

PARENT SATISFACTION WITH DIABETES TECHNOLOGY IN CHILDREN WITH  
TYPE 1 DIABETES MELLITUS

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A thesis submitted to the faculty of The University of Mississippi in partial fulfillment of  
the requirements of the Sally McDonnell Barksdale Honors College.

Oxford  
October 2013

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This thesis is dedicated to my brother, William Gray Carter and all Type 1 Diabetics.

## ABSTRACT

Laura Brooke Carter: Parent Satisfaction with Diabetes Technology in Children with Type 1 Diabetes Mellitus

(Under the direction of Dr. Donna West-Strum)

**Purpose:** To increase glucose control, advanced technologies are being integrated into diabetes self-management in children with Type 1 Diabetes Mellitus (T1DM). Two technologies being adopted is Continuous Subcutaneous Insulin Infusion (CSII), more commonly known as insulin pumps (pumps) and Continuous Glucose Monitoring (CGM). The purpose of the study was to better understand the experiences of parents whose T1DM child is using insulin pumps and CGM devices in diabetes self-management.

**Methods:** This study was approved by the University of Mississippi IRB. A cross-sectional study was conducted using a sample of parents in the Mid-South region of the U.S. The local chapters of JDRF and Camp Hopewell sent an e-mail inviting parents to participate with a link to the electronic survey. A follow-up e-mail reminder was sent a week after the initial e-mail was sent. SPSS 20.0 (Chicago, IL) was used to calculate frequencies and descriptive statistics.

**Results:** 98 parents of children with T1DM responded to the survey, with only 47 families indicating their child was currently using an insulin pump and/or CGM device. Participants described the relationship they experience with their physician. Then, participants reported which members of their health care team helped them integrate technology into their child's diabetes self-management and the support they receive pertaining to integrating technology into the child's diabetes self-management. Respondents indicated their sources of information about integrating advanced diabetes

technology into their child's diabetes management. Participants also ranked the benefits and barriers associated with insulin pump and CGM device use.

**Conclusion:** Families with better patient-physician relationship quality and with more perceived support from their diabetes health care team were more satisfied with insulin pump use. However, few children in this geographic area have integrated CGM into diabetes self-management. There are psychosocial issues to consider when integrating insulin pumps and CGM into diabetes self-management. Some healthcare professionals, including pharmacists, may be underutilized. As more patients attempt to adopt advanced technologies, it will be important for pharmacists to be trained to help patients use their insulin pump and CGM devices.

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## **BACKGROUND**

Juvenile diabetes (Type 1 diabetes mellitus (T1DM)) is an autoimmune disease causing insulin production to stop within the beta cells of the pancreas. Insulin is a hormone produced by the beta cells of the pancreas and functions to promote anabolism by regulating blood glucose concentrations (Fox, 2011). Without insulin, excess glucose remains in the blood, leading to serious health problems. The Juvenile Diabetes Research Foundation (JDRF) estimates that as many as three million Americans have T1DM. It is also estimated that more than 15,000 children and 15,000 adults are diagnosed with T1DM each year in the United States (JDRF, 2013).

In Type 1 diabetes management, patients must balance diet, exercise, insulin management, and blood glucose level monitoring in order to maintain appropriate glucose levels within the body. Too little glucose in the blood (hypoglycemia) or too much glucose in the blood (hyperglycemia) results in detrimental health effects for patients (Fox, 2011). The Mayo Clinic notes that hypoglycemic effects occur quickly and can result in anxiety, shakiness, sweating as well as confusion, blurred vision, seizures, and loss of consciousness. The effects of too much glucose in the blood (hyperglycemia), on the other hand, often occur later in life. Early symptoms include frequent urination, increased thirst, blurred vision, fatigue and headache. Later signs include damage to extremities, neuropathy, retinopathy, heart problems, and brain damage (The Mayo Clinic, 2013). Therefore, monitoring glucose levels and appropriate use of diabetes medication is essential to the life and health of diabetes patients. The Diabetes Control and Complications Trial (DLCT) study in T1DM shows that “intensive” glycemic control can lower the risk of long-term diabetes complications (DLCT Research Group, 1993).



Measuring glucose levels can be achieved using many different modalities. The Oral Glucose Tolerance Test (OGTT) evaluates the efficiency of the body to metabolize glucose and is considered to be the “gold standard” in the diagnosis of diabetes. This test is accepted as a diagnostic modality by the American Diabetes Association, The World Health Organization, The International Diabetes Federation, and many other organizations (Sacks, 2011). Another essential test for patients with diabetes is the measurement of HbA1C. The HbA1C test analyzes the non-enzymatic attachment of glucose to hemoglobin. Because the life span of a red blood cell is approximately one hundred and twenty days the HbA1C test allows health care professionals to measure the average blood glucose concentration during the preceding 8-12 weeks. Good long-term glycemic control results in lower HbA1C values and fewer complications for patients (Sacks, 2011).

The HbA1C goals for children, according to the American Diabetes Association, are < 8.5% for patients younger than 6 years old, < 8.0% for patients between ages 6 to 13, and < 7.5% for patients between the ages of 13 to 20 years old. Despite the importance of tight glycemic control these targets were only met by 64, 43, and 21% of patients, respectively (Wood et al., 2013). Juvenile patients with Type 1 diabetes are treated with intensive insulin regimens; yet many patients are unable to achieve and maintain recommended HbA1c targets (JDRF-CGM, 2010). It is often difficult for patients to determine how much insulin is needed, to monitor blood glucose continuously using a blood glucose meter, and to eat appropriately at all times.

## **Newer Technologies in Diabetes Self-Management**

In order to increase glucose control, newer, advanced technologies are being integrated into diabetes self-management. Continuous subcutaneous insulin infusion (CSII), more commonly known as insulin pumps (pumps), has been available for use since the 1980s. Insulin pumps are a diabetic technology that replaces insulin shots by delivering insulin in three unique ways. Pumps deliver insulin through small tubing called a cannula into a catheter that is inserted into the skin. Insulin is then absorbed from the subcutaneous tissue. Pumps have a basal rate that delivers small increments of rapid/short-acting insulin at programmed rates throughout the day to match the patient's baseline insulin requirements. The basal rate replaces long-acting insulin injections and accounts for approximately 50% percent of a person's total daily insulin needs. Next, pumps deliver boluses that provide additional insulin boosts to account for ingested carbohydrates or hyperglycemia (Boyd & Boyd, 2008). Finally, pumps can deliver corrections, which adjust pre-meal blood glucose values (Klobassa & Moreland, 2013).

