Pediatric Diabetes 2012: 13(Suppl. 16): 62–75
doi: 10.1111/j.1399-5448.2012.00914.x

Pediatric Diabetes

Original Article

Criteria for Centers of Reference for pediatric diabetes – a European perspective

Danne T, Lion S, Madaczy L, Veeze H, Raposo F, Rurik I, Aschemeier B, Kordonouri O, the SWEET group. Criteria for Centers of Reference for pediatric diabetes – a European perspective.
Pediatric Diabetes 2012: 13 (Suppl. 16): 62–75.

'SWEET' is an acronym standing for 'Better control in pediatric and adolescent diabeteS: Working to crEate CEnTers of Reference (CORs)' and is based on a partnership of established national and European diabetes organizations such as International Diabetes Federation, Federation of European Nurses in Diabetes, and Primary Care Diabetes Europe (PCDE, www.sweet-project.eu). A three-level classification of centers has been put forward. In addition to centers for local care, SWEET collaborating centers on their way to being a COR have been defined. Peer-audited CORs with a continuous electronic documentation of at least 150 pediatric patients with diabetes treated by a multidisciplinary team based on the International Society for Pediatric and Adolescent Diabetes (ISPAD) Clinical Practice recommendations have been created in 12 European countries. In 2011, they cared for between 150 to more than 700 youth with diabetes with an average hemoglobin A1c between 7.6 and 9.2%. Although these clinics should not be regarded as representative for the whole country, the acknowledgment as COR includes a common objective of targets and guidelines as well as recognition of expertise in treatment and education at the center. In a first step, the SWEET Online platform allows 12 countries using 11 languages to connect to one unified diabetes database. Aggregate data are de-identified and exported for longitudinal health and economic data analysis. Through their network, the CORs wish to obtain political influence on a national and international level and to facilitate dissemination of new approaches and techniques. The SWEET project hopes to extend from the initial group of centers within countries, throughout Europe, and beyond with the help of the ISPAD network.

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Key words: audit – electronic health record – HbA1c – quality control – reference centers

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Submitted 5 April 2012. Accepted for publication 16 April 2012

In the 1990s, a group of leading pediatric diabetes centers chose to compare their outcomes by means of a centralized determination of the most relevant laboratory value of prognostic importance for the long-term outcome, the hemoglobin A1c (HbA1c). This Hvidøre Study Group on Children's Diabetes published their first paper in 1997 (1) and showed that there was great variation in mean HbA1c from 7.4 to 9.1% in 2873 children and adolescents with diabetes between centers in 21 countries. In the centers where youth had lower HbA1c they did not necessarily have higher rates of hypoglycemia. The subsequent Hvidøre studies have systematically examined why the centers were so different, but center differences still persisted (2, 3). To date, all the Hvidøre studies suggest that positive outcomes are influenced by consistent messages and philosophies by all team members, good psychosocial support, defined targets, and structured consistent education to achieve active self-management (4).

Previous research within the 'Better control in pediatric and adolescent diabetes: working to create Centers of Reference (SWEET)' project regarding systems for quality control in pediatric diabetes care in Europe demonstrated that these existed in 9 of the 27 countries (5) and differed widely in their coverage, the set of indicators collected, and their feedback to the participants. Probably, the most extensive system was operating in Germany and Austria; their Diabetes Patienten Verwaltung, German Electronic Health Record for Diabetes-Initiative covered up to 80% of all existing pediatric and adolescent patients [over 27 000 individuals in 2005 (6), collecting and processing a wide spectrum of data from every diabetic patient]. Already in 2008 they were able to show that comparing the time period of 1995–1997 to 2003–2004, the percentage of pediatric patients within the HbA1c target range had increased significantly from 25% to above 45%. As published in the previous papers of this supplement, the main finding of the SWEET analyses of current status was the extreme heterogeneity of pediatric diabetes care systems across the European Union (EU); yet, at this stage of the project we cannot assess whether (and to what extent) this heterogeneity is reflected in the metabolic control or quality-of-life of patients. Over the past 3 yr, multidisciplinary SWEET Centers of Reference (CORs) have been created, defining and providing appropriate diabetes care for young people. However, there remains more work to be done. Next to communicating about appropriate care and treatment, the SWEET project identified the need for a continuous monitoring system, which will also provide a tool to import data to an online system for data management (7). As such, a database was created about Diabetes Care across Europe with the purpose to monitor and reduce inequalities in care between and within countries. Benchmarking between centers will identify cost-efficient delivery of care, leading to reduced inequalities, improved care and health outcomes, and efficient use of resources. The present paper reviews the process and the prerequisites of becoming a COR and describes the initial data collected. In conclusion, in addition to ongoing data analysis with benchmarking on an international level, the major advantages for implementing a system of CORs and becoming a COR are fourfold:

