

**Title of Project:** Patient-Centered Data Visualizations for Diabetes

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**Inclusive Dates of Project:** 05/01/2015 - 04/30/2018

**Federal Project Officer:** Steve Bernstein

**Acknowledgement of Agency Support:** This work was funded by the Agency for Healthcare Research and Quality (AHRQ), grant number R21HS023865. The views expressed herein are those of the authors and do not necessarily represent that of the funding agency.

**Grant Award Number:** R21HS023865

## 1. Structured Abstract

**Purpose:** Primary aims of this research were to: (1) examine visualizations for diabetes-related and other personal health data; (2) understand adolescent, caregiver, and healthcare provider needs related to comprehending and using complex data; and (3) develop candidate visualizations allowing adolescents and parents to view their diabetes data in conjunction with contextual information.

**Scope:** The convergence of large amounts of data from medical devices, mobile technology, and cloud computing, with the power of patient-centered research, has the potential to revolutionize the way in which adolescents with type 1 diabetes, a technologically savvy population, engage in self-management of their disease.

**Methods:** We assessed the data visualization landscape, conducted ethnographic interviews with teens and caregivers as well as focus groups with diabetes providers, and conducted a pilot study where participants used a mobile app to collect diabetes and contextual data which was used to create personalized data visualizations.

**Results:** There was a significant amount of variation across diabetes data platforms and a lack of standardization in data presentation. There were a number of barriers to data visualization described by patients and providers (interoperability issues, lack of convenience, lack of integration into clinical workflow), but both groups stressed the importance of including contextual information with diabetes data. Pilot study participants were able to identify context-based trends to a greater extent, were able to triangulate data using multiple datastreams to discover new insights, and were able to generate possible solutions for addressing context-based patterns.

**Key Words:** type 1 diabetes, adolescents, data visualization, contextual data

## 2. Purpose

The specific aims of this project were as follows:

- Specific Aim 1a: To perform environmental scans of existing data visualization techniques from commercial diabetes software and consumer-facing mobile technology.
- Specific Aim 1b: To perform a literature review of data visualization and interactive techniques for viewing longitudinal data that may have the potential to enhance patients'/families' ability in interpreting their health/healthcare data.
- Specific Aim 2: To understand adolescent/caregiver/provider information needs related to diabetes and for understanding complex longitudinal data.
- Specific Aim 3a: To devise a list of candidate visualization techniques, develop a software prototype to operationalize these techniques, and iteratively refine the prototype through a series of user studies.
- Specific Aim 3b: To have adolescents with type 1 diabetes collect diabetes data and contextual variables using mobile technology and incorporate this data into the data visualization prototype for usability testing.

## 3. Scope

Published in 1993, the landmark Diabetes Control and Complications Trial (DCCT) demonstrated that intensive insulin therapy (including frequent blood glucose monitoring and insulin administration) for type 1 diabetes (T1D) was associated with delays in the onset of and/or slowing of the progression of microvascular and macrovascular complications.<sup>1</sup> The DCCT set the standard of care for individuals with T1D, which now includes blood glucose monitoring 5-10 times a day, insulin administration at least 4-6 times a day, and calculation of carbohydrates for all meals and snacks.

Regular retrospective review of diabetes data is needed to understand blood glucose trends, identify issues, and solve problems through adjustments in insulin dosing and other self-care

behaviors in order to maintain and/or improve glycemic control.<sup>2</sup> Adolescents are a particularly important group to target for data engagement as their glycemic control is suboptimal; only 21% of adolescents aged 13-19 years meet the American Diabetes Association goal of a Hemoglobin A1c (HbA1c) less than 7.5%.<sup>3</sup> A majority of patients, especially adolescents, do not utilize their data for developing insights about self-management,<sup>4,5</sup> despite evidence that routine review of this data is associated with improvements HbA1c.<sup>4,6</sup>

Diabetes self-management activities generate an enormous amount of data. Tools and technologies that facilitate the exploration and examination of multiple streams of longitudinal data using interactive visualization techniques continue to evolve. However, at the start of this project period, many existing displays were used outside of the healthcare setting, had not been evaluated for usability or understanding, and/or did not specifically focus on the patient as the user. Though additional datastreams exist that are may helpful for making sense of diabetes data and generating insights about self-management, standard diabetes data visualizations often display only blood glucose numbers, without providing such contextual information. These data are often easily and passively collected from smartphones such as physical activity levels and location, a proxy for environment.

Adolescents with type 1 diabetes are an ideal population for innovating a novel, personalized data visualization system that integrates large amounts of clinical data with contextual data collected from mobile phones, providing opportunities for greater engagement, insight, and problem-solving in order to improve glycemic control.

#### 4. Methods

**Specific Aim 1a:** A focus group of experienced health information experts and diabetes care experts were convened to discuss consumer-facing information systems for viewing diabetes data. There were a total of six different commercial systems identified, however, due to multiple versions of the same software, nine different iterations of the software were used for comparison. The consumer-facing information systems included were Tandem Diabetes Care, Glooko (home version), Glooko+Diasend (clinic version) with multiple daily injections only, Glooko+Diasend (clinic version) with insulin pump & continuous glucose monitor (CGM), Medtronic CareLink, Medtronic CareLink for the MiniMed 670G hybrid closed-loop system, Dexcom Clarity, Tidepool, and Abbott Freestyle Libre software. In addition to systems for viewing diabetes data, we reviewed consumer-facing systems for visualizing personalized health records (PatientsLikeMe) and fitness tracking devices (Fitbit) to understand how these systems present individual-level data.

**Specific Aim 1b:** We conducted a comprehensive literature review of existing methods for visualizing longitudinal healthcare data published in the literature. We performed a search of articles in PubMed, IEEE, and ACM Digital Library using the following search terms: Diabetes, Data Visualization, Computer Graphics, User Interfaces, Computer Displays, and Data Displays. We identified eligible articles that focused on digital displays of diabetes patient data (both web and mobile visualizations) which led to an initial batch of 474 papers across the three databases. We employed a dual review approach for determining relevance, with two reviewers excluding articles first based on titles and abstracts, and then excluding others based on full-text article review. We excluded studies that consisted of visual representations of metabolic or genetic pathways, virtual simulations, and workflow/scheduling tools and applications. Qualitative and quantitative articles of any study type that made use of visual representations of diabetes data were included; the displays provided did not need not be fully implemented or tested by a patient group to be included. There were just 30 articles which met the criteria. A

total of 50 images were manually extracted from the 30 studies included in the final synthesis and put into a database.

**Specific Aim 2:** We conducted semi-structured ethnographic interviews with adolescents with type 1 diabetes (n=20) and their caregivers (n=17). Adolescents ranged in age from 12-17 years, with duration of T1D of >1 year to 13 years, and with varying levels of glycemic control (range: HbA1c from 5.9% to 12.4%) at the time of interview. We asked about the following topics:

- Diabetes management, barriers, and obstacles
- Social/family relationships and diabetes
- Barriers to downloading, viewing, and accessing their diabetes data
- How they currently use their diabetes data
- Goals for viewing and using their diabetes data
- Interest in combining diabetes data with additional contextual datastreams
- Desired features of diabetes data visualizations / types of data visualizations and interactive features they might find useful
- Heuristics they typically use to make decisions about insulin management

We also conducted two focus groups with health care providers with expertise in diabetes. Participants included six endocrinologists and two certified diabetes educators (CDEs) from six hospital systems across the U.S. participating in the T1D Exchange Quality Improvement Collaborative. Each focus group lasted approximately one hour, during which providers were asked about:

- Barriers to downloading, viewing, and accessing diabetes data
- Current methods and technologies used for diabetes data exchange and communication in the clinic and privacy concerns
- Provider preferences regarding sharing of diabetes and personal data
- Interest in combining diabetes data with additional contextual datastreams
- Desired features of diabetes data visualizations / types of data visualizations and interactive features they might find useful
- Heuristics they typically use to make decisions about insulin management

**Specific Aim 3a:** Through analysis of our findings from the environmental scans, review of the literature, and interviews and focus groups with patients, caregivers, and health care providers, our team selected key visualizations to be included in our prototype. We recruited two teens and one caregiver to review and give feedback on our initial designs, and their insights were used to revise the visualizations for our final prototype which was created using Tableau software.

