



# Well, it depends... Investigating the Needs and Expectations for Blood Glucose Predictions in People with Type 1 Diabetes

Master's Thesis

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# Abstract

Type 1 diabetes (T1D) is a chronic autoimmune disease that results in the body's inability to produce the insulin required to maintain healthy blood glucose levels. As T1D commonly develops during childhood, people with T1D require lifelong and intensive self-management to avoid life-threatening health complications. Self-management of T1D is a complex process that involves multiple interdependent factors, frequent anticipation of future blood glucose changes and complex decision-making processes. Recent advances in technology, such as continuous blood glucose monitors or hybrid closed-loop systems have facilitated this process. Nonetheless, self-management remains time-intensive and poses a high burden. Recent approaches use machine-learning-based algorithms to generate blood glucose predictions to facilitate the complex decision-making processes involved in self-management. However, there is a lack of research addressing the individualized and human-centered needs and expectations of people with T1D regarding blood glucose predictions. In the following thesis, we set out to capture and analyze the lived experience of people with T1D including their needs and expectations of apps supporting blood glucose predictions. To this end we designed and developed a prototype MOON-T1D supporting blood glucose predictions, on the basis of a systematic literature review. Subsequently, we conducted an Experience Sampling Method study coupled with semi-structured interviews with three individuals with T1D who used MOON-T1D over the course of five days. Finally, we used three case-studies and conducted a reflexive thematic analysis, which resulted in four distinct themes, to report on design opportunities and challenges of blood glucose predictions to effectively and individually support people with T1D.

# Zusammenfassung

Typ-1-Diabetes (T1D) ist eine chronische Autoimmunerkrankung, die dazu führt, dass der Körper nicht in der Lage ist, das zur Aufrechterhaltung eines gesunden Blutzuckerspiegels benötigte Insulin zu produzieren. Da T1D meist schon im Kindesalter auftritt, sind Menschen mit T1D ihr Leben lang auf intensives Selbstmanagement ihrer Krankheit angewiesen, um lebensbedrohliche Komplikationen für ihre Gesundheit zu vermeiden. Selbstmanagement im Zusammenhang mit T1D ist komplex und involviert unterschiedliche voneinander abhängige Faktoren, konsistentes Vorausdenken, und schwierige Entscheidungsprozesse. Neuste Fortschritte bezüglich Technologien für T1D, wie kontinuierliche Blutzuckermessgeräte oder Hybrid-Closed-Loop-Systeme, erleichtern das Selbstmanagement. Dennoch bleibt Selbstmanagement belastend und zeitaufwändig. Zur Unterstützung des Selbstmanagements von T1D gibt es Ansätze, die auf maschinellem Lernen basierte Algorithmen verwenden, um diese komplexen Entscheidungsprozesse zu erleichtern. Es mangelt jedoch noch an Forschung, die sich mit den individuellen und auf den Menschen fokussierten Bedürfnissen und Erwartungen von Personen mit T1D hinsichtlich Blutzuckervorhersagen auseinandersetzt. In der vorliegenden Arbeit wollen wir die gelebte Erfahrung, Bedürfnisse und Erwartungen die mit einer solchen App in Verbindung stehen erfassen und analysieren. Dazu haben wir zuerst, basierend auf einer systematischen Literaturrecherche, einen umfassenden Prototyp entwickelt, der unter anderem auch Blutzuckervorhersagen generiert. Als nächstes haben wir eine 5-tägige Experience Sampling Method-Studie und zwei Interviews mit drei Typ-1-DiabetikerInnen durchgeführt, um ihre individuellen Erfahrungen mit unserem Prototypen in ihrem Alltag zu erfassen. Zum Abschluss diskutieren wir mittels drei Falltudien und einer reflexiven thematischen Analyse mit vier Themen das Potenzial und die Herausforderungen bei der effektiven und individuellen Unterstützung von Menschen mit T1D beim Selbstmanagement ihrere Krankheit.

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## **Chapter 1**

# Introduction

Type 1 diabetes (T1D) is a chronic autoimmune disease where the insulin-producing cells in the pancreas, known as beta cells, are attacked and destroyed by the body's immune system [42]. Because insulin is a vital hormone that transfers glucose from the blood to the body's cells, people with T1D are dependent on exogenous insulin supplementation [160]. Type 2 diabetes (T2D), on the other hand, is characterized by an ineffective use of insulin in general, also known as insulin resistance or reduced insulin sensitivity [160]. Although T1D and T2D are often addressed within a general diabetes care approach that focuses primarily on the needs of T2D, recognizing and addressing their differences is crucial for effective disease management, especially for T1D. Be-cause the onset of T1D happens most frequently in childhood, it is also called adolescent diabetes. Combined with T1D's irreversibility, T1D self-management therefore poses a lifelong obligation for people living with it.

The goal of T1D self-management is to keep blood glucose values within a pre-defined target range. Failure to do so results in symptoms that can greatly reduce the quality of life of people with living with T1D. Too high blood glucose levels, also known as hyperglycemia, can cause symptoms such as noticeable lack of energy, muscle weakness, tiredness, nausea, stomach ache, poor concentration, confusion, impaired vision and drowsiness [99]. Too low blood glucose levels, also known as hypoglycemia, can cause symptoms such as tachycardia, headache, hunger attacks, restlessness, confusion and cold sweats [99]. Besides the decrease in quality of live, T1D can also have dangerous and potentially live-threatening short term effects, such as loss of consciousness or diabetes induced coma [38]. On the other hand, long-term health complications of poor blood glucose management include diabetic retinopathy, nephropathy, end-stage renal disease, cardiovascular disease and necrosis in lower extremities leading to amputation [159].

Effective T1D self-management is therefore crucial, but at the same time very complex. Blood glucose values are affected by a multitude of factors, such as nutritional contents of food, physical activity, insulin injection, stress and sleep, which can all have different effects and effect duration [110, 95]. More than 95% of the daily self-management is done by the patients themselves [54] and is deeply embedded in their daily lives, leaving them to deal with a multitude of self-care decisions across different situations [35, 55, 54, 25, 57, 41]. The frequency of daily decision-making and the complexity of self-management puts a significant burden on users [41]. This burden has been partly lifted by technologies such as continuous blood glucose monitoring (CGM), insulin pump therapy, carbohydrate and activity tracking or even more advanced systems that partially automate insulin delivery, which are known as hybrid closed-loop systems [20]. However, balancing the different factors involved in T1D self-management remains difficult. As a consequence, many individuals living with T1D are unable to adhere to the recommended clinical guidelines [103].

One approach to help individuals with their T1D self-management is to support decisionmaking with blood glucose predictions. Anticipating how daily decisions will affect blood glucose is a crucial component of self-management [41]. However, estimating future blood glucose values that are influenced by a multitude of interdependent factors poses a great challenge and high burden to people with T1D [44, 41, 56, 97] Through recent advances in predictive and personalized analysis of health data [165], the prediction of blood glucose values through machine learning presents new opportunities to reduce the burden of T1D management [167, 4, 142]. However, research addressing the needs of people with T1D for blood glucose predictions and how they would affect their practices and daily lives is sparse.

Furthermore, T1D self-management is a highly individual and personal process, for example due to individual's unique physical reactions to the same treatment but also due to individual's unique perception of and emotional connection with their condition. Facilitating self-management through predictions, as well as considering how these predictions are presented and visualized, is therefore not a straightforward task. Additionally, technologies designed for blood glucose predictions are often designed without a human in the loop [73].

In our previous study on the potential and practicality of blood glucose predictions we found that there is a need for an app that supports people with different needs regarding prediction horizon and interface design [15]. During the survey study, participants were presented with two different ranges of accuracy regarding a blood glucose prediction (+/- 0.5 mmol/L and +/- 2mmol/L). They were then asked if either of the ranges seemed useful to them and how much time they would be willing to invest to receive such a prediction [15]. Barth and Huang [15] found that users would want to see predictions independent of accuracy and that predictions could motivate carbohydrate recording of meals. The authors also discovered the need for blood glucose prediction technologies to integrate with existing devices of participants [15].

In the present thesis, we want to explore the needs and expectations tied to blood glucose predictions more deeply by assessing it from a qualitative user-centered perspective. We further hope to shed light on and account for the lived experience of people with T1D when using mobile apps that support blood glucose predictions. Through an investigation of the real-world experiences of individuals with T1D, we aim to identify challenges related to the adoption of technology that supports blood glucose predictions. Specifically, we seek to uncover challenges related to (1) the incorporation of such technology into daily routines, (2) the potentially fluctuating needs and expectations of individuals with T1D, and (3) emotional factors that may serve as either enablers or barriers to adoption. To do so, we formulated the following three research questions (RQ):

- $RQ_1$  How do the current management practices affect blood glucose predictions?
- $RQ_2$  What is the lived experience of people with T1D using an all-encompassing blood glucose prediction *app*?

#### $RQ_3$ What factors and everyday aspects shape people's needs and expectations of blood glucose predictions?

To answer our research questions, we designed, developed and deployed a prototype of a mobile app called MOON-T1D. MOON-T1D provides users with blood glucose predictions and the ability to view and enter blood glucose values, physical activity, insulin administration, and food intake. To understand participants lived experience, their practices as well as their needs and expectations in relation to blood glucose predictions, we conducted a qualitative user study. The user study consisted of two semi-structured interview sessions and an Experience Sampling Method (ESM) study with the deployed version of MOON-T1D. We analyzed the data obtained through the interview and the ESM-study using an elicitation of three cases studies of our three participants, as well as a reflexive thematic analysis [30].

The contributions of this thesis are:

• A systematic literature review of apps providing blood glucose predictions for people with T1D.

- A visual analytics tool MOON-T1D, that allows users to enter and view data regarding blood glucose, food intake, insulin injection and physical activity. MOON-T1D provides users with a comprehensive semi-random prediction of their blood glucose values one hour into the future.
- Three case-studies reflecting on our three research questions and providing valuable insights into the lived experience of people with T1D using a mobile app that shows blood glucose predictions.
- A reflexive thematic analysis of participants' responses to interview questions and an ESMstudy. Subsequently, the presentation of four themes deduced from this reflexive thematic analysis. Namely, (1) *control and empowerment*, (2) ways of *sense-making and understanding*, (3) *emotions and experiences* and (4) *engagement and support*.
- Implications for the design of technologies to address individual practices as well as related needs and expectations of users with T1D.

The thesis is structured as follows: In Chapter 2, we provide a background on T1D selfmanagement and related work of existing technologies approaches and visualizations. In Chapter 3, we introduce our prototype MOON-T1D, including its design, the algorithm used and visual interfaces. In Chapter 4, we discuss our methodological approach. In Chapter 5, we present and reflect on the results of the qualitative user study in the form of case studies and a reflexive thematic analysis. In Chapter 6 and 7, we discuss design implications and reflect critically on our work. We also suggest ways to further advance our research goals and objectives. We end this thesis with Chapter 8 by drawing an overall conclusion.

## **Chapter 2**

# **Related Work**

In this master's thesis, we will develop and evaluate an app for type 1 diabetes (T1D) selfmanagement, with a particular focus on blood glucose predictions. We will begin with breaking down the related work into the following five parts: First, some general information on T1D, including its distinction from the better known type 2 diabetes (T2D), and T1D self-management. Second, an overview of factors that affect blood glucose. Third, an overview of existing technologies for T1D self-management. Due to the limited amount of existing technologies providing interface descriptions we conducted a systematic literature review and app store search. Fourth, machine learning-supported blood glucose predictions. And lastly, an overview of designs and visualizations frequently used in apps for T1D self-management.

### 2.1 Background on Type 1 Diabetes

In this section, we will first discuss the differences between type 1 diabetes (T1D) and type 2 diabetes (T2D). We will then continue with diabetes self-management practices as formalized by the American Association of Diabetes Educators (AADE) in their seven stage framework.

#### **2.1.1** Type 1 Diabetes $\neq$ Type 2 Diabetes

Diabetes mellitus is a chronic disease characterized by a lack or ineffective use of insulin. Insulin is a hormone that stimulates body cells to absorb glucose from the blood, thereby regulating blood glucose levels. Elevated blood glucose due to a lack of insulin can have severe repercussions on the body's functioning, particularly on the nerves and blood vessels, with the potential to cause significant harm and life-threatening acute conditions [160]. Diabetes is one of the leading causes of death worldwide, with 6.7 million people having died in 2021 alone due to diabetes-related causes [74]. When talking about diabetes, it is crucial to consequently distinguish between T1D and T2D.

T2D arises from the body's resistance to insulin, often triggered by consistent over-consumption of calories or lack of physical activity. T2D typically arises in adulthood. However, it is preventable or can be delayed by adopting healthy lifestyle habits, such as maintaining a balanced diet and engaging in regular physical activity. This form of diabetes is more prevalent than T1D, and accounts for 95% of all diabetes cases worldwide [160].

*T1D* is an autoimmune disease, where the immune system creates antibodies that destroy the pancreatic beta cells responsible for the body's insulin production. If pancreatic beta cells are destroyed, the body becomes unable to transfer glucose from its blood to its cells. As a consequence, glucose can no longer be used as a source of energy for any metabolic processes of the cells [42].

T1D typically first occurs in childhood or adolescence, which is why its also referred to as adolescent diabetes. While people with T2D may not need exogenous insulin, T1D requires insulin administration and close blood glucose control [160]. Even tough T1D is less common than T2D 8.75 million people are affected worldwide [111].

#### 2.1.2 Self-Management – The AADE7 Model

Self-management and self-management education are crucial elements for patients to successfully manage their diabetes. In the case of T1D, self-management revolves around the goal to keep blood glucose levels within a predefined *target range*. This target range is typically between 4.4 – 10.0 mmol/L, but can vary across individuals [7]. While the body of a healthy person produces insulin continuously to keep blood glucose levels stable while in a fasting state, it also increases insulin production after food consumption as a reaction to the spiking blood glucose levels. People with T1D must continuously manage these two tasks themselves in an effort to emulate how the body responds to changes in blood glucose levels.

Self-management of T1D is a process that is not only influenced by many interdependent factors but also needs to be embedded in the daily lives of those affected. Self-management of T1D is therefore highly individualized. For example, a person that has a very active lifestyle will have very different T1D management needs than a person with a mostly sedative lifestyle.

In an effort to meet these demands, the American Association of Diabetes Educators outlines a seven stage framework for self-management of diabetes under the *AADE7 Self-Care Behaviors*[5]. The AADE7 framework is based on a holistic and person-centered approach, comprised of the following seven behaviors:

**Healthy coping** addresses the psychological factors that influence the ability of a person to cope with their disease. One example of a psychological factor is the positive attitude required to cope with the burden of diabetes and the constant demands of self-management in a healthy manner. This positive outlook should extend to diabetes itself, self-management, relationships with others and overall quality of life. It is therefore a prerequisite to achieve and develop the other 6 behaviors [5].

**Healthy eating** refers to the adoption of beneficial eating habits [5]. Food amount, food type and their respective effects on blood glucose play a central role in diabetes management. Needing to constantly control food intake and having to eat at times that are not directed by hunger increases the risk of sub-clinical and clinical eating disorders. Consequently, adopting healthy eating habits to reduce this risk is paramount for people with T1D [59].

Taking medication is essential, especially for T1D management. Some challenges for taking medications appropriately among people with T1D are fear of needles, social stigma, fear of hypoglycemia, lack of knowledge and monetary costs [102, 136]. Additionally, psychological factors such diabetic distress, feeling overwhelmed or even depressive symptoms can lead to diabetes denial resulting in medication non-adherence [115]. Pallayova and Taheri [115] proposed recommendations for people with T1D, focusing on diabetic distress. Recommendations included the development of a strong relationship between patient and clinicians, or providing education. Ultimately, medication non-adherence can lead to serious consequences for patients' health and social life. To prevent this, Pallayova and Taheri [115] suggested that negative emotions and the challenging aspects of T1D, which frequently impact people with T1D and their loved ones, should be explained and understood early on [115].

**Monitoring** of T1D involves more than just checking blood glucose levels. It encompasses monitoring of medication such as insulin, nutritional intake (with a focus on carbohydrates), activity, sleep, psychological factors like stress, and various other self-care constructs [5]. Although some people with T1D still use paper and pencil to monitor their blood glucose, technological advances now allow for continuous blood glucose monitoring using sensor technology. The avail-

ability of continuous blood glucose monitoring sensors such as FreeStyle Libre (Abbott Diabetes Care, Alameda, CA, USA), Dexcom (Dexcom, San Diego, CA, USA), and Medtronic Guardian (Medtronic, Northridge, CA, USA) has revolutionized patients' monitoring possibilities. It enables patients to monitor their glucose levels in real-time, allowing them to make decisions regarding medication or activity based on trends rather than relying on single momentary values obtained through finger pricks [5].

**Reducing risk** refers to behaviors that minimize or prevent diabetes related short and long term complications. Short term complications associated with hypoglycemia arise primarily from decreased attention or mental flexibility that can lead to dangerous situation, for example when driving a car [46]. However, acute hypoglycemia can also result in a life-threatening situation when going unnoticed or unattended, for example when being asleep or when having fallen unconscious due to a hypoglycemic state. Short term complications associated with hyperglycemia (i.e., blood glucose levels are too high) are primarily related to ketoacidosis, an acute imbalance in the body's pH- and electrolyte-levels that can quickly become life-threatening when not attended to. Long term complications of hypoglycemia are primarily in the form of cognitive impairments resulting from long-lasting or repeated hypoglycemic states [129, 130, 29]. Long term complications of hyperglycemia include retinopathy (damage to the eyes), neuropathy (damage to the nerves), nephropathy (damage to the kidneys), and cardiovascular problems [39].

**Problem-solving** is another very important behavior for people with T1D in order to properly self-manage their disease. The constant control over blood glucose levels, trying to reach immediate goals such as lowering or elevating blood glucose, as well as other, less specific diabetes related behaviors require constant decision-making and a series of mental processes. These processes and decisions can be facilitated by problem-solving interventions [132]. For example, Hill-Briggs and Gemmell [67] have highlighted the importance of problem-solving by showing its association with better HbA1c (a biomarker for long-term glycemic control) levels, improved self-efficacy, and better self-monitoring.

Overall, the AADE7 framework provides a good overview of the complexities and challenges of successful T1D self-management, as well as potential starting points for solutions to facilitate T1D self-management. For the scope of this master's thesis, we will primarily focus on *Monitoring* and *Problem-solving*, although the other stages of self-management will also be taken into account for design and development choices.

#### 2.1.3 Influences on Blood Glucose

Effectively monitoring and managing blood glucose levels is arguably the most fundamental part of T1D self-management. In the following section, we will briefly explore some of the most relevant factors that influence blood glucose levels of people with T1D. Generally, factors that influence blood glucose levels can be either elevating (i.e. increase blood glucose) or lowering (i.e. decrease blood glucose).

Factors that elevate blood glucose levels include:

• Food consumption results in an increase in blood glucose levels due to the calorific value (i.e. the energy contained in food) of carbohydrates, fats, and proteins. How strongly blood glucose levels are affected by the same amount of food (e.g. 1g of carbohydrates) is different from person to person. While the amount of carbohydrates consumed per meal has the strongest impact on blood glucose levels, other factors such as the amount of proteins and fats also have a major effect on the postprandial (i.e. after-meal) blood glucose profile [116]. For example, Paterson et al. [116] showed that the addition of fats to a meal decreases the early (first 1-3h) postprandial glycemic response but can induce hyperglycemia in the late postprandial period.

- **Stress** typically causes an increase in blood glucose levels. While studies found that stress hormones induce a consistent hyperglycemic response, the response to psychological stressors can differ individually [144, 143].
- **Illness** is usually associated with an enhanced release of counter regulatory hormones (e.g. epinephrine/norepinephrine, glucagon, cortisol, and growth hormone) that increase glucose production in the liver. Additionally, illness can induce a state of insulin resistance due to a decrease in peripheral glucose usage [86]. This results in frequent hyperglycemia and difficulty to control blood glucose levels during illnesses.
- **Pain**. Acute severe pain can decrease insulin sensitivity due to an increase of the s-cortisol value, the serum growth hormone value and the Plasma epinephrine concentrations, which results in an overall increase in blood glucose levels [62].
- **Dehydration** can increase blood glucose levels because the amount of water in the bloodstream is lower, increasing the concentration (or relative amount) of glucose in the blood. [157]

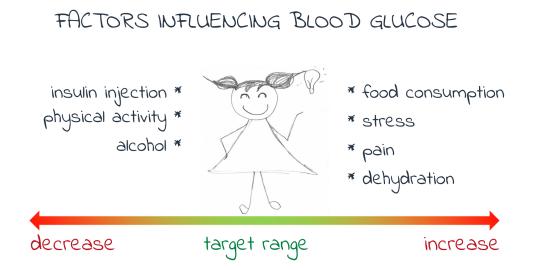
Factors that lower blood glucose levels include:

- **Insulin injections** lower blood glucose levels by transporting glucose from the blood into the cells, where it can be used as energy [107]. Insulin sensitivity (i.e. how much one unit of insulin will lower blood glucose levels) is individually different and can change depending on various factors such as the time of day [34], activity levels [66], and hormones [162]. Insulin absorption time (i.e. how fast the injected insulin enters the bloodstream) is also individually different and depends on factors such as insulin type, injection volume and injection location [60]. Notably, while insulin primarily lowers blood glucose levels, a lack of insulin causes a raise in blood glucose levels of people with T1D.
- **Physical activity** lowers blood glucose levels by an insulin-independent increase in the absorption of blood glucose and by increasing insulin sensitivity. How much blood glucose levels are lowered and the speed of the effect depends on the type and duration of the exercise performed. The long term blood glucose lowering effect can last for up to 24 hours, again depending on the exercise. Importantly, blood glucose levels typically first rise shortly after exercising due to the stress and adrenaline produced by the body [6].
- Alcohol inhibits the supply of glucose provided by the liver while alcohol is being metabolized, thereby lowering blood glucose levels.

An overview of the different factors that can affect blood glucose levels in people with T1D is depicted in Figure 2.1. To sum up, people with T1D need to constantly consider and monitor a multitude of factors and their potential interactions in order to try to keep their blood glucose levels well-balanced.

## 2.2 Technologies for Diabetes

Technological advances in glucose monitoring and management systems have enhanced blood glucose control and greatly facilitated T1D self-management. New technologies support or even automate some of the behavioral factors from the AADE7 framework associated with diabetes self-management. Additionally, new technologies also greatly reduce the complexity of managing the different factors that affect blood glucose levels. In the following section, we will discuss recent technologies that support tracking of blood glucose levels, insulin administration, carbohydrate intake and physical activity. We conclude this section with systems that combine and automate blood glucose tracking with insulin delivery, which are known as closed-loop systems.



**Figure 2.1:** Illustration of the various factors that impact an individual's blood glucose levels. (left) Factors that decrease blood glucose levels are depicted, including insulin injection, physical activity, and alcohol consumption. (right) Factors that increase blood glucose levels, such as food consumption, stress, pain, and dehydration, are shown. Keeping a balance between increasing and decreasing factors is necessary to maintain for people with T1D in order for the blood glucose to stay within the target range (middle).

#### 2.2.1 Blood Glucose Tracking

Currently used blood glucose monitoring devices can be divided into two categories, (1) blood glucose meters and (2) continuous glucose monitors.

**Blood glucose meters (BGM)** require the extraction of blood from the patient, mostly done by a finger prick. BGM devices are typically small, show the blood glucose concentration a few seconds after app, and require only a fraction of a microliter of blood [20]. BGM are quite accurate, with the mean difference in relation to a reference measurement device (i.e. the mean absolute relative difference; MARD) between 5 to 10% [135, 145].

**Continuous glucose monitoring (CGM)** systems require the patient to wear an intradermal disposable sensor measuring the glucose concentration in the interstitial fluid(i.e. the fluid surrounding the cells). Measurements are taken at intervals of one to five minutes, or as requested by the patient. The values are then stored within the sensor and usually transmitted to a smartphone, smartwatch or the cloud. As the sensors used in CGM systems can not directly measure the patient's blood glucose levels, they are estimated through the measurements obtained from interstitial fluid [20]. Consequently, there may be a delay with respect to the actual blood glucose value of about four minutes on average, potentially longer if blood glucose levels are fluctuating rapidly [134]. Recent randomized trials in adults with T1D that need multiple daily injections have shown that the use of a CGM has a positive effect on HbA1c and reduction of hypoglycemia [19, 91]. Comparable positive effects were found for the use of a CGM in adults with T1D who use insulin-pumps instead of injections [63].

Real-time CGM sensors include Dexcom G6 (Dexcom, San Diego, CA, USA), Medtronic Guardian Sensor 3 (Medtronic, Northridge, CA, USA), and the Senseonics Eversense system (Senseonics, Germantown, MD, USA). Previously referred to as flash glucose monitoring systems, the Abbot FreeStyle Libre (Abbott Diabetes Care, Alameda, CA, USA) allows for measurements to be viewed only upon scanning the sensor. From version 2 on, the FreeStyle Libre sensor also includes hypoand hyperglycemic alarms. However, they have not yet been evaluated for people with frequent severe hypoglycemia or impaired hypoglycemia awareness [20]. While the Dexcom G6 and the FreeStyle Libre are factory calibrated, the Medtronic Guardian Sensor 3 and Senseonics Eversense require at least two calibrations with a blood glucose monitor per day [20]. Measurements obtained through CGM sensors are typically visualized in interfaces including the ten metrics for clinical care [20], which are described in more detail in Appendix B.1.

#### 2.2.2 Insulin Delivery Tracking

Insulin can be delivered to patients using either an insulin injection or through a continuous subcutaneous insulin infusion, also called insulin-pump or insulin-pump therapy.

**Insulin injections** can be done either manually by drawing insulin from a vial for each injection, or by using an insulin pen that is either pre-filled and disposable or fillable and reusable [20]. Because the body's normal insulin secretion involves continuous low-level basal insulin secretion as well as increased postprandial bolus insulin secretion, insulin injections must somehow mimic this behavior without requiring patients to inject continuously. For this reason, patients use a longer-acting basal insulin that covers the time between meals and a short-acting bolus insulin taken around meals to account for the additional carbohydrate intake [68]. Newer insulin pens also offer wireless connections to mobile apps to record insulin dose, injection time and bolus calculations [20].

**Insulin pumps** are available either as patch pumps or as tethered pumps. Patch pumps deliver insulin from a pod directly attached to the patient's skin. Tethered pumps, on the other hand, are typically placed somewhere in or on the patients clothing but require a tube that connects the infusion site with the pump. Being continuously connected to the body of the patient, insulin pumps of any kind only need one type of insulin. Basal insulin secretion is adopted by the pump through automated continuous delivery of small insulin doses. Mealtime bolus insulin secretion, however, has to be initiated manually by the person wearing the pump.

Insulin pumps allow patients to program different basal rates of insulin infusion during the day, as well as different patterns of delivering bolus insulin (e.g. all at once or in multiple smaller doses). The ability to deliver bolus insulin not all at once can be important because carbohydrate absorption rates, for example, vary greatly between fatty and non-fatty foods. Insulin pumps sometimes include bolus calculators that are usually integrated in the pump or an external hand-set. However, whether people with T1D take up an insulin pump instead of injections varies widely between and within countries [20]. While some studies found the use of an insulin pump to improve HbA1c and lower the risk of hypoglycemia [123], other studies caution that pump malfunctions and problems with infusions sets are frequent [64, 117]. Out of 33 recorded malfunctions per 100 pump-years, 19% were severe pump malfunctions, such as complete pump breakdown [64, 117]. Additionally, it has been found that multiple daily injections are on average 1.4 times cheaper than pump therapy, which is particularly relevant for pump uptake in low and middle income countries [127]. Another widely recognized weakness of pump therapy are the infusion sets. They can be the cause of insulin aggregation, inflammation, infections at the infusion site, and kinking of the tubing[20].

#### 2.2.3 Automated Insulin Delivery Systems

Automated insulin delivery systems, also known as closed-loop systems or artificial pancreases integrate blood glucose tracking with automated insulin delivery by using three main components: a CGM sensor, an insulin pump, and an underlying algorithm. Similar to conventional insulin-pump therapy, automated insulin delivery systems mimic the continuous secretion of insulin at low levels by providing small, continuous doses of basal insulin. However, unlike conventional insulin-pump therapy, automated systems use an algorithm to regulate the amount of insulin administered and interrupt insulin delivery if a low glucose threshold is reached. The algorithm utilizes data from the CGM device and previous insulin deliveries to regulate current insulin delivery [20]. The first system to automate insulin delivery as a function of glucose concentration or predicted glucose concentration was the Medtronic 670G (Medtronic Diabetes, Northridge, CA, USA). While current automated insulin delivery systems emulate the body's basal insulin secretion, bolus insulin secretion is not automated due to the delayed effect of insulin on blood glucose. Because users of automated insulin delivery systems are also referred to as hybrid closed-loop system [20].

In a three-month randomized controlled trial, an algorithm for automated insulin delivery systems developed by the University of Cambridge (Cambridge, UK) has shown to significantly reduce hyperglycemia, hypoglycemia and HbA1c concentration compared to a control group that used sensor-augmented pump therapy [148]. However, a major limitation of automated insulin delivery systems is the slow onset and long-lasting effect of insulin. While an algorithm could detect that a meal has been eaten, the response of insulin secretion would be too slow to prevent postprandial hyperglycemia. If insulin is delivered preemptively in order for it to be used faster and prevent blood glucose rise, the continued and long-lasting effect of the insulin results in hypoglycemia later. While hybrid systems address this problem by requiring users to input their carbohydrate intake, a fully automated system would only be possible with the use of faster-acting insulin or an alternative insulin delivery method [20].

#### 2.2.4 Carbohydrate Tracking

Although numerous factors affect glycemic control, carbohydrate intake has the most significant impact on blood glucose levels, particularly with regard to postprandial blood glucose [47]. Hence, tracking and managing of carbohydrate intake plays a central role in successful T1D selfmanagement. The National Institute for Health and Care Excellence (NICE) guidelines for T1D in adults recommend the use of strategies like carbohydrate counting to determine the amount of insulin needed for a given meal [108]. While weighting food and calculating the amount of carbohydrates in relation to the total amount remains the most accurate method, it is not always feasible (e.g. in a restaurant) [44].