Studies have shown that insulin pumps improve diabetes self-management. Boyd and Boyd (2008) noted that the utilization of insulin pump therapy allowed patients to achieve equivalent or better glycemic control while using less insulin. Additionally, patients using insulin pump therapy experienced fewer and less severe hypoglycemic events (Boyd & Boyd, 2008). Mednick and colleagues (2004) conducted a survey where 22 children with T1DM and their parents were asked to complete a satisfaction with insulin pump therapy questionnaire. The results indicated that both parents and the children were satisfied with the insulin pump use. They agreed that insulin pump usage

increased the flexibility related to eating, sleeping, and food variety (Mednick, Cogen, & Streisand, 2004).

Although insulin pumps have shown to improve blood glucose control, they are not used widely. It is believed that only 22% of youths with T1DM have used insulin pump therapy. The direct cost of insulin pump therapy is estimated to be twice the cost of traditional multiple daily injections (MDI). Insulin pump therapy use is associated with high household incomes, having private healthcare insurance, a higher level of parental education as well as being Caucasian (Shukman, Palmert, & Daneman, 2012). Estimates of discontinuation in children and adults range from 0-64% (Gonder-Frederick, Shepard, & Peterson, 2011). Some reasons for discontinuation include skin discomfort, infection at infusion site, anxiety about technology, body image concerns, cost/insurance issues, technical difficulties with pump, inconvenience, and dislike or difficulty with needle insertion (Gonder-Frederick et al., 2011). Few studies have examined child and parent experiences with insulin pumps in the real world.

A newer diabetic technology designed to improve glucose control is Continuous Glucose Monitoring (CGM). CGM is used to continuously monitor blood glucose levels by providing frequent, real-time feedback about glucose levels and retrospective 24 –hour glucose profiles (JDRF, 2010). A CGM device is a sensor that records blood glucose levels throughout the day and night, providing up to 288 blood sugar measurements every twenty-four hours. A CGM device has a tiny glucose-sensing instrument under the skin and the rest of a CGM device is held in place by adhesive material on the top of the skin.

Additionally, the CGM device has alarms to alert patients to hyper- or hypoglycemia (Bloomgarden, Freeman, & Derobertis, 2008). By alerting juvenile patients to changes in blood glucose, the CGM device seeks to provide better control of blood sugar for patients. Remote glucose monitors can be used with CGM. Remote glucose monitors allow parents to monitor blood glucose throughout the night. CGM technology can dramatically improve day-to-day management of diabetes and promises to be a major advancement in diabetes care (JDRF-CGM, 2010). It is important to note that a CGM device still requires self-monitoring of blood glucose (SMBG) for accurate calibration of CGM.

Real-time use of CGM allows parents to respond promptly to hyperglycemia or hypoglycemia and provide more stable glucose levels (JDRF Continuous Glucose Monitoring Study Group, 2010). Recent studies have confirmed the clinical benefits of using CGM including making day-to-day decisions based on 1-minute glucose readings, threshold and projected glucose alarms, and glucose trend arrows that enable the observation of the rate and direction of glucose change (Bloomgarden et al., 2008). However, the JDRF Continuous Glucose Monitoring Study Group stated, “While these studies suggest promise for CGM, questions remain regarding the potential effects of its incorporation into diabetes management on psychosocial and patient-reported outcomes. The extent to which CGM exerts positive or negative psychosocial effects could influence patients’ frequency and persistence of CGM use” (JDRF Continuous Glucose Monitoring Study Group, 2010).

CGM is generally well-tolerated in children with T1DM for short intervals; however, their use declines over extended time periods. Tansey and colleagues found that more frequent monitoring was associated with higher satisfaction for parents of youths enrolled in the JDRF CGM trials. Parents like having glucose trend data and the opportunity to detect hypoglycemia and correct out-of-range glucose levels. However, there are common barriers to continued use, including insertion pain, system alarms, and body issues (Tansey et al., 2011). The Journal of Health Technology Assessment notes that infection at injection site, difficulty with needle insertion, insurance difficulties, and the technical aspects of CGM use often effect integration of CGM into diabetic care (Cummins et al., 2010). Two barriers to using CGM are abundance of data increases anxiety and lack of information about how to use technology (Godnder-Frederick et al., 2011).

As use of CGM is associated with improved glucose control, clinicians will need to find ways to help patients overcome barriers and set realistic expectations to promote its use in children with T1DM. New strategies to increase acceptance and long-term use are needed for youth with T1DM. Gonder-Frederick and colleagues suggested more provider support, more education, and more monitoring will be necessary to improve the adoption and utilization of CGM (Gonder-Frederick et al., 2011). Currently, little is known about the psychosocial aspects of integrating CGM into diabetes self-management in children with T1DM in the real-world (JDRF Continuous Glucose Monitoring Study Group, 2010).

Gonder-Frederick and colleagues (2011) reviewed studies that have investigated adoption of insulin pumps or CGM systems and concluded that more work is needed to understand how to help patients adopt and utilize advanced technologies in diabetes self-management. More studies are needed to investigate the experiences of parents and children who are currently using insulin pumps and CGM in today's health care system. Clinical trials have shown the clinical benefits of using these newer, advanced technologies and have provided insight into the use of these technologies. Yet, there is a need to further understand the experiences of parents and children with T1DM in integrating these technologies into their diabetes self-management routines in the real-world.

### **Provider Support with Advanced Diabetes Technology**

The importance of glycemic control cannot be stressed enough for juvenile T1DM patients. "Unlike many other chronic conditions, complications associated with diabetes are preventable. Patient engagement is absolutely necessary to change negative behaviors and to facilitate the self-confidence necessary for effective self-management." (Gruber, 2010). The patient-physician relationship is one key variable influencing patient engagement and diabetes self-management. Heisler et al. (2002) noted that to facilitate patient self-management for chronic diseases, a shift to more collaborative patient-provider interaction styles with joint definitions of problems, treatment goals, and management strategies is needed. Additionally, enhancing patient-provider communication and shared decision making have been shown to result in greater patient satisfaction, adherence to treatment plans, and improved health outcomes (Heisler et al.,

2002). A positive therapeutic alliance can improve glycemic control in T1DM patients (Attale, 2010). Similarly, Heisler et al. (2002) found that provider communication effectiveness influences diabetes self-management. Furthermore, they found that increasing the amount of information about diabetes and treatment improves patient understanding and improves diabetes self-management.

The ability to access and utilize information about diabetes care can improve patient understanding and self-management. This supports the importance of including information about newer, advanced technologies in diabetes self-management programs. Information about newer technologies will be essential to integrating their use into diabetes self-management. It is likely that relationships with health care providers and availability of information can facilitate the integration of technology into diabetes self-management in juvenile patients with T1DM. Additional research is needed to better understand how health care providers and accessible information can influence technology integration into diabetes self-management.

