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Pediatric Diabetes

Original Article

Heterogeneity in the systems of pediatric diabetes care across the European Union

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Background: It is known that the systems of pediatric diabetes care differ across the member states of the European Union (EU). The aim of this project was to characterize some of the main differences among the national systems.
Methods: Data were collected using two questionnaires. The first one was distributed among leading centers of pediatric diabetes (one per country) with the aim of establishing an overview of the systems, national policies, quality control (QC) and financing of pediatric diabetes care. Responses were received from all 27 EU countries. The second questionnaire was widely disseminated among all 354 International Society for Pediatric and Adolescent Diabetes members with a domicile in an EU country; it included questions related to individual pediatric diabetes centers. A total of 108 datasets were collected and processed from healthcare professionals who were treating more than 29 000 children and adolescents with diabetes. Data on the reimbursement policies were verified by representatives of the pharmaceutical and medical device companies.
Results: The collected data reflect the situation in 2009. There was a notable heterogeneity among the systems for provision of pediatric diabetes care across the EU. Only 20/27 EU countries had a pediatric diabetes register. Nineteen countries had officially recognized centers for pediatric diabetes, but only nine of them had defined criteria for becoming such a center. A system for QC of pediatric diabetes at the national level was reported in 7/26 countries. Reimbursement for treatment varied significantly across the EU, potentially causing inequalities in access to modern technologies.
Conclusions: The collected data help develop strategies toward improving equity and access to modern pediatric diabetes care across Europe.

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Key words: delivery of health care – reimbursement – QC

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Diabetic children in most European countries benefit from advanced diabetes care and education. Unlike in many other regions of the world, the access is generally not limited by individual social or economic status, by excessive distances to the healthcare providers or by insufficient numbers of adequately trained healthcare professionals. Despite this favorable situation, the outcomes of pediatric diabetes care in Europe are considerably heterogeneous, as previously indicated by the Hvidoere study group (1). In their report comparing selected indicators among 21 pediatric diabetes centers from 17 European countries (2), the average glycosylated hemoglobin (HbA1c) level of the centers' patients significantly varied from 7.4 to 9.2%, whereas the centers did not differ in the frequency of hypoglycemia or diabetic ketoacidosis. Most importantly, the ranking of the centers was remarkably stable over time. The authors concluded that some of the centers were able to implement different treatment regimes more successfully than others. In a later study by the Hvidoere group (3), Swift et al. demonstrated that the therapeutic targets (i.e., the ideal and acceptable HbA1c values as perceived by the parents and adolescents) could explain a considerable proportion of the HbA1c variation among the centers.

The profound differences in average HbA1c levels, one of the major outcome indicators, and the different therapeutic targets set at different centers, may point to a significant heterogeneity in the systems of education and care provided to the diabetic children and their families. The underlying reasons for these variations are presently unknown. Comprehensive assessment of current options in the provision of pediatric diabetes care may help in delineating strategies toward its improvement - including determining the minimum internationally accepted standards and establishing internationally recognized centers.

The aim of the present report was to assess the heterogeneity in the pediatric diabetes care systems in the member states of the European Union (EU) using data obtained from leading health professionals.

Materials and methods

The data were collected using a questionnaire survey among representatives of diabetes care from every EU member state. The survey was done within the framework of the SWEET project (described in the Editorial, pages 1–4).

Two sets of structured questionnaires were utilized for data collection. The first questionnaire, concerning the current status of diabetes care in the EU states, was sent to the heads of the leading pediatric diabetes centers in each of the 27 EU member states. These centers (one per country) were identified on the basis of either scientific or clinical achievements or on the basis of a previous collaboration with the SWEET co-ordinators. This 15-page questionnaire was designed to collect data on the system of pediatric diabetes care, national policy frameworks regarding diabetes care, the quality control (QC) of pediatric diabetes care and its financing.

The second questionnaire (shorter, five pages) was widely disseminated among European members of the International Society for Pediatric and Adolescent Diabetes (ISPAD) using its public address list. All members with a domicile in an EU country were e-mailed a request for help along with this questionnaire. It collected information related to individual pediatric diabetes centers, particularly information on their personnel, practices and attitudes. In order to maintain consistency, the questions from this second (shorter, five pages) questionnaire were also included in the first (longer) questionnaire.

