

Supplemental Figure 1. Parental attitudes towards type 1 diabetes clinical trials survey

PERSONAL BACKGROUND

1. How far do you travel from home to get to appointments here at Vanderbilt?
_____ minutes/ hours of driving
2. Guardian's (**your**) year of Birth: _____
3. Guardian's (**your**) Sex:
 - ☐ Female
 - ☐ Male
4. What is your race?
 - ☐ White
 - ☐ Black or African-American
 - ☐ Asian
 - ☐ Pacific Islander
 - ☐ American Indian or Alaska Native
 - ☐ Other: _____
5. Guardian's (**your**) highest level of education completed:
 - ☐ Less than high school
 - ☐ High school or GED
 - ☐ 2 year college
 - ☐ 4 year college/university
 - ☐ Graduate school
6. Which one of the following categories best describes your yearly household income from all sources?
 - ☐ Less than \$40,000
 - ☐ \$40,000 to \$59,999
 - ☐ \$60,000 to \$79,999
 - ☐ \$80,000 to \$99,999
 - ☐ \$100,000 and above
 - ☐ I do not know
7. What is **your child's** current insurance coverage?
 - ☐ TennCare only
 - ☐ Medicaid only
 - ☐ Private insurance only
 - ☐ TennCare + Medicaid
 - ☐ TennCare + private insurance
 - ☐ Medicaid + private insurance
 - ☐ TennCare + Medicaid + private insurance

FAMILY HISTORY OF TYPE 1 DIABETES:

1. How many children do you have? (They can be of *any age*. Please include children by birth, by marriage, and by adoption) _____ (number of children)
2. For your child who has had Type 1 diabetes the **longest**, in what year was he/she first diagnosed?
_____ (YYYY)
3. Please rank **how much you agree** with this statement: "I am worried my child will develop complications from diabetes":

<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
(strongly disagree)	(disagree)	(neutral)	(agree)	(strongly agree)
4. If you have a child/children with Type 1 diabetes, what was his/her/their **most recent A1c**? Please choose the number that is closest to this A1c value for **each child**:

Child 1:	Child 2:	Child 3:	Child 4:
<input type="checkbox"/> 4% <input type="checkbox"/> 5% <input type="checkbox"/> 6% <input type="checkbox"/> 7%	<input type="checkbox"/> 4% <input type="checkbox"/> 5% <input type="checkbox"/> 6% <input type="checkbox"/> 7%	<input type="checkbox"/> 4% <input type="checkbox"/> 5% <input type="checkbox"/> 6% <input type="checkbox"/> 7%	<input type="checkbox"/> 4% <input type="checkbox"/> 5% <input type="checkbox"/> 6% <input type="checkbox"/> 7%
<input type="checkbox"/> 8% <input type="checkbox"/> 9% <input type="checkbox"/> 10% <input type="checkbox"/> 11%	<input type="checkbox"/> 8% <input type="checkbox"/> 9% <input type="checkbox"/> 10% <input type="checkbox"/> 11%	<input type="checkbox"/> 8% <input type="checkbox"/> 9% <input type="checkbox"/> 10% <input type="checkbox"/> 11%	<input type="checkbox"/> 8% <input type="checkbox"/> 9% <input type="checkbox"/> 10% <input type="checkbox"/> 11%
<input type="checkbox"/> 12% <input type="checkbox"/> 13% <input type="checkbox"/> 14% <input type="checkbox"/> 15%	<input type="checkbox"/> 12% <input type="checkbox"/> 13% <input type="checkbox"/> 14% <input type="checkbox"/> 15%	<input type="checkbox"/> 12% <input type="checkbox"/> 13% <input type="checkbox"/> 14% <input type="checkbox"/> 15%	<input type="checkbox"/> 12% <input type="checkbox"/> 13% <input type="checkbox"/> 14% <input type="checkbox"/> 15%

HISTORY OF CLINICAL TRIAL PARTICIPATION

1. Are you aware that there are clinical trials for **Type 1 diabetes**?
☐ No
☐ Yes
2. Are you aware that there are clinical trials for Type 1 diabetes **at Vanderbilt**?
☐ No
☐ Yes
3. From what **sources** have you received information about Type 1 diabetes clinical trials (including Vanderbilt sources and all other sources)?

