### **PSYCHOSOCIAL ASPECTS (J PIERCE, SECTION EDITOR)**



# Implementation of Psychosocial Screening into Diabetes Clinics: Experience from the Type 1 Diabetes Exchange Quality Improvement Network

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#### **Abstract**

**Purpose of Review** Although advances in diabetes technology and pharmacology have significantly and positively impacted diabetes management and health outcomes for some, diabetes care remains burdensome and can be challenging to balance with other life priorities. The purpose of this article is to review the rationale for assessment of psychosocial domains in diabetes care settings and strategies for the implementation of psychosocial screening into routine practice. Survey data from the Type 1 Diabetes Exchange Quality Improvement Network is highlighted.

**Recent Findings** Implementation of psychosocial screening requires identifying the population; selecting validated tools to assess target domains; determining frequency of screening and mode of survey delivery; and scoring, interpreting, documenting, and facilitating referrals such that these processes are part of clinical workflows.

**Summary** Recognizing the influence of psychosocial factors for people with diabetes (PWD), professional society guidelines for comprehensive diabetes care recommend the integration of psychosocial screening into routine care.

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### Introduction

Management of type 1 diabetes (T1D) requires lifelong attention to blood glucose patterns and insulin dosing. Although advances in diabetes technology and pharmacology have significantly and positively impacted diabetes management and health outcomes for some, diabetes care remains burdensome and can be challenging to balance with other life priorities. Recognizing the influence of psychosocial factors for people with diabetes (PWD), professional society guidelines for comprehensive diabetes care recommend the integration of psychosocial screening into routine care [1, 2]. Variable resources and clinical structures can influence the degree to which practices are able to implement recommendations.

Implementation of psychosocial screening requires identifying the population; selecting validated tools to assess target domains; determining frequency of screening and mode of survey delivery; and scoring, interpreting, documenting, and facilitating referrals such that these processes are part of clinical workflows [3–6]. The purpose of this article is to review the rationale for assessment of psychosocial domains in diabetes care settings and strategies for the implementation of psychosocial screening into routine practice. Survey



data from the Type 1 Diabetes Exchange Quality Improvement network (T1DX-QI) [7] that is based on real-world practice in the USA is highlighted along with consideration of future directions for integration of psychosocial screening into diabetes care.

### **General and Diabetes-Specific Patient-Reported Outcomes**

For PWD, there are many validated psychosocial tools that can be used to assess general areas of function and diabetes-specific domains. Select measures are summarized in more depth by Young-Hyman et al. [1, 2]. When planning the implementation of patient reported outcomes (PROs) into clinical care, measures should be evaluated in terms of whether they are meaningful for and actionable within one's own clinic population. The measures should be psychometrically sound and age-appropriate for the target population. They should also be of reasonable length, administer easily, and scored in real time so the results can be incorporated into a same-day clinic visit [1].

### **General Domains of PROs**

Within general domains, depression and anxiety are frequently assessed constructs given the disproportionate risk for development of these conditions among PWD and the relation between these constructs and health outcomes such as glycemic levels [1, 8, 9]. Although most adolescents with T1D fall in the low-risk category for depressive symptoms (83.4–88.2%), it is important to screen for symptoms of depression given that there is a significant subgroup of PWD (11.6–18.2%) who are at moderate or high-risk for depression with 5.4% to 8.6% endorsing suicidal ideation crosssectionally [10]. By comparison, data for youth with type 2 diabetes at four academic medical centers yielded even higher rates of depressive symptoms and thoughts of selfharm on routine screening [11]. Depressive symptoms commonly impact diabetes self-management [8] and may also reflect how a PWD is adapting to diabetes and its management [12]. Therefore, standardized methods to identify these symptoms (e.g., Patient Health Questionnaire PHQ-9 [13]) are important to promote early detection and opportunities for further clinical assessment, referral, and treatment [1, 14, 15]. Anxiety comorbidities also warrant screening in PWD. The estimated lifetime prevalence of generalized anxiety disorder is estimated to be around 19.5% and can be very disruptive to the lived experience with diabetes [16]. Given this, a combined depression-anxiety screening approach (e.g., Patient Health Questionnaire PHQ-4 [17], or General Anxiety Disorder, GAD-7 [18]) that routinely assesses internalizing symptoms associated with both depression and anxiety proactively could be beneficial [19].