The questionnaires were implemented using the Adobe LiveCycle Designer as active pdf documents. They were distributed among the potential recipients and were collected using the built-in e-mail connectivity function. The recipients were repeatedly reminded if they failed to return the questionnaire in due time and were encouraged to identify other diabetologists if they did not feel competent to answer. There were up to three reminders for the 15-page questionnaire; all 27 national representatives provided us with the requested data set. The shorter five-page questionnaire that had been sent to 354 European ISPAD members required one reminder and was received from 107 (30.2%) of the addressees. The collected data were then processed using a set of Perl 5.10 scripts and analyzed in the Stata 9.0 statistical software and Microsoft Excel.

The collected data reflect the situation in 2009, with later updates on the reimbursement of treatment modalities provided courtesy of the representatives of major manufacturers of insulin, glucometers, insulin pumps and continuous glucose monitoring (CGM) (Novo Nordisk, Bagsvaerd, Denmark; Eli Lilly, Indianapolis, IN, USA; Bayer AG, Leverkusen, Germany; Johnson & Johnson, New Brunswick, NJ, USA; Roche, Basel, Switzerland; Dexcom, San Diego, CA, USA; Medtronic, Fridley, MN, USA). These data on reimbursement reflect the situation as of November 2010.

Results

Organization of care and education

The overview of the systems of diabetes education and care is presented in Table 1. Selected data on the diabetes care systems are now available at the SWEET project website, along with an on-line comparison tool (Fig. 2).

Table 1. Characteristics of the diabetes care systems in the European Union countries

Item	Options	Countries, n of 27
Pediatric diabetes register (incidence register)	•No diabetes register	7
	•Operative register or registers	20
	Scope	
	•National register	13
	•Local or regional register(s)	7
	EURODIAB member	
	•Yes	16
	•No	4
Surveillance of mortality data	•Not available	11
	•Prospectively recorded	5
	•Retrospective survey	9
	•Not answered	2
Patient organizations for children with diabetes*	•Exclusively pediatric	14
	•Common with adults	12
	•not established/not answered	1
Professional diabetes organization	•Operative	26
	•Not established/not answered	1
Centers for pediatric diabetes (officially recognized)	•Non-existent	8
	•Exist	19
	Status of the center is	
	•Permanent	12
	•Pending to reapplication	7
	Status rendered by	
	•Ministry of Health	13/19
	•Diabetes society	6/19
	•Health insurance provider	4/19
	•Other authority	2/19
	Criteria for becoming a center defined	
	•Defined	9
	•Not defined	10
	Participation of a center in a QC† program is	
	•Mandatory	7
	•Voluntary/QC not available	12
Quality control system in pediatric diabetes‡	•Non-existent	18
	•Exists	9
	Organized at the level	
	•National	7
	•One or two centers§	2
	Indicators collected	
	•Glycosylated hemoglobin	9
	•Diabetic ketoacidosis, frequency	9
	•Severe hypoglycemia, frequency	7
	•Growth data	6
	•Quality of life	0
	•Microalbuminuria	6
Education of diabetic patients	•The content is determined by a nation-wide plan of diabetes education	4
	•The content is determined by individual centers	23
Standards of care	Existence of national standard criteria for pediatric diabetes control	
	•Yes	18
	•No	9
	If not, are criteria for adults used?	
	•Yes	1/9
	•Partly	5/9
	•Not stated	3/9
Guidelines for complications screening	•Not existent	11
	•Yes	16
	Are they ISPAD compliant?	
	•Completely	3/16
	•In most instances	11/16
	•In part	2/16

*A list of patient organizations, professional diabetes organizations and their web addresses is given in the Table S1.
†QC, quality control.
‡Specifications of the QC systems are shown in Table 2.
§In small countries, the QC is a mutual data exchange between diabetes centers or a data audit.

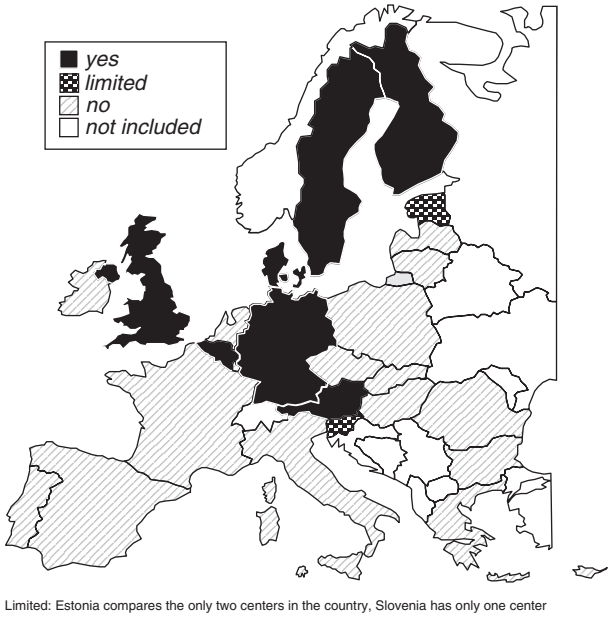


Fig. 1. EU countries with implemented quality control systems.

