



# Sweetness & light

Standards of paediatric diabetes care vary greatly across the EU. [Dr Jeremy Allgrove](#) and [Dr Sheridan Waldron](#) report on the SWEET project, which aims to reduce inequality and improve care and education for all children with diabetes

**O**n 14 November 2007, 36 children and young people of different nationalities visited the European Parliament in Strasbourg. They came to celebrate World Diabetes Day, and also to highlight the challenges they and their families face every day, as well as the many differences in access to age-appropriate diabetes care and education across Europe.

In response to this call for action, a network of high-profile diabetes organisations, foundations and corporate sponsors came together to form the European 'Better Control in Pediatric and Adolescent Diabetes: Working to Create Centres of Reference' project – or SWEET Project EU, as it is more handily known.

Professor Thomas Danne, a paediatric diabetes expert at the Kinderkrankenhaus auf der Bult

in Hannover, Germany, submitted the initial application to the EU's Executive Agency for Health and Consumers. A total of 13 EU countries, including the UK, supported this application (see 'SWEET partners', page 33), as well as many key diabetes organisations such as the International Society for Pediatric and Adolescent Diabetes, the Federation of European Nurses in Diabetes, the International Diabetes Federation, Europe and Primary Care Diabetes Europe.

Financial support for the project came from a number of sources: the EU, several of the major pharmaceutical companies, Foundation Hannoversche Kinderheilanstalt, Medtronic Foundation and Diabetes Foundation UK. The latter, a charity that supports diabetes research, particularly in the area of juvenile

diabetes, has provided further funds that have allowed SWEET to develop key areas of care specific to the UK as part of Work Package 4 of the SWEET project (see objective 4, below).

With the aim of bringing about major change for children and young people with diabetes across the continent, the SWEET project began in April 2008 and is scheduled to finish in March 2011. Its key goals include: improving the early detection, diagnosis and control of Type 1 and Type 2 diabetes; advancing care and treatment; optimising standards to reduce inequalities in care; limiting illness and mortality; and attaining a good quality of life for all children and young people with diabetes and their families.

SWEET is a unique initiative – no other project has ever compared and contrasted diabetes care in children and young people across the EU. It also involves young people, parents and carers in advisory capacities, as well as specialists, GPs, nurses, dietitians, educators, psychologists and policymakers from a number of EU countries.

### Objectives and evaluation

SWEET has clear deadlines to deliver six specific objectives, in order, as follows:

1. Find out more about diabetes in children and young people across the EU, and discover what care they receive. SWEET has done this by organising the collection and monitoring of data on diabetes prevalence, the cost of diabetes care, service provision and organisation, and the policies in place for diabetes. SWEET has already achieved this objective and submitted a report to the EU, although it has not yet been published. The data are extremely interesting, as they highlight enormous differences in the provision of diabetes care across the EU.
2. Develop and promote a set of recommendations to reduce inequalities and establish equal standards for diabetes treatment and care across the EU. These recommendations are almost ready for publication some time in 2010.
3. Draft recommendations for good practice in paediatric patient diabetes education, to encourage the introduction of diabetes education programmes for children, young people and their parents or carers that are appropriate to the age and maturity of the participants.
4. Draft recommendations to support healthcare professionals to provide high-quality, specialised diabetes care through paediatric training programmes.

### SWEET partners



Thirteen countries are currently involved in SWEET: the Czech Republic, France, Germany, Greece, Hungary, Italy, Luxembourg, Netherlands, Poland, Portugal, Romania, Sweden and the UK. It is hoped that the other 14 EU states will join later.

5. Develop a Type 1 and Type 2 diabetes 'Paediatric Toolbox' to provide step-by-step instructions to help healthcare professionals deliver the best possible care, share information and promote good practice (see 'All tooled up', page 34). This information will be gathered from the specific objectives above and used to determine the structure of centres of reference.
6. Pilot the recommendations from the Toolbox in three EU centres across Europe and evaluate this by the end of the project.

SWEET uses a two-pronged approach to evaluation. First, members monitor their own work and review that of their peers. Second, continuous monitoring is carried out by the external Advisory and Assessment Committee (AAC), which was established by SWEET and consists of MEPs and representatives from EU-level organisations (including the European Group



**The SWEET Steering Group meets three times each year to make sure the project is on course to achieve its objectives**

## All tooled up

The SWEET Paediatric Toolbox Resource will include:

1. A handbook/CD ROM or website compendium for healthcare professionals identifying guidelines for:
  - epidemiology, anatomy and physiology
  - prevention and screening of diabetes
  - clinical targets
  - differential diagnosis of diabetes and appropriate therapies
  - age-appropriate educational programmes
  - nutritional management
  - psychology and wellbeing
  - short-term and long-term complications of diabetes.
2. Recommended materials for use in patient education programmes.
3. Description of the necessary components of courses or packages necessary for healthcare professional training and updates.
4. Description of the structure and functions of the centres of reference.

on Ethics in Science and New Technologies – EGE – and the Alliance for European Diabetes Research – EURADIA), primary care organisations (Primary Care Diabetes Europe – PCDE), and health advocacy organisations (such as the Associação Protectora Dos Diabéticos De Portugal). The AAC convenes in parallel with SWEET meetings three times per year. Upon completion of all six objectives, SWEET will submit a final report to the EU and Diabetes Foundation UK.

