Improving Outcomes for People with Type 1 Diabetes Through Collaboration Summary of Type 1 Diabetes Exchange Quality Improvement Collaborative Studies

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KEYWORDS

• Type 1 diabetes • Population health • Quality improvement • Health equity

KEY POINTS

- Type 1 Diabetes Exchange Quality Improvement Collaborative (T1DX-QI) is a network of 55 type 1 diabetes and 10 type 2 diabetes clinical centers in the United States.
- T1DX-QI uses real-world data, benchmarking, and quality improvement to drive collaborative change.
- Insights from major learning networks like T1DX-QI can contribute to diabetes population health improvement.

INTRODUCTION

People with type 1 diabetes (PwT1D) make a myriad of decisions daily that are impacted by several psychological and physiologic states.¹ Acute and chronic complications in the sea of life transitions make managing T1Ds (T1D) burdensome and challenging.^{2,3}

In the United States, the estimated economic cost of diabetes management is more than \$300 billion annually.⁴ Studies show that the most of the people with diabetes including PwT1D do not meet the American Diabetes Association standards for glycemic outcomes.^{5,6} Coordinated efforts to understand health outcomes, identify process inefficiencies, and effectively implement solutions can reduce the burden of disease for PwT1D.

There are several organizations and large population-based networks working to expand our understanding and drive improvement in T1D outcomes globally.⁷ One

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of the US-focused T1D research organizations is the T1D Exchange (www. t1dexchange.org). T1D Exchange is a Boston-based nonprofit with a mission to improve outcomes for the PwT1D through analyzing real-world evidence and driving collaborative change.

In 2010, T1D Exchange established the T1D Exchange clinic registry (T1DX-Research) that was coordinated by the JAEB Center.⁸ T1DX-Research clinics participated in epidemiologic studies, clinical trials, and real-world outcome studies.

A landmark study from the T1DX-Research found worse mean glycated hemoglobin (HbA1c) outcomes in 2016 to 2018 as compared with 2010 to 2012. This finding was alarming considering the advancement in diabetes technology and standards of care in that period.⁹ Furthermore, other international registries that incorporated quality assurance, benchmarking, and quality improvement (QI) reported improved outcomes.¹⁰

In 2016, through funding support from the Loena M and Harry B Helmsley Charitable Trust, T1D Exchange established the T1D Exchange Quality Improvement Collaborative (T1DX-QI). T1DX-QI started as a pilot with 10 centers focused on population health by advancing health equity, real-world studies, and QI. T1DX-QI has grown to a network of 55 T1D and 10 type 2 diabetes (T2D) centers as at the time of writing this article.^{11–13} Fig. 1 illustrates the geographic distribution of the T1DX-QI centers.

POPULATION HEALTH RESEARCH INSIGHTS FROM TYPE 1 DIABETES EXCHANGE QUALITY IMPROVEMENT COLLABORATIVE

Since 2020, the T1DX-QI has contributed a wide, multidimensional impact on collaborative centers and the larger diabetes community. Overall population health insights from T1DX-QI studies have been categorized into four key domains as summarized below.

Electronic Medical Record Data are an Effective Source for Real-World Studies on Type 1 Diabetes Outcomes

T1DX-QI centers share de-identified electronic medical records (EMRs) data of more than 120 variables with the coordinating office at least monthly.^{14–17} T1DX-QI centers work with the coordinating office to map EMR data fields to corresponding variables in the T1DX-QI data specification, which are validated monthly for data quality assurance.

This real-world data support center-to-center benchmarking, population health insights, and QI studies. T1DX-QI has supported diabetes device coverage advocacy and national quality measures using insights from its' real-world studies. Findings from relevant T1DX-QI EMR data from real-world studies are summarized in Table 1. Major insights include.