Insulin use and tight glycemic control are difficult for most juvenile T1DM patients. Although the incorporation of newer, advanced technologies into diabetes care has increased the patient's ability to control their blood glucose, adoption of technology is not widespread. Further study is needed to understand how to improve the integration of technology into diabetes self-management, especially in children and adolescents. Furthermore, health care provider relationships and the availability of information about newer technologies are likely to play a role in the adoption and integration of technology

into diabetes self-management. Throughout this study, we sought to better understand the experiences of using these newer, advanced technologies, specifically insulin pumps, of parents with children with T1DM.

## **PURPOSE**

The purpose of this study is to better understand the experiences of parents whose T1DM child is using advanced technologies (i.e., insulin pumps and/or CGM) in diabetes self-management. The specific objectives were:

1. To describe perceived health care provider support for integrating advanced technologies into diabetes self-management in children with T1DM
2. To identify information sources for integrating advanced technologies into diabetes self-management in children with T1DM
3. To describe satisfaction (benefits and barriers) of parents of children with T1DM using insulin pumps and CGM
4. To explore the relationship between perceived health care provider support and satisfaction with insulin pumps

**H<sub>1</sub>:** The better the patient-physician relationship quality, the more satisfied the parent of a child with T1DM will be with the insulin pump

**H<sub>2</sub>:** The higher the perceived diabetes health care team support, the more satisfied the parent of a child with T1DM will be with the insulin pump

The results of this study will assist in determining how health care providers and others can improve the integration of advanced technologies into diabetes self-management in children with T1DM. The results will inform health care providers on how to improve



diabetes self-management training programs and other resources necessary to facilitate the integration of advanced technologies into everyday diabetes self-management.

## **METHODOLOGY**

### **Data Collection:**

The study was approved by the University of Mississippi IRB. The study used a cross-sectional survey design. The survey was administered online and required about fifteen minutes to complete. Each potential participant was sent an e-mail invite with a follow-up reminder one week later.

### **Sample:**

Mid-South parents who have a T1DM child 18 years old or younger using an insulin pump and/or CGM were invited to participate in the study. The Northwestern Arkansas, West Tennessee, and Mississippi chapters of the Juvenile Diabetes Research Foundation (JDRF) agreed to send an email invitation that contained a link to the survey to their members. A follow-up e-mail was sent one week later. The Nashville JDRF chapter placed a link on their Facebook page. Camp Hopewell in Oxford, MS which offers a summer camp specifically for children with T1DM, also sent the survey to parents in their database who have children with T1DM. The invite e-mail provided information about the purpose of the study and that the study was voluntary and anonymous. To identify parents who had a T1DM child under the age of 18 and who were using advanced technology, several screening questions were included in the survey.

### **Survey Instrument:**

The electronic survey was developed using Qualtrics<sup>®</sup>. It quantitatively measured the variables, necessary to address the study objectives. The survey is attached in Appendix

A. Screening questions asked the potential participant if he/she had a child with T1DM who is currently 18 years old or younger. If the participant answered yes, he/she was asked if the child was currently using an insulin pump or continuous glucose monitor (CGM). If he/she answered no, he/she was asked to identify reasons for not using advanced technologies. If he/she answered yes, he/she qualified to the complete survey.

### **Survey Questions:**

The first part of the survey included demographic and health status variables about the parent respondent or child with T1DM. A technology anxiety variable was also included in the survey to use as a covariate to account for differences in people's general perceptions of technology. This variable is measured using six items adapted from a technology anxiety scale used by Meuter, Ostrom, Bitner, & Roundtree (2003).

The next part of the survey measured perceived health care provider support using two measures.

- The patient-physician relationship quality was measured using a scale adapted from Worley, 2006. Parents indicated on a 7-point linear numeric scale whether they strongly disagree or strongly agree with eight items pertaining to the quality of the relationship with the primary health care provider for their child's diabetes care.
- Perceived diabetes health care team support for integrating technology into diabetes self-management was measured. This measure was adapted from the Health Care Climate Questionnaire, which is a 10-item instrument that

measures provider support (i.e., the extent to which health care providers acknowledge and support patients' self-management of chronic illness). This measure has been used in patients with mental health disorders and had a Cronbach's alpha of 0.95 (Perron, Zeber, Kilbourne, & Bauer, 2009). The measure was adapted to include technology integration into the items.

Respondents were also asked to identify from a list of potential providers who they considered to be part of their child's diabetes health care team who help them integrate technology into diabetes self-management.

The third part of the survey included questions about sources of information about diabetes technology. This information was used to measure which sources parents rely on for information about how to integrate advanced technologies into diabetes self-management. Respondents were also asked about their perceptions of information quality. The parent was asked to indicate the strength of various information attributes using a semantic differential scale.

The fourth part of the survey included questions about the parent's and child's experiences with insulin pumps (e.g., number of years using pump, how many pumps used). Insulin pump satisfaction was measured using the Insulin Pump Therapy Satisfaction questionnaire. This questionnaire is a standardized measure of satisfaction with insulin pump that includes four items related to satisfaction, preparedness, ease of use, and ease of use relative to expectations and six additional items that assess key areas of life change associated with using the pump. In a previous study, these 10 items had

acceptable reliability with a Cronbach's alpha of 0.69 (Mednick et al., 2004). To assess the barriers to insulin pump use, a question with several barriers identified from the literature was included whereby parents select the most common barriers to continued use.

The final part of the survey addressed satisfaction with CGM devices. We adapted the CGM Satisfaction Scale to use in this study. The CGM Satisfaction Scale was designed to measure the impact of using CGM on diabetes management and family relationships and on satisfaction with emotional, behavioral, and cognitive effects of CGM use.

(Juvenile Diabetes Research Foundation Continuous Glucose Monitoring Study Group, 2010). This scale included two subscales: a benefits of CGM subscale with 19 items (Cronbach's alpha =0.93) and a hassles of CGM subscale with 20 items (Cronbach's alpha=0.93). We selected 11 items from each subscale to include in our survey. Parents indicated their agreement with each item using a 7-point linear numeric scale where 1 = Strongly disagree and 7 = Strongly agree.

The survey was professionally examined for face validity by diabetes experts. Three diabetes health care professionals were asked to critique and comment on the survey questions and items. Face validity is important to ensure that the measure represents all facets of the concept. Their comments were used to make revisions in the survey content. Further, a pretest of the instrument was undertaken by administering it to three parents at a diabetes clinic to determine the approximate time needed to complete the entire

questionnaire, the wording, and item clarity. Based on the feedback from the pretest, the instrument was revised before administering it to parents.

**Analysis:**

Once the survey was closed, data were transferred from Qualtrics<sup>®</sup> to SPSS 20.0 (Chicago, IL) for analysis. Data were reviewed for missing data and any survey missing responses to more than 50% of the eligible items were deleted from the analysis file. Frequencies and descriptive statistics were calculated. Correlation coefficients were calculated to test the hypotheses at the 0.05 level of significance.

