

SUPPLEMENTARY MATERIALS

Table S1. Parent and Pediatrician Subgroups

Parent Subgroup Pair	Parent Subgroup Description	Size (n)
T1D experience	Parents who have T1D or have a child with T1D	164 (16.4%)
	Parents who do not have T1D or have any children with T1D	838 (83.6%)
Youngest child's age	Parents whose youngest child is age 5 or younger	544 (54.3%)
	Parents whose youngest child is older than 5	458 (45.7%)
Child's insurance	Parents of children who do not have insurance or who have Medicaid	318 (31.7%)
	Parents of children with insurance other than Medicaid	684 (68.3%)
Pediatrician Subgroup Pair	Pediatrician Subgroup Description	Size (n)
Experience managing T1D	Pediatricians who provide medical management of T1D directly or in coordination with a specialist	287 (57.4%)
	Pediatricians who do not provide medical management of T1D	213 (42.6%)
Patient's insurance	Pediatricians who reported that 50 percent or more of their patients either have Medicaid or do not have insurance	191 (38.2%)
	Pediatricians who reported that less than 50 percent of their patients either have Medicaid or do not have insurance	309 (61.8%)
Practice location	Pediatricians who practice in an urban area	170 (34.0%)
	Pediatricians who practice in other areas (rural or suburban)	330 (66.0%)
	Pediatricians who practice in rural areas	45 (9.0%)
	Pediatricians who practice in other areas (urban or suburban)	455 (91.0%)
	Pediatricians who practice in a rural area	45 (9.0%)
	Pediatricians who practice in a suburban area	285 (57.0%)
	Pediatricians who practice in an urban area	170 (34.0%)

T1D = type 1 diabetes.

Table S2. Parents Demographic Characteristics

Question	Parents (N = 1,002)
All parents	
Age (in years)	
Mean (SD)	38.7 (9.69)
Gender	
Female	722 (72.1%)
Male	278 (27.7%)
Other	2 (0.2%)
Race/Ethnicity ^a	
American Indian or Alaska Native	21 (2.1%)
Black or African American, non-Hispanic	139 (13.9%)
Asian or Pacific Islander	55 (5.5%)
White, non-Hispanic	748 (74.7%)
Hispanic	79 (7.9%)
Other	9 (0.9%)
Prefer not to share	7 (0.7%)
Marital status	
Single/never married	118 (11.8%)
Married/living as married/civil partnership	770 (76.8%)
Divorced or separated	99 (9.9%)
Widowed/surviving partner	15 (1.5%)
Health insurance ^a	
Private insurance	727 (72.6%)
Medicaid	183 (18.3%)
Medicare	105 (10.5%)
No health insurance/Do not know	41 (4.1%)
Other	26 (2.6%)
Veterans	24 (2.4%)
Highest level of education completed	
Less than high school degree or equivalent	16 (1.6%)
High school or equivalent (e.g., GED)	119 (11.9%)
Some college or technical school	228 (22.8%)
Associate's degree (2-year college degree)	103 (10.3%)

Question	Parents (N = 1,002)
4-year college degree (e.g., BA, BS)	308 (30.7%)
Graduate school coursework or degree (e.g., MBA, MS, MD, PhD)	228 (22.8%)
Household income	
< \$49,999	299 (29.8%)
\$50,000 to \$74,999	208 (20.8%)
\$75,000 to \$99,999	170 (17.0%)
\$100,000 to \$149,999	176 (17.6%)
\$150,000 or more	123 (12.3%)
Do not know/ Prefer not to say	26 (2.6%)
Employment status	
Employed full time	553 (55.2%)
Employed part time	107 (10.7%)
Self-employed	60 (6.0%)
Homemaker	188 (18.8%)
Student/Retired/Disabled/Not looking for or unable to work	73 (7.3%)
Unemployed but looking for work	21 (2.1%)
Geography	
Rural	183 (18.3%)
Suburban	477 (47.6%)
Urban	342 (34.1%)

Max = maximum; min = minimum; SD = standard deviation.

^a This question allows for multiple responses; therefore, the total number of responses may not add up to the total number of people who answered the question.

Table S3. Pediatrician Demographic Characteristics

Question	Pediatricians N = 500
All pediatricians	
Age (in years)	
Mean (SD)	47.2 (11.27)
Gender	
Female	298 (59.6%)
Male	198 (39.6%)
Prefer not to answer	4 (0.8%)
Approximately how many years have you been treating children?	
Less than 5 years	36 (7.2%)
5-10 years	114 (22.8%)
11-20 years	155 (31.0%)
More than 20 years	195 (39.0%)
Approximately how many children do you treat each week? Please include in your estimate the total number of children you personally treat each week.	
Less than 50 each week	28 (5.6%)
50-100 each week	253 (50.6%)
More than 100 each week	216 (43.2%)
I'm not sure	3 (0.6%)

Max = maximum; min = minimum; SD = standard deviation.