**Specific Aim 3b:** We recruited 15 teens with T1D and their caregivers from the C.S. Mott Children's Hospital Pediatric Diabetes Clinic. Teen participants were 13-17 years old, English-speaking, and had been diagnosed with diabetes for more than six months at the time of enrollment. All of the teen participants and their caregivers had been previously interviewed by the research team to better understand how they utilize their diabetes data (see Specific Aim 2).

Because two weeks' worth of data is considered minimally sufficient for understanding blood glucose trends, teen participants were asked to collect diabetes and contextual data for 21 days using DReflect, a context-enhanced, mobile diary application developed by our research team. Of note, the DReflect mobile application was developed for the Android operating system, which made participant recruitment difficult, as many teens who expressed interest in the study used mobile phones running on iOS; this ultimately led to reduced number of participants (15, instead of 30). DReflect collected GPS-based location and self-reported mood, stress, carbs ingested,

insulin doses, blood glucose values, and free-text notes. In addition, there was a feature that allowed teens to add personalized hashtag notes when logging other data (e.g., #eatout, meaning ate at a restaurant; #junkfood; #exercise; #guestimate, representing a guessed carb amount; #missedbolus, indicating a missed insulin bolus). A data summary was also generated on the app for each day’s data, which the teen could refer to when completing an end-of-day diary noting the different activities that occurred during the day. If the teen did not use the app during the day, they would be asked to explain in the end-of-day diary what prohibited them from logging that day. Parents of the teenage participants were also asked to complete an end-of-day questionnaire for each day over the same 21-day period. The questionnaire asked parents about their day including family routine, unusual events in their and/or their child’s day, and what, if any, challenges were experienced in regard to managing diabetes.

After the 3-week data collection period, we interviewed the teens and parents using context-enhanced visualizations created from their data. We asked participants to describe how they interpreted the different visualizations and for their preferences on the varying design elements (e.g., color, graph style, variables included). We also asked participants about how the data displays improved their understanding of their experiences over the 21 days of the study using guided questions as well as thinking out loud exercises while reviewing the data visualizations.

## 5. Results

**Specific Aim 1a:** While comparing and contrasting each diabetes data visualization software, twelve categories of data views and features were identified: logbook, modal day, statistics overview, aggregate by day of the week, aggregate by hour, single day, multiple single day, bolus by meal aggregate, data sufficiency, data variability, aggregate compare, and interactivity. The table below shows the different views and features available for each of the software systems, and they are described in detail below.

Categories	Tandem Diabetes Care	Glooko w/CGM (Home)	Glooko+Dias end (Clinic) - MDI	Glooko+Dias end (Clinic) - Pump/CGM	CareLink (Medtronic)	CareLink (Medtronic) - 670G	Dexcom Clarity	Tidepool	FreeStyle Libre
Logbook	x	x	x	x	x	x		x	
Modal Day			x	x		x	x	x	
Statistics Overview	x	x	x	x	x	x	x	x	x
Aggregate by day of the week	x	x	x	x			x		
Aggregate by Hour		x	x	x	x		x		x
Single Day	x	x					x		
Multiple Single Day			x	x		x	x	x	x
Bolus Meal/Aggregate		x			x	x			x
Data Sufficiency				x			x	x	
Data Variability	x	x	x	x	x	x	x	x	x
Compare					x		x		
Interactivity	x	x	x	x			x	x	x

- Logbook (7 of 9 systems). The logbook view was included in all systems except for the two CGM-exclusive systems, Dexcom Clarity and Abbott Freestyle Libre. The logbook view triangulates blood glucose, carbs, and insulin all in one view, typically over a 2-week period and recapitulates what was traditionally recorded in paper logbooks. It is a more traditional tool, commonly used by endocrinologists and CDEs and provides detailed data about diabetes behaviors and blood glucose trends. The logbook delivers one of the most comprehensive views of data as it includes: discrete blood glucose values for each measurement, carbs ingested at each meal, insulin administered (based on the amount of carb and blood glucose value at each measurement), and blood

glucose 2-hours post-meal. It also gives daily estimates of total daily dose of insulin, and total basal and bolus insulin. The calendar-style format also makes it easy to interpret the data based on day or the week (e.g., weekends vs. weekdays) and/or in relation to specific events (e.g., sports or gym class on certain days of the week).

- Modal Day (5 of 9 systems). The modal day view overlays blood glucose values by time on a single graph with multiple days of data. Each day of data is denoted by a different color or symbol. This view provides a summary in the context of a daily view, which is used to identify consistent patterns of high and low blood glucose values so that users can make insulin or behavioral adjustments related to those periods of day.
- Statistics Overview (9 of 9 systems). This report typically consists of overall statistics for the given time period for: (1) glucose, including mean/median glucose and standard deviation, number of blood glucose values, average number of blood glucose values per day, time in range (% of values above, in range, and below the target); and (2) insulin, including average total daily dose of insulin, average daily bolus insulin, average daily basal insulin, basal to bolus ratio, number of boluses per day; and (3) a number of statistics relevant for individuals on insulin pumps, including food bolus, correction bolus, quick bolus, average daily override.
- Aggregate by Day of the Week (5 of 9 systems). This visualization shows days of the week on the x axis with blood glucose numbers as the y axis. Blood glucose values are plotted on the graph in various formats such as lines, scatterplots, or columns.
- Aggregate by Hour (6 of 9 systems). The aggregate by hour visualization shows glucose values by time of day over multiple days and may include median and percentiles of times in range. This view works well for identifying patterns associated with time of day and activities occurring at that time. For instance, looking at peaks or valleys associated with a time of day and a certain activity (e.g., eating a meal, exercising, or sleeping) can be considered a pattern if it happens frequently, suggesting a change may be necessary if blood glucose is not well controlled. This view is also frequently used for assessing if correction or nighttime insulin doses need to be adjusted.
- Single Day (3 of 9 systems). A single day view that shows 24 hours of glucose monitoring as well as basal and bolus insulin, carbs, corrections, and pump setting changes that occurred in that time frame.
- Multiple Single Day (6 of 9 systems). This view shows days in strips of 24 hours with multiple graphs representing each day in the selected time reference range. This data visualization may only include blood glucose values or it may also include carbs, basal, and bolus insulin.
- Bolus by Meal Aggregate (4 of 9 systems). The bolus by meal aggregate view defines a range of time typically associated with a meal time and records the before, during, and after blood glucose values as well as the number of carbs consumed and the amount of insulin taken. Organization of this data varies from naming breakfast, lunch, dinner, and overnight values to breaking a 24-hour period up to morning, early afternoon, evening, and overnight hours, commonly associated with times of meals.
- Data Sufficiency (3 of 9 systems). The data sufficiency view shows the validity of blood glucose values based on CGM calibrations, how long the sensor has been worn, and the total CGM sensor duration. These factors are important for ensuring that the data from the CGM are reliable.
- Data Variability (9 of 9 systems). The data variability function shows the range of data and standard deviation between readings for data from glucometers, pumps, and CGMs.
- Compare (2 of 9 systems). On software with the compare feature, blood glucose values from two different time periods can be compared side to side. Blood glucose trends as well as statistics such as average glucose, standard deviation, and time in range are displayed. This view is especially useful if an individual changes their diabetes self-

management regimen, to assess if the change made a difference in their blood glucose control.

