



# Patient-Reported Experience and Outcome Measures in People Living with Diabetes: A Scoping Review of Instruments

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Accepted: 16 May 2021 / Published online: 27 May 2021  
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## Abstract

**Background** Diabetes mellitus is a global public health concern, with over 463 million people living with this chronic disease. Pathology complexity, management difficulty, and limited participation in care has resulted in healthcare systems seeking new strategies to engage people living with diabetes. Patient-reported experience measures (PREMs) and patient-reported outcome measures (PROMs) were developed to address the gap between the healthcare system expectation and patient preference.

**Objective** This study aimed to review the existing literature on PREMs and PROMs specific to type 1 and 2 diabetes, and report the dimensions they have measured.

**Methods** A scoping review was conducted from January 1985 to March 2020 of six databases, MEDLINE, EMBASE, PsycINFO, CINAHL, Scopus, and BiblioPro, to identify PREM and PROM instruments specific for type 1 and 2 diabetes.

**Results** Overall, 34 instruments were identified, 32 PROMs and two PREMs. The most common instrument included outcomes related to quality of life at 44% ( $n = 15$ ), followed by satisfaction (whether with treatment, device, and healthy habits) at 26% ( $n = 9$ ). Furthermore, instruments regarding personal well-being accounted for 15% ( $n = 5$ ). For instruments that measure experiences of persons with diabetes, there were two scales of symptoms, and one related to the attitude patients have toward the disease.

**Conclusions** Diabetes-specific validated instruments mainly focus on quality of life, education, and treatment, and sometimes overlap each other, in their subscales and assessment dimensions. Constructs such as cultural and religious beliefs, leisure, and work life may need more attention. There appears to be a gap in instruments to measure experiences of individuals who “live with diabetes” and seek to lead a “normal life.”

## Key Points for Decision Makers

Disease-specific instruments are tailored to patient needs, avoiding irrelevancies from other generic measures.

It is vital to use an adequate instrument, with an adequate construct for measurement.

Patient-reported outcome measure instruments usually focus on patients' quality of life; other aspects such as the social context should also be considered.

We found no cross-culturally validated or on-site developed instruments to be used in low-income and middle-income countries; more research is needed.

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## 1 Introduction

Chronic non-communicable diseases pose a challenge for healthcare systems. The global prevalence of diabetes mellitus among adults (aged 20–79 years) was estimated at 9.3% (463 million people) in 2019, and is expected to rise to 10.2% (578 million) by 2030 [1]. Patient-centered care can be challenging to define, but common concepts are: disease and illness experience (patient-as-person), whole person (biopsychosocial perspective), common ground (sharing power and responsibility with healthcare provider), and patient-doctor relationship [2].

Since the 1990s, research has increasingly placed quality of life (QoL) in the spotlight, as an essential health outcome in diabetes, in some cases, if not “the ultimate goal” of treatment [3]. Currently, clinical trials should include the evaluation of the psychological aspects of patients, treatment satisfaction, well-being, and QoL, which are referred to as patient-reported outcome measures (PROMs) [4, 5]. For better intervention on health-disease processes, a patient with a chronic condition must be an active protagonist [6, 7]. Therefore, it is essential to incorporate the patient’s viewpoints into the organization of healthcare. Accordingly, it has been verified that when the patient perceives that his/her perspective, experience, and decisions about the illness are taken into account, there is more active and effective participation and cooperation in the treatment plan [8, 9]. The incorporation of instruments known as patient-reported experience measures (PREMs) has made it possible to make the patient visible within the context of the healthcare systems and include their experience in the management of chronic pathologies. The PREM and PROM instruments respond to the objectives of achieving patient-centered care.

Diabetes prevention and control are challenges for healthcare and social professionals, services, and systems. It also has a high economic and social impact [10]. The promotion of healthy lifestyles, the control of risk factors (diet, weight management, physical exercise), diabetes education, and patient self-care are essential elements in controlling the disease’s progression and the social and health burden it represents [11]. However, these are not the only factors that need to be considered. Significant evidence exists regarding the influence of psychosocial stress on risk factors, acceleration of disease, and overall health of individuals [12]. A recent study showed that daily stress related to work and an increased perceived risk of physical health may influence outcomes in diabetes care [13].

The experiences and results measured by patients change according to the local socio-cultural context. Healthcare systems and their results are not homogeneous and could change within the same region. Accordingly,

it is necessary to understand how patients construct and interpret their disease. Healthcare systems need to adapt to patients’ needs, create a climate of trust, and act to improve adherence and the quality of care [14].

This study aimed to review disease-specific patient-reported outcomes and experience measures that currently exist for individuals with type 1 and 2 diabetes and what dimensions they measure. We attempt to provide a synthesis of these instruments for policy makers and researchers in order for them to choose the most suitable instrument for their intended purpose.