Technologies can greatly facilitate the tracking of nutritional information, such as the amount of carbohydrates, by providing access to nutrition databases that offer detailed information for a wide variety of products. One popular example of such a technology is the MyFitnessPal app [149], which allows users to either scan the barcode of a product or search for a product manually in a large database. Newer approaches such as DietSensor use 3D measurement systems to estimate nutritional content of a meal, which allows users to obtain nutritional information by taking a picture of their food [93]. However, both approaches are subject to inaccuracies when estimating the nutritional content of a meal, with an average absolute error of 33% for DietSensor and 51% for MyFitnessPal [93].

At this point, it is important to highlight another problem associated with carbohydrate tracking. Namely, apps associated with weight loss through tracking nutritional intake have been shown to contribute to and exacerbate eating disorder behaviors [49]. In addition, Gonzalvo et al. [59] recently reported that people with T1D have already a heightened risk of developing an eating disorder. Using nutrition tracking apps, as they exist today, may therefore further increase the already heightened risk of developing an eating disorder for people with T1D.

To track carbohydrates in everyday life, people with T1D regularly guess their carbohydrate intake to reduce the burden of recording nutrition intake at every meal. However, Brazeau et al. [31] found that even people who have lived with T1D for many years have a mean error of about

	Activity	Synchronisation	BG	Integration CHO	insulin
T1Exercise [146]	Guidance on how exercise affects blood glucose levels. Provides suggestions regarding bolus, food intake and start glucose level, according to planned exercise.	-	manual	-	-
Diabits [82]	Tracking of heart rate	Fitbit Apple Watch	CGM	-	automatic
Glucose Buddy [10]	Automatic tracking of steps, walks and cardio activities	Apple Health	CGM	food database	manual
One Drop [72]	Tracking of activity related data from different devices and support for manual entry	Apple Health Kit Apple Watch Fitbit	CGM finger prick	food database	pump data
bant [152]	Capture step counts from other apps	Apple Health	finger prick	from other app	-
MySugr [105]	Fitness and activity tracking from other apps	Apple Health Google Fit	finger prick	manual	pump data
GlucoseZone [58]	Guidance and videos for exercise and exercise related goals. Helps manage pre- and post-exercise glucose levels	Apple watch Apple Health Kit	-	-	-

**Table 2.1:** A selected number of activity tracking apps for individuals with diabetes and their functionalities. Functionalities, besides activity tracking include food databases, CGM connections, inclusion of pump data as well as synchronisation with smart watches.

20% when guessing the actual carbohydrate content of their meal. The ability or experience of guessing carbohydrate content precisely has been found to be associated with effective blood glucose control. Namely, Bishop et al. [23] found that individuals who made the most accurate carbohydrate estimates had lower total HbA1c levels.

#### 2.2.5 Activity Tracking

While physical activity shows mixed results for the improvement of glucose control in people with T1D, it has been linked to decreased risk of cardiovascular disease, reduced need for insulin and increased psychological well-being [36]. Despite these positive effects, people with T1D participate less frequently in physical activity than people without T1D. Lower participation in exercising among people with T1D has been attributed to fear of exercise-related hypoglycemia and the difficulty of controlling blood glucose levels before, during and after exercise [32]. Short and high intensity exercise is often associated with an increase in blood glucose levels, whereas long and low intensity exercise tends to lead to a decrease in blood glucose levels [151].

Managing blood glucose levels during exercise is a complex task, as various factors can impact blood glucose behavior during physical activity [37]. For example, high-intensity activities usually cause hyperglycemia, while longer duration of exercise can cause hypoglycemia. However, the effect of these factors differs individually [37]. Tracking physical activity and considering its impact on blood glucose levels is therefore crucial for people with T1D to avoid severe negative consequences. However, Kime et al. [79] found that adults with T1D base most of their decision-making and physical activity on personal trial and error, rather than input from the medical community or apps [79]. Recent advances in technologies for activity tracking provide personalized solutions that can be integrated with CGM devices. A selection of activity tracking apps for individuals with diabetes is provided in Table 2.1.

#### 2.2.6 Summary

Technological advances have changed the possibilities and opportunities for people with T1D to successfully self-manage their condition. Recent technologies overall simplify and improve T1D self-management, even to a point of emulating certain aspects of bodily functions, such as basal insulin secretion by automated insulin delivery system. However, despite significant advancements in T1D self-management through technologies such as CGM systems, insulin pumps, or apps for tracking carbohydrates and physical activity, it is important to highlight that these systems come with notable drawbacks. One such drawback is, for example, the amount of time

required to input the necessary information, which many systems do not consider and that may create an additional burden on the daily lives of people with T1D.

### 2.3 Blood Glucose Prediction

In recent years, machine learning algorithms that predict blood glucose levels by using CGM and varying types of user data have received considerable attention in research [167, 4, 142]. In the following section, we will outline the benefits of blood glucose predictions for people with T1D, the accuracy achieved for different prediction horizons, the trust required in these predictions and, lastly, we will present currently available apps that support blood glucose predictions.

#### 2.3.1 Benefits of Blood Glucose Predictions

Anticipating the impact of medication, food, exercise and other factors is part of the daily routine of people with T1D. For example, people with T1D must constantly consider the effect of meals and snacks on their blood glucose levels and determine the necessary amount of insulin to prevent hyper or hypoglycemia when consuming food. However, as previously mentioned, blood glucose levels can be influenced not only by food consumption but also by other factors, such as stress or physical activity [110, 95]. Anticipating the complex and interactive effect of multiple factors on blood glucose levels can be challenging for people with T1D due to the numerous variables involved. Research has shown that only about 30% of young adults with T1D are able to consistently maintain their blood glucose levels within the target range, which highlights the difficulty of managing the condition [20, 133]. Using machine learning-based methods to support the prediction of blood glucose trajectories can greatly benefit individuals with T1D. By warning patients in advance, they are able to take preemptive actions to prevent onset of hyper- or hypoglycemia, rather than reacting to poor glucose values after they already occurred. Such a proactive approach could greatly improve people's overall management of T1D and reduce their risk of long-term complications. Additionally, accurate and reliable blood glucose predictions may be integrated into hybrid closed loop system, allowing for preventative changes of the basal insulin secretion [20].

Battelino et al. [17] reported that using predictions of low blood glucose to initiate insulin secretion in continuous subcutaneous insulin infusion (CSII) systems can significantly decrease the number of hypoglycemic events. Additionally, the use of blood glucose predictions may compensate for the inaccuracies and time delays associated with continuous glucose monitoring systems, particularly during periods of rapid blood glucose fluctuations [134].

#### 2.3.2 Accuracy of Blood Glucose Predictions

The increasing use of wearable technologies, sensors, mobile health apps and point-of-care devices yields a substantial amount of data, which, in turn, has boosted discussions about the use of machine learning-based algorithms in the literature [158]. In recent years, deep learning has become state of the art method for glucose predictions. For example, in August 2020 Rubin-Falcone et al. [128] won the second Blood Glucose Level Prediction challenge with a deep learning model that reduced prediction error (RMSE) to 1.01 mmol/L for predictions reaching 30 minutes into the future [128]. A more recent publication by Zhu et al. [168] achieved an RMSE of 1.96 +/- 0.32 mmol/L 60 minutes into the future. However, comparing the accuracy of blood glucose predictions remains challenging due to factors such as different evaluation metrics, diverse datasets, and the use of non-public datasets [82].

Keywords	"blood glucose prediction" OR "blood glucose" AND prediction AND diabetes
Publication Year	AND app OR application OR smartphone OR platform OR mobile OR handy >2018
Included Journal & Conferences	Related to Mhelath, Diabetes, AI, Medecine, Computer Science, HCI, etc. Full list of included sources can be found in the supplementals Table C.1
Exclusion Criteria	interfaces neither sufficiently described nor shown (2) description of the same app (1) prediction of BG levels but no app with human input (14) non-invasive blood glucose estimations (3) focus on other technologies (4) predicts something else than BG level /app is the means to another end in the paper (28) reviews (4)

Table 2.2: Search query and number of papers excluded by the listed exclusion criteria

#### 2.3.3 Trust in Blood Glucose Predictions

In order for individuals with T1D to utilize and benefit from predictions, they must have trust in the reliability of the predictions. Stawarz et al. [139] found that people with T1D felt confident in knowing their blood glucose levels in everyday situations, which led to them rejecting machine learning-based decision support when dealing with such everyday situations. The authors conclude that machine learning support would be more valuable for people with T1D when facing unexpected situations. Similarly, van Bon et al. [155] evaluated the potential acceptance of an artificial pancreas in the future by using a Technology Acceptance Model-Centered survey. Despite the fact that all of the respondents used an insulin pump, only 38-41% expressed confidence in the accuracy of insulin dosage administration and the reliability of the blood glucose meter when using an artificial pancreas [155]. In addition, Barnard et al. [13] revealed that perceived burden and distrust in the technology could potentially impede the success of artificial pancreases. The research also discovered a correlation between the level of trust in an artificial pancreas and the quality of glucose control it could deliver [154]. Trust in CGM information, on the other hand, was linked to the perceived usefulness of the system [84]. Hence, trust in blood glucose predictions and the underlying methods (i.e. machine learning or artificial intelligence) plays an important role when it comes to the acceptance and usability of such predictions.

#### 2.3.4 Apps Supporting Blood Glucose Predictions

Although apps supporting blood glucose predictions do exist, only few of them have been thoroughly studied and discussed in literature. Therefore, we undertook a systematic literature review and performed app store searches, the results of which will be presented in this section. At this point, it is important to distinguish between blood glucose predictions that are used for closed loop system and those that are used for people using daily injections. The latter serves and encourages people with T1D to modify their behavior regarding insulin administration, food intake, and physical activity in order to maintain optimal blood glucose levels. In this thesis, we will focus on the predictions that should impact and encourage changes in peoples' behaviors.

To identify the relevant literature and apps for blood glucose predictions, we first conducted a systematic literature review utilizing the SCOPUS database. We used the search query outlined in Table 2.2, which resulted in the retrieval of 62 relevant documents. Subsequently, 46 were excluded based on the exclusion criteria listed in Table 2.2

In addition to the systematic literature review, we also evaluated 60 apps from the Google Play

and Apple Store, which were found using similar keywords as presented in Table 2.2. Detailed results regarding included and excluded apps can be found in Appendix: C.2 Only 5 of the 60 apps supported blood glucose predictions, of which one overlapped with the papers found in the SCOPUS database. Overall, 10 apps supported blood glucose level predictions, 4 of which were found through the app stores and 6 through the literature review. A table of all assessed apps (Appendix: C.2) and their functionalities (Appendix: D.1) can be found in the Appendix.

**Example Apps** One example app is Diabits, which was introduced and evaluated by Kriventsov et al. [82]. Diabits is a mobile app that creates personalized patient models to predict blood glucose fluctuations up to 60 minutes into the future The main interfaces of the Diabits app are depicted in Figure 2.2. Blood glucose level predictions are presented in the form of an integer number and a dotted line chart, without any information about uncertainty. Their prediction model relies mostly on data from a CGM device. Although insulin and nutritional information are incorporated into the prediction models, they only play a minor role for the actual prediction. This is because users typically do not provide sufficiently detailed information about their insulin and food intake [82].



**Figure 2.2**: The main interfaces of Diabits [82]. (left) The current blood glucose level of 77 mg/dL  $\approx$  4.3 mmol/L is presented as a numerical value and a line chart visualization. Additionally, the system provides a prediction for the blood glucose level one hour into the future. (middle) List-like history visualization of carbohydrates consumed and insulin administration. (right) Visualization showing the Glycemic Management Indicator of 6.6%, time in range, average blood glucose of the past 3 hours, and an area chart depicting the probability of a hyperglycemia or hypoglycemia occurring within the next eight hours. There are also insights about the current blood glucose behavior in text form. (Source: [82])

Another example is ARISES, which was introduced and evaluated by Zhu et al. [168]. ARISES uses CGM data, daily entries of meals and insulin as well as a sensor wristband that capture physiological measures, to predict blood glucose levels as well as the risk of hypo- and hyper-glycemia. Zhu et al. [168] focused on showing the effect of physiological measurements on blood glucose level predictions neglecting design and user-experience aspects of their app. The authors reported a significant association between physiological measurements and hypo- and hyperglycemic events one hour later, i.e. high inter-beat intervals lowered odds of hypoglycemia occurrence.

**Summary** Out of the ten apps, half of them (5/10) supported a prediction horizon of 60 minutes, followed by 4 hours (2/10). Other prediction horizons like 2 and 3 hours were only supported by single apps. The goals of the various apps encompassed both very general and very specific goals. More general goals were, for example, empowerment for better decision making and predicting blood glucose values. More specific goals were, for example, assessment of changes in blood glucose levels after physical activity, decision support at mealtimes and testing of hypothetical prediction scenarios. The factors that were used for predicting blood glucose levels were manifold. All apps (10/10) included current blood glucose levels to generate their prediction. Most apps (7/10) included carbohydrate intake in their prediction algorithm. About half of the apps included physical activity (6/10) or insulin administration (5/10). Factors such as stress, sleep and alcohol consumption were least commonly considered for blood glucose predictions. On average, each app supported only slightly more than just one type of CGM sensor (mean = 1.1sensors), indicating an overall very low level of support for various CGM sensors. Half the apps (5/10) supported synchronisation with finger prick glucose meters and about one-third (3/10)supported manual entry of blood glucose values. Regarding insulin administration, only one app was connected to an insulin pen or pump, while the rest required users to enter insulin administration manually. Carbohydrate intake entries were mostly manual (5/10) with some apps supporting semi-automated carbohydrate entries such as a food database search (1/10) or automatic food recognition and portion estimators (1/10). About two-thirds of the apps (6/10) are commercially available.

#### 2.3.5 DIY Blood Glucose Predictions

When discussing apps for blood glucose predictions for people with T1D, it is important to also consider the do-it-yourself (DIY) systems. DIY systems are part of DIY diabetes, a phenomenon that has been around for many decades. DIY diabetes refers to the trend of people with T1D taking diabetes management into their own hands by using non-commercial and independent solutions and techniques. As part of the #WeAreNotWaiting movement, people with T1D started to develop and distributed DIY remote monitoring software, self-replacing CGM transmitter batteries, or even DIY artificial pancreas [87]. The three most commonly used DIY systems are Open APS, AndroidAPS, and Loop, which will be briefly described in the following.

- **Open APS** was originally developed to increase the notification volume of CGM devices. Originally, Open APS was a hybrid closed-loop system, where patients would manually enter and issue meal boluses and notify the system of carbohydrate intake. Open APS therefore introduced the concept of dynamic carbohydrate absorption, which considers the non-linear and unpredictable nature of carbohydrate absorption. Open APS further introduced super-microboluses (SMBs) with the goal to front-shift the peak insulin activity and safely respond to rising blood glucose levels. SMBs administer insulin in small fractions at five-minute intervals. This enables certain users to forego issuing meal boluses or alerts based on their carbohydrate consumption. Other features included in Open APS are: Autosens, which assesses whether a person using the system has a different insulin sensitivity factor (ISF) today compared to the last 24 hours and adjusts insulin recommendations accordingly. Auto-tuning, which iteratively adjusts basal insulin, ISF and carbohydrate ratio based on data from the past few weeks. Advanced Meal Assist, which allows to ramp up insulin administration faster after a meal entry when given reliable carbohydrate entries [88].
- Android APS is a mobile app that connects directly to the insulin pump. It relies on Open APS' functionalities to provide automatic insulin dosage calculations [8].

 Loop is an open source hybrid closed-loop iOS app. Loop can be used in open-loop or closed-loop fashion. In the open-loop mode, Loop predicts blood glucose levels and recommends the appropriate insulin dosage. In the closed-loop mode, Loop predicts blood glucose levels and automatically administers insulin based on the available data. In comparison to OpenAPS and AndroidAPS, Loop requires users to enter their carbohydrate intake and estimated absorption time [92].

Regarding blood glucose predictions, it is important to note that none of the three aforementioned DIY closed-loop systems use machine learning-based approaches to estimate future blood glucose levels. Loop, for example, uses the following fixed prediction function to estimate the change in blood glucose levels [92]:

$$\Delta BG[t] = \Delta BG_M[t] + (\Delta BG_I[t] + \Delta_C[t] + \Delta BG_{RC}[t]) \times min(\frac{t-5}{15}, 1)$$
(2.1)

Similarly, the predicted blood glucose at time t is estimated as follows [92]:

$$\hat{BG}[t] = BG[t_0 + \sum_{i=5}^{t} \Delta BG[t_{0+1}]]$$
(2.2)

Additionally, the setup of either of the three systems is time intensive and requires technical knowledge and/or affinity. Individuals with T1D who do not want to use a pump may find that either they cannot use DIY closed loop systems or the functionalities available to them are very limited. This is because these DIY systems are primarily designed for people who use pumps as their mode of insulin delivery.

### 2.4 T1D App Design and Visualizations

In this section, we will discuss the different designs and visualizations used in apps supporting self-management for people with T1D. Our focus lies on the visualization of past, current and future blood glucose values in mobile apps. First, we will provide an overview of different types of designs and visualizations used in mobile apps for people with T1D, followed by how current apps visualize blood glucose predictions and uncertainty by drawing on our results from the systematic literature review from Section 2.3.4.

#### 2.4.1 Functionalities and Visualization Paradigms in T1D Mobile Apps

Journaling and monitoring are very common functionalities of diabetes apps [70]. They typically allow to report blood glucose levels, medication intake, dietary habits and physical activity. Concordantly, all ten apps identified in our systematic literature review allowed to record blood glucose levels. The Human-Computer-Interaction (HCI) community has played a significant role in enhancing these apps by, for example, introducing novel features such as flexible attachments for contextual data [140] or the use of digital photography to support memory and help the understanding of the current health state [138, 53].

A crucial role of apps designed for T1D management is to help users comprehend personal data, which can be very complex. Mamykina et al. [94] demonstrated how health monitoring tools

can help people make informed decisions by highlighting connections between past behavior and current health status. To facilitate interpretation of the data an to observe correlational patterns more easily, many T1D apps employ standard graphic visualizations, such as charts, tables, and graphs [27].

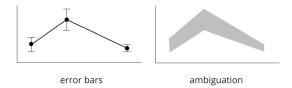
To identify interfaces that are commonly used for diabetes self-management, Katz et al. [76] conducted a qualitative study on this subject. Their research focused on T1D-specific user requirements, as well as the benefits and limitations of these interfaces. The authors identified the following eight user interface designs for people with T1D, some of which are briefly described in the following: data tables, daily journals, daily logbooks with connected plots, non-connected scatter plots, pop-up cards, statistics, and pie charts.

- Data tables are an extension of the hand written diabetes diaries, which are still used by some people with T1D. Data tables are also the most common visualization choice [163]. When supported with color-coding, they enable rapid assessment of multiple days and allow to quickly identify salient patterns [76]. Building on data tables, Prioleau et al. [121] proposed a PixelGrid approach to present blood glucose data through a color based matrix plot. The PixelGrid has been found useful by participants for the identification of salient patterns [121].
- **Daily journals and logbooks** are often key features of diabetes self-management apps, where users typically see a list-like history of their recorded data, such as blood glucose values, carbohydrates, etc. However, this approach has very limited usefulness when it comes to identifying patterns over multiple days. Even with the addition of a connected plot that scrolls in unison with the diary, this drawback persists [76].
- **Connected and non-connected scatter plots** are frequently used to display time series data (i.e. data indexed on an ordered time dimension). Scatter plots as a mean to display time series data without any connecting lines between data points has been found to be overwhelming and to make it difficult to derive actionable insights from the visualization [76]. On the other hand, Katz et al. [76] found that scatter plots with connected dots can provide a comprehensive understanding of blood glucose fluctuations and effectively convey the frequency of blood glucose tests. Notably, Bartolome and Shah [16] suggested that time-series visualizations were more suitable for examining short-term data, but were less effective for analyzing data spanning longer periods (>1 week).
- **Pop-up cards** are frequently used as a meta design method to present additional information in a way that allows interfaces to remain uncluttered [76]. However, Katz et al. [76] highlighted that pop-up cards can create excessive cognitive load for users.
- Statistics and pie charts are generally valued for providing performance benchmarks and a clear indication of issues that require attention [76]. In a recent investigation of technologies available to monitor and manage diabetes, Nooriafshar [109] proposed a pie chart for the analysis of past blood glucose data.

In their analysis of existing visualization and design interfaces, Katz et al. [76] reported that current approaches present a lot of limitations, especially that they require much interpretation from the user instead of providing explicit and actionable recommendations. Mamykina et al. [94] have further highlighted the importance of presenting health information carefully in order to avoid reinforcement of biases. Lastly, Zhang et al. [163] pointed out that there exists an overall lack of evaluation regarding how well certain views facilitate meaningful interpretation of diabetes data.

#### 2.4.2 Visualizing Blood Glucose Predictions and Uncertainty

As is the case with most predictions, the prediction of blood glucose values is subject to some degree of uncertainty. In the following, we will outline some concepts and characteristics of uncertainty visualizations, as discussed in the existing literature. Olston and Mackinlay [113] defined two common forms of uncertainty: statistical uncertainty and bounded uncertainty. Statistical uncertainty depends on the underlying statistical model and the inherent randomness of the sampled variables to approximate the true value. Statistical uncertainty is usually represented as a most likely estimate surrounded by error bars that indicate the degree of uncertainty (or confidence), an example of which is depicted in Figure 2.3 (left). Bounded uncertainty, on the other hand, provides an interval [L, H] that is guaranteed to contain the true value. To represent bounded uncertainty, Olston and Mackinlay [113] proposed ambiguation, where a particular estimate is indicated as an area across a range of values without any information about its probability distribution. An example of ambiguation in the form of a line chart is depicted in Figure 2.3(right) [113].



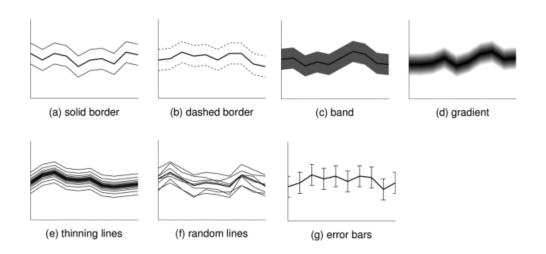
**Figure 2.3**: Error bars and ambiguation applied to a line chart. On the left a error bar visualization of uncertainty for a lien chart. Each point is connected by a line segment and additionally a error bar is added to each point. On the right a visualization using ambiguation to show uncertainty applied to a line chart. No information about the probability distribution can be derived from the visualization. (adapted from [113])

Another distinction of uncertainty visualizations has been unanimously discussed by Brodlie et al. [33], Bonneau et al. [28] and Tak et al. [147]. These authors agreed upon two categories of uncertainty visualization techniques: 1) encoding uncertainty through the visual properties of the data point, which represents uncertainty very intuitively and with little visual clutter and 2) encoding uncertainty through additional visual components, which represents uncertainty at a higher level of detail but introduces cluttering.

In a user study with non-experts, Tak et al. [147] tested seven different uncertainty visualizations including solid and dashed borders, bands, gradients, thinning lines, random lines and error bars (Figure 2.4). They showed that, without labelling, most participants intuitively interpret the certainty of a visualization to be highest around the center and decreasing toward the outside [147].

To understand how current mobile apps for people with T1D visualize blood glucose predictions and uncertainty, we analyzed the 10 apps from our systematic literature review (Section 2.3.4) as well as the visualizations from the two DIY closed-loop mobile apps (Section 2.3.5). One of the 12 resulting systems was deemed unsuitable for analysis because it did not visualize blood glucose values or predictions, leaving us with 11 apps for evaluation. We identified the following five concepts and approaches to visualize blood glucose level predictions and uncertainty:

**Vertical Line Separation** Most apps (7/11) chose to separate the past values from the future values using a vertical line mark. The vertical line mark indicates the current point in time, while values to the left are in the past and values to the right are in the future. Four apps chose to use



**Figure 2.4**: Seven uncertainty visualizations tested on event sequences by non-experts. Both (a) and (b) depict uncertainty using a dotted or solid border, respectively. (c) and (d) use a solid or gradient fill for the area between the borders, respectively. While (d) allows for an assumption about where the most likely value could lie, (c) does not. (e) uses thinning lines with decreasing density towards the borders, allowing for some assumption about the likelihood of values. (d) uses semi-randomly generated lines. Finally, we have error bars in (e) following the same concept as Figure 2.3 (adapted from [147])

a dashed vertical line mark, while three apps used a solid line mark. All apps chose a different color for the vertical line mark contrasting the color of the blood glucose values.

**Text Elements** About one-quarter of the apps (3/11) used text elements to represent blood glucose level predictions. However, such text elements were never used exclusively but only juxtaposed to a graphical visualization of the data. All apps depicting predictions as text used only a single blood glucose value (e.g. 5.6 mmol/L). Contrary to our expectation, no prediction intervals (e.g. 5.6-7.6 mmol/L) were used to indicate prediction uncertainty. Prediction uncertainty was only indirectly implied through the use of formulations such as "Your glucose is *likely* to go low" or *"Eventually* 4.5 mmol/L", or by placing the word *"Estimate"* below the blood glucose level prediction.

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**Dashed Line Chart** Almost all apps (10/11) visualized blood glucose predictions using a dashed line mark. The majority of them (8/10) used only a single dashed line to visualize predictions, as depicted in the neighboring Figure. While most (6/8) switched from a solid line to dashed line visualization as depicted in the neighbor-

ing Figure, few (2/8) already used a dashed line mark to visualize past glucose values and only changed the shape of the dot for future glucose values. Out of the single dashed line visualizations, one app (1/8) also changed the color of the line mark to distinguish the prediction better from the past blood glucose.



**Ensemble Display** Out of all apps with dashed line marks, one (1/10) visualized blood glucose level predictions and uncertainties using an ensemble display, as depicted in the neighboring Figure. The different prediction paths are encoded using a dashed line mark, while the colors discriminates between paths. This was the case

for the AndroidAPS closed-loop system [8], which provides users with several different scenarios (i.e. paths), from which users can choose the one that reflects their current situation best. For example, a first path depicts a blood glucose level prediction if the user were to consume an unplanned meal. A second path shows a blood glucose level prediction if everything stays as it currently is in terms of continuous subcutaneous insulin secretion and active carbohydrates. A third path demonstrates a prediction if only the effect of the insulin is considered. Finally, the fourth path shows what would happen if insulin delivery is stopped. While the different paths could suggest some kind of uncertainty, looking at each individual scenario does not convey any information about uncertainty.



**Lower and Upper Bound** Out of all apps with dashed line marks, one (1/10) depicted prediction uncertainty by also using dotted line marks for the lower and upper bound of the prediction [166]. This app used colors to distinguish between lower, upper and prediction line marks, as is depicted in the neighboring Figure.



**Bounded** Out of all apps, one (1/11) encoded the blood glucose prediction using a solid line, which resulted in the vertical line mark being the only distinguishing factor between past and future blood glucose values. In this app, uncertainty of the prediction was visualized using a bounded area visualization. While the color of the predic-

tion line mark and its surrounding bounded area were the same, the bounded area used a higher opacity to be distinguishable from the prediction line [92]. Unfortunately, the documentation of the app did not disclose how they calculated the uncertainty of the prediction, leaving unclear whether the depicted uncertainty is statistical or truly bounded.

So far, we identified six visualization types for blood glucose predictions and their uncertainty from our systematic literature review. Of course, there are many other possibilities to visualize predictions and their uncertainty. Some noteworthy approaches to visualizing personalized meal-time blood glucose predictions for people with T2D have been presented by Desai et al. [40]. Using a focus group approach with people with T2D, they evaluated seven different visualizations of blood glucose predictions, which are depicted in Figure 2.5. Overall, they found that simple and explicit designs were preferable. However, due to the differences between T1D and T2D discussed in Section 2.1.1 we include some of the proposed visualizations in the second part of our study, but they did not guide our prototype design.



**Figure 2.5**: Screenshots of the seven visualizations shown to focus groups of patients with T2D. Going from left to right (1) gradient number line, depicting a within range value, (2) a segmented number line showing a value of 11.7 mmol/L, (3) a speed dial which is supposed to be action oriented, a traffic light visualization highlighting the predicted blood glucose of 9.2 mmol/L, (4) a cartoon visualization using an angry sun in a desert to show a too high blood glucose value, (5) a line glucose curve color coded according to in range or out of range values, and (6) a multi-line chart depicting the uncertainty of the predicted blood glucose value [40]. (Source: [40])

# **Chapter 3**

# **Prototype of MOON-T1D**

In this chapter, we present the prototype of MOON-T1D that will be used during our user study described in Section 4.2. First, we will introduce general requirements for MOON-T1D that are based on our systematic literature review and our previous study on blood glucose predictions [15]. Second, we will introduce the design process involved in creating MOON-T1D. Third, we will outline the methods and algorithms used to create the different visualizations of blood glucose predictions implemented in MOON-T1D. Finally, we will present the visual interfaces and functionalities of MOON-T1D.

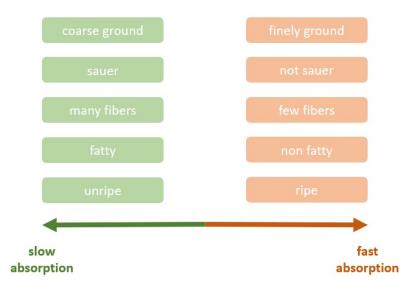
## **3.1 General Requirements**

In the previous chapter we presented a systematic literature review identifying existing apps that support blood glucose predictions. The following requirements for the prototype of MOON-T1D are derived from the functionalities of existing apps, the results from our previous study [15] and additional functionalities needed to answer our research questions.