- Interactivity (5 of 9 systems). Some data platforms did allow interactivity in data visualizations, allowing the user to change the time frame of visualizations dynamically.

Among the nine diabetes data systems that were reviewed, we identified a great deal of variation in the characteristics of the visualizations:

- Different types of representations including pie charts, bar graphs, open/closed circles,
- Different definitions of low, normal, and high blood glucose values: Low thresholds varied from <80, <75, or <70; normal ranges included 75-175, 70-180, or 80-180; high thresholds varied from >175 or >180 (all values in mg/dL)
- Different systems for showing ranges of blood glucose values: Three-tier (low, normal, and high) vs. Five-tier (very low, moderately low, normal, slightly high, and very high)
- Names of categories for ranges of blood glucose: 'Below,' 'Within,' 'Above,' 'Values below goal,' 'Values within goal,' and 'Values above goal'
- Statistical distributions varied from 0<sup>th</sup>%-90<sup>th</sup>%, 10<sup>th</sup>%-90<sup>th</sup>%, 25<sup>th</sup>%-75<sup>th</sup>%
- Y axes on graphs ranged from 0-350 mg/dL, 40-400 mg/dL, and 0-500 mg/dL
- A range of colors spanning from red, orange, yellow, purple, green, light blue, dark blue, and with differing colors used to depict high and low blood glucose values depending on the system
- There were different elements that did or did not exist across visualizations (e.g., 'Set change', 'Average number of bolus overrides/day', 'Average days between primes')

In addition to the extensive review of diabetes data visualization platforms, the research team also reviewed consumer-facing systems for visualizing personalized health records (PatientsLikeMe) and fitness tracking devices (Fitbit).

*PatientsLikeMe*. A digital personalized health record and online community, PatientsLikeMe provides a platform for patients with chronic diseases to record, view, and share their health information with others.

- Users create a profile that can include a bio, age, location, and a list of chronic disease/disorders they live with
- Health information recorded includes: symptoms, treatments, mood, and stress
- Visualizations vary for each disease. For example, rheumatoid arthritis includes:
  - Tracking of different symptoms (joint pain, swelling, stiffness)
  - Color-coding to indicate different types of symptoms (spectrum of colors from yellow to red to indicate mild to severe pain)
  - Indications for whether they are on or off treatment to be able to compare symptoms
- Users can modify the date range and update graphs dynamically and can hover over data points on the graph for more details
- There are two levels of privacy settings: 'members only,' which allows only members of PatientsLikeMe to see your profile or 'public,' which allows both member and non-members to view a profile
- There is a social element so that other members can 'follow' each other and/or send private messages to connect with other members

*Fitbit*. A brand of wearable fitness trackers, Fitbit devices record activity including steps and heart rate and users have access to a web-based database that provides visualizations of the data in relation to goals and overall progress.

- Users create a profile to access their data through the web or mobile, which is automatically synced from their device
- Health information recorded includes: steps, distance, calories burned, floors climbed, active minutes, exercise tracked by category (e.g., run, sport, aerobic), sleep, weight tracking, food/calories consumed, water intake, heart rate, steps per hour
- Some visualizations not only provide metrics but are designed for behavior change
  - The first five health categories (steps, distance, calories, floors climbed, active minutes) are displayed as a daily view of progress circles, where the outline of the circle is filled in based on progress toward the goal for that day
  - Most of the datastreams have customizable target ranges for each activity as well as proposed thresholds such as, “The American Heart Association recommends 10,000 steps a day to reap the health benefits of walking”
  - Badges are featured to provide rewards for completing certain levels of activities
  - Heart rate or exercise graphs are expressed as a line graph with interactive features such as maximum and minimum heart rate as well as time spent in the fat burn, cardio, or peak heart rate zones
  - Depending on the volume of data generated, data can be displayed in daily, weekly, monthly, yearly averages
- Users can adjust viewing to different time intervals (daily, 7-day, or 28-day view, or since an account was opened) and hovering over a data point displays the date the activity was completed and the exact numerical value
- Users have the ability to lock certain information that won’t be shared with others or limit what is available to view by friends and global users (e.g., locking weight loss data). Data can be shared with others through the ‘friends’ feature of Fitbit, which allows Fitbit users to request to become friends and enables each party to see each other’s selective data.

**Specific Aim 1b:** Across the 30 articles included in the final analysis, there were a variety of diabetes data representations provided, though the representations were much less comprehensive than what we found in the commercial data systems and much more dated in terms of features (a number had PalmPilot-like interfaces that predate the smartphone). The visualizations fell into two categories: dashboard data displays and mobile views, either designed to be single user vs. collaborative (i.e., for a patient to use with a physician or family member). Some of the mobile views were for logging data, for supporting meal/nutrition tracking, and for goal setting. With regard to data review, the platforms in these studies were used to identify patterns of hypoglycemia and hyperglycemia, and provided views of the impact of nutrition and physical activity on blood glucose patterns. Again, as we noted in our environmental scan, we found lots of variation in the representations whether statistical (heat maps, bar graphs, dot plots, scatter graphs, pie charts) or tabular (logbook view). They used different groupings (e.g., three tiers up to seven tiers of blood glucose categories), different representations of color to indicate different ranges and or different days of the week. Unfortunately, none of the studies evaluated the effectiveness of different types of data visualizations for supporting data discovery or insights, but rather were merely demonstrations of tools that had been developed for research studies.

### **Specific Aim 2:**

#### **ETHNOGRAPHIC INTERVIEWS: ADOLESCENTS AND CAREGIVERS**

##### Diabetes Management, Barriers, and Obstacles

*Monitoring and Insulin Delivery.* Nine adolescents used a CGM, of which eight also used an insulin pump and one delivered insulin via multiple daily injections (MDI). The remaining eleven did not use a CGM, opting to solely use a glucometer for checking blood glucose; of these, six



used insulin pumps and five delivered insulin via MDI. The majority of adolescents that were interviewed reported checking their blood glucose with a glucometer four to six times per day, most often before meals/snacks, before and/or after exercise, and at bedtime, with many noting that they will check more frequently if feeling symptoms of hyper- or hypoglycemia. Two teens reported checking more than six times per day, one of whom had been diagnosed for less than one year at the time of the interview, while one teen reported only testing twice per day—the minimum number necessary for calibrating the CGM.

*Remembering Management Activities.* As far as remembering to complete self-management activities, three interviewees stated that they don't use or need reminders because living with T1D—and the management that goes along with it—is such a part of their routine. However, most adolescents reported that they 'sometimes' forget self-management activities like testing their blood glucose and giving insulin, often because they are busy with other things. Some teens who struggled with remembering described using reminders to help keep them on track, including using reminder features on their insulin pumps, setting alarms on their cell phones, leaving notes on the kitchen table, or receiving verbal reminders from family members and friends. While at least one teen reported that such reminders were 'annoying,' it was acknowledged that they are helpful. Another important factor for remembering that was mentioned is having an overall routine, such as during the school year.