## 2 Methods

A scoping review of studies published in peer-reviewed journals was conducted. The Joanna Briggs Institute [15] protocol has been followed, and the Preferred Reporting Items for Systematic Reviews and Meta-Analyses—Extension for Scoping Reviews (PRISMA-ScR) checklist was used [16]. The study protocol is available from the corresponding author.

### 2.1 Inclusion Criteria

Studies specific to type 1 and 2 diabetes that collected, developed, or validated PROMs were included to examine: (a) QoL, (b) emotional stress, (c) symptoms, (d) adherence to treatment, and (e) satisfaction with treatment; and experience measures such as (1) living with diabetes and (2) the healthcare system. As there were no restrictions on age, the studies were selected from the young, adult, and older populations. Studies in both English and Spanish were included. Articles validating instruments on other diseases such as gestational diabetes, diabetic foot ulcers, selection of nutritional supplements, and other non-specific diseases such as high blood pressure, metabolic syndrome, or cardiovascular disease were excluded.

### 2.2 Data Sources and Search Strategy

The selected databases included MEDLINE, EMBASE, PsycINFO (via OvidSP), CINAHL, Scopus, and BiblioPro. The research team agreed on the terms and appropriately modified each database. The articles were limited to the English and Spanish languages, published between January 1985 and March 2020. Specific publication types were excluded from the search strategy, such as editorials and case reports. A combination of Medical Subject Headings (MeSH) and free-text terms were used. Three groups of terms were generated to describe: (1) the population; (2) instruments, surveys, and PREMs/PROMs; and (3) psychometric properties. Terms within each group were combined

with the Boolean operator “OR.” BiblioPro is a patient-reported measures database available in Spanish, and it was manually searched to look for possible instruments. In a complementary method, manual searches were performed in Google Scholar to identify the gray literature in different countries, which are not available in the already-mentioned scientific databases. The OvidSP database search is available in the Electronic Supplementary Material.

### 2.3 Selection of Reviewers

JMD conducted the search strategy in the databases. JMD and MG reviewed all titles and abstracts to identify potentially relevant studies. When a consensus was not achieved between both reviewers, a third researcher (JJM) reviewed the study and disagreements were addressed to reach a consensus. All the reviewers could read Spanish and English. Studies in the local language included an abstract that allowed the authors to decide if it had to be included for full-text reading. JMD and MG performed full-text reading of articles for inclusion. No unpublished studies were found, and neither was there a need to contact any of the authors included.

### 2.4 Data Extraction

Data extraction from each study was performed by all authors using a standardized Excel sheet. The sheet included the year of publication, whether PROM or PREM, number of items, outcome, dimensions, target population, mode of administration, recall period, number of participants, response options, range of scores, administration time, original language, and number of citations. Information about the design and the validation procedure used in each instrument was also included.

### 2.5 Data Synthesis

A qualitative and descriptive analysis of the data was conducted for each variable from which information was extracted. The researchers generated categories according to dimensions and its most recent definitions. The presence or absence of information in each variable was coded. Heterogeneity in the methods and measures applied was described when possible.

### 2.6 Quality Evaluation

The Consensus-based Standards for the Selection of Health Measurement Instruments (COSMIN) checklist was employed to evaluate the studies' methodological rigor [17]. The psychometric results reported in the studies

were described and categorized into the COSMIN measurement properties.

## 3 Results

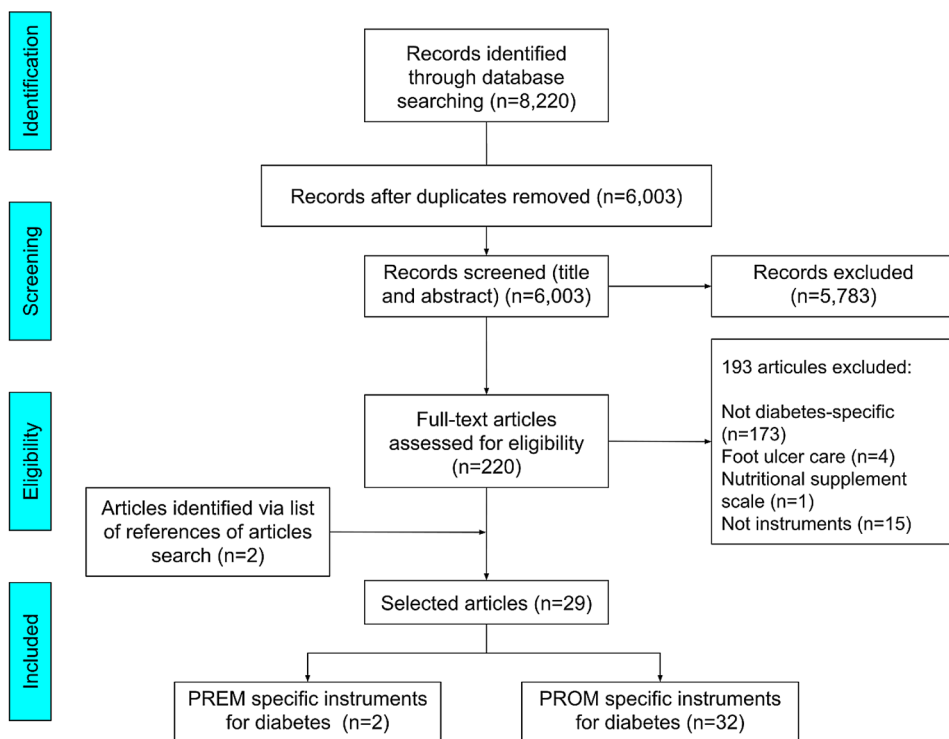
Overall, 8220 records were identified, of which 6003 remained after the exclusion of duplicates. After the review of titles and abstracts, 5783 studies were eliminated. Consequently, 220 articles were assessed with full-text reading, of which 193 were excluded, of these 173 were not diabetes-specific instruments, 15 did not include any patient-reported measure, four were related to ulcer foot care, and one was a nutritional scale. After the inclusion of two articles identified by searches of references, 29 articles meeting all inclusion criteria were included. Figure 1 shows this process of selecting studies.