### SWEET in the UK

Each country participating in SWEET has its own base of operations. The initial UK site is Barts and the London NHS Trust, which is charged with leading on the project's fourth objective – diabetes education programmes for healthcare professionals. We the authors, Dr Jeremy Allgrove and Dr Sheridan Waldron, are the UK members of the SWEET EU Steering Group, which meets three times a year. It includes a representative from each of the participating countries to ensure that the project remains on track within the specified timescale.

SWEET UK recently carried out a survey of the diabetes education available to patients and healthcare professionals across the country. Building on reports soon to be published by Diabetes UK and the Royal College of Paediatrics and Child Health, this survey demonstrates that the UK is in desperate need of the recommendations SWEET is developing for diabetes education (objectives 3 and 4).

Preliminary data from the SWEET survey, which surveyed 81 healthcare professionals, consisting of a mixture of paediatricians, dietitians, diabetes nurse specialists and psychologists, shows considerable variation in the provision and standard of diabetes education programmes across the country.



**KICK-OFF is a structured education programme for 11–16-year-olds with Type 1 diabetes based on the adult carbohydrate counting course DAFNE (Dose Adjustment for Normal Eating)**

Specifically, it reveals that:

- Only 5 per cent of respondents provide diabetes education for patients at every stage, from diagnosis onwards, and have a written curriculum for patient courses.
- 62 per cent offer both individual and group education.
- 84 per cent are providing more schools with education since the introduction of multiple injection therapy and continuous subcutaneous insulin infusion.
- 33 per cent run a structured education programme for patients. Those respondents who do run such programmes use various approaches: motivational interviewing (2 per cent); insulin adjustment and carbohydrate counting (52 per cent); a mixture of psychosocial aspects, motivational interviewing, insulin adjustment and carbohydrate counting (23 per cent); and general education on subjects such as ‘sick day rules’ and physical activity (18 per cent).
- 52 per cent reported receiving significant training in children’s diabetes, but the majority was obtained in the workplace rather than through a taught course.
- 93 per cent would like to see a structured accredited programme of education for the multidisciplinary team.
- 86 per cent would like a national diabetes plan that includes guidelines and criteria for paediatric patient and healthcare professional education.

**Complementary SWEET**

Prompted by many recent surveys (the National Diabetes Audit, the Royal College of Paediatrics and Child Health, Diabetes UK, NICE guidelines), the Department of Health (DH) has recently acknowledged the need to improve care for children and young people with diabetes. Sir Liam Donaldson, Chief Medical Officer, has stated that they “should have

access to the best clinical care that empowers them to manage their condition on a day-to-day basis” – in hospitals, at home and at school.

Through NHS Diabetes, the DH has begun a National Paediatric Diabetes Network initiative to link together and improve the existing regional diabetes paediatric networks (DPNs). These networks are currently developing a philosophy of care that includes improving outcomes and quality of life, defining key targets, sharing ideas between diabetes service commissioners, and relating these to the National Service Framework for Diabetes, NICE guidelines and the ‘Making Every Young Person with Diabetes Matter’ campaign.

The DPNs’ aims in the UK closely complement those of SWEET, and it is hoped that when SWEET’s recommendations are implemented, they will complement the DPNs and any other initiatives already started in the UK. They should also set standards that can be applied in all EU states, even those not currently involved in the project.

While keeping to the same overall principles, the way SWEET is implemented in each country will need to adapt to local circumstances and take into account local service provision and different funding methods and accreditation processes. To that end, SWEET UK would like to concentrate on developing diabetes education programmes for patients and healthcare professionals, as its recent survey reveals this to be a pressing issue in the UK. It is hoped that SWEET will attract funding beyond 2011, so that it can continue to improve standards of care across the EU, using the results from the pilot sites and the continually developing Toolbox.

*Dr Jeremy Allgrove is a Consultant Paediatric Endocrinologist and SWEET Project Leader.*

*Dr Sheridan Waldron is a Paediatric Diabetes Dietitian and SWEET Project Co-ordinator.*

*They are both based at the Royal London Hospital.*

**i** For more on SWEET, visit [www.sweet-project.eu](http://www.sweet-project.eu), which includes information about the 13 participating countries.

Royal College of Paediatrics and Child Health, *Growing up with Diabetes: Children and Young People with Diabetes in England*: [www.rcpch.ac.uk/research/research-activity/current-projects/national-diabetes-survey](http://www.rcpch.ac.uk/research/research-activity/current-projects/national-diabetes-survey)

NICE guidelines: [www.nice.org.uk/nicemedia/pdf/cg015niceguidelineupdate.pdf](http://www.nice.org.uk/nicemedia/pdf/cg015niceguidelineupdate.pdf)

*Making Every Young Person with Diabetes Matter*: [www.dh.gov.uk/en/publicationsandstatistics/publications/publicationspolicyandguidance/dh\\_073674](http://www.dh.gov.uk/en/publicationsandstatistics/publications/publicationspolicyandguidance/dh_073674)

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