*Carb Counting.* All adolescents reported engaging in carb counting to some extent, though it was the behavior that warranted the most assistance from caregivers. Several teens mentioned that they eat a lot of the same meals and snacks so they are familiar with the carb counts of these foods; a couple of teens specifically said they have certain values 'memorized.' Interviewees also reported using nutrition labels on packages, with numerous teens and parents mentioning they use measuring cups and scales to assess portion sizes. If a nutrition label wasn't available (e.g., when eating out at a restaurant), nearly all participants said they looked up carb information online with the most frequently cited resources being Google and the CalorieKing mobile app. Parents also described helping to determine carb counts for home cooked foods and meals. Generally, adolescents received some help with carb counting from parents (and sometimes also school staff, friends, or other relatives), either in-person at the time of the meal or through virtual communication such as texting of photos. Of note, two parents revealed that their teens 'know' how to count carbs, but when unsupervised, they tend to guess the amount.

*Adjustments for Exercise.* A majority of adolescents participated in sports on a regular basis and required adjustments like consuming an uncovered snack before and/or after participating in an activity and consuming small amounts of carbs throughout activity (e.g., drinking Gatorade) to avoid hypoglycemic events. Of the adolescents who used insulin pumps, several strategies were implemented to prevent or counteract lows, including disconnecting their pump during the sporting event or by setting a temporary basal rate to reduce the amount of insulin delivered into the body during the activity period. Other athletes reported disconnecting their pump during activity so it wouldn't get in the way or to avoid damage to the pump itself. Since exercise typically impacts blood glucose levels, adolescents reported they more frequently monitored their blood glucose levels before, during, and after physical activity.

*Biggest Challenges.* The biggest challenges of diabetes reported by adolescents included remembering to complete diabetes self-management tasks (e.g., testing, bolusing, carb counting) and/or having all necessary supplies on hand needed to carry out these self-management activities. Other obstacles included the nuisance of device alarms, especially when they occur in less than ideal locations such as in a quiet classroom at school. Others

reported that diabetes can make social interactions more difficult as self-management activities often interrupt what they're doing. One teen also mentioned being self-conscious when needing to perform self-management activities around unfamiliar faces.

### Social/Family Relationships and Diabetes

*Family Relationships and Sharing of Management Responsibilities.* Division of diabetes-related responsibilities differed across interviewees, with respondents falling along a continuum ranging from very little responsibility to nearly total independence. Virtually all of the adolescents interviewed were responsible for monitoring their blood glucose during waking hours, counting carbs, calculating insulin doses, and administering insulin, though they occasionally received some help from their parents or other caregivers. Parents were primarily responsible for downloading and reviewing diabetes data, contacting the clinic team, picking up prescriptions, and ordering supplies. Among teens who used insulin pumps and CGMs, there were mixed responses regarding responsibility for changing pump and sensor sites. The majority of teens and parents reported that they communicate regularly about diabetes management, both in-person and virtually via phone calls, text messaging, or remote monitoring of diabetes data using mobile apps like Dexcom Share. Interviewees described various reasons that adolescents contact their parents, including communicating about blood glucose numbers, especially when experiencing hyper- or hypoglycemia, asking for help with carb counting or insulin dosing, or in cases of illness (e.g., presence of ketones).

*School and Activities.* Most of the interviewees described supportive school environments, with teachers, school nurses, and other school staff allowing teens to eat snacks and use cell phones and diabetes devices as needed in class as well as providing assistance with carb counting and insulin dosing if necessary. One mother said that the school nurse follows her daughter on Dexcom Share so she can help monitor her blood glucose throughout the day. Additionally, two adolescents had parents who worked in their schools and were also available to help if needed. While school staff mostly seemed to be accommodating to students with T1D, a couple of parents and teens mentioned they've had issues with teachers and schools adhering to 504 plans. For the adolescents involved in sports and other extracurricular activities, coaches, trainers, and teammates seemed to be aware of their diabetes diagnosis and trained on what to do in case of emergency

*Friends and Social Life.* The adolescents' responses varied as to how comfortable they feel disclosing their T1D diagnosis and self-management responsibilities to friends and others in social situations. Some said they have no concerns. A couple of teens said they have close friends who also have T1D and described that it's comforting to have a friend who understands what T1D is and all of the management activities that go with it. Inversely, some teens described T1D as more of a pain point in social contexts. One adolescent said that some students at his previous school made fun of him for his diabetes. Others expressed a desire to keep their disease more private, choosing to only share with close friends in case of emergency and complete self-management activities behind closed doors. One mother thought that a CGM might help her daughter in social situations, noting that "She could just look at her phone and not... anything that would make it more convenient and not so obvious." Self-management can also be challenging when out with friends as teens reported being distracted or not wanting to take time away from what others are doing in order to test blood glucose, administer insulin, etc.

### Barriers to Downloading, Viewing, and Accessing Their Diabetes Data

About a third of interviewees described barriers to downloading, viewing, and accessing their diabetes data with the most cited reason being that the process of downloading is too complicated. Two adolescents and their parents explained that they didn't have the necessary

cables to connect their devices to a computer, as such cords often do not come with the device and must be purchased separately. Many preferred viewing their data via a mobile app, rather than downloading to computer; however, a couple of families mentioned app issues including unavailability or incompatibility with their phones' operating system. One mother also explained that they did not have internet access at home so they couldn't download the teen's devices to the corresponding web-based software.

### How They Currently Use Their Diabetes Data

A common theme across interviews was that achieving blood glucose control can be challenging, but that data can often help patients and caregivers identify and solve issues. Many teens, as well as some parents, mentioned that they review blood glucose data in real-time throughout the day, but as far as retrospective review, parents were the primary reviewers.

*Data Collection.* When first diagnosed, all individuals with T1D are instructed to keep a written log book with their blood glucose numbers, carbs, and insulin doses. As adolescents adopt new technologies (i.e., insulin pumps and CGMs), many families stop keeping written logs and utilize data visualization software that can display the data captured by the devices. However, some families prefer to keep written logs of diabetes data, especially among families where the adolescent was not using an insulin pump or CGM and therefore only have a glucometer that can be downloaded. Other common reasons for preferring paper tracking included familiarity with the medium and simplicity ("To me, that's easier, to write it down and see it rather than on a computer and have to keep on scrolling through"). Inversely, those who preferred to review data tracked by the devices using visualization software find the digital reports to be more intuitive, making it easier to spot patterns and trends. A majority of adolescents and parents reported that, in addition to essential diabetes-related data, they also record contextual information of interest including large or uncommon meals/foods, exercise, pump/sensor site changes, menstrual cycles, illness, and notable changes to routine (e.g., vacation, soccer tournament, spent the night at grandma's).

*Frequency of Review.* The frequency at which data was reviewed varied widely across interviewees. All participants reported routinely viewing data in some way, though this typically was by reviewing device data in real-time throughout the day (e.g., CGM readings) or by reviewing blood glucose values at the end of a day or week by manually reviewing the glucometer. Among those who downloaded device data to software, several families reported downloading data weekly, while others ranged from every few weeks to every three months (before going to clinic for a quarterly appointment). Some families said they never download device data at home and only have devices downloaded by the clinic staff at appointments. It was commonly stated that data will be reviewed more frequently if noticing a pattern and/or if an insulin dose change was made in order to more closely monitor.