### 3.1 Description of the Studies

Patient-reported outcome measure instruments were the most prevalent, accounting for 94% ( $n = 32$ ) and PREM instruments, only 6% ( $n = 2$ ). In the last 10 years, a notable increase was observed with the instruments, thus doubling the number. Regarding the instruments, outcomes related to QoL were the most common at 44% ( $n = 15$ ), followed by those that measured satisfaction (whether with treatment, device, or healthy habits) at 26% ( $n = 9$ ), and the well-being of the person accounted at 15% ( $n = 5$ ). Two scales of symptoms associated with diabetes and one instrument related to the attitude of patients having the disease complete the selected outcome measures. Finally, only two instruments that measure the experiences of the person with diabetes were found. The number of items showed a high variability range from 7 to 41. Of these instruments, 13 were specific for application in type 2 diabetes, unlike 17 instruments used indistinctly in the two most common presentations of pathology (types 1 and 2), thereby leaving only four specific instruments for patients with type 1 diabetes. Most of the instruments were designed for the adult population, representing the 85% ( $n = 29$ ). Table 1 shows the main characteristics of the selected instruments.

English was the predominant language for the development of the selected instruments, accounting for 74% ( $n = 25$ ). The most cited PROM is the Summary of Diabetes Self Care [18], and the sample size is heterogenous, with a range from 146 to 3594 participants in the included studies. Table 2 includes information related to the mode of administration, recall period, number of participants,

**Fig. 1** Preferred Reporting Items for Systematic Reviews and Meta-Analyses—Extension for Scoping Reviews (PRISMA-ScR) diagram. *PREM* patient-reported experience measure, *PROM* patient-reported outcome measure



response options, range of scores, administration time, original language, and the number of citations.

### 3.2 Dimensions

The selected instruments independently reported a total of 75 dimensions. Different constructs were included such as emotional distress, where the most commonly used instrument is Problem Areas in Diabetes (PAID) [19]. Healthy lifestyles and habits such as the Diabetes Health Profile 1 [20] and 18 [21], or the Diabetes Self-Management Questionnaire (DSMQ) [22]; patient education and engagement, where the Summary of Diabetes Self Care [18] and more recently the Diabetes Intention, Attitude and Behavior Questionnaire (DIAB-Q) [23] are conspicuous. Others were related to mobility, self-sufficiency in daily activities, treatment, emotional support (of the social circle or caregiver), and hypoglycemia or hyperglycemia symptoms. However, instruments specific to patients with type 1 diabetes tend to include questions related to satisfaction with the medical device, such as the Treatment Related Impact Measure for Diabetes Device (TRIM-DD) [24] or expectations about insulin treatment, and Expectations About Insulin Therapy (EAITQ) [25]. The other dimensions measured but in PREM instruments were patients' perceived experience concerning healthcare, communication with the professional, care planning, care delivery,

and patient-centered care. Table 3 includes a summary of all dimensions of selected instruments after review of instrument composition.

### 3.3 Quality Evaluation

The most frequently reported property was construct validity ( $n = 29$ ), followed by content and criterion validity ( $n = 28$ ), face validity ( $n = 20$ ), and responsiveness ( $n = 17$ ). Internal consistency was usually presented as Cronbach's  $\alpha$  ( $n = 25$ ) with values of over  $> 0.70$ . In 16 studies, Cronbach's  $\alpha$  was presented as a single sum of the total scale and its dimensions, as opposed to nine studies that presented values for each of the dimensions. Test-retest was the least reported psychometric quality, only 15 studies (44%), and in most of the cases, authors reported the result of the intra-class correlation coefficient. Table 4 includes properties of each of the selected studies.

