

Education and training in paediatric diabetes: the UK position. Survey on behalf of the SWEET Project 2008–11

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Abstract

The aim of the three-year SWEET Project EU was to establish Centres of Reference for Paediatric Diabetes in order to improve standards of care for children and young people (CYP) with diabetes across Europe. Part of this project involved making recommendations about education of CYP and their families, as well as of health care professionals (HCPs). The following UK data collected in 2009 contributed to the SWEET final data collection. Information covered diabetes education to CYP with diabetes, their families, staff in schools and HCPs. An online questionnaire was circulated to HCPs who were involved in the care of CYP with diabetes.

Responses from 100 HCPs were received, mainly from larger more specialised clinics and included all members of the multidisciplinary team (MDT). Results showed that few services have written comprehensive educational curricula for CYP; programmes of education are predominantly focused on education for insulin adjustment/carbohydrate counting protocols and pump therapy, with major deficiencies in psycho-social interventions, family communication, continuing education and transition programmes. Learning outcomes are not adequately assessed and programmes are rarely linked to diabetes outcomes.

These deficiencies exist partly because paediatric diabetes has not been recognised or contracted as a specialty service. The majority of HCP posts in paediatric diabetes do not demand prior experience in the specialty. Standardised and accredited initial and continuing professional development opportunities are severely limited and often there is little support from NHS trusts. The functioning of MDTs could be improved through agreed team philosophies, consensus on targets and increased MDT 'business meetings'. Respondents gave overwhelming support to the development of a National Paediatric Diabetes Framework that includes accredited, validated, structured education programmes for CYP, their families, schools and HCPs. Copyright © 2011 John Wiley & Sons.

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Key words

diabetes; education; survey; paediatric; training; recommendations; outcomes

Introduction

Over the past three decades, the results of surveys of paediatric diabetes services in the UK have been published, most recently the fifth survey in 2010.¹ Although there have been substantial improvements within services, recent national data in the UK still suggest that diabetes control is consistently poor² in comparison to other European countries that are members of the SWEET Project.³ The SWEET Project EU³ was initiated for this very reason as variable standards of care and diabetes outcomes had been identified across Europe. The UK was one of the founder members of the SWEET Project.

Data from the UK surveys showed improvements in standards: 98% of clinics are being run by consultants with a special interest in diabetes;

fewer clinics but with larger patients lists; paediatric diabetes specialist nurses attending clinics increasing from 61% (1988) to 94% (2008); paediatric dietitians in clinics increasing from 37% (1988) to 93% (2008). Despite improvements, the results cannot be generalised to all units and deficiencies still exist in dietetic provision, psychological support, the transition process and lack of emergency 24-hour contacts from the paediatric diabetes team. As diabetes management becomes progressively more complex, greater provision and higher standards of education for all (children and young people [CYP], parents/carers, school staff and health care professionals [HCPs]) are required to produce improved clinical outcomes. There is a scarcity of information about educational

provisions and standards in paediatric diabetes. The fifth survey showed that 70% of the 205 clinics provided structured patient education, most being locally developed programmes as no validated educational programmes for CYP exist.¹ One of the aims of the SWEET Project⁴ is to assess educational provision in the EU for CYP, their families and HCPs, and this paper describes the results of a survey of such provisions in the UK.

Methodology

A questionnaire was designed to collect information on the diabetes education of (a) CYP with diabetes and their families, (b) staff in schools, and (c) HCPs. There were four sections (53 questions, with subsections), and space was available for open qualitative commentary. The sections included:

- Clinic demography, organisation and standards of care.
- Education environment and communication.
- Content of education and programme delivery.
- HCP training, continuing professional development (CPD) of HCPs and future developments.

The questionnaire was designed by a multidisciplinary team (MDT) of clinical experts in paediatric diabetes. It was based on questions that had face validity and, although not piloted, a 'test and re-test' of its reproducibility was performed.

The questionnaire was distributed via email by the secretaries of the following groups to HCPs in paediatric diabetes care across the UK (England, Wales and Northern Ireland) in September 2009 over a three-month period. In the case of psychologists, personal communication was used because of a lack of a national psychologists group. The professional groups circulated were: Association of Children's Diabetes Clinicians; British Society for Paediatric Endocrinology and Diabetes (BSPED); Diabetes Management and Education Group of the British Dietetic Association; Royal College of Nursing (paediatric diabetes nursing section); and personal communication with psychologists working with CYP with diabetes.

