



T1D Exchange Quality Improvement Collaborative: A Learning Health System to Improve Outcomes for All People With Type 1 Diabetes

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Medical advances, including the development of new medications and advanced technologies, have the potential to improve outcomes for youths and adults with type 1 diabetes, but that potential has not yet been fully realized, particularly in minority groups and those with low socioeconomic status (SES). The report by Majidi et al. in this issue (1) adds to the growing literature exposing racial and ethnic inequities in type 1 diabetes. These data, derived from a mostly young cohort (76% <26 years of age), show that non-Hispanic Blacks experienced higher rates of diabetic ketoacidosis (DKA), higher A1C levels, and lower use of technology compared with non-Hispanic Whites. Non-Hispanic Black patients with type 1 diabetes who are hospitalized with coronavirus disease 2019 are also more likely to present in DKA (2). There is a crucial need to address barriers to care and provide resources to overcome unjust and avoidable health disparities that persist within nondominant racial and ethnic groups (3). Understanding and addressing these barriers can be achieved by understanding our current state and implementing interventions to decrease barriers and improve outcomes.

In 2016, the T1D Exchange established the T1D Exchange Quality Improvement Collaborative (T1DX-QI). This collaborative started with 10 pilot sites, which

were primarily well-respected, academic pediatric diabetes centers. Its initial focus was on children and adolescents/emerging adults with type 1 diabetes, the group who has the highest A1C levels (4,5). Since then, the T1DX-QI has continued to expand, now encompassing 30 centers across the United States (Figure 1), and is beginning to direct attention to adults as well as youths with type 1 diabetes. Participating centers strive to improve care delivery and health outcomes and reduce barriers to care for everyone with type 1 diabetes by sharing best practices and data benchmarking (6).

Quality improvement (QI) approaches have been more extensively used in type 2 diabetes than in type 1 diabetes. The relatively few previous type 1 diabetes QI publications primarily describe activities in pediatric diabetes centers and are from single sites (7–11). Reports in this special collection of articles (1,12–14) highlight the value of using QI approaches within a learning network to reveal systemic barriers and health care disparities and to improve real-world outcomes. (See Supplementary Materials for a full listing of the T1DX-QI Writing Group.) These goals are being accomplished with QI methodology across a growing network of centers committed to sharing data and lessons learned and with input from multiple constituencies, including people with diabetes, their family members, health care professionals from a variety of disciplines, community members, behavioral specialists, computer and informatics experts, health care administrators, and others. The publications in this special collection from the T1DX-QI describe promising early results from some of the work emanating from this learning network.

As the T1DX-QI expanded and engaged in data-sharing and QI initiatives, areas of focus evolved based on need. Additional information about how the T1DX-QI is constructed, organized, and governed has been previously described (6). The collaborative's clinical leadership group reviews the American Diabetes Association's (ADA's) *Standards of Medical Care in Diabetes*, national best practices, and local sites' data and operations. Based on this information and after discussion with the