- A common objective of targets and guidelines
- Recognition of expertise in treatment and education
- Political influence on a national and European level
- Implementation and dissemination of new approaches and techniques

Methods

During the European project period seven SWEET meetings were organized. All project partners including the Steering Committee of International Society for Pediatric and Adolescent Diabetes (ISPAD), International Diabetes Federation (IDF), and Federation of European Nurses in Diabetes, an independent Advisory Assessment Committee including a representative of a parent's organization and a medical ethics specialist, corporate partners, and other key stakeholders (e.g., pediatric diabetes research organizations) were invited. The definition of a COR and the outline of the process to become a COR have been the product of these discussion based on the information collected during project, which is outlined in the other papers of this supplement. The process toward a COR included the following steps: (i) application (ii) need to submit electronic data annually (iii) nomination for Collaborative Center (iv) need to meet criteria during 3 yr (v) audit (vi) nomination for COR. The requirements and criteria for a SWEET Collaborative Center and SWEET COR are summarized in Table 1.

National and regional differences will make it necessary that children will be treated in a system of different levels of care. Depending on local circumstances, not every European country will need all the levels of care that are proposed within the SWEET project; however, we suggest that at least one COR with the best level of care should be established in each country, although several countries will have significantly more CORs. Within the SWEET project, we distinguish between three levels of care:

- *Level 1: Regular hospital/practice: care for its own geographical area*:

Particularly in sparsely populated areas primary care physicians will play an important role to deliver care on a local basis. Models for the collaboration

Table 1. Summary of requirements for becoming a Center of Reference (COR)

Requirements for a SWEET Collaborative Center
Has an electronic health record with longitudinal data (minimum: age, diabetes duration, gender, diabetes type, and hemoglobin A1c) of 150 patients with an age of ≤18 yr
Is involved in a quality circle with this data
Employs a pediatrician with diabetes expertise and a nurse with pediatric diabetes expertise
Knowledge and skills of a dietician, psychologist, and/or social worker are present
Follows the International Society for Pediatric and Adolescent Diabetes (ISPAD) guidelines
Includes at least one ISPAD member
Fulfills national requirements for specialist education
Has out-patient diabetes services with confirmed in-patient access
Requirements for a SWEET COR
Member of SWEET e.V. – payment of membership fee
Need to submit data annually (usually every 6 months) to the central server (at least twice)
One-year no data transfer: 'yellow card'
Two-year no data transfer: loss of present accreditation
Audit every 5 yr
Criteria of a SWEET COR – checked by peer review/audit
Sufficient activity and capacity to provide relevant services at a sustained level of quality
Capacity to provide expert advice, diagnosis, or confirmation of diagnosis, to produce or adhere to good practice guidelines, and to implement outcome measures and quality control
Multidisciplinary approach with pediatric diabetes expertise
High level of expertise and experience, as documented through publications, grants, or honorific position, teaching and training activities
Strong contribution to research
Involvement in epidemiological surveillance such as registries
Close links and collaboration with other national and international expert centers, and capacity to network
Close links and collaboration with patient associations where they exist
Appropriate arrangements for patient referrals from other European Union countries
Appropriate capacities for diagnosing, following up, and managing patients with evidence of good outcome where applicable

between these level 1 points of care with specialized multidisciplinary teams have been developed, for example, in the Federal State of Schleswig-Holstein in Germany (8) or in its most extreme form with the Outreach Clinics in Australia (9).

- *Level 2: SWEET Collaborating Center*:

The adherence of a large proportion or number of patients is covering a geographical area that contains a number of regular hospitals. This center would be a prospective COR but may lack some characteristics at the time. Collaboration within the SWEET project with help of the SWEET toolbox will help to raise the bar to eventually become a COR if it so desires. It is mandatory as a SWEET Collaborating Center to submit anonymous data on quality control to the SWEET database.

- *Level 3: SWEET COR*:

Such a center would fulfill level 2 on addition to all criteria outlined below and would be involved in the development of 'new state of the art' treatment strategies: research (applied and/or basic), education, and should be leading and taking initiatives in national programs (reimbursement, guidelines, and education), linked with international collaborations on related matters. In addition to a regular submission of data like a SWEET Collaborating Center, a COR will undergo peer review with an audit process described below.