## RESULTS

In this pilot study, 98 parents responded to the survey. Of the 98 parent responses, 66 parents indicated that they did have a child eighteen years old or younger with T1DM. From the 66 responses, 18 parents indicated that their child does not currently use an insulin pump or CGM while 48 parents indicated that their child does use an insulin pump or CGM. One parent of the 48 parent responses only provided demographic information in the survey and was therefore excluded. Thus, the survey produced 47 final responses from parents of children with T1DM who are currently utilizing an insulin pump and/or CGM device. Table I below indicates these results.

<b>Table I: Parents Responses to Pilot Study</b>	
<b>Information requested</b>	<b>Survey Responses</b>
Completed surveys	98
Do you have a child with Type 1 Diabetes who is currently 18 years old or younger?	Yes: 66 No: 32
Is your child currently using an insulin pump and/or a CGM to manage his/her diabetes?	Yes: 48 No: 18
Only provided demographic information	1
Total number of parent responses to the survey who have a child eighteen years old or younger that is currently use an insulin pump and/or CGM device.	47

The eighteen parents whose children do not use insulin pumps and/or CGM devices were asked to select reason(s) for not using advanced diabetes technology. From the list of reasons for not using advanced diabetes technology, the two most common reasons were cost issues (33%) and the potential for interference with sports, playing outside, or other

activities (22.2%). Other issues included pain or discomfort with infusion or insertion site, body image concerns, and health care provider had not recommended.

Forty-seven participants had a child currently using an insulin pump and/or CGM and participated in the survey. Forty-three of the 47 participants were white, 36.2% live in a rural community, and 76.6% have a college degree or higher. Ninety-six percent have private insurance. On the technology anxiety scale, the mean score on the six items was 3.96, indicating that a parent's natural technology aptitude does not strongly affect their desire to adopt and use diabetes technology.

Sixty-four percent of the respondents had a male child with diabetes. The mean child's age was 13.87 (range 6-18), and the mean age when diagnosed with T1DM was 8.09. Sixty-two percent of respondents indicated that their child's HbA1c at last visit was less than 8.0%, and 23.4% indicated it was between 8-9%, and 14.9% indicated it was above 9%.

***Objective 1:** To describe perceived health care provider support for integrating advanced technologies into diabetes self-management in children with T1DM*

Patient-physician relationship quality was measured using eight items, where the participant rated on a 7-point scale the level of agreement with each item. The results are shown in Table II. The overall mean score for patient-physician relationship quality for



the eight items was 6.28, indicating a positive relationship with the primary health care provider in general.

<b>Item</b>	<b>Mean Score*</b>
My child's primary health care provider is trustworthy	6.62
I trust that my child's primary health care provider will alert me of any problems with my child's diabetes	6.49
There are times when my child's primary health care provider seems sincere	6.13
My child's primary health care provider always puts my child's best interests first	6.17
I am satisfied with my child's primary health care provider	6.17
I receive useful information about my child's diabetic technology from my child's primary health care provider	5.93
I value the services that my child's primary health care provider provides to my child and me	6.41
I am grateful for the individualized attention my child receives from his/her primary health care provider	6.29

\*7-point scale where 1 = strongly disagree and 7 = strongly agree

Participants were asked to indicate who they considered to be part of the child's diabetes health care team who help integrate diabetes technology into the child's diabetes management, as indicated in Table III. Participants reported that on average they had 3.83 members on their health care team that helped them integrate technology into their child's diabetes self-management. Parents were then asked about the support they receive from the diabetes health care team pertaining to integrating technology into the child's diabetes self-management. Individual item scores for the nine items are provided in Table IV. The scale demonstrated good internal consistency reliability (Cronbach's alpha

= 0.98). The overall mean score for the nine items was 5.97 (range = 1.78 to 7.00), indicating support with room for improvement.

<b>Health Care Team Members</b>	<b>Frequency of Health Care Team Member Utilization N (%)</b>
Pediatric Endocrinologist/Endocrinologist	38 (80.9%)
Certified Diabetes Educator (CDE)	27 (57.4%)
Diabetes Technology Company Representative	23 (48.9%)
Nurse/ Nurse Practitioner	19 (40.4%)
Pediatrician/Other Family Doctor	16 (34%)
Diabetic Supplier	11 (23.4%)
Pharmacist	11 (23.4%)
Dietician	9 (19.1%)
Board Certified – Advanced Diabetes Manager (BC-ADM)	4 (8.5%)

<b>Item</b>	<b>Mean Score*</b>
I feel that my child's diabetes health care team has provided me choices and options with advanced diabetes technology.	5.95
I feel understood by my child's diabetes health care team.	6.14
My child's diabetes health care team conveys confidence in my ability to make change with advanced diabetes technology.	6.26
My child's diabetes health care team encourages me to ask questions about advanced diabetes technology.	5.93
My child's diabetes health care team tries to understand how I see things before suggesting a new way of doing things with advanced diabetes technology.	5.86
My child's diabetes health care team made me aware of what to expect from using advanced diabetes technology.	5.88
My child's diabetes health care team has provided training on advanced diabetes technology.	5.81
My child's diabetes health care team regularly reviews my child's progress while using advanced diabetes technology.	6.00
My child's diabetes health care team makes sure we stay in regular contact.	5.88

\*7-point scale where 1 = strongly disagree and 7 = strongly agree

*Objective 2: To identify information sources for integrating advanced technologies into diabetes self-management in children with T1DM*

Respondents indicated where they received information about integrating advanced diabetes technology into their child’s diabetes management. Interestingly, respondents identified health care professionals as well as local diabetes advocacy groups, the Internet, and family and friends as sources of information. Parents rated the quality of information on a semantic differential scale from one to seven, where a higher number is more positive, by indicating how relevant, consistent, beneficial, adequate, and useful the information is. The respondents indicated the information quality was high, with a mean score of 6.09 for the five items.

<b>Information Sources</b>	<b>Frequency N(%)</b>
Pediatric Endocrinologist/Endocrinologist	25(53.2%)
Local Advocacy Group	24 (51.1%)
Diabetes Technology Company representative	22 (46.8%)
Internet	20 (42.6%)
Certified diabetes Educator (CDE)	15 (31.9%)
Friends and Family	13 (27.7%)
Nurse/ Nurse Practitioner	11 (23.4%)
Diabetic Supplier	7 (14.9%)
Pediatrician/Other Family Doctor	4 (8.6%)
Dietician	3 (6.4%)
Pharmacist	3 (6.4%)
Board Certified – Advanced Diabetes Manager (BC-ADM)	1 (2.1%)

***Objective 3: To describe satisfaction (benefits and barriers) of parents of children with T1DM using insulin pumps and CGM***

42 respondents indicated that their child was using an insulin pump, at the time of the survey, in their diabetes self-management. Of the 42 respondents, 62.8% had used their current insulin pump for more than two years, and 18.6% had used three or more different insulin pumps. The majority of respondents indicated that either the diabetes technology company representative (41.9%) or a CDE (39.5%) initially trained them on the use of the technology. Others indicated that a nurse, physician, or BC-ADM trained them initially.

