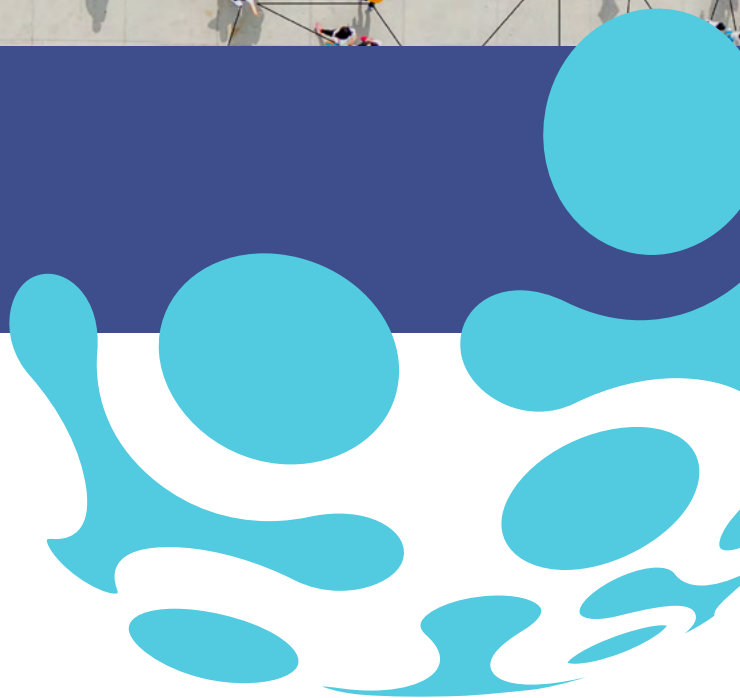




2020 ANNUAL REPORT



FROM OUR CEO



Dear T1D Exchange Community Members,

The year 2020 put us all to the test. A global pandemic brought with it unprecedented health, economic, political, and social challenges that impacted our nation in many significant ways. For T1D Exchange, these challenges also highlighted the value of the ambitious programs and resources we've developed to improve the care provided to people with type 1 diabetes (T1D). T1D Exchange and its programs grew stronger under this pressure as we adapted to combat some of these challenges.

Like most organizations, we had to adjust to working remotely without sacrificing the efficiency, quality, and productivity of our work. I am truly proud of how well our organization executed this transition, meeting over video calls while juggling the real-life responsibilities and interruptions in our home office environments. We successfully mobilized nearly everything we do while still making remarkable progress in the work that we do.

While operating remotely, the Quality Improvement Collaborative (QIC) expanded from 12 to 30 clinics that care for over 45,000 people with T1D. This growth far exceeded our initial goal, enabling us to create a greater impact with our work on studying and implementing best practices to improve outcomes. The growth is also a testament to the value and potential of the QIC to mobilize, coordinate and execute on a range of important initiatives.

As you will read in this report, one initiative involved working with 65 clinics, many of which were not in the QIC, to collect data on the impact of COVID-19 in people with T1D. With over 600 cases of COVID-19 documented in people with T1D through the QIC's survey in 2020, we gathered valuable information on the presentation, progression, and outcomes of the virus in this population.

Our published research on COVID-19 and T1D made headlines across the medical community and mainstream media when it provided priceless insights into how the pandemic affects the T1D population, including the relationship of one's blood sugar control to the severity of the infection, and the relationship of device use, such as insulin pumps and continuous glucose monitors (CGM). This work also uncovered some disturbing data related to racial health disparities, particularly on device use and rates of diabetic ketoacidosis.

The QIC also demonstrated its ability to drive real-world improvements in T1D care with better methods for identifying patients struggling with depression and successfully lowering HbA1c levels in the most challenging age groups.

Given the rapid growth of telemedicine, the QIC also conducted a survey on the strengths and weaknesses of telemedicine for the T1D population. This work uncovered that while centers were able to quickly transition visits from in-person to virtual, many patients were unable to receive routine HbA1c tests or initiate insulin pump or CGM use.

Another key program is our T1D Exchange Registry, which gathers information directly from people with T1D or their caregivers via an online questionnaire. The number of people enrolled doubled in size during 2020 to 11,000 individuals. With the data collected from the diverse group of Registry participants, we can research a wide range of topics about how individuals are faring in their day-to-day lives.

In 2020, we built the infrastructure to add more information to this growing set of real-world evidence, including the integration of additional survey data, and CGM device data into our environment. We also enhanced our ability to recruit participants for our research and for studies other researchers might conduct. This research ranges from simple surveys to in-person visits for innovative new treatments.

Thanks to the remarkable growth across our key programs, we have dramatically increased our ability to conduct custom research projects for key non-profit and industry partners. We now have several efficient mechanisms to assess real-world issues, rooting out the most significant ones, and making changes in care that produce better outcomes for people with T1D.

In 2021, we will build on the groundwork laid in 2020. Specifically, we will continue to build our collection of CGM data, take on a more meaningful role in the screening of those at risk for developing T1D, work to minimize disparities in care through our evolving Health Equities program, and leverage virtual care in the post-COVID-19 world.

We're excited to share the progress we've made in 2020 and the very important work we will be doing in 2021. None of this would be possible without the generous support we've received from The Helmsley Charitable Trust, enabling us to further our mission of improving the lives of people with T1D.

T1D Exchange is making a difference now for those living with this disease. We are grateful for everyone who is dedicated to making it happen.



David Walton, CEO T1D Exchange

CONTENTS

FROM OUR CEO	2
EXECUTIVE SUMMARY	5
THE T1D EXCHANGE QUALITY IMPROVEMENT COLLABORATIVE	6
COVID-19 & T1D	21
THE POWER OF THE PATIENT VOICE	27
PARTNERSHIPS & COLLABORATIONS.....	34
NATIONAL DIABETES AWARENESS MONTH	35
RELAUNCHING	37
LOOKING AHEAD.....	40
THANK YOU	42



EXECUTIVE SUMMARY

DURING A YEAR OF ADVERSITY FOR MANY, T1D EXCHANGE MADE A DIFFERENCE

In a year of uncertainty for so many, T1D Exchange continued in its mission to support people with T1D by leveraging our programs and infrastructure to reach more clinics, engage our vast online community, and grow the number of people who share their experiences in our Registry.

The COVID-19 global pandemic sidelined many, but T1D Exchange was able to positively contribute to the T1D community through our Quality Improvement Collaborative (QIC) and the “COVID-19 and Type 1 Diabetes Surveillance” study.

The QIC also worked to help clinics across the country transition effectively to telemedicine-based care. In the T1D population, it was critical to identify what aspects of care patients were potentially missing in a telemedicine platform, such as A1c measurements and reviewing blood glucose data.

During a year when health care providers were under tremendous pressure, the QIC gained 18 new participating clinics - increasing the total number of people with T1D supported by the QIC to over 45,000 – and paving the way for an invaluable number of studies in the coming years.

Throughout this report, we will look closely at T1D Exchange’s many contributions and achievements in the last year, demonstrating and applauding the collective efforts of all of our partners in research, clinical care, industry, advocacy, and more.

Just as those living with T1D must be relentless in their daily pursuit of health, we are devoted to accelerating life-changing research, data analysis, improvements in care and access to care for everyone with T1D, as we strive towards our vision of better, longer lives for all with T1D.

In 2020, we made tremendous progress in the organization’s programs, including:

- Grew the Quality Improvement Collaborative to 30 clinics by adding 18 new sites, and over 45,000 people with T1D by the end of 2020.
- Led research on the treatment and outcomes of COVID-19 in those living with T1D
- Surpassed 11,000 participants in our Registry
- Received an average of 300 daily responses to our “Questions of the Day”
- Produced 37 abstracts and publications
- Conducted nine custom research studies including work with: Eli Lilly and Company, Dexcom Inc., Zealand Pharma, Medtronic, Vertex Pharmaceuticals, and LifeScan.
- Promoted several research studies including work with: University of Tennessee, Knoxville, Oregon Health & Science University, University of California, Davis, Diatech Diabetes, Medtronic, and Insulet.

THE T1D EXCHANGE QUALITY IMPROVEMENT COLLABORATIVE

While the world was put on hold due to COVID-19, we did not press pause on our efforts to improve care for those living with type 1 diabetes. Creating the Quality Improvement Collaborative (QIC) is by far one of this organization's greatest endeavors, and its growth, success, and purpose in 2020 were remarkable.

In 2016, T1D Exchange launched the QIC initiative as a pilot program of 10 centers. By working collaboratively and using data to refine best practices, the QIC aims to enhance the quality of care, and improve outcomes for people living with T1D.

Amidst a global pandemic, the QIC proved its value in supporting people with T1D, and we are looking forward to its continued growth.