*Real-time Review & Management.* Teens and parents also discussed regularly reviewing data on devices throughout the day and reacting to the real-time data, either when experiencing repeated high or low readings in a short amount of time or in response to alerts from their CGM. CGM alerts can be particularly helpful, providing alarms when blood glucose readings are out of range, but also providing arrows that indicated the direction (high or low) their blood glucose is trending and the rate at which it is occurring. For example, one teen explained, "If my blood sugar is at like 73 and going up, I pretty much just ignore it because it says I am going up. Then, that should be good because I want to go up from that. But if it's at like 180 and going up, I will check my sugars, see where it is and if it's like getting high, I will give myself a correction." Other real-time management behaviors included eating an uncovered snack to prevent low blood glucose when the CGM shows their blood glucose is trending down or giving a correction

dose of insulin if continuing to see a rise in blood glucose after giving an initial bolus insulin dose.

*Retrospective Review & Problem Solving.* Parents reported that they would review the data, either by themselves or with their child, to better understand what was happening with their child's diabetes. Some described the variables they prefer to look at, including: percentages of high, low, and in-range blood glucose values; percentages of basal and bolus insulin; average blood glucose; and the number of blood glucose checks, times that carb amounts were entered into pump, bolus and correction insulin doses were administered, and site changes. Parents also discussed looking for patterns/trends and 'trouble spots' in the data. One mother explained she abides by "[the clinic]'s rule of 50% of numbers above 200, over 3 consecutive days" as qualifying as a pattern. Other parents shared the same consensus that out of range blood glucose values must occur at least 3 days within 7-10 days' worth of data in order to be considered a pattern. The patterns that are identified by the Dexcom system and presented in the download report (e.g., "[Name] had a pattern of highs from 6-8 AM") were also said to be helpful. Once a pattern is spotted, parents then try to determine what could have caused that outcome (e.g., repeated missed boluses, activities, basal insulin dose), often looking to contextual information for clues.

#### Goals for Viewing and Using Their Diabetes Data

Several parents and teens commented about goals they had for viewing and using their diabetes data. One mother thought it would be helpful if her teen was more consistent with logging data, particularly contextual information, as he would gain a better understanding of how his behaviors impacted his glycemic outcomes. She explained, "He's not really connecting, 'I eat this, I feel this way,' and like, that's why I would like him to start keeping track, so he can know." A couple of adolescents and parents commented that they would like to review data more frequently to better understand adherence and blood glucose control. One mom specifically mentioned wanting to improve her documentation of contextual information because it helps her reflect on blood glucose trends; at the time of the interview, she made a plan to start taking notes using the calendar on her phone to help with this.

#### Interest in Combining Diabetes Data with Additional Contextual Datastreams

*Contextual Variables of Interest.* A large number of interviewees expressed interest in accessing contextual data and developing a better understanding of how different contextual factors impact diabetes and troubleshooting possible solutions for issues like patterns of high and low blood glucose values. Contextual information that adolescents and parents thought would be useful for understanding diabetes included exercise (e.g., type of activity, time, duration), location (e.g., school, home, work), changes in schedule (e.g., weekdays vs. weekends, vacation), stress, and hormone fluctuations. Two parents also described wanting to better understand how day-to-day diabetes self-management relates to longer-term outcomes like HbA1c and risk of future complications.

*Technology Tools for Viewing and Integrating Data.* Several teens and parents thought it would be helpful to have a mobile and/or web-based app for diabetes management for collecting and displaying both diabetes and contextual data as well as provide reminders and alerts. Mobile capabilities were preferred across respondents as smartphones are now exceedingly common. In a couple of interviews conducted very early in the project period, both adolescents and parents said they would like to have real-time access to diabetes data via a mobile app. Since then, several device manufacturers have released products and compatible apps that offer this option. Two interviewees also desired a functionality by which CGM and pump data could seamlessly interact, no longer requiring the user to manually enter blood glucose numbers from

a glucometer and/or CGM into the pump. Like mobile apps for monitoring, such 'artificial pancreas' systems are now available on the commercial market.

### Desired Features of Diabetes Data Visualizations / Types of Data Visualizations and Interactive Features They Might Find Useful

As parents were most often the ones responsible for reviewing diabetes data, most of the visualization opinions came from them. In general, teens reported that they liked seeing the variation in their own blood glucose, but mostly in terms of a single-day graph. Parents, on the other hand, were more interested in blood glucose patterns and averages, especially those that incorporate multiple variables of interest (e.g., blood glucose, carbs, insulin, etc.). Overall, parents were split on the medium, with some preferring digital tools and other preferring to manually log data. Of those who preferred digital tools, interviewees described which existing features they find helpful as well as features they wish were available.

*Easily Identifiable Patterns/Averages.* One common theme was that parents wanted to clearly see blood glucose patterns and averages via a data (i.e., a graph or chart) as well as statistics. There are multiple data visualization views on software such as Glooko+Diasend, which allow users to identify patterns in blood glucose. One such example is the modal day overlay, where a 24-hour period of blood glucose is graphed against time. In this view, each individual day is represented by a different colored line, so if there were multiple lines that dipped or spiked around the same timeframe, this would easily indicate a pattern. For example, one mother commented that this view helped her to see drops in blood glucose were occurring at the same time each night and concluded that an insulin adjustment was needed to avoid overnight lows. Logbook was another popular view as it provides an at-a-glance view of one or more weeks of data, including blood glucose values, carbs, and insulin (basal and bolus) for each day, with an average calculated for individual days and in total. Parents reported that this view was helpful to see how their child was managing on a day-to-day level as well as overall. It was mentioned by one parent that this was the page most commonly viewed by their doctor as well, so they were familiar with how to interpret that display. Color coding, in general, was a feature that several parents reported was useful as it draws quick attention to numbers outside of the target range.

*Desired Features.* Only one parent expressed desire for a feature that is currently not available, which would compare average blood glucose at specific times of days across multiple days. Her specific requests were average blood glucose values at lunchtime and before bed. At the time of the interview, her current diabetes software did not support this feature; even though it tracked blood glucose by time of day, the values weren't tied to specific contextual information such as what time her child ate lunch or what time they went to bed.

### Heuristics They Typically Use to Make Decisions About Insulin Management

Based on identification of patterns/trends when reviewing data, some parents said they will independently make adjustments to their child's insulin regimen, though most admitted they only felt comfortable making small changes, such as adjusting basal rates in small increments, while others would focus on self-management behaviors (bolusing, carb counting, etc.) to try to correct the issue. Many parents mentioned that they do not make dose adjustments without first consulting with the CDE or endocrinologist, with one mother explaining, "I don't feel comfortable doing it. I mean, it's his life, you know?"

Several parents discussed specific patterns and adjustments they've made. One mother recounted that her son had experienced some overnight lows during his tennis season, so she gradually lowered his nighttime basal rate to ensure he did not experience hypoglycemia. Two mothers of teen girls talked about increasing insulin doses during menstruation, when hormones

appear to cause blood glucose to rise. One mother described that she typically increases her daughter's basal insulin dose by one unit during her menses while another explained that her daughter usually requires additional correction doses to keep her blood glucose in range.