Several workshops have outlined the definitions for becoming a 'Collaborating Center' in order to eventually qualify to become a 'COR': in order to ensure sufficient resources, the Center should treat at least 150 patients with an age of ≤18 yr. This minimum patient number is justified below. The qualified multidisciplinary approach has to be guaranteed by having a pediatrician with diabetes expertise and a nurse with pediatric diabetes expertise. In addition, the presence of knowledge and skilled dietitian, psychologist, and/or social worker is recommended. To ensure links to the International Scientific Community, at least one ISPAD member has to be employed at the Center. There is the need to have an electronic health record with longitudinal data documentation on, at least, the following: age, diabetes duration, gender, diabetes type, and HbA1c. This is required as a basis for continuous process and outcome data evaluation. It is required to participate in quality circle inclusive data analysis and to follow the ISPAD guidelines (10). The respective national curriculum for specialist education needs to be fulfilled, and out-patient diabetes services with confirmed in-patient access need to be established. SWEET members felt that the same treatment philosophy should be followed through the whole circle of care.

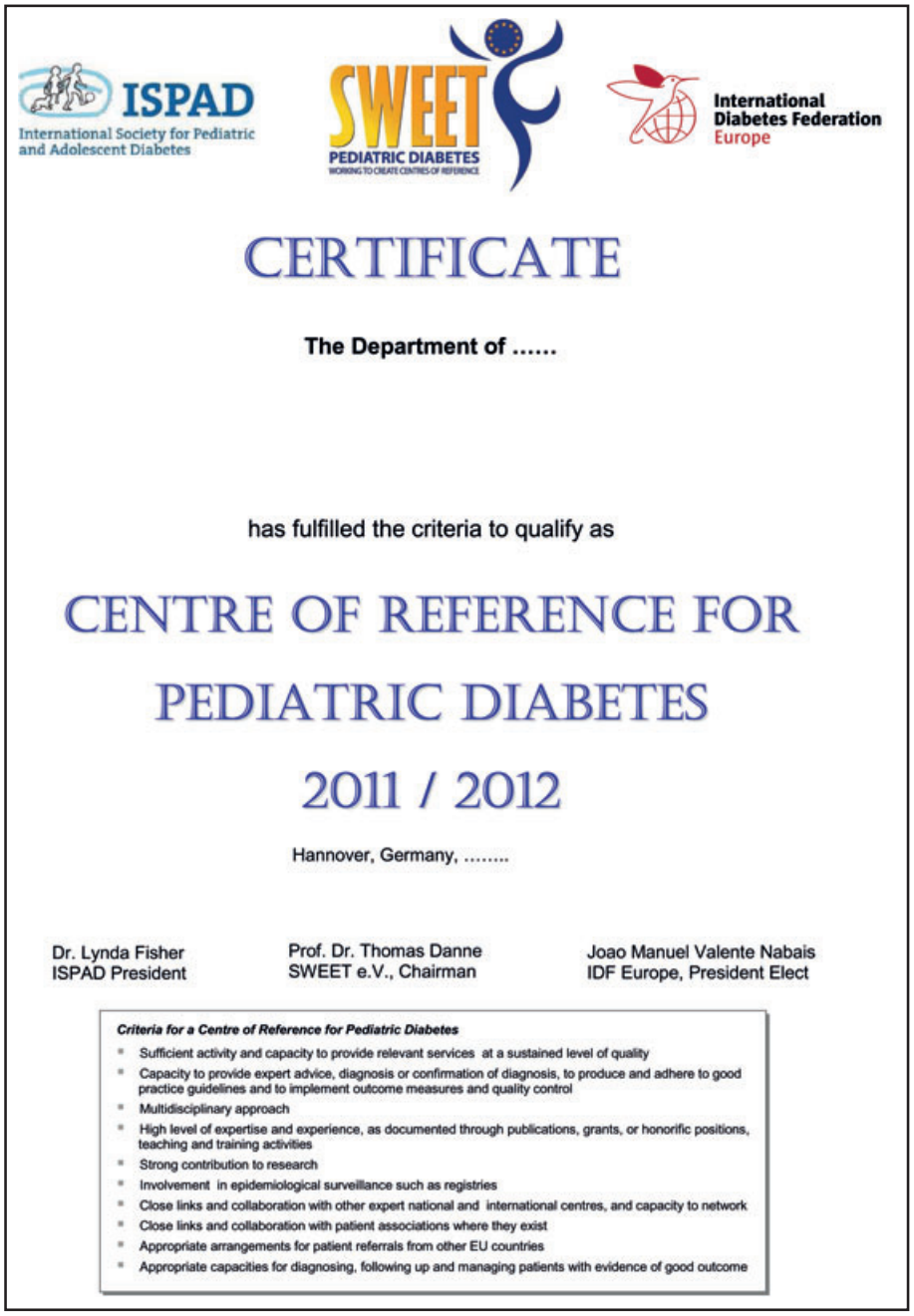

Fig. 1. Example certificate of a Center of Reference (COR). All CORs are approved by International Society for Pediatric and Adolescent Diabetes (ISPAD) and International Diabetes Federation (IDF) Europe for a time period of 2 yr. Depending on sufficient submission of longitudinal data, the certificates are renewed every year with a repeated audit process every 5 yr.