### **Diabetes-Specific Domains of PROs**

For PWD, condition-specific domains can reveal additional clinically relevant PROs. The extant literature has identified several areas that PWD, families, diabetes clinicians, and mental health providers may find important to assess in the clinical setting. Diabetes-related distress, the emotional response specific to living with diabetes that may encompass fatigue of relentless self-management tasks and prospect of long-term complications, is distinct from more general constructs, such as depression [20]. In pediatrics, diabetes distress occurs in approximately one third of PWD and can negatively impact diabetes management behaviors and glycemic outcomes [21]. PRO measures such as the Problem Areas in Diabetes (PAID) [22, 23] and the Diabetes Distress Scale (DDS) [24] have been developed for use in diabetes clinics to assess this construct.

PWD are also more likely to struggle with disordered eating behaviors (DEBs), due in part to the heightened focus on food and eating behaviors that are necessary components of daily diabetes management [25, 26]. Estimates of DEBs in PWD are typically higher than in the general population and suggest that 21-31% of adolescents with T1D are at risk for disordered eating [27, 28]. When these behaviors do occur, they are often associated with undesired diabetes outcomes, such as elevated or fluctuating glucose levels and long-term diabetes-related complications [28, 29]. For PWD, it can be important to use tailored PRO measures to assess diabetesspecific DEBs because some diabetes management behaviors (e.g., carbohydrate counting, meal planning) can lead to inaccurate results on general measures of disordered eating [26, 30]. Both the Diabetes Treatment and Satiety Scale (DTTS-20) [1] and the Diabetes Eating Problems Survey (DEPS-R) [31] have been developed for use with PWD.

Fear of hypoglycemia is yet another potential PRO domain to consider assessing. PWD who experience fear of hypoglycemia may engage in some diabetes management behaviors (e.g., administer lower insulin doses than indicated) and daily activities (e.g., limit physical activity or participation in social events) for fear that they will experience low blood glucose levels [32–34]. This can, in turn, negatively impact glucose levels and quality of life for PWD; therefore, assessing fear of hypoglycemia can help identify individuals who may benefit from specialized behavioral health interventions to address this challenge. The Hypoglycemia Fear Survey (HFS) originated in 1987 [35] and updated in 2011 for adults (HFS-II) [36] with modified versions for youth and parents [32] is a widely used measure. The Children's Hypoglycemia Index (CHI) [37] and updated



version (CHI-2) has also been studied in adolescents with T1D [38].

While diabetes-specific PRO measures often assess constructs from a deficit model, there is value in exploring more resilience and strength-based domains. In recent years, there has been growing support for exploring more positive approaches to PRO implementation [39, 40]. For example, diabetes-specific quality of life tools (e.g., PedsQL 3.2 Diabetes Module, Type 1 Diabetes and Life, T1DAL) [41, 42], diabetes resilience (Diabetes Strengths and Resilience Measure for Adolescents With Type 1 Diabetes, DSTAR-Teen) [43], and diabetes self-efficacy for self-care tasks (Self-Efficacy for Diabetes Scale) [44, 45] are related to improved health outcomes and can help improve diabetes providers' understanding of areas to bolster for PWD. Additionally, as pediatric patients approach the transition to adult diabetes care, it can be beneficial to assess transition readiness to promote health care providers' ability to address any gaps in preparation (Readiness of Emerging Adults Diagnosed with Diabetes in Youth, READDY) [46-49]. In sum, the value of diabetes-specific measures in addition to or in lieu of more general PRO measures should be carefully considered based on the goals of screening, the targeted clinical population, and availability of trained providers to address diabetes-specific concerns.

### **Social Determinants of Health**

Furthering the American Diabetes Association recommendations for annual psychosocial screening [9], Lipman and Hawkes [50] suggest that universal and structured screening for social determinants of health (SDOH) also be included in every PRO measurement endeavor. SDOH constructs provide information about an individual's economic stability, access to health care services, transportation, housing, food security, features of their neighborhood and environment, education, and social context. Diabetes management, psychosocial functioning, and SDOH are inextricably intertwined. Therefore, interventions based on PRO outcomes that neglect consideration of relevant SDOH factors will not yield the best outcomes, particularly for individuals with chronic health conditions, like PWD. In addition to individual factors, systemic influences on diabetes-management and health outcomes should be considered. Formal SDOH screening tools, such as Health Leads<sup>©</sup> Social Needs Screening Toolkit (https://healthleadsusa.org/), Hunger Vital Sign [51], and the Family fIRST survey [52], are examples of SDOH screeners that can be used as part of a comprehensive PRO implementation program. When faced with SDOH screening, a family with SDOH needs may feel targeted or singled out by these questions or may have hesitation to respond accurately due to fear of consequences (e.g., provider bias, immigration, legal). It is important that families are informed that the screening process is administered to all patients as well as how information from their responses will be used, including how results may benefit their care (i.e., provide linkages to resources to support the family's goals and identified needs).