## 4 Discussion

Undoubtedly, QoL and patients' experiences and feelings should be assessed using qualitative methods, but we also need quantitative measures for clinical trials or for evaluating healthcare services [8, 47]. Outcome measures based on patient feedback are indispensable to move toward

**Table 1** Overview of the included instruments

Instrument	Year	Type	Items	Outcome <sup>a</sup>	Dimensions (subscales) <sup>a</sup>	Diabetes type	Target population
Decisional Balance for Insulin Injection (DBII) [26]	2019	PROM	13	Attitude	Advantages Disadvantages	2	Adults
QoLHypo [27]	2018	PROM	13	QoL	Impact of hypoglycemia on the health-related QoL	2	All ages
Diabetes Injection Device Experience Questionnaire (DID-EQ) [28]	2018	PROM	10	Satisfaction	Device characteristics Global items	2	Adults
Swedish National Diabetes Register (SNDR) [29]	2018	PROM PREM	33	Patient experience Healthcare service experience	How you feel; worries; capabilities to care for your diabetes; barriers; support (family and friends); support (provider); medical services	1 and 2	Adults
Diabetes acceptance scale (DAS) [30]	2018	PROM	20	QoL	Acceptance	1 and 2	Adults
Questionario ViDa con diabetes tipo 1 [31]	2017	PROM	34	Well-being	Interference of diabetes in everyday life; self-care; well-being; worry about disease	1	All ages
DHP—3D [32]	2017	PROM	3	QoL	Mood; eating; social limitations	2	Adults
DHP—5D [32]	2017	PROM	5	QoL	Mood; eating; social limitations; hypoglycemic events; vitality	2	Adults
Diabetes Strengths and Resilience Measure for Adolescents with Type 1 Diabetes (DSTAR—Teen) [33]	2017	PROM	12	Well-being	Positive intrapersonal processes (confidence and coping) Positive interpersonal processes (support and effective parental involvement)	1	Adolescents
Diabetes Intention, Attitude and Behavior Questionnaire (DIAB—Q) [23]	2016	PROM	17	QoL	Intention to engage in self-care behaviors	2	Adults
Current Health Satisfaction Questionnaire (CHES-Q) [34]	2015	PROM	14	QoL	Current health Knowledge of diabetes	2	Adults
National Diabetes Audit (NDA)—Patient Experience of Diabetes Services Survey [35]	2014	PREM	15	Healthcare service experience	Care planning; care provision; healthcare checks	1 and 2	All ages
Diabetes self-management Questionnaire (DSMQ) [22]	2013	PROM	16	Satisfaction	Glucose management Dietary control; physical activity; healthcare use	1 and 2	Adults
The Ability to Perform Physical Activities of Daily Living Questionnaire (APPADL) [36]	2012	PROM	7	QoL	Self-reported ability to perform physical activities	2	Adults
Expectations about Insulin Therapy (EAITQ) [25]	2010	PROM	10	Satisfaction	Expectation about insulin therapy; delivery system	2	Adults
Diabetes Symptom Checklist-Revised (DSC-R)[37]	2009	PROM	34	Symptom scale	Symptomatology: hyperglycemic, hypoglycemic, psychological-cognitive, neurological-fatigue, cardiovascular, neurological-pain, neurological-sensory, and ophthalmologic	2	Adults
Treatment Related Impact Measure for Diabetes (TRIM-Diabetes) [24]	2009	PROM	28	Satisfaction	Treatment burden; daily life; diabetes management; psychological health; compliance	1 and 2 insulin requiring	Adults

Table 1 (continued)