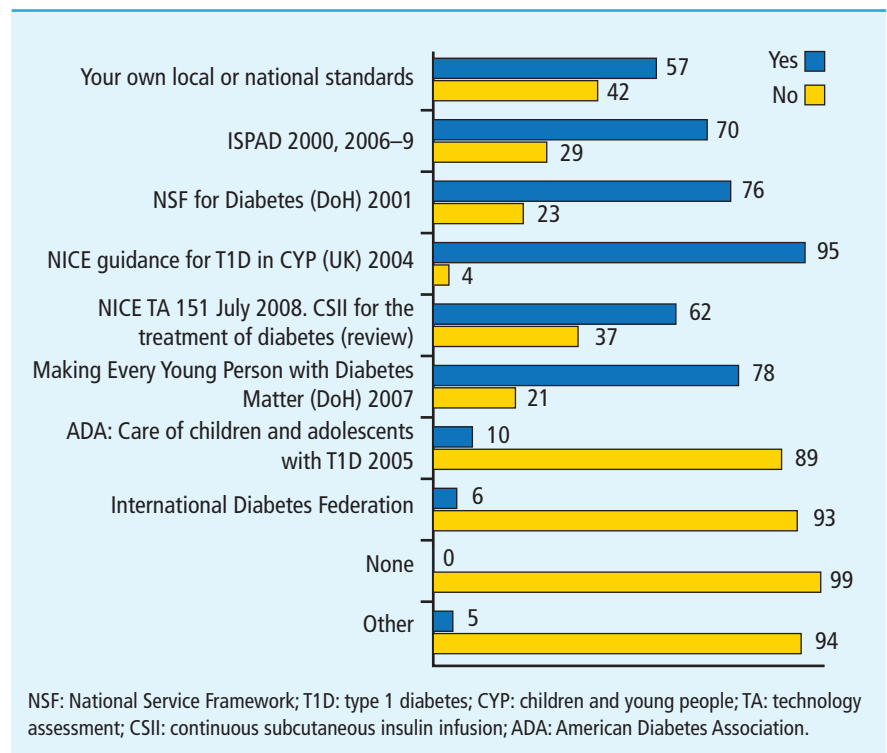


Figure 1. Standards of care, guidelines and recommendations

The questionnaire was designed to complement surveys from Diabetes UK,^{1,5,6} and the recent National Diabetes Survey undertaken by the Royal College of Paediatrics and Child Health (RCPC) commissioned by NHS Diabetes.⁷ The questionnaire was not sent to adult diabetologists, GPs or social workers. The questionnaire was adapted for use by the SWEET Project and disseminated to the EU members of the SWEET Project in the same year.

Results

Responses were received from 100 HCPs as follows:

- Paediatricians with a special interest in diabetes (n=23).
- Paediatric endocrinologists/diabetologists (n=8).
- General paediatricians (n=4).
- Paediatric diabetes nurses (n=38).
- Dietitians with interest in paediatric diabetes (n=17).
- Paediatric or adult dietitians (n=5).
- Psychologists (n=3).
- Psychiatrists (n=2).

The 100 respondents came from 68 separate hospitals and represented 33% of the services that currently supply care to CYP with diabetes (n=205).¹ Replies were received from at least one respondent from all

regions of the UK (except North East); 25% of replies were received from the Yorkshire and Humber region.

Clinic demography, organisation and standards of care

Clinic size: only 6% worked in clinics of <40 patients whereas 68% had >100 patients. Three worked in clinics of >400, but no respondent felt it was ideal.

Multidisciplinary teams: 83% reported they worked in an integrated and cohesive MDT; 16% said they did not; 30% either said that there was not a focused agreed philosophy within the MDT or gave no answer; 52% said that the MDT had 'business' type meetings, 17% case study meetings and 6% had journal clubs.