- 1. Diabetes technologies can improve glycemic outcomes and are associated with reduced complications for PwT1D.^{18–20}
- There are several modifiable (eg, the use of diabetes technology, depression, body mass index) and non-modifiable factors (eg, race, ethnicity) that directly impact glycemic outcomes for PwT1D.^{21–24}
- 3. There are various opportunities for population health improvement and learning from benchmarking with other international T1D registries.^{7,18}

A Comprehensive Data Sharing Infrastructure Can Support Surveillance and Emerging Needs

Coordinated data sharing efforts are a key component of effective population health improvement. Standardized data collection supports real-time decision-making for

T1D Exchange Quality Improvement Collaborative





the deployment of resources, targeted interventions, and future activities in public health emergencies. 25

When COVID-19 emerged in March 2020, the T1DX-QI swiftly initiated a data sharing program dedicated to quantifying the impact of the pandemic on PwT1D.

Table 1 Type 1 diabetes exchange quality improvement collaborative real-world data relevant studies			
Author Date	Title	Key Findings	
Akturk et al, ²¹ 2022	Factors Associated with Improved Hemoglobin A1c among Adults with Type 1 Diabetes in the United States	Obesity, positive screen for depressive symptoms, public insurance, and minority race were associated with reduced odds for optimal glycemic outcomes for adult PwT1D.	
Demeterco-Berggren et al, ²² 2022	Factors Associated with Achieving Target HbA1c in Children and Adolescents with Type 1 Diabetes: Findings from the T1DX-QI Collaborative	Children and young adults with T1D and HbA1c <7% were more likely to be privately insured, non-Hispanic White, and effectively using diabetes technology.	
DeSalvo et al, ⁶⁰ 2021	Patient demographics and clinical outcomes among type 1 diabetes patients using continuous glucose monitors: Data from T1D Exchange real- world observational study	PwT1D using continuous glucose monitors (CGM) had less severe outcomes including diabetes ketoacidosis (DKA) and severe hypoglycemia (SHE) and had better glycemic outcomes compared with those not using CGM.	
DeSalvo et al, ¹⁸ 2022	Transatlantic Comparison of Pediatric Continuous Glucose Monitoring use in the DPV Initiative and T1D Exchange Quality Improvement Collaborative	CGM users have lower HbA1c values compared with non-CGM users both in the United States and Germany.	
Ebekozien et al, ⁵⁹ 2023	Seven Years Trends (2016–2022) in Glycemic Outcomes and Technology Use for Over 48,000 People with Type 1 Diabetes from the T1D Exchange Quality Improvement Collaborative	HbA1c trends have significantly decreased in a positive direction, whereas diabetes device use has increased in use.	
Garey et al, ²³ 2022	The association between depression symptom endorsement and glycemic outcomes in adolescents with type 1 diabetes	Approximately 30% of adolescents had mild or major depressive symptoms, with an increased risk for DKA.	
Lanzinger et al, ⁷ 2022	A collaborative comparison of international pediatric diabetes registries	Collaboration, data, and active benchmarking are all key components to successful registry development in diabetes care.	
Lee et al, ²⁴ 2021	Feasibility of Electronic Health Record Assessment of Six Pediatric Type 1 Diabetes Self- Management 2 Habits and Their Association with Glycemic Outcomes	Six habits related to the effective use of diabetes technologies are associated with improved glycemic outcomes in PwT1D.	
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Table 1 (continued)		
Author Date	Title	Key Findings
Mungmode et al, ¹⁷ 2022	Making Diabetes Electronic Medical Record Data Actionable: Promoting Benchmarking and Population Health Improvement Using the T1D Exchange Quality Improvement Portal Collaborative	The T1DX-QI benchmarking Portal allows data sharing between clinical centers and is a centralized platform for resource sharing to improve outcomes for PwT1D.
Noor et al, ¹⁹ 2023	An Observational Crossover Study of people using Real-Time Continuous Glucose Monitors (CGMs) vs Self-Monitoring of Blood Glucose (SMBG): Real- World Evidence using EMR Data from over 12,000 people with Type 1 Diabetes	PwT1D who switched from self- monitoring of blood glucose to CGM had elevated HbA1c value.
Noor et al, ²⁰ 2022	Hybrid Closed Loop Systems and Glycemic Outcomes in Children and Adults with Type 1 Diabetes: Real World Evidence from U.S. Based Multi-Center Collaborative	Hybrid closed-loop system use is associated with increased time in range and lower HbA1c for PwT1D.