## FOCUS GROUPS: HEALTHCARE PROVIDERS

### Barriers to Downloading, Viewing, and Accessing Diabetes Data

*Time.* Overwhelmingly, all providers (both physicians and CDEs) were in agreement that time is the number one barrier to accessing and viewing data in clinic. Physicians and CDEs have a limited amount of time for each office visit, and each minute is valuable to the patient and provider. To help improve efficiency, most clinics have their medical assistants download the patient's devices (glucometer, pump, and/or CGM) after checking in for their visit. This allows time for the data to be downloaded so the physician can readily access the data as soon as they enter the room. While this is helpful, diabetes devices generate a large amount of data, and the limited visit time means providers usually only have time to focus on the red flags in the data (low and high blood glucose readings) rather than explore every detail. As one physician put it, "We are extremely jealous of every second that we have."

*Data Formatting.* The presentation of the data can also have an impact on the time-burden of diabetes data review. Clinicians cited a need for a universal format of data since different proprietary software systems (e.g., Glooko+Diasend, Medtronic CareLink, Dexcom Clarity) display data in various ways. It may take the clinician a few extra moments to orient themselves to the data layout, an inconvenience when they are already pressed for time in a visit. Not to mention that physicians are seeing patients back-to-back and the data format may be switching from visit to visit, depending on which devices the patient uses.

*Viewing Preferences.* Each device download report usually has about ten pages, though they can be longer depending on which devices are used and what visualization options are selected. Some clinicians prefer paper copies of the data reports, which make it easier to see the 'whole picture' because they can spread out the pages in front of them and see multiple views side-by-side. When viewing on a computer screen, clinicians usually have to scroll through various pages and toggle to the electronic medical record (EMR) as they make sense of the data which can be more challenging and time consuming. Providers who favored paper copies of data reports also mentioned that they can take notes and highlight trends directly on the pages as they review with the patient which they feel is more effective for teaching. Additionally, focus group participants unanimously agreed that viewing the data in color is preferred because it's easier to see values and spot patterns, however this may not always be possible due to non-availability of color printers.

*Interoperability Issues.* Clinicians expressed frustration regarding interaction with electronic medical record (EMR) systems. While some clinics are able to directly upload the device data to the patient's chart, others must export the data download as a PDF and scan it into the chart. Manually uploading PDFs to the EMR system is time consuming, both for the staff who must scan and link the files, but also for the provider who has to locate it in the chart at the start of their patient visit. Plus, scanned PDFs result in the loss of discrete data which can be helpful for population-level monitoring.

*Technological and Financial Considerations.* Technological and financial concerns related to software systems were also brought up as potential barriers. First and foremost, software license agreements with diabetes data software management services are costly. Signing exclusively with a single company may be less expensive overall and provide a universal platform, but it may not be compatible with all devices. In addition, clinicians also reported

problems with the upkeep of software. Software updates, either from the manufacturer or the institution, can result in software incompatibility for the user. For instance, one provider gave the example that their clinic could not download a necessary update to Tidepool since their system had not updated their browser.

Current Methods & Technologies Used for Diabetes Data Exchange & Communication in Clinic Data Exchange and Communication. Clinics used varying software systems, including Glooko+Diasend (which requires a subscription by the clinic and/or patient), proprietary software developed by diabetes device manufacturers such as Medtronic CareLink or Dexcom Clarity, and free services like Tidepool, with all providers using at least one of these software programs (if not all). Between visits, patients and/or caregivers may reach out to the clinic via phone, email, or the EMR patient portal if they want an endocrinologist or CDE to review their data. All providers were in agreement that patient data review was more reactive than proactive, meaning they typically only look at a patient's most recent data if the patient or caregiver request it. Data is shared with the clinic team in several ways: patient/caregiver can call and relay blood glucose numbers verbally over the phone; patient/caregiver can send logs and/or PDF reports via email, fax, or attach to a portal message; or patient/caregiver can download devices to their data software account and provide the clinic access via a sharing code.

*Privacy.* Based on the responses from focus group participants, most providers do not feel comfortable accessing patient data when the patient is not in clinic, unless the patient reached out, specifically asking them to do so. A couple of issues were raised regarding on-demand access to patient data. Most importantly, providers were concerned about liability, noting that even if they have access to view patients' device data unprompted, they cautioned that such review could set a dangerous precedent that the clinical staff is always monitoring patients' blood glucose and therefore patients and/or caregivers do not need to be monitoring it on their own. Secondly, they simply do not have the time to explore patients' data on a routine basis.

#### Provider Preferences Regarding Sharing of Diabetes and Personal Data

All providers agreed that having contextual information related to the patient's diabetes data is ideal as it helps provide a more complete picture and helps to explain variations in the data (e.g., patterns of highs and lows). While this information can be very insightful, providers voiced concern on what information should be shared as well as how often. Providers felt that while it is beneficial to have this information, it isn't their right to know every aspect of a patient's life, and from a liability perspective, sharing personal data should be patient-initiated. A trusting relationship between the patient and provider is also crucial and it's important that patients have a clear understanding of how their data will be used. It was also acknowledged that collecting contextual information is time consuming for the patient, and providers have limited time to utilize contextual data during a clinic visit. Therefore, it was stressed that if such information is collected, there should be realistic expectations regarding how much information should be recorded and interpreted.

#### Interest in Combining Diabetes Data with Additional Contextual Datastreams

Clinicians were in agreement that combining diabetes data with contextual information collected by mobile technology would be beneficial to diabetes care. Common contextual datastreams of interest included exercise, food intake, sleep, alcohol use, stress levels, menstrual cycles, caffeine intake, and bolus behavior (i.e., missing boluses, over or under-bolusing, etc.). While providers would like to have this contextual data available to view alongside diabetes data, there was concern about the time burden for both the patient and provider. Focus groups participants expressed interest in the idea of automating the collection of contextual data (e.g., by syncing a Fitbit or other fitness tracker with their diabetes data software) as it would be less burdensome

to the patient while also increasing the likelihood that the contextual information would be captured.

### Desired Features of Diabetes Data Visualizations / Types of Data Visualizations and Interactive Features They Might Find Useful

Focus group participants mentioned several diabetes data visualizations and features that would make it easier to synthesize data. The classic logbook view was highly desired among providers as this was the view nearly everyone is trained on, so they feel they can abstract and process data quicker with this view. Many providers also desired interactive data overlay views, where they are given a daily or weekly blood glucose overview and then can hone in on the details of a specific day/time. In addition to the data displays, providers cited often using the sections of that data report that provide an overview of behavior (e.g., using the bolus wizard, suspending pump, filling pump, time between site changes, boluses per day, etc.) as well as statistics reports that detail the number of blood glucose values, average blood glucose, percentage of blood glucose values within the target range, standard deviation of blood glucose values, etc. While there were differing opinions on which view is best overall, the general consensus was that different visualizations of the data may be needed given the specific scenario, and ultimately, preferences will vary by provider.