### Survey Data from T1Dx-QI

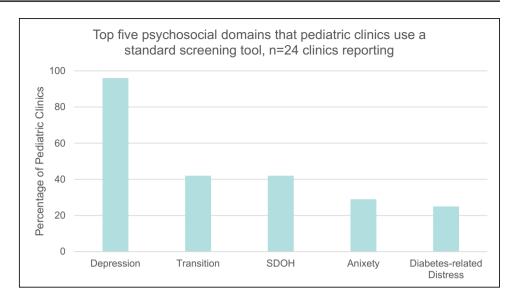
The T1DX-QI collaborative [7, 53] is a network of over 40 pediatric and adult centers that shares best practices to improve outcomes for people with T1D. A 22-item clinical practice survey was administered to participating sites in the T1DX-QI from October 5 to November 19, 2021 (n = 24 pediatric centers and 8 adult sites). Data from items relevant to psychosocial screening were cleaned and sorted, and an analysis was completed in Rstudio. Fisher tests were used to compare the percentage of psychosocial screening tools used by clinics. The differences between pediatric and adult sites were calculated.

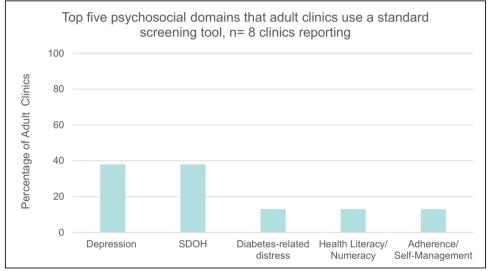
Overall, 96 % of pediatric centers reported using at least one patient reported standardized screening tool, 79 % reported using 2 or more; half of adult centers endorsed the use of at least one screening tool in routine practice. The most common psychosocial domain assessed by both pediatric (23 of 24 centers, 96%) and adult settings (3 of 8 centers, 38%) was depression (see Fig. 1). Screening for SDOH and diabetes-related distress was also reported in both settings. Assessment of readiness to transition to adult care was unique to pediatric settings and reported by 10 clinics. With regard to specific measures, clinics reported use of various tools [19] including PHQ-9 (n = 24) [13], PHQ-2 (n = 7), PHQ-4 (n = 5) [17], GAD-7 (n = 5) [18], Hunger Vital Sign (HSV-2) (n = 6) [51], READDY (n = 4) [49], and PAID (n = 3) [22, 23]. Additionally, clinics reported screening in the following domains without specifying measures used: social determinants of health (n = 13), disordered eating (n = 5), diabetes related quality of life (n = 3), adherence/ self-management (n = 3), diabetes strengths/resilience (n = 2), and health literacy/numeracy (n = 2).

Varying degrees of psychosocial screening were reported by the T1DX-QI participating sites. Both pediatric and adult centers endorsed benefits of screening including an increase in provider awareness of psychosocial needs and opportunities to discuss them with PWD (see Fig. 2). The most common challenges reported by participating sites included time constraints, difficulty integrating screening into the workflow, and determining how to react to patient responses, particularly in settings with limited social work or other mental health resources (see Fig. 3). Respondents highlighted the value of family/peer support, diabetes online community, as well as free and confidential phone/text/online mental health resources. Of note, one adult center leveraged data



Fig. 1 Top five psychosocial domains reported by pediatric clinics, n = 24, and adult clinics, n = 8, used as standard screening tools amongst participating clinics in the T1DX-QI network





from local depression screening within their clinic as well as data from the T1DX-QI network to secure additional social work resources.

### Organizational Approaches to PRO Implementation

The integration of guidelines into clinical practice can take a variety of forms. In this section, we discuss examples from the literature and the T1DX-QI collaborative highlighting a range of implementation strategies and considerations across a variety of care models and clinical contexts. Communication between PWD, families, and the clinical team about the purpose of screening with PROs and how information will be used is essential. It is important to help PWD and families feel comfortable with the screening process and notify them in anticipation of being offered a screener what to expect.

Co-production with PWD and families in the T1DX-QI network is immensely helpful in development of education materials and designing procedures around best ways to communicate findings and available resources that are linguistically and culturally appropriate and considers the varied literacy levels of patients and families (i.e., concise, available in languages other than English).

