



Universiteit
Leiden
The Netherlands

Potency of quality indicators in Dutch and international diabetes registries

Bak, J.C.G.; Serné, E.H.; Wouters, M.W.J.M.; Valk, H.W. de; Mul, D.; Sas, T.C.J.; ... ; Verheugt, C.L.

Citation

Bak, J. C. G., Serné, E. H., Wouters, M. W. J. M., Valk, H. W. de, Mul, D., Sas, T. C. J., ... Verheugt, C. L. (2024). Potency of quality indicators in Dutch and international diabetes registries. *Diabetes & Metabolic Syndrome: Clinical Research & Reviews*, 18(1).
doi:10.1016/j.dsx.2023.102920

Version: Publisher's Version

License: [Licensed under Article 25fa Copyright Act/Law \(Amendment Taverne\)](#)

Downloaded from: <https://hdl.handle.net/1887/4214413>

Note: To cite this publication please use the final published version (if applicable).



Diabetes & Metabolic Syndrome: Clinical Research & Reviews

journal homepage: www.elsevier.com/locate/dsx

Potency of quality indicators in Dutch and international diabetes registries

Jessica C.G. Bak^{a,b}, Erik H. Serné^a, M.W.J.M. Wouters^{b,c}, Harold W. de Valk^d, Dick Mul^e, Theo C.J. Sas^{e,f}, Mark H.H. Kramer^a, Max Nieuwdorp^a, Carianne L. Verheugt^{a,*}

^a Amsterdam University Medical Centers, Amsterdam, the Netherlands

^b Dutch Institute for Clinical Auditing, Leiden, the Netherlands

^c Leiden University Medical Center, Leiden, the Netherlands

^d University Medical Center Utrecht, Utrecht, the Netherlands

^e Center for Pediatric and Adult Diabetes Care and Research, Rotterdam, the Netherlands

^f Erasmus Medical Center, Rotterdam, the Netherlands

ARTICLE INFO

Keywords:

Diabetes mellitus

Quality indicators

Quality of care

ABSTRACT

Background: Diabetes mellitus forms a slow pandemic. Cardiovascular risk and quality of diabetes care are strongly associated. Quality indicators improve diabetes management and reduce mortality and costs. Various national diabetes registries render national quality indicators. We describe diabetes care indicators for Dutch children and adults with diabetes, and compare them with indicators established by registries worldwide.

Methods: Indicator scores were derived from the Dutch Pediatric and Adult Registry of Diabetes Indicator sets of other national diabetes registries were collected and juxtaposed with global and continental initiatives for indicator sets.

Results: This observational cohort study included 3738 patients representative of the Dutch diabetic outpatient population. The Dutch Pediatric and Adult Registry of Diabetes harbors ten quality indicators comprising treatment volumes, HbA1c control, foot examination, insulin pump therapy, and real-time continuous glucose monitoring. Worldwide, nine national registries record quality indicators, with great variety between registries. HbA1c control is recorded most frequently, and no indicator is reported among all registries.

Conclusions: Wide variety among quality indicators recorded by national diabetes registries hinders international comparison and interpretation of quality of diabetes care. The potential of quality evaluation will be greatly enhanced when diabetes care indicators are aligned in an international standard set with variation across countries taken into consideration.

1. Introduction

Diabetes mellitus and its associated comorbidity represent an important public health issue, affecting 463 million adults worldwide with concomitant healthcare expenditures of 760 billion dollars annually [1]. Effective diabetes management is crucial to prevent complications, which is reflected by the close inverse relationship between the quality of diabetes care and the risk of cardiovascular events [2]. Quality of care is assessed by quality indicators, defined as standardized, evidence-based measures of health care quality consisting of clinical parameters [3]. Quality indicators provide physicians with feedback about delivered care and compare these to predefined standards of care [2]. Nationwide diabetes registries are often the source of national diabetes quality indicators. Whether clinical parameters become quality

indicators depends on healthcare professionals, feasibility to collect indicator data, healthcare organizations [4], and stakeholders involved. Around the world, several countries developed quality indicators for diabetes care [3]. Twelve national clinical diabetes registries were identified in our previous systematic review, comprising 7,181,356 patients [5], one of which is the Dutch Pediatric and Adult Registry of Diabetes (DPARD), a nationwide registry including adults and children treated for diabetes mellitus in outpatient clinics across the Netherlands [6].

Numerous studies have shown the ability of quality indicators to improve diabetes management and reduce mortality and costs; they may be used as a tool to evaluate the quality of care, to determine the variability in delivered care both regionally between healthcare facilities and nationally or internationally, and to highlight potential pitfalls and

* Corresponding author. Department of Vascular Medicine, Amsterdam UMC, location AMC, Meibergdreef 9, 1105, AZ, Amsterdam, the Netherlands.

E-mail address: c.verheugt@amsterdamumc.nl (C.L. Verheugt).

<https://doi.org/10.1016/j.dsx.2023.102920>

Received 2 May 2023; Received in revised form 11 August 2023; Accepted 29 November 2023

Available online 9 December 2023

1871-4021/© 2023 Published by Elsevier Ltd on behalf of Research Trust of DiabetesIndia (DiabetesIndia) and National Diabetes Obesity and Cholesterol Foundation (N-DOC).

opportunities for quality improvement at all levels [7]. While these merits are widely recognized, large steps are to be made towards international concordance of quality indicators, which would render the indicators more suitable for enhancing global improvement of diabetes care. However, the global variation in quality indicators and their suitability for comparison is unclear and not previously studied.