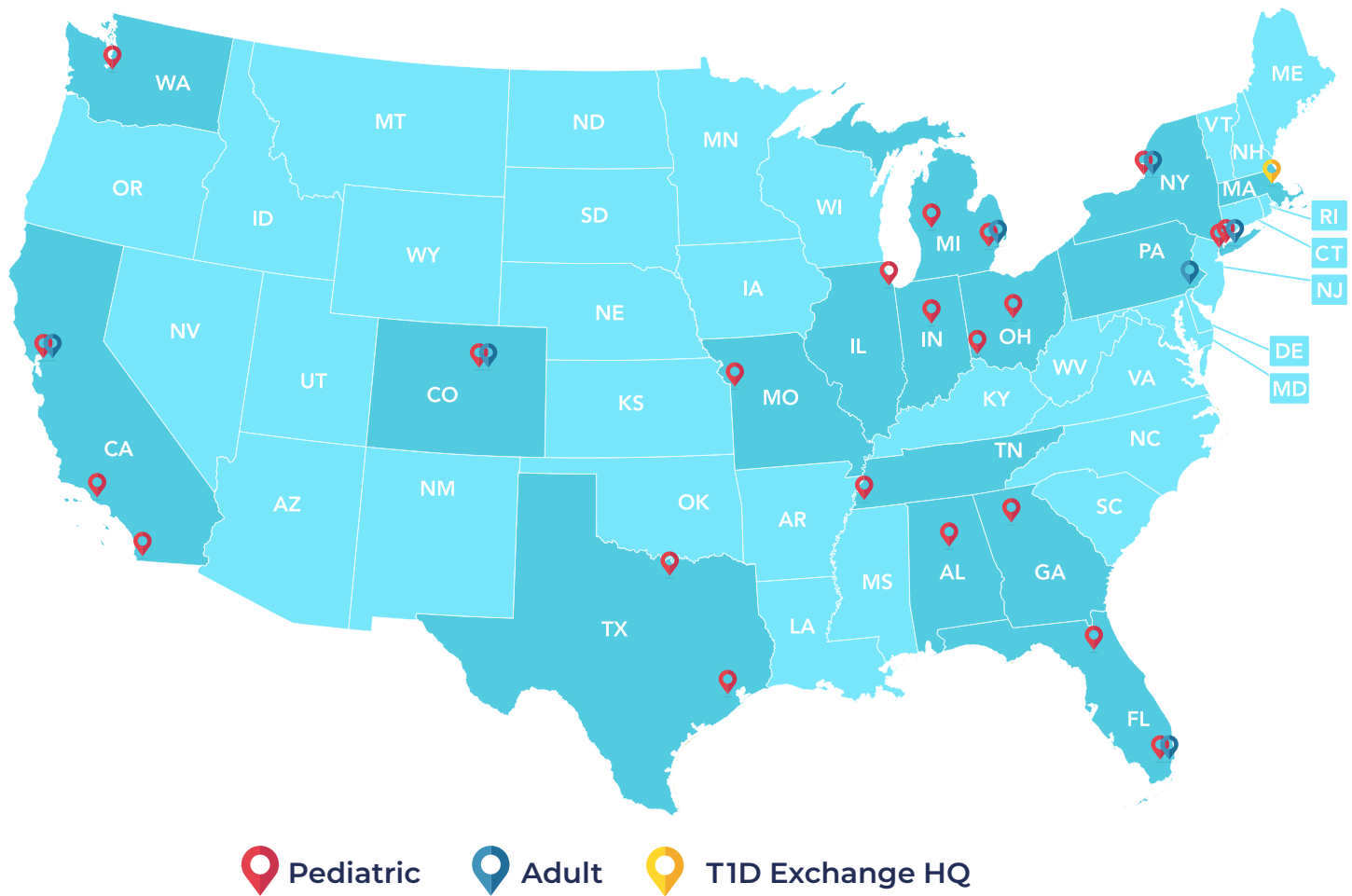


QUALITY IMPROVEMENT COLLABORATIVE CELEBRATES 30 CLINICS AND COUNTING!

The Quality Improvement Collaborative is made up of a network of U.S. diabetes centers whose clinicians and professional staff use data and implementation science to achieve best practices of care. The QIC brought 30 clinics together by the end of 2020, with 33 total as of February 2021. These clinics are situated across the United States and collectively treat more than 45,000 individuals with T1D. QIC member clinics share data and use business intelligence reporting tools via the T1D Exchange QI portal to measurably improve the lives of their patients with type 1 diabetes.

The QIC has achieved unprecedented success because it relies on an embedded and systemic approach: individual providers are empowered to identify areas of unmet need within their respective clinics. They make targeted changes in care that scale up through the QIC to create best practices, which are then shared and implemented by members at other clinics.

"We are proud of the QIC's rapid growth to 30 clinics this year, demonstrating that our data sharing and collaborative improvement approaches are adding real value across the T1D landscape," said Osagie Ebekozien, Vice President of Population Health and Quality Improvement at T1D Exchange. "By working together with leading U.S. diabetes clinics, we are testing and implementing real-world solutions with benefits that can be scaled to the diabetes community."



QIC CLINICS

LOCATION

SUNY Upstate Medical University, Joslin Diabetes Center Adult Clinic

Children's Mercy Hospital

Barbara Davis Center for Childhood Diabetes, Children's Hospital Pediatric Clinic

University of Michigan Hospitals-Michigan Medicine, C.S. Mott Children's Hospital

Nationwide Children's Hospital

Penn Rodebaugh Diabetes Center, Penn Medicine

Baylor College of Medicine, Texas Children's Hospital

Cincinnati Children's Hospital Medical Center

Stanford Pediatrics, Lucile Packard Children's Hospital

Barbara Davis Center for Diabetes, Adult Clinic

Wayne State University (Adult Clinic)

Stanford Adult Diabetes Clinic

Rady Children's Hospital

University of Florida Diabetes Institute (Pediatric)

SUNY Upstate Medical University, Joslin Diabetes Center Pediatric Clinic

Spectrum Health, Helen DeVos Children's Hospital

Seattle Children's Hospital

NYU Langone Health, Pediatrics

Children's Hospital of Los Angeles

University of Miami, Miller School of Medicine Adult Clinic

University of Miami, Miller School of Medicine Pediatric Clinic

Le Bonheur Children's Hospital, University of Tennessee

Cook Children's Medical Center

Northwell Health, Cohen Children's Medical Center

University of Alabama at Birmingham (Pediatric)

NYU Langone Adults

Emory University, Children's Healthcare of Atlanta

Weill Cornell Medicine

Indiana University Health

Lurie Children's Hospital

Grady Memorial Hospital

Syracuse, NY

Kansas, MO

Aurora, CO

Ann Arbor, MI

Columbus, OH

Philadelphia, PA

Houston, TX

Cincinnati, OH

Palo Alto, CA

Aurora, CO

Detroit, MI

Palo Alto, CA

San Diego, CA

Gainesville, FL

Syracuse, NY

Grand Rapids, MI

Seattle, WA

New York, NY

Los Angeles, CA

Miami, FL

Miami, FL

Memphis, TN

Fort Worth, TX

Queens, NY

Birmingham, AL

New York, NY

Atlanta, GA

New York, NY

Indianapolis, IN

Chicago, IL

Atlanta, GA

*As of December 2020



The Collaborative focuses on increasing the percentage of T1D patients in participating clinics that meet the American Diabetes Association (ADA) glycemic management target of A1c less than seven percent. Clinics have access to an innovative QI data portal, which aggregates electronic medical record data and generates real-time, comparative insights for improvement efforts.

The Collaborative's studies have yielded critical information, with numerous publications and presentations at international conferences such as American Diabetes Association and the International Society for Pediatric and Adolescent Diabetes in 2020.

"By joining the T1D Exchange's QIC, we have the opportunity to learn from others' research and contribute

research from our respective clinics," said Janine Sanchez, MD, Director of Pediatric Diabetes at the University of Miami and an Associate Professor of Pediatrics.

"The platform provides consistent, real-time exchange and peer-to-peer resource and knowledge sharing. Through the initiative, we can work to identify and address gaps in care, driving positive change for people living with T1D and ultimately helping people with diabetes lead healthier, longer lives", continued Sanchez.

With a goal of growing to 37 participating clinics by the end of 2021, we eagerly anticipate the impact this groundbreaking program will have on the quality of life for people with T1D.

NOVEMBER'S LEARNING SESSIONS TO ACCELERATE COLLABORATION



QIC members met virtually on November 9th and 10th for the second of two learning sessions held annually. The conference brought QIC clinics together to further their understanding of the QI portal's functionality, share insights, results and goals, and network.

Presentations covered a range of topics, including an update on achieving ADA glycemic management standards, identifying issues in access to care, depression screening, telemedicine, and cardiovascular health in adults with T1D.

2020 QUALITY IMPROVEMENT AWARDS

Joining the QIC is a commitment, calling for both time and persistence from the staff within every participating clinic who are devoted to making it a priority.

This year, we honored the following individuals and clinics for their contributions to making the program a successful effort in improving the lives of people with T1D.

Outstanding Principal Investigator Award

This award recognized a Principal Investigator (PI) who has gone above and beyond in their leadership, QI methodologies and population health research across the collaborative.

This year we recognize two PIs, one in Pediatric Endocrinology and another in Adult Endocrinology, who have been exceptional in mentoring other faculty members, leading scholarly initiatives, and impacting patient lives through multiple QI and Population Health projects in the collaborative.



Pediatrics
Manmohan Kamboj, MD
Nationwide Children's Hospital



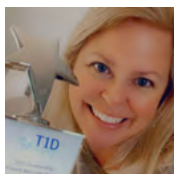
Adult
Llona Lorincz, MD
University of Pennsylvania



Outstanding Patient Advocate Award

This award recognizes the dedication, hard work, and passion of a T1D Exchange Patient/Parent Advocate.

This year, we celebrate an exceptional leader who has been remarkable in supporting local and collaborative-wide improvement and population health efforts.



Amy Ohmer

Outstanding QI Coordinator Award

This award recognizes a QI Coordinator who has gone above and beyond in program engagement, supporting the team’s QI and population health project, data sharing, and active contribution to the QIC’s overall success.