The accreditation is delivered by SWEET with approval from ISPAD and IDF Europe. For those Centers that have been approved as Collaborative Centers for at least 1 yr they may be then recognized as COR (Fig. 1). As the COR is based on sustained efforts in for care of children and adolescents with diabetes, 1 yr was felt as minimum for establishing a continuum of exchange between the new and established members of SWEET. Each COR needs to submit data annually (usually every 6 months) to the central server. This is needed as incomplete data collection or patients 'lost to follow-up' were considered as important factors in evaluating process quality data. For the ongoing data collection, it was proposed that 1-yr no data transfer would result in a warning 'yellow card', whereas 2-yr without data transfer would result in a loss of the present accreditation. The electronic data review needs to be checked by an auditing visit to each Center with peer review every 5 yr. As a balance between cost and effort of regular assessment vs. the risk of infrequent

peer review, such a cycle was chosen as a consensus of the original SWEET group and will be reevaluated on a continuous basis.

Results

Initial data analysis of the centers from different countries in Europe reporting their 2011 data showed a high fill in rate of almost 100% (Fig. 2). The number of patients treated varied significantly between the centers. The mean age of the patients is dependent on if the pediatric diabetes clinic is caring for young adults as well, that is how, and at which age, the transition to adult care is locally arranged. We can conclude that in centers with about the same tradition of transferring the patients at the age of 18 yr, the mean age of the whole group is about the same in the different countries, around 13 yr. There has been a trend during the latest 20 yr in Northern Europe to lower age at diagnosis (11) but the majority of patients are teenagers. In some centers, the follow-up age limit is extended to fulfill the wishes and needs of patients beyond the 18–25-yr old until they a reach more established treatment results. As can be seen from Fig. 3, the amount of the different health care professionals (HCPs) per patient largely varies and does not simply reflect the time-consuming efforts associated with insulin pump treatment. Also, the admissions rate varies largely, which is assumed to be related to local logistic and/or financial reasons.

The duration of diabetes in the treated patients tracks in parallel as expected with the age of the patients and is around 7 yr. As the data were uploaded retrospectively as well as prospectively, a first glimpse at changes in metabolic control within the center is possible (Fig. 4), although potential bias regarding representativeness of data and differential completeness of follow-up need to be assessed further. Clearly, presently the data are biased as the number of patients entered in a lot of participating centers was not representative for the whole center. The longitudinal changes of the average HbA1c have already led to intense discussions between the members of the SWEET group and will likely lead to changes in local practices aiming at further improvement of outcomes.

As much as transparency through data exchange and a quality circle are the most important tools for quality development, the SWEET group has introduced the principle of frequent peer review by means of an external audit process as additional tool in the process of becoming a COR. A structured form was developed to guide the peer review (Appendix). To sustain the high level of care this external center visit needs to be repeated every 5 yr. For the initial 12 centers approved by ISPAD and IDF Europe, this audit was provided by members from the original SWEET group. The auditors needed to follow a structured interview and personal center visit to check all aspects relevant for COR application (Appendix). Within the structure of the new legal entity SWEET e.V., it is planned to develop an independent audit process of auditors trained in the specific aspects relevant to pediatric diabetology. Currently, the documents of the audit and the COR application are reviewed by the boards of ISPAD and IDF Europe after a recommendation by the SWEET board.

Discussion

The present report summarizes the discussions on the process of becoming a COR and the initial data collected from the first 12 CORs. Through extensive structures in health care, it is indispensable to concentrate diabetes relevant information and to gain more efficiency in all aspects through a sophisticated networking of the parties. The outcome of the interdisciplinary care of the patients in medical practices, hospitals, and ambulatory health care centers as well as the implementation of integrated utility supply contracts needs evaluation. A reliable, computerized, on-line registry for diabetes-related variables facilitates and admits focus on indicators of quality and process in the daily work at the local, out-patient clinic. The registry can be used for comparison of data within the diabetes unit but also as a tool for comparison and benchmarking between different units in the country and between countries.

In Sweden, there exists an operational national registry of pediatric diabetes data since 2000 (SWEDIABKIDS). Since the web-based on-line registry was introduced in January 2008 with unblinded results from every clinic, there is an obvious trend toward better outcome data in those clinics using the data actively (12).