Four items were used to measure satisfaction with insulin pumps, preparedness for transition to insulin pumps, ease of use of insulin pumps, and difficulty of insulin pumps use compared to expectation. Participants responded to these four questions, where a higher number indicated a more positive response. The results are provided in Table VI.

When the results were scaled from one to five, the average satisfaction sum was 3.83.

Parents also reported the benefits of insulin pump integration by indicating the changes in the quality of your child's/your life as a result of using the insulin pump. Parents rated the benefits by indicating any changes in the quality of your child's/your life as a result of using an insulin pump from 1 = much worse to 5 = much better. These results are provided in Table VII. All agreed to some extent that the insulin pump had improved their child's quality of life.

<b>Item</b>	<b>Mean Score</b>
Satisfaction with insulin pump	3.95
Preparedness for transition to insulin pump	4.05
Ease of use of insulin pump	3.91
Difficulty of insulin pump compared to expectation	3.51

<b>Benefits</b>	<b>Mean Benefits Score</b>
Flexibility of Meal Schedule	4.60
Food Variety	4.49
Flexibility of Sleep Schedule	4.47
Knowledge of Diabetes	4.09
Level of your child's responsibility	3.88
Worry related to diabetes	3.81

\*5 point scale where 1=much worse, 2= worse, 3=about the same, 4=better, and 5=much better

Study participants also reported the top four challenges they have experienced as a result of integrating insulin pumps into their child's diabetes care. The most common barriers reported were infusion site rotation issues (57.4%), cost and insurance issues related to insulin pump supplies (52.2%), infusion site is uncomfortable/painful (44%), fear of device malfunction (40.4%), and body image concerns (29.8%). Other barriers experienced by a few participants included school issues, interference with extracurricular activities, operating the pump, and calculating carbohydrate meal content. Participants did not indicate that there were barriers related to lack of health care provider support or lack of information.

Only 13 of the participants indicated that their child was currently using a CGM. Thirty-eight percent had been using a CGM for two or more years, and sixty-nine percent were initially trained to use the CGM by either a CDE or a diabetes technology company

representative. Three of the 13 have used a remote monitor. As shown in Table VIII, respondents indicated their level of agreement with each benefit item. The mean score for all 11 benefit items was 4.90. Table IX shows the level of agreement with each barrier item. The mean score for all 11 barrier items was 3.27.

<b>Item</b>	<b>Mean Score*</b>
makes adjusting insulin easier	4.85
helps to keep low blood sugars from happening	4.77
has helped us learn how to treat low sugars better	3.85
shows patterns in blood sugars that we didn't see before	5.85
helps us prevent problems rather than fixing them after they have happened	5.31
allows more freedom in daily life	5.08
makes it clearer how some everyday habits affect blood sugar levels	5.54
makes it easier to complete other diabetes management duties	4.54
has helped adjust pre-meal insulin doses	4.00
has made me worry less about my child having low blood sugars	4.85
helps in adjusting doses of insulin needed through the night	5.31

\*7-point scale where 1 = strongly disagree and 7 = strongly agree

<b>Item</b>	<b>Mean Score*</b>
causes others to ask too many questions about diabetes	3.00
makes us think about diabetes too much	2.67
causes too many hassles in daily life	3.83
sometimes gives too much information to work with	2.18
is uncomfortable or painful	5.08
has been harder or more complicated than expected	3.50
makes it harder for my child to sleep	2.92
shows more "glitches" and "bugs" than it should	4.33
interferes a lot with sports, playing outside, etc.	3.00
alarms too often for no good reason	3.17
the feedback from device is not useful	2.00

\*7-point scale where 1 = strongly disagree and 7 = strongly agree

***Objective 4:** To explore the relationship between health care provider support and satisfaction with insulin pumps*

**H<sub>1</sub>:** The better the patient-physician relationship quality, the more satisfied the parent of a child with T1DM will be with the insulin pump

**H<sub>2</sub>:** The higher the perceived diabetes health care team support, the more satisfied the parent of a child with T1DM will be with the insulin pump

The third objective was to explore the relationship between health care provider support and satisfaction with insulin pumps. The overall mean score for the 8 items related to patient-physician relationship quality was used to measure relationship quality, and the one item pertaining to satisfaction with insulin pump was used as the insulin pump satisfaction measure. To examine if the patient-physician relationship quality was related to satisfaction with insulin pump, a correlation coefficient was calculated. Table X presents the correlation coefficient between the two variables. The results indicated that these two variables are significantly correlated. The hypothesis (H1) is supported. Therefore, the better the patient-physician relationship quality, the more satisfied the parent of a child with T1DM will be with the insulin pump.

<b>Table X: Correlation between Patient-Physician Relationship Quality and Insulin Pump Satisfaction</b>		
	<b>Satisfaction with insulin Pump</b>	<b>Relationship Quality</b>
<b>Satisfaction with insulin pump Pearson correlation</b>	1.0	.344
<b>Sig. (2-tailed)</b>		0.030
<b>N</b>	43	40
<b>Relationship quality Pearson correlation</b>	.344	1
<b>Sig. (2-tailed)</b>	0.030	
<b>N</b>	40	43

Table XI presents the correlation coefficient between the perceived diabetes health care team support and satisfaction with insulin pump use. The overall mean rating for the perceived diabetes health care team support scale was used to measure perceived support, and the one item pertaining to satisfaction with insulin pump was used as the insulin pump satisfaction measure. The results indicated that these two variables are significantly correlated. Hypothesis 2 was supported. Therefore, the higher the perceived diabetes health care team support, the more satisfied the parent of a child with T1DM is with the insulin pump.



<b>Table XI: Correlation between Perceived Diabetes Health Care Team Support and Insulin Pump Satisfaction</b>		
	<b>Satisfaction with Insulin Pump</b>	<b>Perceived Diabetes Health Care Team Support</b>
<b>Satisfaction with insulin pump Pearson correlation</b>	1	0.341
<b>Sig. (2-tailed)</b>		0.027
<b>N</b>	43	42
<b>Perceived Diabetes Health Care Team Support Pearson correlation</b>	0.341	1
<b>Sig. (2-tailed)</b>	0.027	
<b>N</b>	42	43

## **DISCUSSION**

Diabetes is a multi-faceted disease. For parents with a child with diabetes, health care provider support is essential in adopting, utilizing, and integrating new diabetes technology. The goal of diabetes technology integration is to improve a child's healthcare outcomes and give the parents more control of their child's diabetes management. Our project was conducted through an Internet survey in which 42 parents indicated that they currently use an insulin pump to manage their child's diabetes and 13 utilize a CGM device. The parents that participated in the survey had children who had adopted and integrated advanced technology into their child's diabetes self-management. Also, the majority of parents who participated in the survey had private health insurance, lived in an urban area, and were financially stable. This is consistent with the literature. The average age of the child with diabetes was about 14 years old.