### Identifying the Population and Selecting Validated Tools

When considering the eligible population and selecting which PROs to incorporate into clinical care, teams must consider whether the measures have been validated for use with the specific ages or developmental level, language, and culture of the target population. Clinics may want to consider caregiver-specific measures (e.g., diabetes distress or quality of life for



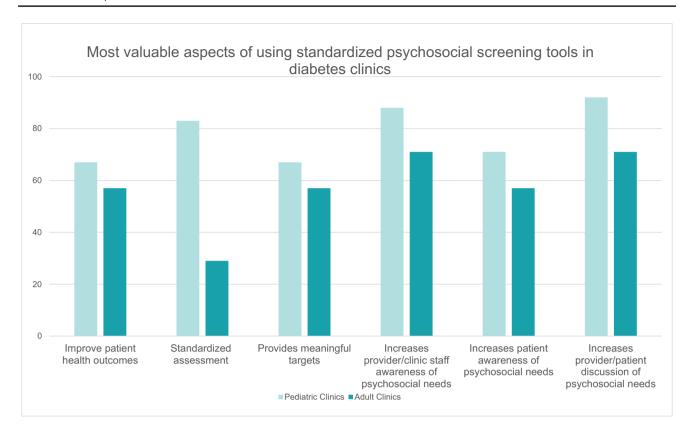


Fig. 2 Benefits of standardized psychosocial screening integrated into routine diabetes care visits reported by pediatric centers, n = 24, and adult centers, n = 8 in the T1DX-QI network

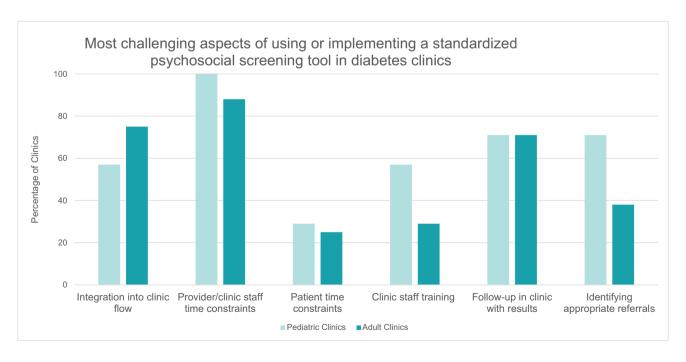


Fig. 3 Most challenging aspects of standardized psychosocial screening integrated into routine diabetes care visits reported by pediatric centers, n = 24, and adult centers, n = 8, in the T1DX-QI network

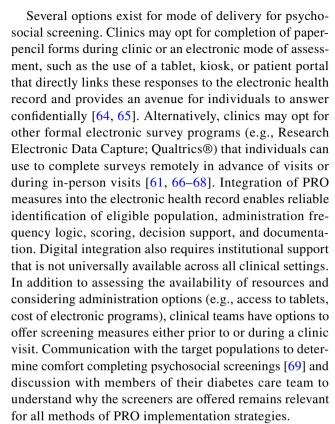


parents/caregivers) to gain a better understanding of family functioning and adaptation to diabetes [4–6]. Research data on the consistency between parent-proxy and youth reports are mixed, particularly for certain constructs (e.g., healthrelated quality of life or HRQOL, diabetes family responsibility, diabetes distress) and across developmental periods. For example, some findings suggest that parent-proxy measures underestimate the youth experience of HRQOL and recommend prioritizing child and adolescent self-reports [54]. On other diabetes-related constructs (e.g., family conflict, family responsibility), respondent discrepancies between youth and parent/caregiver reports may be vital to understanding barriers and predictors of successful diabetes management [55, 56]. When psychometrically validated measures are available for both youth and parent/caregiver respondents, teams may opt to obtain youth self-report data or both youth and parent perspectives [5, 6]. This experience of partners of adults with diabetes is an important area for ongoing research and consideration for adult clinical care settings [57–59].

### **Determining Screening Frequency and Mode of Administration**

According to the current ADA's Standards of Medical Care in Diabetes – 2022 [9], the administration of both general and diabetes-specific PROs is recommended. The timing and frequency of PROs are suggested at the first visit, at routine intervals (at least annually), as well as any time there is a significant change or life transition for the PWD, including the onset of complications, hospitalization, and/or transitioning from pediatric to adult care, pregnancy, and/or changes associated with entering older adulthood [9]. When determining the administration schedule of PROs, teams must balance frequency with which screening will be most beneficial while accounting for feasibility of administering multiple simultaneous PRO measures for both PWD and clinic staff [60]. Many clinic settings opt for 6-month (two times annually) or annual (once per year) screening protocols [3, 61, 62]. Clinics deploying quarterly screening often measure a single or limited group of psychosocial constructs (e.g., depression screening only) versus a more comprehensive battery of constructs [63].

