone
- Living with parent
- Living with partner
- Brother/sister
- Foster family
- Roommate
- Other:

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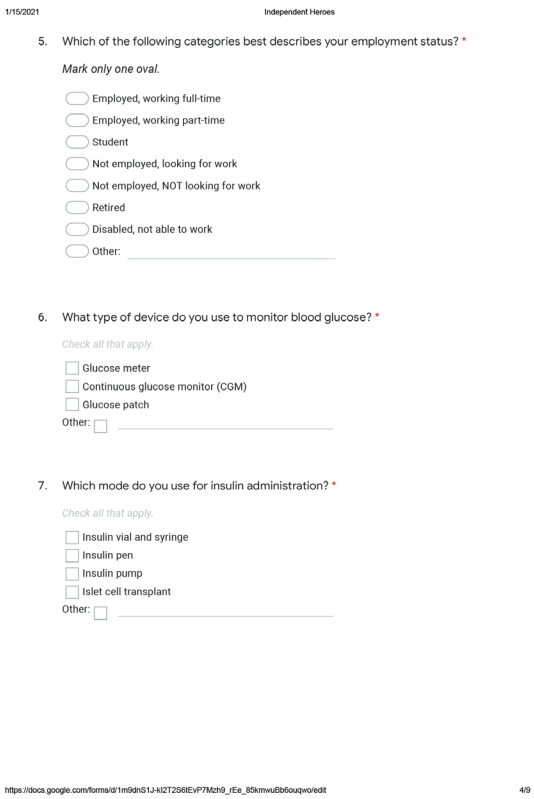


1/15/2021 Independent Heroes

5. Which of the following categories best describes your employment status? *

Mark only one oval.

- Employed, working full-time
- Employed, working part-time
- Student
- Not employed, looking for work
- Not employed, NOT looking for work
- Retired
- Disabled, not able to work
- Other:

6. What type of device do you use to monitor blood glucose? *

Check all that apply.

- Glucose meter
- Continuous glucose monitor (CGM)
- Glucose patch
- Other:

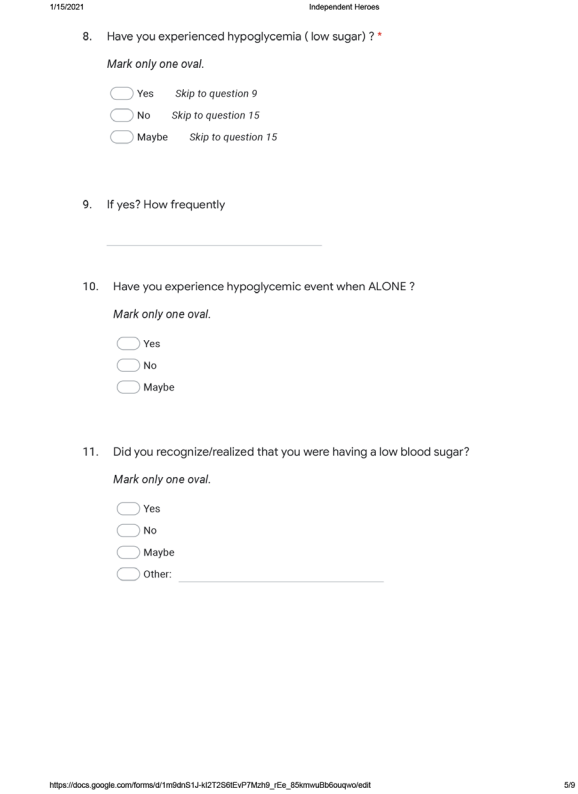
7. Which mode do you use for insulin administration? *

Check all that apply.

- Insulin vial and syringe
- Insulin pen
- Insulin pump
- Islet cell transplant
- Other:

https://docs.google.com/forms/d/1m9dnS1J-kI2T2S6tEvP7Mzh9_rEe_85kmwuBb6ouqwo/edit 4/9

Figure 37: User survey form(2/5)



1/15/2021 Independent Heroes

8. Have you experienced hypoglycemia (low sugar) ? *

Mark only one oval.

- Yes *Skip to question 9*
- No *Skip to question 15*
- Maybe *Skip to question 15*

9. If yes? How frequently

10. Have you experience hypoglycemic event when ALONE ?

Mark only one oval.

- Yes
- No
- Maybe

11. Did you recognize/realized that you were having a low blood sugar?

Mark only one oval.

- Yes
- No
- Maybe
- Other:

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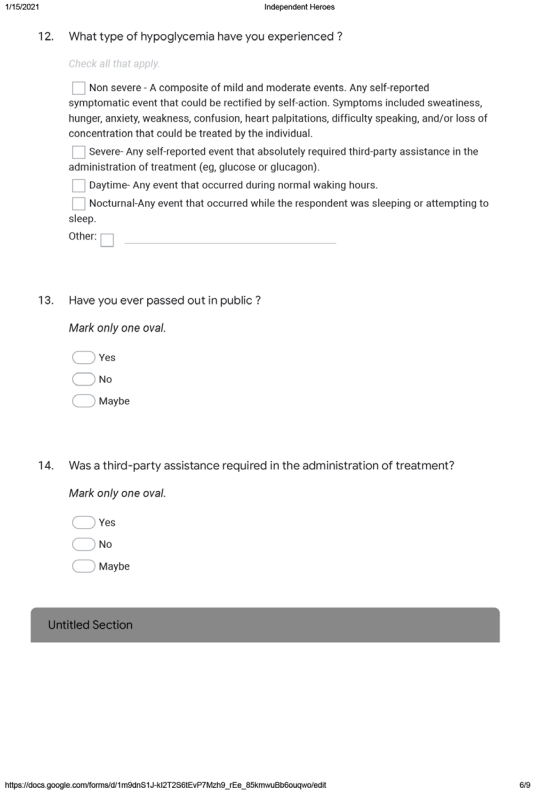

1/15/2021 Independent Heroes

12. What type of hypoglycemia have you experienced ?

Check all that apply.

- Non severe - A composite of mild and moderate events. Any self-reported symptomatic event that could be rectified by self-action. Symptoms included sweatiness, hunger, anxiety, weakness, confusion, heart palpitations, difficulty speaking, and/or loss of concentration that could be treated by the individual.
- Severe- Any self-reported event that absolutely required third-party assistance in the administration of treatment (eg, glucose or glucagon).
- Daytime- Any event that occurred during normal waking hours.
- Nocturnal-Any event that occurred while the respondent was sleeping or attempting to sleep.
- Other:

13. Have you ever passed out in public ?

Mark only one oval.

- Yes
- No
- Maybe

14. Was a third-party assistance required in the administration of treatment?

Mark only one oval.