- The all Encompassing App and Integration As already identified by Desai et al. [40], who conducted a study with people with T2D, participants would like to have an allencompassing app. All encompassing means that the app allows participants to view and add blood glucose values, insulin administration and carbohydrate consumption. In our previous study [15], we further found that also people with T1D would like an app to integrate with their CGM devices, their insulin pens or pumps and their activity tracking devices. This highlights the desire also of people with T1D to see blood glucose, consumed carbohydrates, insulin administration and activity all in one app.
- Carbohydrate and Insulin Absorption For users to assess what is affecting their blood glucose at any point in time, they need to know which factors (e.g. insulin, carbohydrates, etc.) are still having an active effect. Both carbohydrates and insulin are not immediately absorbed upon ingestion/administration. As described in Section 2.1.3, the time it takes for carbohydrates to be absorbed depends on various factors, such as the amount of carbohydrates consumed, the overall fattiness and many more (for a detailed overview see Figure 3.1). Once carbohydrates have been consumed, it would be useful to see how long these carbohydrates might affect the blood glucose levels of people with T1D, also to support their decision-making.

It would therefor be desirable for MOON-T1D to have a model that describes carbohydrate absorption (presented in Section 3.3.1) as well as a visualization that clearly shows the user how many carbohydrates are still left to be absorbed (shown in Section 3.4.1). The duration

of insulin's blood glucose lowering effect is influenced by several factors that determine the rate at which insulin is absorbed by the body after administration (Figure 3.4 depicts different insulin absorption curves). These factors include, for example, insulin type, amount of insulin, and administration location. For MOON-T1D to have a mathematical model that simulates insulin absorption (described in Section 3.3.2) and a visual representation of the remaining active insulin (shown in Section 3.4.1) would be beneficial for users to better understand the dynamics of insulin activity in their body.



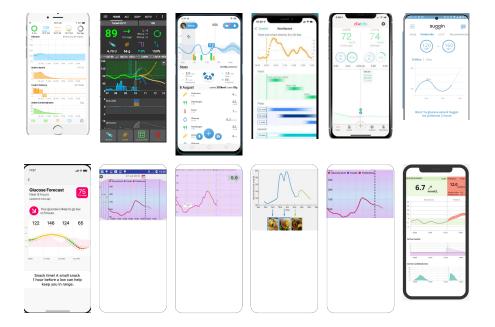
**Figure 3.1**: Factors affecting carbohydrate absorption and therefore the effect of carbohydrates on the blood glucose level of people with T1D. On the left are factors such as fatty foods that slow down carbohydrate absorption and might even slow down absorption of other foods consumed. On the right are factors that speed up carbohydrate absorption of food consumed. (Source: Figure created by author based on information from Scheiner [131])

- Blood Glucose Predictions Blood glucose predictions are perceived as useful and desirable by people with T1D [15], and including them in MOON-T1D is crucial to answer our research questions on blood glucose predictions (*RQ*<sub>1</sub>, *RQ*<sub>3</sub>). We therefore needed to implement a machine learning algorithm for blood glucose predictions that works with the data that we collect from participants. The specific requirements of the blood glucose prediction algorithm are described in Section 3.3.4.
- Ease of Use The study conducted by Desai et al. [40] suggests that people with T2D prefer simple visualisation. Similarly, Grasso et al. [61] and Kayyali et al. [78] identified a positive relationship between ease of use and the acceptance of technology. Thus, designing MOON-T1D for usability was an important requirement for us. To achieve high usability, we went through several design iterations and tried to base our design on existing apps that participants might be familiar with. This iterative design process is further described in Section 3.2.
- Food Database To allow for an easy and fast entry of nutritional contents of foods, a food database is required. Because our sample included both English and German-speaking participants, a bilingual and freely accessible food database was needed. We also needed the food database to include a search functionality to allow users to search for specific food

items with detailed nutritional information for an optimal assessment of carbohydrate absorption time. Additionally, we created a dedicated product storage on the server to ensure that any products generated by the participants would not be shared with the selected food databases.

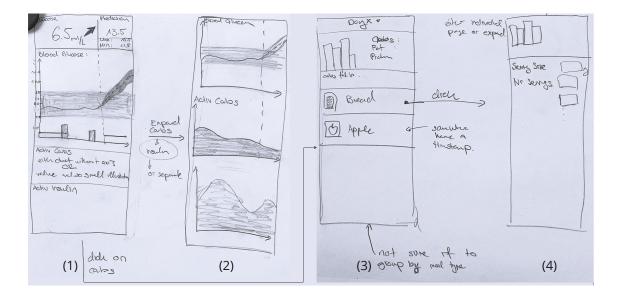
- Hardware and Software Requirements To allow for the replication of a natural everyday life experience, participants should be able to use MOON-T1D on their own mobile devices. Which meant for us that we had to create a deployed version of the app. Because we anticipated participant recruitment to be challenging, we wanted to avoid excluding participants due to their mobile operating system. Thus, another requirement was that MOON-T1D needed to be cross-platform, supporting iOS and Android operating systems. Further software requirements can be found in Section 4.4.
- Data Security: To ensure participants' data security, their data had to be stored on a secure server and each participant needed their own login. We decided to use the secure servers hosted by the University of Zurich to store participants' data. Moreover, we did not want to use participants' real blood glucose values in order to avoid working with highly sensitive medical data. This meant that we had to create reasonable but randomly generated blood glucose values. The requirements for generating semi-random blood glucose predictions are described in Section 3.3.3.

# **3.2 Prototype Design**



**Figure 3.2**: Home screens of apps that were analyzed and compared in Section 2.3.4. The existing designs served as an inspiration for our own design. From left to right and top to bottom we have Loop [92], AndroidAPS [8], DiabTrend [43], Quin [71], diabits [82], Suggin [101], One Drop [72], ARISES [168], [166], GlucOracle [41], [90], and the app-design from our previous study [15].

This section describes the design process of MOON-T1D. The design of MOON-T1D is based on a systematic analysis of existing apps supporting blood glucose tracking and prediction (see Section 2.3.4), our design developed for our previous work [15], and insights gained from a dashboard design pattern workshop. Using the comparison of user-interface designs as a starting point for our app design allowed us to understand the current state-of-the-art in the field and identify common design patterns. To compare the different designs we created a board depicted in Figure 3.2, where we depicted different visual interfaces separated by functionality they provide. This allowed us to easily compare different designs and provided us with a starting point for app design. Using our knowledge from existing apps, the author of this thesis attended a workshop on dashboard design patterns, which was inspired by the paper of the same name from Bach et al. [11]. During the course of the workshop a first sketch of MOON-T1D was created using the dashboard design patterns as guidance, depicted in Figure 3.3. Based on our analysis of existing app designs and insights gained from the workshop, we prioritized usability and ease of use in the selection of designs for our app.



**Figure 3.3**: An initial sketch of MOON-T1D was developed during a dashboard design pattern workshop led by Benjamin Bach at the University of Zurich. The created interface comprises four sketches: (1) An overview separated into past and future values by a vertical line. On top, there is a panel depicting the current blood glucose with an arrow indicating its future direction. Below is a line chart showing the blood glucose value and its prediction with a superimposed bar chart depicting physical activity. Finally, there is an active insulin and active carbohydrates view, both showing some kind of statistical summary of the respective values. (2) The same overview but now depicting the active insulin view and active carbohydrate view using an area chart. The y-axis depicts insulin and carbohydrates to be absorbed and the x-axis shows the time. (3) A meal history depicting, on top, a summary of carbohydrates consumed during one day using a bar chart. Just below is a history of products consumed, such as apples. (4) A single product where users can adjust serving size and number of servings. (Interactions) Swiping the active insulin or carbohydrate view in (1) will change their visualization such that the Overview will look as depicted in (2). Clicking on the active carbohydrates view in (1) will redirect the user to (3). Clicking on one of the listed products in (3) will redirect the user to (4).

## **3.3** Methods

This sections describes the algorithms used to create the different visualisations described in Section 3.4. First, the absorption of carbohydrates and insulin by the body is described followed by a description of the algorithm that is used to create semi-random blood glucose values and the algorithm used to create the blood glucose prediction.

## 3.3.1 Modelling Carbohydrate Absorption

We decided to model carbohydrate absorption mathematically using an adapted version of the algorithm used by Loop [92]. All carbohydrates raise blood glucose levels, however the speed and degree to which they get absorbed by users is highly variable. Since carbohydrate absorption is variable and user dependent, users are allowed to input how long they think it will take for the carbohydrates to be absorbed (similar to Loop's approach [92]). Taking a more conservative approach, we extended the absorption time entered by users by 50% following the suggestions from Loop [92]. Thus, the minimum absorption rate (MAR) is calculated using the following formula:

$$MAR = \frac{CHO}{1.5 \times d} \tag{3.1}$$

where *d* is the absorption time in hours entered by the user and *CHO* is the number of carbohydrates in grams. We generated semi-random blood glucose values, explained in Section 3.3.3, that are influenced by carbohydrate entries and insulin entries from users instead of collecting blood glucose values from a CGM. Since my blood glucose values are generated taking the carbohydrate absorption into consideration, we are not considering the observed blood glucose change to adapt the absorption rate as done by the algorithm of Loop [92].

### 3.3.2 Modelling Insulin Absorption

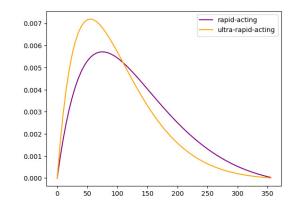


Figure 3.4: Exponential insulin activity curve  $(Ia_t)$  for ultra-rapid-acting insulin (orange) with a peak active time of 55 minutes, and rapid-acting insulin (violet) with a peak active time of 75 minutes, both have an action duration of 360 minutes

We used the algorithm implemented in Loop [92] to model the amount of active insulin left in the body as an exponential insulin curve with two user-adjustable inputs: 1) the insulin peak time (PT) and 2) the duration of insulin action (DIA). The default value for PT is 55 minutes for ultra-rapid-acting insulin (e.g. Fiasp) and 75 minutes for rapid-acting insulin (e.g. Novorapid). The default value for DIA is 6 hours. The exponential insulin activity curve  $Ia_t$  (Figure 3.4) uses the following algorithm:

$$Ia_t = \frac{S}{\tau^2} \cdot td \cdot \left(\frac{1 - td}{DIA} \cdot e^{\frac{-td}{\tau}}\right)$$
(3.2)

PT is the insulin peak time in minutes after giving the dose (55 minutes for Fiasp).

*DIA* is the total action duration of insulin activity in minutes (360 minutes for both Fiasp and Novorapid).

 $\tau = \frac{PT \cdot (1 - \frac{PT}{DIA})}{(1 - \frac{2 \cdot PT}{DIA})}$ ; the time constant of exponential decay in minutes.

 $a = \frac{2 \cdot \tau}{D I A}$ ; the rise time factor in minutes.

 $S = (1-a+(1+a) \cdot e^{\frac{-DIA}{\tau}})^{-1};$  the auxiliary scale factor.

 $td = t - t_0$ ; the number of minutes passed since insulin injection.

Following from the insulin activity curve, the percentage of insulin remaining in the body at time t (also called the Insulin On Board; IOB) can be derived as follows:

$$IOB_t = 1 - S \cdot (1 - a) \cdot \left( \left( \frac{td^2}{\tau \cdot DIA \cdot (1 - a)} - \frac{td}{\tau} - 1 \right) \cdot e^{\frac{-td}{\tau}} + 1 \right)$$
(3.3)

Multiplying the IOB at time t with the insulin injected at time  $t_0$  results in the units of insulin remaining in the body.

### 3.3.3 Semi-Random Blood Glucose Generation

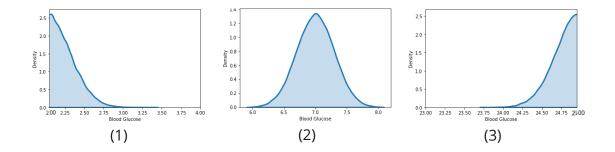
To generate random but reasonable blood glucose values taking into account carbohydrate consumption and insulin delivery the algorithm needs to adapt to four different states; 1) only the current blood glucose data is considered 2) the user consumed carbohydrates 3) the user injected insulin and 4) the user injected insulin and consumed carbohydrates.

To make semi-random values look like reasonable blood glucose values the following key factors need to be considered:

- 1. The change in blood glucose level from time t to time t+1 needs to be reasonable. A blood glucose value does not jump from 5.0 mmol/L to 10.0 mmol/L in a time interval of 5 minutes, even though both values are within the range of possible blood glucose values.
- Values below 2.0 mmol/L rarely occur, and most of the currently available CGM do not show an exact value below a certain threshold. Thus, a lower bound should exist on blood glucose value generation.

- 3. Values above a certain threshold are usually not displayed in current CGM apps. While an upper restriction on blood glucose might not be necessary, we did not want the generated values to reflect extreme and potentially dangerous situations, thus an upper limit on blood glucose values is needed.
- 4. Showing extremely high or extremely low values might also put stress on participants as they represent extreme and potentially dangerous situations for people with T1D [38, 159] thus a hard lower and hard upper bound on the random blood glucose generation is needed.

State 1 - Default To create the default semi-random blood glucose values algorithm, we decided to use a normal distribution. The semi-random blood glucose level was constructed as follows: Addressing the generation of a reasonable next value given the current blood glucose, we created a truncated normal distribution with the current blood glucose as the mean ( $\mu$ ) of the distribution and a standard deviation of  $\sigma = 0.5$  as well as a lower and upper bound of the current value +/- 1.0 mmol/L. We chose a value of +/- 1 mmol/L based on comparing the highest rate of change used for their visualizations by different CGM manufacturers which was between 0.1 and 0.2 mmol/L per minute [80]. Generating a new value every 5 minutes we decided to use +/- 1 mmol/L. For example, if the previous blood glucose value was  $BG_{t-1} = 7.0 \text{ mmol/L}$  then the next blood glucose value will lie between  $BG_t \subseteq [6.0, 8.0] \text{ mmol/L}$ . How likely a value is is depicted in Figure 3.5. To address too high values, we implemented an overall upper threshold of 25.0 mmol/L. If a value is generated that is above 25.0 mmol/L then the upper bound of the distribution is set to be equal to the mean ( $\mu$ ), only allowing for smaller values to be generated. Additionally, if the current value was above 25 mmol/L we set the lower bound of that distribution to be 25.0 - 3 = 22 mmol/L. The same concept is applied to address too low blood glucose values. If a generated blood glucose value falls below 2.0 mmol/L the lower bound is set to be equal to the mean ( $\mu$ ) of the distribution.



**Figure 3.5**: Probability of the next blood glucose value. The x-axis depicts the blood glucose value while the y-axis depicts the probability for each value to be sampled. In the middle there is the truncated normal probability with a mean  $\mu$  of 7.0 mmol/L, standard deviation  $\sigma$  of 0.5 mmol/L, a lower bound of 7 - 1 = 6 mmol=L and an upper bound of 7 + 1 = 8 mmol/L. On the left is the case depicted that the previous blood glucose value was below 2.0 mmol/L. While  $\sigma$  stays the same (0.5 mmol/L), the lower bound and  $\mu$  are set to the same value (2 mmol/L) while the upper bound is set a bit higher, namely to 4.0 mmol/L. On the right is the probability of the next blood glucose value if the previous blood glucose value was above 25.0 mmol/L. The upper bound of the distribution is set to equal its mean (25 mmol/L) while the lower bound is decrease to 23.0 mmol/L.

**State 2 - Carbohydrate Consumption** The second state the algorithm can be in is if the user consumed carbohydrates, raising blood glucose levels. To account for the effect carbohydrate consumption has on the blood glucose level, the mean ( $\mu_{t+1}$ ) used for generating the next normal distribution to determine the next blood glucose value is adapted according to the following formula:

$$\mu_{t+1} = BG_t + \left(\sum_{i=1}^n (COB_{(t+1)i} - COB_{(t)i}) \cdot CBGR\right)$$
(3.4)

where COB(t) are the carbohydrates on board at time t (see Section 3.3.1) and CBGR ( Carbohydrate Blood Glucose Raise), represents how much the blood glucose is raised by one gram of carbohydrates consumed. Additionally, we increase the upper bound of our truncated normal distribution by 0.25 mmol/L to allow for a more rapid blood glucose raise.

**State 3 - Insulin Injection** The third state of the app is if the user injected insulin, which should lower the blood glucose. The following formula is used to account for the decrease in blood glucose:

$$\mu_{t+1} = BG_t - \left(\sum_{i=1}^n (IA_{(t+1)i} - IA_{(t)i}) \cdot ISF\right)$$
(3.5)

where IA(t) represents the remaining insulin in the body at time t (see Section 3.3.2) and ISF is the insulin sensitivity factor that represents how much the blood glucose falls after injecting one unit of insulin. Also, the lower bound of the truncated normal distribution is decreased by 0.25 mmol/L.

**State 4 - Insulin and Carbohydrates** To address the state of the blood glucose if there is insulin and carbohydrates actively absorbed in the body, we chose to combine the above two approaches leading to a proportional increase or decrease of the blood glucose depending on the effect of the amount of carbohydrates and amount of insulin being absorbed.

$$\mu_{t+1} = BG_t + \left(\sum_{i=1}^n (COB_{(t+1)i} - COB_{(t)i}) \cdot CBGR\right) - \left(\sum_{i=1}^n (IA_{(t+1)i} - IA_{(t)i}) \cdot ISF\right)$$
(3.6)

The lower and upper bound are both raised by 0.25 mmol/L to account for the increased uncertainty usually associated with carbohydrate consumption and insulin administration.

### 3.3.4 Modelling Blood Glucose Predictions

To make the prediction look real for the users we decided to use an existing prediction algorithm, that would be used on our semi-randomly generated blood glucose values.

The requirements that we decided to base our prediction algorithm selection on the following:

1. **Training Data** For the prediction model to reflect and accurately predict blood glucose values of users we needed an algorithm that has been trained on a large, accurate, and com-

plete dataset of blood glucose values of people with T1D. It is important that the algorithm is trained on data from CGM devices of people with T1D since using data of patients with T2D might show very different blood glucose carbohydrate and insulin patterns. Since we tried to simulate CGM blood glucose values for patients with T1D with our semi-random blood glucose generation algorithm its is important that the training data reflects this. Using CGM data, blood glucose values are recorded regular time intervals. Using finger prick blood glucose data on the other hand, the entered values could be sporadic and at heterogeneous time points. This is because blood glucose values are not automatically collected instead users decide when to measure their blood glucose values of a patient with T1D, which means that the training data for our prediction algorithm needed to reflect that.

- 2. Consideration of Insulin and Carbohydrate Entries by Users: To accurately reflect user data and enhance the credibility of shown values, it is essential to have a prediction algorithm that takes into account carbohydrate and bolus entries of users. By incorporating bolus and carbohydrates in the prediction algorithm making it more precise, we hope that users understand why entering this data would be important.
- 3. **Prediction Horizon:** We decided that one hour prediction horizon would be enough as it is frequently used for example in the Blood Glucose Prediction Challenge (BGLP) of the International Workshop on Knowledge Discovery in Healthcare Data. Using a one hour prediction horizon meant that it was essential to also predict values between the present and one hour into the future at reasonable time intervals. This is important as, first, values that are closer in time can be predicted with greater accuracy. Second, when a straight line is drawn on the continuous blood glucose line chart between the current blood glucose and the value one hour into the future, it appears highly unrealistic when compared to the generated values. Thus we decided to generate predictions for the following horizons 10, 20, 30, 40, 50, and 60 minutes into the future.
- 4. Prediction Performance: As we will make several predictions at different time intervals, the speed of the prediction is slower. For a prediction to be usable in everyday life it needs to be fast enough such that users do not have to wait too long making it unusable for "just quickly checking the BG values".

In the following we present our solutions addressing the listed requirements. While there is a one to one mapping between the same named paragraph and list items the Machine Learning paragraph addresses requirement (2) and (3).

**Training Dataset** We were able to acquire the OhioT1DM dataset, consisting of 134'790 training examples [98]. The OhioT1DM dataset consists of data from 12 individuals with T1D, including 8 weeks of CGM entries collected every 5 minutes, as well as information on the bolus and basal insulin doses delivered by their pump and self-reported carbohydrate estimates. A more precise description of the dataset can be found here [98]. The OhioT1DM dataset has been used in several Blood Glucose Level Prediction (BGLP) Challenges and was specifically designed to facilitate research in blood glucose level prediction.

**Machine Learning Algorithm** We chose to use the ML model of Freiburghaus et al. [52]. Their ML model was trained on the OhioT1DM dataset and ranked first in the ranking of camera ready results of the Blood Glucose Level (BGLP) Prediction Challenge 2020. Their model includes the CGM data, basal and bolus insulin as well as meal/carbohydrate values, addressing requirement (2). Freiburghaus et al. [52]'s camera ready version achieved a  $RMSE = 0.97 \ [mmol/L]$  and  $MAE = 0.62 \ [mmol/L]$  for a 30min prediction horizon and a  $RMSE = 1.87 \ [mmol/L]$  and

 $MAE = 1.29 \ [mmol/L]$  for a 60 minutes prediction horizon. Additionally, their model allows to create predictions for every 5 minutes prediction horizon up to 60 minutes addressing requirement (3).

**Prediction Performance** While Freiburghaus et al. [52]'s ML model allows us to create predictions at reasonable time intervals of 5 minutes from 5 to 60 minutes. Running the pre-processing needed, i.e. getting the data from our different locations and converting some blood glucose values to mg/dL from mmol/L etc, as well as generating a prediction of blood glucose value for each time interval was not immediate. We thus decided to modify the algorithm from Freiburghaus et al. [52] to only predict at time intervals of 10 minutes each, instead of every 5 minutes. This resulted in a more performant solution for the end user while smoothing out the prediction curve.

## **3.4** Visual Interfaces of MOON-T1D

In this section, we will present the prototype of the mobile app MOON-T1D and its interfaces. First we will present the *Overview*, in Section 3.4.1, depicting all the information needed by users for their daily decision making. Followed by the *Insulin Views*, in Section 3.4.2, allowing users to enter new insulin injections and view a history of past injections. Third we show the different ways to add, create and view meal entries in the *Meal Views* in Section 3.4.3. And finally we introduce the *Activity Views* (Section 3.4.4) where users can view and enter physical activity. We will use the following fictional example of Abby to further illustrate a potential usage of the different interfaces and how they could support Abby in managing her blood glucose levels.

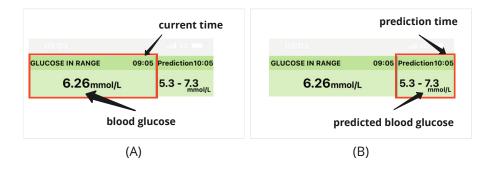
**Abby's Case:** Abby, a 30 years old office worker, just ate her lunch with her colleagues in a restaurant. In the restaurant, she ordered a plate of spaghetti with tomato sauce. To prevent a high peak after her meal, she took an estimated amount of insulin while waiting for the meal. Today Abby is a bit more under pressure as she has to presentation some of her work this afternoon in-front of the whole office. During moments of high stress and high required performance it is essential for Abby to have a stable and good blood glucose. If her blood glucose would be too high or too low she might not perform well during her presentation.

## 3.4.1 Overview

When looking at an app for T1D users, the most important thing for them is their current blood glucose and the decision-making involved in keeping the blood glucose in range. Decision-making of users, playing a major role in T1D management, is mostly determined by 4 factors: blood glucose (current, past and future), insulin, carbohydrates and activity. Providing T1D users with a comprehensive overview should include all the necessary information to assess their current condition and make informed decisions, such as whether to administer insulin or consume carbohydrates. This interface consists of four parts, 1) a *Blood Glucose Top Panel* showing detailed blood glucose information 2) a *Blood Glucose View* information over time 3) an *Active Carbohydrates View* over time and 4) an *Active Insulin View* over time.

The overview page is divided into two sections by a gray line, with the left section displaying data from the past two hours and the right section showing the predicted data for the next hour. Showing what happened in the past informs the user about what influences their current state, i.e. how much insulin and/or carbohydrates are still affecting their blood glucose level. Showing the future can inform the user about the change in blood glucose level they can expect in the next few hours.

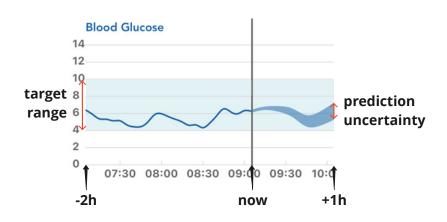
**Blood Glucose Top Panel** The goal of the *Blood Glucose Top Panel* is to provide an exact numerical value of their current and future blood glucose. This allows users to grasp their exact current and future blood glucose level more quickly, instead of trying to read the exact value from the *Blood Glucose View*. The *Blood Glucose Top Panel* depicts on the left what the current blood glucose of the user is, and on the right the prediction range within which the blood glucose will lie one hour into the future, depicted in Figure 3.6. The panel changes color, to reflect whether a blood glucose value is within range or not. Using an ample like schema, green signifies within range, red signifies too low and orange signifies too high. Red is chosen to communicate the immediate danger of hypoglycemia to the users. The color choices are in line with the colors used by apps such as "Libre Link" (Abbott Diabetes Care, Alameda, CA, USA) [24] or OneDrop [72].



**Figure 3.6**: Blood Glucose Top Panel depicting the current blood glucose level at 09:05 AM of 6.26 mmol/L (left) and the predicted blood glucose range lying between 5.3 and 7.3 mmol/L at 10:05 AM (right). The green background color changes to either orange for hyperglycemia or red for hypoglycemia.

Blood Glucose View The goal of the Blood Glucose View is to inform users about blood glucose fluctuations of the past that could still affect the future, while also providing them with a forecast of their blood glucose behavior in the upcoming hours. As an example, if the current blood glucose value of the user is 6.3 mmol/L (within range), as presented in Figure 3.7, and was stable in the past it will most likely remain stable unless the users changes a blood glucose affecting factor i.e. consumes some carbohydrates. If, on the other hand, the user's blood glucose curve was more fluctuaneous and had a steep rise to reach the 6.3 mmol/L the users should be more alert as their blood glucose is changing very fast. One of the goals of showing a blood glucose prediction is such that users can recognize and prevent hypo- or hyperglycemia in advance. Additionally, its reduces the burden of handling the complex influences on ones blood glucose level that they would need to consider to make a forecast themselves. The blood glucose view depicts blood glucose values in mmol/L (y-axis) over time (x-axis) using a line mark. The light blue band in the middle, as depicted in Figure 3.7, represents the blood glucose target range, which by default is between 4.0 mmol/L and 10.0 mmol/L, in line with [7]. The left side displays simulated blood glucose values from the past two hours, while the right depicts a blood glucose prediction one hour into the future.

The *uncertainty* of a blood glucose level prediction is shown using an area chart. Assessing different uncertainty visualizations in Section 2.4.2 we decided to use an area chart as an *ensemble display* or line mark visualization of *lower and upper bound* could be confusing for users. Additionally in our previous study users seemed to like the design of predictions shown, which is similar to the one in use now. Since short-term predictions are more accurate than long-term ones, the

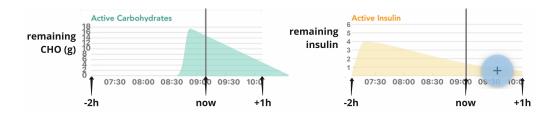


**Figure 3.7**: Blood glucose curve line chart including a blood glucose prediction area chart. The past blood glucose over the last two hours, from 7:00 AM till 9:00 AM, had slight fluctuations but stayed within the target range of 4.0 to 10.0 mmol/L. To the right of the current time and blood glucose of 6.3 mmol/L, there is a blood glucose prediction area chart showing the uncertainty one hour into the future. In this example, the blood glucose is predicted to be between 5.3 and 7.3 mmol/L at 10:00 AM.

range reflecting the uncertainty of blood glucose predictions increases over time. The exact range in which the blood glucose value could lie after one hour is displayed in the *Blood Glucose Top Panel*.

Active Carbohydrates View The goal of this view is to help users assess how and if their blood glucose is still affected by any carbohydrates consumed. The *Active Carbohydrates View* shows the user the carbohydrates that are currently active in their body. The y-axis represents the number of carbohydrates (in grams) remaining in the users body and the x-axis represents the time. The amount of carbohydrates remaining in the body is shown using an area chart. The forest green used to depict the area chart is used throughout the whole app for any carbohydrate related views. How the carbohydrate absorption of foods is calculated can be found in Section 3.3.1. In Figure 3.8 you can see that at 08:30 the user consumed a meal containing 18g of carbohydrates. At the current time 09:05 there are about 15g of carbohydrates that have not jet been absorbed.

Active Insulin View The goal of this view is to show the user how much insulin is left to be absorbed, such that they can assess how the insulin affects their blood glucose. This is important for users if e.g. their blood glucose is too high after a meal even though they injected insulin before the meal. In this scenario, it is important for the user to know how much insulin is still to be absorbed such that they can see if they need to adjust their blood glucose by injecting another dose or if there is still enough insulin left. The *Active Insulin View* shows the user the short-term insulin that is still being absorbed by their body. The y-axis represents the units of ultra or rapid-acting insulin (units) still remaining to be utilized by the body and the x-axis represents the time. We decided to not visualize long term insulin, to reduce the complexity of the visualization. This is reasonable as for an average user, the dosage of long-acting insulin in multiple daily injection insulin therapy tends to remain relatively constant over time. In Figure 3.8 it is visible that at 07:05 a user injected 4 units of rapid acting insulin of which 2 units are currently still remaining to be absorbed.



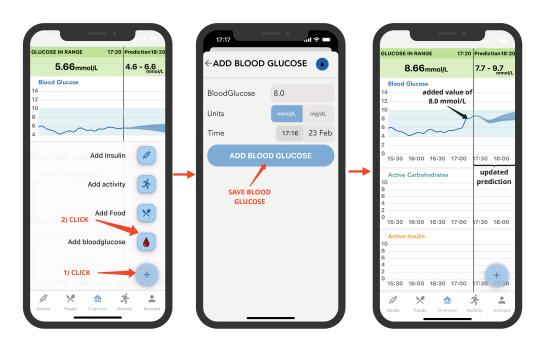
**Figure 3.8**: Extracts from the Overview of MOON-T1D, (left) The *Active Carbohydrate View* provides a visualization of the remaining carbohydrates in the body, using a area chart. In this example 18g of carbohydrates were consumed at 08:30 and at 09:05 about 15g remain to be absorbed. (right) The *Active Insulin View* provides a visualization of the insulin that remains to be absorbed by the body, using an area chart. In this example 4 units of ultra-rapid-acting insulin were injected at 07:00 and at the current time 09:05 about 2 units remain to be absorbed.