This awardee currently supports two QI teams in the collaborative. She is an exemplary QI Coordinator, and we are especially fortunate to have her working with the collaborative.



Margie Greenfield
SUNY Upstate
Pediatric & Adult QI Teams

Outstanding Team Award

This award recognizes two exceptional QI teams.

The first team is a foundational member of the QIC that has consistently demonstrated advanced QI and population health improvement capacity. This team has also mentored new members, supported other collaborative sites, and actively contributed to the QIC’s overall success. We are beyond grateful for their dedication to the program and their patients.

The second team is newer to the QIC, having joined in 2020, but they have been phenomenal in engagement, data mapping, learning, and sharing resources with other collaborative members. We are so grateful for their devotion to the QIC and their patients.



Foundational Team
Texas Children’s Hospital



New Team
Rady Children’s Hospital





QUALITY IMPROVEMENT HIGHLIGHTS FROM 2020

As we share some highlights from the collection of our published research from 2020, we look forward to the continuation and expansion of this important work in 2021, and in particular, our work addressing health equity and the growing use of telemedicine. The following are highlights of some of the impactful research from our participating QIC clinics.

- **COVID-19 Hospitalization in Adults with T1D: Risk & Outcomes**

In a year filled with unknowns surrounding the Covid-19 pandemic, the T1D Exchange QIC launched a study on April 6th to provide some answers. This study found that patients with T1D and COVID-19 were more likely to be hospitalized if they were older, identified as Non-Hispanic Black, were covered by public insurance, had a higher HbA1c, and/or had hypertension.

- **A Practical Framework to Integrate Health Equity**

The T1D Exchange QIC developed a ten-step framework to guide health care providers in their efforts to improve the health of everyone with T1D. This framework is a tool that can be used to help pave the way for a more equitable healthcare system.

- **Improving Continuous Glucose Monitor (CGM) Use**

Ten diabetes centers in the T1D Exchange QIC successfully proved that we can increase CGM use through assessing and removing barriers to adoption, developing CGM patient education classes, and advocating for state Medicaid coverage. By understanding the best methods to increase CGM usage, we are one step closer to improving outcomes for all people living with T1D.





QIC “CHANGE PACKAGES” MEAN REAL-WORLD IMPROVEMENTS IN T1D PATIENT CARE

“Change packages” are the culmination of many clinics testing one hypothesis, running and completing a study, analyzing the data, and using this data to determine best practices. These best practices are then packaged so that the successful change can be shared and implemented in other endocrinology clinics.

Much like a playbook in sports, the change package is intended to be a pragmatic guide of

proven best practices, testable ideas, tools, and strategies that can be adapted to various settings, thereby accelerating implementation. The change package offers everything one site will need to replicate the same change in their practice in an effort to see the same improvements in care and outcomes for their patients with T1D.

Instead of starting at square one with their own hypothesis and having to work through every step, the QIC enables other clinics to begin at a significantly more advanced stage. This means clinics following that particular change package’s recipe can rapidly apply a tested and proven method of improving care.

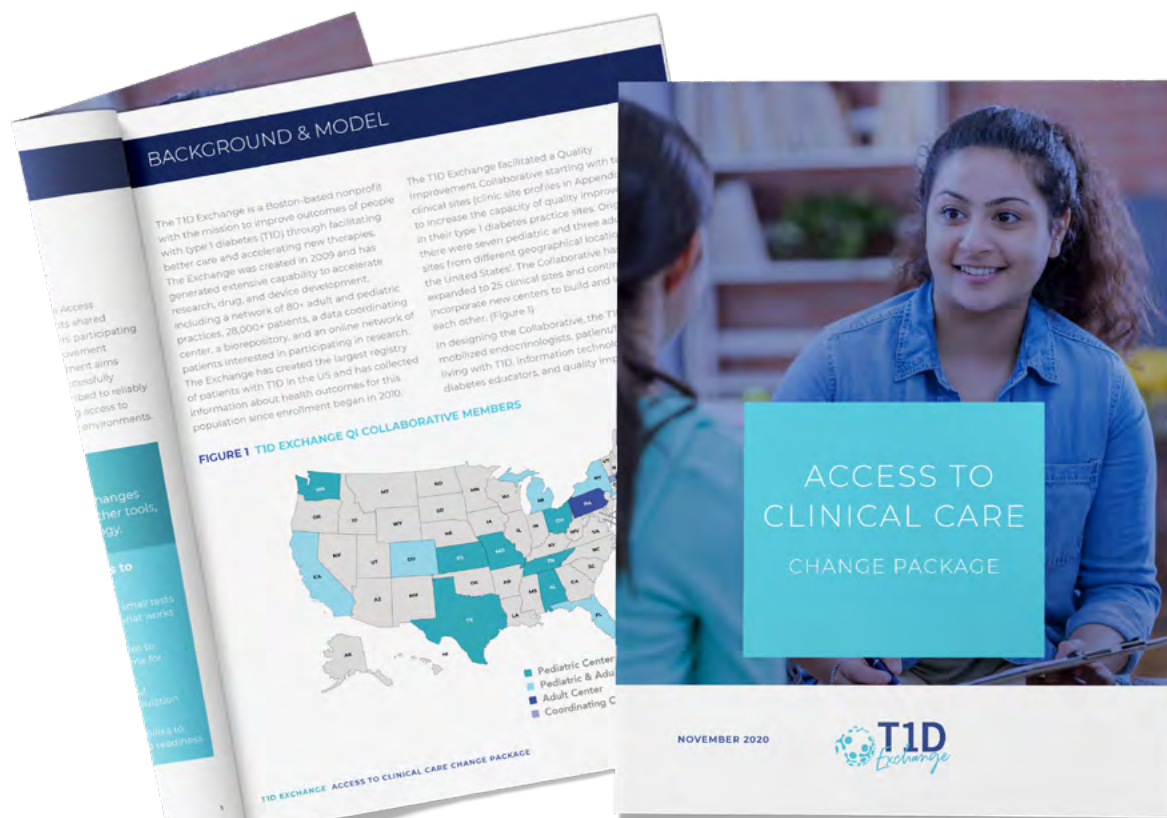
ACCESS TO CLINICAL CARE

Regular outpatient appointments and medication management are crucial for patients with type 1 diabetes. The American Diabetes Association recommendation is for pediatric patients to be seen at least four times per year.

Unfortunately, many patients fail to receive the services they need because of barriers to access, including issues such as time and cost of travel, the concern of missing work or school, transitioning from pediatric to adult care, and lack of childcare for other family members. While

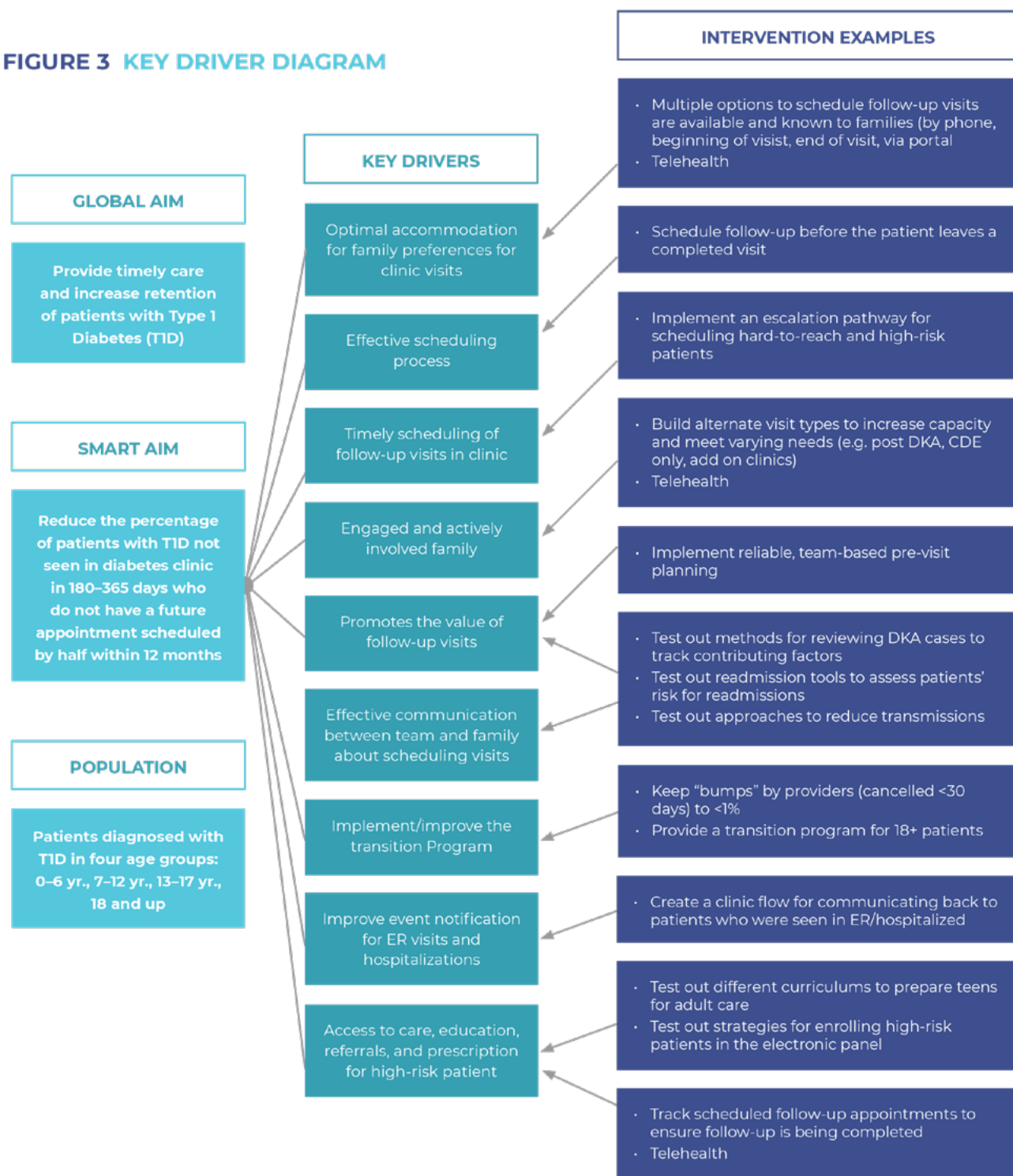
some clinics have a “patient navigator” dedicated to helping patient populations that need support, many clinics do not.