- Yes
- No
- Maybe

Untitled Section

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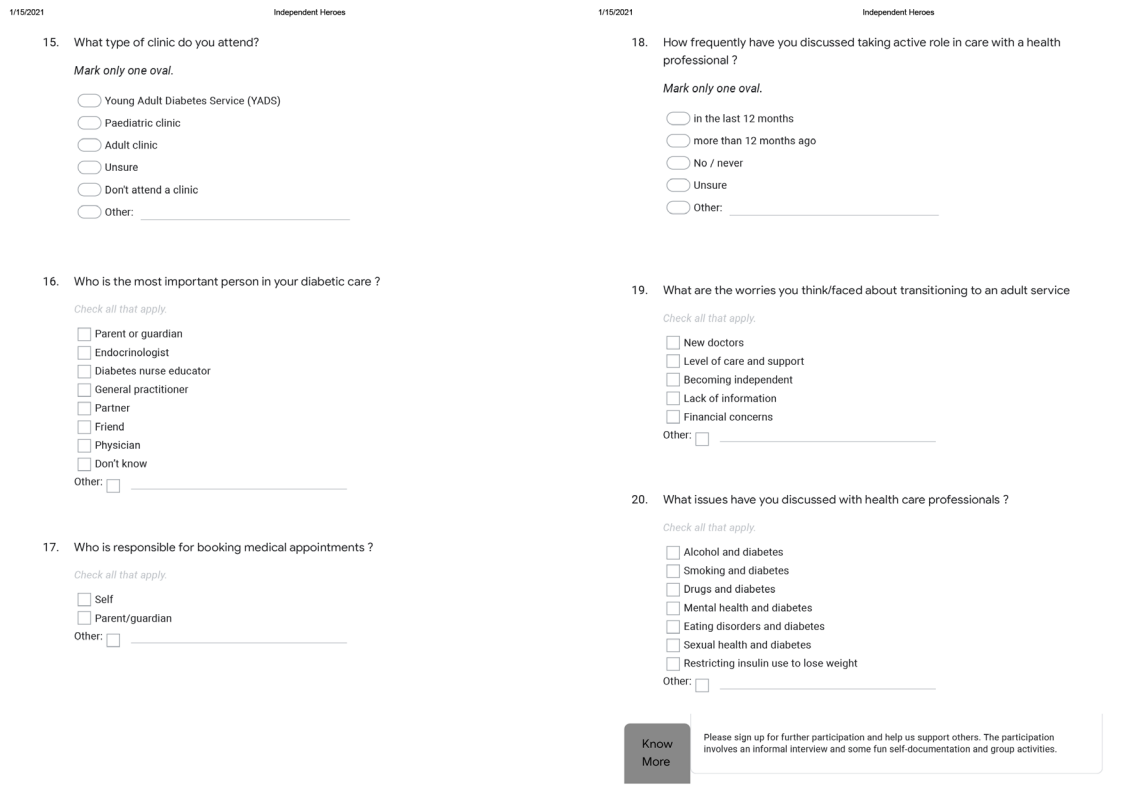
Figure 38: User survey form(3/5)



1/15/2021 Independent Heroes

15. What type of clinic do you attend?

Mark only one oval.

- Young Adult Diabetes Service (YADS)
- Paediatric clinic
- Adult clinic
- Unsure
- Don't attend a clinic
- Other: _____

16. Who is the most important person in your diabetic care ?

Check all that apply.

- Parent or guardian
- Endocrinologist
- Diabetes nurse educator
- General practitioner
- Partner
- Friend
- Physician
- Don't know
- Other: _____

17. Who is responsible for booking medical appointments ?

Check all that apply.

- Self
- Parent/guardian
- Other: _____

https://docs.google.com/forms/d/1m9dnS1J-kI2T2S6tEvP7Mzh9_rEe_85kmwuBb6ouqwo/edit 7/9

1/15/2021 Independent Heroes

18. How frequently have you discussed taking active role in care with a health professional ?

Mark only one oval.

- in the last 12 months
- more than 12 months ago
- No / never
- Unsure
- Other: _____

19. What are the worries you think/faced about transitioning to an adult service

Check all that apply.

- New doctors
- Level of care and support
- Becoming independent
- Lack of information
- Financial concerns
- Other: _____

20. What issues have you discussed with health care professionals ?

Check all that apply.

- Alcohol and diabetes
- Smoking and diabetes
- Drugs and diabetes
- Mental health and diabetes
- Eating disorders and diabetes
- Sexual health and diabetes
- Restricting insulin use to lose weight
- Other: _____

Know More

Please sign up for further participation and help us support others. The participation involves an informal interview and some fun self-documentation and group activities.

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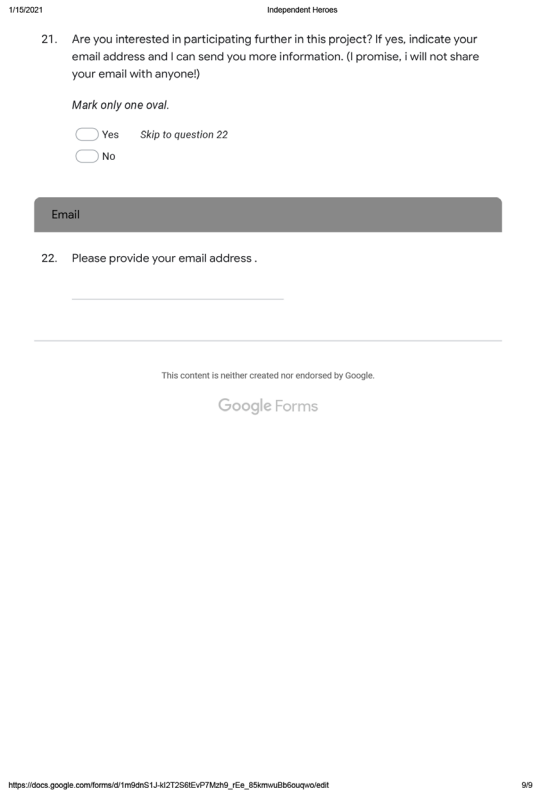
Figure 39: User survey form(4/5)



1/15/2021 Independent Heroes

21. Are you interested in participating further in this project? If yes, indicate your email address and I can send you more information. (I promise, i will not share your email with anyone!)

Mark only one oval.

- Yes *Skip to question 22*
- No

Email

22. Please provide your email address .

_____

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Google Forms

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Figure 40: User survey form(5/5)

9.3.2 SEMI-STRUCTURED INTERVIEWS

Participants who signed up for further engagement in the research study were invited for semi-structured interviews facilitated through zoom video calls. A few predetermined set of questions were asked from the participants,while the rest of the questions are not planned in advance. The questions were as follows:

1. How long have you had diabetes?
2. How often do you have to test your glucose levels?
3. Do you use an insulin pump or injections/pens? How often do you need to inject it?
4. Can you recognize the symptoms of low blood sugar? What symptoms do you experience?
5. Can you recognize the symptoms of high blood sugar? What symptoms do you experience?
6. Have you ever experienced hypoglycemia? Was it severe?
7. How do you treat hypoglycemia?
8. What is the hardest part of diabetic management?
9. Does your diabetes cause you any other problems?
10. What would you like a non-diabetic to know about having diabetes?
11. Have you transitioned from parent-managed care to self-managed care?
12. How complicated was that process?
13. Can you elaborate? What things were most difficult? What helped?
14. Who do you get the support from now?
15. How do you manage your diabetes at your workplace? Was there any instance that makes you feel uncomfortable?
16. Do you hide your diabetes at work or socially?
17. Is there anything you would like to change about your diabetes care? If so, can you explain what you would like to change?
18. Are there any support tools or services that you wished existed to help you manage your diabetes?

The question were structured to cover the transition, and it challenges, however, there were opportunities to spontaneously explore a topic relevant to a particular participant and proceed further with unstructured questions. The conversation was oriented towards hypoglycemia, and its challenges as that issue was prevalent in the survey results.