**Summary and Example** As already hinted at the *Active Carbohydrate View* and the *Active Insulin View* both have an effect on the blood glucose level. Showing them juxtaposed in the main view of MOON-T1D is necessary for users to draw conclusions on how the amount of carbohydrates that are still left to be absorbed might be mitigated by the insulin that is left to be absorbed. If e.g. the user's blood glucose is currently 7.0 mmol/L and rising and the *Active Carbohydrates View* shows that there are still 15g of carbohydrates to be absorbed. A user with a *Carbohydrate Blood Glucose Raise* of 0.22 mmol/L for every gram of carbohydrates, would have an approximate blood glucose of  $(0.22 \text{ mmol/L} \times 15) = 3.3 \text{ mmol/L}$  thus their blood glucose after absorbing all the carbohydrates would be 7.0 mmol/L + 3.3 mmol/L = 10.3 mmol/L and thus the user would have to take some insulin.

If the *Active Insulin View* however shows that there are still 2 units of insulin to be absorbed. Then a user with an *Insulin Sensitivity Factor (ISF)* of 2.0 mmol/L would expect their blood glucose to drop by 2 \* 2.0 mmol/L = 4 mmol/L thus resulting in a blood glucose of 7.0 mmol/L - 4.0 = 3.0 mmol/L once all the insulin is absorbed. As this would be a value below threshold, the user should eat some carbohydrates.

Taking into account both the *Active Insulin View* and the *Active Carbohydrates View* the user might not need to do anything at all as the active carbohydrates and the active insulin might just balance each other out. To confirm this assumption the user can additionally check the blood glucose prediction. Also users do not always have time and capacity to make the calculations above, thus the blood glucose prediction could serve as a good approximation of the calculated value. Additionally, a blood glucose prediction might consider more factors affecting the blood glucose level at the same time as a user.

**Abby's Case:** In Abby's case looking at the Overview before her presentation can help her create a stable blood glucose level, such that she can perform better during her presentation. Looking at the blood glucose chart she can see that after lunch her blood glucose rose more than usual. While a rise can be expected after eating a meal Abby is now not sure anymore that she took enough insulin to counteract the peak. Looking at the Active Insulin view she can see that there is still insulin left to be absorbed by her body and enter her blood stream. The Active Carbohydrates view shows her that there are still carbohydrates to be absorbed by her body. Using the information shown she looks at the prediction, which shows her a small decrease of blood glucose before her blood glucose would rise again. The predicted blood glucose range is between an within target range blood glucose value and an above target range value. Abby now has to decide how and if she wants to lower her blood glucose such that she wont be bothered by it during her presentation.



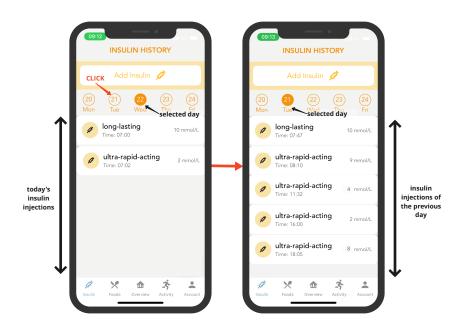
**Figure 3.9**: To add a blood glucose value users first have to select the plus button followed by the add blood glucose button. In the middle we have the *Add Blood Glucose View*, where the user adds a blood glucose value of 8.0 mmol/L at 17:16. On the right you can see that all values from 17:15 until now (17:20) are updated. Comparing the *Overview* on the left with the one on the right it is visible that not only the blood glucose values were updated but also the prediction, to reflect the newly added blood glucose value.

Add Blood Glucose View The goal of this view is for user to test blood glucose values of choice and see how different values change the prediction of the blood glucose. To add a blood glucose value a user has to click on the plus button of the *Overview* screen, and select *Add blood glucose* from the menu. The user can then enter the blood glucose, the blood glucose unit, and the time of when the blood glucose should be added. Two types of blood glucose concentration units are supported, for one the international standard unit mmol/L and mg/dL used in the USA. After adding a new blood glucose value, all values between the time-point of entry and the current time-point will be updated accordingly. Also the prediction will be updated according to the newly generated blood glucose curve. In Figure 3.9 the steps from how to enter a new blood glucose values until the update of the *Overview* are depicted.

## 3.4.2 Insulin Views

Beside showing the insulin available to the body in the *Active Insulin View* users can also gain an overview over the insulin injections per day in the *Insulin History View* and add the insulin they injected in the *Add Insulin View*.

**Insulin History View** The goal of this view is to show the user more detailed information on their daily insulin injections, including the type, the time and units of insulin that were injected. The *Insulin History View* shows a daily history of insulin injections entered by the user, depicted in Figure 3.10. On top, users have a button which allows them to navigate to the *Add Insulin View*. Just below is a small calendar, which allows users to select the date for which they would like to see



**Figure 3.10:** Insulin history of the current (left) and previous (right) day. On the 21st (previous day) the user took 10 mmol/L of long-lasting insulin and 9 mmol/L of ultra-rapid-acting (bolus) insulin for breakfast at around 8am. The user tool 5 mmol/L of bolus insulin for lunch at 11:30 and dinner at 18:05 with 8 mmol/L. At around 16:00 the user took a snack and entered 2 mmol/L bolus insulin. For the current day only the long-lasting (basal) entry of 10 mmol/L and a bolus for breakfast at around 7am of 2 mmol/L is visible.

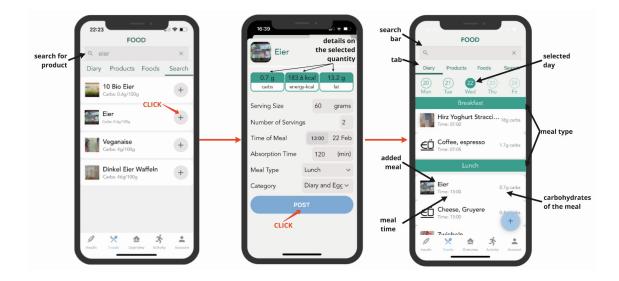
the insulin history. The dates they can select are only past dates and for the purpose of this study users can only go back two days. To prevent users from getting sidetracked by the insulin history, which is not the main focus of our evaluation study outlined in Section 4, users are limited to only go back a maximum of two days. Underneath, a list of insulin administrations of the selected day is shown. Each listed insulin administration shows the type of insulin, administration time and units administered.

Add Insulin View The goal of this view is to add insulin injections to the database. Clicking on the "Add Insulin" button in the Insulin History View redirects the user to the Add Insulin View. The Add Insulin View allows the user to add new insulin injections. The users can select the insulin type, administration location, insulin units injected and the time of insulin injection. The insulin type can be selected from a pre-defined list including ultra-rapid-acting, rapid-acting and longlasting insulin types, the default selection is ultra-rapid-acting. The insulin type determines the peak time and action-duration of the insulin, explained in Section 3.3.2, that defines the shape of the exponential insulin curve, and thus the insulin absorption rate. The administration location can affect the time it takes for the insulin to reach the blood stream. A general guideline for individuals with T1D is that injecting insulin closer to the heart results in a faster onset of action (cf. Section 3.1. The units of insulin injected can be entered as whole and as decimal numbers. To prevent retrospective bias during the user study, insulin injection times can only be entered for the current day. Once the user has submitted the new insulin entry, the views Active Insulin View, Blood Glucose View and Insulin History View will be updated. All the semi-randomly generated values from the time of insulin addition are reset and updated, resulting in an updated Blood Glucose View. Consequently, the prediction based on the semi-randomly generated blood glucose values as well as the insulin entries will be updated. In summary, adding an insulin value updates the *Active Insulin View* such that the user can track the remaining insulin in their body, supports the blood glucose prediction algorithm and allows the adjustment of the semi-randomly generated blood glucose values.

**Abby's Case:** After lunch Abby entered that she took some units of rapid acting insulin in the Add Insulin View, to counteract the carbohydrates that she ate. In the Insulin History View she can check again how many units of insulin she took.

## 3.4.3 Meals Views

The *Meals Views* are designed to help users create meal entries, by searching for existing products or creating new products. The meals view consists of three parts 1) A search bar on top, 2) tabs allowing to navigate to the *Meals Diary View*, *Products Overview*, *Foods Overview*, and the *Search Results View*. Throughout this description we will use products to refer to foods that are either stored in the Food databases or have been created by the user. Meals are products with a predefined serving size and number of servings.



**Figure 3.11:** How a user can search for a product (left), adjust the amount of product (middle), and view the added meals of the current day, including the newly added product (right). (left) The *Search Results View* depicts a keyword search for eggs (in German, Eier) and the resulting entries from the Open Food Facts database [114]. Each result shows an image of the product and the number of carbohydrates per 100g. (middle) The *Add Meal View* depicts the selected product, in this case, eggs. Below the name and image of the product, the nutritional information, such as carbohydrates, for the selected amount of product, is depicted. These numbers change depending on the serving size and the number of servings that can be entered by the user below. Additional values are editable by the user, as described in the *Add Meal* paragraph. (right) The *Meal Diary View* depicts the current day (22nd), meal entries separated by meal type, the meals consumed, including the time of consumption and the number of carbohydrates consumed. Additionally, the newly added product (eggs) is depicted according to the selected serving size and number of servings.

**Meals Diary View** The goal of the *Meals Diary View* is to provide users with the details of the daily meals consumed, including meal type, meal name, time consumed and number of carbohydrates consumed. On top of the *Meals Diary View* a small calendar is displayed where users can select for which day they would like to see their meal entries. As with the *Insulin History View* users can only select a couple of days into the past to view their Meal entries. A list of meals consumed on the selected day is located below the calendar. To structure the meal entries and allow uses to investigate their eating patterns for different meal types, the meals are grouped by meal type. Each item in the list shows a small image of the meal consumed, the name of the meal, the time the meal was consumed as well as the number of carbohydrates and fat it contained. The number of carbohydrates and fat is dependent on the serving size and number of servings that the user entered when adding the meal. The number of calories consumed is intentionally not shown due to the negative impact nutrition tracking apps can have (see Section 2.2.4)

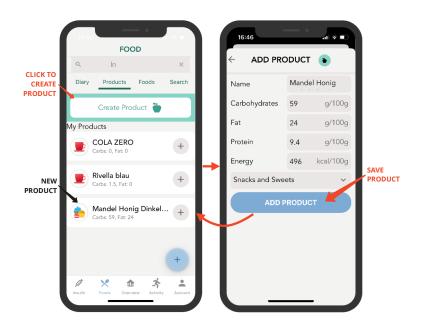
**Add a Meal** To add a meal, users have four options; 1) conduct a keyword search using the *Search Bar* on top of all the *Meal Views* 2) select one of the previously consumed products in the *Food Overview* 3) create their own product in the *Create Product View* and add it as described in 4), and 4) select a previously created Product in the *Products Overview*. Following any of these four steps the user will be redirected to the *Add Meal View*.

1) Search Bar and Search Results View The goal of this view is to allow users to search for products of which they do not know, for example, the number of carbohydrates. The *Search Bar* allows the user to search for a specific product in two food databases; 1) Open Food Facts [114] and 2) FoodData Central [3]. After entering a keyword into the *Search Bar* and hitting enter, the *Search Results View* Tab is automatically selected. The results of the product search is depicted in the *Search Results View*. The *Search Results View* displays a list of found products, in both databases including a product image, the product name, and the number of carbohydrates (grams/100gram) and fat (grams/100gram). Each listed product has a plus symbol with which the user is redirected to the *Add Meals View* which allows users to add the product as a meal.

**2) Food Overview** The goal of this view is to simplify the addition of frequently consumed products for the user. To log a previously consumed product, the user can use the *Food Overview*. The *Food Overview* shows a history of all the products that the user has consumed resp. added as a meal. The consumed products are presented using a list like interface, sorted by how frequent a product has been added by a user. Each product in the list has a plus symbol with which the user is redirected to the *Add Meals View* to re-add their frequently consumed product using a different serving size, number of servings or time consumed. Each product listed shows, how often the user consumed the product, the number of carbohydrates (g/100g) and fat (g/100g), as well as a product image and the product name, similar to the *Search Bar* results.

**3) Create Product View and Products Overview** The purpose of this view is to allow users to add their own products. It allows users to add a menu they frequently consume as a product, or add a product that they could not find in the two food databases provided. To add a product users can select the Products tab and click on the *Create Product* button, redirecting the user to the *Create Product View*. The user can specify the name of the product, the number if carbohydrates, fat, protein and energy per 100g of product, as well as the product category. After creating a product the product will be available in the *Products Overview* and ready to be added as a Meal from there.

**4) Products Overview** The goal of this view is to give users an easy way to see the products that they have created and add them as a meal. The *Products Overview* shows all the products that



**Figure 3.12:** On the left the *Products Overview* and on the right the *Add Products View*. (left) *Products Overview* has on top a product creation button. Just below that there is a list of products that have been created by the logged in user. In this example, cola zero, rivella blau and the newly added product called Mandel Honig Dinkelgebäck. Each product in the list shows an icon, the product name, the number of carbohydrates and fat per 100g of product as well as a plus button. (right) The *Add Product View* allowing users to specify a product by selecting its name, and nutritional values per 100g of product as well as an icon. In this example a product called Mandel Honig Dinkelgebäck is created that contains 59 grams of carbohydrates, 24 grams of fat, 9.4 gram of protein and 496 kcal per 100g of product. Once a product has been created by using the *Add Product View* the product will be displayed in the *Products Overview* 

the user created and allows the user to create new products. Just below the product tab, there is a button for users to create a new product, which will redirect them to the *Create Product View*. The already created products are listed below, including the product image, name, the grams of carbohydrates and fat per 100g. Each listed product has a plus sign button on the right that allows users to redirect to the *Add Meal View* using the created product.

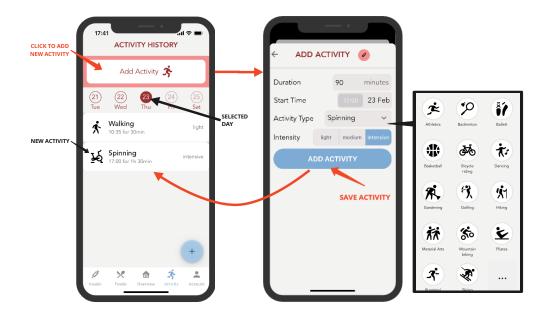
Add Meal View The purpose of this view is to allow users to record and therefor track the meals consumed. We have previously discussed the three different ways to arrive at this view using the *Search bar* with its associated *Search Results View*, *Food Overview*, *Create Product View* and the *Products Overview*. On top of the *Add Meal View* an image of the product as well as the product name is depicted. Below that you can see the nutritional values of carbohydrates, energy and fat for the specified serving size, number of servings and product selected. Changing the serving size or/and the number of servings updates the nutritional values shown. Below the nutritional content visualization the user can specify the serving size, number of servings, time of the the meal, absorption time, meal type and category. The serving size describes the weight of one unit of the product e.g. if an egg is 60 grams heavy the user would enter 60. The number of servings can be entered a decimal numbers and is useful i.e. if the user ate two eggs a 60g each they can enter 2 here. The user can specify when during the current day he consumed the meal. The absorption time allows users to take an educated guess at how long it would take for the food to be absorbed by their body. As carbohydrate absorption is food dependent and also individual for

different users we allow user to specify the carbohydrate absorption time. In the *leaflet* provided to users during the study we present users with some hints at common carbohydrate absorption times (cf. Section F). Users can select a meal type such that users can specify what purpose the meal had (breakfast, lunch, dinner or snack). Finally, users can also select the meal category from a predefined list of categories. Adding a Meal will update the *Meals Diary View*, the *Food Overview* and the *Active Carbohydrate View* in the *Overview*, as depicted in Figure 3.12.

**Abby's Case:** Since Abby ate with her colleague's at a restaurant for lunch she could not weigh her food. Thus she uses the search bar on top to search for the food that she ate; Spaghetti and tomato sauce. She selects the recipe for spaghetti and tomato sauce, using an estimated serving size. Even tough the glycemic index of white pasta is on the lower side she thinks that it will take about 2 hours for the carbohydrates to be absorbed as her meal seemed to contain very little fat. She enters 2h for the absorption rate of the food. After saving she can see her food entry in the food history screen of the app. Going back to the home screen she can see when the peak of carbohydrate absorption will be and thus plan her insulin injection keeping that in mind.

### 3.4.4 Activity Views

The activity Views allows users to add an activity using the *Add Activity View* and look at the *Activity History* of the past few days.



**Figure 3.13:** On the left the *Activity History View* and on the right the *Add Activity View*. The *Activity History View* (left) has on top a button to add new activities. Just below that is a small calendar where users can select a day of history to view. Currently the 23rd is selected. Below the calendar there is a list of activities performed on that day. In this example the user went for a light walk of 30minutes at 10:35 and had an intensive session of spinning for one hour and 30 minutes at 17:00. The *Add Activity View* (right) is where users can add an activity by selecting its duration (min) the starting time, activity type and its intensity. In this example an intensive spinning class of 90minutes that started at 17:00 is about to be added.

**Add Activity View** The goal of this view is to record activities of users. The *Add Activity View* allows users to enter a new activity. Users can specify the activity type, the time the activity was performed, the activity duration, and the activity intensity. Only start times of the current day can be selected. For the activity type the user can select an activity from a pre-defined list of activities, as depicted in Figure 3.13. We allow users to select from three different levels of activity intensity; "light", "medium" and "intensive". Once an activity has been added it will be listed in the *Activity History View*.

**Activity History View** The goal of this view is to allow users to see a history of conducted activities and potentially draw conclusions about the relation of activity and blood glucose concentration. The *Activity History* shows a daily history of the users activity of the current or previous days. On top there is a button allowing to add an activity which will redirect users to the *Add Activity View*. Below, there is a calendar allowing users to view the previous two days of activity. Underneath is a list like interface showing the different activities the users has entered including, activity type, activity start-time, activity duration and activity intensity.

**Abby's Case:** To assess whether some kind of physical activity is still impacting her blood glucose levels, Abby goes back to the previous day to check whether she has done some kind of exercise. This could be important for her to see if her blood glucose might react slightly different than usual.

# **Chapter 4**

# Qualitative User Study Design and Analysis

This chapter presents the study design. First, we provide an overview of the study procedure as well as how we tried to address each of our three research questions. The study procedure is divided into three phases each of which addresses one or two research questions. Next, each of the three phases is described in terms of the methodology used and its specifics. Finally, we will present the methodologies used for analyzing the data produced by the three phases of the study design.

## 4.1 Overall Study Procedure

The overall study procedure comprises a pilot study followed by a three-phase study. The latter encompasses a background and introductory phase, followed by a deployment ESM-study, and a final phase for reflecting on participants experience with MOON-T1D.

The goals of the **pilot study** were twofold: (1) testing MOON-T1D functionality-wise and (2) testing the interview structure and timings. Due to the challenging to find participants with T1D, the pilot study was conducted with five participants recruited within the People and Computing Lab of the University of Zurich along with other students, PhDs, and postdocs from the University of Zurich or ETHZ. Subsequently, the interview questions were adapted to reflect lessons learned from the pilot study.

The **first phase** of our study aimed to address the research question  $RQ_1$ : How do the current management practices affect blood glucose predictions?. This phase employed a questionnaire (5 min), a semi-structured interview (25 min), and an explanation of MOON-T1D (10 min). The objectives were to gather socio-demographic and MOON-T1D setup-related data, to learn about participants' present self-management practices and to introduce and explain MOON-T1D. To learn about participants' current practices we asked participants to describe their daily life with T1D to us and assessed different aspects of interest such as nutritional estimations.

The **second and third phase** of our study aimed to address  $RQ_2$ : What is the lived experience of people with T1D using an all-encompassing blood glucose prediction app? and  $RQ_3$ : What factors and everyday aspects shape people's needs and expectations of blood glucose predictions?

To answer  $RQ_2$  and  $RQ_3$ , we conducted an Experience Sampling Method (ESM) study (5 days) as the **second phase** of the study. Our objectives were to gain an understanding of participants' lived experience with and expectations from blood glucose predictions. We believed that it was necessary for them to use the app in their everyday lives. To understand participants experiences they received a limited number of notifications (between two and three) leading to a short

questionnaires that participants could complete directly in MOON-T1D. The questions presented captured prediction and uncertainty-related preferences, as well as questions regarding their current situation and willingness to invest time.

The **third phase** of the study consisted of a semi-structured interview (30 min). Our goal was to evaluate participants' perception and experience with MOON-T1D ( $RQ_2$ ) and particularly the predictions shown in MOON-T1D ( $RQ_3$ ). The questions were specifically designed to capture different aspects of their experience and understand their perception of MOON-T1D and ESM-study answers.

# 4.2 Participant Recruitment

To recruit participants, we created a flyer, which is displayed in Appendix G.1. Subsequently, we reached out to 17 diabetologists, a medical newsletter, and a center for endocrinology to ask if they would be willing to distribute the flyer to their patients. To be eligible to participate in the study, individuals needed to be between 18 and 70 years old, diagnosed with diabetes for at least 12 months, regularly use an Android or iOS smartphone, and have a sufficient level of proficiency in either English or German. Informed consent was obtained from participants in phase 1 before starting the demographic questionnaire (The informed consent can be found in Appendix I). Human subjects approval from the faculties ethics board was obtained prior to the study, attached in Appendix H.1. The recruitment period of diabetologists and participants alike ran from the 13th of February 2023 to the 17th of April 2023. As an incentive participants received a grocery voucher worth between \$150 and \$180.

## 4.3 Phase 1: Questionnaire, Interview, Training

This section presents the first session with participants which consisted of (1) obtaining informed consent, (2) a demographic questionnaire, (3) the initial interview on participants' practices, and (4) participant training with MOON-T1D.

### 4.3.1 Demographic Questionnaire

Just after obtaining informed consent from participants, we gave participants a small questionnaire, presented in Appendix: E. Participants were allowed to ask any questions regarding their understanding of the terms and concepts presented in the questionnaire. The goal of the questionnaire was to collect demographic information and values, such as insulin sensitivity, necessary for pre-setting MOON-T1D. The demographic information collected was tailored to get background information on participants' T1D management and included among others their HbA1c and how long they have lived with T1D. The parameters required for pre-setting MOON-T1D included measurements needed for the calculations presented in Section 3.3, such as insulin sensitivity and target blood glucose range. We hoped to decrease the drawback of using semi-randomly generated blood glucose values by at least tailoring MOON-T1D according to their specifics Additionally, also current tools allow adjustment of target ranges and insulin sensitivity factors, as presented in Section 2.3.4.

### 4.3.2 First Interview

During the initial semi-structured interview, our goal was to understand participants self-management including the challenges they face. We also aimed to gain insight into participants' familiarity and

understanding of various aspects of T1D self-management, with a focus on blood glucose predictions.

The interview structure was designed to ensure a smooth entry into the interview by starting with two open-ended questions. The design of the interview was intended to create a natural conversation flow, avoiding abrupt shifts in topics that may potentially disrupt participants and impede their ability to convey their thoughts effectively. Furthermore, we attempted to ask participants about specific life situations and/or had backup questions or examples in case participants found certain questions difficult to answer or provided little context.

Because we anticipated, that the majority of our participants would speak German or Swiss-German, we translated the interview questions to German. During the interview, if participants felt more at ease expressing themselves in Swiss-German, one of the authors would translate the questions on the fly. The interview questions were iteratively refined by the two authors. Moreover, two pilot interviews were conducted to ensure that our interview questions were clear, comprehensible and sufficiently detailed. Based on the pilot interviews the question structure was revised. Additionally, questions were reformulated for clarity and to avoid one-word answers from participants. Finally, we created additional comprehensive examples to help participants understand the questions better or to encourage them to provide more detailed accounts of their experiences.

In the following list we detailed the interview questions, accompanied by an explanation of the underlying motivation for each inquiry and additional prompts aimed at providing more precise information to the participants if required.

#### 1. What motivated you to participate in this study?

*Clarification options:* What is your opinion of our flyer? What aspects of our study did you (dis)like? What aspects of this study interested you the most?

*Reason:* This question was aimed at anticipating and understanding participants expectations of this study. Additionally, things participants pointed our might help us with participant recruitment in the future.

#### 2. Can you describe how you manage your diabetes on a daily basis?

*Clarification options:* Can you describe to me how you managed your diabetes today? *Reason:* The goal of this question was twofold. For one we wanted to use an open-ended question to make the start of the interview easy for participants. Additionally we also wanted to gain insight into participants' current practices.

## 3. **How happy are you with your current diabetic control?** *Tentative follow-up questions:* If participants answer no, ask them why they are not happy with their diabetic control?

Clarification Options: How content are you with your blood glucose?

Reason: We wanted to assess participants relationship with their diabetes.

#### 4. How knowledgeable do you feel regarding your diabetes self-management?

*Clarification Options:* For example regarding: (1) existing technologies (2) how you handle your blood glucose in different situations (3) what affects your blood glucose levels. *Reason:* OUr objective is to ascertain whether there is a disparity in expertise among participants and to identify any discernible variations in their perceived T1D self-mangment knowledge. Moreover, we aimed to determine whether participants perceive the process of obtaining information about their diabetes to be straightforward.

#### 5. How knowledgeable do you feel regarding nutrition related to diabetes management? *Reason:* To assess participants' knowledge regarding the nutritional content of food. We

hoped that this would allow us to contextualize their behavior and opinion on MOON-T1Ds *Meal Views*.

#### 6. How comfortable do you feel regarding nutritional estimations of food?

*Clarification Options:* For example would you feel confident about your carbohydrate estimation of your [breakfast-lunch-dinner], *Reason:* To investigate how confident participants are regarding nutritional estimations and whether support in that area would be beneficial.

#### 7. What are techniques you use to manage your nutrition intake?

*Clarification Options:* If you think about today's [breakfast-lunch-dinner], how would you assess its carbohydrate content?

*Reason:* We wanted to understand participants' dietary practices with respect to carbohydrate intake and food consumption.

#### 8. What kind of diabetes-related technologies are you currently using?

*Clarification Options:* To clarify, the technologies could be for the management of insulin injections, blood glucose, activity, nutrition tracking, etc.

*Reason:* We wanted to understand what technologies participants' are familiar with to potentially distinguish between participants based on the technologies they use. Moreover, the technologies participants' use can have an impact on their self-management practices, see Section 2.2.

#### 9. What kind of diabetes-related apps are you currently using?

*Clarification Options:* An example would be if you use a nutrition tracking app or an app to see your CGM data.

*Reason:* We wanted to assess the types of apps participants' are already acquainted with. This could help us understand what participants may compare MOON-T1D to and whether they currently employ multiple apps to manage their diabetes.

#### 10. Are you content with the technologies that you are currently using?

*Tentative follow-up questions:* Why are you [not] content with the current apps that you are using?

*Clarification Options:* Are there any pros or cons of your [technology name]?

*Reason:* Our goal was to understand participants' perceived drawbacks of the technologies they currently use.

# 11. How much time do you think you currently spend on average per day taking care of diabetes-related activities?

*Tentative follow-up questions:* Do you think that is too much time spent? What do you spend the most time on?

*Clarification Options:* How much time did you spend looking at your [name of blood glucose device and insulin device] yesterday?

*Reason:* To evaluate the amount of time individuals typically allocate towards diabetes management. This could help us determine the extent to which participants' are willing to invest time in documenting T1D management data.

# 12. Do you feel like you have a good idea of how your blood glucose levels change throughout the day?

*Tentative follow-up questions:* Do you sometimes adjust your activities to your blood glucose? *Clarification Options:* To clarify, with this, we mean more the general blood glucose curve during a day depending on what you do.

*Reason:* We hoped that this question would invoke thoughts about participants' practices and behavior.

#### 13. Are there things you do to anticipate your blood glucose?

*Clarification Options:* If you think about [a previous situation they described] do you do anything in order to assess how your blood glucose will change in the future?

*Reason:* We wanted to understand whether participants already anticipate their blood glucose values and how they would do that.

14. Have you heard of blood glucose prediction, or even used an app supporting blood glucose prediction?

*Tentative follow-up questions* In what context did you hear about blood glucose predictions? What kind of apps have you used?

Reason: Our goal was to understand participants' knowledge of blood glucose predictions.

#### 15. Do you think blood glucose prediction could be useful for you?

*Tentative follow-up questions:* How could they be useful to you? Why are they not useful to you?

*Clarification Options:* If I would tell you now that your blood glucose will be [some value] mmol/L one hour into the future - would that be useful to you?

*Reason:* The aim of this question was to discern whether participants' answer regarding usefulness would change after using MOON-T1D in the ESM-study.

## 4.3.3 Participant Training

For participants to effectively use MOON-T1D during the 5-day deployment ESM-study, we provided them with an initial introduction to MOON-T1D. Using the smartphone of one of the authors, the introduction of MOON-T1D was structured as follows:

- *Login Screen:* We informed participants that they will receive an anonymous login utilizing their participant number, one day after the study.
- Proceeding to the *Overview* we explained the blood glucose visualization and associated prediction. We also clarified here how the semi-random blood glucose generation works (see Section 3.3.3). Additionally, we told participants that they can test and enter fictitious blood glucose values.
- Next we explained the *Active Carbohydrate View* to participants by first showing them the different ways they can add carbohydrates as described in Section 3.4.3. Subsequently we explained to participants how the created entry or entries affected the visualization shown in the *Active Carbohydrate View*.
- Next we introduced the *Insulin History View*, explaining how to add an insulin entry and show participants how their entry affects the *Active Insulin View*.
- Finally, we provided participants with a quick introduction to the **Activity Views** by adding a new activity and showing them the resulting *Activity History View*.

After every view introduced, we asked participants if they have any questions. It is important to note that the extent of instructions provided may have varied depending on the participants' level of comprehension. To ensure participants' understanding of MOON-T1D, and their ability to independently operate it throughout the 5-day study, we asked them to complete the following tasks:

- Please add the carbohydrates you ate this [morning \* lunch \* dinner] to the app.
- Please add a new blood glucose value to the app.

 Please tell me what kind of actions you would take provided with the data shown on the app's home screen.