<input type="checkbox"/> None	<input type="checkbox"/> Healthcare provider (Nurse, Physician, etc.)
<input type="checkbox"/> Family/Friend	<input type="checkbox"/> Other: _____
<input type="checkbox"/> Media (internet, TV, radio, etc)	
4. Was the information you received about Type 1 diabetes clinical trials **easy to understand**?

<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> N/A
(not at all)	(a little)	(some)	(a great deal)	(completely)	(not applicable)
5. Have you ever ***been asked*** to enroll a child **with Type 1 diabetes** in a Type 1 diabetes clinical trial?
☐ No
☐ Yes, and I agreed to enroll **every time** I was asked.
☐ Yes, and I agreed to enroll **some of the times** I was asked.
☐ Yes, but I chose **not** to enroll **every time** I was asked.
6. Have you ever ***been asked*** to enroll a child **who does not have** Type 1 diabetes in a Type 1 diabetes clinical trial (ex: a clinical trial to prevent or better understand Type 1 diabetes)?
☐ Not applicable - I have no children that *do not* have Type 1 diabetes.
☐ No
☐ Yes, and I agreed to enroll **every time** I was asked.
☐ Yes, and I agreed to enroll **some of the times** I was asked.
☐ Yes, but I chose **not** to enroll **every time** I was asked.

7. If you **have been asked** to enroll **any** of your children in a Type 1 diabetes clinical trial, do you feel that your healthcare providers gave you **enough clear information** to make the decision to enroll or not to enroll your child?
- ☐ Not applicable - I have **not been asked** to enroll any children in a Type 1 diabetes clinical trial.
 - ☐ No
 - ☐ Yes, **some** of the times.
 - ☐ Yes, **most** of the times.
 - ☐ Yes, **all** of the times.
8. If you were **now** approached about enrolling a child **with Type 1 diabetes** in a Type 1 diabetes clinical trial, how **willing** would you be to enroll him/her?
- ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5
- (not at all) (a little) (some) (a great deal) (completely)
9. If you were **now** approached about enrolling a **non-diabetic child** in a Type 1 diabetes clinical trial (ex: prevention trial), how **willing** would you be to enroll him/her?
- ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ N/A
- (not at all) (a little) (some) (a great deal) (completely) (Not Applicable)

CLINICAL TRIAL GOALS: A *clinical trial* is scientific research to generate knowledge for better medical practice. Please share with us how the goal of the clinical trial would affect your decision to enroll your child. How **interested** would you be in enrolling your child/children in studies with the following goals:

- | | Not at all | A little | Some | A great deal | Completely |
|--|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|
| 1. Studies that may determine the <i>risk of type 1 diabetes</i> in my..... <input type="checkbox"/> 1 non-diabetic children. | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| 2. Studies that may determine the <i>risk of complications</i> in my..... <input type="checkbox"/> 1 child/children with diabetes. | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| 3. Studies that may <i>improve diabetes control</i> for my child..... <input type="checkbox"/> 1 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| 4. Studies that may increase the time that my child with..... <input type="checkbox"/> 1 diabetes <i>does not need shots</i> (the “honeymoon” period). | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| 5. Studies that may <i>reverse</i> (“cure”) diabetes..... <input type="checkbox"/> 1 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| 6. Studies that may <i>prevent</i> diabetes..... <input type="checkbox"/> 1 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |

INTEREST IN TYPES OF CLINICAL TRIALS

1. Each clinical trial is different, so people who participate may have to do different things depending on the study. We would like to know more about how *specific tasks* that may be part of a Type 1 diabetes clinical trial *may influence your decision* to enroll your child. **How comfortable** would you feel if your child were asked to:

- | | Not at all | A little | Some | A great deal | Completely |
|--|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|
| a. Give blood with a finger-prick | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| b. Have their blood drawn..... | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| c. Take IV injections..... | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| d. Receive blood transfusions..... | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| e. Do exercises..... | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| f. Be interviewed..... | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| g. Stay in the hospital to receive medicine..... | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| h. Have diet limited/restricted..... | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| i. Take medicine by mouth..... | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |

	Not at all	A little	Some	A great deal	Completely
j. Undergo surgery.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
k. Be exposed to animal tissues (ex: cow or pig islets).....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
l. Be exposed to human stem cells.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
m. Receive a new vaccine.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
n. Receive a placebo (inactive medicine).....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

2. For the tasks where you marked “**not at all**” or only “**a little**” comfortable, please list any reasons why you were not as comfortable with these tasks:

3. There are lots of things that might **affect** a parent/guardian’s decision to enroll a child in clinical trials. How much would the following **influence your decision to enroll a child** in a Type 1 diabetes clinical trial?