The experts from British Columbia Emergency Health Services (BCEHS) were also asked a set of questions which are as follows:

1. Have you encountered cases where people with diabetes have become unconscious because of extreme hypoglycemia?
2. When do people call paramedics if a person is experiencing hypoglycemia? How do you treat them? Do you give them Glucagon? What type of Glucagon do you use?
3. Does a patient carry fast-acting oral gel with them? Why/why not? Do you inform the person's emergency contact regarding the incident? How are they contacted?
4. Can an automated voice message call 911 and inform them of a medical emergency? Does 9=11 accept such calls?
5. Can you explain about the automated 911 devices?
6. Can a novice person not administer Glucagon?
7. Who is trained to use a Glucagon injection in case of severe hypoglycemia?
8. Can an unknown person administer it? Can a first responder administer Glucagon?
9. How do you think a person/ bystander /family member can respond quickly when someone is experiencing hypoglycemia?
10. How can a person with hypoglycemia communicate some of their needs with the people around them?
11. How do you think the presence of a bystander can be taken advantage of when a person is experiencing hypoglycemia?

9.3.3 BLOGS AND PODCAST

This shows some of the Reddit and Type one nation blogs run by the diabetic community.

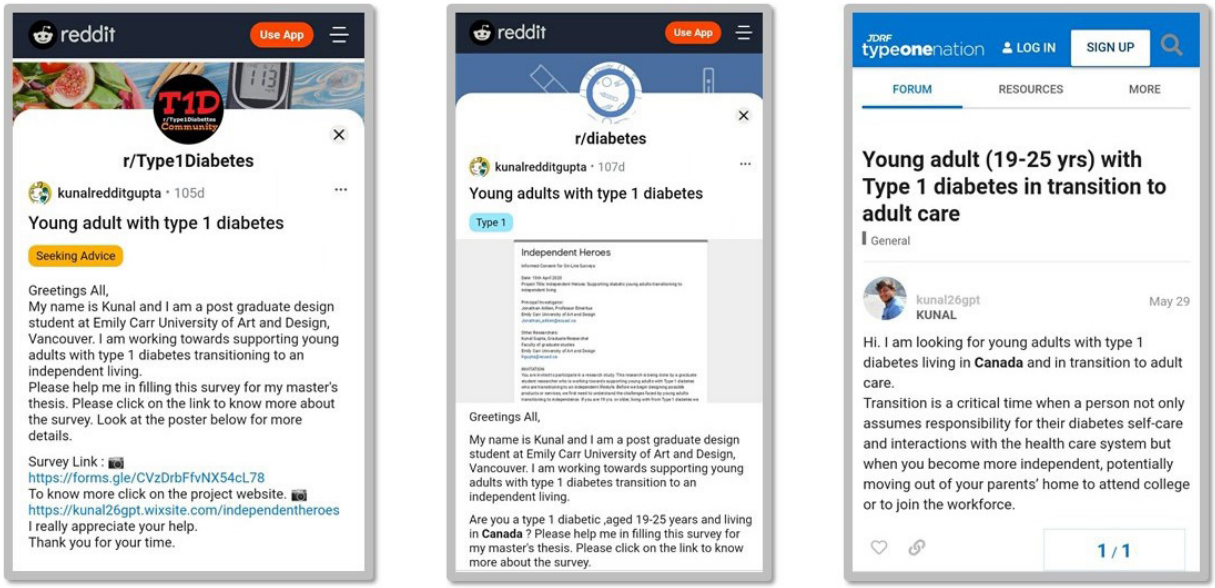


Figure 41: Screenshot of survey posted on Online blogs

Here are some of the podcasts that facilitated plenty of conversation between different diabetics.

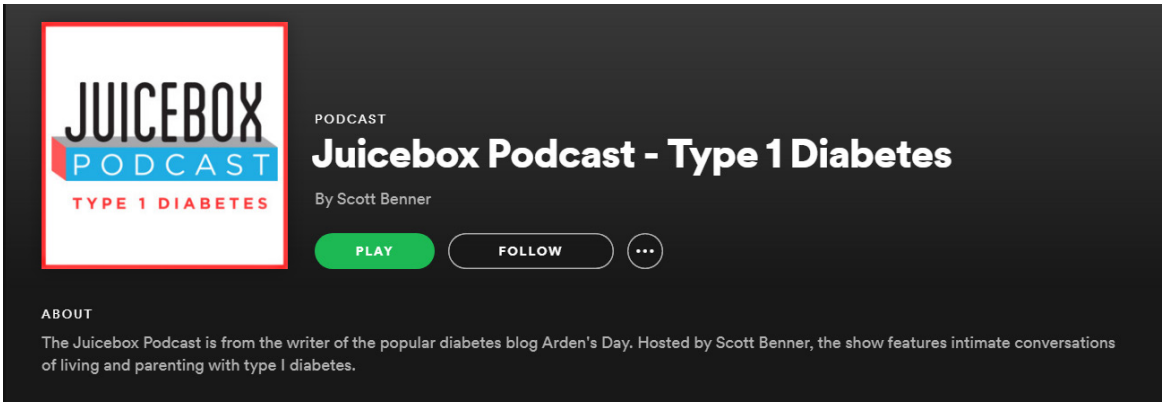


Figure 42: Screenshot of podcast from spotify (1/2)

