T1DX-QI Data Governance and Data Science Committee Charter

Last Updated: July 30, 2026

Purpose

The T1D Exchange Quality Improvement Collaborative (T1DX-QI) established the Data Governance and Data Science Committee (DGDSC) to provide strategic oversight of the Collaborative's clinical data sets, data infrastructure, and data use. The Committee is responsible for ensuring that Collaborative data are collected, managed, governed, and used in ways that advance clinical quality improvement, research, patient safety, and operational excellence while maintaining high standards of data quality, privacy, ethical stewardship, and regulatory compliance.

Structure and Processes

Membership

Members will consist of endocrinologists, faculty, and other subject-matter experts who are actively working with and committed to pediatric, adult, and older adult populations with diabetes and who contribute to the development, use, governance, or stewardship of T1D Exchange data sets. Member appointments are for two-year terms, with the option to renew.

Committee Co-Chair Terms

Co-chairs serve two-year terms to lead the T1DX-QI DGDSC. Whenever possible, the Committee will be led by one pediatric and one adult co-chair.

New co-chairs are identified through a peer- and self-nomination process and have been an existing member of the Committee. If no nominations are received, the current co-chairs may outreach to potential candidates to encourage nominations. If no existing members are nominated, or if nominees are new to the Committee, retiring and newly appointed co-chairs may have overlapping terms to support continuity and ensure a smooth leadership transition.

Meetings

The DGDSC will meet at least quarterly.

Responsibilities and Duties

The following functions represent the Committee's primary recurring responsibilities. They are intended to serve as a guide, with the understanding that the Committee may undertake additional responsibilities and establish priorities and procedures as needed.

The Committee will strive to balance regulatory compliance, fiscal responsibility, data quality, and system performance to promote the sustainability of the T1DX-QI's data sets,

technology, and population health management resources, including the evaluation and oversight of emerging technologies such as artificial intelligence and machine learning tools used in data analysis, clinical decision support, or research applications. The Committee will evaluate, respond to, and prioritize opportunities, data requests, and initiatives in accordance with the Committee's review processes (Appendix A).

For data requests from the U.S. Food and Drug Administration (FDA), the Committee reserves the right to review analysis results and approve content by a quorum of Committee members. Requests from national organizations (e.g., CDC, NIH, or HHS) and the associated analysis results require, at a minimum, review by the Committee co-chairs.

As external data requests increasingly originate from a broader range of entities including device manufacturers, and multi-stakeholder registries the Committee will maintain a tiered review framework that scales with data sensitivity, entity type, and intended use, rather than relying solely on agency-specific designations. The Committee will periodically reassess this framework as the external partner landscape evolves.

To support these activities:

Committee Co-Chairs will:

- Contribute to the long-term vision, goals, priorities, and deliverables of the Committee.
- Develop meeting agendas and facilitate discussions with Committee members on data proposals, ongoing projects, priorities, and potential partnership opportunities.
- Prioritize new data elements, proposed changes to the data specification, and other data-related initiatives for Committee review and approval.
- Recommend key areas of focus and promote best practices for data collection, governance, and stewardship across the Collaborative.

Committee Members will:

- Attend quarterly Committee meetings and actively participate in reviews and discussions.
- Review and approve proposed changes to the data specification, clinical decision support tools, artificial intelligence/machine learning applications, and other technology enhancements , including evaluation of model performance, validity, and potential bias where applicable.
- Review and approve data use requests, sponsored projects, and other proposals requiring Committee oversight.
- Review data security and privacy practices, including incident response protocols, and recommend improvements in coordination with T1DX-QI IT/security resources.
- Ensure Committee review processes keep pace with emerging technologies, regulatory changes, and industry standards affecting data governance, security, and analytics.