Care guidelines: a breakdown of these is shown in Figure 1. Most commonly used were NICE type 1 guidance⁸ (95%), the Department of Health document,⁹ NSFs,^{10,11} NICE technology assessments,¹² or ISPAD recommendations and guidelines.¹³ Nearly 60% also use care protocols generated locally, utilising a large number of sources such as BSPED (for diabetic ketoacidosis), pump guidelines etc.

Glycaemic targets: agreed targets for HbA_{1c} in the MDT were acknowledged by 74%.

Networks: 77% were part of a local, regional or national clinical network that compared clinical outcomes.

Education environment and communication

Environment: 63% offered education to CYP (in the hospital environment) both to individuals and in groups; 33% offered just individual based education.

Diabetes training for school staff was undertaken by 92%, but only 76% offered training in blood glucose testing and injections. Several commented that either lack of time or authorisation prevented such school involvement. Eighty-four percent said that the increasing usage of multiple dose insulin therapy has increased the demand for more diabetes education in the school setting.

Physical space for training: 12% said that the space allocation for education is good. Many negative comments were made describing a lack of clinic and office space with no education rooms, especially for group education.

Communication with patients: 97% of HCPs use telephone communication directly with patients, 85% emails and 59% texts, while others mentioned the frequency of personal letters, leaflets, newsletters and even meetings at local cafés for one-to-one contacts.

Content of education and programme delivery

Diabetes education: fully comprehensive structured education programmes, from diagnosis onwards, with written curricula were only reported by 4% of respondents (Table 1); 45% described the education that they deliver as comprehensive and delivered by the MDT.

Structured patient education (SPE) programmes: HCPs from 46% of hospital services stated that they had some form of 'structured programme' of education available for CYP and families. However, doctors and diabetes

Diabetes education delivered	% of respondents
Comprehensive educational provision <i>plus</i> all stages of diabetes education from diagnosis onwards as a comprehensive, written, structured education curriculum	4
Comprehensive educational provision <i>plus</i> a structured education programme directed at specific areas <i>or</i> such a programme is in development	16
Comprehensive educational provision delivered by the paediatric diabetes multidisciplinary team	45
Comprehensive educational provision delivered predominantly by one health care professional. (Delivered predominantly by the paediatric diabetes specialist nurse, but in one case it was an adult specialist nurse and in another the diabetes dietitian)	34

Table 1. Diabetes education: provision and programmes supplied

specialist nurses (DSNs) gave different responses when asked this question, showing a lack of agreement as to what constitutes SPE. Of those who reported SPE programmes, the ones offered were from ongoing paediatric research programmes (e.g. KICK-OFF, CASCADE, FACTS), the adult SPE programme delivered in their hospital, or in-house programmes based on specific topics such as insulin adjustment and carbohydrate counting courses (e.g. CarbCounting4Children Course [CC4CC]; Flexible Adjustment around Basal Bolus [FABB]).

Clearly defined curricula were reported for the following areas: insulin adjustment and carbohydrate counting (82%); carbohydrate counting (71%); insulin pump treatment (63%); education at diagnosis (58%); transition protocol (47%); and annual age/maturity specific education or continuing education (26%).

Outcomes of educational programmes: 61% of respondents had learning outcomes to their programme. Knowledge (27%), practical skills (23%) and behaviour change (18%) were the most common, followed by clinical outcomes (e.g. HbA_{1c} and body mass index) (15%), and quality of life (6%). These outcomes reflect the type of educational programme described, namely that most (55%) were insulin adjustment and carbohydrate counting programmes with far fewer involving psychologically based curricula.

The delivery of education: parents and young people are virtually always (79%) taught together. The delivery was usually shared between the DSN and the dietitian, reflecting the carbohydrate counting and insulin adjustment topics in most educational packages. The courses were most often 1–2 hours perhaps over two or three sessions and were said to be regularly updated, but details were not given. Effectiveness was measured, but comments revealed that this was most often performed by simple in-house, non-validated questionnaires, multiple choice questionnaires (MCQs), 'patient satisfaction' and 'patient understanding' of the topics. Overall, 74% of respondents said that they were not directly involved with either the development or training of these programmes.