The first two questions are aimed to ensure participants are able to operate MOON-T1D. The last question serves the purpose of testing participants' comprehension that the data entered and visualizations presented should not have an impact on their diabetes management. Additionally, we will provide participants with a leaflet described and depicted in Appendix F.

## 4.4 Phase 2: ESM-Study

To collect data from participants during their daily lives using, MOON-T1D we used the Experience Sampling Method (ESM) [153]. Using an ESM allowed us to capture participants' responses "in the moment". To reduce the burden placed on participants, we decided against using a diary study. This is because in a diary study, participants would have needed to remember to check their app to fill out their diaries at a specific time [153]. Moreover, using the ESM, participants cannot fabricate diary entries at a later point in time. We excluded using an elicitation diary study, where participants capture media and discuss it at a later point in time with researchers, which could introduce retrospection bias, [153]. Sending our ESM-study questionnaire regularly, we hoped to engage participants in the app and encourage reflection of the usefulness of predictions. Of the six potential challenges that arise when using the ESM, as presented by Van Berkel et al. [153], we specifically want to mention how we addressed the three most challenging ones for this work:

- **Participant Burden Challenge** describes the heightened burden of answering questions throughout participants' daily routine [153]. We employed a four-tiered approach to address this challenge. First, we sent participants a limited number of notifications per day (between 2-3 notifications). Second, once a notification was received, we regularly reminded participants to complete the questionnaire. However we allowed participants to postpone the completion of the questionnaire for up to two hours after receiving the first notification. Third, we designed our questions, mostly using drop-downs with informative most common choices, such that minimal text input was required from participants. We however also provided the option to enter an alternative text-based answer if desired by participants. And finally, we split our ESM-study questionnaire into two parts to avoid participants needing to spend too much time at once when filling out the questionnaire.
- Participant Retention Challenge pertains to study dropouts due to frequently required interaction with MOON-T1D [153]. We tried to address this challenge with an incentive strategy. We provided participants with a base compensation of 150 CHF and an additional compensation depending on whether participants filled our 50% 75% or 100% of the ESM-study questionnaires.
- Platform Heterogeneity Challenge referred to the large number of different devices that present variations regarding hardware and software requirements [153]. In our case, we had to consider the different mobile operating systems (iOS vs. Android) and device screen size as well as notification reception. We, therefore, chose React-Native, which allowed us to build a cross-platform mobile app. Additionally, MOON-T1D was tested on eight different mobile phones three of which were using an iOS and five an Android operating system. We tested th notifications of MOON-T1D by sending notifications at different and sometimes nonsensical time intervals, such as sending the same questionnaire twice while the previous questionnaire was not answered jet. We also tested different screen sizes on the various mobile phones used.

	Day 1	Day 2	Day 3	Day 4	Day 5
Breakfast		ESM			ESM_MEAL
Early morning			ESM_MEAL	ESM	
Later morning					
Lunch	ESM	ESM_MEAL			ESM
Early afternoon				ESM	
Later afternoon		ESM			
Dinner			ESM	ESM_MEAL	
After dinner	ESM				
Before bedtime					ESM

**Figure 4.1:** Schedule of ESM-study questionnaire notifications sent to the participants. Each schedule was adapted to the unique lifestyle regarding mealtimes of participants. ESM represents the first questionnaire on blood glucose prediction, while ESM\_MEAL represents the questionnaire regarding willingness to spend time.

During the five consecutive study days ESM-study notifications were scheduled according to the pre-defined scheduling plan, depicted in Figure 4.1. We designed the question schedule to capture responses while being in various situations throughout the participants' day. Each of the schedules was individually adapted to the meal times from participants, obtained in the *Demographic Questionnaire*. The ESM-study questionnaire was available in two languages and consisted of the following questions:

#### 1. How do you feel physically right now?

*Input Type:* Likert scale *Input Options:* Selection from very bad (1) to excellent (5) *Reason:* We wanted to assess participants current physical state. This could be interesting to later determine whether participants' physical state had any influence on their answers.

#### 2. How do you feel emotionally right now?

*Input Type:* Single choice with optional text input *Input Options:* relaxed, energetic, happy, stressed, tired, down, sad, other (text input) *Reason:* We wanted to capture participants' current psychological state, to contextualize our

findings. It could be interesting to see whether participants' psychological state influences their answers.

#### 3. What are you doing right now?

*Input Type:* text input *Reason:* To understand participants situational context.

# 4. What actions would you take given the above-indicated blood glucose level? [see Figure 4.2 (left)]

*Explanation:* Please answer the question in light of your current situation and the indicated blood glucose.

Input Type: Single choice with optional text input

*Input Options:* nothing, inject insulin, eat something, do physical activity, re-measure my blood glucose in the near future, other (text input)

*Reason:* Since we will show participants the same question before and after seeing the prediction of their blood glucose, we might be able to notice changes in behavior that are caused by the prediction.

#### 5. Is the blood glucose prediction shown above useful to you?

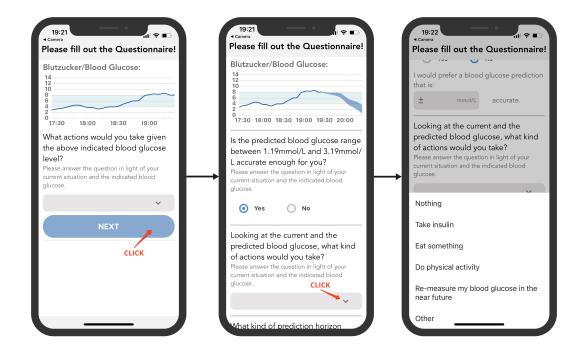
*Explanation:* Please answer the question in light of your current situation and the indicated blood glucose.

Input Type: Single choice with optional text input

*Input Options:* yes, no (follow up question)

*Follow-up question:* Please explain your answer in a few words. (text input)

*Reason:* To assess whether participants' find predictions always useful independent of their current situation.



**Figure 4.2**: The ESM-study questionnaire is sent to participants' mobile phones two to three times per day. On the left is a visualization of the past two hours of blood glucose values with a single select question on what actions they would take. In the middle is the same visualization but with a prediction one hour into the future. There is a single select radio button style question on prediction accuracy and a single select question on the actions they would take. On the right, you can see the options provided on what actions participants would take.

6. Is the predicted blood glucose range between [current blood glucose - 0.5] mmol/L and [current blood glucose + 0.5] mmol/L accurate enough for you? [see Figure 4.2 (center)] *Explanation:* Please answer the question in light of your current situation and the indicated blood glucose.

Input Type: Single choice with optional text input

*Input Options:* yes, no (follow up question)

*Follow-up question:* I would prefer a blood glucose prediction that is: +/- [text input] accurate.

*Reason:* We wanted to determine how precise a blood glucose prediction would need to be for participants' and whether that changes depending on the situation?

7. Looking at the current and the predicted blood glucose, what kind of actions would you take? [see Figure 4.2 (center)]

*Explanation:* Please answer the question in light of your current situation and the indicated blood glucose.

Input Type: Single choice with optional text input

*Input Options:* Same as for question 4.

*Reason:* We wanted to understand how blood glucose prediction influences our participants behavior. To check whether participants answers changed compared to question 4.

#### 8. What kind of prediction horizon would you like right now?

*Explanation:* Please answer the question in light of your current situation and the indicated blood glucose.

*Input Type:* Single choice with optional text input

*Input Options:* less than 30 minutes, 30 minutes, 1 hour, 2 hours, 3 hours, 4 hours, 5 or more hours

*Reason:* To assess participants currently desired prediction horizon. To understand whether the prediction horizon differs depending on participants' situation.

#### 9. I feel like my answers were influenced by the following:

Input Type: Single choice with optional text input

*Input Options:* the blood glucose is stable, the blood glucose is changing fast, the blood glucose is too low, the blood glucose is too high, sports activity, carbohydrate consumption, feeling uncomfortable, nothing in particular, other (text input)

*Reason:* To see what participants think influenced their answers.

The second questionnaire was more about how much time they would be willing to invest in different daily situations.

1. Would you be willing to spend 2 minutes recording information about your recent food intake to receive a blood glucose prediction right now?

Input Type: Single choice

Input Options: yes right now, no but within the next hour, no

*Reason:* Determine the time participants would be willing to spend to record their food intake.

#### 2. Please explain your answer in a few words.

*Input Type:* text input *Reason:* Give participants the opportunity to reason about their choice.

3. What do you feel influenced your answer?

*Input Type:* Single choice with optional text input

*Input Options:* I currently don't have time, My future blood glucose is currently not that important, I would like to know my future blood glucose, nothing in particular, other (follow up question)

*Follow-up question:* Please specify in a few words what influenced your answer. *Reason:* Understand what could have influenced participants' answers.

# 4.5 Phase 3: Post ESM-Study Interview

During the final interview, conducted after the ESM-study, we tried to capture participants' perceived experiences and thoughts evoked through the use of MOON-T1D and our questionnaire in the past few days. The interview structure, language, and question refinement were reflective of the initial interview described in Section 4.3.2.

The interview consisted of two parts, the first was mostly about participants' experience and concluded by asking participants to click around the app and tell us what they liked or disliked about each view. The second part focused mostly on the predictions generated by the app and participants' experience with them. Followed by a final evaluation of different ways in which a blood glucose prediction could be visualized.

#### 1. What was your experience using MOON-T1D over the past few days?

*Tentative follow-up questions:* What did you like about using MOON-T1D? What did you dislike about using MOON-T1D?

Clarification Options: How was it for you to use MOON-T1D yesterday?

*Reason:* This should be an easy entry question into the second interview. Our aim is to gather additional insights from participants regarding their experience using an "all-encompassing" app, beyond the questions we have prepared for participants.

#### 2. Did you learn anything new while using the app?

*Clarification Options:* Did you learn anything about your blood glucose while using the app? (intended to make the question more concrete)

*Reason:* The question is intentionally open-ended to understand the potential benefits that such an app may offer to participants, Additionally we wanted to determine whether participants have acquired any novel insights or knowledge while using MOON-T1D.

#### 3. Were you able to navigate and use the app easily?

*Tentative follow-up questions:* Was there something that you found difficult to understand in the app?

*Reason:* To evaluate the user experience of MOON-T1D and identify potential areas of dissatisfaction.

4. Which of the functionalities of the app did you think could be the most useful to you? *Tentative follow-up questions:* Why did you think this functionality was particularly useful? *Reason:* To have an overall understanding of why MOON-T1D could be useful to participants.

#### 5. How much time do you think you spend per day interacting with the app?

*Tentative follow-up questions:* Was that too time intensive for you? What took you the most time?

*Clarification Options:* How much time did you spend [last day of usage] using the app? (making it more concrete)

*Reason:* To assess participants perceived usage of MOON-T1D. We also potentially hoped to see if there is a discrepancy between participants perceived usage and their actual usage recorded during the ESM-study.

#### 6. Would you keep using the app as is if possible?

*Tentative follow-up questions:* Why would you [not] want to keep using MOON-T1D? What would need to change for you to want to use the app?

*Reason:* To assess participants experience with MOON-T1D and changes that they would need, hinting at possible challenges.

7. Could you click around the app for me and point out things that you liked or disliked about the app?

*Tentative follow-up questions:* Why did you think [statement of participant]? *Clarification Options:* What did you think about [view name]? *Reason:* To provide an easy way for them to recall things while looking at the app. Get an idea of the perceived benefits and drawbacks of the different views and their designs.

#### 8. What did you think about being able to see a prediction of your blood glucose?

*Tentative follow-up questions:* What did you find [answer of participant] about it? *Reason:* This should provide us with general feedback on predictions. Additionally, we want to start with an open-ended question regarding the predictions to help participants ease into the topic of predictions. This allows us to potentially discover things we did not anticipate about their behavior and perception of the predictions shown.

9. Do you think that predictions have the potential to change your perception of your blood glucose?

*Tentative follow-up questions:* What did you think changed your perception of your blood glucose behavior?

*Clarification Options:* If the current app that you are using would show predictions in the future how would that affect your diabetes management? (intended to provide participants' with a more concrete example)

*Reason:* Elicit whether participants' think that seeing a blood glucose prediction would affect their perception of the blood glucose behavior. To see what the potential impact of showing blood glucose predictions could be.

10. While using the app, did you feel there were times when you would have liked to see a prediction of your blood glucose more than others?

*Tentative follow-up questions:* Why do you think it would be more important for you to see predictions if [their answer]?

*Clarification Options:* Do you think predictions are always equally useful to you independent of your current situation?

*Reason:* Assess whether, in certain situations, a prediction is more useful than in other situations.

# 11. You mentioned you would like to see a prediction before you do [answer to previous questions] - how far into the future would the prediction ideally be?

*Tentative follow-up questions:* Does that change if you receive a prediction while [another situation that is potentially more "normal"]

*Reason:* To understand whether participants' ideal prediction horizon changes depending on the situation.

- 12. When answering the ESM-study questionnaire, you entered that you wanted to have a prediction horizon [of, between] [their answers to question 8 in Section4.4]. Can you explain to me why you wanted [this particular, different] prediction horizon(s)? *Reason:* We hoped this question would help us to understand participants' ESM-study questionnaire answers about different prediction horizons.
- 13. When filling out the ESM-study questionnaire, you said that an accuracy of +/-[their an-swer] mmol/L would be accurate enough for you can you explain why? *Tentative follow-up questions:* Why was the accuracy sometimes +/-[their answer] mmol/L and sometimes +/-[their answer] mmol/L *Clarification Options:* +/-[their answer] mmol/L, for example, means for a blood glucose of 5.0 mmol/L between [5.0 mmol/L - their answer] and [5.0 + their answer] mmol/L.

*Reason:* Helping us to understand participants' ESM-study questionnaire answers on how precise a prediction would need to be for them.

14. With blood glucose predictions, it is generally the case that the further into the future we try to predict, the greater the error we can expect. [Handing participants Figure 4.3] Therefore, on the left you can see a prediction horizon of 2 hours with a prediction between 7.0 mmol/L and 11.0 mmol/L, meaning +/- 2 mmol/L. On the right you can see a prediction horizon of 30 minutes into the future with a prediction between 8.0 mmol/L and 9.0 mmol/L, meaning +/- 0.5 mmol/L. Which of these 2 predictions would you prefer and makes more sense regarding your daily management?

*Tentative follow-up questions:* Why do you prefer [their answer]? At what level of inaccuracy would a prediction no longer make sense for you?

*Reason:* To comprehend what kind of trade-off participants would be willing to make between prediction horizon and prediction accuracy.

15. Until now, you have always received a prediction based on what you have entered. But now there is another way I could make blood glucose predictions for you, it is called "what if" predictions. I'll explain it to you best with an example. For example, "If I eat 2 [croissants] now, what would my blood glucose be versus if I eat one [croissant]?" If you had the option to have "what if" predictions - would you prefer them?

*Tentative follow-up questions:* Do you think you would use the what if predictions everyday or not?

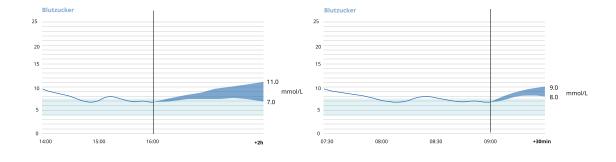
*Reason:* To assess also different kinds of predictions and their particular usefulness, inspired by Mamykina et al. [95].

#### 16. Did you like the design of the prediction?

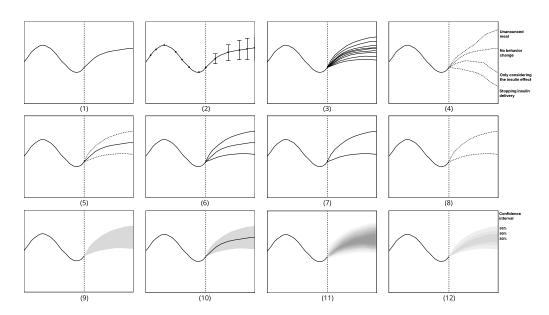
*Tentative follow-up questions:* What did you [not] like about it? Would you prefer the prediction to be textual [pointing at the Top Panel] or non-textual [pointing at the Blood Glucose View]?

*Clarification Options:* Looking at the prediction shown here, do you think the way it is presented to you is intuitive?

*Reason:* To assess participants visualization needs regarding blood glucose predictions. And additionally to evaluate what they thought about our design of predictions.



**Figure 4.3**: Participant preference for predictive glucose uncertainty visualizations. During the second interview, participants were presented with two options for predictive glucose uncertainty visualizations. Option A (left) displayed a prediction horizon of 2 hours with a range of 7.0-11.0 mmol/L meaning an accuracy of +/- 2 mmol/L. Option B (right) displayed a prediction horizon of 30 minutes with a tighter range of 8.0-9.0 mmol/L and thus a greater accuracy of +/- 0.5 mmol/L.



**Figure 4.4**: Continuous blood glucose prediction visualizations. Participants were presented with a series of blood glucose prediction visualizations, designed to seamlessly continue the representation of past blood glucose levels. With a focus solely on the design of the visualizations, participants were asked to provide feedback on what they liked or disliked about the various options presented. There was no expectation for participants to address all options. These visualizations draw upon related work on predictive blood glucose visualizations, as well as uncertainty visualization presented in Section 2.4.2. All figures were created by the author.

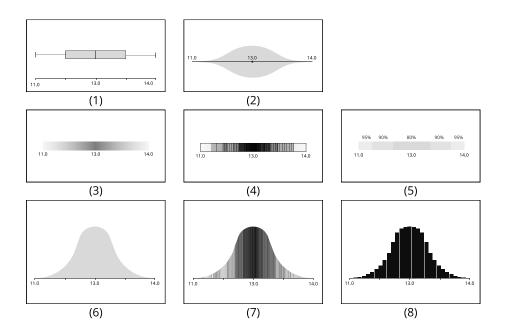
17. [Showing participants Figure 4.4] These are different ways we might show blood glucose predictions to you - can you look at these and point out things you like or don't like about them? Do you potentially have a favorite one?

*Tentative follow-up questions:* What do you [dis-]like about visualization Number [their answer]?

*Reason:* Getting an idea about what kind of blood glucose prediction and associated uncertainty designs participants like. Getting a hint on if there is a preferable way of visualizing blood glucose predictions and its uncertainty.

18. [showing participants Figure 4.5] These are different ways we might show blood glucose predictions to you - can you look at these and point out things you like or don't like about them? Would you potentially prefer them compared to the others? [Explanation that you could then select a specific point in time for which you would see this visualization] *Tentative follow-up questions:* What do you find [their answer] about it? Why do you prefer [their answer] of the two ways of visualizing blood glucose predictions? *Clarification Options:* These visualizations show you the probability of your predicted blood glucose to be between 11.0 and 14.0 mmol/L in different ways. The idea would be that you could check for different points in time, e.g. 2 hours into the future, how these probability distributions would look like.

Reason: Same reasoning as for the previous question.



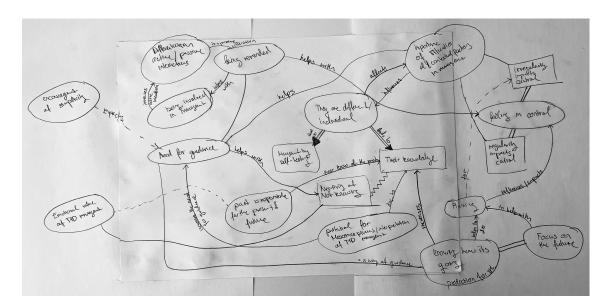
**Figure 4.5**: Point predictions. Illustration of different visualization methods for representing the prediction probability and its uncertainty for a single point in time. The top two plots are a box plot and a violin plot that are representing the prediction probability. The middle three plots visualize uncertainty using a gradient plot, a stripe plot, and an interval plot to represent prediction probability. The bottom three plots represent the probability as a normal distribution using density, density + stripe plot, and density + bar plot. All visualizations were created by one of the authors and based on uncertainty visualization papers from Kay et al. [77] and Van Der Veer et al. [156].

# 4.6 Data Analysis

To analyze our interview data as well as the responses obtained from the ESM-study questionnaire, we conducted a six-phase reflexive thematic analysis [30]. The phases consisted of (1) data familiarization, (2) data coding, (3) initial theme generation, (4) theme development and review, (5) theme refining, defining and naming, and (6) writing up [30]. Our interest in the lived experience of people with T1D using a mobile app meant that we adopted a broadly experiential orientation to our research. Being aware of how one is situated with regards to their research, as well as one's subjectivity, are important parts of reflexive thematic analysis [30]. I believe that this is particularly true in my case, as my own experiences of living with T1D will influence my approach to this analysis, as well as how participants might interact with and respond to me. Throughout the coding process, I was aware that while some of the things participants mentioned may resonate with events or thoughts that I experienced myself, others might not. I therefor tried to challenge myself throughout this process to try and assume different roles and therefor perspectives when understanding participants' comments.

Following the first **familiarization phase** of analysis, one author identified the following interesting analytical observations among others.

• The first observation we made was that participants treated the interview as if we wanted to convince them of our app. This made us aware that even though we specifically stated that this study was not about the particular software shown that it might have been difficult for participants to abstract that away.



**Figure 4.6**: Thematic map developed to visualize the relations between different initial themes and subthemes derived from the third phase of thematic analysis [30]. The round box represent subthemes while the round boxes represent our initial themes. Connection between boxes were added to show and understand the relationship between themes. Double lines meant that the relationship or influence was strong, while dotted lines indicated that the relationship was weak. The normal lines just indicated a relationship between themes while the zigzag lines indicate an opposing relationship. The map was meant to help the authors discover and understand patterns discovered in the dataset.

- The second observation we made was that for some participants it seemed to be extremely important to repeatedly state that they were happy with their management, also in relation to the impact the condition has on their lives.
- The third observation we made was that trying to use an app that did not show their own blood glucose values was differently difficult for participants. We, therefore, tried to reflect upon and consider that influencing aspect throughout the rest of our analysis

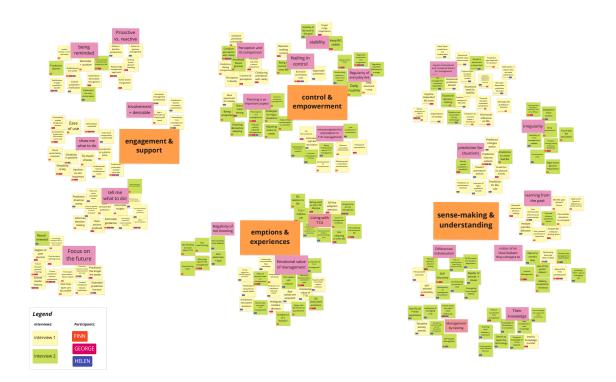
For the first phase of our thematic analysis data coding we decided to follow a systematic inductive coding approach [30], our research questions focus on the experience and perspective of our participants. Coding was done by the author of this thesis. We started the analysis with mostly semantic coding, which worked well to express users' concrete opinions and preferences. During the coding process, it became apparent that latent codes could better capture the participants' reasoning behind their answers and choices. Thus, we identified both semantic and latent meanings by concentrating on the lived experiences of individuals with T1D. During the coding process, we initially segregated the coding of the first and second interviews to enable the identification of any potential shift in participants' perspectives after using our app in the ESM-study. The initial coding process resulted in a total of 131 codes for the first interview and 179 codes for the second interview across all three participants. Each code was associated with a comment explaining its meaning in more detail and reflections of the author on the coded text part. We decided to add this to capture thoughts and reflections while coding such that a third party looking at a later stage at the different codes can gain some knowledge of the thoughts the code creator had behind assigning this code. We then moved to refine our initially generated codes by looking at and reviewing our codes for both interviews separately and in combination. This was done by the author of this thesis. We adopted this approach to ensure that we were aware of any similar codes developed in both interviews, as it was probable that participants would express comparable thoughts or perspectives in both instances.

To develop our **initial themes (phase 3)** one author reviewed the codes of the first and second interviews of all participants. Initially, one author grouped codes into 23 sub-themes. They were all somehow interconnected and evolved around participants' needs and their perceptions of the app.

Overlapping into phase four of the analytical process was the generation of a thematic map by one author, depicted in Figure 4.6. Phase four, **developing and reviewing** themes, involved a lot of reviewing of the original text abstracts related to codes and rewriting and redefining our subthemes as well as trying to relate them into larger over arching themes, done by the author. During that time we decided to write a case study for each of our three participants, that would complement the themes we were about to develop. To write the case study one author went through each of the interviews again and tried to understand particular differences between the participants that we wanted to explore in greater depth for our case study. This process of reviewing and analytically differentiating between our participants also highlighted common themes. The process involved in shaping our case studies therefore also helped us in our theme refinement and reviewing as the fifth phase of the analytic process.

For the fifth phase, **refining**, **defining**, **and naming themes**, two authors conducted an iterative refinement session where one author tried to explain each theme in their own words as well as its relation to the other themes. This process of verbalizing the core concept of each theme helped us to understand which themes were related or needed reworking. After an intensive session of the two authors redefining and reordering codes and subthemes, we arrived at our four themes presented in Section 5.3, and depicted in Figure 4.7.

For the sixth and final phase, **writing matters for analysis**, selected representative data extracts and created the analytic narrative the result of which you can find in Section 5.3.



**Figure 4.7**: Final version of our theme development board. The board reflects our four final themes using orange sticky notes: first *control and empowerment* (top middle), second *sense making and understanding* (right), third *emotions and experiences* (bottom middle) and fourth *engagement and support*. Each theme group on the board comprises codes from all participants and from both interviews conducted. Several subthemes are shown using light-pink sticky notes, some of which will be discussed in Section 5.3. The light-yellow and light-green sticky notes represent the codes developed during the coding phase and included in the final diagram. The light-yellow sticky notes are from our first interview (see Section 4.3.2) while the green sticky notes are from our second interview (see Section 4.5). A label is added to each sticky note to indicate the participant(s) who made the statement(s) associated with the code. An orange label represents FINN, a pink label represents GEORGE and a violet label represents HELEN. (source: this diagram was created by the author using miro)

## Chapter 5

# Results

In the following chapter, we will present our results in the form of three case studies, a crossparticipant discussion of the individual case studies, and a thematic analysis. The case studies, on the one hand, serve as an introduction to our three participants. On the other hand, the case studies are used to discuss relevant aspects of the personal interviews and the ESM-study data related to the participant's unique experience with T1D and T1D self-management. Insights across the three case studies will be discussed in a short case study discussion. Lastly, the case studies and their discussion will be complemented by a thematic analysis consisting of four unique themes.

### 5.1 Case Studies

In this section, we will discuss the results of the two interviews and the ESM-study in the form of three case studies, one for each of our three participants. We will first briefly introduce our participants, who we will call GEORGE, FINN, and HELEN for the sake of anonymity. We will then continue to discuss some of the most relevant content from the personal interviews and findings from the ESM-study in relation to the participants' experience with their daily T1D self-management. Lastly, we will also discuss their thoughts on the usefulness of predictions, prediction horizon, prediction accuracy, and visualization preferences.

**GEORGE**, our first participant, joined our study due to his interest in new developments regarding closed-loop systems and mobile apps for T1D self-management. GEORGE is over 65 years old and has lived with T1D for 53 years. Although GEORGE has lived with T1D for many years, he does not have any health complications. GEORGE currently uses a closed-loop system consisting of a tethered insulin pump from Medtronic and a sensor from Guardian. GEORGE only uses the manufacturer-specific app for the Guardian sensor. He is quite happy with his current T1D management and stays within his personal blood glucose target range (5.5-7.5 mmol/L) about 80-90% of the time. He feels that all information necessary for his T1D management is provided to him either by the support group meetings or by his diabetologist. With one exception; he does not feel informed at all about which effect different foods have on his T1D management. Being retired, GEORGE has a regular daily schedule, with his wife usually cooking known meals for him. In his free time, GEORGE regularly plays badminton and goes cycling, which he is very passionate about. GEORGE has never heard of blood glucose predictions before but is interested in them.

**FINN**, our second participant, is between 45-54 years old and has lived with T1D for 32 years. FINN has been using an insulin pump for 19 years but switched to using an insulin pen and the FreeStyle Libre sensor a few years ago. Regarding apps, he only uses the app provided by the manufacturer of his sensor. FINN is overall content with his T1D management and stays within his personal target blood glucose range (4.0-7.0 mmol/L) about 65% of the time. Being part of a larger T1D self-help association, FINN feels like he has a satisfactory level of knowledge about T1D management. FINN's day-to-day life is quite diverse, as he works irregular shifts at the airport. This also means that his mealtime schedule is quite irregular, depending on which shift he is working. For example, he eats his breakfast sometimes at 03:30 AM and sometimes at 11 AM. In his free time, FINN likes to hike, swim, bike, and travel. FINN has some experience with blood glucose predictions on his FreeStyle Libre sensor, where the rate of anticipated blood glucose concentration change is indicated through text marks (i.e. arrows pointing up or down) [85].

HELEN, our third participant, is between 18-24 years old. HELEN has lived with T1D for 9 years and is currently using a closed-loop system. HELEN also uses the pump from Medtronic and the Guardian sensor, but no app whatsoever. HELEN is currently not satisfied with her T1D management, although her blood glucose values are within her personal target range (5.6-6 mmol/L) about 66% of the time. Notably, she entered a very narrow blood glucose target range. HELEN feels well informed about her diabetes management and existing technologies for T1D management. As a student HELEN, feels like her daily routine is very irregular. In her free time HELEN likes to go for long walks and do different kinds of sports. She has some limited experience with blood glucose predictions, mostly in the form of text messages and notifications such as "will soon be low". In the following, we will now outline and discuss our participants' most interesting answers from the two interviews and the ESM-study in more detail.

#### 5.1.1 GEORGE

GEORGE describes his daily T1D self-management as being exceptionally well controlled and involving very little effort from his side. He is overall happy with the technologies that he is currently using and only hopes for small improvements regarding already existing aspects of them. One central theme that emerges from his description of his T1D management is how much it impacts his life:

GEORGE: "But basically, I don't look at it [blood glucose levels] very often. I don't know how it is for others - how often they look at it. My attitude is that I don't have to live according to the course of my blood glucose - I live and then see how the course of my blood glucose is."