Using DPARD, this study aims to describe the quality indicators of clinical diabetes care in the Netherlands, to show the preliminary results, and additionally, to put these indicators in a broader perspective by comparing them with indicators reported by national diabetes registries worldwide. In line with findings in our previous review showing absence of alignment in recorded parameters in national diabetes registries, we hypothesize that there is discordance in quality indicators registered in national diabetes registries worldwide.

2. Methods

2.1. Study population

This observational cohort study included patients visiting one of six outpatient clinics in Dutch Pediatric and Adult Registry of Diabetes (DPARD) between January 1, 2020, and January 1, 2021. DPARD is launched in 2017 and governed by the Dutch Institute for Clinical Auditing (DICA), known for facilitating nationwide audits. DPARD is a quality registry of adult and pediatric outpatient diabetes care in the Netherlands [6]. Exclusion criteria are gestational diabetes and diabetes treated in primary care. Data are collected from electronic health records, processed, and stored by Medical Research Data Management (MRDM), compliant with Dutch and European privacy laws [8]. Data are encrypted to prevent tracing back to individual patients. According to Dutch and European Privacy Protection Laws, no ethical approval or informed consent was required for this study.

2.2. Quality indicators in DPARD

Quality indicators consist of clinical parameters. When healthcare professionals deem clinical parameters appropriate for feedback on delivered care, clinical parameters become quality indicators. Clinical auditing is a quality improvement cycle assessing provided healthcare against predefined standards of care. Quality improvement is initiated by reporting benchmarked feedback to healthcare professionals [9]. When standards are not met, actions are taken. In DPARD, quality indicators have been recorded since 2020, covering structural, process, and outcome indicators. Twenty-six quality indicators are provided to hospitals via weekly updated online reports with individual hospitals anonymized. Indicator results from hospitals are benchmarked against the national average using funnel plots with 95 % confidence intervals. Selected indicators for internal use may be made publicly available (external use) after consideration by all mandated parties, including the board of DPARD, patient federations, healthcare insurance companies, and scientific associations. In DPARD, ten external quality indicators are assessed, including six process indicators and four outcome indicators. The average measurement of each external quality indicator across all participating hospitals was assessed. The patients in the denominator are the number of patients visiting diabetes outpatient clinics of either internal medicine or pediatrics during 2020. Process measures are expressed as percentages of patients monitored at least once during the previous 12 months or the number of patients receiving treatment during this period. HbA1c was expressed as mg/dL with mmol/mol and percentages between brackets with cut-off values below 168 mg/dL (58 mmol/mol, 7.5 %) or above 241 mg/dL (86 mmol/mol, 10.0 %); the most recent HbA1c value was considered. BMI was calculated as weight in kilograms divided by height square in meters. The cut-off value for adult age was 18 years and older; the pediatric endocrinology department used cut-off values up to/including 18 years and above. Diabetes type was derived from the clinical classification entered into electronic

health records by medical professionals. Missing data were included in analyses unless mentioned otherwise. Descriptive statistics were used to assess patient characteristics, disease, and treatment outcomes. Due to non-parametrical data distribution, medians were used for descriptives. Analyses were performed using SPSS (IBM SPSS Statistics for Windows, version 26.0) and R (RStudio, version February 1, 5019).

2.3. Quality indicators worldwide

Indicator sets recorded in the national diabetes registries were juxtaposed with indicators that were proposed on a global level (Organisation for Economic Cooperation and Development, OECD) [10] and (International Consortium for Health Outcomes Measurement, ICHOM) [11], in the United States (Centers for Disease Control and Prevention, CDC) [12], and Europe (European Core Indicators in Diabetes, EUCID) [13]. National diabetes registries around the world with verifiable and publicly available datasets have been identified previously [5]. Indicator sets of these registries were collected from published data, annual reports published online, and original websites of the registries. Only variables defined by the registries as quality indicators were included. Registries were excluded if no published information on quality indicators was found. Quality indicators comprise structure, process, and outcome indicators. Structure indicators give information about healthcare organization, process indicators gain insight into healthcare processes, and outcome indicators provide outcomes in the short or long term. When multiple indicators were combined in one composite endpoint, those indicators were displayed separately. Inclusion terms of similar quality indicators could differ between registries, i.e. on population selection, cut-off values, and time frames. Lipid profile comprised HDL, LDL and/or total cholesterol. Nephropathy included creatine, eGFR and/or measurement of urinary albumin. Lifestyle advice covered smoking, physical activity and/or diet. Glucose-lowering treatment included insulin or oral therapy. Treatment of risk factors was described as antihypertensive, antithrombotic and/or lipid-lowering therapy. Cardiovascular complications were myocardial infarction, coronary artery disease, left ventricular systolic dysfunction, stroke, or cerebrovascular disease. Mortality was described as either all-cause mortality or reported cause of death diabetes mellitus, ketoacidosis, or cardiovascular disease.

3. Results

Between November 2017 and January 2021, 22,692 patients were included in DPARD, 3738 of whom visited the diabetes outpatient clinic during 2020 across six medical centers (four secondary hospitals and two tertiary centers), comprising 8 % of all Dutch general hospitals. Structural follow-up of children occurred in two centers; follow-up of adults occurred in all hospitals.

Table 1 shows all DPARD outpatients in 2020. Of 3425 adults and 313 children, 3384 were treated at a department of internal medicine and 354 at pediatric endocrinology. Median age was 56.0 years in adults and 13.0 years in children. Median diabetes duration was 8.0 years in adults and 4.0 years in children. Sex distribution was comparable, with 53.3 % men in adults and 52.1 % boys in children. Among adult patients, 48.0 % had type 1 diabetes, whereas of children, 93.6 % had type 1 diabetes. Hospitals did not provide diabetes classification in 1.9 % of adults and in 1.0 % of children. Median BMI was 27.7 kg/m² in adults and 20.2 kg/m² in children. Median HbA1c in adults was 175 mg/dL (61.0 mmol/mol, 7.7 %) and in children 183 mg/dL (64.0 mmol/mol, 8.0 %).

