



T1D
Exchange

Data Science Committee Meeting

February 2024

Co-chairs: Joyce Lee, Marina Basina

Agenda

- Welcome and introductions- Dr. Lee & Dr. Basina
- T1D Exchange Updates- Emma, T1D Exchange
- Core data elements definitions discussion- Dr. Lee
- Discussion of diabetes distress scale and data spec- Dr. Roberts

Mapping Updates

- **34** sites fully mapped (from 32 sites in Q4)
- **6** in validation phase
- Data completeness scorecards
 - Scorecards will be distributed in Q2

Core Data Elements Definitions Discussion

Adding Diabetes Distress Screening to T1DX-QI Data Specifications

Diabetes distress (DD) is described as the negative emotional impact of living with diabetes

ADA guidelines: “Assess youth with diabetes for psychosocial and diabetes-related distress, generally starting at 7–8 years of age”

DD is associated with higher HbA1c, lower self-esteem, lower satisfaction with life and self-efficacy

Diabetes Distress and Depression Screening are different, albeit complementary

Proposed Data Spec Additions:

1. Screened for DD at encounter yes/no
2. Tool used for screen (PAID vs. DDS vs. other)
3. Item number of tool
4. Total score