Instrument	Year	Type	Items	Outcome <sup>a</sup>	Dimensions (subscales) <sup>a</sup>	Diabetes type	Target population
TRIM-Diabetes Device [24]	2009	PROM	8	Satisfaction	Device function; device bother	1 and 2 insulin requiring	Adults
Diabetes Productivity Measure (DPM) [38]	2006	PROM	14	QoL	Life and work productivity impairments	1 and 2	Adults
Diabetes Medication Satisfaction (DiaMedSat) [38]	2006	PROM	21	Satisfaction	Burden; efficacy; symptoms	1 and 2	Adults
Diabetes Symptom measure (DSM) [38]	2006	PROM	30	Symptoms	High blood sugar; low blood sugar; neurophysiology; general	1 and 2	Adults
Insulin Treatment satisfaction Questionnaire (ITSQ) [39]	2004	PROM	22	Satisfaction	Inconvenience of regimen; lifestyle flexibility; hypoglycemic control; insulin delivery device; satisfaction	1 and 2	Adults
Diabetes Quality of Life Measure Brief Clinical Inventory (DQOL) [40]	2004	PROM	15	QoL	Self-care behavior; satisfaction with diabetes control	1 and 2	Adults
Diabetes empowerment scale (DES) [41]	2000	PROM	28	Psychosocial self-efficacy	Psychological aspects of diabetes; assessing dissatisfaction; readiness to change	1 and 2	Adults
Summary of Diabetes Self Care (SDSCA) [18]	2000	PROM	12	QoL	Diet; exercise; self-analysis	2	Adults
Diabetes Health Profile (DHP - 18) [21]	2000	PROM	18	QoL	Psychological distress; barriers to activity; disinhibited eating	2	Adults
ADDQoL [42]	1999	PROM	19	QoL	QoL; social; work	1 and 2	Adults
Multidimensional Diabetes Questionnaire (MDQ) [43]	1997	PROM	41	QoL	Perceptions related to diabetes and social support; positive and misguided reinforcing behaviors related to self-care; self-efficacy and outcome expectancies	2	Adults
Diabetes Fear of Injection and Self-testing Questionnaire (D-FISQ) [44]	1997	PROM	30	Satisfaction	Fear of self-injecting; fear of self-testing	1 and 2	Adults
Diabetes Health Profile (DHP-1) [20]	1996	PROM	32	QoL	Psychological distress; barriers to activity; disinhibited eating	1	Adults
Problem Areas in Diabetes Scale (PAID) [19]	1995	PROM	20	Well-being	Depression; social support; health beliefs; coping style	1 and 2	Adults
Diabetes Treatment Satisfaction Questionnaires (DTSQ) [45]	1988	PROM	8	Satisfaction	Treatment satisfaction; burden from hyperglycemia and hypoglycemia	1 and 2	All ages
Hypoglycemia Fear Survey [46]	1987	PROM	27	QoL	Behavior; worry	1	Adults

PROM patient-reported outcome measure, PREM patient-reported experience measure, QoL quality of life

<sup>a</sup>As reported by authors

**Table 2** Selected studies characteristics

Instrument	Mode of administration	Recall period	Participants	Response options	Range of scores	Administration time, minutes	Original language	Number of citations <sup>a</sup>
DBII [26]	–	–	332	Strongly disagree/ strongly agree	1–5	–	Taiwanese	2
QoLHypo [27]	Paper sheet	–	227	Never/always	0–2	–	Spanish	2
DID-EQ [28]	Mail	Present perception	142	Strongly disagree/ strongly agree Not at all confident/ completely confident Very dissatisfied/ very satisfied Very difficult/ very easy	1–4	–	English	5
SNDR [29]	Mail	–	972	–	–	–	Swedish	14
DAS [30]	Paper sheet	2 weeks	606	Never true for me/ always true for me	0–3	–	German	14
Cuestionario ViDa [31]	Paper sheet	–	578	Strongly disagree/ strongly agree	1–5	30	Spanish	7
DHP - 3D [32]	Interview	–	150	Never/always Very easy/not at all easy	0–3	–	English	4
DHP-- 5D [32]	Interview	–	150	Never/always Very easy/not at all easy None of the time/ all of the time	0–3	–	English	4
DSTAR-Teen [33]	Online	–	260	Never/almost always	1–5	–	English	28
DIAB - Q [23]	Online	1 week	1015	Strongly disagree/ strongly agree Not at all valuable/ extremely valuable	1–7	–	English	10
CHES-Q [34]	Online	Present perception	1015	Strongly disagree/ strongly agree	1–7	–	English	10
NDA [35]	Online	12 months	714	–	–	–	English	21
DSMQ [22]	–	8 weeks	261	Does not apply to me/ applies to me very much	0–3	–	German	269

**Table 2** (continued)

Instrument	Mode of administration	Recall period	Participants	Response options	Range of scores	Administration time, minutes	Original language	Number of citations <sup>a</sup>
APPADL [36]	Paper sheet	Present perception	146	Unable to do/ not at all difficult	1–5	< 5	English	9
EAITQ [25]	Paper sheet	–	240	Strongly disagree/ strongly agree	1–7	–	English	9
DSC-R [37]	Paper sheet	4 weeks	3594	Not at all/ extremely	1–5	–	English	73
TRIM-D [24]	Online	2 weeks	507	Not at all satisfied/ extremely satisfied Not at all convenient/ extremely convenient Never/almost never Inter- feres/almost Always/ always interferes	1–5	5	English	65
TRIM-DD [24]	Online	2 weeks	507	–	1–5	1	English	65
DPM [38]	Online	–	409	–	–	< 2	English	88
Dia-MedSat [38]	Online	–	409	–	–	4	English	88
DSM [38]	Online	–	409	–	–	2	English	88
ITSQ [39]	Online	4 weeks	402	No bother at all/a tremen- dous bother Does not interfere at all/interferes tremen- dously No planning at all/a tremendous amount of planning Extremely confident/ not at all confident Not at all worried/ extremely worried	1–7	–	English	112
Brief DQOL [40]	Mail	–	498	Never/all the time Very satisfied/ very dis- satisfied	1–5	–	English	150



