Individual QI projects from single institutions

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The Type 1 Diabetes Composite Score: An Innovative Metric for Measuring Patient Care Outcomes Beyond Hemoglobin A_{1c}

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Abstract

Introduction: Patient outcomes resulting from optimal type 1 diabetes (T1D) care have historically focused on driving a single metric, hemoglobin A_{1c}. Our objectives were to design, build, and launch an aggregate clinical indicator that comprehensively reflects patient management status beyond hemoglobin A_{1c} alone. This project aimed to show proof of principle that an aggregate score comprised of T1D outcome metrics could be built to track quality performance. **Methods:** We established an electronic medical record-based diabetes registry and utilized its population health modules to design and build this diabetes care metric. Elements representing optimal diabetes management, as defined by current guidelines and expert opinion, were identified. Nine elements fall into categories of management tools, care assessments, and complications risk. The Type 1 Diabetes Composite Score (T1DCS) aggregates these outcome measures to reflect the overall diabetes care status for each patient. Higher scores suggest better management and overall improved patient health. **Results:** We launched this metric build in November 2018 and applied the scoring to our T1D population (≈1,900 patients). The T1DCS quickly provides a summary of current diabetes management status. T1DCS viewed over the registry cohort demonstrates a normal distribution, and scores improved from March to September 2019, reflecting better care and outcomes, and illustrating the potential to track program effectiveness. **Conclusions:** The T1DCS is a useful metric to evaluate the clinical status of T1D patients, assess the capability of a clinical program to achieve optimal diabetes outcomes, identify patient diversity opportunities, and document outcome improvement as a novel comprehensive quality measure. *(Pediatr Qual Saf 2020;5:e354; doi: 10.1097/pq9.0000000000000354; Published online September 25, 2020.)*

INTRODUCTION

Type 1 diabetes mellitus (T1D) is a chronic metabolic condition affecting millions of children and adults worldwide. T1D incidence and prevalence are increasing, with over 60,000 new cases annually in the United States alone.[1,2] Daily comprehensive care and periodic surveillance can minimize the risk of long-term multisystem organ complications associated with poor metabolic control, including retinopathy, nephropathy, neuropathy, cardiovascular disease, and acute complications like diabetic ketoacidosis and severe hypoglycemia. Direct medical costs related to T1D exceed $16 billion and are rising.[3] Despite numerous advances in insulin delivery and glucose monitoring, achieving adequate glycemic and metabolic control remains challenging, particularly in youth, as evidenced by worsening hemoglobin A_{1c} (HbA1c) trends.[4] Adherence to the recommended intense insulin regimens remains a significant barrier,[4,5] and a recent analysis concluded that only a minority of youth with T1D achieve American Diabetes Association (ADA) and International Society for Pediatric and Adolescent Diabetes (ISPAD) goals for HbA1c.[4]

Although HbA1c is universally recognized as the reference marker for glycemic control and a risk factor for complications,[6] this metric alone does not truly reflect overall management. For example, HbA1c reflects neither glycemic variability nor hypoglycemia frequency or severity, both known to affect acute and chronic complications.[6,7]

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In addition to quarterly HbA1c assessments, current ADA and ISPAD guidelines recommend several surveillance and risk reduction measures, including regular quarterly blood pressure monitoring, annual urine screening for microalbuminuria, and periodic lipid profile analysis.[8,9] Due to the multicomponent nature of such monitoring, our objective was to create a multifaceted and nuanced metric to reflect diabetes care outcomes beyond HbA1c.

The ADA recommends that "efforts to assess the quality of diabetes care and create quality improvement (QI) strategies should incorporate reliable data metrics, to promote improved processes of care and health outcomes."[10] In creating an aggregate metric to evaluate care quality and outcomes, we aimed to incorporate a population health approach to T1D by using current clinical practice recommendations to optimize diabetes care and achieve treatment goals. The Type 1 Diabetes Composite Score (T1DCS) concept began with an interest in developing a QI metric that complements the use of HbA1c in diabetes care management but also better reflects overall achievement of clinical goals as defined by current guidelines and best practices. This metric can also grade clinical diabetes program performance on both patient and population levels. Clinical information systems and a population health data management approach, we first built a T1D patient registry to help us develop and deliver this new metric.