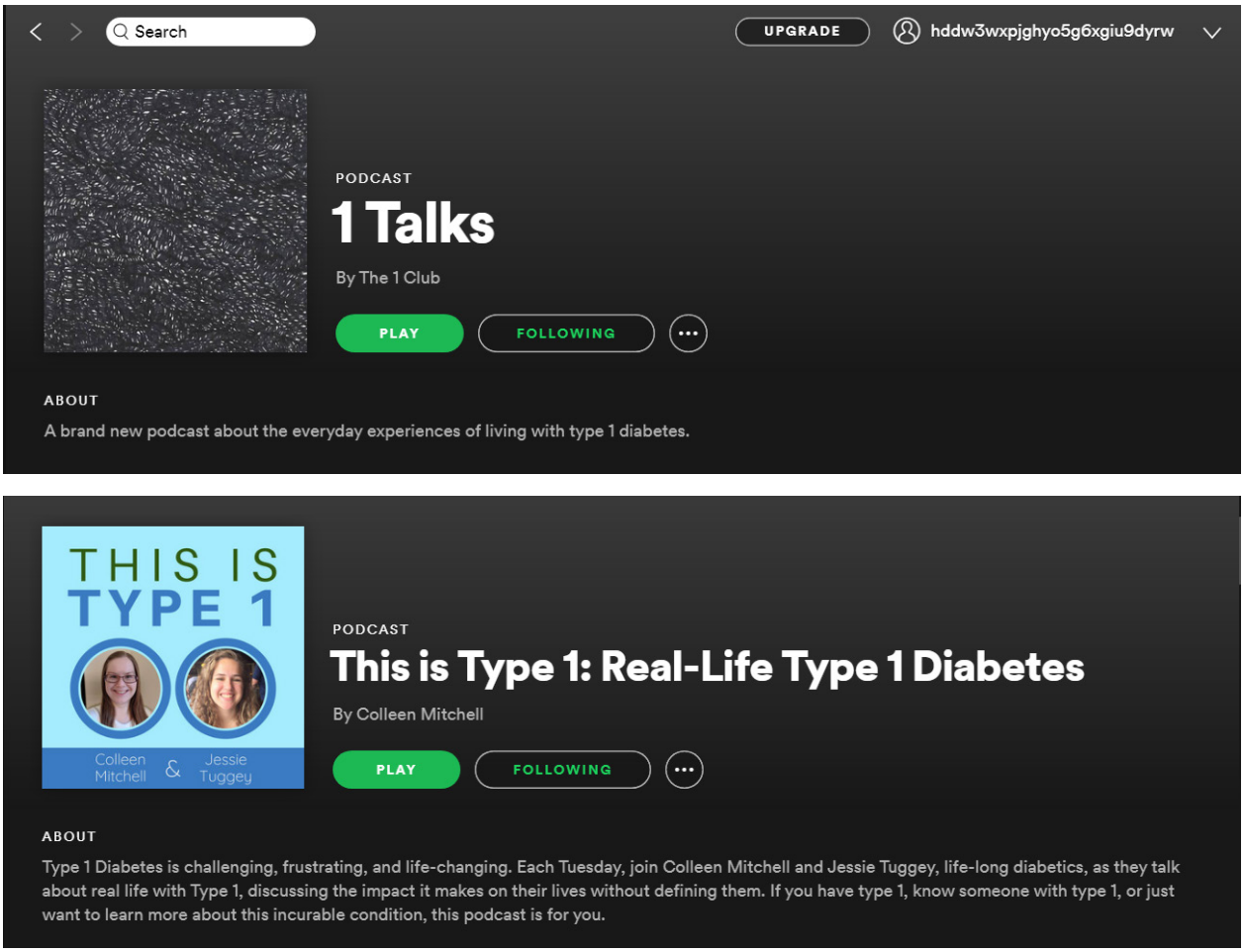


Figure 43: Screenshot of podcast from spotify (2/2)

9.3.4 CULTURAL PROBE

A cultural probe is a research methodology that is utilized to understand the experience of others. Coronavirus made it challenging to conduct the ethnographic study and observe the user physically in their environment. Hence, I decided to go for digital cultural probes. It consists of three activities specific to living with type 1 diabetes, which allows them to record events, feelings, or interactions. The purpose of utilizing this research tool was to gather a deeper understanding of their feelings and daily life. The probe was made available to participants through an online collaborative platform called MIRO.

The probe functioned as visual diary, allowing the young adults to:

- Observe and reflect on their experiences of living with type 1 diabetes and challenges faced.
- Provide an insight into the life of a type 1 diabetic.