Fig. 1 shows the 2020 indicator scores of five volume indicators for diabetes mellitus, all process indicators. Due to incomplete results, scores could not be provided for two quality indicators. Of 354 patients treated at the pediatric department, insulin pump therapy was reported in 164, whereas 512 of 3384 patients at the department of internal medicine were recorded using insulin pump therapy.

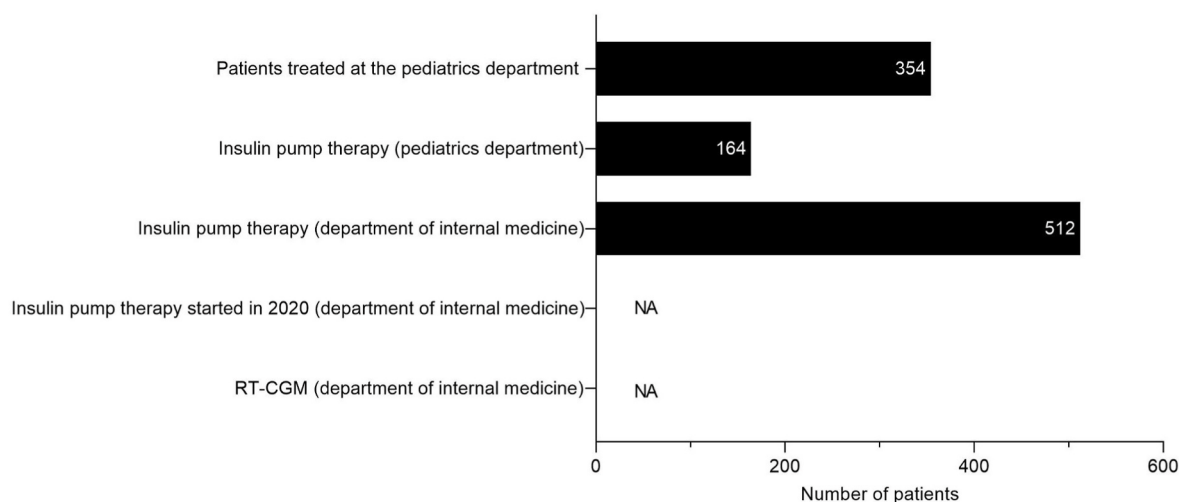
Table 1

Characteristics of adult and pediatric outpatients included in Dutch Pediatric and Adult Registry of Diabetes in 2020.

	Total (n = 3738)	DM type 1 (n = 1938)	DM type 2 (n = 1564)	Adults (n = 3425)	Children (n = 313)
Age (years)	54.0 (1.0–97.0)	41.0 (1.0–97.0)	64.0 (19.0–95.0)	56.0 (18.0–97.0)	13.0 (1.0–17.0)
Male sex (%)	53.2	53.3	52.8	53.3	52.1
Smoker (%)	9.6	9.4	10.0	10.4	0.6
Non-smoker (%)	55.4	54.9	59.3	56.5	43.1
Unknown (%)	35.0	35.7	30.8	33.1	56.2
Diabetes duration (years)	7.0 (0.0–72.0)	7.0 (0.0–72.0)	9.0 (0.0–63.0)	8.0 (0.0–72.0)	4.0 (0.0–16.0)
BMI (kg/m ²)	26.9 (14.0–49.4)	24.6 (14.0–47.1)	30.59 (18.2–49.3)	27.7 (16.0–49.4)	20.2 (14.0–36.3)
<20 (%)	6.8	11.6	0.5	3.0	48.2
20–24 (%)	21.4	30.8	10.1	19.9	37.7
25–29 (%)	24.2	24.6	23.5	25.4	11.5
≥30 (%)	24.5	12.4	40.8	26.6	1.3
Unknown (%)	23.1	20.7	25.1	25.1	1.3
Diabetes type					
Type 1 (%)	51.8	100.0	NA	48.0	93.6
Type 2 (%)	41.8	NA	100.0	45.7	0.0
Other/secondary (%)	0.5	NA	NA	0.4	0.6
Diabetes mellitus unspecified	4.0	NA	NA	4.0	4.8
Unknown (%)	1.8	NA	NA	1.9	1
Systolic blood pressure (mmHg)	132.0 (70.0–235.0)	127.0 (81.0–192.0)	137.0 (70.0–235.0)	133.0 (70.0–235.0)	108.0 (81.0–127.0)
Diastolic blood pressure (mmHg)	77.0 (40.0–126.0)	78.0 (42.0–110.0)	77.0 (40.0–126.0)	78.0 (40.0–126.0)	70.0 (46.0–83.0)
eGFR (ml/min)	84.0 (3.0–100.0)	99.0 (6.0–100.0)	71.0 (3.0–100.0)	84.0 (3.0–100.0)	100.0 (100.0–100.0)
Urine albumine (mg/l)	10.0 (0.2–6175.0)	6.0 (0.3–5555.0)	18.0 (0.2–6175.0)	10.0 (0.2–6175.0)	5.00 (2.70–1690.0)
HDL Cholesterol (mmol/l)	1.3 (0.3–3.9)	1.6 (0.5–3.8)	1.1 (0.3–3.9)	1.30 (0.3–3.9)	1.6 (0.6–3.2)
LDL Cholesterol (mmol/l)	2.4 (0.1–8.4)	2.5 (0.5–6.5)	2.2 (0.1–8.4)	2.4 (0.1–8.4)	2.4 (0.6–6.4)
HbA1c (mg/dL)	175.4 (80.8–404.2)	172.8 (86.0–404.2)	178.1 (80.8–401.6)	175.4 (80.8–404.2)	
HbA1c (mmol/mol)	61.0 (25.0–148.0)	60.0 (27.0–148.0)	62.0 (25.0–147.0)	61.0 (25.0–148.0)	64.0 (35.0–136.0)
HbA1c (%)	7.7 (4.4–15.7)	7.6 (4.6–15.7)	7.8 (4.4–15.6)	7.7 (4.4–15.7)	8.0 (5.4–14.6)

Numbers are stated as a median (range) or percentage (%).