QI approaches using metrics such as clinical care scores have successfully improved clinical performance and decreased errors in pediatric cancer, chronic kidney disease, pulmonology, and otolaryngology.[11–13] More recently, a similar approach has been reported in pediatric diabetes using process measures and shown to improve care delivery.[14] This QI initiative leveraged our electronic medical record (EMR) with a diabetes patient registry to design, build, and launch a T1DCS that would be a robust yet straightforward aggregate metric built using outcome measures. We hypothesize that this aggregate score could serve as a more global diabetes clinical program metric. Our primary objective was to create an easily scored metric per nationally accepted outcome goals that is trackable over time yet available in real time for use in the clinic. This first-of-its-kind "metric combining metrics" utilizes outcome measures to assess diabetes clinic performance.

METHODS

Setting

This QI project was performed at Nationwide Children's Hospital, a large free-standing academic pediatric medical center, serving communities in Ohio and surrounding Midwest states. Endocrinology at Nationwide Children's Hospital regularly follows approximately 1,900 children and adolescents with T1D and manages >300 new-onset T1D patients yearly.

Interventions

A robust electronic health information infrastructure allowed us to design and launch a diabetes patient registry utilizing population health modules within the EMR. A multidisciplinary "Diabetes QI" team, including the medical team (physicians, advanced practitioners, diabetes nurse educators, and social workers), clinical informaticists, data analysts, and QI specialists, created the T1D Health Registry in stages. After initial design work to assemble the registry conceptual framework, we identified and defined the target patient population. The Clinical Informatics team surveyed medical providers to identify key clinical performance indicators. They developed and built the corresponding metrics, including optimizing the processes for incoming, storing, and retrieving data within the EMR. The Clinical Informatics team, in conjunction with the providers, then validated each metric over several iterative cycles. Final planning and execution of "Go-live" included optimizing the user experience, as well as training and implementation. Additional refinements postrelease helped optimize the registry, data collection, and display. Finally, the QI support team facilitated downstream analysis. The T1D Health Registry went live in the summer of 2017.

Composite score development began by identifying clinical elements associated with the best outcomes in T1D care. The multidisciplinary team assembled and proposed key drivers. We identified 9 critical elements reflecting optimal diabetes management that would minimize risk for future complications and other adverse outcomes, such as severe hypoglycemia and diabetic ketoacidosis. These individual elements and their relative weighted scoring were determined and refined by a combination of consensus expert opinion and national and international guidelines per ADA and ISPAD. These elements (Table 1) fall under the domains of management tools (HbA1c, Continuous Glucose Monitoring [CGM] use), diabetes care assessment (diabetes clinic visit attendance, acute care visits [emergency department or inpatient hospitalization]), and complications risk (low-density lipoprotein level, urine microalbumin ratio, blood pressure, episodes of severe hypoglycemia, complication diagnosis code in the medical record). Each element contributes to a positive score based on an optimal goal, and the aggregate sum of the element scores gives a total score. The 9 elements lead to a total possible composite score of 18 based on the scoring rubric (Fig. 1). A higher score would be associated with better compliance with guideline targets and better clinical outcomes. Based on modeling and rapid improvement cycles, score ranges were used to define categories denoting low (15–18 points), moderate (10–14 points), or high (0–9 points) risk of adverse outcomes and color coded for easy viewing within the EMR.