For GEORGE, not letting his blood glucose direct his life also means that he does not adapt his activities to his blood glucose level. Of course, he takes insulin if his blood glucose is too high, but he tries to not let his blood glucose dictate other aspects of his life. Assigning his T1D selfmanagement a low priority also means that he does not check his blood glucose level very often. However, analyzing his responses from the ESM-study showed that GEORGE did indeed adapt his behavior depending on the blood glucose level prediction shown to him, which is somewhat contradictory to his answers from the personal interview.

Specifically, GEORGE would have changed his behavior more than half of the times (5/9) after seeing a prediction of his blood glucose. While some of the behavioral changes were in relation to insulin injections, there was also one unexpected change in behavior that related to getting active instead of eating something due to a rising blood glucose. MOON-T1D tries to actively involve users in T1D management and provides extensive options for recording factors that influence blood glucose, such as detailed information on consumed meals. This did not align very well with GEORGE's need of moving T1D management to the background. For GEORGE to frequently use an app like MOON-T1D, the recording process would need to be simplified and more automatic.

While GEORGE recons that his blood glucose and nutritional estimations are impeccable when at home, he mentions that both are more challenging when abroad or in restaurants:

GEORGE: "So, abroad on vacation, it always looks a little different, especially when it comes to hidden carbohydrates. Like sweet sauce in Asian countries, these flour sauces, whatever, I have to watch out a little more"

This is also the only instance where GEORGE mentions an emotional connection to the need of controlling his blood glucose. He describes that during vacations, if his blood glucose values do not decrease, it can make him feel desperate. Indicating a potential need for support in foreign countries and with unknown foods.

Physical activity, such as playing badminton or cycling plays a central role in GEORGE's life and therefore in his diabetes management. It is also in the context of physical activity where he first mentions the potential usefulness that predictions could provide for him:

GEORGE: "But of course, in principle, it would be an advantage if I already knew how it [blood glucose] would behave if I now play [badminton] for an hour or half an hour, and the [insulin] pump would automatically adjust to that."

GEORGE expresses a preference for support using predictions in targeted situations, as opposed to requiring constant support throughout the day.

**Usefulness of Predictions** For GEORGE, the usefulness of blood glucose prediction was very much tied to the provision of notifications, which needed to be at least 2 hours into the future, and in relation to the effect of physical activities. Implementing notifications that actively remind users of predicted blood glucose fluctuations would align very well with GEORGE's preference for his T1D management being more in the background of his daily live:

GEORGE: "If the notification comes already 1-2 hours in advance, that would of course be ideal, rather than if I only find out when the blood glucose is already dropping."

**Prediction Horizon** Regarding the prediction horizon, GEORGE explicitly stated in the interview that he prefers predictions to be no less than two hours and no more than three hours into the future.

GEORGE: "I am always doing something different; office, garden, bike, walk. There then a forecast of more than 3 hours would certainly not be useful. [...] Exactly so 1 to 2 hours makes sense but not longer."

While he initially considered an indefinite prediction horizon, he limited his preference to three hours, arguing that too many variables could affect the accuracy of the prediction over a more extended time period. This was also reflected in his answers in the ESM-study, where he consistently selected between one and three hours, with two hours being the most frequent selection.

**Prediction Accuracy** In contrast to the other participants, prediction accuracy seemed to play a very important role for GEORGE:

GEORGE: "Yes, so the less accurate it would be, the less sense it makes to make a prediction at all. For me, the +/- 2 mmol/L is too big a difference. There I could almost say; that I could then do without the forecast for the next 2 hours, if the difference is this large."

**Visualization Preferences** The visualization method chosen by GEORGE reflects his preference for accuracy. For continuous predictions, he favored clearly visible and text accompanied probabilities in percentages:

GEORGE: "This is one of my favourites! Here [Figure 4.4, image 12] I can see the probability, what is most probable, much better then if I have only two lines, like here [Figure 4.4, image 5] or if the chart looks like this [Figure 4.4, image 9]. What is marked here [Figure 4.4, image 12] with 80% probability is what I would use to change something regarding my diabetes management."

Although the visualization of the point prediction in Figure 4.5, image 5 also presented a text accompanied probability, this particular visualization went against GEORGE's need for parsimony. He preferred visualizations that depicted the probability of the predicted blood glucose level at a single point in time, as shown in Figure 4.5, with a particular preference for image 4. To conclude, GEORGE showed a preference for visualization methods that align with his needs for accuracy and simplicity.

### 5.1.2 FINN

FINN invests quite a lot of time in his T1D management, checking his blood glucose once per hour on a daily basis. However, throughout the interview, it seemed important to him to convey that he has a laid-back attitude toward his T1D management:

FINN: "So it happens in passing and is always done in a few seconds – totally easy. [later in the interview] I always have the meter with me to check, and I always have something sweet or very sweet, or snack bars in the car. Something to eat if it [his blood glucose] should go down. But everything without effort, without preparing it"

There seems to be discrepancy between FINN's management perception and his actual practices. FINN perceives his management as very laid-back, but he also diligently checks his blood glucose every hour of the day. FINN's laid-back attitude aligns with his opposing perception of the ideal diabetic, which could only be derived trough analyzing what he perceives himself no to be. In FINN's eyes, the ideal diabetic always has his blood glucose under control and is not as relaxed as he himself is. Additionally, the HbA1c of the ideal diabetic seems to be lower then what FINN's HbA1c is. His comparison to the ideal diabetic was quite interesting and will be discussed further in the thematic analysis (Section 5.3.2).

However, not being perfect (and accepting not being perfect) was a repeated theme in his relation to his T1D as well as in his management practices:

FINN: "Well, I've never been the model diabetic. I don't want to be. For my safety, I am rather a little bit higher than too low. [...] and I don't want to be the model diabetic and the nerd. I am also not annoyed when I am on vacation and estimate novel food totally wrong, and then have extremely high values for four hours. Then I know where it comes from, correct it and look how it goes down in the next four hours."

Interestingly, it were not just FINN's management practices, such frequently checking his blood glucose levels, which did not seem very laid-back. For example, FINN also frequently checks how accurately his perception reflects the actual state of things, be it when guessing his own blood glucose or guessing the carbohydrate content of the food he is about to eat:

FINN: "I then think to myself, this slice of bread could be 30g, and then I'm happy when it weighs 33g."

This might be a behavior to keep a sense of control over his management, which will be discussed more in-depth in Section 5.3.1. Spontaneity seems to be another important aspect of FINN's life, which, again, was in line with his laid-back perception of his T1D management. However, this does not mean that he is unprepared for a bad situation when doing something spontaneous or leaving in a hurry:

FINN: "I'm the type: "I take my bike and go" [...] I think, yeah I'm getting a little shaky, it [blood glucose] might go down. But then I have something sweet to drink with me or an apple or a cookie, [...]"

Although FINN mentioned that the process of getting used to MOON-T1D was time intensive at the beginning, he liked MOON-T1D and its functionalities very much. Because of MOON-T1D, FINN described an increase in his involvement and frequency regarding his T1D management. He felt that the app's functionality of providing past, present and future blood glucose levels enhanced his engagement with and active involvement in T1D self-management:

FINN: "Whether I have learned something new might be the wrong wording. But as a reminder and to keep me engaged [with blood glucose control] and that I look more often how it's going [with the blood glucose], which I thought was very cool."

Contrary to GEORGE, FINN felt that active involvement in one's T1D management is desirable and increases his feeling of control.

FINN has already encountered blood glucose predictions in the FreeStyle Libre app, where arrows indicate the expected rate change of blood glucose levels [85]. However, he believed that visualizing a time dimension alongside the prediction, rather than solely knowing whether blood glucose levels increase or decrease, was advantageous and easier for him to comprehend:

FINN: "But the [MOON-T1D] app is actually better, and more intensive and simpler. With the Libre, however, you have an arrow that shows you the direction it [blood glucose] is going, but you don't know exactly whether that's in 15 minutes or in an hour. "

Because physical activity plays a big role in his daily routine, FINN expressed a desire to retrospectively analyze and compare similar past, present and future situations. However, he expressed concerns about the challenges to identify similar activities which occurred more than 14 days ago:

FINN: "Yes, I would then wonder the next time when I am out and about 1-2 days later doing the same walk, in terms of running, stretching and effort. And then wonder why I feel lower in terms of the value compared to yesterday. Then I would look again at the values from yesterday, the insulin and what kind of fruit I ate, for example, and would learn from that how to do it next time, so that I have a super value."

**Usefulness of Predictions** FINN mentioned that predictions would always be useful to him, especially in combination with notifications. While he generally desired a two-hour time frame for predictions, FINN highlighted that for situations that he deemed important emotionally or performance-wise, predictions would need to be further into the future:

FINN: "So suppose you were getting married at the registry office, then you don't want to have a hypoglycemia and collapse in that moment, [...]"

**Prediction Horizon** FINN's preference for a two-hour prediction horizon can be attributed to his belief about his blood glucose not changing enough during one hour for a prediction to be useful. This indicates that participants may have a feeling for how their blood glucose will behave during the next hour, and a prediction would only serve to assess their estimation. A prediction horizon that reaches longer into the future, on the other hand, provides information which participants find very difficult to properly estimate. However, FINN mentioned that a prediction that reaches more than two-hours into the future would allow him to make necessary adjustments to keep his blood glucose in range, based on something that he does not already know. He considers a longer projection into the future to be more accurate for understanding his blood glucose levels

and determining potential adjustments. FINN also mentions that extended predictions could be useful for him in situations where he is unable or finds it difficult to check and respond to his blood glucose:.

FINN: "Or even when I'm driving in the city, I don't always check my blood glucose with the Libre. I get in the car and drive off. If the car ride, however, is longer, I go on vacation, then it would be cool to see what the blood glucose looks like."

**Prediction Accuracy** When offered a choice between a longer prediction horizon and a more accurate prediction, as presented in Section 4.5 question 14, FINN prefers a longer prediction horizon. Although a more accurate prediction reaching two hours into the future would be desirable, he believes that he would be able to take preventative actions even if the prediction is less accurate:

FINN: "And if I know that the blood glucose is going to be between 7 and 11 mmol/L in 2 hours, I could adjust accordingly. I would then say that, yes, all this is a bit high and therefore I supplement some insulin, maybe just to be careful 1 unit and then the 11 eventually becomes the 9."

**Visualization Preferences** Regarding prediction visualizations, FINN prefers visualizations that have an indication of what the "main" prediction is (see Figure 4.4, image 10). Seeing the probability of his blood glucose being within a certain range is also appealing to him. For Figure 4.4, image 7, FINN expresses concerns regarding misinterpretation of the prediction. Interestingly, FINN highlights his potential bias towards assuming a more favourable outcome, which could result in him responding undesirably:

FINN: "[...], as with this one I only see lines and I would think to myself well, well it will be the lower line for sure. [...] you don't deal with it and then it's the upper line in the end."

Regarding the point predictions (Figure 4.5), FINN believes they would also be useful. He prefers Figure 4.5, image 7 due to its visual appeal and comprehensibility. However, he does not express a concrete desire between point predictions (see Figure 4.5) and continuous predictions (see Figure 4.4) of visualizing the predicted blood glucose value.

#### 5.1.3 **HELEN**

HELEN is the only participant who expressed some concerns about how she currently manages her T1D. She believes that she has not properly adapted her T1D management to her current lifestyle, which she mentioned to be less regular than her former lifestyle. HELEN participated in our study because she wanted to be more involved in her T1D management and better understand her condition. She finds that the irregularity of her life makes it harder for her to control her blood glucose levels. HELEN mentions that her daily diabetes routine is dominated by avoiding hypo- and hyperglycemia, and by frequently correcting her blood glucose.

Along these lines, HELEN perceives a lack of support for a daily routine that is similar to hers. She also mentions a discrepancy between how she personally experiences her T1D self-management and what she was told or taught about diabetes management:

HELEN: "[...] so the school knowledge that you're taught [about diabetes] is just a daily routine that a forty-year-old person has, who has everything well-regulated. [...] For everything else that needs a little more flexibility, you have to learn it, like, yourself." This need to adapt the theory of T1D management to the patient's individual situation was also discussed by Beran and Golay [22]. Beran and Golay [22] conducted an interview with 101 people living with T1D, in order to understand how they perceive the education that is provided on T1D management by the health systems. As was the case with HELEN, participants of the study mentioned the need to adapt the theory to one's individual lifestyle. However, in the study's sample, participants perceived their health care professionals to be flexible and knowledgeable with regards to this individual adjustment [22].

Understanding one's individuality when managing T1D is an important topic for HELEN. HELEN would like to impart her self-taught knowledge to the devices she uses, but is currently unable to do so. She believes that the insulin pump's limited ability for personalization may lead to the device misinterpreting certain situations:

*HELEN: "[...], so there are just nuances in everyday life that I do not enter into the device [pump], which it then interprets incorrectly."* 

HELEN would like to convey her knowledge about nutritional content of meals, as well as her bodies reaction to known meals and situations. That is, despite her perceived sub-optimal skills with regards to nutritional estimations. HELEN believes that she has a better understanding of how her body will respond to specific meals, and she also thinks that her insulin pump is accustomed to compensate for any inaccuracies:

HELEN: "I am aware that I am usually off [with estimating carbohydrates]. On the other hand, it's also like this: I'm off the mark, but I know that my body reacts in a certain way with a certain meal."

HELEN points out that "just knowing" what would need to change in one's T1D management does not mean that the change is possible to implement. For HELEN, the inability to implement changes was related to her psychological well-being. Specifically, she mentions that she sometimes does not have enough energy to take the actions required to successfully manage or change a T1D state:

*HELEN: "But that [diabetes management] is basically psychological, because I don't always have the energy to do all these things that I need to do to manage the diabetes."* 

This emotional aspect in HELEN's T1D management was also reflected in her attitude towards her past blood glucose values. HELEN believes that it is important to not only see future values, but also review past readings, so that she is able to judge her management over the course of the whole day. HELENs words to explain the relation between seeing past glucose values and their emotional aspect goes as follows:

HELEN: "You have to manage your diabetes all the time and when your diabetes [blood glucose] was very bad and you see that it's getting better. Or that it [blood glucose] was good before and now it's not good anymore. That you see the day as a whole and not just the next 2 hours as all or nothing."

Her statement suggests that it is important to see past values to avoid only receiving negative feedback when current blood glucose values are out of range. Instead, she believes that past blood glucose value can reveal an improvement, e.g. from 17.0 mmol/L to 11.0 mmol/L. Additionally viewing the current blood glucose in context of the whole day would allow her to see that even tough the current blood glucose is out of range this might not have been the case for the whole day. Including the context of a blood glucose value could be important, for understanding the current situation, decision making and emotional stability. The emotional value of T1D management will be further discussed in Section 5.3.3.

**Usefulness of Predictions** HELEN thought that blood glucose predictions were extremely useful, especially to assess whether she has taken the appropriate measures to maintain or achieve a target blood glucose level. She gives the following example for a situation where the interpretation of her blood glucose behavior is ambiguous:

HELEN: "Sometimes you estimate it [amount of carbohydrates], [...] then you have to inject [insulin] [...]. If it [blood glucose] goes up, I then ask myself, is it going up now because [...] I ate, or did I inject wrong [too little]. For things like that, a prediction would be extremely interesting. "

Particularly, HELEN finds predictions directed at trying to help her understand ambiguous situations desirable.

**Prediction Horizon** The results from the ESM-study questionnaire indicate that HELEN desires a prediction horizon between one and four hours. During the interview, HELEN clarified that, in general, she would like to have a two hours prediction horizon. However when her blood glucose values are too high, then an extended prediction horizon would be desirable:

HELEN: "Then, of course, I would ask myself whether the blood glucose goes down in the next hour or in the next 4 hours. Because sometimes when the pump fails, you have extremely high values, and then you usually have to be patient."

**Prediction Accuracy** HELEN preferred an extended prediction horizon over a higher accuracy in the scenario presented to her (see Section 4.5). Similar to FINN, she mentions that she would manage ambiguous predictions by taking a small does of insulin. Although she selected the longer prediction horizon with a predicted blood glucose between 7 - 11 mmol/L, she believes that this particular prediction would be particularly valuable to her. The reason being that changes between a value of 4.0 and 8.0 mmol/L would drastically impact which actions she would take, for example deciding to go for a walk or avoiding to do so:

HELEN: "At 8 mmol/L, it would feel easy for me to still go for a walk. At 6 mmol/L, it would be just on the boarder of ok to go for a walk. But at 4 mmol/L, I would no longer go for a walk."

**Visualization Preferences** Regarding prediction visualizations, HELEN clearly preferred a prediction that showed her the source of uncertainty for which way the prediction would go:

HELEN: "Is this [uncertainty in Figure 4.4, image 9] because it just can't predict in general, or because it's [the prediction] thinking that there might be more insulin or more exercise or more eating? That [uncertainty] is why I think [Figure 4.4, image 4] is great."

HELEN also preferred predictions that clearly indicated what the "main" prediction is (Figure 4.4, image 2 and 10). Overall, HELEN preferred prediction visualizations that include some form of explanation with it and that have a presumably understandable reason for its uncertainty.

### 5.2 Case Study Discussion

In this section, we will discuss some of the most interesting and relevant aspects that emerged from our case studies more closely. To this end, we summarized these aspects in four comprehensive statements spanning across the individual case studies.

### 5.2.1 We Want Past, Present and Future

Our participants showed the need for a visualization of past, present and future blood glucose values as well as the need for a visualization of active insulin and active carbohydrates. To address this requirement, a system would need to support retrospective analysis on the one hand, and a way to connect insights gained from past values to current or future values on the other hand. Similar situations from the past may help participants to deal with their current situation or to anticipate future blood glucose values.

Past values could also provide information about what influenced the blood glucose prediction, helping users to trust and understand blood glucose predictions. Increasing users' understanding of why something is happening can help them feel in control of their condition, which is an important aspect that will also be discussed more in-depth in the thematic analysis (Section 5.3.1). Going one step further, users could potentially even support machine learning algorithms by providing their knowledge of routine situations as input to the algorithm. Using such a human-in-the-loop approach could allow future apps to overcome the users' rejection of predictions in routine situations, which has been discussed by Stawarz et al. [139]. Future apps could also highlight how a current situation differs from the most similar past situations. This may provide users with a more solid foundation to base their decision-making on, while also accounting for the many individual nuances encountered in everyday-life of people with T1D.

#### 5.2.2 Let Me Micro-Manage

When presented with uncertainty in relation to an ambiguous blood glucose prediction, two participants decided to still take action. We showed participants that their blood glucose values will be between 7.0 (within target) and 11.0 mmol/L (above target) two hours into the future. HELEN and FINN both decided that they would take action to decrease the probability of their blood glucose exceeding the upper target bound, regardless of the high uncertainty. They both thought that injecting a small amount of insulin would cause the prediction uncertainty range to shift slightly down, so that that their blood glucose would most likely be within target range. While this approach could work in practice, the question to ask is if such micro management of blood glucose values is desirable or to be encouraged. For people using an insulin pump, administering a small dose of insulin could be done with a single click. For people doing multiple daily injections, administering a small dose of insulin would mean an additional injection. For one, frequently injecting into the same site increases the risk of Lipohypertrophy [14], which can cause sever fluctuations in insulin absorption, resulting in higher blood glucose concentrations after a meal and more frequent profound hyperglycemia [50]. Additionally, such forms of micromanagement may result in T1D becoming a bigger part in people's life. In turn, the expectations associated with the possibility of being able to prevent even slightly out of range values might cause participants additional stress and require constant attention and vigilance. [14]

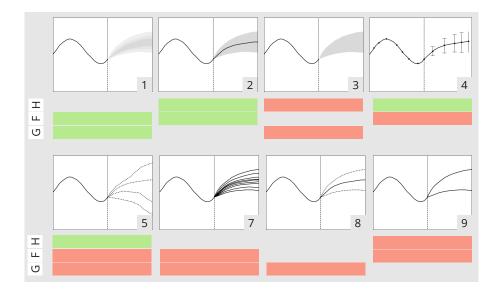
#### 5.2.3 Prediction Horizon - Well, It Depends...

Depending on the participants' current situation, their requirements regarding the prediction horizon changed. For their everyday life, participants agreed that a prediction horizon beyond one hour, particularly two hours, would be required. Only one app that we reported on in our systematic literature review provided a prediction horizon of two hours. Most prediction horizons were one hour and few were four hours (see Table D.2). For high-stakes situations (e.g. job interview, exam or marriage), however, participants desired predictions reaching further into the future. Similarly, participants also desired extended predictions when their blood glucose was significantly out of range. While situation dependent prediction horizons would be an interesting

feature, they also provide challenges and come with a few drawbacks. For example, extending prediction horizons may greatly increase the complexity of the underlying machine learning algorithm. Having an extended prediction horizon also has a clear trade-off with prediction accuracy. The further a prediction lies in the future, the less accurate this prediction becomes. For GEORGE, this cost of an extended prediction horizon was not acceptable. GEORGE even preferred only seeing 30 minutes into the future, just because the prediction was more accurate. However, FINN and HELEN preferred the extended prediction horizon despite the decreased accuracy. These differences in situational and accuracy related desires for prediction horizons highlight the flexibility that an app for people with T1D should ideally provide. A one-fits-all approach most certainly would not work for our participants, and there is clear indication that more personalization is needed.

#### 5.2.4 Visualizations - We Disagree!

Regarding prediction visualizations, our participants even disagreed on whether point predictions or continuous predictions were more useful. GEORGE found that single-point in time predictions would be more useful due to their clearness and simplicity. FINN and HELEN thought of point predictions as a nice addition, but not strictly necessary and most definitely not preferable. As presented in Figure 5.1, our participants also did not agree on one visualization of blood glucose predictions to be the most ideal. While all participants pointed out that intelligibility, such as clear prediction direction and actionable-insights were important aspects of a blood glucose prediction visualization, they also found individually different visualizations to best fulfill their needs. The quite opposing needs of participants regarding prediction visualization highlights once again the dire need for personalized visualizations. Importantly, the prediction visualization that participants prefer the most may not necessarily be the one that allows them to choose the most appropriate action.



**Figure 5.1**: Participants' preferences for prediction visualizations, in response to the presentation of Figure 4.4. The green rectangles indicate that a participant liked the visualization, while the red rectangles indicate dislike. G, F, and H denote the responses of GEORGE, FINN, and HELEN, respectively.

### 5.3 Thematic Analysis

In this section, we will present the four themes found during our thematic analysis of both interviews and ESM-study answers. The themes entailed (1) expressions of feeling in *control and empowered*, (3) ways of *sense-making and understanding* T1D, (4) the *emotions and experiences* on the T1d journey, and (4) desired*engagement and support* from T1d systems.

#### 5.3.1 What Does It Take to Feel in Control and Empowered?

The theme *control and empowerment* explores what aspects can support and empower people with T1D to feel in control of their condition and life. But what do control and feeling in control mean in the context of T1D management? This theme was informed by various states related to control including (1) feeling in control, (2) maintaining control and (3) loosing control.

One way of feeling in control was to maintain a **regular daily routine**. Following a daily routine was associated with feeling safe and confident in their T1D self-management. For our participants, a regular daily routine meant, among other things, performing activities and eating meals at the same time, as well as eating similar meals.FINN specifically refers to feeling confident in his T1D management, as he eats similar things in his daily life that allow him to keep his blood glucose levels under control:

FINN: "We eat more or less the same thing 90% of the time. You have the same croissant, the same fruit and the same meat dish at your favorite Italian restaurant. And there you know how much [carbohydrates] it [meal] is and how much [insulin] I need for it [meal]."

Similarly, Hamilton et al. [65] identified that maintaining a daily routine is an enabler to sustaining Dose Adjustment for Normal Eating (DAFNE) self-management behaviors. DAFNE, is an education program, that improves the quality of life and HbA1c values for 12 months. A regular daily routine could establish a predictable pattern of blood glucose responses to different situations.

Investigating whether this regularity was actively chosen as an approach by participants to maintain stable blood glucose or was just their preferred way of living could reveal their intrinsic motivation and approach to blood glucose levels. As a result it may facilitate the development of customized designs for users, based on the identified approach and trade-offs regarding blood glucose levels.

Unfortunately, while individuals would prefer to remain in control, irrespective of irregularities, this is not always achievable. In instances where daily life is **irregular**, compensatory actions, such as frequent blood glucose measurements, can help to account for the unpredictability and foster some sense of control or agency. Having a very irregular daily life, HELEN chooses to react spontaneously to her blood glucose levels, suggesting that she has to adapt to her blood glucose levels quite often, be it by injecting additional insulin or consuming additional carbohydrates. HELEN believes that the irregularity of her lifestyle cannot be changed, but the associated complexity of blood glucose management is difficult for her.

HELEN: "I also think that because I have such an irregular daily routine, I often just have to check [her blood glucose] spontaneously."

This finding is in line with previous research, Balfe et al. [12] found that students thought it was difficult to maintain regular self-care practices at university. Students attributed their management difficulties to the irregular nature of student life and the desire to not let their diabetes affect their studies [12]. Hamilton et al. [65] corroborates that the lack of a routinised life is a potential barrier to diabetes self-management.

The **alignment of perception and reality** was also an aspect influencing and shaping participants' sense of control. Comparing their perception of the world with the reality of it was a way in which participants could remain in control. While participants were not very explicit in expressing that the adoption of the aforementioned behavior would make them feel more in control, it became apparent by their language and use of words (e.g. "checking themselves"). To control their perception of reality, participants used an objective measure such as a scale or blood glucose measuring device as GEORGE highlights:

GEORGE: "Yes, so every now and then I take the scale out again, it's always ready somewhere. Then I take a guess [of how many carbohydrates a food contains] and see if I'm still inside the range."

Being able to accurately estimate the carbohydrate content of a meal was found to be associated with lower glycemic variability [31]. Throughout the interviews, the participants engaged in frequent self-reflection, exemplified by their recognition of personal biases and the potential for misperceiving carbohydrate quantities.

A noteworthy characteristic of our participants is that they have been living with T1D for 9 - 53 years. Despite their years of experience, they keep questioning and reflecting on their judgment, indicating a commitment to ongoing learning and self-improvement, allowing for their management practices to evolve, presenting a different range of challenges for researchers and users alike. A more concrete and practical example of the temporal changes that can affect blood glucose management was mentioned by FINN.

FINN: "Basically, the apples - they used to be much smaller than they are today, so I would say that an apple weighed much less then and then I know that they are bigger now."

This shows a need for devices to adapt not only to participants themselves but also to the rapid rise and evolution of their surroundings and the technologies available.

Feeling in control encompassed also reasoning about why one was not in control. The participants frequently attributed their **loss of control** to factors such as misinformation or inadequate device capabilities. Devices not being able to capture the information needed to achieve stability in T1D management was often associated with the inability to transfer their knowledge. We highlight this issue later on in Section 5.3.2. Explanations of their loss of control were mostly associated with external factors, while some participants recognized that their perception could be held accountable.

FINN: "[...], as with this one [see Figure 4.4 Image 8] I only see lines and I would think to myself well, well it will be the lower line for sure."

The comment from FINN illustrates that their desire to be in the target range can influence their objectivity potentially leading to a loss of control. In this specific case, visualizations depicting ambiguous blood glucose values might be interpreted by participants in a favourable way not reflecting reality. To avoid the misinterpretation of prediction visualizations in general, designers need to account for users desires, which may lead them to misinterpret the visualizations.

**Planning** was used to maintain control. Planning included arranging for different potential scenarios such as hyper or hypoglycemia, but also daily life management adjustments to effectively address situations demanding increased control.

HELEN: "For example, when I have an exam, I make sure that I don't eat too many carbohydrates for my morning meal so that it [blood glucose] remains more stable afterwards."

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This quote indicates that the degree of planning required can depend on situational knowledge. Also, there could be a cost associated with gaining control over one's T1D management, particularly in high-pressure situations. Striving for stability and associated control can be particularly pronounced in high-pressure environments, such as exams, where the cost of instability and control loss may be perceived as higher. It remains to be discussed if such self-imposed restrictions should be supported by blood glucose predictions, whether predictions should help with decision-making in high-pressure situations, or help avoid a trade-off altogether.

#### 5.3.2 Ways of Sense-Making and Understanding T1D

The theme of *sense-making and understanding* encompasses topics related to understanding one's T1D in different situations and contexts, acknowledging and rejecting idealized notions, and accepting the disease as a unique and individual experience.

One interesting topic raised in several comments from participants was the idea of an **ideal diabetic**. Participants rooted this notion in their daily life by adhering to a structured daily routine, having complete control over their condition, or rejecting a lenient management approach. The structured daily routine and condition management control are closely related to our previous theme, specifically the positive impact control has on blood glucose values. HELEN, has this idealistic idea of what it means to be in full control:

HELEN: "I have such a picture of people with diabetes who have it super under control, about people who have their lives fully structured."

While achieving such idealistic diabetes management seemed to be something desirable overall, all participants concretely distanced themselves from the idealistic image. Trying to be ideal could impose a number of restraints, such as having a regular schedule, that participants did not want to comply with.

FINN: "I enjoy, even if I sometimes know that I should better not eat something because it is very sugary [...] - I enjoy it anyway."

Knowing that eating something sugary might affect his blood glucose in a bad way does not stop FINN from eating and enjoying the sugary food, which he could not otherwise. This loss, which could be associated with trying to be the ideal diabetic, presents an interesting trade-off. It also suggests that striving for perfection in T1D management may not lead to an improved quality of life. This is in line with previous research by Pollock-BarZiv and Davis [119], where they reported an association between T1D management perfectionism and eating disorders. Highlighting the dangers that could emerge from trying to achieve some idealistic notion of T1D management [119]. The question here is where this ideal comes from and why does the ideal not go beyond being in control of one's blood glucose.

At times, the idealistic outlook towards managing T1D encompasses not only the practical aspects but also influences the mindset one should have towards their diabetes management. The perception that there is a correct way to think about T1D management became apparent in the following statements.

FINN: "I don't think about it [blood glucose] and if I have higher values for a week, then it's just like that. So I sleep quietly at night and I don't wake up because of any - so it doesn't bother me at all."