	Not at all	A little	Some	A great deal	Completely
a. Your religious or cultural beliefs.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
b. Your child’s age.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
c. Your child’s sex.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
d. Your child’s personality.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
e. Your child’s overall health.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
f. The length of the study.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
g. Lack/cost of transportation.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
h. Any fear you have of giving injections.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
i. Any fear your child has of receiving injections.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
j. Any fear of your child being a “guinea pig”.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
k. Any fear of results not being private/ confidential.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
l. Any fear of having to pay for the research treatment.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
m. Lack of trust in research.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
n. Risk that your child may have side-effects from the study...	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

4. There are many things that might **motivate or encourage** a parent/guardian to enroll a child in clinical trials. How much would the following **make you want to enroll a child** in a Type 1 diabetes clinical trial?

	Not at all	A little	Some	A great deal	Completely
a. Contributing to science.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
b. Benefit for your child	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
c. Benefit for other children in the future.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
d. More access to your doctor at no cost as..... part of the study	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
e. Money/financial compensation.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
f. Influence of friends and relatives.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

TRIAL COMMITMENT: We would like to know more about how *the degree of commitment* involved in participating in Type 1 diabetes clinical trial *may influence* your decision to enroll your child. **Please tell us what you think is appropriate to ask of you and your child in the following situations:**

1. If your child were placed on an oral medicine,☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐ More
how many times each day would you be willing to administer it? times/day
2. If your child were placed on an oral medicine,☐0 ☐6mo ☐1yr ☐2 yr ☐5 yr ☐10 yr ☐Lifetime
for how long would you be willing to administer it?
3. If your child were placed on an injected medicine,.....☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐ More
how many times each day would you be willing to administer it? times/day
4. If your child were placed on injected medicine,..... ☐0 ☐6 mo ☐1yr ☐2 yr ☐5 yr ☐10 yr ☐Lifetime
for how long would you be willing to administer it?
5. **How many times per year** would you be willing.....☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐ More
to allow your child's blood to be drawn? times/year
6. **How many times per year** would you be willing.....☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐ More
to come to the clinic with your child? times/year

ATTITUDES TOWARDS CLINICAL TRIALS: Please read the following statements and indicate how much you **agree** with each by scoring on a scale from 1(strongly disagree) to 5 (strongly agree)

- | | Strongly disagree | Disagree | Neutral | Agree | Strongly agree |
|--|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|
| 1. My child's participation in Type 1 diabetes research is..... <input type="checkbox"/> 1
important to find a cure. | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| 2. It is more important to give money to Type 1 diabetes..... <input type="checkbox"/> 1
research than to participate in it. | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| 3. Enough people are already participating in Type 1 diabetes..... <input type="checkbox"/> 1
clinical trials. | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| 4. Healthcare providers generally have the best interest of..... <input type="checkbox"/> 1
patients in mind when they ask them to enroll in clinical trials. | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| 5. The decision to enroll my child in a clinical trial makes..... <input type="checkbox"/> 1
me uncomfortable because I feel it is a decision my child
should make when he/she is old enough to do so. | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| 6. I am afraid research may harm my child/children..... <input type="checkbox"/> 1 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| 7. Drug companies will prevent a cure from being tested..... <input type="checkbox"/> 1 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| 8. I would be uncomfortable with a trial that could cause <i>any</i> <input type="checkbox"/> 1
increase in the risk of diabetes in my non-diabetic children. | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| 9. I am afraid that a diabetes prevention trial could <i>cause</i> my..... <input type="checkbox"/> 1
at-risk child to develop diabetes. | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| 10. I would value protection from complications of diabetes..... <input type="checkbox"/> 1
almost as much as a cure. | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| 11. If my child became uncomfortable (tummy ache, occasional..... <input type="checkbox"/> 1
nausea with medicine) taking a medicine, I would withdraw
from the trial. | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| 12. I would give my non-diabetic child one shot every day..... <input type="checkbox"/> 1
to delay diabetes for 5 years or more. | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |

Thank you for completing our survey. Please slide it in the locked box when you are finished.

ADDITIONAL COMMENTS: _____