T1DX-QI centers shared data on symptoms, complications, and outcomes for PwT1D and COVID-19 as part of a multicenter surveillance study.²⁶

Results from the multiyear COVID-19 study are summarized in **Table 2** and major highlights briefly outlined below.

- 1. PwT1D had an increased risk for thromboembolism and hospitalizations as compared with people without diabetes.^{27,28}
- T1DX-QI identified contributors to adverse outcomes for PwT1D with COVID-19. Contributors include the presence of other comorbidities, age, baseline HbA1c, and so forth.²⁹⁻³⁴
- Clinical findings and outcomes on newly diagnosed PwT1D during the COVID-19 pandemic^{35,36} were identified and shared broadly to support clinical care management.

Type 1 Diabetes Outcomes Can Be Improved by Reducing Variations and Optimizing Workflows

QI is a systematic approach to examine processes to improve patient outcomes, care, and clinic workflow.³⁷ T1DX-QI centers use QI methods and tools to understand local center practices, identify contributing factors, and test potential solutions. Participation in an learning health system (LHS) like the T1DX-QI allows centers to rapidly learn from dozens of relevant and simultaneous initiatives, and swiftly incorporate best practices and lessons learned for prompt translation of best practices into real-world processes.

The T1DX-QI has published multiple manuscripts on QI frameworks and initiatives, as summarized in Table 3. Using process improvement frameworks, T1DX-QI centers have.

Table 2
Type 1 diabetes exchange quality improvement collaborative COVID-19 surveillance relevant
studies

Author Date	Title	Key Findings
Alonso et al, ³³ 2021	Diabetic ketoacidosis drives COVID-19-related hospitalizations in children with type 1 diabetes	Elevated baseline HbA1c is the major association for COVID-19 hospitalization and diabetes ketoacidosis (DKA) among children with T1D.
Beliard et al, ³⁶ 2021	Increased DKA at presentation among newly diagnosed type 1 diabetes patients with or without COVID-19: Data from a multi-site surveillance registry	Over 60% of new-onset T1D diagnosis with or without COVID-19 presented with DKA.
Demeterco-Berggren et al, ³² 2022	Age and Hospitalization Risk in People with Type 1 Diabetes and COVID-19: Data from the T1D Exchange Surveillance Study	PwT1D age 40 years and older with COVID-19 had greater risk for hospitalizations.
Ebekozien et. al, ²⁶ 2020	Type 1 Diabetes and COVID-19: Preliminary Findings From a Multicenter Surveillance Study in the US	Over half of patients with COVID- 19 presented with hyperglycemia and roughly 30% had DKA.
Gallagher et al, ³¹ 2022	Differences in COVID-19 outcomes among patients with type 1 diabetes: first vs late surges	PwT1D with COVID-19 had increased adverse events in the first surge compared with those during the later surge.
Lee et al, ⁶¹ 2021	Adoption of Telemedicine for Type 1 Diabetes Care During the COVID-19 Pandemic	The COVID-19 pandemic led to an increased adoption in telemedicine visits during the pandemic.
Mann et al, ²⁹ 2022	Comorbidities increase COVID-19 hospitalization in young people with type 1 diabetes	The presence of additional comorbidities along with T1D led to an increased risk of hospitalization in adults and pediatrics PwT1D and COVID-19.
Miyazaki et al, ⁶² 2023	Association between health insurance type and adverse outcomes for children and young adults with Type 1 Diabetes and SARS-CoV-2	Publicly insured PwT1D with COVID-19 had an increased risk of hospitalization.
Noor et al, ³⁴ 2021	Diabetes Technology Use for management of type 1 diabetes (T1D) is associated with fewer adverse COVID-19 outcomes: Findings from the T1D Exchange COVID-19 Surveillance Registry	PwT1D with evidence of diabetes device use had lower rates of DKA and hospitalizations with COVID-19 compared with without documented use of diabetes devices.
O'Malley et al, ⁶³ 2021	COVID-19 Hospitalization in Adults with Type 1 Diabetes: Results from the T1D Exchange Multi-Center Surveillance Study	Continuation of care and glucose baseline should be prioritized to optimize care for PwD.
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Table 2 (continued)		
Author Date	Title	Key Findings
Tallon et al, ²⁸ 2023	Diabetes status and other factors as correlates of risk for thrombotic and thromboembolic events during SARS-CoV-2 infection: A nationwide retrospective case- control study using <i>Cerner Real-</i> <i>World Data</i>	PwT1D had an increased risk for thromboembolic events during COVID-19 illness than those without diabetes.
Tallon et al, ²⁷ 2022	Impact of diabetes status and related factors on COVID-19- associated hospitalization: A nationwide retrospective cohort study of 116,370 adults with SARS-CoV-2 infection	The increased risk in hospitalization for T1D compared with T2D needs further research and inquiry.
Wolf et al, ³⁵ 2022	Increase in newly diagnosed type 1 diabetes in youth during the COVID-19 pandemic in the US: A multi-center analysis	There was an increase of T1D diagnosis and DKA presentation during the COVID-19 pandemic than in the previous year (2019).