The score was built based on EMR functionality as part of the population health module. Population health modules encompass functionality within the EMR that allows population-level analytics, to summarize and report

Table 1. The Type 1 Diabetes Composite Score

	Definition	Optimal Scoring/Goal
Management tools		
HbA1c	Most recent HbA1c	ADA goal of 7.5% or below*
Continuous Glucose Monitoring	Recent CGM use	Active regular CGM use
Diabetes care assessment		
Diabetes clinic visits	No. clinic visits attended in previous rolling 12 months	At least 4 visits per year
Acute care visits	No. emergency department visits or inpatient admissions in previous rolling 12 months	No ED/IP visits required
Complications risk		
Lipids: LDL	LDL value in most recent lipid profile (up to 5 years look-back)	LDL ≤ 100 mg/dL
Urine microalbumin ratio	Urine microalbumin ratio value in most recent urine screening (up to 12 months look-back)	Negative microalbuminuria (Urine microalbumin <0.030 mg/mg Cr)
Hypertension screening: blood pressure	Most recent blood pressure measurement	BP results <95th percentile for age, sex, and height
Severe hypoglycemia	Episodes of severe hypoglycemia (as defined by seizures, loss of consciousness, or requiring assistance with treatment) since the previous clinic visit	No episodes of severe hypoglycemia
Overt complication diagnosis	ICD-10 visit diagnosis-related to diabetes complications of retinopathy, nephropathy, neuropathy	No complication-related diagnoses

*HbA1c <58 mmol/mol.
BP, blood pressure; Cr, creatinine; ED, emergency department; ICD-10, International Classification of Diseases, 10th revision; IP, in-patient; LDL, low-density lipoprotein.

population health information within a patient registry database. This approach allows healthcare systems to more efficiently monitor and coordinate health care delivery, quality, and cost and, specifically, make comparisons about demographics, such as age, gender, geography, and/or reimbursement/insurance. The registry helped compile the relevant data across clinic encounters and used the laboratory results database to make the appropriate comparisons and analyses. We then built the scoring mechanism into the EMR and deployed the T1DCS in our clinics via interfacing tools such as a health registry dashboard ("Diabetes Dashboard") and specialized clinic schedule views to display the pertinent data. EMR informatics specialists further optimized the interface to display the score in dashboards and clinic schedule views for clinic previsit planning (PVP) and clinic use in real time.

Ethical Considerations

This work was identified as QI and did not involve human subjects research; thus, it was exempt from Institutional Review Board review and approval.

RESULTS

We successfully launched this metric build in the fall of 2018 and applied the scoring analysis to our large T1D population. The T1DCS reflects the relative value of each clinical element when evaluating each patient. The score quickly provides the patient and provider with a summary of the current diabetes management status in the clinical setting (Fig. 2). As the score also displays any shortcomings in complying with recommended guidelines per ADA and ISPAD and attaining their goal outcomes, targeted education and intervention plans can be appropriately devised through PVP and in real time. The scoring platform's intended use was as an "in-clinic dashboard" in addition to PVP functionalities with the clinic/schedule view (Fig. 3). Also, single patient snapshot views were built for use during the clinic visit to show the strengths of current care and any opportunity for improvement, and it updates in real time ("Hover bubble," Fig. 3).

The registry cohort (n = 1,880 per our initial reporting in March 2019) has a mean age of 14.8 years (range: 2.0–34.6), is 54.5% male, and self-identifies as 77.1% White, 14.2% Black/African American, 4.6% biracial/multiracial, 2.2% Latino/Hispanic, and 1.3% Asian. Of note, 4% (n = 66) of our population indicated Somali ethnicity, reflecting our sizeable Somali immigrant population in central Ohio. T1DCSs ranged from 3 to 18 points, with a mean and median score of 11.9 and 12, respectively, out of 18 possible points.

Individual scores can be viewed over the entire T1D population to demonstrate trends in score data distribution and population health information. Following the launch in November 2018 and a 4-month registry enrollment period, we evaluated the scoring in our cohort. The T1DCS applied over the registry cohort population demonstrates a normal distribution (Fig. 4A). We observed a right shift in scores on a population level over 6 months (March to September 2019), consistent with clinical care improvement and progress in QI efforts (Fig. 4B).