**Table 2** (continued)

Instrument	Mode of administration	Recall period	Participants	Response options	Range of scores	Administration time, minutes	Original language	Number of citations <sup>a</sup>
DES [41]	Mail	–	375	Strongly agree/ strongly disagree	1–5	–	English	693
SDSCA [18]	Mail	7 days	127	How many days have you ...	0–7	–	English	2400
DHP - 18 [21]	Mail	–	426	Never/always Never/very often Not at all/very much Very likely/ not at all likely	0–3	7	English	97
ADDQoL [42]	Paper sheet	–	154	A great deal better/a great deal worse Increased a great deal/ decreased a great deal	– 3 to + 3	–	English	678
MDQ [43]	Mail	–	249	Not at all important/ very important	0–6 0–100	–	French	225
D-FISQ [44]	Mail	Past month	266	Never/always	0–3	–	Dutch	67
DHP-1 [20]	Mail	–	2239	Never/always Never/very often Not at all/very much Very likely/ not at all likely	0–3	–	English	150
PAID [19]	Paper sheet	–	451	No problem/ serious problem	0–6	–	English	1251
DTSQ [45]	Paper sheet	Few weeks	219	Very dissatisfied/very satisfied None of the time/most of the time Very flexible/ very inflexible	0–6	–	English	420
Hypoglycemia Fear Survey [46]	Paper sheet	–	158	Never/very often	1–5	–	English	539

Please refer to Table 1 for the full instrument name

<sup>a</sup>According to Google Scholar

**Table 3** Dimensions reported in the selected instruments

Instrument	Dimensions								
	QoL	Emotional distress	Lifestyle	Education and engagement	Treatment <sup>a</sup>	Support	Social	Medical services	Symptoms
DBII [26]					✓				
QoLHypo [27]	✓								
DID-EQ [28]					✓				
SNDR [29]		✓		✓		✓	✓	✓ <sup>b</sup>	
DAS [30]		✓	✓						
Cuestionario ViDa [31]	✓	✓	✓	✓					
DHP—3D [32]		✓	✓						
DHP—5D [32]	✓	✓	✓						
DSTAR-Teen [33]				✓		✓			
DIAB—Q [23]				✓					
CHES-Q [34]	✓			✓					
NDA [35]								✓ <sup>b</sup>	
DSMQ [22]			✓		✓				
APPADL [36]			✓						
EAITQ [25]					✓				
DSC-R [37]									✓
TRIM-D [24]		✓	✓		✓				
TRIM-DD [24]					✓				
DPM [38]			✓						
Dia-MedSat [38]					✓				✓
DSM [38]									✓
ITSQ [39]			✓		✓				
Brief DQOL [40]				✓	✓				
DES [41]		✓		✓	✓				
SDSCA [18]			✓	✓					
DHP—18 [21]	✓	✓	✓						
ADDQoL [42]	✓					✓	✓		
MDQ [43]			✓	✓			✓		
D-FISQ [44]					✓				
DHP-1 [20]	✓	✓	✓						
PAID [19]		✓	✓	✓		✓			
DTSQ [45]		✓			✓				
Hypoglycemia Fear Survey [46]		✓		✓					

Please refer to Table 1 for the full instrument name

QoL quality of life

<sup>a</sup>Treatment satisfaction or dissatisfaction, satisfaction with device, satisfaction with insulin treatment, fear of self-testing

<sup>b</sup>Stands for patient-reported experience measure dimensions; care planning, care provision, healthcare checks, and provider support

person-centered care. These metrics should cover all dimensions relevant to them. Patients with diabetes are often under significant psychological distress because of strict adherence to medications, changes in their daily activities, patterns such as diet and exercise, and fear of long-term macrovascular and microvascular complications, which will undermine their QoL [48].

Diabetes-related distress is defined as patients' concerns about the self-management of diabetes, perception of

support, emotional burden, and access to quality healthcare [49], and is associated with poorer glycemic control and QoL [50–52]. This life experience of the individual with diabetes needs to be measured to provide strategies to cope with diabetes-related distress and properly achieve patient-centered care [53]. However, the traditional management and decisions made in diabetes have focused on reducing glycosylated hemoglobin levels for the prevention of long-term complications. This approach can incur in treatments that are