This QIC Change Package serves to identify and re-engage patients who have been “lost to follow-up”, which refers to patients who were once active patients (or research participants) attending a clinic for regular follow-up but became “lost” to routine appointments.



KEY DRIVER DIAGRAM

FIGURE 3 KEY DRIVER DIAGRAM



DEPRESSION SCREENING

Depression is a contributing factor to suboptimal health outcomes and is common among adolescents and adults with chronic health conditions such as diabetes. When present, depression in adolescents with T1D is associated with less frequent blood glucose monitoring, higher A1c values, and increased rates of diabetes-related hospitalizations.

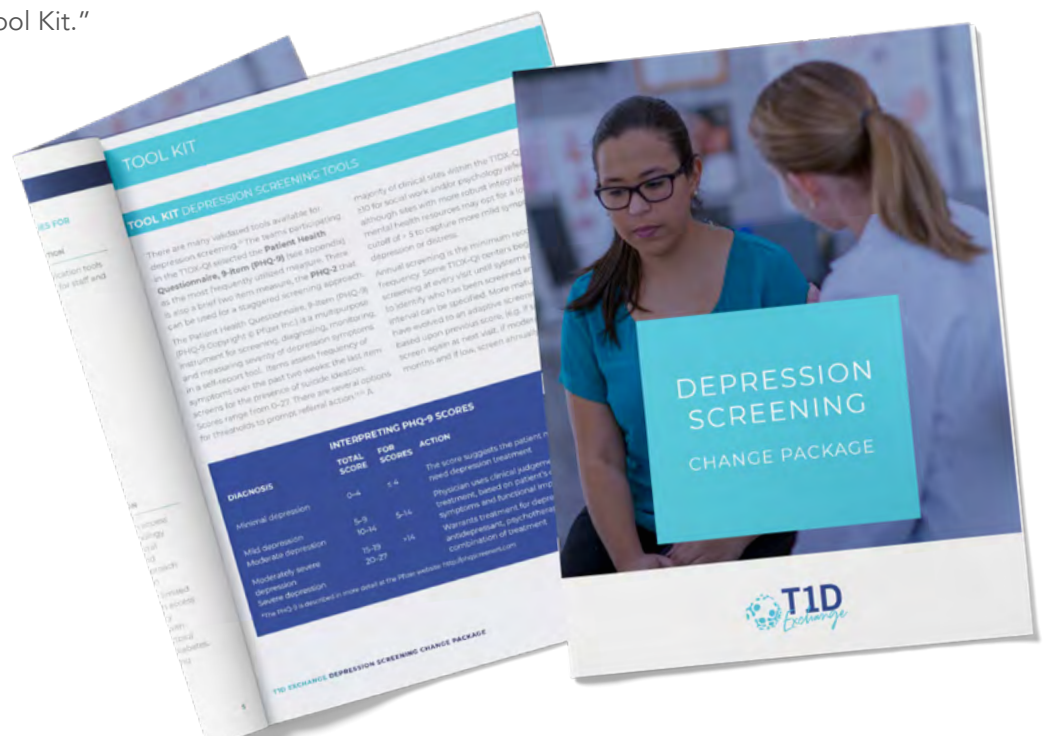
Given the impact of depression on outcomes, patients with diabetes should be screened annually using age-appropriate screening measures and patients with positive screens should receive further evaluation and treatment as necessary.

This change packet offers extensive guidelines for screening, scoring, and intervening in patients struggling with depression, ensuring that fewer patients “slip through the cracks” in the mental health screening process referred to as the “Depression Screening Tool Kit.”

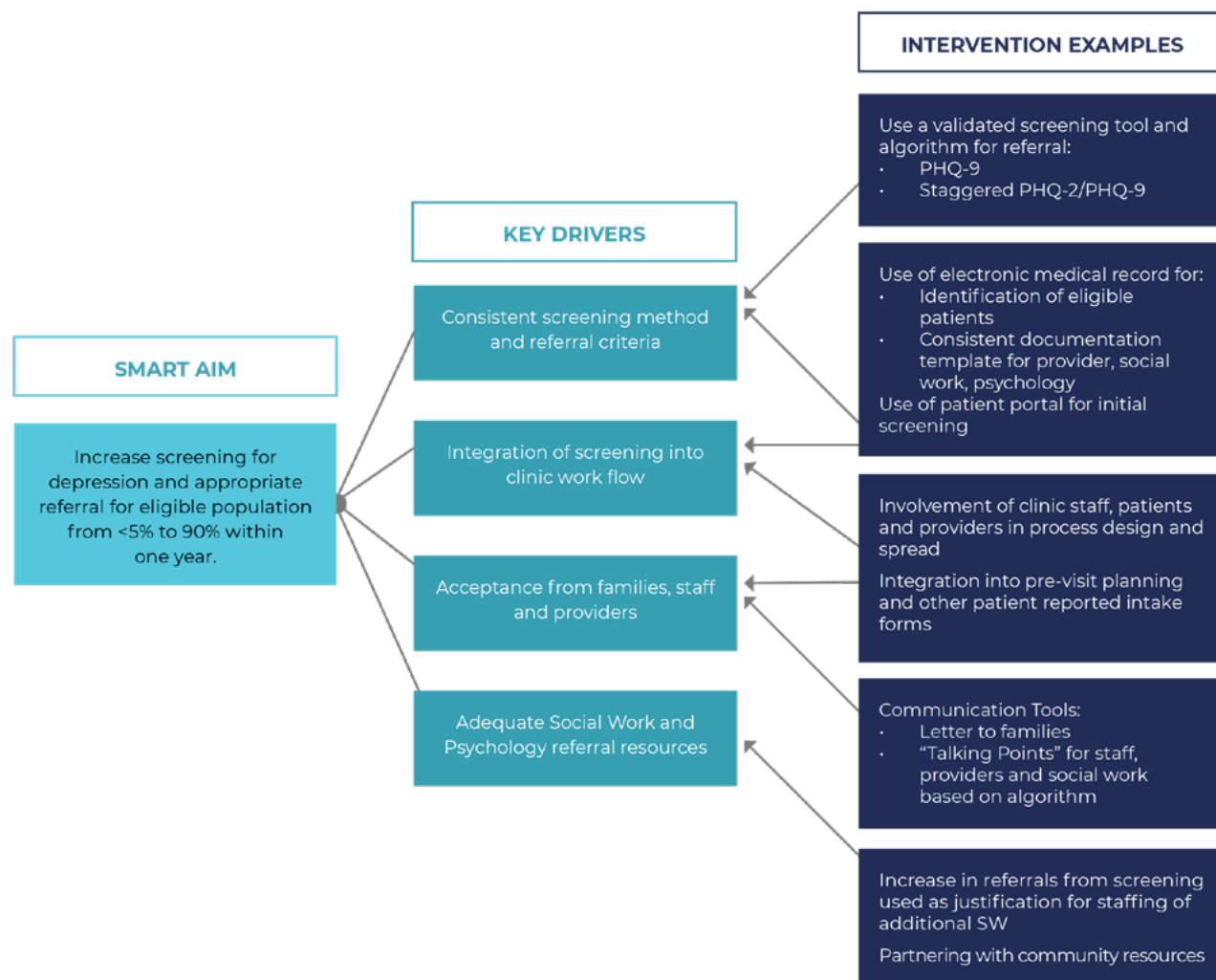
The Depression Screening Tool Kit: Working together, seven clinical centers shared resources and QI methodology to successfully advance depression screening for youth and adults with diabetes. These clinics increased rates of screening from a baseline of 10% to nearly 70% over an 18-month period, representing approximately 700 additional individuals with T1D receiving psychosocial screening per month nationwide. The resources within this change package can equip sites with tools to accelerate the adoption of a reliable depression screening process.

Key Driver Diagram

Systematic depression screening in adolescents and adults with T1D can be reliably implemented with clinically significant results, identifying depression in patients sooner which allows for sooner intervention, support, and treatment.



KEY DRIVER DIAGRAM



A key driver diagram is a theoretical model for improving a process. The left side of the figure includes a SMART (specific, measurable, achievable, realistic, time-bound) aim. The aim should be a precise statement of what the team hopes to achieve as determined by measurable changes that can be accomplished in a given time frame with available resources (people, time, support). The center column lists key drivers that are essential components for the aim to be accomplished.

For depression screening, these include:

1. consistent method for screening with objective referral criteria
2. seamless integration into clinic workflow
3. acceptance of psychosocial screening in diabetes clinic from families, staff, and providers and
4. adequate social work and psychology referral resources to respond to positive screens.