Figure S1. Example Choice Question: Parent Survey

Which screening test would you choose for your child?





Screening Test Feature	Screening Test A	Screening Test B
How your child gets the test	Blood draw with a needle	Finger prick
When and where your child gets the test	Same day at your doctor's office or at their preferred lab	A different day at a separate lab or clinic
Your personal out-of-pocket cost for the screening test	None (\$0)	\$50
<i>And, for children who test positive today:</i>		
Education and monitoring through blood tests	Education and blood tests every 6 months Risk of DKA at time of diagnosis is 3%-4%	Education only Risk of DKA at time of diagnosis is 15%-20%
An optional treatment is available to delay type 1 diabetes	No treatment exists to delay type 1 diabetes	Optional treatment delays type 1 diabetes by 2 years Side effect: 1%-2% risk of serious infection
Which screening test would you choose?		

Figure S2. Example Choice Question: Pediatrician Survey

Which screening test would you choose to implement in your practice?

Screening Test Feature	Screening Test A	Screening Test B
How a child gets the test	Urine sample	Venipuncture
When and where a child gets the test	Same day at your office or at your preferred lab	A different day at a separate lab or clinic
A family's out-of-pocket cost for the screening test	None (\$0)	\$5
<i>And, for children who test positive today:</i>		
Level of education and monitoring provided	Education only Risk of DKA at time of diagnosis is 15%-20%	Education and blood tests every 6 months Risk of DKA at time of diagnosis is 3%-4%
An optional treatment is available to delay type 1 diabetes	No treatment is available	Optional treatment delays type 1 diabetes by 1 year Side effect: nausea
Which screening test would you choose for your practice?		

Survey Excerpts

The survey included descriptions of type 1 diabetes, the differences between type 1 diabetes and type 2 diabetes mellitus, diabetic ketoacidosis (DKA), and what it was like to care for a child with type 1 diabetes. Excerpts of the text from the survey instrument are included below.

Type 1 Diabetes is Different From Type 2 Diabetes

As you may already know, type 1 diabetes and type 2 diabetes are very different diseases, but they both result from problems with the body making or using insulin.

Type 1 diabetes: People with type 1 diabetes need to take insulin several times a day, every day, to control their blood sugar levels. Currently, there is no cure for type 1 diabetes, and it cannot be prevented with a healthy diet or active lifestyle

About 1 in 300 children in the United States develops type 1 diabetes by the age of 15 (that is less than 1% of children)

About 90% of the time, children do not have a family history of type 1 diabetes before they are diagnosed

Type 2 diabetes is different: Sometimes people with type 2 diabetes need to take insulin or other medications, but not as frequently as people with type 1 diabetes. Often their blood sugar levels can be controlled through diet and exercise.

This survey is about **type 1 diabetes**. Please review the information in the box about **type 1 diabetes**.

Important Things to
Remember About
Type 1 Diabetes

- Currently, there is no cure
- It cannot be prevented
- It is **not** caused by an unhealthy lifestyle
- People with type 1 diabetes need insulin **every day to survive**

Caring for a Child With Type 1 Diabetes

The goal of people with type 1 diabetes is to keep their blood sugar in a healthy range. Caring for a child with type 1 diabetes can be a lot of work, and parents and caregivers can find it stressful, especially in the beginning. The amount of work depends on the age of the child. Younger children need a lot of help, while older children can do more for themselves.

Children with type 1 diabetes need about 6 to 8 doses of insulin every day to survive and control their blood sugar levels. In most cases, especially early in the disease, children are given insulin through injections with a needle.

Blood sugar that is too high or too low can be dangerous.

Blood sugar is affected by the food a child eats, how active they are, and lots of other factors. Blood sugar levels are monitored with finger pricks 6 to 10 times during the day and night, even while children are asleep.

Type 1 diabetes can lead to serious long-term health complications such as vision problems, kidney disease, heart disease, and nerve damage, but the risk of these complications is reduced with good blood sugar management.

When children with type 1 diabetes are not with their parents or caregivers, someone else (school staff, other parents or family members) must monitor the child's blood sugar and give them insulin.

Diagnosis of Type 1 Diabetes

Currently, many children are first diagnosed with type 1 diabetes during a potentially life-threatening, high blood sugar event called diabetic ketoacidosis (DKA). DKA is caused when blood sugar levels are too high or by a severe infection, illness, or dehydration.

Most DKA events require emergency treatment from a medical professional to prevent long-term health complications or death.