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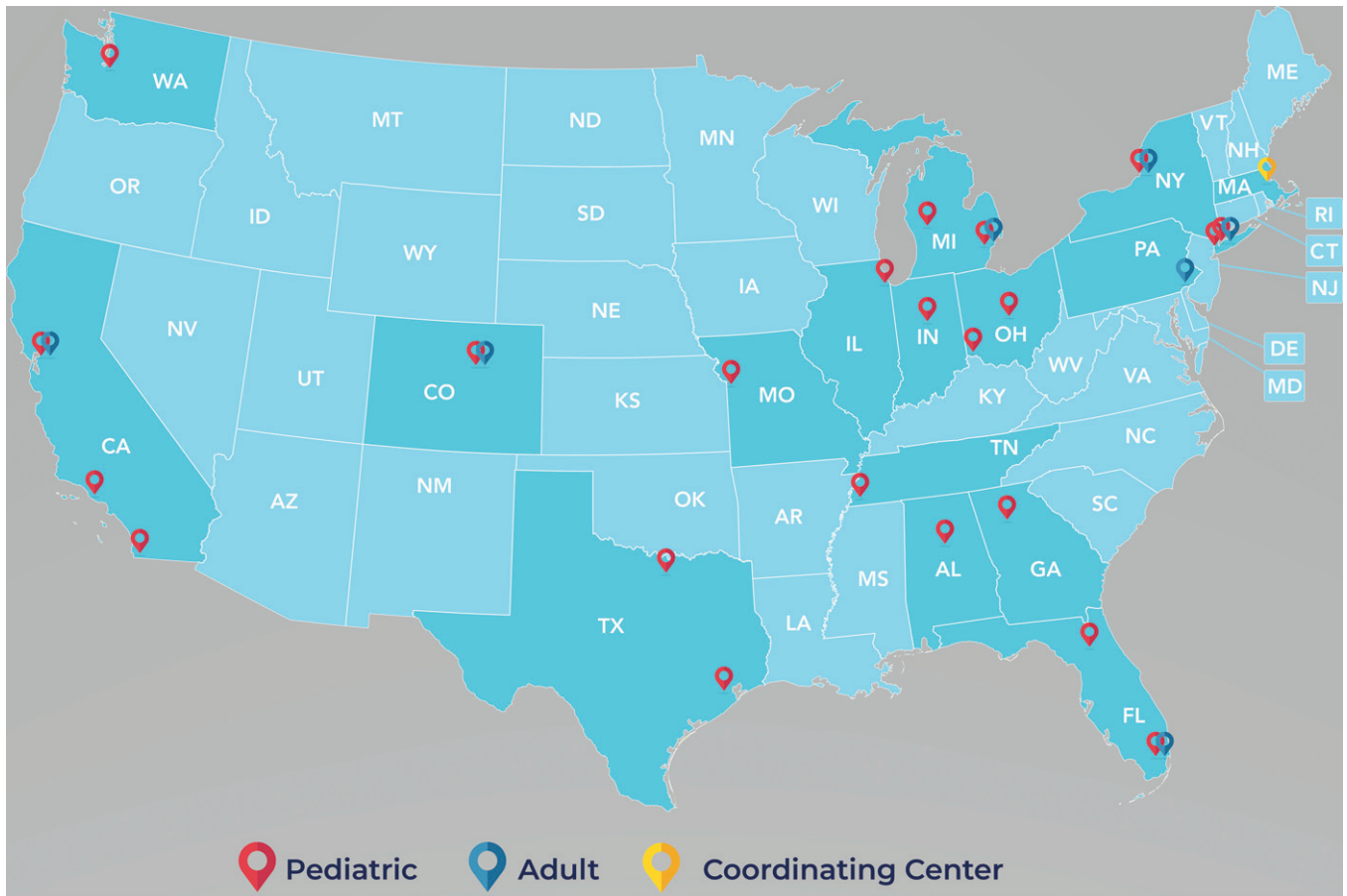


FIGURE 1 Geographical distribution of T1DX-QI sites. Sites marked include the Barbara Davis Center for Diabetes, University of Colorado (adult clinic); the Barbara Davis Center for Diabetes, University of Colorado (pediatric clinic); Baylor College of Medicine, Texas Children’s Hospital; Children’s Hospital of Los Angeles; Children’s Mercy Hospitals and Clinics; Cincinnati Children’s Hospital Medical Center; Cook Children’s Medical Center; Emory University Children’s Healthcare of Atlanta; Indiana University Health (pediatric clinic); Le Bonheur Children’s Hospital, University of Tennessee; Ann and Robert H. Lurie Children’s Hospital of Chicago; Nationwide Children’s Hospital; Northwell Health, Cohen Children’s Hospital; NYU Langone Medical Center (adult clinic); NYU Langone Medical Center (pediatric clinic); Penn Rodebaugh Diabetes Center, Penn Medicine (adult clinic); Rady Children’s Hospital; Seattle Children’s Hospital; Spectrum Health Helen Devos Children’s Hospital; Stanford University (adult clinic); Stanford Children’s Health; Lucille Packard Children’s Hospital; SUNY Upstate Medical University (adult clinic); SUNY Update Medical University (pediatric clinic); University of Alabama at Birmingham (pediatrics clinic); University of Florida Health (pediatric clinic); University of Miami Health System (adult clinic); University of Miami Health System (pediatric clinic); University of Michigan, C.S. Mott Children’s Hospital; Wayne State University (adult clinic); Weill Cornell Medicine (pediatric clinic); and the T1D Exchange Coordinating Center.