As the survey data were analyzed, it appeared that a parent's inherent technology aptitude does not affect their adoption of technology. Parents without superior technology skills were able to adopt and integrate technology. Although diabetic technology can be complex, it is accessible to families with both proficient and limited technology skills.

In order to attempt to understand a parent's experience with technology, it is essential to understand how health care providers can support the integration of advanced technology into diabetes self-management. The relationship between physicians and a patient and their family is key in diabetes care. Most of the parents surveyed used an endocrinologist or a pediatric endocrinologist as their primary diabetes healthcare provider. It was found that a better relationship with the physician resulted in parents who were more satisfied with T1DM technology. Survey participants identified that they

felt their relationship with their child's primary health care provider was generally a positive relationship. As seen in Table II, parents reported their child's primary health care provider was trustworthy, sincere, and put the needs of their child first.

Due to the complexities of diabetes management, a health care team is essential to achieving diabetes goals. Survey participants had a variety of different individuals on their health care team in addition to a primary health care provider who helped them integrate advanced technologies into their self-management. Specifically, the certified diabetes educator and the technology company representative play a pivotal role in training patients/parents about the newer technology. Some health care professionals, including pharmacists or dieticians, may be underutilized with respect to integrating technology into diabetes self-management. As more patients attempt to adopt advanced technologies, it will be important for the entire diabetes health care team to support the adoption and integration of these technologies. Thus, more insulin pump and CGM training for all professionals providing diabetes care may be needed.

The participants appeared to perceive support for integrating technology; however, there is room for improvement. For example, parents rated the items related to technology training, awareness of what to expect from technology, and encourages me to ask questions about technology lower than some of the other items. Other results from the survey indicated that even these adopters of technology still perceive barriers to using the technology and dealing with some of the psychosocial issues resulting from the use of technology. Again, it is suggested that further training may be needed to ensure diabetes health care providers are prepared to facilitate the adoption and utilization of insulin

pumps and CGM. This adoption has clinical, psychosocial, and economic implications that must be considered by the diabetes health care team.

The results emphasize the need for health care professionals to be trained and confident with diabetic technology and patient care. It may be important that every member of a patient's diabetes health care team be knowledgeable and helpful if asked about integrating technology or technology-related challenges. Moreover, these results may also indicate that patients may not be utilizing the resources provided by these health care professionals. It is essential that health care professionals are not only educated about diabetes technology but also make their abilities accessible to patients when and if questions and concerns arise. If health care professionals are able to receive training and feel comfortable assisting patients with technology related problems, it is possible to improve the patients' perceived provider support. Improving perceived support is likely to improve the parent's satisfaction with the technology.

Many benefits and barriers to utilizing diabetes technology exist. The benefits to using insulin pumps related to flexibility of meal schedule and sleep schedule, allowing the child/parent to have an improved quality of life. The parents did not seem completely satisfied with the use of the insulin pump, although they have adopted its use. Parents indicated that it was not easy to use and that it was more difficult to use compared to what was expected. When provided with a list of sixteen common barriers to using insulin pumps, three top barriers to technology emerged including problems with infusion site rotations, cost and insurance issues related to insulin pump supplies, and the fear of device malfunction. These top barriers identified with the insulin pump related to how the device functions as opposed to how the technology impacts the daily life of the

child. This finding may indicate the need for continued improvement of the technology as well as better ways to train and educate parents about the technology. Health care providers will also need to be mindful of the cost burden associated with advanced technologies.

Furthermore, the results show that incorporation of diabetes technology did not alleviate worry related to diabetes, body image concerns, or the social aspect of device usage. Although diabetes technology aids in diabetes self-management, more support is necessary to combat the psychosocial issues related to technology integration. By addressing some of the psychosocial aspects of technology integration, it may be possible to increase satisfaction and adoption of technology in juvenile diabetes management.

These results suggest that parents and children need continued support and training to integrate technology into diabetes self-management. There are clinical, economic, and psychosocial issues that need to be addressed. All diabetes providers need to be prepared to facilitate the adoption and use of insulin pumps and CGM in T1DM children. Furthermore, there will be an increased need for providers who are experts in diabetes technology, such as the Certified Diabetes Technology Clinician. These providers will be important in training patients on how to use the technology, troubleshooting when the technology malfunctions, and helping the patient adapt to the use of technology.

This pilot study begins to shed light on the nature of diabetes technology adoption and integration and the diabetes health care team support for technology integration. It provides insight into the experiences of parents with T1DM children who are using technology. These parents were not participating in other clinical trials so these results

reflect adopting technology in the real-world, particularly in the south. Further investigation is needed to better understand the psychosocial aspects of technology integration as well as methods to increase perceived support for adopting diabetes technology. Research is needed to understand how various education and training programs can improve the adoption of these technologies. One important part of this research will be the nationwide technology survey planned by JDRF to better understand technology usage in patients with diabetes and their caregivers.

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## APPENDIX

**Demographics**

Your thoughtful responses are very important to us. We appreciate you taking the time to complete the survey.

Do you have a child with Type I Diabetes who is currently 18 years old or younger?

- Yes  
 No

If you have more than one child with Type I Diabetes, please keep your oldest child ( $\leq 18$  years) with Type I Diabetes in mind while answering the remainder of this survey.

For this study, we are interested in your perceptions regarding **Advanced Diabetes Technology**.

**Advanced Diabetes Technology includes insulin pumps and/or continuous glucose monitors, as defined below:**

**Insulin Pump:** An insulin pump is a small device about the size of a small cell phone that is worn externally and can be discreetly clipped to your belt, slipped into a pocket, or hidden under your clothes. It delivers precise doses of rapid-acting insulin to closely match your body's needs

**Continuous Glucose Monitor (CGM):** CGM is a medical device that records blood glucose levels throughout the day and night. A CGM has a tiny glucose-sensing device under the skin and the rest of a CGM is held in place by tape on the top of the skin

Is your child currently using an insulin pump and/or a CGM to manage his/her diabetes?

- Yes  
 No

Has your child ever utilized an insulin pump and/or a CGM to manage his/her diabetes?