Lastly, the right hand column lists potential interventions, or testable ideas, that relate to each of the drivers.

A young girl with dark hair in two braids, wearing a bright yellow dress over a grey shirt, is smiling and looking towards a woman whose back is to the camera. The woman has long, wavy brown hair and is wearing a white lab coat. They are in a clinical setting with a blurred background.

HIGHLIGHTING NEW CLINICS: MIAMI PEDIATRICS

"We're always asking ourselves, 'what can we do to make our care better and more efficient?'" explained Sanchez. "A lot of times it's easy to figure out what patients need, but how do you do that in the most efficient manner? We look forward to being part of the QIC to help us continue to provide good care for our patients in the most efficient manner."

Janine Sanchez, MD, and Director of Pediatric Diabetes at the University of Miami.



COVID-19 & T1D: RESEARCH, KEY FINDINGS, AND RESOURCES



In March 2020, T1D Exchange recognized that COVID-19 was spreading rapidly throughout the nation.

“During these unprecedented times, there are a plethora of unanswered questions on the impact of COVID-19 on the T1D community. We realized that a population health surveillance study is imperative to better understand potential outcomes and inform intelligent quality improvement initiatives,” said Osagie Ebekozien, MD, MPH, CPHQ, and Vice President of Population Health and Quality Improvement at T1D Exchange.

A protocol was written and submitted to the Institutional Review Board and approved in a record-breaking two hours. We quickly secured the generous support of the industry and research community, including Abbott Diabetes, Dexcom, JDRF, Lilly, Medtronic, Insulet Corporation, and Tandem Diabetes Care.

The T1D & COVID-19 Surveillance Study focused on individuals with T1D who are suspected or confirmed to have contracted COVID-19. This was the first U.S.-based, multi-center study to examine patient characteristics and outcomes among individuals with confirmed or suspected COVID-19.

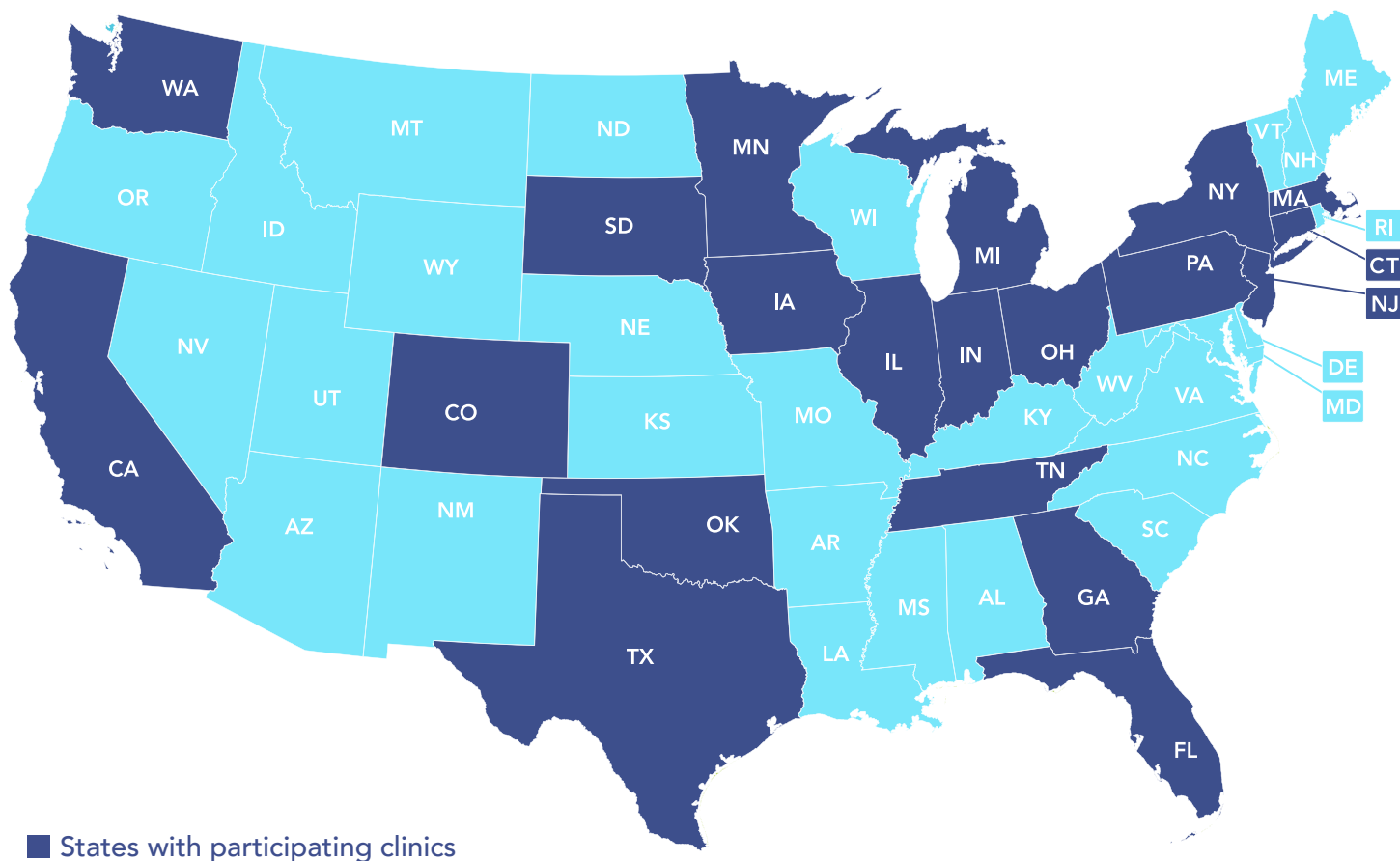
The initial collection of data began in April 2020, with increasing interest each week from new clinics outside of the QIC, quickly growing to more than 65 participating clinics.

T1D Exchange produced a 32-question survey that participating clinics completed regarding any patient with T1D with suspected or diagnosed COVID-19. The survey gathered information on many aspects including the patient’s most recent HbA1c value, presenting symptoms, gender, race, ethnicity, height, weight, BMI, insurance coverage and medications.

“We hosted weekly meetings each Friday, sharing data gathered from the week before and everything we were learning about the impact of COVID-19 on people with T1D from each clinic’s submitted surveys,” explains Nicole Rioles, the QIC’s Director.

The expectation of gathering data for three or four months quickly changed as the pandemic worsened. The data collection effort continues in 2021, with over 800 case submissions from healthcare centers across the country received by the end of 2020.

KEY FINDINGS: WHAT WE'VE LEARNED SO FAR ABOUT COVID-19 & T1D



Initial results from the earliest surveillance research with 33 COVID-19 confirmed positive cases and 31 COVID-19-presumptive cases, had the following key findings:

- The most prevalent presenting symptom was high blood sugar, followed by fever, cough, nausea, and fatigue
- More than 50 percent of cases reported hyperglycemia.
- Nearly one-third of cases experienced DKA and required hospitalization.
- More than 50 percent of cases had no adverse COVID-19 or diabetic outcomes.
- There were two reported deaths among adult patients with other underlying comorbidities.
- People of color with T1D are four times more likely to experience DKA compared to their non-Hispanic White peers.

Key-findings highlighting significant health inequities in the T1D population:

- Non-Hispanic White patients had a lower median A1c at baseline (8.3%) compared to non-Hispanic Black (11.7%) and Hispanic (8.9%) patients.
- Non-Hispanic White patients were more likely to be on CGM and/or insulin pumps and also to be covered by private insurance than non-Hispanic Black or Hispanic patients.
- Non-Hispanic Black and Hispanic patients were significantly more likely to present with DKA following COVID-19 (61% and 24% of cases, respectfully) compared to non-Hispanic White patients (7%).
- When data were adjusted for age, A1c, sex, and insurance type (public or private), the association between DKA and non-Hispanic Black or Hispanic identity became even stronger.
- Non-Hispanic Black and Hispanic patients were also more likely to be hospitalized (68% and 40% of cases, respectfully) than non-Hispanic White patients (19% of cases).

“This is the first major study to examine racial-ethnic inequities for people with type 1 diabetes and COVID-19 that are brought on by structural and systemic racism,” said Ebekozen. “We used a diverse cohort of patients with type 1 diabetes and found there is a significantly increased risk of poor outcomes for Black and Hispanic patients with COVID-19 and diabetes.”

The study’s findings on racial inequities among people with T1D and COVID-19 were published in [The Endocrine Society’s Journal of Clinical Endocrinology & Metabolism](#) and reported on by several media outlets, including [EndocrineNews](#) and [US News](#).

“Our findings of troubling and significant inequities call for urgent and targeted interventions, such as culturally appropriate DKA awareness campaigns, increased CGM coverage for minority patients, and health care provider participation in a Quality Improvement Collaborative”, Ebekozen added.

Ebekozen has presented two actionable items to improve outcomes and mitigate disparities in COVID-19 and T1D:

1. Identify and redirect attention on patients susceptible to these social inequities.
2. Stand up for systemic change in your community, taking data-driven approaches to move policy in the right direction.

Our research on COVID-19 and T1D continues while also driving a significant amount of awareness and interest in the T1D Exchange’s Quality Improvement Collaborative.