At least one incidence register was operating in 20/27 countries; 16 of these registers were members of the EURODIAB initiative, therefore, those data were included in the last report (4). Seven countries (Bulgaria, Cyprus, Estonia, France, Greece, The Netherlands, and Portugal) reported that there was no operative pediatric diabetes register, whereas France reported having several regional registers under development. Mortality data were prospectively collected only in Great Britain, Hungary, Lithuania, Slovakia, and Slovenia.

The patient and professional organizations are listed in Table S1. Of the patient organizations, 14/26 were dedicated to childhood diabetes only, whereas 12/26 were shared with adults.

Officially recognized centers for pediatric diabetes existed in 19/27 countries. The authorities rendering the status of the centers differed among countries, and the powers and responsibilities were often shared among institutions. The most frequently involved authority was the Ministry of Health (13/19 countries). The participation of each center in a QC program was mandatory in 7 of these 19 countries.

Systems for QC in pediatric diabetes care existed in 9 of the 27 countries (Austria, Belgium, Germany, Denmark, Estonia, Finland, Great Britain, Slovenia, and Sweden, Fig. 1) and differed widely in their coverage, the set of indicators collected and their feedback to the participants (Table 2). All systems collected data on the glycosylated hemoglobin levels and the frequency of diabetic ketoacidosis. None of the systems collected data on the quality of life.

Some countries had centrally determined standards for the content of diabetes education (France, Slovakia, Slovenia, and Sweden), and 18/27 countries also had national standard criteria for pediatric diabetes control. Of those that lacked these criteria, six used the criteria for adults, either completely or in part. Published guidelines for the screening of complications existed in 16/27 countries, and most were compliant with those issued by the ISPAD (5).

Responsibilities of the diabetes care providers

To learn about the system for sharing responsibility in diabetes care, we asked participants to rate on a 5-point scale from 0 (never) to 4 (always), the role of healthcare providers in five common tasks in diabetes care: prescription of insulin, prescription of glucometers and strips, provision of education, prescription of insulin pumps, and provision of long-term follow-up, including complications screening. The respondents were asked to rate the roles of pediatric diabetologists, diabetologists for adults, pediatricians and general practitioners. The distribution of the sums of the ratings then was used as indicator for the involvement of the different specialists in diabetes care.

