

CASCADE

Children and Adolescent Structured Competencies Approach to Diabetes Education

Issue 1 January 2009

Thank you for your support and commitment to the CASCADE trial

Welcome to the first CASCADE newsletter. We hope you find it interesting and informative!

Introducing CASCADE

Managing diabetes within a full and active life is challenging for both children and young people. Despite parental support and 'expert' education many children and young people struggle to control their diabetes. Combining educational and psychological approaches can achieve engagement, motivation and long term-change for adults. The question is whether similar programmes that have appeared promising with small numbers of children and young people can be delivered in busy clinics more widely, and whether they are acceptable and effective for children and their families.

Funded by the NIHR Health Technology Assessment programme, this trial will evaluate the delivery, acceptability and impact of a programme of sessions offered to 3-4 similarly aged

children or young people (and parents). The aim is to develop confidence in the use of flexible self management approaches including how to adapt the amount of insulin given, eat normally and manage daily challenges such as exercise, illness, and holidays.

In this evaluation, Clinical Nurse Specialists in 13 clinics, chosen randomly from 26, will attend training workshops. 572 children and young people (aged 8-16) and their families from all 26 clinics will be invited to participate in the programme and a two-year follow-up. This will ensure sufficient numbers to be confident about the impact on control of diabetes (measured by HbA1c). We shall look at how easy the programme is to deliver, how well it is received, how much service users participate and the impact on outcomes such as health related quality of life, self management behaviour, and service use. The costs of the programme will be compared with the economic impact of improvements in HbA1c and reduced risk of long term complications.

Clear, written information will be provided to those eligible to participate in the study. Children and young people will be invited to assent to participation, and their parents to give informed consent.

Meet the team

The trial will be guided by a multi-disciplinary group, including two service users, and focus groups of children and young people. The team includes members with extensive research expertise who have run similar large scale trials and a clinical team recognised nationally and internationally as experts in supporting the management of diabetes. The following is a very brief introduction to members of the CASCADE team.

The four institutions in the project are led by Dr Deborah Christie consultant clinical psychologist at the University College London Hospital (UCLH). Dr Christie and Rebecca Thompson, the lead Diabetes Specialist Nurse (DSN) at UCLH will coordinate the delivery of the intervention programme. Also part of the UCLH team are Dr Russel Viner Consultant and Directorate of Adolescent Medicine, (UCLH and Great Ormond Street Hospital) and Peter Hindmarsh, Professor of Paediatric Endocrinology with special interests in diabetes and adrenal disorders at the UCL Institute of child health.

The research team is coordinated by Dr Vicki Strange at the Social Science Research Unit (SSRU) at the Institute of education. Two researchers officers (Carol Vigurs based at SSRU and Claire Planner from the School of Pharmacy (SoP) will be working closely with participating clinics to support recruitment and data collection. Also part of the research team are Professor Sandy Oliver (SSRU) and Professor Felicity Smith and Professor Ian Wong (SoP). Finally expertise in trial study design and

analysis is provided by Dr Elizabeth Allen and Professor Diana Elbourne from the London School of Hygiene and Tropical medicine (LSGTM) who will carry out the randomisation and statistical analysis.

Clinic recruitment update

We have currently recruited 25 of the 26 clinics required to carry out the study. Carol Vigurs and Claire Planner have been supporting sites to obtain local ethics and R&D approvals. Ten clinics are about to start recruiting eligible young people and their families.

Distribution of participating clinics



Contact details:

For queries relating to ethics and R&D, recruitment of young people and their families and data collection please contact either Claire Planner at the School of Pharmacy or Carol Vigurs at the Social Science Research Unit:

Claire Planner can be contacted on claire.planner@pharmacy.ac.uk tel: 020 7874 1539

Carol Vigurs can be contacted on c.vigurs@ioe.ac.uk tel: 0207 612 6613

For queries relating to training and the delivery of the intervention please contact Rebecca Thompson, Lead Diabetes Nurse at the UCLH rebecca.thompson@uclh.nhs.uk