The number of patients widely varied among CORs; moreover, we could observe a significant bias toward university hospitals and centers from countries with a more advanced system of quality control. Clearly, the participating SWEET clinics should not be regarded as representative for the whole country but as a basis to establish the criteria. Thus, the present evaluation cannot determine the minimum effective size of a center. Nevertheless, we observed within the project that the centers in the lowest quartile are less likely to have a qualified pediatric specialist nurse, an educator, or a psychologist (Table 3 in reference 5). Although we may assume that the responders of the SWEET questionnaire 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 quality control system is determining a minimum number of patients. This 'critical mass' of patients enables an allocation of

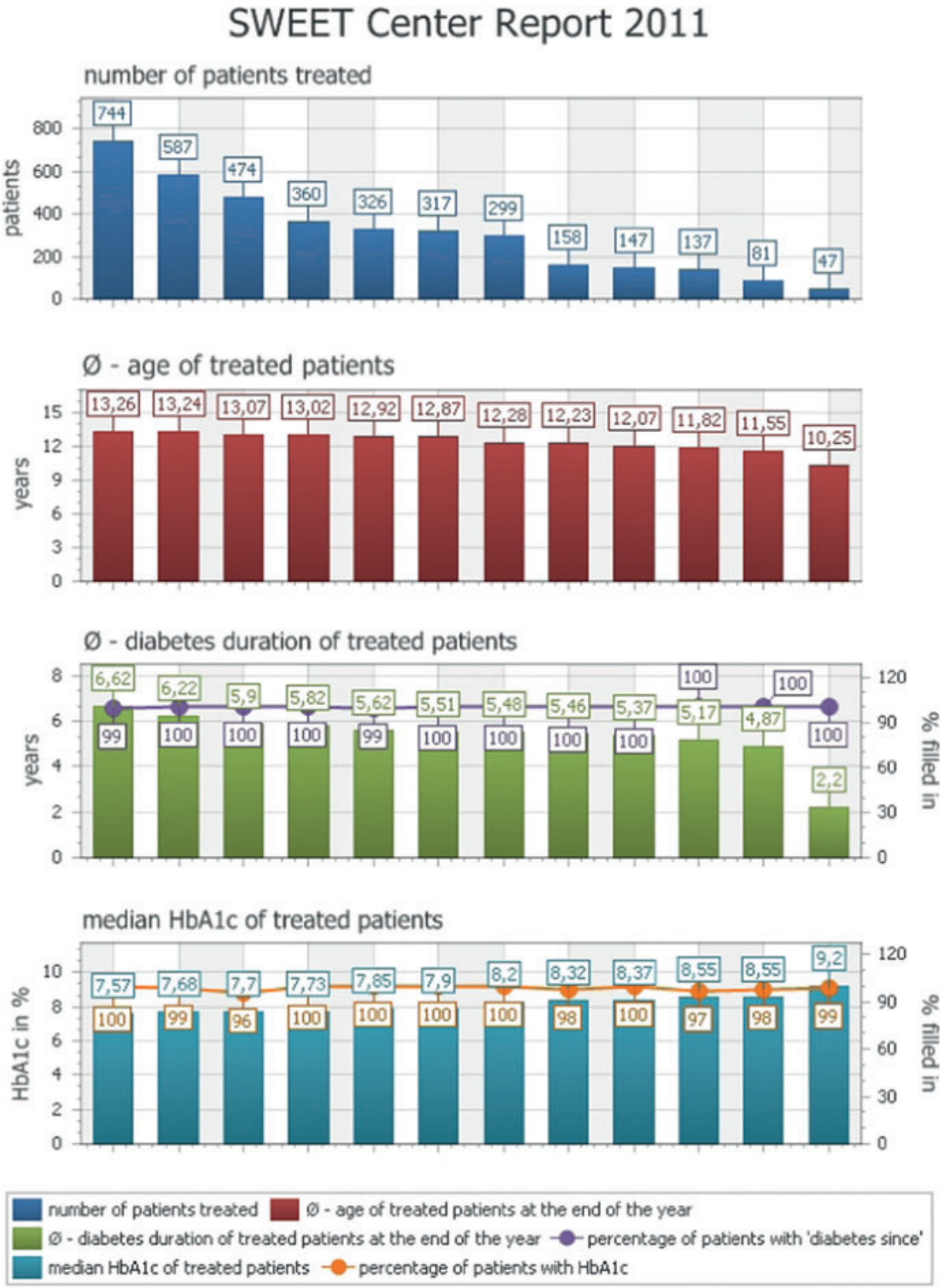

Fig. 2. Status of the resubmission of data of the initially approved Centers of Reference. Not all centers were able to submit electronic data of 150 patients with an age of <19 yr at the due date (top panel). The boxes on the bars represent the total number of patients or the mean age, diabetes duration, or hemoglobin A1c (HbA1c) at the different centers. The completeness of the data (in %) can be seen in the little box beneath the average HbA1c. Bars are grouped according to mean, so not all individual center data are placed at the same position.