Following this initial proof-of-principle phase, we continued the project study period. We have applied this metric in our institution to improve our care delivery system via enhanced decision support and customized PVP. This approach has also helped track progress in our QI efforts, such as CGM adoption, annual laboratory screening, and multidisciplinary clinic support.

DISCUSSION

Numerous metrics are typically monitored and tracked to help evaluate glycemic control and risk for metabolic complications in patients with T1D. We designed and built

Management Tools

HbA1c	**0** >12 % [>108]	**1** 10.6 – 12.0 % [92 – 108]	within 3% **2** 9.6 – 10.5 % [81 – 91]	within 2% **3** 8.6 – 9.5 % [70 – 80]	within 1% **4** 7.6 – 8.5 % [60 – 69]	GOAL **5** ≤ 7.5 % [≤ 58 mmol/L]
CGM Use	**0** none	**1** Intermittent	**2** Regular use			

Care Assessment

DM Clinic Visits	**0** 0-1/ year	**1** 2/ year	**2** 3/ year	GOAL **3** ≥ 4/ year
Acute Care Visits	**0** ≥1/ year	**1** none		

Complications Risk

Lipids: LDL	abnormal **0** >130	**1** 100-130	GOAL **2** <100 mg/dL
Urine microalbumin	abnormal **0** > 0.030	GOAL **1** ≤ 0.030	
HTN: High BP	abnormal **0** >95th %ile	GOAL **1** normal	
Severe Hypo	**0** ≥1/ year	GOAL **1** none	
Overt Complications	**0** ≥1 Dx		**2** none

Fig. 1. The T1DCS Rubric. %ile indicates percentile; BP, blood pressure; DM, diabetes mellitus; Dx, diagnosis; HTN, hypertension; Hypo, hypoglycemia; LDL, low-density lipoprotein.

a multicomponent score to more globally reflect an individual's diabetes management status beyond the HbA1c metric: the T1DCS. This novel metric helps evaluate the clinical status of our patients with T1D in complying with nationally and internationally accepted guidelines for care. Here, we aimed to provide proof of principle that an aggregate score comprised T1D outcome metrics could be built leveraging the EMR and diabetes patient registry systems to track QI project progress longitudinally.

The compilation of individual T1DCS scores across our registry cohort allows us to view our T1D population at a glance and track them over time. The initial