**Table 4** Evaluation of psychometric properties

Instrument	Reliability		Validity				Respon- siveness
	Internal consistency	Test-retest	Face validity	Content validity	Criterion validity	Construct validity	
DBII [26]	$\alpha = 0.78\text{--}0.92$	–	–	✓	–	✓	–
QoLHypo [27]	$\alpha = 0.901$	ICC = 0.92	✓	✓	✓	✓	✓
DID-EQ [28]	$\alpha = 0.80$	ICC = 0.92	–	✓	✓	✓	✓
SNDR [29]	–	Weighted Kappa = 0.78	✓	✓	–	–	✓
DAS [30]	$\alpha = 0.96$	$r = 0.89$	✓	✓	✓	✓	✓
Cuestionario ViDa [31]	$\alpha = 0.71\text{--}0.86$	$r = 0.78$	✓	✓	✓	✓	✓
DHP—3D [32]	–	–	–	–	–	–	–
DHP—5D [32]	–	–	–	–	–	–	–
DSTAR-Teen [33]	$\alpha = 0.89$	–	✓	✓	✓	✓	–
DIAB—Q [23]	$\alpha = 0.30\text{--}0.68$	ICC = 0.63–0.84	✓	✓	✓	✓	✓
CHES-Q [34]	–	ICC = 0.63–0.83	✓	✓	✓	✓	✓
NDA [35]	–	–	–	–	–	–	–
DSMQ [22]	$\alpha = 0.84$	–	✓	✓	✓	✓	–
APPADL [36]	$\alpha = 0.89$	ICC = 0.91	–	✓	✓	✓	✓
EAITQ [25]	$\alpha = 0.82$	ICC = 0.80	✓	✓	✓	✓	–
DSC-R [37]	$\alpha = 0.69\text{--}0.87$	–	✓	✓	✓	✓	✓
TRIM-D [24]	$\alpha = 0.94$	ICC = 0.85	✓	✓	✓	✓	✓
TRIM-DD [24]	$\alpha = 0.80$	ICC = 0.89	✓	✓	✓	✓	✓
DPM [38]	$\alpha = 0.95$	–	✓	✓	✓	✓	–
Dia-MedSat [38]	$\alpha = 0.79\text{--}0.91$	–	✓	✓	✓	✓	–
DSM [38]	$\alpha = 0.95$	–	✓	✓	✓	✓	–
ITSQ [39]	$\alpha = 0.92$	$r = 0.94$	✓	✓	✓	✓	✓
Brief DQOL [40]	$\alpha = 0.85$	–	–	✓	✓	✓	–
DES [41]	$\alpha = 0.96$	ICC = 0.79	–	–	✓	✓	✓
SDSCA [18]	IIC = 0.20–0.77	ICC = 0.53	✓	✓	✓	✓	✓
DHP—18 [21]	$\alpha = 0.71\text{--}0.88$	–	–	✓	✓	✓	–
ADDQoL [42]	$\alpha = 0.85$	–	✓	✓	✓	✓	–
MDQ [43]	$\alpha = 0.70\text{--}0.91$	–	–	✓	✓	✓	–
D-FISQ [44]	$\alpha = 0.94$	–	–	–	✓	✓	–
DHP-1 [20]	$\alpha = 0.77\text{--}0.86$	–	✓	✓	✓	✓	✓
PAID [19]	$\alpha = 0.95$	–	–	✓	✓	✓	–
DTSQ [45]	$\alpha = 0.76$	–	✓	✓	✓	✓	✓
Hypoglycemia Fear Survey [46]	$\alpha = 0.90$	ICC = 0.89	–	✓	✓	✓	✓

Please refer to Table 1 for the full instrument name

$\alpha$  Cronbach  $\alpha$  coefficient, ICC intra-class correlation coefficient,  $r$  Spearman rank correlation coefficient

complex and intrusive with the patient's QoL. In the last two decades, attempts have been made to measure the relationship between glycemic control and psychosocial functioning [9, 54, 55].

The last disease-specific, health-related QoL systematic review for diabetes was conducted more than a decade ago [56]. Since then, research on PROMs has gained ground, doubling in number as shown in the present study. In this review, only specific diabetes instruments have been

considered because these are tailored to meet patients' needs. Generic instruments assess constructs or feelings relevant for anyone, leaving aside domains such as lifestyle flexibility or interference of diabetes in everyday life [57].

The correct use of the most appropriate instruments must be accurately determined by the researcher, focusing on the outcome pursued in the protocol [58]. Frequently, instruments are not appropriately selected for the purpose as explained by Speight et al. [3]. Additionally, we should

also consider that dimensions can overlap. If we group the reported dimensions of the selected studies according to what they actually ask and measure, the characteristics would be as follows: lifestyle represents 20% ( $n = 14$ ), treatment (includes satisfaction with treatment and devices) represents 18% ( $n = 13$ ), emotional distress represents 17% ( $n = 12$ ), education represents 15% ( $n = 11$ ), QoL represents 10% ( $n = 7$ ), social relations and support represent 13% ( $n = 9$ ), and finally, others (includes general questions and symptoms) represent 4% ( $n = 3$ ). Conversely, PREM instruments address patients' perception of medical services, and the following dimensions were reported, care planning, care provision, healthcare checks, and support provided by healthcare professionals.

Among the most widely used PROMs for measuring the QoL of patients with diabetes are the ADDQoL, the WHO Well-Being questionnaire, and the EuroQoL-5D. However, two of these three are not specific to diabetes [3]. The three most cited scales are SDSCA (2400), PAID (1251), and DES (693). If we include ADDQoL, they mainly focus on healthy lifestyles, diabetes-related distress, and social support. Aspects such as whether individuals received integrated health and social care when required, how their occupational or leisure activities with friends and family are affected, or how their social and religious customs are respected within the framework of the healthcare they receive are areas that have not received sufficient attention in these instruments, although these are relevant issues for patients [59].

