



T1D
Exchange

Data Governance Committee Meeting

February 13, 2025

Data Governance Meeting Agenda

1. Welcome
2. Updates on Industry Sponsored Projects
3. Decisions regarding post-SOW timeline of July 2025
4. Next meeting



Updates on Industry Sponsored Projects

February 2025

Active sponsored projects

Project name	Project timeline	Centers participating	Datasets	Sponsor
IMPROVAID	June 2024-December 2025	Stanford, UC Davis, Northwestern, Mount Sinai, Washington University, Johns Hopkins, NYU Mineola, Children's Mercy, Cincinnati Children's, University of Wisconsin, Children's Healthcare of Atlanta, UC Davis	Qualitative data: focus groups with centers Qualitative data: EMR, device use, AID initiation, A1c outcomes	Medtronic
Increasing Diversity in Referrals to the 880 Study	November 2024-April 2025	Northeastern, Penn Medicine, UPMC, NYU Langone	Deidentified data: Number of people identified for referral to study Number of people who contacted trial centers Number of people recruited for participation.	Vertex

Active sponsored projects

Project name	Project timeline	Centers participating	Datasets	Sponsor
Screening T1D	April 2024-November 2025	University of Florida, Rady Children's, Texas Children's, Indiana University, Children's National, Lurie Children's	Qualitative data: focus groups with centers Quantitative data: Number of people screened for antibodies Number of people with confirmed antibodies (single and multiple) Number of people monitored, Number of people with DKA events [who have been monitored] Number of people with teplizumab prescriptions.	Sanofi
Health Equity BPA	May 2024-April 2027	Johns Hopkins University, UT Southwestern, Hassenfeld Children's, Nationwide Children's, Seattle Children's, Grady Memorial, SUNY Upstate, Adult	Qualitative data: focus groups with centers Qualitative data: Progression in A1D, CGM, and CGM use Change in proportional difference in pump use btw white and non-white individuals Change in A1c	Breakthrough

Active projects not yet sponsored

Project name	Timeline	Centers participating/ interested	Datasets
T2D Pediatrics	Sept 2024-	Cincinnati, Cook, CHLA, CHOA, Children's Mercy, Children's National, Indiana, Lurie, Johns Hopkins, Nationwide, Nemours, NYU Hassenfeld, Rady, Seattle, Spectrum, Stanford, Texas Children's, Wisconsin	A1c below 7%, hyperlipidemia and statin use, SGLT2 use, GLP1 use, microalbuminuria screening, BMI, CGM use, blood pressure.
T2D Adults	Jul 2020-	SUNY, Stanford, Grady, UPMC, Boston Medical Center	Race/ethnicity, Insurance type %, CGM use, Mean A1c, A1c below 8%.

Active projects not yet sponsored

Project name	Timeline	Centers participating/ interested	Datasets
Diabetes Distress	Jun 2023-	BMC, OHSU, Nationwide, Cincinnati, UAB, Seattle Children's, University of Michigan, Hassenfeld Children's, Texas Children's, Indiana University, University of Wisconsin	T1-DDS-8 T1-DDS-30 PAID-T PAID P
Transitions of Care	Jun 2023-	BDC, OHSU, Miami, Lurie, UCSF, Nationwide, Michigan, Mount Sinai, Seattle, Cincinnati, Albert Einstein, UC Davis, Helen Devos	Care transitions Got Transition READDY

Active projects not yet sponsored

Project name	Timeline	Centers participating/ interested	Datasets
HCL	Jun 2023-	Utah, Weill Cornell, University of Miami, SUNY Adults, Rady Children's, Texas Children's, UC San Francisco, Stanford, Le Bonheur, Cincinnati, Mount Sinai	Device use
4T	2026?	Nationwide, Johns Hopkins, UC Davis, The Cleveland Clinic, University of Wisconsin, UT Southwestern, University of Florida, Texas Children's, Barbara Davis Center, CHLA, Rady Children's, Cincinnati, Seattle, Children's Mercy, Stanford	Team member FTE, TIR, TITR Race/Ethnicity Insurance, Proportion with A1c <7%, Date of diagnosis, TIDE (RPM platform): Tidepool/Glooko data

Statements of work update

- 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 come from special project payments.
- Clinics are eligible to participate in special projects after the data mapping process is completed.
- For the sustainability of the Collaborative, T1DX is identifying grant opportunities and sponsored projects to support clinic time/effort in Collaborative projects.

Post-SOW timeline of July 2025

Questions for discussion:

Do clinics need a zero-dollar SOW that is tied to the Coordinating Center's Portal Protocol to help institutions understand the on-going relationship in the Collaborative that is broader than smaller, finite industry-sponsored (and/or grants' sponsored) projects?

What else is needed?

Questions