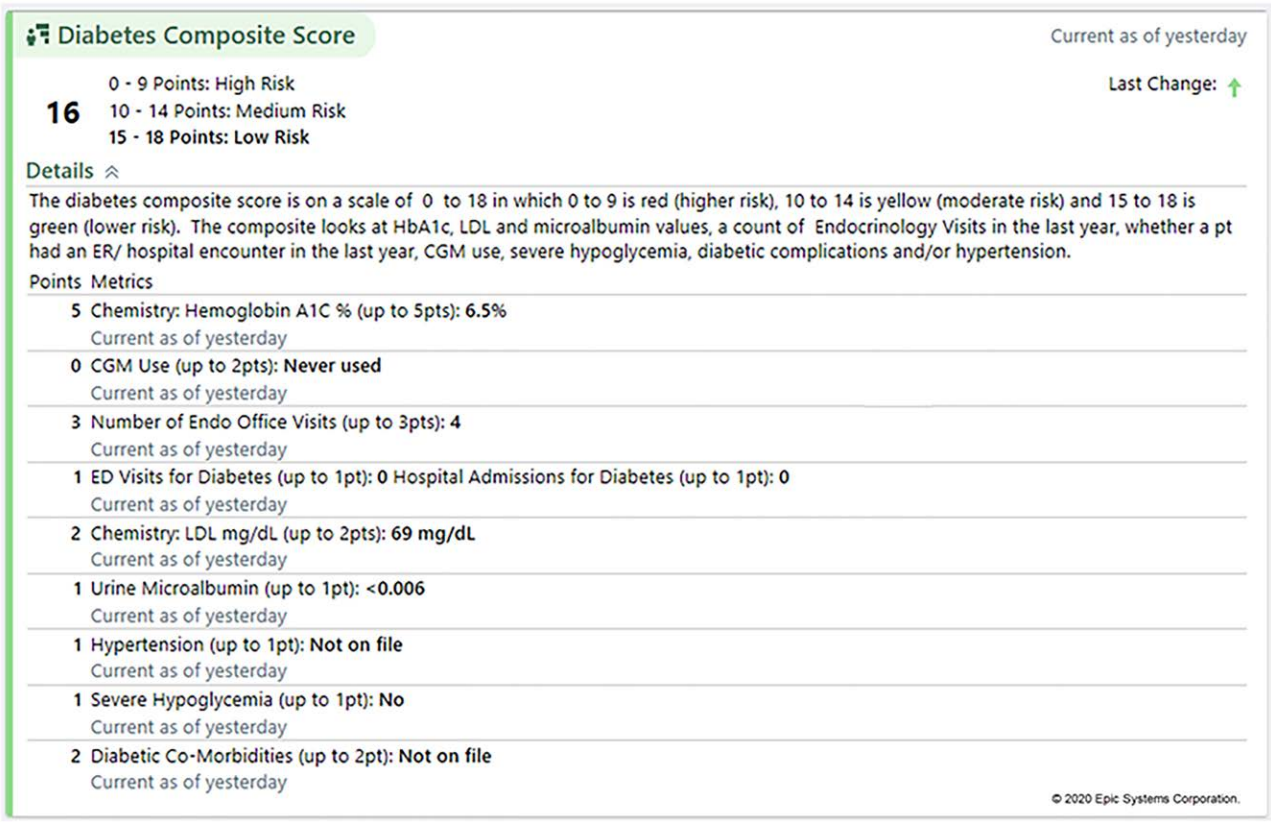

Fig. 2. Sample screenshot of an individual patient's T1DCS. "Not on file" signifies that no flagged abnormalities were detected. "Not on file" for hypertension and diabetic comorbidities indicates normal blood pressure and lack of diabetic complication diagnoses, respectively. ENDO indicates Department for the sample clinic schedule [ENDOCRINE]; ER or ED emergency room; LDL, low-density lipoprotein; pt, patient; pts, points.

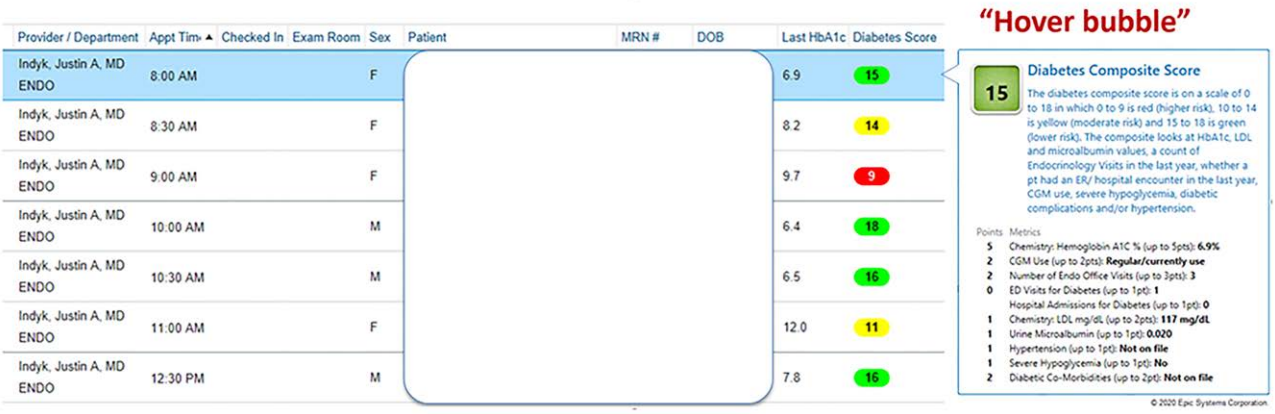

Fig. 3. Sample screenshot of a provider's clinic schedule view. "Not on file" signifies that no flagged abnormalities were detected. "Not on file" for hypertension and diabetic comorbidities indicates normal blood pressure and lack of diabetic complication diagnoses, respectively. ER or ED indicates emergency room; LDL, low-density lipoprotein; pt, patient; pts, points.