sites both individually and as a group, high-priority focus areas for QI are identified, and interventions and processes are formulated. Data-sharing and regular coaching calls with sites, as well as monthly network-wide virtual meetings during which challenges, potential solutions, and opportunities are discussed, help facilitate the successful implementation of each initiative. In this special collection, we present the results of two of these clinical interventions.

The benefits of the use of continuous glucose monitoring (CGM) in improving health outcomes for people with type 1 diabetes are now well established (15–19), and this technology has been incorporated into the

ADA’s 2021 Standards of Care (20). Prahalad et al. (12) describe a QI project to increase the use of CGM in 12- to 26-year-old patients with type 1 diabetes followed in 10 clinics. Staff were trained in and used QI methodology, including the use of SMART (specific, measurable, achievable, realistic, and time-bound) aims and PDSA (plan-do-study-act) cycles (21). Successful PDSA cycles are highlighted on monthly collaborative calls and at the group’s annual meeting. Examples of tested interventions in this project include assessing and addressing barriers to CGM, redesigning workflows, coaching patients, and offering mobile technology classes (12). These changes resulted in a 21% increase in CGM use across the participating T1DX-QI sites in 22

months; individual clinic improvements ranged from nonsignificant change to 25%.

Lyons et al. (13) describe QI interventions in five clinics in the T1DX-QI to increase insulin pump use among 12- to 26-year-old patients with type 1 diabetes. Clinics tested interventions, including better supporting patients through education, coaching, shared decision-making, facilitation of insurance processes and pump onboarding, and sharing of tools and insights. These interventions resulted in a 13% improvement in insulin pump adoption across the collaborative.

There are several limitations to these reports. There is no control group, and it is difficult to assess the influence of other external factors such as changes in state Medicaid policies and the policies of private insurers. Data were shared directly from electronic medical records (EMRs) to a central data warehouse at the T1D Exchange. Although EMR data transfers from different sites may not be identical, the T1DX-QI used common data definitions and quality assurance methods to clean the data to minimize this problem. In addition, these studies were conducted in academic medical centers, and some had resources not available in other health care settings. Even in these centers, however, challenges and health care inequities remain, with much work needed to eliminate racial and ethnic disparities and improve care and quality of life of patients.

The T1DX-QI emphasizes the value of using real-world data from EMRs, generated from everyday practice encounters (in-person or televisits), to develop and disseminate practical tools and learnings that can be quickly adopted. This is an admirable beginning. As summarized by Ginnard et al. (14), health care delivery, access, self-management, psychosocial support, and social determinants of health (SDOH) need to be addressed. The authors emphasize the value of learning health systems such as the T1DX-QI and define critical components, including personnel with analytics capabilities to measure and display data over time and the infrastructure to disseminate successful QI initiatives that can be implemented widely by clinical teams caring for people with diabetes. Within the T1DX-QI and in the data shared in this special collection (1,12–14), success in achieving desired outcomes strongly correlates with adherence to QI methodology, as observed in clinics that diligently tested change starting with pilot endeavors and then implementing and refining comprehensive, systematic practice changes.