Even without DKA, when children are diagnosed with type 1 diabetes, they are often admitted to the hospital for several days for monitoring. At the hospital, parents are taught how to manage their child's type 1 diabetes and give insulin through an injection. This short stay in the hospital requires parents to digest a lot of information during an already stressful time.

Thinking About a New Screening Test for Type 1 Diabetes

The purpose of childhood screening tests is to find possible diseases in otherwise healthy children before they have any symptoms of disease. For this survey, we are going to describe different types of screening tests for type 1 diabetes.

A positive test result means that your child will develop type 1 diabetes in the future.

About half of children develop type 1 diabetes within 5 years after getting a positive screening test result, while the other half will develop type 1 diabetes after more than 5 years.

The benefits of getting a screening test and knowing your child will one day have type 1 diabetes are:

- Having time to learn about the early signs and symptoms of high or low blood sugar and possibly preventing DKA

- Preparing yourself, your child, and other family members for the day when your child will need care for their type 1 diabetes every day

- Considering the cost of different options for care and making appropriate choices

A **negative test** result means that there is no evidence today that your child might one day develop type 1 diabetes. However, children can develop type 1 diabetes over time.

A negative test result today does not mean that your child will never develop type 1 diabetes. It only means that there's no evidence of your child developing type 1 diabetes today.

This new test is accurate at the time of testing, but because children can develop type 1 diabetes at any age, it is recommended that the test be repeated at least 3 times between the ages of 6 months and 17 years, if the first test result was negative.

Features of a Screening Test for Type 1 Diabetes

Later in this survey we will ask you to think about different screening tests that can tell you if your child will develop type 1 diabetes sometime in the future.

The screening test features described in this survey will include:

How your child gets the screening test

When and where your child gets the screening test

Your personal out-of-pocket cost for the screening test

And, for children who test positive

Level of education and monitoring through regular blood tests

Whether an optional treatment is available to delay type 1 diabetes

The next few screens of this survey will describe the features of the screening test.

Screening Test Feature: How Your Child Gets the Screening Test

The screening test requires a sample of your child's saliva, blood, or urine.

Later in this survey, we will ask you to consider screening tests that use 4 different ways to collect the sample. Please assume that tests with all types of samples are equally accurate.

Saliva sample	A plastic collection device with absorbent material at the end is placed in the mouth to collect saliva.
Finger prick	Using a sterile device with a small needle inside, the tip of the finger is punctured to get a small amount of blood.
Urine sample	3 ounces of urine is collected privately in the restroom using a cup. For young children, a cotton pad can be placed in the diaper and rung out into a cup.
Blood draw with a needle	A needle is inserted into a vein in your child's arm to draw out a vial of blood.

Screening Test Feature: When and Where Your Child Gets the Screening Test

Your child may get the screening test at different times and locations.

Later in this survey, we will ask you to consider 2 different times and locations where the screening test will take place.

Same day at your doctor's office or at their preferred lab	Your child gets the screening test at the doctor's office during your child's regular well-child visit or at their doctor's preferred lab the same day as the regular visit.
A different day at a separate lab or clinic	Your child gets the screening test at a separate lab or clinic at a different location and on a different day.

Screening Test Feature: Your Personal Out-of-Pocket Cost for the Screening Test

There may be an out-of-pocket cost for the screening test that is not covered by your child's health insurance.

Later in the survey, we will ask you to consider screening tests with different personal, out-of-pocket costs. The cost will range from \$0 to \$50 for the test.

Level of Education and Monitoring Provided for Children with Positive Screening

Test Results

Many children who have type 1 diabetes experienced a condition called diabetic ketoacidosis (DKA) when they were diagnosed. DKA is dangerous because it can lead to brain swelling, impaired memory and thinking, and even death. If not treated, DKA can be life threatening and may require emergency treatment.

Screening tests, combined with education and monitoring, can...

- Reduce the risk of DKA when a child is diagnosed
- Reduce a child's risk of other long-term health complications associated with type 1 diabetes

Education

If the screening test results show your child will develop type 1 diabetes, your child's doctor will give you education on how to recognize the early signs and symptoms of type 1 diabetes such as increased urination, increased thirst, or weight loss. When you think your child is developing the symptoms, your doctor can test your child to see if they need to start taking insulin.

Currently, without screening and education on the early signs and symptoms of type 1 diabetes, 30% to 40% of children with type 1 diabetes experience DKA at the time of diagnosis.

The table below describes how education reduces the risk of DKA at the time of diagnosis.