- 1. Illuminated variations in clinical processes and structures, such as QI capacity,³⁷ clinic staffing,³⁸ and barriers to telemedicine implementation³⁹ and smart insulin pen prescription.⁴⁰
- Improved the rates of continuous glucose monitors (CGM) and insulin pumps prescription, depression screening, and so forth.^{41–43}
- 3. The mean HbA1c for PwT1D in the T1DX-QI network in 2022 to 2023 (n = 81,455) was favorable improved at 8.1% compared with the mean HbA1c in 2016 to 2017 of 8.8% (0.7% improvement; P < .01) (Fig. 2).

Type 1 Diabetes Outcomes Can be Improved by Advancing Health Equity and Supporting Advocacy

Health inequities persist in many disease states, including diabetes, despite recent improvements in glycemic outcomes and improved diabetes technology prescriptions.⁴⁴ Even in well-intentioned efforts, improvements may not be equitably experienced by race, ethnicity, sexual orientation, immigration status, and other determinants of health.^{45,46}

To advance diabetes health equity, the T1DX-QI organizes a multipronged approach⁴⁷ to identify and effectively address inequities, as summarized in Table 4.

- It is critical to illuminate inequities in diabetes' health outcomes^{48–51} and technology use. For example, T1DX-QI studies have demonstrated that non-Hispanic Black (NHB) PwT1D were more likely to experience diabetes ketoacidosis (DKA) as compared with non-Hispanic White PwT1D.^{48,49} In addition, studies from the T1DX-QI show that NHB children with T1D experience higher HbA1c, higher rates of DKA, and severe hypoglycemia.⁵⁰
- Diabetes centers can adapt traditional approaches and tools to advance health equity in QI and research spaces.^{52,53}
- Inequities in T1D outcomes should be addressed with multiple approaches including addressing provider bias⁵⁴ and inequity in clinical, insurance, and pharmacy or durable medical equipment prescription processes.⁵⁵