BMI = body mass index, eGFR = estimated glomerular filtration rate.

**Fig. 1.** External volume indicators with scores over 2020 in the Dutch national diabetes registry

Indicator scores are stated as a count per specialty (internal medicine or pediatrics). NA = results not yet available. Number of patients with diabetes mellitus treated at the department of internal medicine = 3384. Number of patients with diabetes mellitus treated at the paediatrics department = 354. , RT-CGM = real-time continuous glucose monitoring.

Fig. 2 shows the five external diabetes indicators reflecting a percentage over 2020, four of which are outcome indicators. The only process indicator was foot examination, performed in 47.5 % of patients treated at internal medicine. The four outcome indicators were on HbA1c control in pediatrics. Among children, 63.6 % had an HbA1c between 168 mg/dL (58 mmol/mol, 7.5 %) and 241 mg/dL (86 mmol/mol, 10 %).

Nine national clinical diabetes databases with publicly published quality indicators were identified from our review on national diabetes registries i.e. Sweden [14], Finland [15], Denmark [16], Norway [17], The Netherlands [6], Germany [18], Scotland [19], England [20,21],

and the United States [22]. Table 2 shows all indicators in national diabetes registries and whether these match with indicators proposed on a global level (OECD and ICHOM indicators) [11], in the United States (CDC indicators) [12], and Europe (EUCID indicators) [13]. Structure indicators are included in ICHOM, CDC, EUCID indicator sets and recorded by Sweden, Finland, and Scotland. Both CDC and EUCID have structure indicators on the incidence and prevalence of diabetes mellitus. ICHOM and Scotland registry include indicators on socioeconomic status. Process indicators are published by all registries except Finland and Norway. HbA1c measurement and eye examination are the only process indicators included in all four OECD, ICHOM, CDC, and EUCID

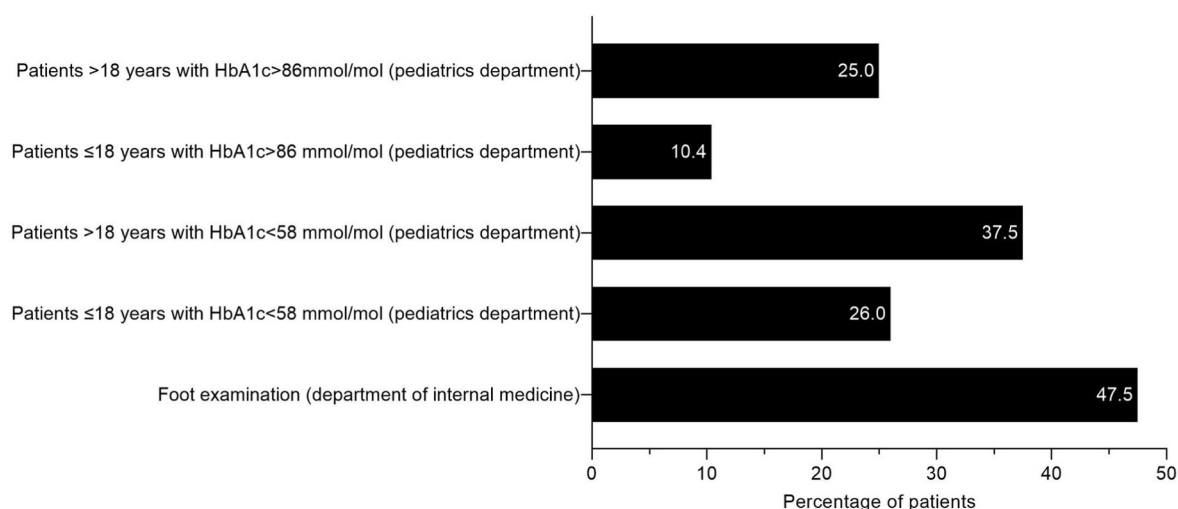


Fig. 2. External diabetes indicators with scores over 2020 in the Dutch national diabetes registry

Indicator scores are stated as percentage (%). Number of patients with diabetes mellitus patients ≤18 years above 18 years treated at the pediatrics department = 346. Number of above 18 years with diabetes mellitus treated at the paediatrics department = 8.

indicator sets. Process indicators on treatment (glucose-lowering and cardiovascular risk treatment) are not included in OECD, ICHOM, CDC, and EUCID indicators. Scotland has reported the most process indicators of all registries. None of the process indicators is published by all quality registries and vice versa. Eye, foot, and nephropathy screening were the process indicators recorded most often by registries.

Table 3 shows an overview of all outcome indicators recorded and advised. Variation exists in (intermediate) outcome indicators published among national registries and international, American, and European initiatives. Denmark does not report outcome indicators. The outcome indicators proposed in all four OECD, ICHOM, CDC, and EUCID indicators are mortality, lower-extremity amputation rates, and the intermediate outcome indicator lipid control, none of which are all recorded by one single registry. Of all outcome indicators, HbA1c control is stated by all except the CDC and Finland. Scotland has reported the most outcome indicators and is the only registry recording indicators about foot ulcers, peripheral arterial disease, severe hypoglycemia, hospitalization, mortality, and cardiovascular revascularization. None of the outcome indicators are reported consistently by all quality registries.