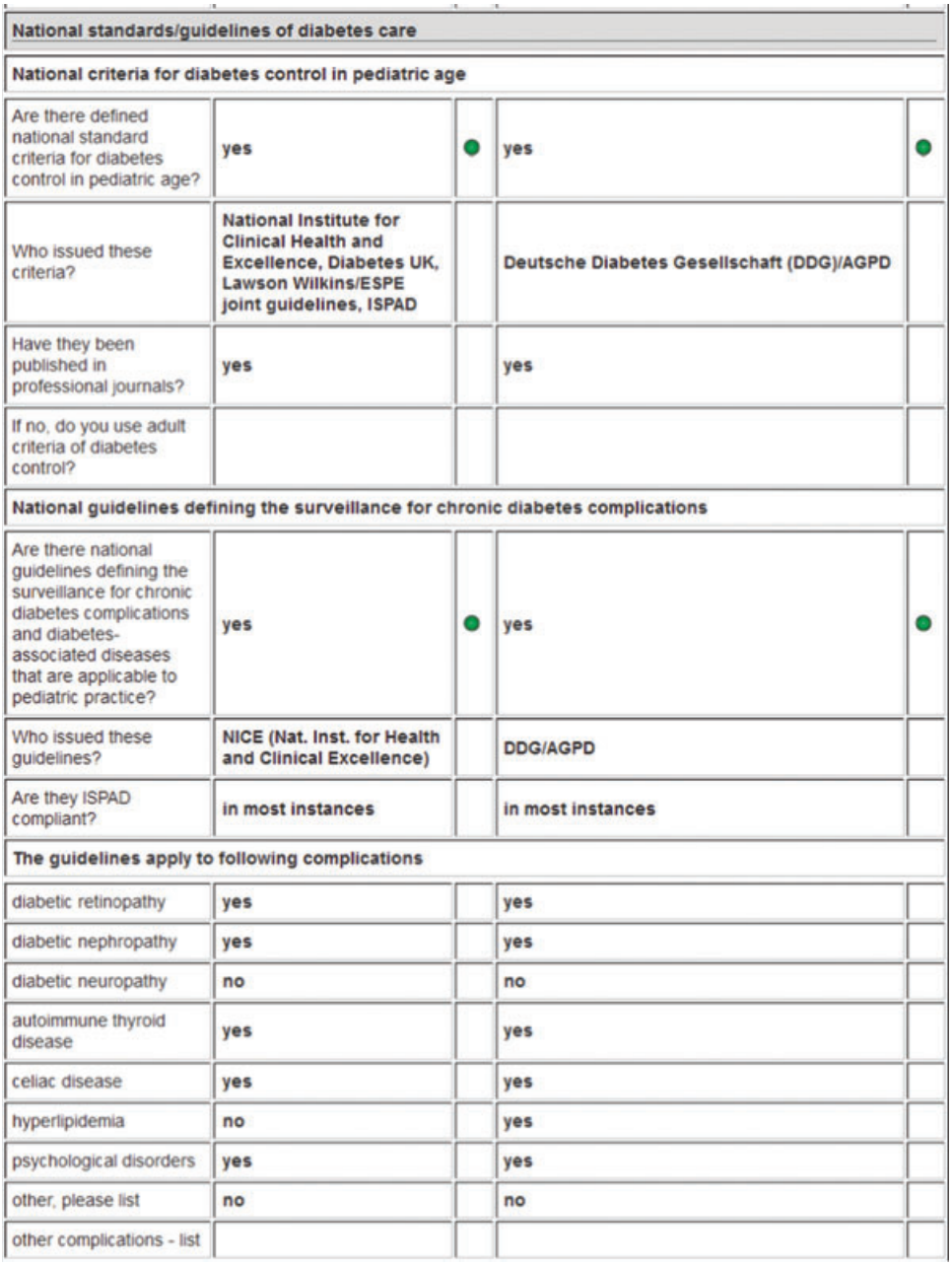
In most countries, pediatric diabetes care was almost exclusively in the hands of the pediatric diabetologists with little or no contribution by the diabetologists for adults (Austria, Bulgaria, Germany, Hungary, Italy, Estonia, Greece, Lithuania, Luxembourg, Poland, Slovakia, Slovenia, Spain, Sweden, and the Czech Republic). Other models involved a stronger contribution of the pediatricians (Finland, France, Ireland, and the Netherlands), the general practitioners (Great Britain and Lithuania) or the diabetologists for adults (Portugal, Denmark, and Belgium). In Romania, pediatric and adult diabetologists, as well as pediatricians, were equally involved in pediatric diabetes care.

Reimbursement for diabetes care

Although human recombinant insulin was covered in all 27 EU countries (with 95% or higher reimbursement), three countries did not cover insulin analogues or the cost to the patient was >5% of the price. Insulin pens were reimbursed by health insurance in 13/27 countries, whereas in the others, the costs were covered by the pharmaceutical industry.

Personal glucometers were reimbursed or given for free in all except three countries (Estonia, Latvia, and Malta). The limits for reimbursement of glucometer strips varied widely, with criteria differing not only among but also within countries (data not shown). In general, strips for four daily measurements seemed to be covered in all countries.

CGM devices were reimbursed in 7/27 countries, with various restrictions, ranging from specific patient



National standards/guidelines of diabetes care				
National criteria for diabetes control in pediatric age				
Are there defined national standard criteria for diabetes control in pediatric age?	yes	●	yes	●
Who issued these criteria?	National Institute for Clinical Health and Excellence, Diabetes UK, Lawson Wilkins/ESPE joint guidelines, ISPAD		Deutsche Diabetes Gesellschaft (DDG)/AGPD	
Have they been published in professional journals?	yes		yes	
If no, do you use adult criteria of diabetes control?				
National guidelines defining the surveillance for chronic diabetes complications				
Are there national guidelines defining the surveillance for chronic diabetes complications and diabetes-associated diseases that are applicable to pediatric practice?	yes	●	yes	●
Who issued these guidelines?	NICE (Nat. Inst. for Health and Clinical Excellence)		DDG/AGPD	
Are they ISPAD compliant?	in most instances		in most instances	
The guidelines apply to following complications				
diabetic retinopathy	yes		yes	
diabetic nephropathy	yes		yes	
diabetic neuropathy	no		no	
autoimmune thyroid disease	yes		yes	
celiac disease	yes		yes	
hyperlipidemia	no		yes	
psychological disorders	yes		yes	
other, please list	no		no	
other complications - list				