population score data showed a normal distribution, and over 6 months, the score curve shifted to the right (higher T1DCS), suggesting an improvement in clinical care outcomes (Fig. 4B). We hypothesize that this right shift may reflect multiple process improvements in clinical care, including increased patient CGM adoption within our population. More importantly, this example demonstrates how the T1DCS can be used in population tracking to identify and resolve care gaps and as a metric for diabetes clinical program performance.

This data analytics approach to QI in the diabetes care arena is novel and has broader implications for population health. As this metric can gauge improvements

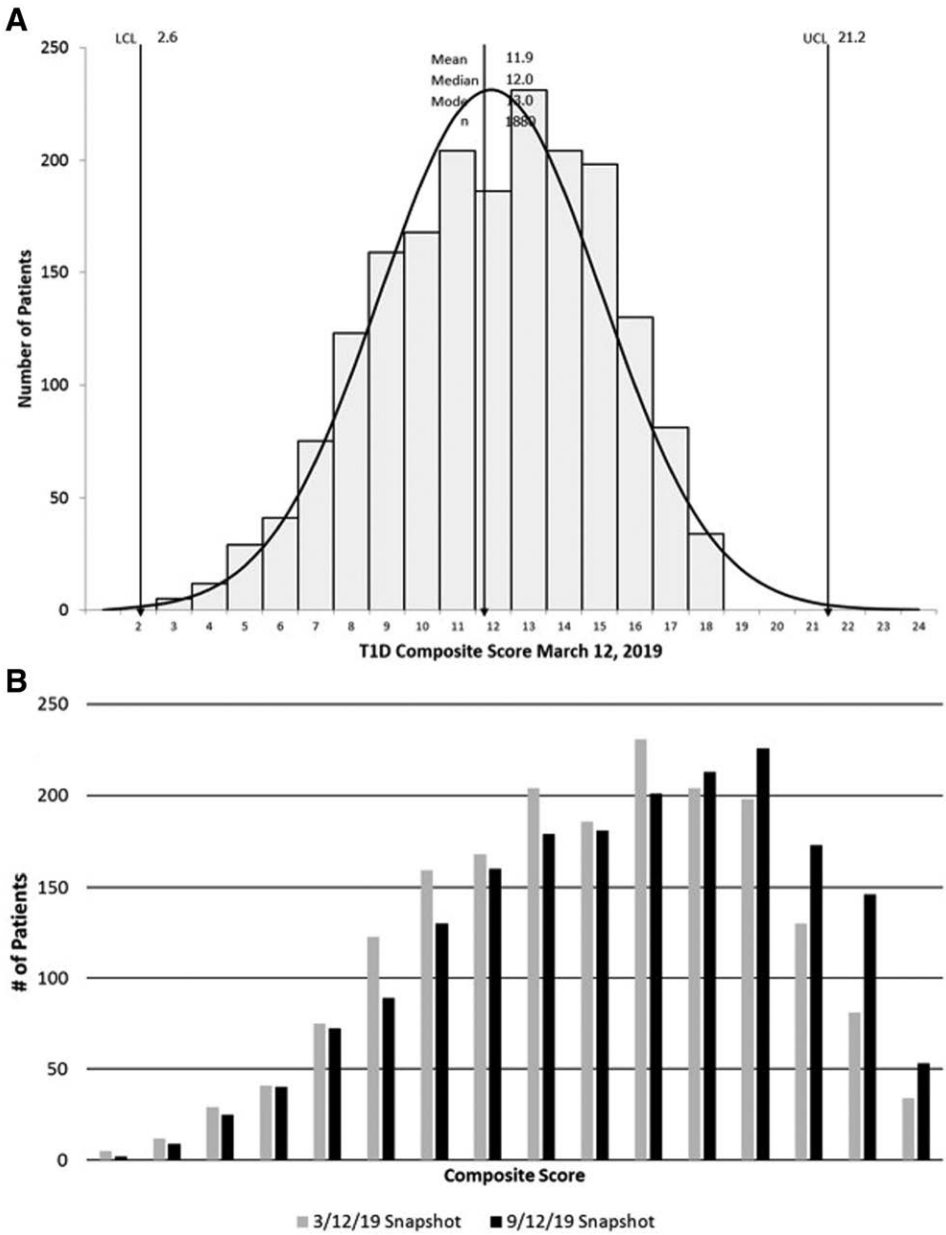

Fig. 4. T1D Registry population represented using the T1DCS. A, Snapshot at the inception of T1DCS, and (B) population score shift over a 6-month interval. LCL indicates lower control limits; UCL, upper control limits.

longitudinally within an institution and across diabetes clinics in multiple institutions, it can develop into a new standard in monitoring diabetes care.

This scoring model does have limitations. Among the major parameters tracked by current ADA and ISPAD guidelines, the only component not addressed is ophthalmology examinations (or retinal photography), which was deferred in this iteration of the score as we did not have an adequate clinical and EMR framework to track this individual component. In addition to retinal/ophthalmologic examination, the score can potentially be improved by adding additional elements considered relevant in monitoring diabetes care and preventing complications, such as measures of psychological burden related to diabetes, including quality of life or diabetes-related distress.[5,15] Other indicators that reflect the burden of care can be considered, such as missed school days related to diabetes.[16,17] Time in range and other similar CGM metrics can potentially be incorporated as well, as accepted clinical targets to guide diabetes management are now formalized.[18] This pilot project aimed to demonstrate that this metric concept is feasible and has the potential for further use in diabetes clinical care and improvement toward best outcomes. As this score build requires a robust informatics infrastructure for data capture, data integrity, and EMR build, this scoring paradigm's generalizability may not be immediate,