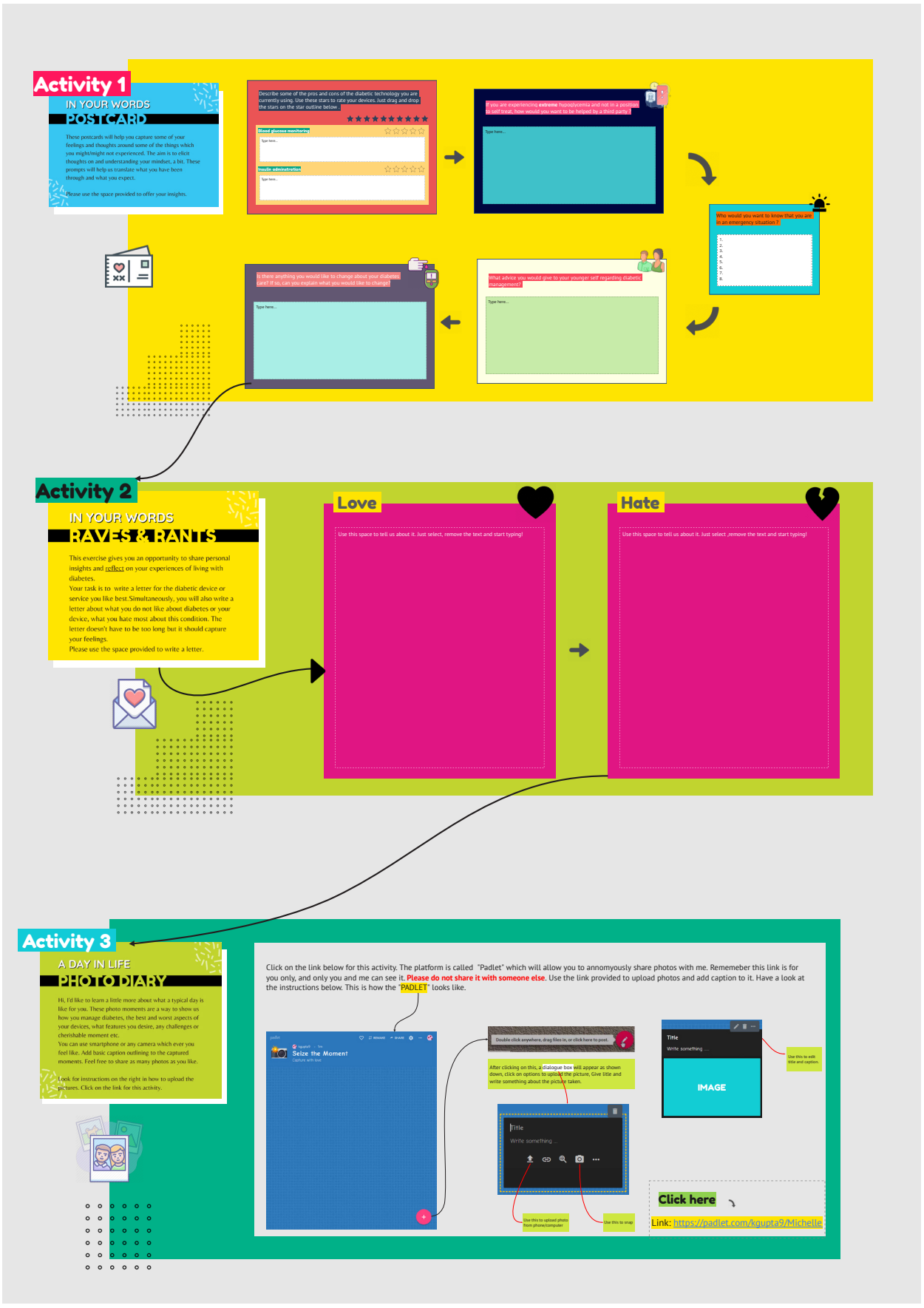


Figure 44: Cultural Probe Activities

9.4 Scenarios of Use

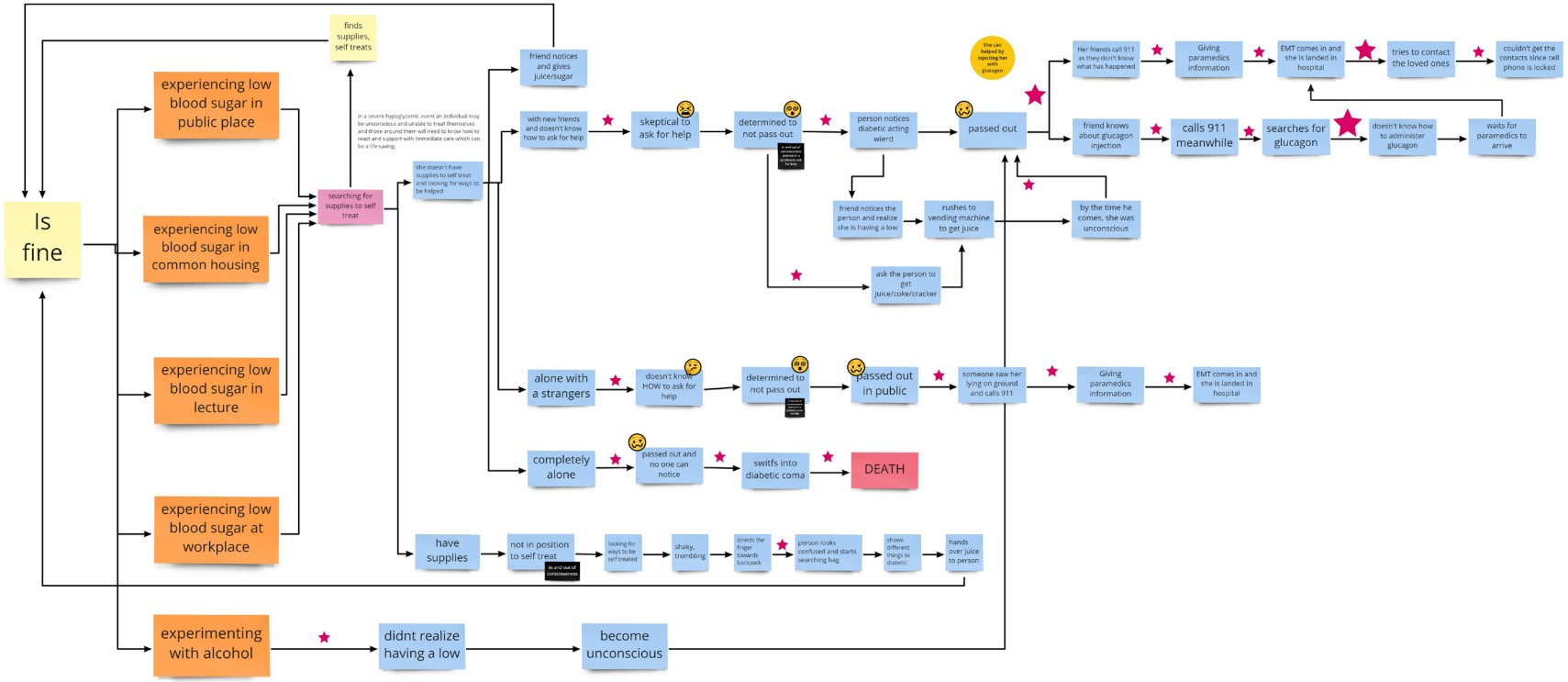


Figure 45: System map of scenario from first person(diabetic) perspective

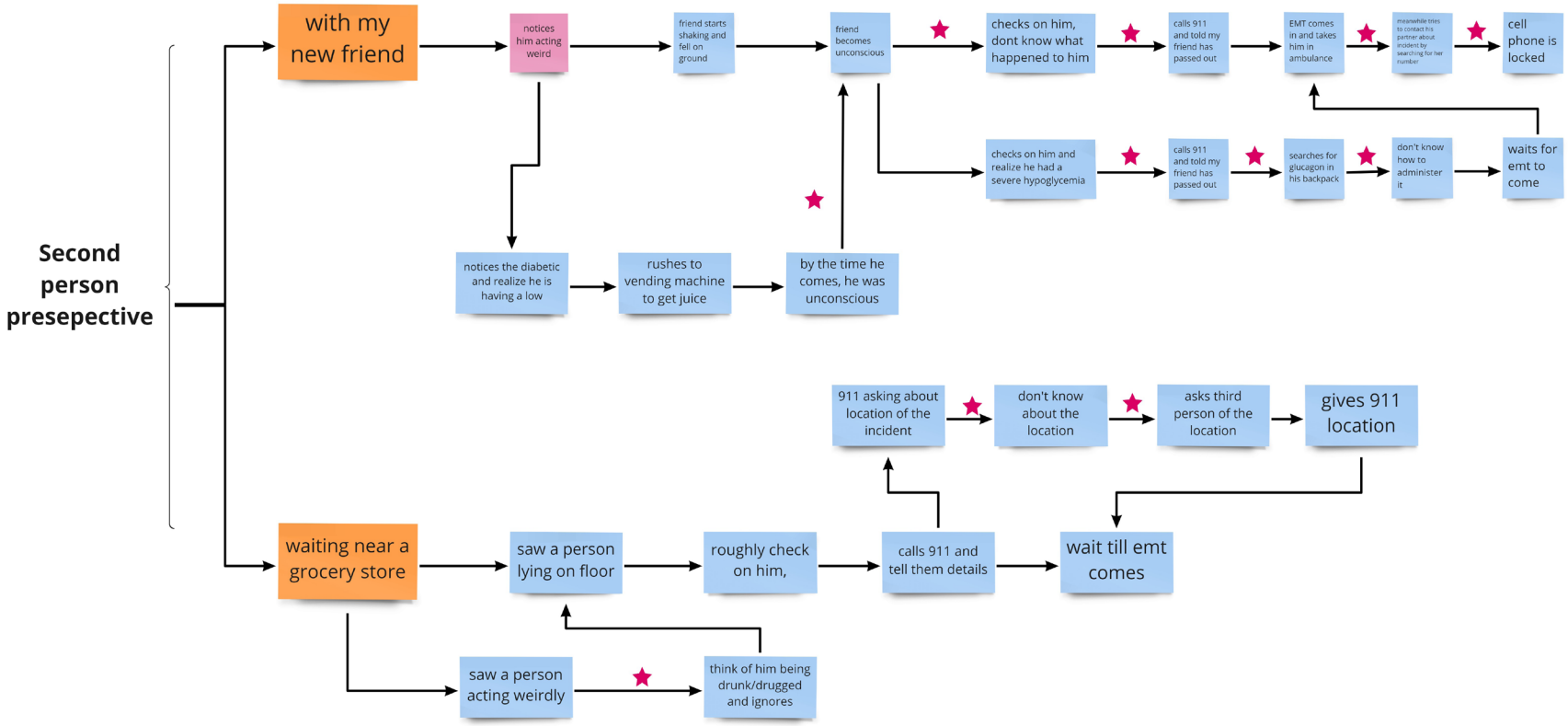


Figure 46: System map of scenario from first second (person observing diabetic) perspective

Below are the detailed scenarios listed with pain points and design opportunities.