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Table 3

Type 1 diabetes exchange quality improvement collaborative clinic practice variations and quality improvement relevant studies			
Author Date	Title	Key Findings	
Alonso et al, ¹⁴ 2020	Establishment of the T1D Exchange Quality Improvement Collaborative (T1DX-QI)	The T1DX-QI promoted collaboration and shared learning using QI methodologies to improve outcomes for PwD.	
Corathers et al, ⁴³ 2023	Implementation of Psychosocial Screening into Diabetes Clinics: Experience from the Type 1 Diabetes Exchange Quality Improvement Network	Diabetes outcomes are not solely measured by HbA1c and total person health including psychosocial aspects should be incorporated into care.	
Gallagher et al, ³⁸ 2023	Variations in Clinic Staffing for Adult and Pediatric Diabetes Centers in the US: Data from T1D Exchange	Staffing ratios trend more favorably in the pediatric T1D centers as compared with adult centers indicating a high level of disparities.	
Gandhi et. al, ⁶⁴ 2023	Insulin Pump Utilization 2017– 2021 for over 22,000 Children and Adult with Type 1 Diabetes: Multi- Center Observational Study	Insulin pump utilization has increased 7% over the past 5 years.	
Ginnard et al, ⁶⁵ 2021	Quality Improvement in Diabetes Care: A Review of Initiatives and Outcomes in the T1D Exchange QI Collaborative	T1DX-QI quality improvement studies have resulted in improved care processes.	
Grimaldi et al, ⁶⁶ 2023	Connecting from Afar: Implementation of remote data sharing for patients with Type 1 diabetes on insulin pump therapy	Encouraging patients to sign up for the portal during clinic visits led to an uptake of patients sharing pump data.	
Lee et al, ³⁹ 2023	Institutional Barriers to the Successful Implementation of Telemedicine for Type 1 Diabetes Care	Telemedicine rates remained 20% higher than rates pre- pandemic despite a decrease in rates during the start of the pandemic.	
Lyons et al, ⁴² 2021	Increasing Insulin Pump Use among 12–26 Year Olds with Type 1 Diabetes: Results from the T1D Exchange Quality Improvement Collaborative	Insulin pump uptake increased by 13% over a 22-month intervention testing period.	
Marks et al, ³⁷ 2022	Baseline Quality Improvement Capacity of 33 Endocrinology Centers Participating in the T1D Exchange QI Collaborative	It is essential to invest in QI capacity specifically in centers that are smaller in size, serve adult patients, or serve minoritized groups.	
Ospelt et al, ⁴⁰ 2022	Facilitators and Barriers to Smart Insulin Pen Use: A mixed-method study of multidisciplinary stakeholders from diabetes teams in the United States	Most providers agreed that the potential benefits of smart insulin pen use outweigh the barriers.	
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Table 3 (continued)		
Author Date	Title	Key Findings
Peter et al, ⁶⁷ 2023	Prevalence of fear of hypoglycemia in adults with type 1 diabetes using a newly developed screener and clinician's perspective on its implementation	Fear of hypoglycemia is prevalent in PwD and is a leading factor in how diabetes is managed.
Prahalad et al, ⁴¹ 2021	Multi-Clinic Quality Improvement Initiative Increases Continuous Glucose Monitoring Use Among Adolescents and Young Adults with Type 1 Diabetes	CGM uptake increased by 21% over a 22-month intervention testing period.



Fig. 2. Improvement in mean HbA1c (n = 81,455) from the T1DX-QI 2016/2017 as compared with 2022/2023. (*Courtesy of* T1D Exchange Quality Improvement Collaborative.)

Type 1 Diabetes Exchange Quality Improvement Collaborative health equity and population health improvement advocacy relevant studies