For clinics that assess multiple PROs, a staggered approach allows for PRO evaluations to be spread out over the year and enables a holistic approach over time. Additionally, some PRO measures (e.g., a depression screener) may lend themselves to an adaptive frequency, where those screening in the low-risk range are then administered the measure on an annual basis, those in the moderate risk receive it every other clinic visit, and those in the high-risk range are given the measure at every clinic visit. This allows for more frequent monitoring of the higher risk individuals but does not overly assess the low-risk population [10].



Pre-screening (i.e., asking PWD and/or their parents/ caregivers to complete screenings before visits) has implications for other screening protocol-related decisions (i.e., removal of questions about suicidality) and confirming who is answering the screening questions (PWD or proxy). Protocols for PROs must include procedures around how to respond in a timely manner when screeners are completed outside of business hours and individuals endorse high-risk questions that need an immediate response and cannot wait for their next scheduled visit. To overcome some of these obstacles, clinics may routinely collect screening measures at the start of the PWD's clinic visit and then review and share findings with the care team throughout the visit to facilitate real-time identification of concerns and relevant referrals. This method, though demonstrated to be feasible across several clinical contexts [3, 6, 70, 71], may increase the length of appointments and/or the check-in process [3].

### Integrating Scoring, Interpretation, Documentation, and Referral Action into Clinical Workflows

Scoring and documentation, including identifying the diabetes team member responsible for these tasks, is important in the development of optimal PRO screening protocols. Depending on the preferred mode of delivery,



teams must factor in time and resources (e.g., finances, space, preparation) to promote successful implementation of measures to PWD and relevant family members/caregivers. Staff training is paramount and may include screening procedures, scoring, and interpretation of measures, as well as documentation expectations. Clinics must determine clinical thresholds for each selected measure that will be considered positive and warrant interventions in the context of a diabetes visit [72]. In addition, standard protocols must be developed to address high-risk responses on screeners. A summary of considerations for integrating depression screening into clinical workflow amongst pediatric and adult sites in the T1DX-OI network are described in a change package document (https://info.tldexchange. org/download-our-depression-screening-change-packa ge). Teams with access to other services such as psychology/behavior medicine or social work may seek to align annual visits to coincide with when PRO screenings are administered [65]. Timely access to a social worker or psychologist may be beneficial to facilitate behavioral/ mental health interventions and referrals [3, 70, 73, 74]. From a pragmatic perspective, behavioral health providers may be able to bill for their clinical services including the assessment (administration, interpretation, scoring, risk assessment, and safety planning) and consultation services with patients and/or families as they relate to the screenings [3, 75].

## Additional Considerations: Team Composition, Stakeholder Responses, and COVID-19

### **Team Composition**

In addition to logistical considerations for the completion of measures, the composition of the diabetes team is another noteworthy factor to consider during psychosocial screening decision-making. Several T1DX-QI clinical teams provided insights around the development and implementation of their psychosocial screening protocol. For example, some teams described close collaboration between psychology and/or social work providers and the diabetes care teams. For teams with embedded mental or behavioral health clinicians, these clinicians are often tasked with responding to any patients who endorse critical or high-risk questions on PRO screenings during the visit and provide further clinical assessment for treatment planning for services. Referrals for outpatient services may include a referral to an internal psychology or psychiatry department, primary care/adolescent medicine, or to a community-based agency, school-based services, and/ or free and confidential mental health supports available via phone/text/chat online. Notably, adult diabetes clinics report limited access to social work and outpatient mental health referral services with lower likelihood of embedded interdisciplinary team members as compared to pediatric health delivery settings. Certified diabetes care and education specialists (CDCES) can be trained through a new ADA program, https://professionaleducation.diabetes.org/ProductInfo/BHD22, on how to work with people experiencing diabetes distress and other challenges.