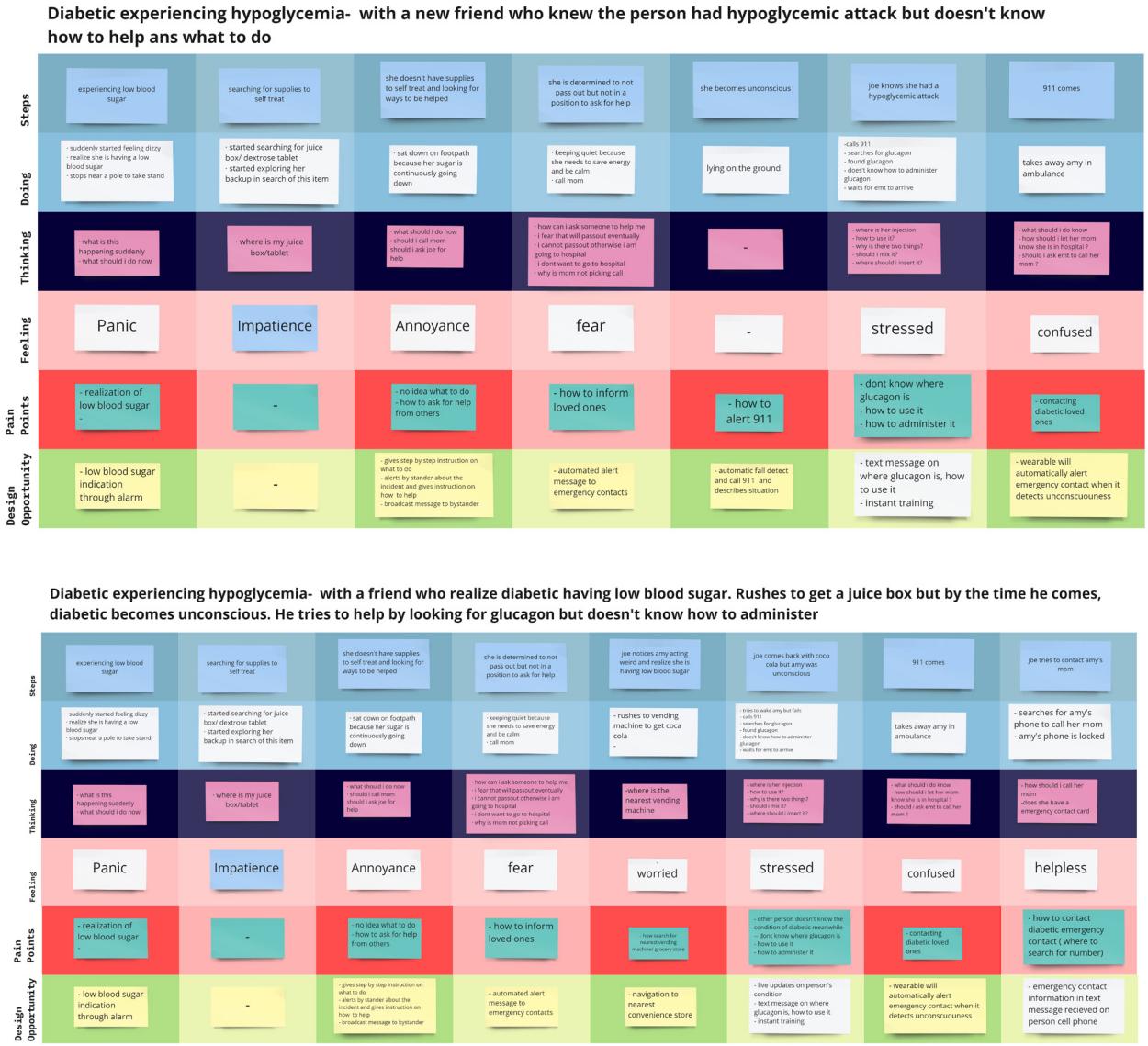
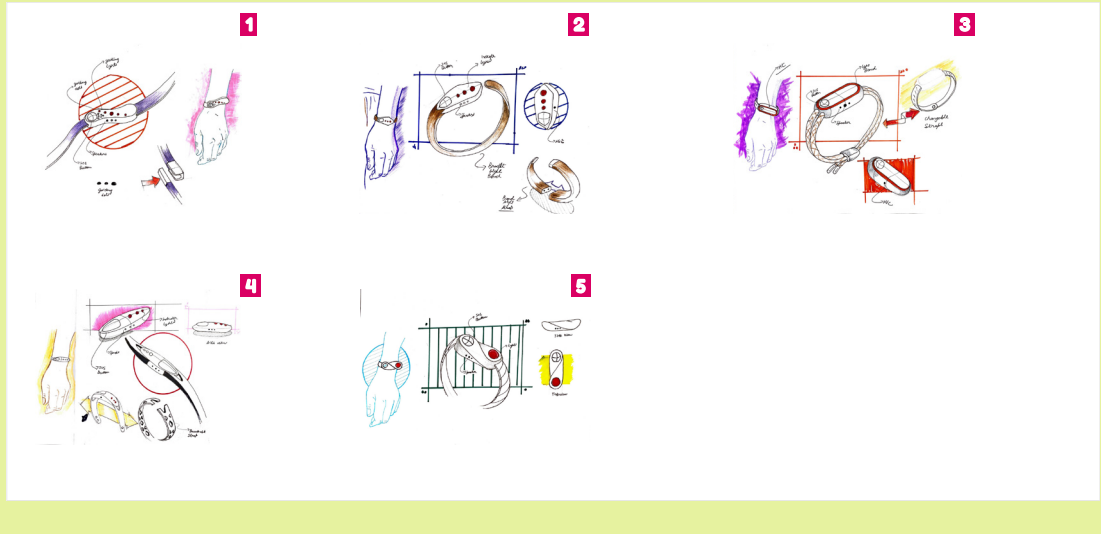


Figure 47: Scenarios of use

9.5 User Feedback

GET FEEDBACK

I've learnt and built something. Now its time to share with people whom I'm designing for and see what you think.
We will be going through the cue cards at the bottom to get into specifics of developing the product.



Voting Dots 1 2 3

Use the dots to rank the ideas that you like

Card 1

Which form/design excites you and why?

Unique/ different shape

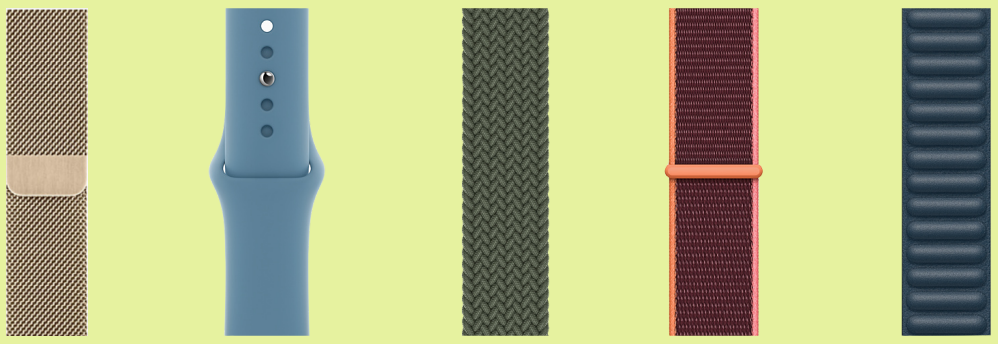
VS

Generic shape

Card 2

Would you like to wear something that has a unique shape/form or something that has a more generic form (eg, fitbit) ?

Band/strap design



Metal | Silicone rubber | Braided | Textile | Leather

Card 3

what material would you prefer? silicone, leather, textile, beaded etc.

Color

VS

Card 4

What are you thoughts on the color? Do you prefer standard colors(black/grey) or funky colors?

Strap closure

VS

Strap with pin and tuck closure

Strap with no buckles or clasps

Card 5

Which type of strap/band closure do you prefer or would like to have ?