Author Date	Title	Key Findings
Ebekozien, ⁵⁵ 2023	Roadmap to Achieving Continuous Glucose Monitoring Equity: Insights from the T1D Exchange	CGM equity is determined by the removal of barriers and intentionally undoing injustices in the current system.
Ebekozien et al, ⁵³ 2022	Achieving Equity in Diabetes Research: Borrowing from the Field of Quality Improvement Using A Practical Framework and Improvement Tools	A 10-step framework coupled with the lived experience perspective is an effective way to create equitable care and management.
Ebekozien et al, ⁵² 2020	Equitable Post-COVID-19 Care: A Practical Framework to Integrate Health Equity in Diabetes Management	Health equity can be addressed using the 10-step framework to identify barriers and create solutions to expand care in an equitable way.
Ebekozien et al, ⁴⁸ 2021	Inequities in Diabetic Ketoacidosis among Patients with Type 1 Diabetes and COVID-19: Data from 52 US Clinical Centers	In PwD with a COVID-19 diagnosis, non-Hispanic Black (NHB) patients had a greater presentation of DKA compared with non-Hispanic White (NHW) patients.
Ebekozien et. al, ⁴⁷ 2022	Addressing Type 1 Diabetes Health Inequities in the United States: Approaches from the T1D Exchange QI Collaborative	T1DX-QI is actively addressing health inequities and intentionally collaborating with stakeholders to close the disparity gap using a comprehensive multistep framework.
Khan et al, ⁶⁸ 2023	Advancing Diabetes Quality Measurement in the Era of Continuous Glucose Monitoring	As diabetes technology evolves, the direction of care to be comprehensive and equitable should adapt as well.
Lavik et.al, ⁴⁹ 2022	Trends in type 1 diabetic ketoacidosis during COVID- 19 surges at seven US centers: highest burden on non-Hispanic Blacks	NHB experienced diabetes ketoacidosis (DKA) at a higher proportion compared with NHW in both 2019 and 202 during the COVID-19 pandemic.
Majidi et al, ⁵⁰ 2021	Inequities in Health Outcomes in Children and Adults with Type 1 Diabetes: Data from the T1D Exchange Collaborative	Significant differences were seen in NHW and NHB patients including DKA presentation, limited technology, and severe hypoglycemia episodes in the latter group.
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Table 4 (continued)		
Author Date	Title	Key Findings
Odugbesan et al, ⁵⁴ 2022	Implicit Racial-Ethnic and Insurance Mediated Bias to Recommending Diabetes Technology: Insights from T1D Exchange Multi-Center Pediatric and Adult Diabetes Provider Cohort	Diabetes technology prescription is influenced by provider implicit bias based on insurance and race/ ethnicity.
Odugbesan et al, ⁵⁸ 2023	Increasing Continuous Glucose Monitor (CGM) Use for Non-Hispanic Black and Hispanic Patients with Type 1 Diabetes (T1D): Results from the T1D Exchange Quality Improvement Collaborative Equity Study	The disparities between NHW and NHB CGM users were reduced by 5% and NHW and Hispanic patients was reduced by 6%.
Ospelt et al, ⁵¹ 2023	The Impact of Climate Change on People Living with Diabetes: A Scoping Review	Negative outcomes enhanced by climate change can lead to severe complications or even death for PwD.
Walker et al, ⁶⁹ 2023	Addressing Global Inequity in Diabetes: International Progress	Interventions to address health equity in minority groups require multilevel practices along with a shift of framework and clinic practice.

DISCUSSION

Although presented in separate categories here, each of the above-described domains contributes to improving care for PwT1D. The infrastructure of a multicenter improvement collaboration, including expertise in data integration, analysis, visualization, QI, health equity, and broader network coordination, serves to support population health improvement.

Through an extensive and validated data sharing process, the T1DX-QI has examined real-world trends, benchmarked outcomes across centers, and identified specific opportunities for improvement. T1DX-QI resources support centers to test and implement local success stories and spread best practices throughout the network. Intentional adaptations of frameworks and approaches support health equity. The existing capabilities support this work in the face of unprecedented public health emergencies like the COVID-19 pandemic to implement expeditious surveillance.

There is urgency in multicenter T1D collaboration that is driven by the increase incidence of diabetes,⁵⁶ COVID-19 exacerbated inequities, and persistence of avoidable barriers to care.⁵⁷

The T1DX-QI model of sharing, networking, and collaboration has demonstrated improvement in T1D population health outcomes and equity.^{58,59} There is strength in collaboration to improve the outcomes and reduce inefficiencies in T1D management.

CLINICS CARE POINTS

- Real-world data can provide valuable clinical insights to type 1 diabetes care management.
- Diabetes technologies are associated with improved outcomes for people with type 1 diabetes.
- Clinic efficiency and effectiveness can be improved with quality improvement methodology.
- Inequities in type 1 diabetes can be reduced with collaboration and care process changes.

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