Support for education: NHS trusts were reported not to support educational programmes in 50% of cases. Lack of secretarial, administrative and financial support was reported. Preparation was based on 'good will' and in HCPs' own time. Overall leadership for these programmes, to help maintain standards, was lacking in two-thirds of cases.

Teaching strategies, methods and tools: programmes used lectures, discussions, games, problem-solving, shared experiences and practical hands-on skills training, including supermarket visits. Resources used were plastic foods, real foods, pictures,

	Doctor (n=35)	Paediatric diabetes nurse (n=37)	Other nurse, e.g. research (n=1)	Dietitian (n=22)	Psychologist (n=3)	Psychiatrist (n=2)
Course designed for paediatric diabetes	9	12	0	0	0	0
Course accredited by a recognised body	4	12	0	0	0	0
Course had a structured training curriculum	6	10	0	0	0	0
Clinical experience in the workplace	24	7	0	0	0	0

Table 2. Type of training received by different health care professionals prior to appointment to a post in paediatric diabetes

	Doctor (n=35)	Paediatric diabetes nurse (n=37)	Other nurse, e.g. research (n=1)	Dietitian (n=22)	Psychologist (n=3)	Psychiatrist (n=2)
Annual individual performance review (IPR) competency in children's diabetes	18	28	1	12	0	0
CPD written information	26	28	1	18	0	0
Peer review	11	9	1	7	0	0
Accredited course	1	8	0	6	0	0
Mentorship	2	5	1	3	0	0
Clinic attachment	3	1	0	3	0	0

Table 3. Type of continuing professional development activity undertaken by health care professionals following appointment to a post in paediatric diabetes

photographs and MCQs with less use of computers or videos. No specific psychological approach (e.g. role play, storytelling) was mentioned.

HCP training, CPD of HCPs and future developments

HCP training: overall, only 45% of respondents received significant training in paediatric diabetes before taking up their posts. Twenty-six percent of doctors, 43% of nurses and only 9% of dietitians said the appointment to their post was dependent on diabetes experience and accreditation.

There were 52 professionals who answered more detailed questions about pre-appointment training: only 41% received education on a course designed for training in paediatric diabetes whereas 59% accumulated clinical experience in the working environment. One-third of those who were on a designated course thought that it was accredited by a recognised body (e.g. BSPED, RCPC, York University, Birmingham Children's Hospital) and 28% thought that the course had been based on a specified

training curriculum. Only 27% reported that the appointment to their diabetes post was dependent upon specific diabetes experience and accreditation. Some respondents commented that they had no experience when appointed, whereas some others said they had worked up to 10 years in diabetes before starting in jobs. Further details of pre-appointment experience by profession are shown in Table 2.

Some respondents had gained specific accreditation at various levels such as diplomas (n=12), certificates (n=9), accreditation at levels 6 & 7 (n=5), and Masters degrees (n=5). Ninety-two percent agreed that a nationally recognised structured accredited programme (curriculum) of education for the MDT should be developed.

Continuing professional development (CPD): of 100 respondents, 59% said they receive annual learning and development plans (individual performance review [IPR]) related to their competencies in paediatric diabetes and 39% said they received

no IPR. Sixty-six percent collect information to provide evidence for continued knowledge, skills and competency to work. However, 32% did not collect any information. Methods used for CPD are summarised in Table 3. The sources of information and guidance quoted were, for example, journals, professional courses, scientific meetings, private reading, information from Diabetes UK or BSPED. A huge variety of courses had been accessed during the last five years, as illustrated by Table 4. National meetings had been attended by 79% and international meetings by 36% (56% were doctors, 33% nurses and 11% dietitians).

Most respondents agreed that numerous factors prevented adequate training, the most significant being lack of time (78%), poor staffing levels (76%) and inadequate funding (74%). Numerous training needs were identified (e.g. pump therapy, carbohydrate counting training, physical activity, behaviour change, psychological aspects, motivational interviewing, age appropriate methods of teaching and

Training course	% of respondents
Structured education programme, e.g. DAFNE	17
Insulin pump course	76
Insulin adjustment course	10
Carbohydrate counting course	27
Counselling course	12
Family communication, e.g. FACTS training	2
Motivational interviewing	30
Conflict resolution	23
Diabetes courses at universities/hospitals	42
Child centred care	4
Age & maturity appropriate education for the child and child learning principles	2
Behaviour change approaches	18
Guidance on age appropriate education tools and resources	3
Children's diabetes holiday camp	29

Table 4. Training courses accessed in the last five years by health care professionals

group facilitation skills), and 67% of respondents felt they required more training in the management of type 2 diabetes.