Overall, the similar indicators between OECD, ICHOM, CDC, and EUCID are eye examination, HbA1c measurement, lipid control, mortality, and lower extremity amputation rates. Of all initiatives, ICHOM included most outcome measures and was the only initiative incorporating patient-reported data. The Netherlands and Scotland are the only registries reporting quality indicators explicitly for children. Definitions about the same indicator vary between registries and inclusion criteria. Annual indicator scores are published publicly online by registries from Sweden, Scotland, England, and partially the Netherlands. Other registries make no mention of the public availability of their indicators.

4. Discussion

4.1. Main findings

The present study described the quality indicators of Dutch diabetes care, showed first indicator scores, and put these into an international perspective of indicators proposed and recorded worldwide. In the Netherlands, indicators are registered in the Dutch Pediatric and Adult Registry of Diabetes (DPARD), the quality registry of all patients treated for diabetes in secondary outpatient care. Ten quality indicators are recorded in DPARD, including five treatment volume indicators and five

indicators providing insight into diagnostics and HbA1c control. Eight other national diabetes registries around the world have reported quality indicators, which were compared to quality indicators proposed by initiatives on a global level (OECD and ICHOM), the United States (CDC), and Europe (EUCID). While considerable variation exists, all initiatives proposed eye examination, HbA1c measurement, lipid control, mortality, and lower extremity amputation rates. HbA1c control is most frequently recorded among registries; no indicator is recorded by all. Only Scotland registered a mortality indicator.

In 2020, 8 % of Dutch general hospitals recorded quality indicators through DPARD, which is expected to rise in the following years due to stimulating measures. DPARD is the only diabetes registry reporting an indicator on treatment volumes. Several studies reported treatment volumes to affect outcomes in diabetes care by lowering emergency department attendances for hypo- and hyperglycemia and by improving composite outcome of HbA1c-blood pressure and cholesterol control. However, cut-off values in treatment volumes are not assessed [23]. Volume indicators also give insight into the number of patients treated in outpatient clinics, which may be used for allocation of care and reimbursement purposes. Foot examination was performed in 48 % of Dutch patients; registries from Sweden, Denmark, Scotland, England, and the USA reported scores ranging from 15 % to 95 %. Comparability of indicator scores is limited, as inclusion criteria and reporting year differ. Sweden reported indicator results from 2020, while other registries published scores from 2014 to 2019. Moreover, indicators derived from electronic health records may lead to underreporting if not entered in a discrete fashion by professionals, as with foot examination.

All registries except Finland record HbA1c control. Scotland and England use similar cut-off points as the Netherlands for HbA1c control. Among Dutch children treated by pediatrics, 26 % had HbA1c values below 168 (58 mmol/mol, 7.5 %), whereas Scotland reported better indicator scores with HbA1c levels below 168 (58 mmol/mol, 7.5 %) in 31–38 % of patients. However, Scotland's registry was founded 17 years earlier, which might partially explain this difference, as multiple national registries have been shown to aid in improving glycemic control over time [24].

At the ADA consensus development conference for performance measures in 2010, indicators combining treatment and threshold measures as intermediate outcomes were seen as innovative in measuring quality of diabetes care [25]. Yet the minority of registries record treatment indicators, only Denmark and England combine treatment with intermediate outcomes. DPARD and the Scottish registry include

Table 2
Overview of structure and process indicators proposed in global, American and European initiatives compared to indicators recorded in national diabetes registries worldwide.

Quality indicators	Global (OECD)	Global (ICHOM)	USA (CDC)	EU (EUCID)	Sweden (NDR)	Finland (FinDM)	Denmark (DADR)	Norway (NDR-A)	The Netherlands (DPARD)	Germany (DPV)	Scotland (SCI- Diabetes)	England (NDA)	USA (DCR)
Structure													
Incidence or prevalence of diabetes mellitus			+	+		+					+		
Smoking status				+	+						+		
Age at diagnosis				+									
Financial barriers to care		+											
Education level											+		
Process													
Volume patients outpatient clinic									+				
BMI, height or weight measured		+		+						+	+	+	
Blood pressure measured		+		+			+				+	+	
Eye examination performed	+	+	+	+	+		+			+	+		+
Foot examination performed			+		+		+		+		+	+	+
HbA1c measured	+	+	+	+			+			+	+	+	
Lipid profile measured	+	+		+			+			+	+	+	
Nephropathy screening performed	+			+	+		+			+	+	+	+
Glucose lowering treatment					+		+						
Insulin pump therapy									+		+		
RT-CGM									+				
Treatment of cardiovascular risk factors					+		+					+	+
Influenza vaccination			+										
Pneumococcal vaccination			+										
Examination of insulin injection marks										+			
Dental clinic visit/ periodontal health		+	+										
Diabetes self-management course			+							+			
Lifestyle advice/smoking status assessed										+	+	+	+
Physical activity assessed					+								+

Proposed indicators (global, USA and EU) on the left side of the thick vertical line and the quality indicators recorded by registries on the right.
OECD = Organisation for Economic Cooperation and Development [10], ICHOM = International Consortium for Health Outcomes Measurement [11], CDC = Centers for Disease Control and Prevention [12], EUCID = European Core Indicators for Diabetes mellitus [13], NDR = National Diabetes Register [14], FinDM = Diabetes in Finland [15], DADR = Danish Adult Diabetes Registry [16], NDR-A = Norwegian Diabetes Register for Adults [17], DPARD = Dutch Pediatric and Adult Registry of Diabetes [6], DPV = Diabetes-Patienten-Verlaufsdokumentation [18], SCI-Diabetes = Scottish Care Information – Diabetes [19], NDA = National Diabetes Audit [20,21], DCR = Diabetes Collaborative Registry [22], BMI = body mass index, RT-CGM = real-time continuous glucose monitoring.