COVID-19 & T1D: FIVE PUBLISHED CLINICAL STUDIES



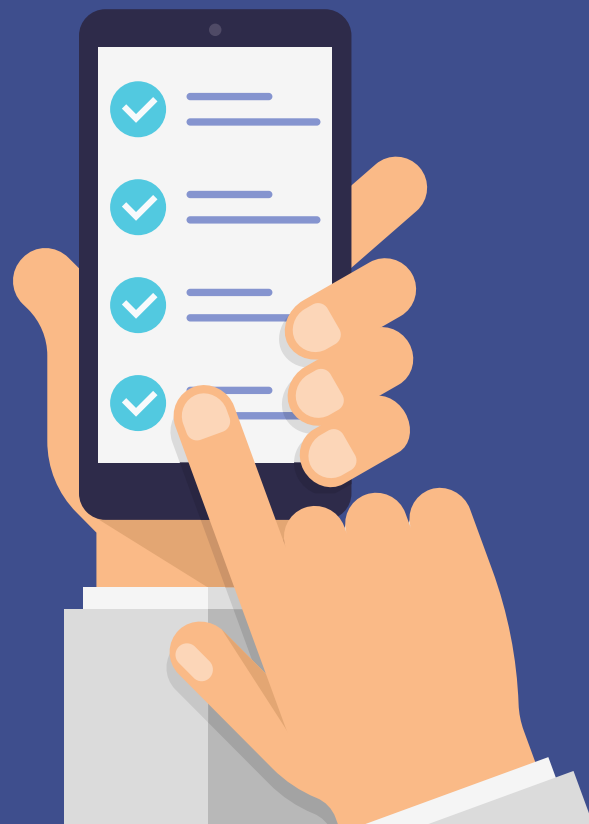
The published research, led by Dr. Ebekozien, was the result of working collaboratively to share results and insights in our monthly “T1D COVID-19 Webinars” for clinicians and peer-review publications.

Thus far, the surveillance study has produced five published manuscripts:

- [“Type 1 Diabetes and COVID19: Preliminary Findings of a Multi-Center US Surveillance Study”](#) examined patient characteristics and adverse outcomes among patients with type 1 diabetes with confirmed cases of COVID-19. Over 600 cases were submitted from clinics across the country.
- [“COVID-19 Hospitalization in Adults with Type 1 Diabetes”](#) analyzed characteristics of adults with type 1 diabetes that were hospitalized with COVID-19. This research led to substantial insights on data surrounding COVID-19 and DKA.
- [“Equitable Post-COVID-19 Care: A Practical Framework to Integrate Health Equity in Diabetes Management”](#) describes how quality improvement (QI) tools and principles can be adapted into a framework for advancing health equity. This 10-ten-step framework can be applied in diabetes care management to achieve improvement, using a hypothetical example of increasing the use of continuous glucose monitors (CGMs) among patients with type 1 diabetes.
- [“Increased DKA at Presentation Among Newly Diagnosed T1D Patients With or Without COVID-19; Data From a Multi-Site Surveillance Registry”](#) identified recurring reports of DKA in people with COVID-19 and diabetes mellitus. Theories include that the virus increases demand for insulin and increases insulin resistance related to cytokine release following COVID-19.
- [“Inequities in Diabetic Ketoacidosis Among Patients with Type 1 Diabetes and COVID-19: Data from 52 US Clinical Centers”](#) uncovered a substantial amount of data indicating that people of color with type 1 diabetes have significantly higher rates of DKA compared to Caucasians. These findings also uncovered core inequities in the diabetes education and care people of color receive.



THE POWER OF THE PATIENT VOICE



In 2020, we watched as the patient voice grew larger and louder. The burden and challenges that come with this chronic illness are both similar and vastly different from person to person.

One commonality that everyone with T1D shares is the fact that this is a condition that never sleeps. Every aspect of life is touched by T1D. Every hour of every day, a person with T1D is working to not only achieve and maintain healthy blood sugar levels but also to simply stay alive.

Two publications resulting from studies with our patient Registry highlighted a few of the significant impacts T1D has on day-to-day life:

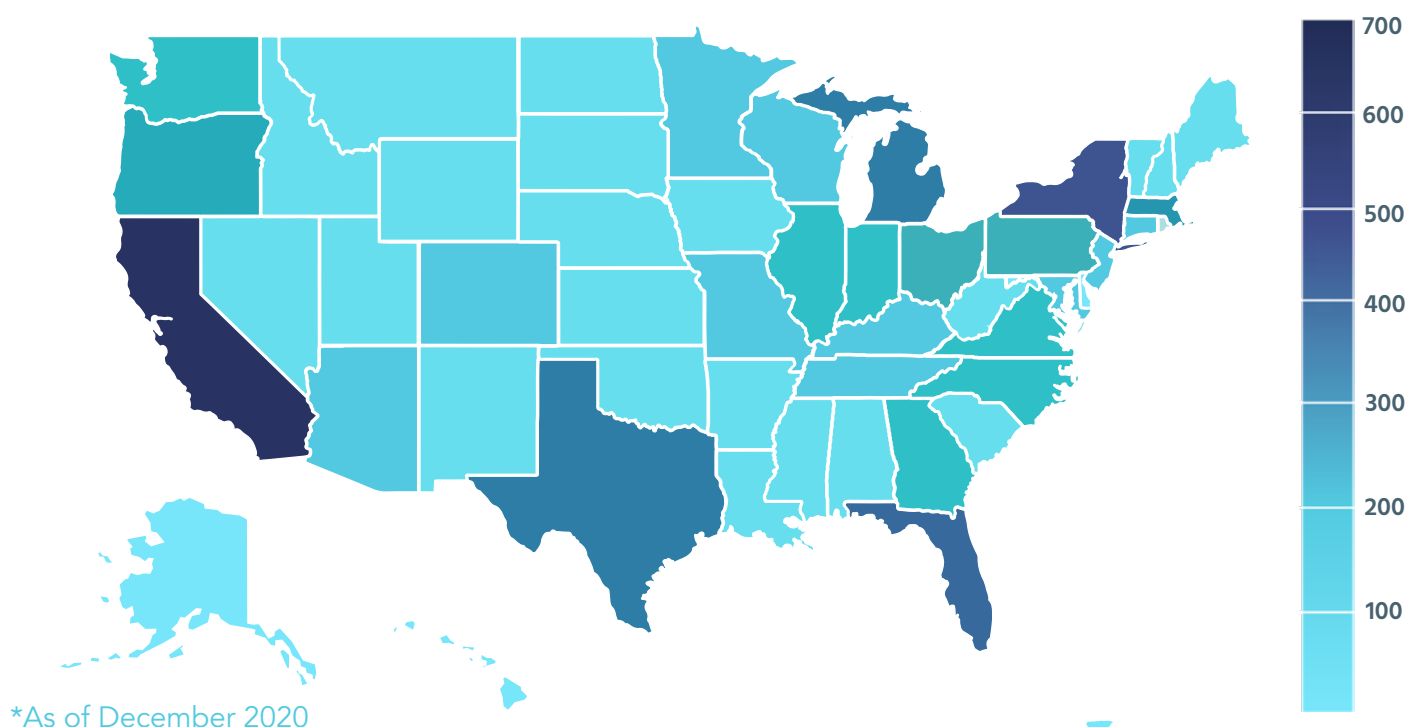
- **“I’ve Had an Alarm Set for 3 a.m. for Decades”** takes a deep dive into just how many people with T1D and their caregivers endure interrupted sleep on a nearly daily basis due to hypoglycemia or to check their blood sugars in case of hypo- or hyperglycemia.
- **“‘I Live in Constant Fear,’ the Daily Impact of Type 1 Diabetes”** looks at how many areas of life are truly impacted on a day-to-day basis because of this disease. Participants highlighted affected areas of life including missed opportunities of all kinds, family life, work and school disruptions, time management, and limitations.

Over the years, the T1D patient voice has also led to changes in the language used to describe aspects of a patient’s health, progress in lowering the price of insulin for people without health insurance, and advancements in device technology.

Striving to improve the treatment and outcomes of people living with T1D cannot happen without reaching out and listening to what they have to say. T1D Exchange is proud to see the rapid growth of our community as we continue to provide opportunities for their voices to be heard.

THE T1D EXCHANGE PATIENT REGISTRY EXCEEDS 11,000 PARTICIPANTS

UNITED STATES HEATMAP OF REGISTRY PARTICIPANTS



*As of December 2020

"Longitudinal analysis is critical to drive meaningful type 1 diabetes research. This project is building a significant dataset to better understand disease management, health, and outcomes over time," said Wendy Wolf, PhD, Vice President of the T1D Exchange Registry. "T1D Exchange believes in giving everyone with type 1 diabetes a voice and the Registry enables everyone in the United States the opportunity to accelerate type 1 diabetes research. I want to personally thank everyone who has contributed to the registry and our other research projects."

Our Registry participants have been unequivocally engaged and loyal despite the many other challenges they've likely faced in their day-to-day lives this past year.

In November of 2020 during National Diabetes Awareness month, we announced reaching an exciting milestone of over 10,000 registered participants and by the end of 2020 exceeded 11,000.

"We are proud to have reached this milestone during a month when we turned the national focus to diabetes, and in particular to T1D which impacts approximately 1.6 million people in the U.S.," said David Walton, Chief Executive Officer at T1D Exchange.

The T1D Exchange Registry is an online longitudinal database of people living with type 1 diabetes that captures data on diabetes management, disease progression, and clinical outcomes from a broad and diverse mix of people living with the disease across the United States. This growing registry allows us to gather data through opt-in research studies that can explore issues surrounding living with T1D, such as:

- How the disease progresses over time.
- Collect insights that help accelerate new treatments and technology for T1D.
- Improve the clinical care provided to people with T1D.
- Inform and advocate decisions around policy and insurance.