A screenshot comparing parameters of pediatric diabetes care among two EU countries (left and right column); http://sweet-project.eu/index.php/country-reports

Fig. 2. The web-based tool for comparison of parameters of the pediatric diabetes care systems.

indications to maximum numbers of sensors per patient. Severe hypoglycemia was one of the most commonly mentioned indications.

Insulin pumps were fully reimbursed without limits in four countries, whereas most countries applied certain restrictions. Four countries had no reimbursement for pumps at the time of the study (Bulgaria, Lithuania, Latvia, and Romania), and a strict national quota of 100 pumps reimbursed per year for children and adults was applied in Portugal. The restrictions varied substantially, being based either on strictly medical indication criteria, on qualification of the prescribing physician, on local funding constraints or on administratively regulated waiting times/prior authorization. The differences among systems for reimbursing consumables for pumps were also complex; whereas some national systems fully reimbursed these consumables, others required co-payments from the patients, covered only limited number of sets per month, or required prior administrative approval (data not shown).

Table 2. Systems of quality control implemented in the European Union countries

Country	Name of the QC organizer	Frequency of indicator collection	Collection of samples*	Feedback	HbA1c	DKA	Hypoglycemia	Growth	Quality of life	Microalbuminuria	Other†
Germany, Austria	DPV	As they are measured	No	Anonymous comparison	Y	Y	Y	Y	N	N	Y
Belgium	Institute of Public Health	Annually	No	Anonymous comparison	Y	Y	Y	Y	N	N	N
Denmark	National register	Annually, some every 3 yrs	Yes	Open	Y	Y	Y	Y	N	Y	Y
Estonia	Comparison of the only two centers in the country	Annually	No	Open	Y	Y	Y	Y	N	N	N
Finland	Finnish Diabetes Association	Every 3rd year	No	Anonymous comparison	Y	Y	Y	N	N	N	N
Slovenia	The only center in the country in collaboration with the hospital		NA	NA	Y	Y	Y	Y	N	Y	Y
Sweden	Swediabkids	As they are measured	no	Open	Y	Y	Y	Y	N	Y	Y
United Kingdom	National Diabetes Audit	Annually	No	General statistics	Y	Y	N	N	N	Y	N

Y, collected; N, not collected; NA, not applicable.
* Collection of biological samples (e.g., for validation of HbA1c) within the QC system.
† The category 'other' includes e.g., screening for coeliac disease, thyroid disease, hypertension, neuro- and retinopathy; smoking, alcohol use.

There was full reimbursement for diabetes education in 11/27 countries. In seven other countries, no separate reimbursements for education were provided (Bulgaria, Greece, Hungary, Lithuania, Poland, Portugal, and Romania). The remaining nine countries applied limits; most often these were defined by frequency (from once in a lifetime to four sessions each year) or setting (reimbursed only if provided to an inpatient). Of note, major differences in the provider payment were reported across the EU (8-29 EUR per education session).

Individual diabetes centers

The 354 ISPAD members with a European domicile returned 107 (30.2%) questionnaires on the diabetes center/practice where they worked. These centers took care of 29 459 patients in total, with a median number of patients of 224. There were 74 university/teaching hospital centers (average size of 320 patients) and 33 centers from other types of hospitals (168 patients on average). Education was provided in 84% of the centers using a plan, which was mostly devised locally. QC was implemented in 68% of the responding centers, mostly those from Germany, Austria, Belgium, Great Britain, Belgium, Sweden, and the Netherlands.

The characteristics of staffing in these centers, stratified by the quartiles of the number of patients, are presented in Table 3. Although the response rate was low and the distribution may have been skewed, there are indices that the increasing size of the center brought about an increased likelihood of employing specialist nurses, educators, and psychologists. Moreover, the non-university centers had a more proportional relationship between the number of physicians and the number of patients as compared to the university hospitals (data not shown).