- Yes  
 No

What has prevented you from integrating advanced diabetes technology (e.g. insulin pump, continuous glucose monitor) into your child's diabetes management? (Check all that apply)

- cost related issues  
 lack of insurance

- infection at infusion/insertion site
- infusion/insertion site is uncomfortable and/or painful
- infusion/insertion site rotation
- fear of device failure
- not convinced of the advantage(s) of using such technology
- device is difficult to operate
- information provided by the device is not easy to understand
- information provided by the device is not useful
- my health care provider(s) (e.g. physician, pharmacist, etc.) have never recommended the use of advanced diabetes technology
- lack of support from health care provider(s)
- lack of support from teacher(s) in my child's school
- interferes a lot with sports, playing outside, etc.
- body image concerns

Please indicate any reasons other than those listed above that have prevented you from integrating advanced diabetes technology into your child's diabetes management:

How old is your child?

How old was your child when he/she was diagnosed with Type 1 Diabetes?

Gender of child with Type I Diabetes

- Male
- Female

Please report your child's most recently recorded HbA1c value/level:

- < 6.5%
- 6.5% to 7.5%
- 7.6% to 8.0%
- 8.1% to 8.5%
- 8.6% to 9.0%
- > 9.0%
- I do not know

What is your race?

- White/Caucasian
- African American
- Hispanic
- Asian
- Native American
- Pacific Islander
- Other (Please specify)

The location you reside in is ...

- Rural (population ≤ 50,000 individuals)
- Urban (population > 50,000 individuals)

What is the highest level of education you have completed?

- Less than High School
- High School / GED
- Some College
- 2-year College Degree
- 4-year College Degree
- Masters Degree
- Doctoral Degree
- Professional Degree (JD, MD)

What is your combined annual household income?

Which of the following best describes the primary type of health insurance that you have?

- No insurance
- Private insurance (e.g., through employers, individual policy, etc.)
- Medicare
- Medicaid
- Tricare
- Veterans healthcare
- Other type of health insurance (Please specify)

**Tech Savvy (New)**

Please indicate your level of agreement with the following statements by selecting a number from 1 to 7 where 1 = 'Strongly Disagree' and 7 = 'Strongly Agree'.

	1 = Strongly Disagree	2	3	4	5	6	7 = Strongly Agree
I am confident I can learn technology-related skills	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have difficulty understanding most technological matters	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel apprehensive about using technology	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When given the opportunity to use technology, I fear I might damage it in some way	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am sure of my ability to interpret technological output	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am able to keep up with important technological advances	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**HCP Relationship Quality**

Who is the primary health care provider that cares for your child's diabetes?

- Pediatrician
- Pediatric endocrinologist
- Endocrinologist
- Nurse Practitioner
- Other (Please specify)

Please indicate your level of agreement with the following statements by selecting a number from 1 to 7 where 1 = 'Strongly Disagree' and 7 = 'Strongly Agree'.

	1 = Strongly Disagree	2	3	4	5	6	7 = Strongly Agree
My child's \${q://QID47/ChoiceGroup/SelectedChoicesTextEntry} is trustworthy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I trust that my child's \${q://QID47/ChoiceGroup/SelectedChoicesTextEntry} will alert me of any problems with my child's diabetes	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
There are times when my child's \${q://QID47/ChoiceGroup/SelectedChoicesTextEntry} seems insincere	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My child's \${q://QID47/ChoiceGroup/SelectedChoicesTextEntry} always puts my child's best interests first	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am satisfied with my child's \${q://QID47/ChoiceGroup/SelectedChoicesTextEntry}	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I receive useful information about my child's diabetic technology from my child's \${q://QID47/ChoiceGroup/SelectedChoicesTextEntry}	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I value the services that my child's \${q://QID47/ChoiceGroup/SelectedChoicesTextEntry} provides to my child and me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am grateful for the individualized attention my child receives from his/her \${q://QID47/ChoiceGroup/SelectedChoicesTextEntry}	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**Diabetes Technology + Support Team + Information Sources**

Who are the individuals that you consider to be part of your child's diabetes health care team who help you integrate advanced diabetes technology into your child's diabetes management? (Check all that apply)

- Board Certified – Advanced Diabetes Manager (BC-ADM)
- Certified Diabetes Educator (CDE)
- Diabetes company representative (e.g. Medtronic)
- Diabetic supplier (e.g. Diabetes Shoppe)
- Dietician
- Nurse/Nurse Practitioner
- Pharmacist
- Pediatric endocrinologist
- Pediatrician
- Other family doctor
- Other (Please specify)

Please rate the following statements regarding your child's diabetes health care team who helps you integrate advanced diabetes technology into your child's diabetes management.

	1 = Strongly Disagree	2	3	4	5	6	7 = Strongly Agree
I feel that my child's diabetes health care team has provided me choices and options with advanced diabetes technology.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel understood by my child's diabetes health care team.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My child's diabetes health care team conveys confidence in my ability to make change with advanced diabetes technology.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My child's diabetes health care team encourages me to ask questions about advanced diabetes technology.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My child's diabetes health care team tries to understand how I see things before suggesting a new way of doing things with advanced diabetes technology.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My child's diabetes health care team made me aware of what to expect from using advanced diabetes technology.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My child's diabetes health care team has provided training on advanced diabetes technology.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My child's diabetes health care team regularly reviews my child's progress while using advanced diabetes technology.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My child's diabetes health care team makes sure we stay in regular contact.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

From which avenues do you receive information regarding integrating advanced diabetes technology into your child's diabetes management? (Check all that apply)

- Board Certified – Advanced Diabetes Manager (BC-ADM)
- Certified Diabetes Educator (CDE)
- Diabetes company representative (e.g. Medtronic)
- Diabetic supplier (e.g. Diabetes Shoppe)
- Dietician
- Friends and family
- Internet
- Local diabetes advocacy groups (e.g. JDRF)
- Nurse/Nurse Practitioner
- Pharmacist
- Pediatric endocrinologist
- Pediatrician

- Other family doctor
- Other (Please specify)

Please select a position on each of the lines below to indicate your opinion about the information you have received about integrating advanced diabetes technology into your child's diabetes management.

I believe the information I have received about integrating advanced diabetes technology into my child's diabetes management has been:

Not at all relevant	<input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/>	Extremely relevant
Not at all consistent	<input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/>	Very consistent
Not at all beneficial	<input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/>	Extremely beneficial
Not at all adequate	<input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/>	Very adequate
Not at all useful	<input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/>	Extremely useful

**Insulin Pump Experience + Satisfaction + Challenges**

We are now interested in your experiences with your child's use of insulin pumps.

Does your child currently use an insulin pump to manage his/her diabetes?

- Yes
- No

For how long has your child been using his/her current insulin pump?