Our Scandinavian and European colleagues have had population-based type 1 diabetes registries for many years that have informed interventions to improve care (22,23). Among their many findings is that variations between centers within countries can be greater than variations between countries. The U.S. reports from the T1D Exchange clinic registry, which enrolled volunteer participants from across the country, showed the need for improvements in many realms of type 1 diabetes care (4,24–30). The highest A1C levels were found to be in adolescents, with even worse results reported from real-world EMR data (4,5). To truly understand the state of type 1 diabetes care in the United States, we need data from diverse practices across the country, including those serving people with type 1 diabetes from all socioeconomic groups, races, and ethnicities and from different practice types (e.g., primary care and endocrinology clinics in urban, rural, and suburban locations).

With the widespread adoption of EMRs, generation of real-world data on type 1 diabetes from diverse areas and practices across the country is now possible. The T1DX-QI provides a platform to collect and analyze these data. This is the first important step. As more centers serving individuals of all ages with type 1 diabetes join the collaborative, additional goals can be addressed. For example, prevention of DKA has been and continues to be a goal in the pediatric population, whereas in older adults, prevention of hypoglycemia is a more important focus.

What else do we need? Device companies must work with EMR vendors so that glucose and insulin data can be transferred directly and automatically from glucose meters, CGM systems, smart pens, and insulin pumps into reportable fields within EMRs. These data include glycemic metrics (i.e., the percentage of time in range [glucose levels 70–180 mg/dL], the percentage of time in hypoglycemia [<70 and <54 mg/dL], the percentage of time in hyperglycemia [>180 and >250 mg/dL], mean glucose [\pm SD], and coefficient of variation), as well as the percentage of time patients use CGM, the number of times they check their blood glucose daily, the number of insulin injections/boluses they administer daily, their total daily insulin dose, and the percentages of that total delivered as basal and bolus insulin. In addition, dates of eye examinations and all laboratory results, including from outside laboratories, should automatically populate laboratory fields in EMRs. The responses to common questionnaires (e.g., the Patient Health Questionnaire [PHQ]-2 and PHQ-9

for depression screening and other patient-reported outcomes) and answers to standardized questions about SDOH also need to be in reportable fields.

To further improve care and reduce burdens for all people with type 1 diabetes beyond the various initiatives adopted by clinics, there is a need to address systemic racism and SDOH. The ADA has increased its advocacy efforts (www.diabetes.org/advocacy) and initiated programs aimed at reducing health care disparities through its Health Equity Now initiative (www.diabetes.org/healthequitynow). Involvement of community leaders and organizations; support of efforts to make devices and medications, including analog insulins, more affordable; elimination of provider barriers to prescribing medications and devices (e.g., prior authorization requirements); and programs targeting the training of non-Hispanic Black and Latinx individuals for health care professions are all necessary. To improve access, advocating for telemedicine to be permanent, with adequate reimbursement, and making affordable Internet services available to all Americans are both crucial. For those with low SES, there should be free Internet access for health care (31). All of these changes are necessary if we are to meet the needs of all people with diabetes.

In conclusion, we need to work together to use data to drive continuous QI, share best practices, overcome therapeutic inertia, confront racism (3,32), address SDOH, and advocate to accelerate change and address the needs of all people with diabetes. The T1DX-QI learning health system has continued to adapt its infrastructure, research network, and leadership to address inequities in type 1 diabetes care (3). As the network evolves and grows, it is adjusting its goals to address the latest and most important challenges facing pediatric and adult diabetes clinics. The results reported in this special collection from the T1DX-QI are encouraging, but the full potential of this learning network to improve outcomes and reduce disparities has yet to be reached. Hopefully, even greater change will soon be realized.

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DUALITY OF INTEREST

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AUTHOR CONTRIBUTIONS

R.S.W., N.R., and O.E. wrote the manuscript. O.E. developed the concept for the manuscript. All authors reviewed/edited the manuscript. N.R. and O.E. are the guarantors of this work and take responsibility for the integrity of this commentary.

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