The future: 88% felt that a National Diabetes Plan that combined criteria and guidelines for paediatric diabetes care for both CYP and HCP education should be introduced.

Discussion

The SWEET Project EU³ was the catalyst to examine paediatric diabetes education policies, practices and performance for CYP with diabetes, their families, school staff and HCPs in the UK. The results indicate that there is no standardisation of accredited education programmes for CYP with diabetes, their families, school staff and HCPs. This variability has been due to lack of recognition of paediatric diabetes as a specialty, although this is now changing.

In the SWEET Project (Work package 4)³ clinic size has been identified as a factor that affects education given to CYP, the minimum size being 150 patients. Many SWEET centres identified numbers well in excess of 400⁴ CYP and they were served by large numbers of qualified diabetes accredited HCPs who were specifically trained in diabetes education.¹⁴ The majority of respondents from the 68 UK centres worked in clinics with >100 CYP, but only three respondents worked in clinics of >400 patients. UK HCPs commented that large, complex case loads and

the increasing demands to provide SPE, without extra resources, placed them under great pressure to deliver high quality individualised diabetes education as highlighted by Spencer and Cooper in this issue of *Practical Diabetes*.¹⁵ Smaller clinics also have fewer HCPs and less flexibility to include SPE as part of routine care.

It is clear that HCPs had put in an enormous amount of effort to develop their own in-house educational programmes and particular individuals within the team gave their 'good will' and 'out of hours' time, in some cases without recognition by managers. However, the survey shows great variability in the content of programmes, written curricula and educational principles, and few were audited or linked to diabetes outcomes. The majority were focused on insulin-adjustment/carbohydrate counting with a minority addressing the importance of family communication or psycho-social issues. At the present time, there is no single paediatric diabetes education intervention in the UK that has been shown to improve outcomes and consequently is validated. However, all national and international guidelines^{3,8-11,13,16} clearly state the necessity to integrate psycho-educational principles into routine care by using, for example, problem solving, goal setting, communication skills, family conflict resolution, coping skills and stress management. It is unclear how much this lack of a standardisation of education programmes for CYP with diabetes in the UK

impacts on outcomes. On the contrary, countries that have adopted standardised approaches to patient education with a national accreditation scheme (e.g. Germany¹⁷) have made a major reduction in HbA_{1c} levels. Respondents also faced difficulties in supporting and educating school staff, especially due to the increase in multiple injection and pump therapy, and these responses correspond exactly with previous findings.¹ These deficiencies in schools were often related to lack of authorisation by NHS trusts (or primary care trusts), and they will continue unless the delivery of education in schools is commissioned and written into service specifications.

Set against this background of diverse programmes, QISMET (Quality Institute for Self Management Education and Training)¹⁸ may offer a solution to develop uniformity, drive consistency and facilitate audit. (QISMET is an independent body that sets standards and provides a national accreditation framework for organisations that supply diabetes self-care management programmes.)

Standardisation does not imply that education to promote self-care management should not be individualised. Currently, Cooper *et al.*¹⁹ are developing an assessment tool to direct CYP to a personalised education agenda; a tool of this kind is essential to facilitate appropriate education by the HCP. These findings show that there is a clear need to have a national approach to standardised age and maturity appropriate education; a national consensus on the content of these programmes; when these programmes are delivered along the care pathway and clearly defined diabetes related outcomes with integrated audit guidelines. The survey also raised concern about the lack of standardisation between centres of protocols, policies and educational materials (as 60% of respondents developed these in-house). Local ownership of materials is important; however, as it is time consuming to produce and regularly audit such materials, a national repository to share resources may be a useful idea for the future.