- < 6 months
- 6 months - 1 year
- 1 - 2 years
- > 2 years

Who initially trained you and/or your child to use an insulin pump?

- Board Certified – Advanced Diabetes Manager (BC-ADM)
- Certified Diabetes Educator (CDE)
- Diabetes company representative (e.g. Medtronic)
- Diabetic supplier (e.g. Diabetes Shoppe)



- Nurse/Nurse Practitioner
- Pharmacist
- Pediatric endocrinologist
- Pediatrician
- Other family doctor
- Other (Please specify)

How many different insulin pumps have you used over the years to manage your child's diabetes?

- 1
- 2
- 3
- 4
- 5 or more

How satisfied are you overall with the insulin pump?

- Very unsatisfied
- Unsatisfied
- Somewhat satisfied
- Satisfied
- Very satisfied

How prepared were you for your child's transition to the insulin pump?

- Very unprepared
- Unprepared
- Somewhat prepared
- Prepared
- Very prepared

How easy is the insulin pump to use?

- Not at all easy
- Somewhat easy
- Easy
- Very easy

Extremely easy

How difficult is the insulin pump to use compared to what you expected?

- Much harder
- Harder
- About what you expected
- Easier
- Much easier

Please indicate any changes in the quality of your child's/your life as a result of using the insulin pump.

	Much Worse	Worse	About the Same	Better	Much Better
Flexibility of meal schedule	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Flexibility of sleep schedule	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Food variety	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Worry related to diabetes	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Level of your child's responsibility	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Knowledge of diabetes	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please rank the **TOP 4** challenges you have encountered when integrating the insulin pump into your child's diabetes management by typing a number from 1 to 4 in the appropriate boxes.

- body image concerns
- calculating carbohydrate meal content when using the insulin pump
- cost and insurance issues related to the insulin pump
- cost and insurance issues related to the insulin pump supplies
- difficulties encountered while operating the insulin pump
- difficulty inserting the insulin pump appropriately into the infusion site
- fear of device malfunction
- information provided by the insulin pump is not easy to understand
- information provided by the insulin pump is not useful
- infection at infusion site
- infusion site is uncomfortable and/or painful
- infusion site rotation
- interferes with child's extracurricular activities
- lack of support from health care provider(s) (e.g. physician, pharmacist, etc.)

- lack of support from teacher(s) in my child's school
- shows more "glitches" and "bugs" than it should

**CGM Qs**

We are now interested in your experiences with your child's use of a continuous glucose monitor (CGM).

Does your child currently use a continuous glucose monitor (CGM) to manage his/her diabetes?

- Yes
- No

For how long has your child been using his/her current CGM?

- < 6 months
- 6 months - 1 year
- 1 - 2 years
- > 2 years

Who initially trained you and/or your child to use a CGM?

- Board Certified – Advanced Diabetes Manager (BC-ADM)
- Certified Diabetes Educator (CDE)
- Diabetes company representative (e.g. Medtronic)
- Diabetic supplier (e.g. Diabetes Shoppe)
- Nurse/Nurse Practitioner
- Pharmacist
- Pediatric endocrinologist
- Pediatrician
- Other family doctor
- Other (Please specify)

Have you used a remote monitor in conjunction with your child's CGM?

- Yes
- No

Please indicate your level of agreement with the following statements regarding the 'BENEFITS' associated with using a CGM by selecting a number from 1 to 7 where 1 = 'Strongly Disagree' and 7 = 'Strongly Agree'.

Using the continuous glucose monitor ...

	1 = Strongly Disagree	2	3	4	5	6	7 = Strongly Agree
makes adjusting insulin easier	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
helps to keep low blood sugars from happening	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
has helped us learn how to treat low sugars better	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
shows patterns in blood sugars that we didn't see before	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
helps us prevent problems rather than fixing them after they have happened	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
allows more freedom in daily life	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
makes it clearer how some everyday habits affect blood sugar levels	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
makes it easier to complete other diabetes management duties	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
has helped adjust pre-meal insulin doses	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
has made me worry less about my child having low blood sugars	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
helps in adjusting doses of insulin needed through the night	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please indicate your level of agreement with the following statements regarding the 'CHALLENGES' associated with using a CGM by selecting a number from 1 to 7 where 1 = 'Strongly Disagree' and 7 = 'Strongly Agree'.

Using the continuous glucose monitor ...

	1 = Strongly Disagree	2	3	4	5	6	7 = Strongly Agree
causes others to ask too many questions about diabetes	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
makes us think about diabetes too much	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
causes too many hassles in daily life	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
sometimes gives too much information to work with	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
is uncomfortable or painful	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
has been harder or more complicated than expected	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
makes it harder for my child to sleep	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
shows more "glitches" and "bugs" than it should	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

interferes a lot with sports, playing outside, etc.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
alarms too often for no good reason	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
the feedback from device is not useful	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**UTAUT Qs**

Please indicate your level of agreement with the following statements regarding continuous glucose monitors (CGMs) by selecting a number from 1 to 7 where 1 = 'Strongly Disagree' and 7 = 'Strongly Agree'.

	1 = Strongly Disagree	2	3	4	5	6	7 = Strongly Agree
The CGM is easy to use	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Using the CGM requires a lot of mental effort	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The CGM is difficult to operate	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Using the CGM improves my ability to make good decisions about my child's diabetic care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Using the CGM allows me to control my child's blood sugar better	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The CGM is a useful tool to manage my child's diabetes	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have the resources necessary to use the CGM to manage my child's diabetes	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have the knowledge necessary to use the CGM to manage my child's diabetes	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Assistance is available when there are difficulties with the CGM	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please indicate your level of agreement with the following statements regarding continuous glucose monitors (CGMs) by selecting a number from 1 to 7 where 1 = 'Strongly Disagree' and 7 = 'Strongly Agree'.

	1 = Strongly Disagree	2	3	4	5	6	7 = Strongly Agree
People who are important to me think my child should use the CGM	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My child's diabetes care team is supportive of his/her use of the CGM	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Friends and family are supportive of my child's use of the CGM	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My child's teachers are supportive of his/her use of the CGM	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Local diabetes advocacy groups are supportive of my child's use of the CGM	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please indicate your level of agreement with the following statements regarding continuous glucose monitors (CGMs) by selecting a number from 1 to 7 where 1 = 'Strongly Disagree' and 7 = 'Strongly Agree'.

1 = 7 =

	Strongly Disagree	2	3	4	5	6	Strongly Agree
Using the CGM is a good idea	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Using the CGM is a pleasant experience	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Using the CGM makes my child's diabetes more manageable	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I intend to continue using the CGM for my child's diabetes management	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I predict I will use the CGM for my child's diabetes management for the next 6 months	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I predict I will use the CGM for my child's diabetes management for the next 12 months	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>