Research has predominantly focused on type 2 diabetes; in this review, only one PROM was specifically designed for adolescents with type 1 diabetes [33]. The psychometric properties of the included studies are reported in most of the instruments, and the administration time varies widely from 2 to 30 min. Nevertheless, this may not be enough, as 60% of them are paper based, and even though half of them have been developed in the last 10 years, online application has not taken over, and they do not seem to be systematically implemented. Barriers for proper implementation of PROMs have been identified, including time in the implementation process, lack of access and support in the inner setting, preparing an organization for implementation, especially training clinicians, and the inability of patients to complete instruments in the intervention process [60, 61].

Not all of the included studies considered patients during the development process of the instrument. To achieve person-centered care, individuals need to be part of the healthcare system and process. Qualitative studies have shown that the personal life experience of "living with diabetes" may be influenced by many barriers including social, economic, and cultural beliefs, personal factors, education, access to information, provider support, and medical treatment [62, 63].

Chronicity, defined as the combination of effects and complications that non-communicable diseases have on

patients, is a challenge for all healthcare systems worldwide. Evaluation frameworks such as Triple AIM [64] or the Chronic Care Model [65] propose a shift in the measurement of outcomes and call for new metrics that incorporate health and social intervention experience and lifetime outcomes. The PREM and PROM instruments, such as those included in this review, have been widely used to assess these chronicity strategies implemented by healthcare services [35, 66, 67]. For people with diabetes, it is particularly relevant to address chronicity because of the comorbidity and impact of the disease on their QoL. These instruments can be used in both population-based and experimental studies focused on measuring an intervention's effectiveness from the patient's point of view. However, some of them, because of their length, may be impractical and have a more research-focused approach.

Undoubtedly, there are many instruments, developed in different countries by various healthcare systems or researchers, that mostly focus on patient satisfaction with their treatment, QoL, or fear of complications from treatment. Of these instruments, 78% were designed in the USA or the UK and were in English, the remainder in Spain (Spanish), Sweden (Swedish), Canada (French), the Netherlands (Dutch), and Germany (German). All of them were developed in high-income countries with strong economies and robust healthcare systems. Disease-specific measures are tailored to patient needs; it is not the same construct or feeling between different chronic diseases. To avoid irrelevancies that could cloud the picture, disease-specific measures will have a greater sensitivity. Generic measures (depressed mood, anxiety, energy, and positive well-being) may be common to everybody, but they will not remain constant across different conditions. Hyperglycemic and hypoglycemic episodes or chronic complications may disrupt these concepts and are confounded in people with diabetes [68]. Therefore, there might be a current need to develop diabetes-specific instruments in low-income and middle-income countries, where social, cultural and economic contexts and access to healthcare are different [69].

There were certain limitations in conducting this review. Despite diabetes being one of the most prevalent chronic non-communicable diseases, there is limited information about pathology-specific PREM instruments, unlike PROMs that have been widely developed over the past few years. This study only included variables related to diabetes, thus any other instrument that has not been specifically developed for patients with diabetes has not been included in the review process.

## 5 Conclusions

It is imperative to harmonize healthcare and direct our efforts in knowing the life experience of a patient in the face of his/her pathology. While there are specific validated instruments for people with diabetes, many of them overlap each other, in their subscales and assessment dimensions. The most developed instrument accounts for those related to education, QoL, and satisfaction, leaving the door open for the development of new instruments that measure the experience of a person who “lives with diabetes” and seeks to lead a “normal life.”

**Supplementary Information** The online version contains supplementary material available at <https://doi.org/10.1007/s40271-021-00526-y>.

**Acknowledgements** We thank Dr. Jose M. Valderas for his valuable input into this study. Jimmy Martin-Delgado is supported by a Santiago Grisolia Scholarship (GrisoliaP/2018/158).

## Declarations

**Funding** This study was supported by Prometeu/2017/173 grant (Generalitat Valenciana, 2017).

**Conflicts of Interest/Competing Interests** Jimmy Martin-Delgado, Mercedes Guilabert, and José Mira-Solves have no conflicts of interest that are directly relevant to the content of this article.

**Ethics Approval** This study is part of a wider project with approval of the Ethics Committee of the Kennedy Clinical Hospital of Guayaquil (HCK-CEISH-19-0041).

**Consent to Participate** Not applicable.

**Consent for Publication** Not applicable.

**Availability of Data and Material** Data and material are available from the corresponding author upon reasonable request.

**Code Availability** Not applicable.

**Author's Contributions** All authors contributed to the study conception and design. JM performed the literature search and database equations. JM and MG double checked the literature search results. Data analysis was performed by all the authors. The first draft was written by JM and MG. All authors critically revised the work and approved its final version for publication.

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