Table 3

Overview of (intermediate) outcome indicators proposed in global, American and European initiatives compared to indicators recorded in national diabetes registries worldwide.

Quality indicators	Global (OECD)	Global (ICHOM)	USA (CDC)	EU (EUCID)	Sweden (NDR)	Finland (FinDM)	Denmark (DADR)	Norway (NDR-A)	The Netherlands (DPARD)	Germany (DPV)	Scotland (SCI-Diabetes)	England (NDA)	USA (DCR)
Outcome													
BMI/weight control		+		+	+			+		+	+		
Blood pressure control		+	+	+	+			+		+	+	+	+
HbA1c control	+	+		+	+		+	+	+	+	+	+	+
Time in range		+											
Lipid control (LDL, total cholesterol)	+	+	+	+	+			+		+	+	+	
Retinopathy/blindness		+		+	+					+	+		
Nephropathy/kidney disease	+	+		+	+					+	+		+
Neuropathy		+											
Cardiovascular complications		+		+		+					+		+
Foot disease (ulcer, Charcots's foot)		+									+		
Peripheral arterial disease		+											+
Erectile dysfunction		+											
Lipodystrophy/screening for insulin injection marks		+								+			
Depressive/psychotic disorders/suicide		+	+			+							
Severe hypoglycemia (with or without coma)		+								+			
Hospitalization/emergency department attendance		+	+							+			
Ketoacidosis and hyperosmolar hyperglycemic syndrome		+											
Mortality	+	+	+	+							+		
Laser therapy for proliferative retinopathy				+									
Dialysis or kidney transplantation		+		+									
Cardiovascular revascularization											+		
Lower extremity amputation rates	+	+	+	+		+					+		
PROMs		+											

Proposed indicators (global, USA and EU) on the left side of the thick vertical line and the quality indicators recorded by registries on the right.

OECD = Organisation for Economic Cooperation and Development [10], ICHOM = International Consortium for Health Outcomes Measurement [11], CDC = Centers for Disease Control and Prevention [12], EUCID = European Core Indicators for Diabetes mellitus [13], NDR = National Diabetes Register [14], FinDM = Diabetes in Finland [15], DADR = Danish Adult Diabetes Registry [16], NDR-A = Norwegian Diabetes Register for Adults [17], DPARD = Dutch Pediatric and Adult Registry of Diabetes [6], DPV = Diabetes-Patienten-Verlaufsdocumentation [18], SCI-Diabetes = Scottish Care Information – Diabetes [19], NDA = National Diabetes Audit [20,21], DCR = Diabetes Collaborative Registry [22], BMI = body mass index, PROMs = Patient Reported Outcome Measures.

insulin pump therapy. Insulin pump therapy is reported in 46 % of Dutch versus 39 % of Scottish children and in 15 % of Dutch versus 11 % of Scottish adults. This is consistent with literature that insulin pump use in the Netherlands is high compared to other European countries [26]. It might also be explained by the fact that Dutch insulin pump therapy is better funded and that indicator scores from Scotland date from one year earlier than DPARD, as insulin pump usage increases over time [27].

Wide variety exists in quality indicators published by national diabetes registries, also in definitions on the same topic and inclusion/exclusion criteria, challenging the comparison of indicators between registries. Of all indicators, HbA1c control is registered most often and focuses solely on adult care, except for the Dutch and Scotland registries that report quality indicators specifically for children. These findings are consistent with current literature and may be explained by the notion that adults can advocate better for high-quality health services [28].

A minority of registries report solid endpoint indicators such as complications, cardiovascular comorbidity, and mortality, which is remarkable considering improvement of clinical outcomes to be the primary incentive for monitoring patients. This sparse reporting may be due to the fact that these indicators often take years to develop, and the required follow-up is more challenging to measure. Moreover, long-term outcomes do not facilitate the short-cycled feedback loop that clinicians need to improve quality of diabetes care. Intermediate outcome measures are associated with long-term outcomes and are thus used as surrogates. Surprisingly, intermediate outcomes (control of blood pressure, HbA1c, and cholesterol) are not included in indicator sets of all registries, although, unlike other indicators, adequate control of these risk factors has been shown to improve outcomes in diabetes care [29]. Moreover, none of the registries reported indicators with patient-reported outcome measures (PROMs), while PROMs are believed to provide a better understanding of the patient population.

4.2. What is already known on this topic

Worldwide alignment of diabetes indicators is essential for enabling international comparison and learning from various care systems, thus setting global standards for quality improvement. Multiple attempts have been made to reach international consensus on diabetes indicators [11,13,25]. Concordance exists between all initiatives regarding eye examination, HbA1c, lipid control, lower-extremity amputation rates, and mortality in indicator sets. This is promising, yet none of these indicators is reported by all registries, and substantial variation exists between indicator sets proposed by initiatives and countries worldwide. Several reasons are conceivable for the discordance in quality indicators between countries. First, defining optimal diabetes care quality measures is under debate [30]. Second, differences in healthcare and practice organization influence the indicator selection process [4]. Third, stakeholders with contrasting interests develop quality indicators. Finally, public transparency of indicator results impacts the content of indicator sets. A system where adverse outcomes bear consequences for healthcare institutions could favor indicators less susceptible to the public opinion. Moreover, a straightforward comparison of aligned indicator scores between countries is difficult, given differences in healthcare coverage, healthcare systems, insurance systems, data collection, and demographics. Consequently, a more refined approach is needed to align diabetes indicators between countries considering national differences. In the future, global (ICHOM and OECD), American (CDC), and European (EUCID) indicator sets may be used as a starting point for developing a standard set of quality indicators. A casemix correction model is crucial to account for variation in patient characteristics between healthcare facilities and nations, using casemix variables suggested by ICHOM. After reaching consensus on international indicator sets and casemix models, national validation should follow.