### **Responses to Psychosocial Screening**

Overall, feedback from T1DX-QI clinical teams about psychosocial and PRO screening in clinical settings is promising and literature on screening approaches that involve PWD, family/caregivers, and members of the diabetes care team is growing. In a recent article by Brodar and colleagues [66], authors describe a process to enhance a screening program for adolescents with diabetes. In a sample of 232 ethnically diverse adolescents with diabetes, 83.1% of eligible were screened and there was a significant increase in requests for both psychological consultations (25%) and other mental health referrals (15.2-57.9%) 10 months after implementation. Similarly, other studies demonstrate positive responses to psychosocial screening protocols by PWD, parents/caregivers, diabetes clinicians, and investigators [69, 71, 76]. Hilliard and colleagues [3] recently published strategies to support diabetes care team members in the process of developing and implementing psychosocial screening protocols with the goal of promoting feasibility and acceptability.

### **COVID-19 Considerations**

The COVID-19 pandemic led to the increased use of telehealth for medical and psychosocial visits in pediatric and adult medical settings, with requisite adaptations to screening procedures from in-person to telehealth and/or electronic modalities [77]. Some clinical settings are unable to implement remote screening procedures, such as the integration of PRO measures into electronic health records [67]. Reported strategies to temporarily overcome common barriers include use of a Qualtrics® survey platform for secure delivery and scoring of measures, generic (rather than personalized) weblinks sent to patients/families for the remote completion of screenings, alterations to the timing of weblink deliveries (i.e., weblinks were sent several days in advance of the youth's visit), and the omission of suicide items on depression screeners to decrease the risk that critical clinical responses would go unaddressed, particularly when measures are completed after-hours[67].



### **Conclusions and Future Directions**

There is growing recognition of the importance of diabetes outcomes beyond Hemoglobin A1c, such as PROs that capture the full lived experience of PWD [78]. This manuscript highlights the relevance of assessing psychosocial domains in routine care of PWD, as well as existing challenges and variations in clinical implementation within participating pediatric and adult clinics in the T1DX-QI network [7]. Survey responses from participating sites in the T1DX-QI network indicate robust interest and perceived benefit of integrating psychosocial screening into routine care consistent with current guidelines. For both pediatric and adult centers, depression screening and SDOH are among the most common domains assessed. Other reported domains currently in use amongst diabetes centers in the T1DX-QI network include diabetes related distress, anxiety, health-literacy and numeracy, self-management, and among pediatric centers, readiness for transition to adult care. The most valued feature of screening reported in the survey data is increased awareness and discussion of psychosocial needs during clinic visits. Common challenges cited are time constraints, difficulty integrating into clinic workflow, staffing constraints, and determining how best to follow up patient responses. Teams reported that these challenges limit widespread implementation, particularly by adult centers with fewer social work and outpatient mental health resources.

While overall provider feedback from T1DX-OI clinical teams around psychosocial and PRO screening processes is promising, understanding PWD, family/caregiver experiences in addition to provider responses are key, particularly as new tools or processes are developed and implemented. Many PRO and psychosocial screening measures are validated for English-speaking individuals and families; thus, further efforts to expand culturally and linguistically appropriate measures are essential. Engagement of patients and families who are culturally and/or linguistically diverse is important to ensure validity and reliability when adaptations are made and administered to those of diverse language and cultural backgrounds. It is also important to consider the impact stigma (including diabetes and weight-related stigma) may have on the potential for open and honest communication between PWD and providers around SDOH and psychosocial needs. Providers can use normalizing language to describe SDOH and psychosocial needs as common in the population and recognize that some questions, while personal and challenging to answer, will help the team to best support the patient and/or family in meeting their goals around diabetes management [79]. Though resources available to individual teams and systems may vary, it is important that teams provide a range of options to patients and families including traditional institutional supports (e.g.,

mental health referral) and other readily available supports online or via text/phone. This helps to respect the cultural values and preferences of a patient/family.

The T1DX-QI collaborative serves as a resource for sharing best practices as well as advocacy for enhanced mental health and social work resources to advance psychosocial care for PWD. Efforts to engage a spectrum of perspectives from PWD, families, caregivers, and interdisciplinary clinical team in the PRO implementation process can help improve logistical facets of the implementation process, and inclusivity. Co-production principles can aid in modifying implementation protocols to be more sensitive to language and cultural considerations, understand perceived biases in the screening process, as well as better meet the needs of diverse PWD. Feedback from PWD, families, and care team members during all steps of the implementation process may increase overall satisfaction and sustainability to overcome barriers to widespread psychosocial PRO implementation over time.

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**Data Availability** The data that support the findings of this study are available from the corresponding author, [SDC], and the T1DX-QI network upon reasonable request.

#### **Declarations**

**Competing Interests** The authors declare no competing interests.

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