Figure 48: User feedback activity

9.6 App Screens - Main Application

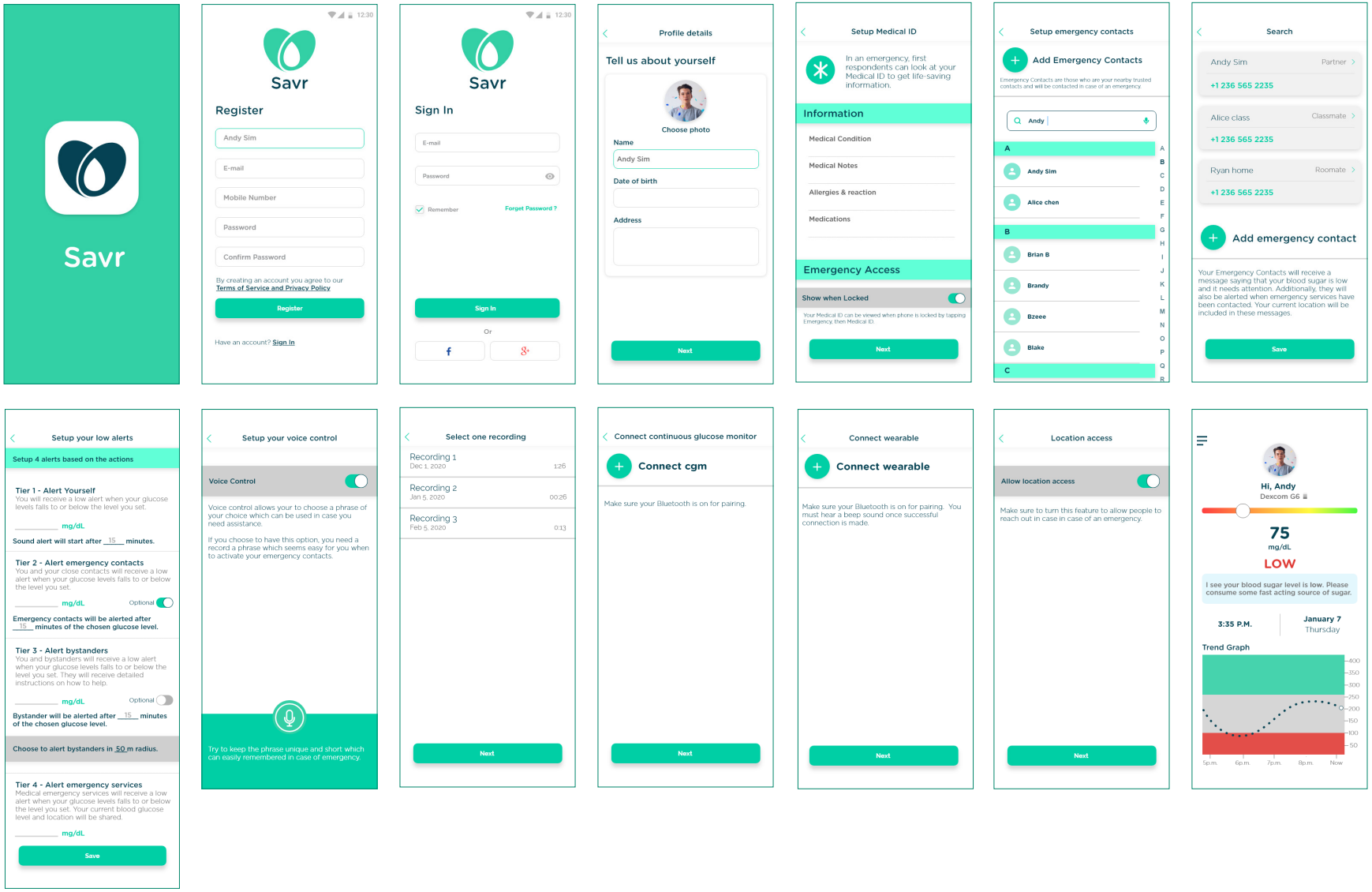


Figure 49: Main application screens(1/2)

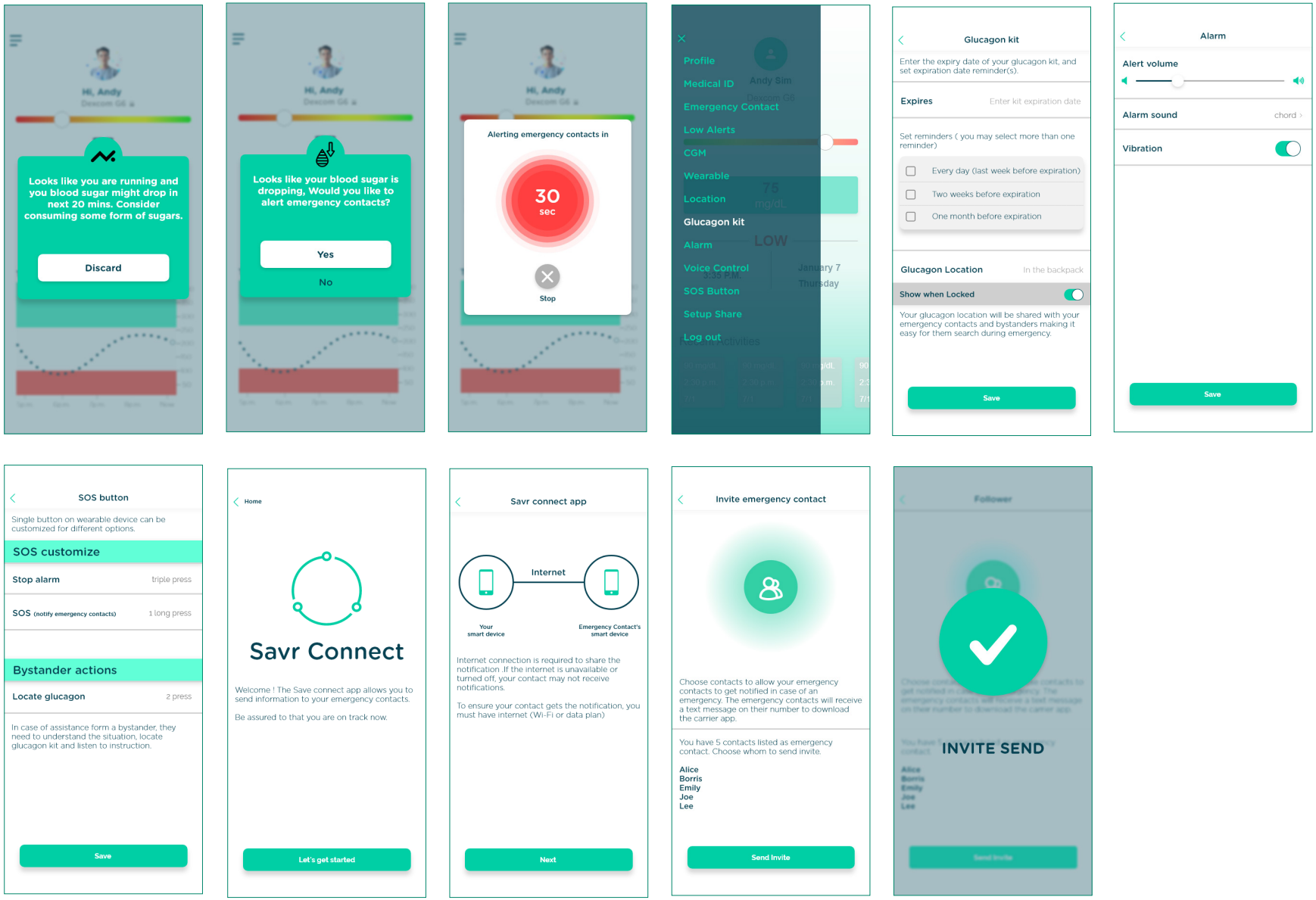


Figure 50: Main application screens(2/2)