4.3. What this study adds

This is the first study providing an overview of quality indicators among diabetes registries worldwide, which could be seen as a step towards the international alignment of quality indicators. In addition, this is the first time quality indicator scores recorded by the Dutch national diabetes registry are shown.

Our preliminary findings suggesting glycemic control is below the standards of other countries recording quality indicators reflecting diabetes care underscore the necessity of future research comparing quality indicator outcomes on an international level. When indicator scores are below the international standard further research is needed to see where in the care process improvements can be made.

4.4. Limitations of this study

Our study focused solely on quality indicators from diabetes registries included in our previously performed systematic review [31] as these registries were verifiable and its indicators publicly available. Furthermore, it is vulnerable to publication bias as it depended on publication of indicator sets by professionals involved in diabetes registries. Additionally, composite indicators combining information on individual quality measures into single scores were displayed as individual indicators. Furthermore, indicator definitions and inclusion criteria differed between registries, possibly compromising comparison of indicator scores. Moreover, DPARD data are derived from electronic health records, rendering data dependent on recording discretely, possibly resulting in underreporting [32]. Finally, DPARD-data were limited to 2020, coinciding with the COVID-19 pandemic and the concomitant shift of hospital care.

5. Conclusion

Diabetes mellitus is a complex chronic disease for which capturing quality of care in indicators is challenging yet important. Globally, nine national diabetes registries record a wide variety of indicators. Inconsistency in diabetes indicators hinders comparison of the quality of diabetes care internationally. The possibilities of quality evaluation will be maximized further when indicators of diabetes care are aligned in an international standard set with the variation across countries taken into consideration.

Declarations

Contributorship: All authors contributed to the study conception and design. The idea for the article was provided by MW and CV. Writing of the manuscript and statistical analysis were performed by JB and CV. JB, CV, MW, and ES drafted the article. CV, MW, MN, ES, and DM commented on previous versions of the manuscript. All authors read and approved the final manuscript. MK and CV are the guarantors of this work and had full access to all the data in the study and take responsibility for the integrity of the data and the accuracy of the data analysis.

Ethics and other permissions

According to the Dutch and European Privacy Protection Laws, no ethical approval or informed consent was required for this study.

Funding

This work was supported by the Dutch Association of Medical Specialists, the Dutch Diabetes Foundation, and the Netherlands Association of Internal Medicine. Neither organization was involved in the organization of the audit, data collection, or interpretation of data. MN is supported by a ZONMW-VICI grant 2020 [09150182010020].

Data sharing statement

The data underlying this article cannot be shared publicly because hospitals delivering data remain the ownership of their data. Furthermore, DPARD-data contains information that could compromise research participant privacy. The data will be shared at reasonable request to the corresponding author.

Declaration of competing interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests: Max Nieuwdorp reports financial support was provided by Netherlands Organisation for Health Research and Development.

Acknowledgments

The authors thank the diabetologists, paediatric endocrinologists, hospital quality assurance employees, and IT-employees from local hospitals across the Netherlands participating in DPARD. Neither organization was involved in the organization of the audit, data collection, or interpretation of data.