The Registry gives everyone with T1D the opportunity to contribute to diabetes research and make a difference in the care and resources provided to those living with the disease. Additionally, the Registry is a powerful resource for conducting our studies and for connecting participants with other research.



30 Days 30 Facts

About the Exchange Registry

6% of participants are 13-17 years old
35% of participants are 18-35 years old
31% of participants are 36-55 years old
20% of participants are over 56 years old



DID YOU KNOW?

Registry:
are diagnosed at 12 years old or younger
are diagnosed at age 13-17
are diagnosed at age 18-35
are diagnosed at age 36-55
are diagnosed at 56 years old or older

DID YOU KNOW?

In the Registry:

19.3% of people with T1D were diagnosed last 5 years
13.6% of people with T1D were diagnosed 5-10 years ago
12.8% of people with T1D were diagnosed 11-15 years ago
54.3% of people with T1D were diagnosed more than 15 years ago

12:34

100%

T1DEXCHANGE Posts

t1dexchange

DID YOU KNOW?

In addition to type 1 diabetes:

9.5% of people with T1D also have **Thyroid Disease** (Hashimoto's Disease or Graves' Disease)

5% of people with T1D also have **Celiac Disease**

2.4% of people with T1D also have **Rheumatoid Arthritis**



84 likes

t1dexchange Fact 12 ✓

In addition to type 1 diabetes:

• 9.5% of people with T1D also have Thyroid... more



DID YOU KNOW?

most common comorbidities in the T1D Exchange Registry:

Disease
Cardiovascular Disease
Infectious Diseases
Mental Health Issues
Depression



DID YOU KNOW?

21 people in the T1D Exchange Registry have had an islet cell transplant



DID YOU KNOW?

people with T1D in The Registry use inhalable insulin



DID YOU KNOW?

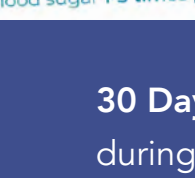
In The Registry:

27.6% of participants use inhalable insulin
12.8% of participants use inhalable insulin
52 participants are Loop



DID YOU KNOW?

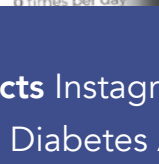
most CGM users check their blood sugar 1-3 times per day.



DID YOU KNOW?

Of Dexcom G6 users:

43.5% check their blood sugar 0 times per day



DID YOU KNOW?

person in the Registry was diagnosed in the last 5 years



DID YOU KNOW?

The Top 3 medical professionals seen for their T1D care:

1. Endocrinologist/Diabetologist
2. Primary Care Physician
3. Certified Diabetes Educator



DID YOU KNOW?

in the T1D Exchange Registry use ultra-fast insulins.



DID YOU KNOW?

3.2% of people in The Registry use over-the-counter insulins

5.7% of people in The Registry use both over-the-counter and prescription insulins



DID YOU KNOW?

Common medications in addition to insulin in the Registry:

Metformin, Glucophage, Fortamet (e.g., Victoza, Saxenda, Byetta) (e.g., Invokana, Farxiga, Jardiance)



DID YOU KNOW?

61% of people with T1D in The Registry use a CGM and insulin pump



DID YOU KNOW?

people with T1D in the Registry received a positive COVID-19 (swab) test.



DID YOU KNOW?

11 people with T1D in The Registry received a coronavirus antibody (blood) test.



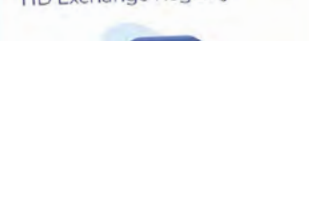
DID YOU KNOW?

There are 28-30 questions in the T1D Exchange Registry Core Questionnaire



DID YOU KNOW?

There is participation from every state and territory in the T1D Exchange Registry



DID YOU KNOW?

15.8% of participants in the T1D Exchange Registry have an immediate family member with type 1 diabetes



30 Days, 30 Facts Instagram Campaign run during National Diabetes Awareness Month 2020 (November)

WITH OVER 11,000 PARTICIPANTS, WE GATHERED MANY NEW AND VALUABLE VOICES IN THE REGISTRY.

Here are a few interesting facts we've learned about our participants:

- **Fact:** The oldest person with T1D in the Registry is 89 years old. The youngest is one year old.
- **Fact:** Half of participants were diagnosed by 12 years old. Surprisingly, the next majority was diagnosed during early adulthood, between the ages of 18 and 35 years old.
 - 50% were diagnosed at 12 years old or younger
 - 15% were diagnosed at age 13-17
 - 25% were diagnosed at age 18-35
 - 8% were diagnosed at age 36-55
 - 2% were diagnosed at 56 years old or older
- **Fact:** More than 360 people report living with T1D for 50 years or longer
- **Fact:** 16 people have had a pancreas transplant and 21 people have had an islet cell transplant.
- **Fact:** 16% have a family member with T1D.
- **Fact:** There is at least one Registry participant from every state and territory in the United States.
- **Fact:** Many people with type 1 diabetes live with another autoimmune disease.
 - 10% also have thyroid disease (Hashimoto's or Graves' disease).
 - 5% have Celiac disease.
 - 2% have rheumatoid arthritis.

THE IMPACT OF TELEMEDICINE

While “telemedicine” certainly existed before the COVID-19 pandemic, it has experienced explosive growth in usage. It is important to determine where telemedicine is effective and where it’s falling short in serving the T1D population. To better understand this, we partnered our resources from the T1D Exchange Registry and our online community with Stephanie Crossen, MD, MPH, a pediatric endocrinologist at the UC Davis Children’s Hospital in Sacramento, California.

“During COVID-19, we know that the use of telemedicine has dramatically increased across the country, but we don’t know yet how well it works in terms of patients being able to access that care and how effective it is,” said Crossen.

Hoping for at least 500 participants, Crossen was thrilled with both the engagement and the ease of surveying people with type 1 diabetes across the country.

“We had over 2,000 participants!” Crossen shared. “I was hoping for at least 500, with a bigger goal of 1,000. I could have never surveyed 2,000 people with type 1 diabetes without a partnership with the T1D Exchange. It was essential and such an easy process.”

Crossen was able to gain valuable insights into the barriers, benefits, and challenges of using telemedicine with the T1D population. T1D Exchange was honored to be part of this academic research, creating another opportunity to hear the patient voice.

“When people with type 1 diabetes participate in research,” said Crossen, “they’re ensuring that the next innovation in care is going to be important to them and make the biggest difference in living with diabetes.”





PARTNERSHIPS & COLLABORATIONS ARE KEY TO THE T1D EXCHANGE MISSION

PARTNERSHIPS IN THE DIABETES COMMUNITY

Thanks to our clinic partners, our growing patient Registry, and our online community, the patient voices within the T1D Exchange have become an increasingly valuable resource for the diabetes industry.

In 2020, we partnered with a variety of companies and organizations working to improve the lives of people with T1D through advancements in technology, and life-saving medications.

Some of our research with partners includes:

Diabetes Technology:

- Providing real-world evidence on the use of CGM technology and outcomes in the QIC to support research focused on different CGM systems in today's market.
- Patients' thoughts and perspectives on different insulin pump infusion technologies.
- Patients' perspectives on the future of wearable diabetes technology and what existing and future aspects of this technology are most important.

Hypoglycemia:

- Identify and understand patients' fears of hypoglycemia to improve the overall support, care, treatment, and prevention of mild-to-severe hypoglycemia.
- Caregiver perceptions of traditional emergency glucagon kits for severe hypoglycemia.
- Patients' frequency of experiencing mild-to-severe hypoglycemia.

We continue to work closely with partners interested in the value of the patient voice, our robust patient Registry and community, and partnerships with endocrinology clinics.





T1D EXCHANGE FOCUSES ON THE PATIENT VOICE DURING NATIONAL DIABETES AWARENESS MONTH IN 2020

In the midst of a global pandemic, the diabetes community united to celebrate an unforgettable National Diabetes Awareness Month (NDAM) throughout November. Countless virtual events and online campaigns promoting awareness, fundraising, and research made for an accessible NDAM marked by resilience and adaptability.

T1D EXCHANGE: REGISTRY FACTS, PERSONAL STORIES, AND NEW EXCITING PARTNERSHIP

T1D Exchange hosted two major online campaigns to commemorate NDAM. With 30 Facts in 30 Days, we shared facts and insights about the T1D Exchange Registry, our comprehensive research study of people with type 1 diabetes in the United States.

These facts called attention to the real impact T1D has on our Registry members, which include people living with type 1 diabetes and parents/guardians of those living with T1D. Looking to learn more? Check out our [Registry info page](#), or revisit our 30 Facts in 30 Days posts anytime on [Instagram](#) or [Facebook](#).

Our second campaign, “Why I Joined”, encouraged video submissions from inspiring, diverse voices in our community. Registry members shared short, personal videos about why they joined the Registry and what diabetes research means to them. Check out one of our favorites from [Christel Oerum of Diabetes Strong](#).