Clinic	1	2	3	4	5	6	7	8	9	10	11	12
Age range	1–32	1-22	0-18	0-19	1–22	0-18	0-20	0.5-21	0 – 21	0-35	0-25	
Nr. of patients	153	170	215	414	491	503	550	587	622	620	880	1020
Clinical admissions	13%	19%	10%	85%	7%	15%	27%	NA	59%	11%	3%	94%
Newly diagnosed in last year	20%	13%	9%	9%	7%	13%	8%	9%	13%	23%	6%	16%
Secondairy referals in last year	13.1%	4.7%	1.4%	4.1%	1.6%	0.8%	4.5%	13.1%	3.4%	0.0%	13.6%	3.0%
Insulinepump use	22%	12%	50%	30%	4%	38%	10%	0%	59%	2%	60%	72%
Patients per fulltime Medical Specialist (cost factor 2.5)	102	89	195	207	98	252	262	196	138	310	281	255
Patients per fulltime Nurse (cost factor 1)	85	77	215	207	123	144	275	294	183	89	152	510
Patients per fulltime other HCP (cost factor 1)	255	113	36	230	164	252	367	245	169	620	244	340
Patients per total number HCP (cost factor 1)	75	60	67	141	76	144	189	148	102	143	153	204

Fig. 3. Heterogeneity in health care delivery: results of the audit process, total number of patients, and profile data and number of patients served by different health care professionals (HCPs).

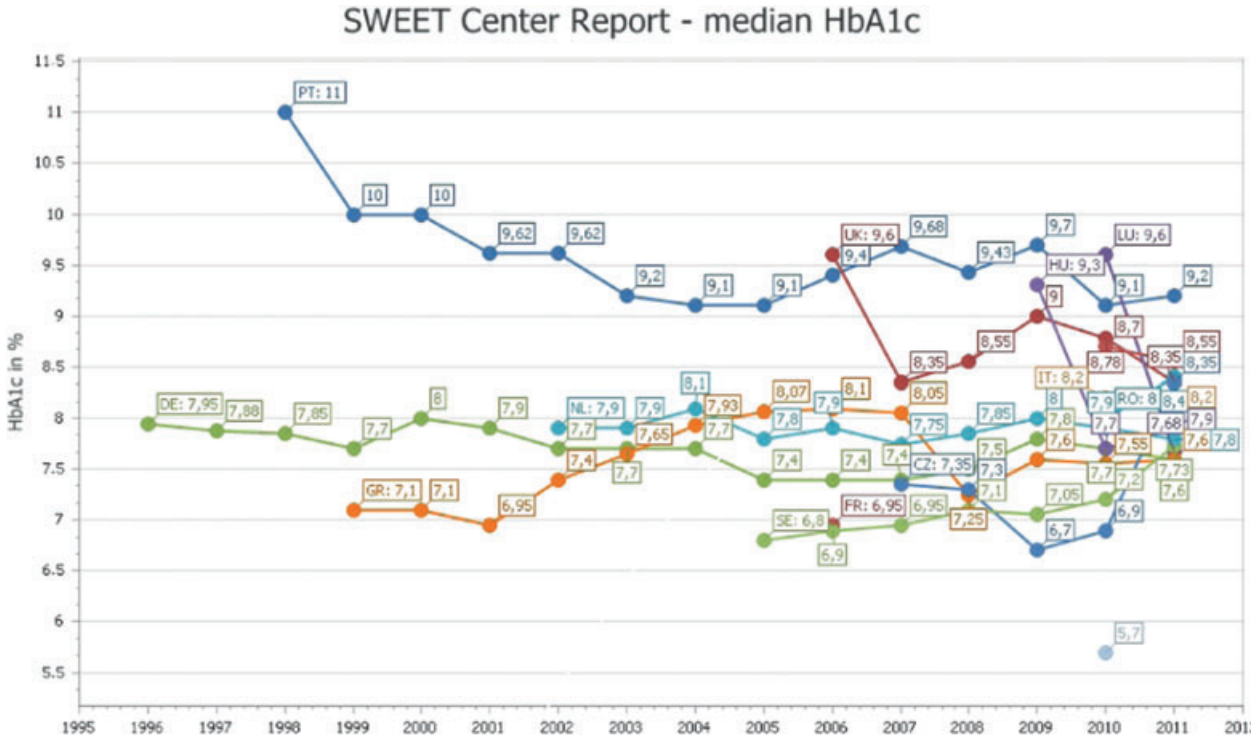

Fig. 4. Longitudinal changes in the hemoglobin A1c (HbA1c) as major outcome parameter of average metabolic control for children with diabetes treated in the different Center of Reference over time.

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.