Savr Connect Application

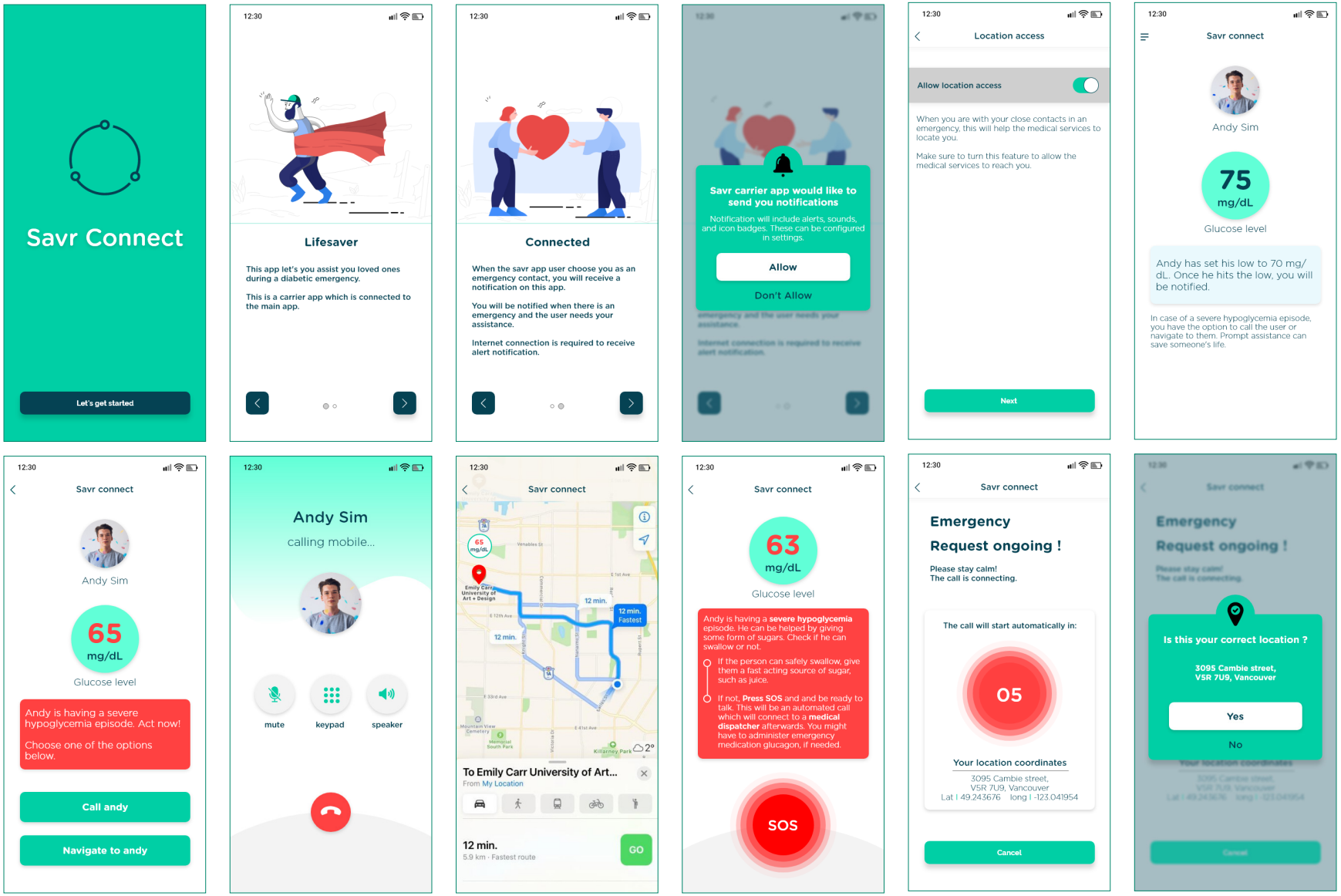


Figure 51: Savr connect application screens(1/2)

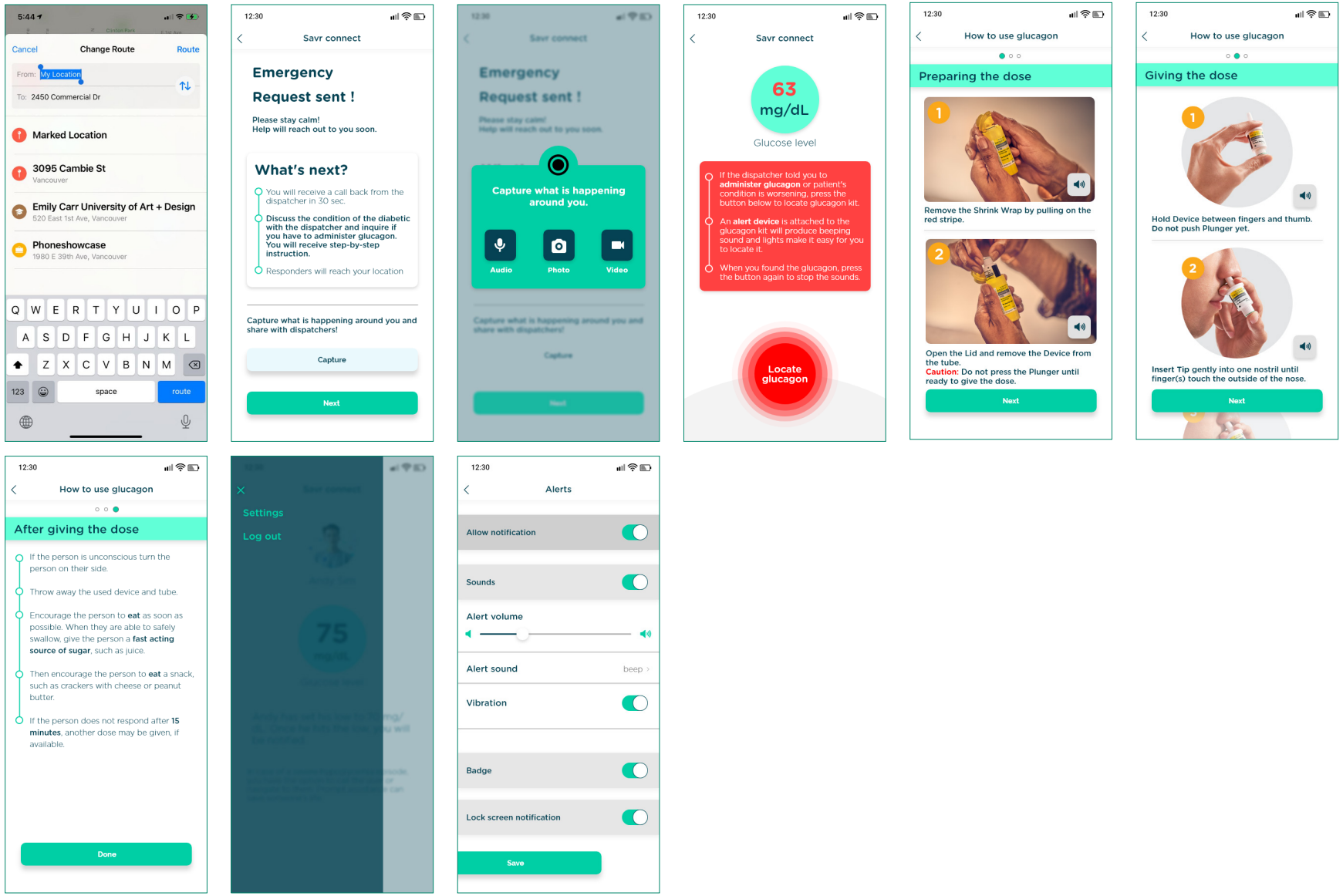


Figure 52: Savr connect application screens(2/2)