- Review IRB and data use protocols, as applicable.
- Establish and refine procedures for data sharing and governance.
- Share best practices for EMR data collection, integration, data quality, and stewardship.
- Evaluate interoperability standards (e.g., FHIR, common data models) and their adoption across participating sites to support data exchange and harmonization.
- Review and provide guidance on the incorporation of real-world data sources, including device-generated data (e.g., continuous glucose monitors, insulin pumps, digital therapeutics), into the Collaborative's data sets.
- Review Collaborative data quality and availability metrics and recommend opportunities for improvement.
- Advise on best practices for sharing data and resources across T1DX-QI platforms and systems.
- Support the establishment of operational standards and collaborate with other T1DX-QI committees to maximize the effective use of technology and data.
- Recommend and prioritize initiatives that advance clinical quality improvement, research, analytics, and technology across the Collaborative, including opportunities for sponsored partnerships.

T1DX Staff will:

- Coordinate meeting scheduling, logistics, agendas, minutes, and recordings.
- Maintain the DGDSC Committee website and supporting documentation.
- Support implementation and communication of Committee decisions and Committee review processes.
- Monitor relevant regulatory, technology, and industry developments (e.g., data privacy law, interoperability standards, AI governance guidance) and flag items warranting Committee attention.

Conflicts of Interest

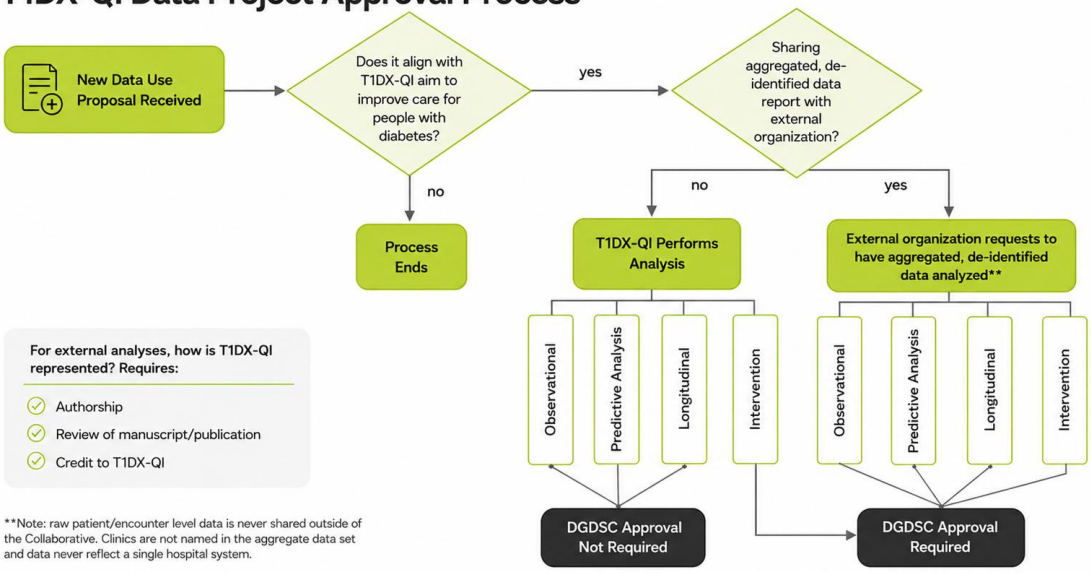
Committee members must abide by T1D Exchange's Conflict of Interest Policy. Members are required to disclose any financial interests or professional relationships with entities whose interests could be affected by the conduct or outcomes of T1D Exchange activities, including any relationships that could influence, or reasonably be perceived to influence, their role on the Committee.

Confidentiality

Committee members will keep all materials reviewed and deliberations of the Committee strictly confidential. If a Committee member is uncertain whether an issue or materials should be treated as confidential, they should consult the Executive Director of Quality Improvement and Population Health at T1D Exchange for guidance.

Appendix A: DGDSC Review Process

T1DX-QI Data Project Approval Process



For external analyses, how is T1DX-QI represented? Requires:

- Authorship
- Review of manuscript/publication
- Credit to T1DX-QI

**Note: raw patient/encounter level data is never shared outside of the Collaborative. Clinics are not named in the aggregate data set and data never reflect a single hospital system.

Last updated: July 22, 2026

t1d exchange