The taskforce of the SWEET project has set the minimum number of patients for the SWEET collaborative centers to 150. As can be seen in the previous paper (5), many centers in Europe will be able to fulfill this criterion. Nevertheless, the audit process revealed that the exact allocation of resources differs considerably. It can be expected that setting such a level will even help to stimulate center growth and increase staffing quantity and quality in many countries. Center size and internal structure of the team influence the health care costs largely. For example, the audit process confirmed that admission rates differ largely between countries and therefore this will have an impact on costs. An appropriate reimbursement on out-patient care and organization of care preventing unnecessary admission will reduce costs. Expenditure for personnel is estimated to be approximately 70–80% of total costs of an out-patient clinic (excluding use of patient consumables). The relationship of these two parameters can be seen in Fig. 3. Despite all differences in attitudes, treatment regimens, and admission rates, the figure suggests that centers can be too small to be cost-effective. Therefore, in some geographical areas, allowing centralization of care may reduce costs. Also, the numbers of patients in many clinics do not justify to specialize a fulltime and focused effort or to have local colleagues with the same focus. Centralization may thus facilitate expertise. The cost savings may then be shifted to more upcoming technologies to further improve the outcome, which is

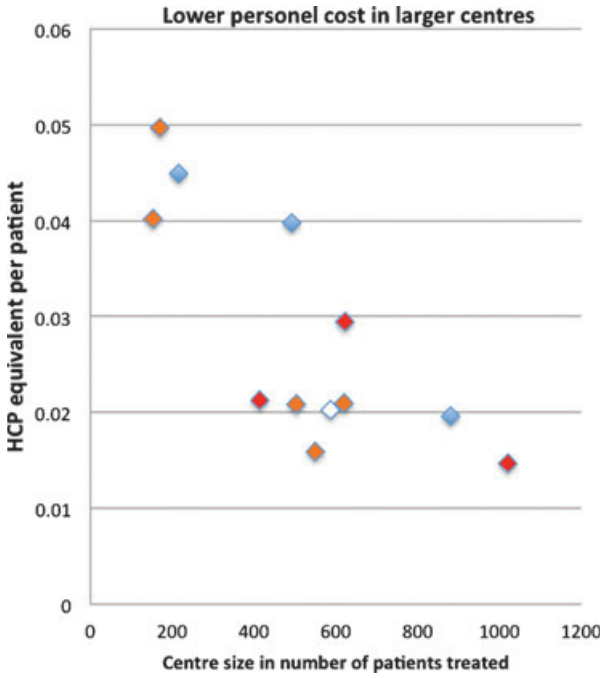

Fig. 5. Estimated relationship between the health care provider (HCP) resources per year of treatment per patient. In these data, the costs for additional personnel involved in hospital are not included. The costs for a medical specialist are estimated as 2.5 times higher compared to other HCP. The virtual equivalent cost of a non-specialist team member is set as 1 for comparative purposes. Red centers gave a hospital admission rate of more than 50% and the orange have more than 10%, whereas others are lower (blue) or unknown (white). Data are based on information collected during the audit process.

of major importance for the long-term cost savings for the treatment for complications. At the same time, the complexity of these new technologies requires expertise for which the changing structure of care is required. Other diseases such as leukemia and cystic fibrosis have already benefited from the changes in the structure of care.

Diabetes is a chronic disease where a high quality of care has a proven impact on the prognosis of the individual patient in terms of life expectancy and quality-of-life (13). It also has an obvious impact on society in terms of medical costs, insurance expenditures, and working capacity of the stricken patients (14). A high quality of care is possible by prospective measurement of the target achievement by the single diabetes unit. The guidelines to follow should be based on evidence, relying on solid data from a high number of patients, who are treated according to a well-defined policy and updated according to the results. The SWEET group has decided as a next step to develop SWEETONLINE to enable the patient to login for access to his/her own patient portal and to fill in forms on quality-of-life measurement. This is thought to be a major step forward to a person-centered care (15).

To sustain the achievements that have been accomplished within the project 2007104: 'SWEET', which has received funding from the EU in the framework of the Public Health Programme, the existing network has been transformed into a legal entity, SWEET e.V., as a registered charity. The leading role of the most important worldwide society for pediatric diabetes, ISPAD, has been implemented in the constitution to ensure that any development within SWEET is closely linked to evidence-based medicine and future developments in pediatric diabetes therapy. SWEET e.V is now an independent legal entity, headquartered for practical reasons in Hannover, Germany. Its constitution was modeled according to a template used by the European Alliance for Diabetes Research (www.euradia.com). SWEET is closely linked to ISPAD, with one of the three positions leading the organization being appointed by the ISPAD executive. According to its agreed statutes, SWEET e.V. is a non-profit organization, aiming to support the creation of CORs for pediatric diabetes. A member of SWEET e.V. can be 'any charity in the area of diabetes and any company that is interested in the aims of SWEET e.V.' The prerequisite for becoming a member is to send an application for membership addressed to the Executive Committee of SWEET e.V. Priorities of SWEET e.V. moving forward are to develop and conduct education programs for health professionals, to accredit dedicated health professionals, such as pediatric diabetologists, to produce and/or accredit education programs for patients and parents, and to audit and approve CORs. Furthermore, SWEET e.V. will organize meetings to discuss SWEET data to exchange information and best practices at national and international levels, to develop and improve pediatric diabetes IT tools, and to collaborate with relevant agencies and organizations. In the short term, SWEET wishes to expand beyond the original SWEET partners and countries.