GEORGE: "But it [blood glucose] usually goes well and I'm also a bit of a guy who says, I don't have to be inside the target range all the time like I am at home, but I take a bit more liberties when I'm abroad."

FINNs statement also shows the need to not only distance themselves from the ideal but also to justify their way of managing their diabetes. There is a sense of rigidity associated with T1D management, exemplified by GEORGE's feeling that he has to take liberties when travelling abroad. This mental burden of how one should manage T1D could be enforced by blood glucose prediction. Participants may experience self-blame if they fail to prevent predicted out-of-range blood glucose values. While predictive tools can be useful for managing T1D, it is important to use them as a tool for informed decision-making rather than a measure of success or failure.

**Individualism** and therefore differences between people with T1D or differences to the ideal diabetic were another topic derived from participants' comments. Some differences relate very specifically to insulin injection or carbohydrate consumption, with varying success among individuals.

HELEN: So if I inject insulin for one bread unit [=10 g carbohydrates] and then immediately go for a walk, then it is as if I had injected insulin for three bread units without eating anything. GEORGE: "So I know that I have to eat a bar while playing badminton, because I move around a lot."

These quotes highlight the different management-related actions taken by HELEN and GEORGE to address physical activity, suggesting that blood glucose predictions need to be personalized to account for individual differences in management.

There is a general awareness of differences regarding T1D management across participants. TParticipants often describe the personal understanding they develop to manage their condition, as a form of self-discovery or **self-teaching**:

FINN: "I always say try and find out what it could be and how much [insulin] I need." GEORGE: "But everything that has to do with the food - yes - I find out myself." HELEN: "For everything else that needs a little more flexibility, you have to learn it yourself."

The need to self-teach the necessary skills to manage T1D creates a strong idea of ownership regarding knowledge and their diabetes management. This became very apparent when HELEN stated that she thinks that having T1D everyday of her life makes her the expert even with respect to her doctor.

HELEN: "So whenever I go to the doctor, he also tells me that I am the expert when it comes to my diabetes. I mean, compared to the doctor, because you have it every day."

Blood glucose predictions could empower and support participants' self-teaching practices. Predictions could help inform their decision-making process. Alternatively, predictions might reduce the need for self-discovery, as individuals can adjust their management based on the predicted blood glucose values. The feeling of ownership of one's condition and belief in personal expertise can impact blood glucose predictions. Reduced trust in predictions may arise when there is a discrepancy between an individual's knowledge based on experience and the prediction provided. This issue has also been discussed by Stawarz et al. [139], who found that participants did not express the desire for decision-making support in routine everyday situations since they had established routines to guide their behavior. One way to address this potential limitation is by incorporating the knowledge of participants. This approach can increase trust and allow for better individualization of predictive algorithms. Therefore, learning from the knowledge and experience of others could be beneficial. On the downside, incorporating participants' own knowledge is non-trivial and may introduce bias.

Participants' knowledge is often reliant on **learning from past situations**. Situational differences seem to be an important construct regarding T1D management and were discussed in several different contexts. The first difference is situational similarities. There is inherently a situational awareness among participants which they use to guide their management in known or previously experienced situations. HELEN for example, uses the curve depicting past blood glucose values or her experience with certain situations to inform why her current blood glucose might be a certain way:

HELEN: "For example, when I do sports just after eating, I know it looks like this [pattern of blood glucose] [...]" HELEN: " [...]if I've been swaying all this time, it's most likely going to go up and down again. [...] and above all I have the feeling that the current blood glucose has a lot to do with how the values were earlier."

To ground this knowledge participants have to do a self-test and analyze their observations for decision-making purposes. The comment from HELEN highlights the importance of looking at a situation as a construct of influences from previous actions or states. It seems to be important to be aware of what might still affect them and what is not affecting them anymore. In the context of blood glucose predictions, this would mean that there is a need to understand how far to look back for things that might still affect the current and future state.

While blood glucose might behave similarly in similar situations, small situational differences need to be considered as highlighted by FINN and GREGOR.

FINN: "Then I would see that I have been cycling before, with a medium intensity for 2 hours and I gave myself this amount of insulin, then of course I could think about whether this is also good today or whether I have to do something else." GEORGE: "Also, when I go for a walk after lunch, for example, I see that the blood glucose lowers quite quickly – that happens less in the morning. That can be explained by the hormones that are released when I get up in the morning."

Situational factors affecting blood glucose are multifaceted and highlighting differences between seemingly similar situations could be beneficial.

However, keeping track of and understanding all the different factors affecting one's blood glucose levels could be overwhelming. By inputting their data into an "all-encompassing" system, apps could support users by finding the most similar situation and highlighting differences between this situation and the current one. A participant put forth the suggestion to store particular recurring situations, in order to provide information to the app regarding anticipated actions.

HELEN: "So what I would find very cool would be if I could save like certain situations. Situations like I eat and then I do sports or I don't eat and then I do sports."

This also highlights the need for the active involvement of the participant, specifically for input on situations that are repeated and they are familiar with.

While we mostly talked about everyday situations, there was an elevated need for predictive capabilities, be it prediction horizon or accuracy, for non-ordinary situations. The importance of providing an accurate or prolonged prediction increased with the level of importance associated with the forthcoming scenario.

FINN: Or at the job interview, if you are looking for a new job, then you want to be in your best shape at that moment and then you might want a longer prediction. GEORGE: So abroad on vacation, it always looks a little different, especially when it comes to hidden carbohydrates.

While FINN highlights that a longer prediction would be needed in high pressure situations such as job interviews, GEORGE shows that new, unknown situations, in this case meals, would increase the need for a prediction. Similarly Stawarz et al. [139] found that decision-making support was preferred for extraordinary situations. Participants propose that machine learning should focus on notifying users about detected irregularities, preventative actions and support after-thefact. Learning from others and providing users with a clear understanding of their current situation is a promising strategy to empower them through informed decision-making. Additionally, using this approach could be even more effective for machine learning models when predicting blood glucose values for unknown situations.

#### **5.3.3** Emotional Value and Experience of T1D

The third theme *emotions and experiences* traverses the experiences and emotions related to T1D management.

Feelings associated with **Living with T1D** form the first subtheme related closely to the experience of participants' condition in everyday life. Throughout the interviews, it became very apparent that living with T1D meant choosing what role the condition would play in their lives. Choosing not to adapt one's life too much to one's blood glucose level seemed to be of emotional importance to participants. Participants repeatedly stated that their life should not be governed by their self-management.

GEORGE: "[...] sure I do something, but I don't adjust my life to it. In the sense of that, I don't say - oh, now it's high, now I have to exercise."

The statement pertains to a choice of how much they will allow the condition to impact and shape their daily lives. Whether such a choice would create a feeling of resignation or acceptance differed individually. This could have implications for blood glucose prediction recommendations. While for some participants it might be useful to receive alternative options of what to do besides insulin injection or carbohydrate consumption, others might not actually want such a recommendation.

In contrast, participants were aware that their perception of a normal live is quite different than that of someone that does not have T1D. Reflecting on how much time he spent managing T1D, GEORGE explicitly made this distinction.

GEORGE: "But basically a quarter to half an hour a day is just part of life – I mean my life."

While participants do not want their blood glucose to direct their lives, they are aware that to some extent it always will. Another example is the effect of hypo or hyperglycemia which is more than a number/data point but goes beyond and might impact their daily routine significantly.

HELEN: "But it's also the case that there have been nights where I've lost whole hours just because of diabetes."

HELEN refers to having hypoglycemic events during the night, which disallow her to fall asleep.

Acceptance of T1D and associated situations were mentioned throughout both interviews. A study conducted by Kamody et al. [75] observed three profiles derived from different questionnaires. The profiles included high acceptance and adherence/low stress, low acceptance/moderate adherence and stress and low acceptance and adherence/high stress. They have shown the importance of accepting T1D as people expressing this acceptance showed a significantly higher health-related quality of life and lower HbA1c [75]. For participants, acceptance was not always related to the condition as a whole but also to specific situations or states they were in such as out-of-range values.

FINN: "So I don't think about why I have high values or why I didn't notice the high values, it's just the way it is and I get along with it."

On the other hand **negative emotions** including self-consciousness were also frequently associated with out or range blood glucose values. Balfe et al. [12] found that being self-conscious about diabetes can trigger diabetes related-distress. For young adults, they found that young adults with T1D felt like having T1D could be stigmatizing and it being exposed would risk undermining their identities as young healthy people [12]. Similarly, our participants expressed some self-consciousness regarding their management. HELEN: "I mean normally a hypoglycemia is not good either, but generally the situations where I meet people at a certain place and then it would be a bit embarrassing for me if something would be with my diabetes, as a check so to speak."

While predictions might help avoid some of these uncomfortable situations for participants, avoidance might not necessarily be the desired strategy. Predictions have the potential to make participants feel more self-conscious by sending notifications in undesirable situations, further discussed in Section 5.3.4. Emotions such as desperation, due to out-of-range blood glucose values, were also mentioned by participants.

GEORGE: "Especially when I travel abroad and the blood glucose does not come down, there I am then sometimes a bit in despair." HELEN: "Yes, I think I would get a little emotional there already. [In the context of prediction of a 4.0 blood glucose value]"

Fear of Hypoglycemia is expressed as anxiety and discomfort among other things and can have a negative impact on reacting appropriately to one's blood glucose level [26]. Fear of hypoglycemia, in individuals with T1D, is commonly underestimated in clinical practice [122] and can result in reducing individuals quality of life [81]. On the other end of the spectrum, Polonsky et al. [120] investigated hyperglycemia aversion. It was found that people that avoided hyperglycemia, spent more time below the target range, experienced heightened impaired hypoglycemic awareness, and recurring severe hypoglycemia episodes [120]. HELEN's comment, suggests that predictions have the potential to reinforce behaviors like fear of hypoglycemia or hyperglycemia aversion. Being more aware of the potential risks in the future having out-of-range blood glucose values might not always be desirable.

HELEN: "I think blood glucose predictions are great, but not if it causes me unnecessary stress or worry."

The comment made by HELEN was made in the context of notifying participants regarding outof-range predicted values. When it would be necessary to notify participants about out-of-range values could be individually different. While some might have a hyperglycemia aversion trait others might have a fear of hypoglycemia. Personalized messages regarding emotional topics such as out-of-range values might therefore be desirable.

#### 5.3.4 How Do I Want to Engage and Be Supported?

The theme *engagement and support* explores speculations on what users want regarding engagement and support from systems grounded in their described practices and the use of MOON-T1D during the ESM-study.

Xx could be grouped into three subthemes that we named; (1) proactive versus reactive approach, (2) tell me what to do (instructions), (3) show me what I need (constraints)

We divided the participant's approach to engagement into a **proactive and reactive approach**. A proactive approach is exemplified by participants actively checking their blood glucose without anything triggering the interaction.

HELEN: "Yes, so if I actively go to the app and look for information, then yes."

While an example of a reactive approach would be that participants react to some signal emitted by the device they are using. This could go as far as participants only looking at their device if they receive some notification.

GEORGE: "Generally, if I do not hear from my pump, everything is ok."

What we asked ourselves in this context is whether such a reactive approach to T1D management is desirable. For some participants, it most certainly is, stating that they would like to move their T1D management to the background, discussed in the case study of GEORGE (see Section 5.1.1).

One commonly mentioned and requested feature by participants was reminders in the e form of **notifications**. We initially associated notifications with a reactive approach to T1D management, we however later realized their potential to foster a proactive approach. Notifications in the context of T1D management could be critical to prevent immediate life-threatening situations such as hypoglycemia-induced coma [38]. Critical prediction alerts were, where however only one of the discussed uses of notifications by participants. Other notification requests were particularly directed at predictions. Providing notifications regarding predicted out-of-range blood glucose values was perceived as very useful for participants' overall management.

GEORGE: "If the notification comes already 1-2 hours in advance, that would of course be ideal, rather than if I only find out when the blood glucose is already dropping."

Drawbacks such notifications could introduce for participants, were previously highlighted in the case study of HELEN (Section 5.1.3) as well in Section 5.3.3, which touches upon disturbance and micro-management. Another drawback of a reactive approach to management could be that the approach does not provide individuals with a comprehensive understanding of their diabetes management. This could result in neglecting important aspects of management such as exercise and the situational impact, previously discussed in Section 5.3.2.

Notifications were however not always associated with a reactive approach to management but also a proactive approach. Being reminded of checking their blood glucose could allow people with T1D to increase their involvement and thus knowledge regarding blood glucose management. Participants attributed their perceived involvement increase to the sent ESM-study questionnaire that served as a reminder for them.

#### FINN: "I automatically became more intensively involved with it."

Showing the desire to be involved and the potential for notifications to increase proactive involvement from participants.

Our second subtheme "**tell me what to do**" captures the need for clear instruction mostly in the form of recommendations. Clear instructions should allow participants to make informed decisions and to gain actionable insights.

While a blood glucose prediction could also be seen as a recommendation participants additionally wanted clear instructive **recommendations** to tell them the best-suited action for their current situation, including the prediction. This relates to the situational aspect of our previous theme, where participants wanted to find similar situations to their current one for decisionmaking. AS highlighted by the following statements:

FINN: "[...]and then I see a recommendation for how many carbohydrates the meal contains and what I have to calculate [talks about bolus calculations] and what I can eat without calculation." HELEN: "Like so in the sense of, the top line [of Figure 4.4 image 4] shows what happens when you stop injecting insulin. It is then like a tip, what you could theoretically do."

While FINN would want recommendations on how much carbohydrate a meal contains and subsequently how much insulin he would have to take for that, HELEN on the other hand talks about more informative predictions. The danger of providing such recommendations is the loss of trust among participants if they are incorrect. While Stawarz et al. [139] found that participants were likely to accept erroneous recommendations, at least in non-ordinary situations, this was not the case for our participants. Due to the individuality of the disease and sense-making process discussed in Section 5.3.2, recommendations would need to be personalized. Also, their individual goals and the emotional connection (discussed in Section 5.3.3) they have to their diabetes management, i.e. fear of hypoglycemia, can affect how such recommendations are perceived and acted upon.

While clear guidance, through recommendations, might be desirable by participants it can also be misleading in cases of situational instability. This can result in individuals following guidance that is not appropriate for their unique circumstances, leading to not only a loss of trust but also suboptimal diabetes management outcomes.

The subtheme **"show me what I need"** imposes certain demands on visual representations to facilitate comprehension and enhance their efficacy in guiding decision-making. This extends to blood glucose prediction visualizations where as discussed in Section 5.2.4 regarding Figure 4.4 a more concrete visualization of predictions including explanations was preferable. Constraining and simplifying visual representations in apps for T1D management is desirable for comprehensibility and ease of use. *FINN: "And everything is presented without bells and whistles, [...]"* Ease of use is desirable due to its association with technological acceptance [61, 78] and long-term engagement [2]. There is a trade however between simplification and potential prediction accuracy. The simplified visualizations and choices presented to participants might not capture the complexity of their condition management or the situation they are currently in. This was also discussed by Desai et al. [40], reflecting on their participants wanting rich but simple solutions. Oversimplifying complex situations might lead to participants overlooking or ignoring information that might result in incorrect conclusions or decisions.

FINN: "There was a bread with 55.3 g or with 32 g and there 66 g carbohydrates, and there one would be enough for me, like an average, I wouldn't need three to choose from."

The example of FINN highlights the potentially introduced inaccuracies also when input is entered. The idea to see already what will happen in the future and therefore prevent undesirable blood glucose outcomes is desirable.

GEORGE: "There I could then see how I need to adjust [insulin blood glucose-wise] for the physical activity. That would be an advantage for me."

There is however also a drawback to this future-focused perspective of T1D management. Having a narrow view of one's blood glucose might introduce negative emotional responses as discussed in Section 5.3.3. With T1D being a condition requiring long-term management a range of factors beyond blood glucose predictions such as regular medical checkups and physical activity need to be considered and captured. Which might not be captured moving to a future-focused approach to blood glucose management.

### **Chapter 6**

## **Discussion and Design Implications**

The aim of this thesis was to investigate the lived experience, expectations, and needs of individuals with T1D regarding an application supporting blood glucose predictions. To achieve this, we developed a prototype mobile app called MOON-T1D which enables users to enter and view blood glucose values, insulin injections, carbohydrate intake, and physical activity while also providing blood glucose predictions. The prototype was utilized in five days ESM-study, complemented by two semi-structured interviews with each participant. The study included three participants with T1D, and aimed to capture their lived experience, practices, expectations, and needs. A reflexive thematic analysis [30] was conducted on the collected data, resulting in four themes: (1) empowerment and control, (2) sense-making and understanding, (3) emotions and experiences, and (4) engagement and support.

The write-up of our analysis consisted of a description of the four themes and the discussion of the three case studies, one for each participant. And we will further discuss implications for the development of an all-encompassing app that includes blood glucose predictions for people with T1D in the following. The discussion will take a more general form as more specific design implications and reflections have been discussed in the discussion of the case studies (Section 5.1) and the thematic analysis (Section 5.3). Although the sample size in our study was limited, as discussed in Section 7, we have gained meaningful insights and developed design implications for mobile apps that support blood glucose predictions. In future research we hope to address individual needs in a more personalized manner and hope to extend our study to include more participants. Further information on our future work can be found in the subsequent discussion on design implications and in the section on limitations and future work in Section 7.

**Control or Controlling?** The feeling of loosing control was described by Strain [141] as one of the seven categories of psychological reactions to chronic illness. McDuffie et al. [100] associated the loss of control with feeling powerless. Similarly, Aujoulat et al. [9] aimed to understand the empowerment evolving from a feeling of powerlessness in patients with chronic conditions. They associated different ways of loosing control with the feeling of powerlessness, where a sense of security and control could help patients to feel empowered [9]. Similarly, our participants expressed different ways of feeling in control. Some associated having a daily routine or regularity with a sense of control, while others felt in control when verifying whether their perception was aligned with reality, e.g. by guessing what their blood glucose value and then measuring it. Moreover participants attributed a loss of control to external factors such as misinformation. Finally, participants felt in control trough planning i.e. by eating differently for an anticipated high pressure situation. Therefore encouraging the feeling of regaining and maintaining control is central to self-management.

Being in control is important for people with T1D to avoid serious health complications [159]. Balfe et al. [12] found that increased control over diabetes could help with diabetes distress. Diabetes distress is a term referring to emotional burden, stressors and frustration that are associated with managing T1D [51, 48]. Feeling in control and acquiring knowledge can empower people with T1D [12]. When designing apps for people with T1D we suggest therefore that researchers and practitioners consider providing the desirable feeling of control for users without encouraging controlling behaviors. One way of helping users gaining more knowledge and feel in control are predictions. Predictions provide users with more information regarding what could happen in the future and allow users to take preventative actions.

The pursuit of T1D-control can however have drawbacks. Some of which were mentioned by our participants, be it self-imposed restrictions to maintain control or an excessive desire towards remaining in the target range, both of which could negatively impact participants' behavior. When feeling in control develops into a controlling behavior, caution is advised. Encouraging controlling behaviors regarding T1D management that turn into a T1D perfectionism can be dangerous and should be avoided. Already the introduction of real-time glucose levels could lead to potential risky choices and an encouragement of a perfectionistic attitude as discussed by Abraham et al. [1] T1D self-management perfectionism has been associated with impaired hypoglycemic awareness [106] and eating disorders [119]. Designers should be aware that their designs supporting blood glucose control might well instead encourage an unhealthy relation to ones diabetes management. How this adverse behavior that could be influenced by predictions could be prevented or recognized to initiate preventative actions would be interesting to study in future work.

**Personalization** Self-management in T1D is mostly done by the patients themselves [54]. Personalization addressing the individuality of chronic conditions has become attainable and is important for patient empowerment. Storni [140] for example, assessed designs of self-care technologies in the context of an ethnographic study. They found that personalization for diabetes management would be desirable to account for conflicting practices and perspectives [140]. Chen [35] investigated the usage of health information system for diabetes management. They found that patients with diabetes had a unique approach to their management, suggesting the system design that accounts for individual differences [35]. Mamykina et al. [96, 95] investigated the use of MAHI (also discussed in Section 2.4.2) to construct and sustain their positive self-image, which was bound to their individual needs. The situational differences regarding self-management was discussed by O'Kane et al. [112]. They found that there were individual differences of technology use and concealment of its use in different familiar situations [112].

Similarly our study participants did not only describe individual differences in situational contexts but also varying preferences for predictions and visualizations. Participants had a notion of an ideal diabetic, against which they compared their own practices. However without fail all participants reported that their management practices did not align with this idealized management. Participants specifically provided us examples demonstrating that what worked for one participant did not work for another. This indicates that participants may not just differ from their constructed management ideal but also from each other. This is why participants felt that T1D self-management was primarily about self-teaching and learning from past situations. While we believe that "more" personalized self-management technologies could be very beneficial for successful management, the degree of personalization that is optimal not only for the perceived need of users but also for their psychological and physical well-being should be assessed in the future. Additionally it may be beneficial to design and implement more sophisticated methods for comparing past situations to the current situation.

**Emotional Visualizations** The emotional value of T1D management has influences on successful management. Diabetes-distress for example is associated with changes in HbA1c levels [89], lower levels of self-care, metabolic outcomes and emotional well-being [137]. The emotional value of T1D self-management was also mentioned by our participants. In particular, participants discussed the act of choosing how much T1D was allowed to influence their daily life practices.Further, acceptance of T1D and negative emotions associated with the condition were discussed.

When designing apps for T1D management, factors such as Fear of Hypoglycemia and aversion of Hyperglycemia should be considered (discussed in Section 5.3.3). The relation of emotions to visualizations was touched upon by Desai et al. [40], where they found that people with T2D expressed a positive emotional response to infographic and methaphorical visualizations. However the positive emotional response to these kind of visualizations did not affect their design preferences. Their visualizations intentionally tried to convey a positive or negative emotion with within range or out of range blood glucose values respectively. They found that participants preferred visualizations that gave them actionable insights instead [40]. Emotions caused by visualizations, might not be all that good especially with respect to fear of hypoglycemia or hyperglycemia aversion. Moreover our participants discussed feeling self-conscious about their condition While predictions for example could help participants in avoiding situations of feeling self-conscious they might as well create them by e.g. sending notifications about an anticipated high blood glucose a inconvenient time. The importance of actionable insights, gained from visualization design was also mentioned by our participants. However, we believe that when designing blood glucose prediction visualization, designers should be extra careful about the emotions their visualization could convey. The goal of predictive visualizations should not be the achievement of the target blood glucose value at all cost. Instead we believe that it should help empower and support a healthy relationship to ones condition.

**Interact With Me** In our case studies and thematic analysis we observed different interaction preferences regarding participants management practices and blood glucose predictions. Some wished to be proactive while others preferred a more reactive approach to management. Proactivity versus reactivity regarding diabetes management has been predominantly studied from a clinicians perspective [69]. D.R. et al. [45] assessed the extend to which information regarding diabetes self-management was sought out actively or passively. Whether interactions with mobile devices for managing T1D should follow and support a more reactive or proactive approach has not jet been explored to our knowledge. Thoolen et al. [150] has investigated proactive coping interventions. They showed that proactive coping was a predictor for long-term self-management [150]. Similarly, Kroese et al. [83] investigated whether the development of proactive coping skills would improve psychological , behavioral and medical well-being of patients. They found that psychological well-being and participants behavior was improved [83].

Another aspect of interactions with technology were notifications and recommendations. Notifications were desirable but for which situations, their frequency and impact differed between participants. Bentley and Tollmar [21] found that notifications can help increase logging activities by users [21]. Similarly our participants describing feeling more involved due to being unintentionally reminded by our ESM-notifications. How to design interaction between technology and users with T1D could be explored in future research.

## **Chapter 7**

## **Limitations and Future Work**

This thesis is subject to several limitations. Due to the difficulty of recruiting participants we were only able to conduct our study with a very limited number of participants (N=3). While we were initially aiming for five participants this quickly proofed impossible. A limitation of this small number of participants is that we are unable to claim any kind of generalizability and can only make suggestions based on our limited knowledge to inspire the design of future applications. Future work would therefore include the extension of this study to include a higher number of participants.

Second, our prototype design was based on previous work. We decided to use this approach since to elicit design requirements by e.g. co-designing an app in addition to building, deploying, and evaluating it would have been beyond the scope of a master's thesis. We also believe that by designing our app based on existing apps, we have a solid representation of the state-of-the-art of mobile apps supporting blood glucose predictions. Nevertheless, not building an app based on stakeholders' requirements has several limitations. Firstly, it can lead to our participants focusing on what kind of additional functionalities or requirements they would have desired. Additionally, participants might focus on or be irritated by certain design choices that could affect the outcome of our research questions. Also, some functionalities that would have made predictions more realistic and useful were not included in the initial design and could therefore not be evaluated. Finally, not including medical experts in the design of an app addressing a medical condition neglects their valuable medical expertise and would have allowed for the app to adhere to medical standards and guidelines. Future work would include user-centered design involving all stakeholders to design an app based on conclusions drawn from this work.

Third, due to the limited time frame of a thesis, not all initially planned design ideas for MOON-T1D were realized. Some design ideas such as including a step tracker, showing physical activity also in the *Overview*, providing blood glucose, activity, carbohydrate and insulin summaries and many more were not implemented in the final prototype. While this might not necessarily have impacted the participants' perception of blood glucose predictions, they might have shifted the users' focus to the more thought through parts of the apps neglecting views such as the *Activity Views*. Future work would therefore include the development of additional functionalities and visualizations balancing the overall design of the app more.

Fourth, the decision to not use the participants' actual blood glucose values was made by us for three reasons. Firstly, to create similar settings for all participants in terms of the blood glucose values they would see. Secondly, to avoid the storage of sensitive medical data of participants, which would require an ethics request beyond the scope of a thesis work. Lastly, connecting manufacturer-specific devices for blood glucose measuring was difficult. However, the use of semi-randomly generated blood glucose values has several limitations. Firstly, participants may not find the predictions as useful as they would if they were based on their actual blood glucose values. Secondly, we cannot make any claims about experiences related to trust in the prediction, as participants never experienced a prediction that was not later confirmed by their values. Thirdly, participants may be less motivated to use and evaluate the app since they do not see their own blood glucose values.

Fifth, we decided upon an algorithm to create this semi-random blood glucose values. We chose to then use the currently visualized semi-random blood glucose values and associated predictions to ask participants about usefulness. Another approach would have been to show participants specifically designed scenarios such as the blood glucose is stable but the prediction shows an increase or the blood glucose is rising and the prediction shows where it would stop rising. This would have allowed us to make more specific statements regarding if blood glucose prediction horizon usefulness or accuracy changes depending on their blood glucose level also and not just their current situation. While we were able to capture some answers related to this in our second interview, future work could try to address this more in depth in a potential quantitative study.

Sixth, we decided to use an actual machine learning algorithm to generate blood glucose predictions based on semi-random blood glucose values and data entered by the users. However, this decision may have introduced some delay in loading the prediction for participants. Moreover, since we did not train the algorithm on our semi-randomly generated blood glucose values, but on values from actual people with T1D, the prediction may have been less accurate for our semi-random values. A simpler approach would have been to create a prediction using only the semi-random blood glucose values. However, the prediction shown to participants may have been improbable to some degree, which could have irritated them. In future work, we will either train the prediction algorithm on our semi-randomly generated values or avoid using an actual prediction algorithm altogether.

Finally, although we may be able to reconstruct what participants saw while answering the ESM-study questionnaire, we can only reconstruct the semi-randomly generated blood glucose values and not the prediction. Furthermore, performing the prediction on the same values again may not necessarily yield the same result. We may be able to partially reconstruct what participants saw regarding predictions in the ESM-study questionnaire based on their answers and by rerunning the prediction algorithm on the same blood glucose values. However, we cannot say with 100% certainty whether participants' reactions differed based on different predictions shown. Therefore, future work should include capturing the prediction shown to participants as well.

## **Chapter 8**

## Conclusion

The present thesis set out to investigate individually different experiences and approaches to T1D self-management, with a particular focus in blood glucose predictions. Based on a systematic literature review and results of our previously conducted study, we designed, implemented and deployed a prototype mobile app called MOON-T1D. With MOON-T1D, users were able to record and view blood glucose values, nutritional content of meals, insulin injections, and physical activity. Additionally, we provided users with semi-random blood glucose predictions based on their recorded data. We then conducted a qualitative user study with three participants with T1D who used MOON-T1D over the course of five days. Our user study consisted of two personal interviews and an ESM-study. The data obtained through the interview and the ESM-study were analyzed using three case studies and a reflexive thematic analysis. The case studies revealed several participant desires, such as being able to view past, present and future blood glucose values. In relation to blood glucose predictions, we were able to observe tendency for micro-management. Participants also expressed different preferences in relation to a prediction horizon versus prediction accuracy trade-off, and differing opinions on how prediction and its uncertainty should be visualized. The thematic analysis yielded the following four themes: (1) feeling in control and empowered, (2) ways of sense-making and understanding, (3) emotions and experiences while living with T1D, and (4) desired *engagement and support*. The first theme provides an account of aspects influencing the feeling of control and empowerment for people with T1D. The second theme outlines different ways in which people with T1D make sense and understand their condition. The third theme explores participants' perceived emotions associated with different experiences related to their condition. The fourth and final theme captures desires regarding interaction, support, and engagement with apps for T1D self-management. Overall, each theme highlights the individually different experiences, practices and expectations of people with T1D in relation to blood glucose predictions. We believe this thesis makes a strong case for the necessity of a substantial degree of personalization to leverage the full potential of the individuality of T1D self-management in the future.

## Appendix A

## **Focus Questions**

We initially came up with several focus questions based on the three research questions. The focus questions were used to guide the questions and design of the two semi-structured interviews.

- $FQ_1$  What are the current practices of people with T1D to anticipate their blood glucose values?
- $FQ_2$  Are participants willing to change their practices to receive blood glucose predictions?
- $FQ_3$  What are participants' perceived benefits and drawbacks of the different factors recorded and shown in MOON-T1D?
- $FQ_4$  What is the lived experience of people with T1D using an "all-encompassing" app?
- $FQ_5$  Does the desire to see a prediction i.e., its usefulness change depending on the situation?
- $FQ_6$  What is the desired prediction horizon of participants does their desired blood glucose prediction horizon change depending on their situation?
- $FQ_7$  What is the desired blood glucose prediction certainty of people with T1D does the certainty required change, depending on the situation?
- $FQ_8$  Is there a trade-off for participants between the accuracy of the prediction and prediction horizon?
- $FQ_9$  Does blood glucose prediction change the action participants would take? How would it change their behavior?