Education	The risk of DKA at time of diagnosis is 15%-20%	Studies found that when parents and children watch for the signs and symptoms of type 1 diabetes, the risk of having DKA when the child is diagnosed is reduced by about half.
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Blood Tests

If your child tests positive, your doctor may offer a program of regular blood tests to monitor your child's blood sugar levels or insulin production, in addition to education. The results of the blood tests will tell your child's doctor when your child has developed type 1 diabetes and needs daily insulin. The blood tests may detect changes in your child's blood sugar or insulin production before they develop signs and symptoms.

Later in this survey we will ask you to consider tests with different education and monitoring options that reduce your child's chance of developing DKA if your child's screening test results are positive. The options are:

Education and blood tests <u>every 6 months</u>	The risk of DKA at time of diagnosis is 3%-4%	<p>In addition to providing education on type 1 diabetes, your child's doctor will measure your child's blood sugar levels or insulin production every 6 months with a blood test.</p> <p>During each visit, a test will be performed using either blood from a finger prick or one vial of blood collected through a needle placed in a vein in your child's arm. Your child may be in the office for up to 2 hours for this test.</p>
Education and blood tests <u>every 3 months</u>	The risk of DKA at time of diagnosis is 1% or less	<p>In addition to providing education on type 1 diabetes, your child's doctor will measure your child's blood sugar levels or insulin production every 3 months with a blood test.</p> <p>During each visit, a test will be performed using either blood from a finger prick or one vial of blood collected through a needle placed in a vein in your child's arm. Your child may be in the office for up to 2 hours for this test.</p>

***An Optional Treatment May Be Available to Delay Type 1 Diabetes for Children
with Positive Screening Test Results***

If the screening test shows that your child will develop type 1 diabetes in the future, there may be an optional treatment available to you that would give your child more time until they develop type 1 diabetes.

If you choose to get the treatment for your child, your child's doctor will teach you how to give your child the treatment.

The treatment is a monthly injection with a needle given at home by an adult.

The benefits of the treatment to delay type 1 diabetes are:

More time until your child develops type 1 diabetes and needs insulin (through multiple daily injections or an insulin pump) for the rest of their lives

A reduction in your child's risk of long-term health complications from type 1 diabetes

The side effects of the treatments to delay type 1 diabetes are either:

Nausea or

The risk of a serious infection

About half of children develop type 1 diabetes within 5 years after getting a positive screening test result, while the other half will develop type 1 diabetes after more than 5 years.

Whether you choose a treatment to delay type 1 diabetes or not, your child will still develop type 1 diabetes. The treatment will give your child more time until they develop type 1 diabetes, but it is not a cure.

If a treatment is available, you can choose whether to give your child the treatment. The treatment is optional.

Later in the survey, we will ask you to consider the following 3 possibilities for whether an optional treatment is available:

No treatment exists to delay type 1 diabetes	No treatments exist to give your child more time before they develop type 1 diabetes.
Optional treatment delays type 1 diabetes by 1 year. Side effect: nausea	A monthly injection is available that will delay type 1 diabetes for 1 year beyond when your child would have developed type 1 diabetes. Your child will have nausea for a few days each month after the injection. They will feel sick to their stomach and will eat a lot less than normal. The nausea usually goes away after a few months of treatment.
Optional treatment delays type 1 diabetes by 2 years. Side effect: 1%-2% risk of serious infection	A monthly injection is available that will delay type 1 diabetes for 2 years beyond when your child would have developed type 1 diabetes. The treatment has a 1%-2% risk of serious infection. Serious infections include diseases such as pneumonia, tuberculosis, or a fungal infection. Serious infections can be treated, although your child may need to go to the hospital. In rare cases, serious infections can be life threatening if left untreated.

Your Opinions About a Screening Test for Type 1 Diabetes

Again, please think about a new screening test that can tell you if your child will develop type 1 diabetes sometime in the future.

In the next 8 questions, we will show you different sets of possible screening tests. For each set of screening tests, please tell us which test you would prefer, Screening Test A or Screening Test B.

Please consider each question individually. The 2 screening tests for comparison will be different in each question

Remember, if you have more than one child, please think about your youngest child when you answer the questions.

Please assume all the tests are equally accurate

Please assume that any additional monitoring tests or optional treatments beyond the initial screening test will be free of charge to your family

Before you answer the following questions, we want to ask you to help us with a problem we have in studies like this one. Because people do not actually have to pay the cost of the test they would choose, they often focus only on whether one cost is larger than another cost, instead of the actual dollar amounts shown and what they would have to give up if they had to pay for the test.

This study will not be used to set prices for type 1 diabetes screening tests, but it will help decision makers understand how important screening test features are to people.

Please help us measure your preferences correctly by carefully considering the dollar amounts shown before deciding which screening test you would choose for your child.