particularly at institutions without population health registries or dedicated informatics staff.

In addition to exploring additional elements worthy of inclusion into the T1DCS, the next steps from a population health perspective include sorting and analyzing data by patient demographics to identify healthcare disparities in our region. A breakdown of score distribution by race, ethnicity, age, sex, and zip code (home address) can quickly be generated. With the ability of the T1DCS to update in real time with new data such as current HbA1c, we would anticipate that this metric can be used for PVP and patient education and counseling during clinic visits to address gaps and opportunities in earned points. Also, as best practices guide the individual elements comprising the T1DCS, there may be applications for patient/family-facing use, to help further guide diabetes education and self-management.

The T1DCS is the first description of a "metric combining metrics" using patient outcome measures (including HbA1c) to assess patients with T1D and diabetes clinic performance. Our institution has begun to use this score in PVP, to document outcome improvement in our QI projects, and to assess our clinical program in achieving optimal diabetes outcomes across a broad range of well-accepted domains.

CONCLUSIONS

The T1DCS is a novel metric to evaluate the clinical status of diabetes care in our patients with T1D in complying with nationally and internationally accepted guidelines for care. Besides its use in monitoring and tracking progress in diabetes care QI initiatives, this metric can also assess a clinical program's capability to achieve optimal diabetes outcomes and document outcome improvement.

This population health and data analytics approach, guided by best practices, can be further developed into a potential new standard in monitoring diabetes care. Further applications may include identifying health care disparities and addressing social determinants of health. There may also be broader applications for patient/family-facing use in patient self-management.

DISCLOSURE

The authors have no financial interest to declare in relation to the content of this article.

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