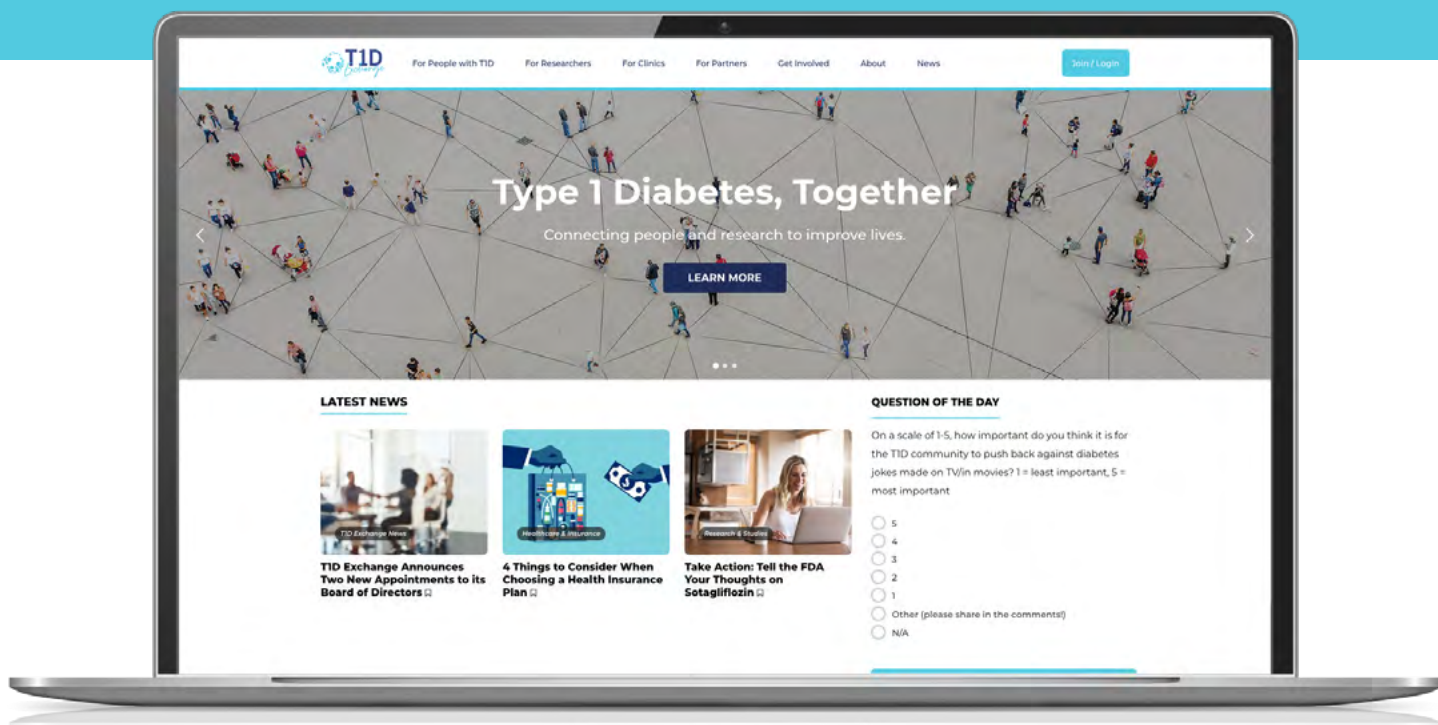


By highlighting a variety of experiences and perspectives, “Why I Joined” helped cast a much-needed spotlight on the value of participating in research and the importance of having diverse participants. We continue this effort having launched in February 2021 a “Voices of Diversity” project.

On November 23rd, T1D Exchange announced a new fundraising partnership with [Express Feedback for Good](#). This campaign allowed our community to contribute to diabetes research by sharing their opinions about products, services, and brand experiences. Each shared opinion had a value of \$2 and the campaign raised over \$16,000 for T1D Exchange.



RE-LAUNCHING OUR ONLINE COMMUNITY



The T1D Exchange online community received a major makeover this past year. The “Glu” website was decommissioned, and its members moved to the completely redesigned T1D Exchange website, which launched in September 2020. Merging both of our old websites allowed us to rethink both the front-end and back-end from the ground up. This will allow for greater flexibility in the future as we look to create new ways to engage with our online community.

This move also allowed us to create a new system for our Questions of the Day (QOTD). On average, the QOTD receives about 300 responses a day: our most popular question received more than 2,400 responses. This feature gives a greater insight to our organization, our partners and our online community.

Moving forward we will be adding more valuable resources from our Quality Improvement Collaborative, integrating this new website with our Registry platform, connecting our community to more research opportunities with partners and academic institutions, and more.

FIVE MOST POPULAR QUESTIONS WE ASKED OUR COMMUNITY IN 2020

QOTD What do you remember about your first year with diabetes?

Most popular responses

- Adapting to a new lifestyle (10%)
- No CGMs (9%)
- No pumps (8%)

QOTD: What symptoms did you have that led to your T1D diagnosis?

Most popular responses:

- Increased thirst (19%)
- Frequent urination (18%)
- Unintended weight-loss (16%)

QOTD: Where do you keep supplies for low blood sugars/hypoglycemia?

Most popular responses:

- At home (16%)
- By the bed (15%)
- In the purse/bag/suitcase (15%)

QOTD: How many appointments did you have in 2020 with your main diabetes healthcare provider?

Most popular responses:

- 4 (30%)
- 3 (27%)
- 2 (23%)

QOTD: What is your connection to diabetes?

Most popular responses:

- I have T1D (75%)
- I have a loved one with T1D (11%)
- I am a supporter of the diabetes community (5%)

POPULAR CONTENT IN THE COMMUNITY

THE TWO MOST-READ ARTICLES IN 2020



THE T1D EXCHANGE GUIDE TO DEALING WITH DIABETES AND CORONAVIRUS (COVID-19)

Throughout the year 2020, people with T1D were faced with the possibility of contracting COVID-19. Targeted to this high-risk population, this in-depth guide offered guidance on how to reduce the risk of contracting COVID-19, and what to expect if you do show symptoms and test positive for the virus.

[> read article](#)

T1D EXCHANGE STUDY: SLEEP LOSS REPORTED AS A MOST FREQUENT DAILY HURDLE IN LIFE WITH TYPE 1 DIABETES

Living with T1D is a 24/7 responsibility, and this was clearly demonstrated in the results of our study. With the benefits of diabetes technology come interrupted sleep due to CGM alarms, low and high blood sugars, and sleep loss long after treating these issues.

[> read article](#)



VALUED PARTNERSHIPS & LOOKING AHEAD FOR T1D EXCHANGE IN 2021

"We could not have asked for a more productive and meaningful year of work amidst a global pandemic," said Rebecca Parkes, Chief Operating Officer. "Our most ambitious program, the QIC, is already proving its potential and impact on the treatment of people with T1D, and we were able to put our strengths and resources to use in the most practical way to support the T1D community during COVID-19."

As we dive into 2021 with so much already underway -- and many new partnerships -- we see a promising future for T1D Exchange and its ability to truly improve and support the dedicated clinicians around the country working to help people with T1D manage this 24/7 disease.

With so much still to learn about improving care and outcomes for this population, we are confident that our energy and efforts are focused in the right direction. To see such positive results from the groundwork we've laid over the past few years only fuels our dedication, enthusiasm, and anticipation to see what more we can achieve.

"These programs are the beginning of something that holds a tremendous number of possibilities for changing the lives of people with T1D," said David Walton, Chief Executive Officer. "Our focus right now is to continue with the same integrity and drive to make a difference and on building a more robust data asset with a focus on device data integration and sharing meaningful insights."

We need to thank everyone who plays such an important role in our work, including members of the QIC at every level who are on the front lines of T1D, the academic institutions who are vital to leveraging our data to its fullest extent, and leading the way in innovative care that puts people with T1D first, industry partners with whom we work closely to effect meaningful, tactical change, and of course the T1D community itself, whose enthusiasm, participation, and knowledge is visible every day on the T1D Exchange Online Community website.

We want to thank all of our T1D Exchange employees for their hard work and dedication. Some of us are directly impacted by T1D, while others have made a conscious choice to apply their skills and experience to helping the T1D cause. We are extremely appreciative of the diligence and collective impact they have produced in a very challenging year.

Finally, we need to thank all the partners, members, and sponsors who make our mission possible and give us support in every aspect of its pursuit.

Thank you,
T1D Exchange



First, we are honored to acknowledge the generous and vital support of the Leona M. and Harry B. Helmsley Charitable Trust. The Trust and its board have been steadfast and critical backers and partners throughout the last 10 years, helping us build the capacity to do this vital work.

THANK YOU TO OUR PARTNERS, MEMBERS AND SPONSORS

- | | |
|-------------------------------------|--|
| Abbott Diabetes Care Inc. | Insulet Corporation |
| American Diabetes Association | JDRF |
| Beyond Type 1 | Juicebox Podcast |
| Children with Diabetes | LifeScan |
| College Diabetes Network | Medtronic |
| Dexcom, Inc. | National Diabetes Volunteer Leadership Council |
| Diabetes Emergency Relief Coalition | Vertex Pharmaceuticals |
| Diatech Diabetes | Xeris Pharmaceuticals |
| DreaMed Diabetes | Zealand Pharma |
| Eli Lilly and Company | |

Thank you to everyone who has participated in the T1D Exchange Online Community and in the T1D Exchange Registry. Without your voice, we would not be able to achieve our mission.

Thank you to our academic study promotion partners, including University of California, Davis, Oregon Health & Science University, University of Tennessee, Knoxville, Joslin Clinic, and Jaeb Center for Health Research.

Thank you to members of our Quality Improvement Collaborative Patient/Parent Advisory Board and Data Governance Committee for their insights and dedication to our mission.

NOTES



11 Avenue de Lafayette
Boston, MA 02111
Phone: 617-892-6100