In this next phase, SWEET seeks therefore to expand the implementation of these reference centers so that all European patients and HCPs have access to innovative diabetes care and information. The most efficient and rapid way to exchange information is by an eHealth system through which young people can communicate and interact with their treatment center by uploading and downloading individual diabetes-related data. In addition, such system will allow for joint studies and the rapid exchange of information between major centers for pediatric diabetology to adequately implement advances in diabetes therapy.

Now that the first CORs have been created, it is the time to expand the implementation of these centers so that all European patients and HCPs have access to innovative diabetes care and information. SWEET seeks to develop and establish an eHealth

system through which young people can interact with their treatment center by uploading and downloading individual data. We look for means so that data can be imported to an online system for data management, creating a database about diabetes care across Europe. This system will allow for monitoring inequalities in care and for benchmarking, leading to reduced inequalities, improved health outcomes, and efficient use of resources. As diabetes is one of the most common chronic diseases in children, the continued work within the SWEET project may serve as an excellent reference model for children suffering from any type of chronic disease.

Conflict of interest

The authors declare no conflict of interest.

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Appendix

Audit form for pediatric diabetes Centers of Reference

Audit form for

Pediatric Diabetes Centers of Reference

www.sweet-project.eu

SWEET	
Date of clinic visit	
Name(s) visiting person(s)	
CLINIC	
Institute	
Department	
Address	
Place	
Country	
Contact person	
Email	
Phone	
Fax	
University affiliated	
Hospital based	
Non-profit institute	
Private clinic	
Outpatient clinic	[ ] General facility also other patient groups
	[ ] Facility dedicated for diabetes

ALL PERSONEL

(1) Paediatric diabetologist, (2) Paediatric endocrinologist, (3) Paediatrician physician, (4) Fellow, (5) Resident peadiatric, (6) Nurse specialist, (7) Dietician, (8) Psychologist, (9) Social worker, (10) other (11)……..(12)……..

care providers nr according list	Experience (years)	Fulltime equivalent for diabetes care only	Patient notes in Paper based dossier	Patient Notes in Electronic Health Record

PATIENTS	Total	type 1	type 2	MODY	Other
Number patients					
Age range					
Number of new patients in last year: Recent diagnosis Elsewhere / referal					
Upper age limit / transition					
% treated continuously					
Insulin regime					
MDI-2xdaily					
MDI-3xdaily					
MDI->3xdaily					
MDI+sensor in last yr					
CSII					
CSII +sensor in last yr					
Avg HbA1c (%)					
% patients HbA1c<7.5					
Avg number of annual visits					
Avg number of annual additional contacts (phone, email, intercurrent out-patient visits					
Hospital admissions in last year:					
- New diagnosis DM					
- DKA					
- Hypoglycemia					
- Total number					
Education					
a-All education by team members or b-(in part) outsourced					
Number of specific group education sessions in last year					

Average group numbers					
Number of specific educations sessions for minority groups in last year					
Number of general info meetings for patients / parents in last year					
Involvement in diabetes camps					
Involved in patient organisations					
Involved in national health care discussions					
Giving lectures					
Authorships in scientific papers					
Participation in clinical trials					

PART II - OBSERVATIONS by visitor (Free txt)	
(inter) national guidelines present and in use: - which one - by whom - consistent use	
Protocols - present - in use - compliance	
Urgent patient calls - 24h service - who?	
Indicators used for quality control of total patient group - which - frequency of evaluation	
Quality of patients health record keeping	
IT facilities	

Team member meetings about: - patient treatment - patient education strategies - improvement strategies - organization issues - attendance of team members?	
Internal organization - formal - leadership - responsibility for patient outcome	
Education program of care providers - internal - external and - for which team members	
Participation and involvement according part 1 of questionnaire	
Attitudes toward improvement strategies	
Greatest impediment for improvement - reimbursement issues for patients - clinical facilities - insurance issues - personnel - financial	

CONCLUDING	
Eligible as EU diabetes reference center	☐ maybe : ☐ yes ☐ no
Impressions, similarities, differences	
Most inspiring experiences	
Most urgent suggestion for improvement	

Location, date

Signature