The SWEET Project³ (Work packages 3 & 4) and UK national guidelines⁸⁻¹⁰ highlight the need for an

MDT to provide optimal education in diabetes.^{4,8-10} However, it is essential that the MDT functions in a fully integrated and cohesive way to achieve the delivery of high quality education. Encouragingly, the majority of HCPs said they work in this way. However, their reported evidence suggested that the team functioning could improve by having regular business meetings, developing agreed philosophies of care and having agreed glycaemic targets (recently shown to improve clinical outcomes).²⁰ Poor MDT cohesiveness reflects a lack of inter-professional training (pre- and post-qualification) on team working with the underlying concepts of patient centred care, excellent communication, development of capacity and clarity of roles.²¹ There were also differences between doctors and nurses regarding the interpretation of SPE within the majority of MDTs in the survey. This would suggest that a nationally agreed definition would be useful – as in the adult diabetes world, with the well-established adult programmes for type 1 diabetes such as DAFNE¹⁴ and for type 2 diabetes such as DESMOND.²² In paediatrics, guidance is less well defined and there has been no validation attached to delivered programmes,¹ although ISPAD has produced some guidelines specifically for paediatrics.¹⁶ This is in contrast to some European countries, e.g. Germany, where the same validated, high quality programme is delivered to all CYP and families²³ – this standardised approach saves an enormous amount of time in developing individual programmes at a local level.

The necessity for structured education creates the need for highly trained HCPs and accredited courses in diabetes education. At present, no diabetes education courses exist. Some European countries do not allow nurses and dietitians to consult with paediatric diabetes patients until they have at least two years of educational experience.²³ In contrast, in the UK, there are workforce issues such as HCPs being appointed to posts without prior experience, no accreditation of HCPs, or limited accredited courses hinder the delivery of high quality patient education. The survey also demonstrated poor structure and

monitoring of CPD activities, in contrast to some EU countries where annual individual performance reviews specifically for paediatric diabetes are mandatory.³ Without regular CPD it will be impossible to maintain a highly trained workforce.

The origin of poor outcomes for UK CYP with diabetes is unknown but it is likely that it is multi-factorial and involves all areas of education. Countries that have improved outcomes, such as Germany and Austria, focused their attention on all the individual elements of education and have, over time, improved the diabetes outcomes of their CYP.¹⁷

The SWEET Project has identified these key areas and work has commenced to progress these initiatives across Europe, and has developed education curricula for CYP and training curricula for HCPs.³ Towards these aims it is essential that paediatric diabetes in the UK is recognised and contracted as a separate, funded specialty within paediatrics (like cancer or cystic fibrosis), and it now appears that recent developments in the national contracting process²⁴ will support this change.

We recognise that there are limitations to this survey; in particular, the small number of respondents and the lack of representation from all areas of the UK. Respondents to the online questionnaire were far from being representative of the entire paediatric diabetes HCP community and expressed the views of relatively larger and more specialised clinics. This may, therefore, reflect better practice than current overall paediatric diabetes care provision in the UK. We speculate that this may be a reflection of the fact that smaller units are more hard pressed and have less time for replying to questionnaires. Nevertheless, we feel that the results give an indication of the deficiencies in the services provided for CYP with diabetes in the UK.

This UK survey indicates that there is a need to standardise paediatric diabetes education in every area of care provision. We suggest that, before substantial improvements in education and diabetes outcomes can occur:

- Paediatric diabetes care needs to be commissioned and funded as a specialty in the UK (this has now

Key points

- Diabetes care for children and young people will benefit from being recognised as a specialty within paediatrics
- A National Paediatric Diabetes Framework needs to be developed and should include accredited, validated, structured education programmes for CYP, their families, schools and HCPs
- Paediatric diabetes outcome data (both biomedical and psycho-educational) should be submitted electronically to the National Diabetes Audit and linked to diabetes outcomes

been recognised by the Department of Health).

- Individualised education is recognised as a key component of care for both CYP and families.
- The content of SPE should be clearly defined and agreed by all HCPs.
- There should be national validated and accredited programmes for CYP, their families, school staff and HCPs (clinical practice and diabetes education).
- Paediatric diabetes networks should continue to evolve and play a key role in care.²⁵
- There should be acceptance that the paediatric national diabetes audit should have 100% coverage to facilitate meaningful audit of outcomes.¹

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Declaration of interests

There are no conflicts of interest declared.

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