References

- [1] Williams R, Colagiuri SAR. IDF diabetes atlas. Ninth edition. 34–9 2019 2019. https://www.diabetesatlas.org/upload/resources/2019/IDF_Atlas_9th_Edition_2019.pdf. [Accessed 1 December 2019].
- [2] Hermans MP, Elisaf M, Michel G, Muls E, Nobels F, Vandenbergh E, et al. Benchmarking is associated with improved quality of care in type 2 diabetes: the OPTIMISE randomized, controlled trial. *Diabetes Care* 2013;36:3388–95. <https://doi.org/10.2337/dc12-1853>.
- [3] Arnold SV, Goyal A, Inzucchi SE, McGuire DK, Tang F, Mehta SN, et al. Quality of care of the initial patient cohort of the diabetes collaborative registry. *J Am Heart Assoc* 2017;6. <https://doi.org/10.1161/JAHA.117.005999>.
- [4] Fulop NJ, Ramsay AIG. How organisations contribute to improving the quality of healthcare. *BMJ* 2019;365. <https://doi.org/10.1136/bmj.11773>.
- [5] Bak JCG, Serné EH, Kramer MHH, Nieuwdorp M, Verheugt CL. National diabetes registries: do they make a difference? *Acta Diabetol* 2020;1:3. <https://doi.org/10.1007/s00592-020-01576-8>.
- [6] Bak JCG, Mul D, Serné EH, de Valk HW, Sas TCJ, Geelhoed-Duijvestijn PH, et al. DPARD: rationale, design and initial results from the Dutch national diabetes registry. *BMC Endocr Disord* 2021;21. <https://doi.org/10.1186/S12902-021-00782-X>.
- [7] Wilf-Miron R, Bolotin A, Gordon N, Porath A, Peled R. The association between improved quality diabetes indicators, health outcomes and costs: towards constructing a “business case” for quality of diabetes care - a time series study. *BMC Endocr Disord* 2014;14. <https://doi.org/10.1186/1472-6823-14-92>.
- [8] Privacy declaration | Government.nl n.d; 2020. <https://www.government.nl/privacy>. March 20.
- [9] Hoeijmakers F, Beck N, Wouters MWJM, Prins HA, Steup WH. National quality registries: how to improve the quality of data? *J Thorac Dis* 2018;10:S3490. <https://doi.org/10.21037/JTD.2018.04.146>.
- [10] Carinci F, Uccioli L, Massi Benedetti M, Klazinga NS. An in-depth assessment of diabetes-related lower extremity amputation rates 2000–2013 delivered by twenty-one countries for the data collection 2015 of the Organization for Economic Cooperation and Development (OECD). *Acta Diabetol* 2020;57:347–57. <https://doi.org/10.1007/S00592-019-01423-5>.
- [11] Greenfield S, Nicolucci A, Mattke S. Selecting indicators for the quality of diabetes care at the health systems level in OECD countries. 2004.
- [12] Centers for Disease Control and Prevention. In: Indicator definitions - diabetes | CDI | DPH | CDC 2015; 2021. <https://www.cdc.gov/cdi/definitions/diabetes.html>. June 15.
- [13] Final report European Core indicators in diabetes project. 2005.
- [14] Gudbjörnsdóttir S, Miftaraj M, Svensson A, Eliasson B E-OK, Franzen S. Annual report 2020 Swedish National Diabetes Register 2020. <https://www.ndr.nu/#/arsrapport> (accessed June 8, 2021).
- [15] Arffman M, Ilanne-Parikka P, Keskimäki I, Kurkela O, Lindström J, Sund R, et al. FinDM database on diabetes in Finland. n.d.
- [16] Jørgensen ME, Kristensen JK, Husted GR, Cerqueira C, Rossing P. The Danish adult diabetes registry. *Clin Epidemiol* 2016;8:429–34. <https://doi.org/10.2147/CLEP.S99518>.
- [17] Cooper JG, Thue G, Claudi T, Løvaas K, Carlsen S, Sandberg S. The Norwegian Diabetes Register for Adults—an overview of the first years, vol. 23; 2013.
- [18] Grabert M, Schweiggert F, Holl RW. A framework for diabetes documentation and quality management in Germany: 10 years of experience with DPV. *Comput Methods Progr Biomed* 2002;69:115–21. [https://doi.org/10.1016/S0169-2607\(02\)00035-4](https://doi.org/10.1016/S0169-2607(02)00035-4). Elsevier.
- [19] Scottish Diabetes Data Group. Scottish diabetes survey 2019. 2019.
- [20] Gadsby R. Quality and Outcomes Framework and National Diabetes Audit results for diabetes care: why are they different? *Article points* 2013;15.
- [21] National Diabetes Audit. National Diabetes Audit: are services providing good quality diabetes care?. 2017.
- [22] Diabetes Collaborative Registry. Program measures & metrics. n.d.
- [23] Coombs LJ, Burston B, Liu D. Importance of an alternative approach to measuring quality in a volume-to-value world: a case study of diabetes care. *BMJ Open Qual* 2017;6:e000216. <https://doi.org/10.1136/bmjopen-2017-000216>.
- [24] Mair C, Wulaningsih W, Jeyam A, McGurnaghan S, Blackburn L, Kennon B, et al. Glycaemic control trends in people with type 1 diabetes in Scotland 2004–2016. *Diabetologia* 2019;62:1375–84. <https://doi.org/10.1007/s00125-019-4900-7>.
- [25] O’connor PJ, Bodkin NL, Fradkin J, Glasgow RE, Greenfield S, Gregg E, et al. Diabetes performance measures: current status and future directions. 2011. <https://doi.org/10.2337/dc11-0735>.
- [26] Ja M, Sh W, Mj L, Mn C, Tw J, Ea D, et al. Glycaemic control of Type 1 diabetes in clinical practice early in the 21st century: an international comparison. *Diabet Med* 2015;32:1036–50. <https://doi.org/10.1111/DME.12676>.
- [27] L van den, B BK, M A, R-M B, E L, von S S, et al. Temporal trends and contemporary use of insulin pump therapy and glucose monitoring among children, adolescents, and adults with type 1 diabetes between 1995 and 2017. *Diabetes Care* 2019;42: 2050–6. <https://doi.org/10.2337/DC19-0345>.
- [28] Forrest CB, Simpson L, Clancy C. Child health services research: challenges and opportunities. *JAMA* 1997;277:1787–93. <https://doi.org/10.1001/JAMA.1997.03540460051032>.
- [29] Krumholz HM, Lee TH. Redefining quality — implications of recent clinical trials. *N Engl J Med* 2008;358:2537–9. <https://doi.org/10.1056/NEJMp0803740>.
- [30] Pogach L, Engelgau M, Aron D. Measuring progress toward achieving hemoglobin A1c goals in diabetes care: pass/fail or partial credit. *J Am Med Assoc* 2007;297: 520–3. <https://doi.org/10.1001/jama.297.5.520>.
- [31] Bak JCG, Serné EH, Kramer MHH, Nieuwdorp M, Verheugt CL. National diabetes registries: do they make a difference? *Acta Diabetol* 2021;58:267–78. <https://doi.org/10.1007/s00592-020-01576-8>.
- [32] Hu Z, Melton GB, Arsoniadis EG, Wang Y, Kwaan MR, Simon GJ. Strategies for handling missing clinical data for automated surgical site infection detection from the electronic health record. *J Biomed Inf* 2017;68:112–20. <https://doi.org/10.1016/j.jbi.2017.03.009>.