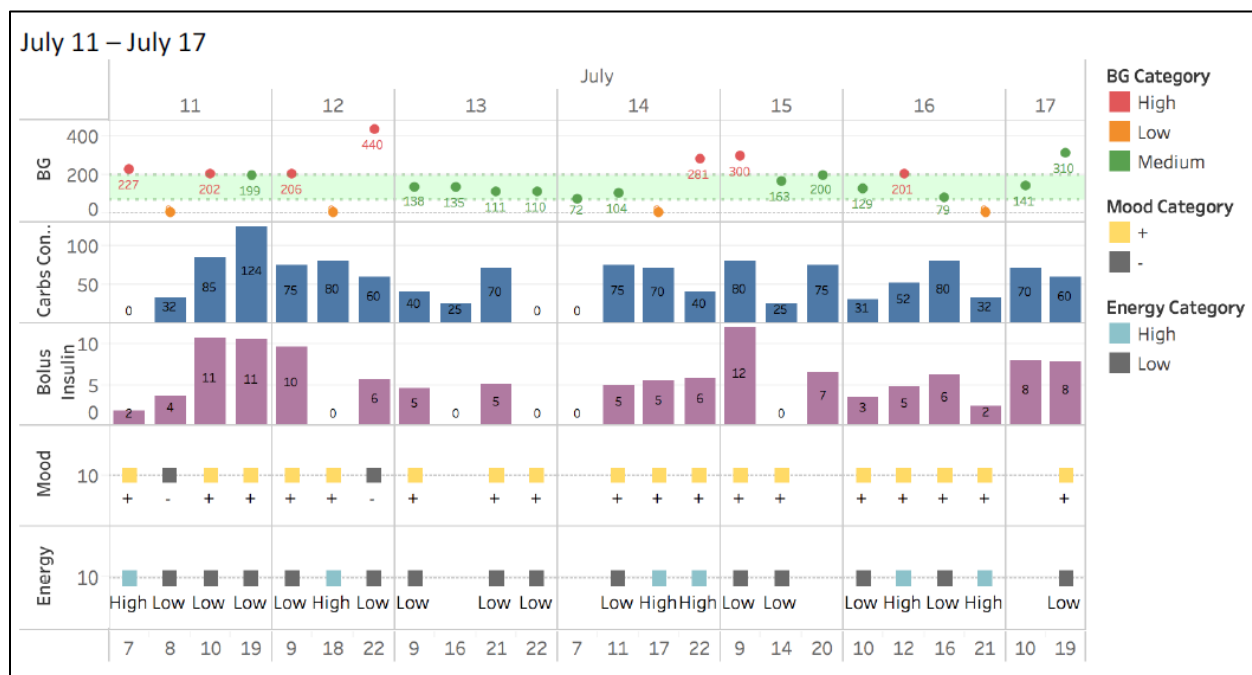
### Heuristics They Typically Use to Make Decisions About Insulin Management

All providers cited that they first look to the data to identify patterns of high and low blood glucose values, with lows being addressed first as they are more worrisome. It was also noted that complete data over several, sequential days (minimum 3-4) is needed to find a true pattern; sometimes there isn't enough data in the report to make sense of what is happening. Providers also look for variability in the data and typically ask for contextual information (e.g., exercise, illness, missed boluses, skipped meals, etc.) which may help explain a given outcome. When coming up with a plan for adjusting insulin doses, providers had varying strategies. Some prefer doing a step-wise plan, where they change one piece of the regimen (e.g., lowering the insulin to carb ratio at breakfast), and if that change doesn't resolve the issue, then they move on to another setting or ratio that could be improved upon. However, some providers were okay with changing multiple settings if they knew one change would not be able to correct the fluctuation they were seeing. Most providers desired some sort of follow-up within a few weeks of recommending a change, in order to assess how the adjustment regimen was working.

**Specific Aim 3a:** Considering that individuals with T1D do not frequently engage in downloading and reviewing their diabetes, we focused on simple visualizations with easy to understand representations of data. Among all of the visualizations we reviewed, we were inspired by the simplicity and user-centered design of Tidepool. Additionally, we opted to include a classic logbook view, given its extensive use in the clinic and hence, the familiarity of patients with this specific format. In selecting aggregate data insights to be displayed in the visualizations, we were guided by Choe et al.'s research characterizing basic visualization insights, such as time trends, averages for data summary, and comparisons.<sup>7</sup> The incorporation of contextual data was inspired by Epstein et al.'s concept of visual cuts wherein an outcome measured is profiled by different contextual parameters (e.g., amount of physical activity against commute time, and location).<sup>8</sup> In deciding on the low-level features of our visualizations (e.g., bars, lines, color), we created multiple versions of displays using the same data and obtained feedback from our pilot study participants. Based on this feedback, we selected bar graphs, circles, solid colors, and abstract keywords for mood, such as high and low, to represent the data.



During their exit interviews, both teens and parents reviewed multiple prototype visualizations that displayed diabetes and contextual data in varying formats and styles. These included: (1) a graph that displayed all of the individual blood glucose, carb, bolus insulin, mood, and energy data points from across the entire 21-day study period; (2) a similar graph, presenting the same variables, but over a reduced time period such as one week (see an example below); (3) a graph that depicted the average blood glucose, carb, bolus insulin, mood, and energy values for each day in the 21-day study period; (4) a logbook view of all blood glucose, basal and bolus insulin, and carb data points from the 21 days; (5) a graph showing all blood glucose values, by day, with labels indicating the hashtags that the teen entered with that value; (7) side-by-side bar graphs of average blood glucose, carb, and bolus insulin over the 21 days for weekdays and weekend days; and (8) side-by-side bar graphs of average blood glucose, carb, and bolus insulin over the 21 days by location.



**Specific Aim 3b:** Overall, the teen participants who used the context-enhanced diary app (DReflect) reported that they found it easy to use. Teens also logged more information than expected. In addition to logging blood glucose values, carbs, and insulin, many participants also logged snacks, random blood glucose checks, and/or correction doses of insulin. Additionally, the majority of teen and parent participants provided diary responses that enriched our understanding of their daily life and diabetes self-management.

**Prototype Visualization Preferences.** Generally, parents of the teen participants indicated a preference for a cumulative summary graph with all of the key information (e.g., blood glucose, carb intake, insulin doses, etc.) in order to pinpoint trends around mealtimes, certain days of the week, and activities/routines. Two mothers specifically discussed finding it helpful to begin by viewing a snapshot-style display featuring averages of the data over a given time period (e.g., 2 weeks or one month) and then moving to a more detailed logbook view that provided the specific information for each day. Both teens and parents also appreciated the inclusion of averages within the visualization rather than just individual data points. Many teens and parents also liked the visualization that showed the teens' hashtag notes because it provided a clear overview of the contextual details in relation to blood glucose values. Another common

preference was the use of color-coding to help with spotting trends. However, some participants found the use of shapes to indicate mood and energy to be confusing; in response to this feedback, we later changed how mood and energy were displayed to iteratively improve the prototype.

*Sensemaking & Problem Solving.* During the exit interviews, participants reviewed the prototype visualizations, displaying their personal data that was collected during the study period. The visualizations integrated diabetes data (e.g., blood glucose values, carbohydrate amounts, insulin doses) with contextual data (e.g., location, mood, stress, hashtags and free-text notes). As they reviewed the visualizations, teens and parents engaged in sensemaking and were able to further analyze the diabetes data in several ways. Participant and parent sensemaking and problem-solving fell into 3 categories: identification of context-based trends, triangulation of information from across datastreams to discover new insights, and generation of possible solutions for addressing context-based patterns.

Participants identified context-based trends in blood glucose values based on additional contextual information including time of day, type of day (weekday vs. weekend day), food, sleep, location, physical activity, and changes in schedule, e.g., school year vs. summer vacation. For instance, one teen and his mother noticed an association between high blood glucose values and his use of the label #running. Another participant reported that there was a clear pattern of in-range numbers when she was in school compared to greater variability when she was at home for the summer: “I can see tons of reds [out of range numbers] from when I was in the summer. But then when I was in school, I can see I have lots of greens [in range numbers].”

