

DED1S: Psychosocial Screening Questionnaire for Parents/ Caregivers of Children Diagnosed with Early-Stage Pre-Symptomatic Type 1 Diabetes

We would like to ask about your thoughts and feelings about your child being diagnosed with early-stage pre-symptomatic type 1 diabetes (T1D). We would like you to think about what that means to you in the context of things that may be better or worse because of this diagnosis. **For each of the questions below, please tick (check) the box that best fits your answer. Please answer every question.**

| | | Strongly Agree (1) | Agree (2) | Neither Agree nor Disagree (3) | Disagree (4) | Strongly Disagree (5) |
|----|--|--------------------------|--------------------------|-----------------------------------|--------------------------|--------------------------|
| 1 | Knowing my child's diagnosis has made me teach them about diabetes | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 2 | Knowing my child's diagnosis has made me think more about living a healthy lifestyle | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 3 | Having my child screened for their risk of T1D was a good idea | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 4 | Knowing my child's diagnosis has helped me to build a strong support system around us | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 5 | It is important that other family members and carers are prepared if they see signs of T1D in my child | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 6 | I am able to cope if symptoms of T1D develop | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | | | | | | |
| | | Strongly Agree (5) | Agree (4) | Neither Agree nor Disagree (3) | Disagree (2) | Strongly Disagree (1) |
| 7 | I worry more about my child's health because of their diagnosis | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 8 | This diagnosis will make it harder for my child to do what they want to do | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 9 | I worry my child's diagnosis will limit their opportunities for friendships | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 10 | Activities may be more limited because of my child's diagnosis | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 11 | Knowing my child's diagnosis has had a negative impact on my quality of life | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 12 | I am over-vigilant about my child's health now we have this diagnosis | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Scoring:

There are two distinct subscales that should be scored separately. Items 1-6 assess positive impact; items 7-12 assess negative impact.

Add the scores for each subscale. Scores can range from 6-30 with higher scores representing greater potential distress.

This project is supported by the Innovative Health Initiative Joint Undertaking (IHI JU) under grant agreement No 101132379. The JU receives support from the European Union's Horizon Europe research and innovation programme and COCIR, EFPIA, Europa Bio, MedTech Europe, and Vaccines Europe, The Leona M. and Harry B. Helmsley Charitable Trust, Breakthrough T1D. Additional funding is provided to associated UK partners through the UKRI (UK Research and Innovation) Guarantee Fund.