Discussion

Our study describes selected aspects of the provision of pediatric diabetes care in the EU member states and illustrates how extremely heterogeneous the systems are. In most EU countries, the systems reflect a dynamic balance between the availability of new (potentially more costly) treatment modalities, and the limited financial and human resources. The purpose of this study was to provide baseline data on the status of care for the SWEET project. This project aims to create a network of centers of excellence that would ensure a stable minimum level of state-of-the-art treatment offered across the whole EU, irrespective of the national borders. The data may thus help to identify the strong and weak aspects of the national systems.

Comparison to previous studies

There were several previous projects with aims related to the subject of our survey. The 'EUDIP' (European Diabetes Indicator Project) project identified a set of indicators (core and secondary process/outcome) offering appropriate surveillance of diabetes mellitus within the EU. The 'EUCID' (European Core Indicators in Diabetes) project piloted this set of indicators in 19 EU countries (the missing countries were Bulgaria, Baltic states, Malta, Hungary, the Czech Republic, and Slovakia, but Turkey was included). As shown in its final report (available from http://ec.europa.eu/eahc/projects/linkedocument/sanco/2005/2005109_1_en.pdf, accessed 21 June 2011), some of the indicators were very difficult to collect, and six countries submitted fewer than 12 of the proposed 36 indicators. Moreover, most indicators were available only from sources that were limited considerably by geography or by time and, therefore, were not representative of the whole population. Another project collecting indicators relevant to diabetes care was the B.I.R.O. (http://www.eubirod.eu/academy/monograph/ monograph.html, accessed 21 June 2011). It aimed to standardize information exchange in diabetes. Their approach was novel in their definition of regions as the units of analysis (reflecting the difficulties of collecting nation-wide data) and in an elaborate electronic transfer of data and statistics. However, it appears

Table 3. Staffing of respondents' diabetes centers and clinics and its relation to the number of patients treated

Quartile of the size of the center (patients)	Physicians involved in the care	Centers having diabetic nurse (%)	FTE diabetic nurse	Centers having an educator (%)	FTE educator	Centers having a psychologist (%)
1 (<129)	1.9	80	0.9	20	1.1	52
2 (130–224)	2.5	93	1.6	36	1.4	86
3 (225–349)	3.1	85	1.9	37	1.8	67
4 (350+)	4.7	100	2.5	46	2.1	88
Average	3.1	90	1.7	35	1.7	74

Values are proportions or an average of the centers in the respective quartile. FTE indicates appointment in full-time equivalents.

that their representation of pediatric data was very limited.

This work did not aim at defining an indicator set; we identified readily available information on the national systems of care that would be useful for the other work packages of the SWEET project. Our study has several known limitations. The primary limitation of the study was that the questionnaire on the diabetes care system was sent to only one person per country. In addition, the accuracy of provided data was verified only for reimbursement by using data from industry. Also, our questionnaire intentionally ignored the internal structure of the healthcare systems that may differ between administrative units within the country (federal states, counties, etc.).

Registers and QC

The knowledge of diabetes incidence and its trends may help in the allocation of realistic resources, material and human, needed to cope with the demands of the future patient load. The lack of any pediatric register in seven countries might affect the ability of their authorities to effectively meet the needs of future pediatric patients. Clearly, authorities from countries without diabetes registers will have to find other ways to estimate the future number of children with diabetes, including retrospective assessment of number of patients. Interestingly, a recent report from Canada indicates that the administrative data (hospitalizations, outpatient visits, etc.) may be surprisingly accurate for assessing the true number of diabetic patients (6).

Conclusions from the Hvidoere study indicate that a proper setting and a knowledge of therapeutic targets help to improve diabetes management (3). This may highlight the need for nation-wide plans for diabetes education (now existing in 4 of 27 countries) and especially the need for wide implementation of standard criteria for diabetes control (currently specific pediatric criteria exist in 18 of 27 countries). Conceivably, the activities of patient organizations may influence the perception of the therapeutic goals, yet our study design did not allow for assessment of such effects.