In addition to understanding the effect of individual contextual factors on diabetes-related measures such as blood glucose values, participants also generated insights across factors to obtain a more comprehensive understanding of a specific situation. This analysis helped them discover new insights and validate existing perceptions or suspicions. For example, one teen participant had higher blood glucose on weekends even though she ate fewer carbs. Though this seemed counterintuitive, when looking at the variation of blood glucose across different locations (home, grandparents’ house, church/youth group, other) and different types of days (weekdays and weekend days), the teen’s mother was not surprised: “It reaffirms what I knew about her grandparents’ house. It doesn’t surprise me at all that her sugars are really high over the weekends and yet she doesn’t eat many carbs, because I don’t know that my parents are generally telling her, ‘Hey did you shoot for that? Do you know how many carbs that is?’” Also, as a part of the triangulation process, a few participants (both parents and teens) moved between visualization displays to derive insights or confirm suspicions. One mother described this process, stating, “I looked at graph one and I could see that, and then... as I would go down and looked at the others, it just kind of confirmed where I was at.”

Teens and parents also used contextual information to explain the data variation when they noticed obvious or unusual discrepancies and brainstorm ideas for actions to improve their diabetes management and achieve better blood glucose control, including changes to insulin doses, eating behaviors, food choices, and/or adherence to self-management activities. For instance, the teen who identified a pattern of high blood glucose values when running reflected on this trend and concluded that the high blood glucose was occurring because he routinely disconnected his insulin pump during runs. His mother noted that she would ideally like her son to keep his pump attached while running to prevent these spikes in blood glucose, but since he prefers to disconnect, they have discussed other options for keeping his blood glucose in range

such as setting a higher temporary basal rate for a period of time after he runs and reconnects his pump.

Overall, participants reported that having diabetes data integrated with context-specific data allowed for more thorough sensemaking and helped them to draw additional meaningful conclusions.

**Discussion & Implications:** This project evaluated the state of data visualizations for patients' diabetes and other health data. Through our environmental scan, we found a significant amount of variation across data platforms regarding data visualizations that are available to patients and caregivers. Furthermore, even among views that were commonly provided, there was a total lack of standardization and significant variation in the presentation of the data, such as different categories of blood glucose values with different thresholds for high and low, different nomenclature, different colors, and different statistical ranges. This leads to confusion among healthcare providers and patients using the tools. When does a patient or provider react to a 'red' blood glucose value? Does red mean high or does it mean low? This can cause confusion for individual patients; if a patient uses a Dexcom CGM sensor and a Tandem insulin pump, the high thresholds differ (>180 for Dexcom and >175 for Tandem) so which do they choose to believe and which color do they choose to react to (the 'high' orange on their pump vs. the 'high' yellow on their sensor)? Furthermore, we found a gap in the literature as many of the studies were dated and/or simply described the use of a particular piece of software to support diabetes management rather than examining the data visualization.

In our interviews with patients and caregivers we learned about many physical barriers to downloading, reviewing, and accessing their data (no cord or internet, or interoperability barriers), the need for more real-time mobile solutions for reviewing data, and the lack of confidence that families have in taking action about regimen changes even after having reviewed the data. Physicians in focus groups also described a number of barriers for viewing data in clinic, including problems with the software for downloading devices, having to use a number of different platforms depending on the devices, and the complexity of viewing data in clinic (some providers print the data since they cannot toggle between the blood glucose data and the EMR for charting, but they need a color printer in clinic to do this). There were questions about providers having continuous access to data outside of the clinic and whether that creates liability, and/or discomfort on the part of the patient. Both providers and patients desired stressed the important of having contextual information to relate to diabetes data to truly understand the patterns (exercise, illness, missed boluses, skipped meals, days of the week, etc.).

Finally, in our exploration of data visualization prototypes with patients and parents, participants were able to identify context-based trends to a greater extent, were able to triangulate data using multiple datastreams to discover new insights regarding their diabetes, and were able to generate possible solutions for addressing context-based patterns using the prototype visualizations that incorporated contextual information. It is clear that contextual data was critical for facilitating problem solving when viewing data, and given the various hashtags used by the teen participants, the contextual data truly needed to be personalized. The opportunity for personalizing contextual data viewed with diabetes data is likely an important feature of any data visualization system.

Implications of this work are as follows:

- There needs to be some consensus and standardization for data visualizations for diabetes. Bergenstal and colleagues did this for a subset of CGM views,<sup>9</sup> but given the

diversity of devices and platforms capturing a wide variety of data types and variables, a broader initiative is needed.

- There needs to be a concerted effort to support the adherence behavior of downloading and reviewing data by patients, as this behavior has been associated with significant improvements in HbA1c, but is not conducted systematically by patients and caregivers
- Data visualizations must provide contextual data to support sensemaking with the data.
- Individuals need to be empowered by clinicians to make independent changes in their self-management regimens; viewing data does not help if no action is taken.
- Personalization of contextual variables provides personal relevance to diabetes data visualization for teens, and provides greater opportunity for problem solving.

## References Cited

1. Diabetes Control and Complications Trial Research Group. The effect of intensive treatment of diabetes on the development and progression of long-term complications in insulin-dependent diabetes mellitus. *N Engl J Med.* 1993;329(14):977-86.
2. Lawton J, Rankin D, Cooke D, et al. Patients' experiences of adjusting insulin doses when implementing flexible intensive insulin therapy: a longitudinal, qualitative investigation. *Diabetes Res Clin Pract.* 2012;98(2):236-42.
3. Wood JR, Miller KM, Maahs DM, et al. Most youth with type 1 diabetes in the T1D Exchange Clinic Registry do not meet American Diabetes Association or International Society for Pediatric and Adolescent Diabetes clinical guidelines. *Diabetes Care.* 2013;36(7):2035-7.
4. Wong JC, Neinstein AB, Spindler M, et al. A minority of patients with type 1 diabetes routinely downloads and retrospectively reviews device data. *Diabetes Technol Ther.* 2015;17(8):555-62.
5. Miller KM, Foster NC, Beck RW, et al. Current state of type 1 diabetes treatment in the U.S.: updated data from the T1D Exchange clinic registry. *Diabetes Care.* 2015;38(6):971-8.
6. Shalitin S, Ben-Ari T, Yackobovitch-Gavan M, et al. Using the Internet-based upload blood glucose monitoring and therapy management system in patients with type 1 diabetes. *Acta Diabetol.* 2014;51(2):247-56.
7. Choe EK, Lee B, Schraefel MC. Characterizing visualization insights from quantified selfers' personal data presentations. *IEEE Comput Graph.* 2015;35(4):28-37.
8. Epstein D, Cordeiro F, Bales E, et al. Taming data complexity in lifelogs: exploring visual cuts of personal informatics data. *Proceedings of the 2014 conference on Designing interactive systems; 2014 June 21-25; Vancouver, BC, Canada.* 2014:667-76.
9. Bergenstal RM, Ahmann AJ, Bailey T, et al. Recommendations for standardizing glucose reporting and analysis to optimize clinical decision making in diabetes: the ambulatory glucose profile. *J Diabetes Sci Technol* 2013;7(2):562-578.

## 6. Publications and Products

The Raj et al. (2017) publication discusses the combined analysis of early data from this project along with data collected in another study. In addition to this article, at least two manuscripts resulting from this project are currently in process.

- Raj S, Newman MW, Lee JM, et al. Understanding individual and collaborative problem-solving with patient-generated data: challenges and opportunities. *Proceedings of the ACM on Human-Computer Interaction* 2017 Nov;1(CSCW):1-18. doi: 10.1145/3134723.