## **Appendix B**

# **Metrics for Clinical Care**

#### Standardized CGM metrics for clinical care: 2019

1 Number of days CGM worn (recommend 14 days) [161, 125]

- 2 Percentage of time CGM is active (recommend 70% of data from 14 days) [18, 161]
- 3 Mean glucose
- 4 Glucose management indicator (GMI) [118]
- 5 Glycemic variability (%CV) target <=36% [104]\*
- 6 Time above range (TAR):% of readings and time. >250 mg/dL (>13.9 mmol/L) Level 2
- 7 Time above range(TAR):% of readings and time 181–250 mg/dL (10.1-13.9 Level 1 mmol/L)
- 8 Time in range (TIR):% of readings and time 70-180 mg/dL (3.9-10.0 mmol/L) In range
- 9 Time below range (TBR):% of readings and time 54-69 mg/dL (3.0-3.8 Level 1 mmol/L)

10 Time below range (TBR):% of readings and time <54 mg/dL (<3.0 mmol/L)</th>Level 2Use of Ambulatory Glucose Profile (AGP) for CGM report

CV, coefficient of variation. \*Some studies suggest that lower %CV targets (,33%) provide additional protection against hypoglycemia for those receiving insulin or sulfonylureas [124, 104, 126].

**Table B.1:** Ten most useful metrics for clinical care selected by panel of expert clinicians and researchers, (adapted from [17])

# Appendix C

# **Detailed Exclusion Criteria**

Detailed exclusion criteria used for the systematic literature review in SCOPUS in Table C.1. Additionally the exclusion criteria used for the app store search in Table C.2.

"blood glucose prediction" OR "blood glucose" AND prediction           Keywords         AND diabetes	
AND dabletes AND app OR application OR smartphone OR platform OR mobile OR handy	
Publication Year >2018	
Related to Mhelath, Diabetes, AI, Medecine, Computer Science, HCI, etc.	
Included Journal and Conferences         Included Journal International Conference On Computational Performance Evaluation Competitions         Included Journal International Conference On Computational Performance Evaluation Competitions         Included Journal International Conference Include International Journal On Clinical International Journal On Computers In Biology And Medicine, BMC Medicine, BMJ Open Diabetes Research And Clinical Pre-         Diabetology International, Frontiers In Endocrinology, International Journal Of Computers And App International Journal Of Computers Communications And Control, International Journ	actice, jystems Letters, lications, ing And Digital Systems, betes, re Biomedical Engineering, Connected Health con Applied
prediction of BG levels but no app with human input (14)	
Exclusion Criteria non-invasive blood glucose estimations (3) focus on other technologies (4)	
products something else than BG level/app is the means to another end in the paper (28)	
reviews (4)	

Table C.1: Search query and number of papers excluded by exclusion criteria including the full list of journals and conferences included

Criteria	Apps	Nr
Do not	Blood Glucose Tracker, mySugr - Diabetes Tracker Log, Glucose	55
support	tracker - Diabeteic diary, Diabtes Diary - Blood Glucose Tracker,	
BG level	Blood Sugar Tracker: Diabetes TEst Glucose Log, Blood Sugar	
prediction	Log - Diabetes Tracker, Blood Sugar Tracker - Diabetes, Blood	
	Glucose Tracker - Track your blood Glucose, Glucose Buddy	
	Diabetes Tracker, Glucose Blood Sugar Tracker, Blood Glucose	
	Tracker Monitor, Blood Glucose Monitor - Sugar TEst Converter,	
	Glucose Tracker - Blood Sugar, Blood Sugar Log - Diabetes,	
	Health2Sync - Diabetes Care, MySugar: Track Blood Sugar, Bood	
	Pressure, Blood Glucose Tracker (Diabetes Tracker), Blood Sugar	
	Converter Pro, Blood Sugar Test Advice Tack, Blood Sugar Di-	
	ary for Diabetes, Diabetes, Blood Sugar Test Info, Beat Diabetes,	
	Intellin Diabetes Management, Blood suger, Blood Sugar Test	
	Info & Advice, Social Diabetes, Blood Sugar, Sugar Test Con-	
	verter, Diabetes Connect, Diabetes & Diet Tracker, BD Diabetes	
	Care App, BeatO: Diabetes Care & Tracker, Klinio: Diabetes Meal	
	Tracker, nBuddy Diabetes, iFORA Diabetes Manager, Diabetes	
	Plus, iHealth Gluco-Smart, Diaguard: Diabetes Diary, Diabetes	
	Diary, Betes - Your Diabetes Diary, Blood sugar diary App, Dia-	
	betes control APP, My Sugar Diary-Diabetes App, Kovoq Sugar-	
	diary for diabetes, t1d Calc, Diabetes, Type 1 Diabetes, DiabiLive,	
	CONTOUR DIABETES app, LibreLinkUp, Undermyfork: Dia-	
	betes app, diasend, CareLink Connect	
Support BG	Suggin, One Drop, DiabTrend, Quin, Diabits	5
level predic-		
tion		

\_\_\_\_\_

**Table C.2:** Results of the App Store searches. On top 55 apps that do not support blood glucose level prediction. On the bottom apps supporting blood glucose level prediction

# **Appendix D**

# **Results of the Systematic Literature Review and App Stores Search**

The two Tables D.1 and D.2 present the comparisons of apps for people with diabetes supporting blood glucose predictions.

App Name	Blood Glucose	Insulin	Carbohy- drates	Activity	Mood
Diabits [82]	Dexcom and Medtronic CGM	Manual	Manual	Manual	No
ARISES [168]	Dexcom CGM	Insulin pen and pump connection	Manual	Empatica E4 writsband	Stress
[166]	Data from: Medtronic En- lite and Dexcom G6 CGM	No	No	No	No
GlucOracle [41]	Manual entry	No	Manual	No	No
[164]	EnliteMMT-7008A CGM	No	No	Xiaomi Mi Band 5	Stress (Xiaomi Mi Band 5)
[90]	Dexcom G4 platinum CGM	Manual	Manual	Manual	Stress (Manual)
Suggin [101]	Nightscout data	Manual	?	Google Fit	No
One Drop [72]	MyStar Plus and Choice CGM, One Drop glucose meter, sync	Manual	Food database	Google Fit, Apple Health, Fitbit	No
DiabTrend [43]	Abott FreeStyle Libre 1 and Enlite-Sensor CGMs and Accu-Check Instant, BETACHEK C50, Dcont NEMERE, MERYkek QKY and Manual entry	Manual and voice	Automatic food recog- nition and portion estimator	Google Fit, Apple Health, Amazonfit Bip	No
Quin [71]	Manual entry, Apple Health sync	Manual	Manual	Apple Health	No

Table D.1: Description of the different types and sources of data captured by mobile apps for people with T1D.

App Name	Factors included in	ML algorithm	Person-	Prediction tar-	Prediction		
	Prediction		alized	get	Horizon		
Diabits [82]	BG data, food intake,	Gradient Boosted	Yes	Blood glucose,	60 minutes		
	insulin administration,	Decision Tree +		insulin and			
	physical activity	SVM		CHO available			
ARISES	BG data, food intake,	Mixed effects lo-	Yes	Blood glucose	60 minutes		
[168]	insulin administration,	gistic regression					
	physical activity	analysis					
[166]	BG data	RU-based RNN	Yes	Blood glucose	30 and 60		
		model, the em-			minutes		
		bedded edge					
		evidential NN					
GlucOracle	BG data, food intake	Data ssimila-	Yes	Blood glucose	3 hours		
[41]		tion, unscented					
		kalman filter					
[164]	BG data	No	No	Blood glucose	60 minutes		
[90]	BG data, food intake,	CRNN	Yes	Blood glucose	30 and 60		
	insulin administration,				minutes		
	physical activity, alco-						
	hol, stress	-			100		
Suggin	BG data, food intake,	?	Yes	Blood glucose	120 minutes		
[101]	insulin administration,						
	physical activity	-					
One	BG data, food intake,	?	Yes	Blood glucose	8 hours BUT		
Drop[72]	physical activity, sleep	-			only for T2D		
DiabTrend	BG data, food intake,	?	Yes	Blood glucose	4 hours		
[43]	sleeping habits						
Quin [71]	BG data, food intake,	?	Yes	Blood glucose	4 hours		
	insulin administration,						
	physical activity						

Table D.2: Description of the prediction related data and the type of visualization of the 10 apps for people with T1D

# Appendix E

# Demographic Questionnaire (English)

The demographic questionnaire used during the study. The questionnaire was available in English and German.

Questionnaire:	
What is your age?	
□ 18-24 years old	□ 45-54 years old
□ 25-34 years old	□ 55-64 years old
45-54 years old	Over 65 years old
With which gender do you identify mos	st?
□ female	
🗆 male	
prefer to self describe:	
At what time do you usually eat breakfast	?
At what time do you usually eat lunch?	
At what time do you usually eat dinner?	
How many years have you lived with typ	
I have lived years with type 1 dia	abetes.
What is your target blood glucose rang	je?
My target blood glucose range is betweer	n and mmol/L.
On average what percentage of the tim	ne is your blood alucose within your
target range?	, , ,
My bood glucose is % of the time v	vithin my target range
What was your last HbA1c approximate	ely?

Note: Your HbA1c is your average blood glucose levels measured over the last 2-3 months My last HbA1c was: \_\_\_\_\_ mmol/L

# What is your insulin sensitivity factor?

Note: Insulin sensitivity factor (ISF): Also called correction factor is a measure of how much (in -77) will 1 unit of insulin lower your blood glucose level. The ISF may vary depending on the time of day. My insulin sensitivity factor is \_\_\_\_\_ mmol/L

# By how many units does one gram of carbohydrates raise your blood glucose?

 When I eat 1 gram of carbohydrates my blood glucose will raise by \_\_\_\_\_ mmol/L

 How do you usually take your insulin?

 Tethered insulin pump
 Insulin syringe

 Patch insulin pump
 Other (please specify below):

 Insulin pen
 How do you measure your blood glucose level?

 Glucose meter (finger prick)
 Continuous glucose monitoring (CGM)

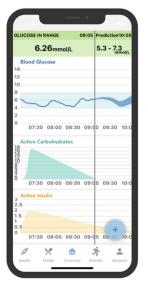
 Other (please specify):\_\_\_\_\_\_

 When do you take insulin in relation to mealtime?

# Appendix F

# Leaflet (German)

Leaflet provided to participants, that should sever as an app manual for them too use as guide throughout the study



### Startseite

Wenn Sie MOON-T1D öffnen, ist dies der erste Bildschirm, den Sie sehen. Er enthält die meisten Informationen, die sie tagtäglich brauchen.

Eine graue Line teilt die Startseite in 2 teile wobei die Linke Seite die vergangenen 2 Stunden anzeigt und die rechte Seite eine Stunde in die Zukunft anzeigt.

Durch nach unten wischen auf Ihrem Smartphone können Sie die Werte jederzeit aktualisieren.

### Blutzucker und Blutzuckervoraussage

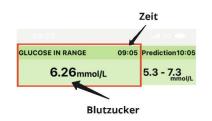
### Blutzucker:

Zuoberst befindet sich auf der linken Seite der jetzige Blutzucker (in der Anzeige 6.26mmol/L) sowie für welchen Zeitpunkt der Blutzucker gilt (hier 09:05). Falls der Zeitpunkt nicht mit Ihrer Jetzigen Zeit übereinstimmt wischen sie bitte auf dem Screen nach unten um die Anzeige zu aktualisieren.

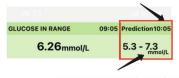
### Blutzuckervorhersage:

Auf der rechten Seite sehen Sie eine Blutzuckervorhersage eine Stunde in die Zukunft. Hier wird vorausgesagt das Ihr Blutzucker zwischen 5.3 und 7.3 mmol/L liegen wird um 10:05.

Der Grund warum Sie keinen exakten Wert sehen, ist weil eine Blutzuckervorhersage bis jetzt immer mit einer gewissen Ungenauigkeit verbunden ist.



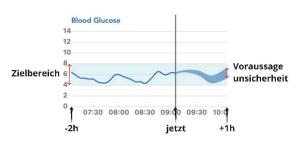
Voraussage Zeitpunkt



Vorausgesagter Blutzucker

### **Blood Glucose Ansicht:**

In dieser Ansicht sehen sie auf der linken Seite Ihren Blutzucker dargestellt (bzw. eine Simulation von Blutzuckerwerten die auf Ihre Eingaben reagiert). Auf der x-Achse sehen sie die Zeit und auf der y-Achse ihre Blutzuckerwerte in mmol/L. Das hellblaue band in der Mitte stellt ihr Blutzuckerzielbereich dar. Auf der rechten Seite sehen Sie die



Blutzuckervorhersage eine Stunde in die Zukunft. Da eine kurzfristige Blutzuckervorhersage genauer ist als eine längerfristiger sehen Sie eine Art Verbreiterung die die zunehmende Unsicherheit der Voraussage beschreiben soll. Die exakte Bandbreite in der Ihre Blutzuckerwerte nach einer Stunde liegen könnten wird zusätzlich auch oberhalb schriftlich angezeigt.

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### Active Carbohydrate Ansicht:

Die Active Carbohydrate Ansicht stellt dar wieviel der von Ihnen eingegebenen Kohlenhydraten noch im Körper aktiv sind bzw. aufgenommen werden.

Die y-Achse stellt die Anzahl Kohlenhydrate in gram dar und die x-Achse die Zeit. Diese Ansicht hilft Ihnen abzuschätzen wie viele Kohlenhydrate noch von Ihrem Körper aufgenommen werden und dadurch wie Ihr Blutzucker eventuell noch durch diese ansteigen könnte.

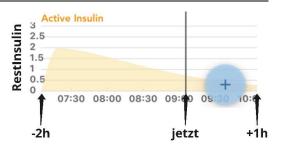
### Restkohlenhydrate 11110040 б 07:30 08:00 08:30 09:00 09:30 10:0 -2h jetzt +1h

**Active Carbohydrates** 

### **Active Insulin Ansicht:**

Die Active Insulin Ansicht stellt dar wieviel des von Ihnen eingegebenen Kurzzeit Insulins (Bolus) noch am wirken ist.

Die y-Achse stellt die Einheiten Insulin dar die noch im Körper vorhanden sind und die y-Achse die Zeit. Diese Ansicht Hilft Ihnen abzuschätzen ob noch Kurzzeit Insulin am agieren und dadurch ob noch eine Blutzuckersenkende Wirkung des Insulin vorhanden ist.

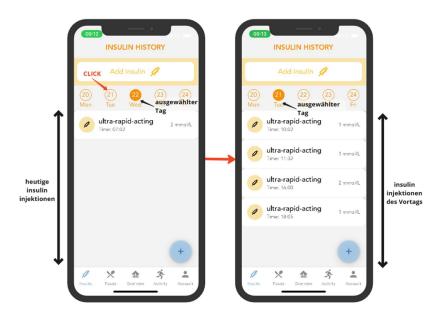


## Insulin Verlauf



Wenn Sie auf das Symbol mit dem Namen «Insulin» unten links klicken kommen Sie zur Insulinverlaufs («Insulin History») Ansicht. Auf der Insulinverlaufs Ansicht sehen Sie alle Insulin werte Die sie

much root Overver Activity Account selbst eingegeben haben und deren Zeitpunkt für den heutigen Tag. Durch anklicken eines vorherigen Tages können Sie den Insulin injektionsverlauf der vorherigen Tage ansehen.



## Insulin Injektion Hinzufügen:



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Bei der Insulineingabe für das Kurzzeit Insulin können Sie das folgende angeben:

- Insulin Type: Die Art des Insulins
  - o Ultra-rapid-acting: dazu gehört fiasp
  - o Rapid acting: dazu gehört Novorapid, Novolog Homolog
  - o Long lasting: dazu gehört Tresiba
- Administration: Wo Sie das Insulin gespritzt haben mit im Moment 2 Optionen:
  - Abdomen: bauch als repräsentative f
    ür schnell wirkende Insulin Injektionsort
  - o Other: anderes als Repräsentation der langsamer ...
  - Insulin Units: Wie viele Einheiten Sie gespritzt haben.
- Time: Der Zeitpunkt an dem Sie das Insulin gespritzt haben.

Mit dem ADD INSULIN button können Sie ihre Eingaben abspeichern – dies kann nicht mehr Rückgängig gemacht werden.

### Mahlzeiten Tagebuch:

Die Mahlzeiten Ansicht besteht aus 3 Teilen. Zuoberst ist immer die Suchfunktion zu sehen. Gerade Darunter sehen Sie unterschiedliche Tabs. Je nachdem auf welchem Tab Sie sich befinden wird auf dem Rest der Ansicht etwas anderes angezeigt.

Im Moment befinden Sie sich auf dem «Diary» Tagebuch tab. Hier sehen Sie das der Heutige Tag (der 22.02.2023) ausgewählt wurde. Die Mahlzeiten, die Sie heute eingenommen haben, gruppiert nach Mahlzeitentyp, sind gleich darunter dargestellt.

Hier sehen sie zum Beispiel das Sie um 07:00 ein Morgenessen (Joghurt und Kaffee) mit 18g und 1.7g Kohlenhydraten zu sich genommen haben.

Darunter sehen Sie das Mittagessen das aus Eiern, Käsen und weiteren Zutaten bestanden hat.

Um die weiteren Zutaten zu sehen können Sie nach unten scrollen.

Falls Sie sich ansehen wollen was für Mahlzeiten Sie in den letzten Tagen gegessen haben können Sie

unterhalb der Tabs den Tag auswählen für den Sie Ihre Mahlzeiten sehen wollen.



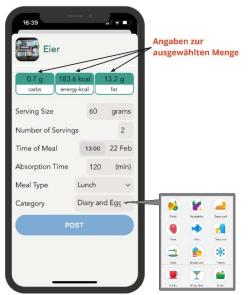


#### Mahlzeit Hinzufügen: Sie haben 4 Möglichkeiten eine Mahlzeit hinzuzufügen: 1 Sie können nach einem Produkt in unserer SUCHE FOOD Produkte Datenbank suchen Hier zum Beispiel eine Suche nach «Weggli» Q weggli × Diary Products Foods Search CLICK Lyoner weggli Per 100g:25g (carbs) 18g + (fat) 2 Sie können ein vorher schonmal hinzugefügtes Foods Diary Products Search Produkt nochmals hinzufügen. CLICK Apple, raw €Ū Per 100g:14.8g (carbs) 0.1a (fat) Sie können ein Produkt kreieren und das Produkt 3 Diary Products Foods Search dann wie in punkt 4) beschrieben hinzufügen. CLICK Create Product 4 Sie können ein bereits kreiertes Produkt Diary Products Foods Search hinzufügen Create Product My Products CLICK COLA ZERO ő + Carbs: 0, Fat: 0

### Mahlzeit Hinzufügen

Um das Produkt als Ihre Mahlzeit hinzuzufügen, müssen Sie folgendes spezifizieren:

- Serving Size: Portionsgrösse in Gramm (oder bei Getränken Milliliter) wieviel Gramm sie des Produktes konsumiert haben (hier: 60g das Gewicht eines Ei's)
- Number of Servings: Wie viele Einheiten der vorgegebenen Produktmenge sie eingenommen haben. (Hier e.g. 2 mal 60g, da für das Mittagessen 2 Eier gebraucht wurden.)
- **Time of Meal:** wann sie gegessen haben (hier um 13:00).
- Absorption Time: Wie lange sie denken das es für Ihren Magen braucht die Kohlenhydrate des Produkts zu absorbieren, hier z.B. 2 Stunden.
- Meal Type: Was für ein Zweck das Essen hatte (Frühstück, Mittagessen, Abendessen oder Snack)



Category: Zu welcher Kategoire von
 Lebensmitteln das Essen gehört (hier: Molkereiprodukte und Eier)

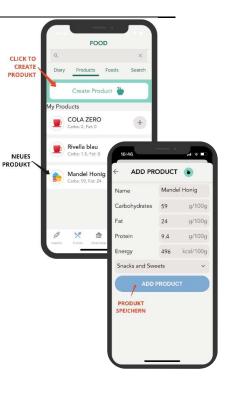
## Produkt kreieren:

Um ein Produkt zu kreieren, navigieren Sie so:

- Klicken Sie auf «Create Product»
- Geben Sie den Namen des produkts an.
- Die N\u00e4hrwerteeinheiten werden zurzeit immer nur als g/100g akzeptieret. F\u00fcr Getr\u00e4nke k\u00f6nnen Sie dies als g/100ml interpretieren.
- Wählen Sie eine Produkt Kategorie
- Um das Produkt abzuspeichern klicken Sie auf «ADD PRODUCT»

Nach dem hinzufügen des Produkts erscheint dieses hier:

Hinweis: Die von Ihnen hinzugefügten Produkte sind nur für Sie zugänglich.



# Aktivitäten Übersicht:



## Aktivität hinzufügen:

Um eine neue Aktivität hinzuzufügen haben Sie folgende 2 Optionen:



Sie können auf der «ADD ACTIVITY» Ansicht folgendes eingeben:

- Duration: Die länge der Aktivität in Minuten
- Start Time: Wann Sie die Aktivität gestartet haben
- Activity Type: Was für eine Aktivität Sie gemacht haben
- Intensity: Wie intensiv die Aktivität war.

Um die Aktivität abzuspeichern, klicken Sie «ADD ACTIVITY»

Hinweis: Dieser Vorgang kann nicht rückgängig gemacht werden.

Hinweis: Nur ultra-rapid-acting und rapid-acting Insuline werden in der Active Insulin Ansicht dargestellt.



## Blutzuckerwerte testen:

Das + Zeichen unten rechts erlaubt es Ihnen einen Blutzuckerwert einzugeben. Nach Eingabe des zu testenden Blutzuckerwerts wird die Blutzuckervorhersage sowie die ab dann zufällig generierten Werte dem von Ihnen eingegebenen Wert angepasst.

SEUCOSE IN RANGE 17:20 Prediction 18:20		GLUCOS		GLUC	DSE IN RANG			ction18:20
5.66mmol/L 4.6 - 6.6	ADD BLOOD	020000			8.66m	imol/L	7.7 -	- 9.7 mmol/L
Blood Glucose 4 2 0	BloodGlucose	8.0		Blo 14 12 10		inzugefügter Vert von 8.0		
~~~~~	Units Time	mmol/L 17:16	mg/dL 23 Feb	8 ~	$\sim$	)		
Add Insulin 🖉 👔	ADD BLOG	DD GLUCO	SE	0 15:	30 16:00	16:30 17:00	17:30	18:00
Add activity	BLUTZUCKE		- I-	Ac	ive Carbohy	drates		alisierte aussage
2) CLICK Add Food	SPEICHER	•,				16:30 17:00	17:30	18:00
Add bloodglucose				10 10 6	ive Insulin			
1) CLICK + +				2	30 16:00	16:30 17:00	17:30	+
Insulin Foods Overview Activity Account				, firsul		Overview A	3°	Account

# Appendix G

# **Recruitment Flyer (English)**

One of the flyers used for recruiting participants. The flyer was available in English and German and two versions were created one with a banner and one without. The banner was meant to be more catchy if diabetologists did not give the flyers directly to patients.



# STUDY OBJECTIVE

We want to develop an application that caters **to your specific needs** for your daily type 1 diabetes (T1D) management.

## For this we need your help!

- Share your ideas and needs with us in an interview.
- Test and evaluate our application in your daily life.





# ARE YOU ELIGIBLE TO PARTICIPATE?

- You have had type 1 diabetes (T1D) for at least 12 months
- You are between 18 to 70 years old
- You use an Android or iOS smartphone

## **INTERESTED? CONTACT US!**

- Via Email: <u>clara-maria.barth@uzh.ch</u>
- Scan the QR-code



Figure G.1: Flyer created in English and German, and distributed to diabetologists, medical newsletters, and a center for endocrinology in Switzerland, to recruit Participants.

Appendix H

# **Ethics Approval**

Ethics approval obtained from the faculties ethics board.



Human Subjects Committee of the Faculty of Economics, Business Administration, and Information Technology

### **Department of Economics**

University of Zurich Blümlisalpstrasse 10 CH-8006 Zurich Phone +41 (0)44 634 37 01 Fax +41 (0)44 634 49 07 www.econ.uzh.ch

Prof. Dr. Michel Maréchal Member of Human Subjects Committee +41 44 63 45191 michel.marechal@econ.uzh.ch

Zurich, February 28, 2023

# Authorization of research project "Diary Study on the Daily use of a Blood Glucose Prediction Application by People with Type-1-Diabetes" (OEC IRB # 2023-015)

To whom it may concern,

The Human Subjects Committee of the Faculty of Economics, Business Administration and Information Technology at the University of Zurich authorizes the research described in Elaine May Huang's research proposal "Diary Study on the Daily use of a Blood Glucose Prediction Application by People with Type-1-Diabetes" (OEC IRB # 2023-015).

Specifically, we have reviewed the information regarding the procedures and protocols that will be implemented to conduct the experiments involving human subjects. We confirm that they comply with all applicable regulations.

We therefore approve the planned research outlined in the proposal.

Yours sincerely,

Prof. Dr. Michel Maréchal Member of the Human Subjects Committee Head of Human Subjects Committee

Page 1/1

Figure H.1: Ethics approval from the faculties ethics board.

# Appendix I

# **Informed Consent (English)**

In the following you can find the informed consent form as presented to the participants. The informed consent was available in English or German.



OEC Human Subjects Committee @Faculty of Business Economics and Informatics

- 4) Will you obtain a signed notice of informed consent from all study participants? If not, please provide further explanation.
  - Yes, I will provide the following informed consent:

## Informed Consent Form:

### Dear study participant,

thank you for your interest and commitment to the study of the lived experience of our mobile application MOON-T1D for people with type 1 diabetes (T1D). This introduction will explain the most important points you need to know before participating.

### Aim of the Study:

The study aims to investigate the lived experience and daily interactions of people with T1D with our application MOON-T1D. The provided application allows you to enter data about insulin administration, interesting fictitious blood glucose values, physical activity, and carbohydrate intake. The values you enter will affect the visualizations shown to you during the user study. We want to investigate the perceived benefits and drawbacks (e.g. time required for carbohydrate entry) of using such an application, in the various everyday situations of people with T1D. We would further like to assess the different needs people with T1D have regarding such an application.

#### Study Content:

The study consists of two interviews and the usage of MOON-T1D for 5 consecutive days, including regular short questions on application usage.

- The first interview will last about 30 minutes and includes questions about your current diabetes management practices and an introduction to MOON-T1D
- The study on your lived experience with the application will last 5 days and includes regular short (ca. 3 min) questionnaires to be filled out by participants.
- The final interview will last about 30 minutes and includes questions on your lived experience with the application, reflecting on opportunities to improve MOON-T1D and eliciting potential opportunities for guidelines for application for people with type 1 diabetes

Note that the second interview can be conducted online or offline, while for the first interview, a live presence is preferable to ease the setup and explanation of the mobile application MOON-T1D

#### **Confidentiality and Anonymity:**

In the context of this study, personal data including the audio recording of the two interviews, questionnaire answers, the voluntarily added data to the application (MOON-T1D), and basic interactions with the application, will be collected by researchers.

Your data will be treated confidentially and will only be accessible to experts for scientific evaluation in an anonymized form, e.g. by using a pseudonym or participant number (e.g. P13). The collected information will only be used for research purposes.

Once the research project has been concluded, the personal data that has been processed will be stored on password-protected machines of researchers in the People and Computing Lab at the University of Zurich. Your data will be kept for five years and will then be destroyed.

#### **Independent Research:**

This is an independent research project that is conducted with the financial support of the University of Zurich. The research project is conducted in the context of a master's thesis by Clara-Maria Barth supervised by the head of the People and Computing Lab Prof. Dr. Elaine



OEC Human Subjects Committee @Faculty of Business Economics and Informatics

M. Huang. Depending on the outcome, the anonymized results may be published in a scientific paper.

### **Requirements:**

- To be eligible to participate, you must fulfill the following criteria:
- 1. Diagnosed with type 1 diabetes for at least 12 months.
- 2. Be aged between 18 and 70 years.
- 3. You use an Android or IOS smartphone regularly

#### Possible Benefits of Participating in this Study:

- You will be able to influence and shape application design and development for type 1 diabetes management by sharing your lived experience with us.
- You will gain insights into your daily diabetes management and your needs for an
  application that would support that.
- You will receive monetary compensation of **150 CHF** for completing all three steps of the study in the form of a Migros, Amazon, or Galaxus gift card.
- You will receive additional monetary compensation of **15** CHF, **25** CHF, **or 30** CHF upon filling out more than **50%**, **75%**, **or 100%** of all the questions during the 5-day application usage study. The additional compensation will be added to the 150 CHF gift card.
- As soon as we publish the results of this user study, we will send you 1) your personalized results of the study and 2) the research paper associated with your results. (Please note that this might take some time until paper completion and publication)

#### Possible Risks and Inconveniences of Participating in this Study:

There are no known risks beyond those of normal mobile phone usage. As we are using simulated blood glucose values, your actual diabetes management should NOT be influenced by this study.

#### Voluntariness:

Participation in this study is completely voluntary. You have the possibility to revoke your consent at any time without having to specify a reason for doing so. Upon revocation of consent, all the data that has been gathered up to that point will be deleted and destroyed upon request.

#### **Insurance Coverage:**

There is no insurance coverage for participants in this study. No claims can be made for any damage that arises in connection with this study.

#### Audio Recording Consent:

□ I \_\_\_\_\_ (Name, Lastname) hereby explicitly consent to the audio recording of both interviews conducted during this study.

### **Consent:**

- I \_\_\_\_\_ (Name, Lastname) hereby confirm that:
- I have read and understood the above information and have no further questions.
  A researcher explained the purpose of the data gathered, as well as the location where it
- will be stored.
  I had the opportunity to ask questions and currently have no further questions regarding the research project.

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