



Data Governance Committee Meeting

May 8, 2025

Data Governance Meeting Agenda

1. Welcome
2. SOW/amendment option
3. T2D projects
 - a) T2D (Lilly/Obesity funding proposal
 - b) Pediatric T2D plans
4. Diabetes screening proposal
5. ROI/health economics data
6. Next meeting: Thursday August 14th 10-11 am

Statements of work

- All contracted SOWs that are not associated with special projects (eg, BPA, Screening, etc) will expire by June 2025.
- T1D Exchange will not be renewing SOW payments after 6/1/2025. All financial support shared after 6/1/2025 will be sourced from special projects.
- Clinics are eligible to participate in special projects after the data mapping process is completed or if relevant data can be reported in Smartsheet.
- For the sustainability of the Collaborative, T1DX is identifying grant opportunities and sponsored projects to support clinic time/effort in Collaborative projects.
- For clinics that wish to extend an SOW no payment Amendment, T1D Exchange will sign an SOW Amendment. Example appears on the next slide.

Statements of work Amendment options

The parties agreed to the existing terms of the executed Agreement and SOW and all other terms and conditions of the Agreement remain unchanged.

1. This Amendment dated on the signature, below, adds the following project work:
The Parties agree that participation in the T1DX-QI Collaborative work continues, without funding, and automatically renews for one (1) year periods and
2. The Contractor may elect to participate in future sponsored projects, with funding. Sponsored projects will include separate Statements of Work for consideration.
3. The Parties agree that all existing terms of the DUA, related to Practice and Business Associate responsibilities, Data and Copyright Ownership, Privacy Laws, Security and the Parties acknowledge that beginning at the date of Amendment signature, the program's dataset will expand to include both type 1 and type 2 diabetes.

T2D plans and grant/funding opportunities

- 1) T2D Lilly/Obesity funding proposal (4-6 centers)
 - a) Mid-May submission (Protocol not yet written)
 - b) T2D with Obesity and GLP-1 prescribing application. Data:
 - i. PwT2D (12 y/o-65); BMI; GLP– prescribing; A1c
 - ii. Potential data (race/ethnicity; public/private insurance; insulin use; CGM)
- 2) Pediatric T2D plans
 - i. 21 active pediatric centers participating in the T2D interventions
 - ii. T2D amendments are being created for DUA. Language being added in to include T2D population
- 3) Adult Centers, T2D mapping goal: 6 centers in 2025. Refer to T2D data specification.

T1D Screening Project funding opportunity

1. Diabetes and Screening. First project 2022-2024 with two pediatric centers participation; Second project 2024-2025 with four pediatric centers participating plus first project centers acting as mentors. [Unconfirmed] third project is being proposed now for four new pediatric centers (TBD). T1D Exchange will do a call for interest.
2. Diabetes screening data funding proposal will be made to Breakthrough in June.
 - a) If funded, four new pediatric centers to be selected in Sept/Oct
 - b) Same data/measures as the current Sanofi funded project.
 - i. Qualitative data: focus groups with centers
 - ii. Quantitative data:
 - A. Number of people screened for antibodies Number of people with confirmed antibodies (single and multiple)
 - B. Number of people monitored,
 - C. Number of people with DKA events [who have been monitored]
 - D. Number of people with teplizumab prescriptions.

Data discussion: health outcomes and health economics

1. Future interest in reviewing claims data results as a proxy for ROI to demonstrate efficacy of QI investments on health outcomes/ health economics/ ROI.
2. Would centers like to pursue this in 2026?
3. Discussion of potential data sets
 1. ACO data/claims data managed by hospitals
 2. PCORI data
 3. Other data sets?

Questions

Next meeting: Thursday August 14th 10-11 am