QC systems may be even more important in ensuring adequate pediatric diabetes care. We identified eight QC systems operating in nine countries. Their scope and range varied widely. The glycosylated hemoglobin, an evidence-based outcome indicator reinforced by the results of the DCCT study (7), was included in all QC systems. It was usually collected along with other outcome data (frequency of hypoglycemia, diabetic ketoacidosis, and hospitalizations) or process data (assessment of hypertension, screening for microalbuminuria, or autoimmune complications, etc.). The currently running QC systems in the EU countries varied widely in the extent of collected data, the coverage of the population, and the published results. Probably the most extensive system was operating in Germany and Austria; their DPV (diabetes data acquisition system for prospective surveillance) covered up to 80% of all existing pediatric and adolescent patients [over 27 000 individuals in 2005 (8)], collecting and processing a wide spectrum of data from every diabetic patient. Another large QC system was being run in the UK. The National Diabetes Audit, whose last pediatric report for England and Wales was published for 2007–2008 (http://www.ic.nhs.uk/webfiles/Services/NCASP/audits%20and%20reports/NDA_Paediatric_Report_2008_2009.pdf, accessed 21 June 2011) identified 13 021 children; yet, the completeness significantly varied both with respect to the coverage of the units providing diabetes care (100% in Wales vs. 40% in England) and of the submitted data. Sweden had a pediatric diabetes quality register called SWEDIABKIDS (9) that contained data from 7660 patients (Annual Report at www.ndr.nu/NDR2/Documents/NDR-Child/AnnualReport-2010.pdf, accessed 21 June 2011); this is a 100% coverage of children with diabetes in the population (G. Forsander, personal communication). Interestingly, the above-mentioned systems used calculations to harmonize the glycosylated hemoglobin values to testing performed in different laboratories by different methods. The QC system of the Danish Childhood Diabetes Registry was the only one that collected representative samples for centralized testing of HbA1c. It covered all pediatric diabetes centers in Denmark (10).

This report cannot answer whether the existence of a QC system improves diabetes outcomes. Several papers have indicated that the levels of glycosylated hemoglobin decrease over time as QC systems are implemented [e.g., (2, 8, 10)], but the reason is unknown. Conceivably, the question on the utility of QC in improving metabolic control may be viewed as a 'soft' analogy to the measurement problems of quantum mechanics; an organized study measuring the glycosylated hemoglobin in a cohort constitutes *per se* a mighty stimulus towards improvement in the care. Any organized measurement, or the doctor's awareness of being assessed, is itself a kind of intervention.

Regardless of its direct effect on the glycosylated hemoglobin levels of patients, a QC system helps a diabetes center keep track of its performance metrics, including the glucose control of its patients, the incidence of hypoglycemia and diabetic ketoacidosis among its patients, its ability to detect and manage diabetes complications, and other process and outcome indicators. Although the organization of a QC system may incur significant costs, any improvement in the glycosylated hemoglobin towards a therapeutic target

may lead to significant societal financial savings, as shown by a health-economic study from the USA (11). Despite the differences between the US and EU in the financing of health services, this reduction in costs may still be very attractive. A German study had pointed in a similar direction, indicating that an increased glycosylated hemoglobin level was an independent predictor of higher total costs for pediatric diabetes care (12).

Access to modern treatment modalities

The main finding of this study is the extreme heterogeneity of pediatric diabetes care systems across the EU, yet at this stage, in our project, we cannot assess whether (and to what extent) this heterogeneity is reflected in the metabolic control or quality of life. As very clearly exemplified by a recent publication from the Hvidoere study (3), predictors of treatment success are very difficult to identify, but the knowledge and motivation of the patient may be a major contributing factor. Little is known about the long-term effects of modern treatment modalities on glycosylated hemoglobin, whereas ample evidence is available on the short- and intermediate-term beneficial effect of insulin analogues, continuous subcutaneous insulin infusion, and CGM. Notably in this context, the existing QC systems do not collect quality of life measures, although this would be feasible using computerized systems

The access to modern treatment and its effective use, including intensive education, may be dependent on who provides the care. In most countries, the pediatric diabetologist played the leading role, although there are models with a stronger contribution by the pediatricians, general practitioners, or diabetologists for adults. Other work packages of the SWEET project have now suggested the minimum standards of staff needed to provide pediatric diabetes care, based upon expert opinion.

The effective size of diabetes centers

The number of patients widely varied among centers; moreover, we could observe a significant bias toward university hospitals and centers from countries with a more advanced system of QC. This study cannot determine the minimum effective size of a center. Nevertheless, we could observe that the centers in the lowest quartile are less likely to have a qualified pediatric specialist nurse, an educator or a psychologist. Although we may assume that the responders are biased toward the more active ISPAD members, the overall picture of centers taking care of almost 30 000 diabetic patients cannot be overlooked. In our opinion, one of the prerequisites necessary for establishing any QC system is determining a minimum number of patients. This 'critical mass' of patients enables an allocation of adequate resources, ensures effective education, and lets the personnel achieve proficiency by daily contacts with the patients. This minimum number may depend on the geographical, institutional, and organizational issues specific to the individual countries. A taskforce of the SWEET project has set the minimum number of patients for the SWEET collaborative centers to 150 [see elsewhere in this issue (13)].

Conclusions

Despite the demonstrated significant differences between countries in terms of the diabetes care systems, the main challenges of diabetes care are identical across the EU. The SWEET project should help ensure standards in pediatric diabetes care across Europe, taking into account local factors, and should promote the internationally recognized criteria and procedures. This survey may help define the current status, unravel the previously unseen weaknesses, and identify the strong aspects of care in the participating countries.

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Conflict of interest

The authors declare no conflict of interest.

Supporting Information

Additional Supporting Information may be found in the online version of this article:

Table S1. Patient organizations for diabetic children and organizations for diabetes professionals.

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References

1. Danne T, Mortensen HB, Hougaard P et al. Persistent differences among centers over 3 years in glycemic control and hypoglycemia in a study of 3,805 children and adolescents with type 1 diabetes from the Hvidore Study Group. Diabetes Care 2001: 24: 1342–1347.
2. de Beaufort CE, Swift PG, Skinner CT et al. Continuing stability of center differences in pediatric diabetes care: do advances in diabetes treatment improve outcome? The Hvidoere Study Group on Childhood Diabetes. Diabetes Care 2007: 30: 2245–2250.
3. Swift PG, Skinner TC, de Beaufort CE et al. Target setting in intensive insulin management is associated with metabolic control: the Hvidoere childhood diabetes study group centre differences study 2005. Pediatr Diabetes 2010: 11: 271–278.
4. Patterson CC, Dahlquist GG, Gyurus E, Green A, Soltesz G. Incidence trends for childhood type 1 diabetes in Europe during 1989-2003 and predicted new cases 2005-20: a multicentre prospective registration study. Lancet 2009: 373: 2027–2033.
5. Donaghue KC, Chiarelli F, Trotta D, Allgrove J, Dahl-Jorgensen K. Microvascular and macrovascular complications associated with diabetes in children and adolescents. Pediatr Diabetes 2009: 10 (Suppl 12): 195–203.
6. Dart AB, Martens PJ, Sellers EA, Brownell MD, Rigatto C, Dean HJ. Validation of a pediatric diabetes case definition using administrative health data in manitoba, Canada. Diabetes Care 2011: 34: 898–903.
7. The Diabetes Control and Complications Trial Research Group. The effect of intensive treatment of diabetes on the development and progression of long-term complications in insulin-dependent diabetes mellitus. N Engl J Med 1993: 329: 977–986.
8. Gerstl EM, Rabl W, Rosenbauer J et al. Metabolic control as reflected by HbA1c in children, adolescents and young adults with type-1 diabetes mellitus: combined longitudinal analysis including 27,035 patients from 207 centers in Germany and Austria during the last decade. Eur J Pediatr 2008: 167: 447–453.
9. Hanberger L, Samuelsson U, Lindblad B, Ludvigsson J. A1C in children and adolescents with diabetes in relation to certain clinical parameters: the Swedish Childhood Diabetes Registry SWEDIABKIDS. Diabetes Care 2008: 31: 927–929.
10. Svensson J, Johannesen J, Mortensen HB, Nordly S. Improved metabolic outcome in a Danish diabetic paediatric population aged 0-18 yr: results from a nationwide continuous Registration. Pediatr Diabetes 2009: 10: 461–467.
11. Minshall ME, Roze S, Palmer AJ et al. Treating diabetes to accepted standards of care: a 10-year projection of the estimated economic and health impact in patients with type 1 and type 2 diabetes mellitus in the United States. Clin Ther 2005: 27: 940–950.
12. Icks A, Rosenbauer J, Haastert B et al. Direct costs of pediatric diabetes care in Germany and their predictors. Exp Clin Endocrinol Diabetes 2004: 112: 302–309.
13. Danne T, Lion S, Madaczy L et al. Criteria for Centers of Reference for pediatric diabetes – a European perspective. Pediatr Diabetes 2012: 13 (Suppl. 16): 62–75.