

Children's Clinical Studies Group

Annual progress report

April 2017-April 2018

In brief

This Clinical Studies Group (CSG) considers all aspects of diabetes in children and young adults. This is a joint CSG with the British Society for Paediatric Endocrinology and Diabetes (BSPED) and the National Institute for Health Research Clinical Research Network (NIHR CRN).

So far, the group has held two face to face meetings and a number of teleconferences.

The group has reviewed priorities for Type 1 and Type 2 diabetes research, according to people living with diabetes, carers and healthcare professionals. They have also reviewed research happening across the UK in the CSG's area. Together, this has allowed the group to create a picture of the research landscape and so far identify four particular research areas of priority.

"It's been a real joy to interact with young people both in the group and at diabetes family events, and bring their 'real life' experiences into the work of the group"

Professor Tim Barrett, Birmingham

Progress so far

Finding research priorities

The group examined research happening across the UK alongside existing research priorities for Type 1 and Type 2 diabetes. These priorities were identified by people with diabetes, carers and healthcare professionals in an exercise known as a Priority Setting Partnership. More information about these priorities and the organisation that runs them, the James Lind Alliance, at:

www.diabetes.org.uk/research/our-approach-to-research/have-your-say

With the needs of children and young people with diabetes in mind, the lay members of the CSG, in collaboration with the [Diabetes UK Grants Advisory Panel](#), reviewed the relevance of each priority in the longlists of the [Type 1](#) and [Type 2](#) diabetes Priority Setting Partnerships. They presented the results to the wider group and together, the group prioritised the outputs.

The results were presented to and endorsed by the Lay & Healthcare Professional Forum (lay and healthcare professional members of all CSGs together).

Stem cell transplantation

In Type 1 diabetes the immune system attacks and destroys the insulin-producing beta cells in the pancreas. This means that people with Type 1 diabetes need to take insulin, either by injection or an insulin pump. Progress in research means that it is now possible to transplant beta cells from a deceased donor into a person living with diabetes, known as an [islet transplant](#). However, there are a limited number of donors available, and the recipient needs to take medications to prevent their immune system from rejecting the transplanted cells.

Most cells in the body have a particular purpose. Stem cells are different and can develop into many different types of cells, including beta cells. CSG7 believes stem cell research for Type 1 diabetes is a priority: in the future, it may be possible to 'grow' an unlimited supply of beta cells to transplant into people with Type 1 diabetes.

Preservation of beta cell function

Protecting beta cells so they can continue to work properly, and in turn produce some insulin, would bring many benefits for people with Type 1 diabetes even if it was not in itself a cure. CSG7 believes research in this area is a priority, to develop treatments which could protect the activity of beta cells and insulin production. This could include treatments that target the immune system.

Variability in glucose control between diabetes centres

The National Diabetes Audit has demonstrated that there are huge variations in the percentage of people reaching their diabetes treatment targets in England and Wales, which is dependent on where they live. The audit has also shown that younger people are less likely to achieve their targets than older people. CSG7 agreed that there is a need for research in this area, exploring why this variation occurs and how to reduce it.

Understanding the genetics of diabetes complications

Research has shown that some children with Type 1 diabetes go on to be at greater risk of complications than others, and this is partly influenced by their genes. However, further research is needed to identify which genes are involved and who is at high risk, so those young people can be monitored and given early treatment. CSG7 believe that 'Why will some children get complications and not others?' is a priority research question.

Engaging with communities

The group has engaged with the Children and Young People's Regional Diabetes Networks to make sure the views of children and young people are represented. These are regional networks that bring together all healthcare professionals caring for children and young people with diabetes. They support each other to set standards in hospitals, collect and learn from hospital data, involve people with diabetes in their work through open events, and share information about research studies. CSG7 aims to, through the collaboration, bring together the childrens' diabetes community and increase the number of healthcare professional and people with diabetes who get involved in diabetes research.

Links and collaborations

Professor John Gregory, a member of CSG7, has also joined CSG 2 (prevention and therapies for Type 1 diabetes). This will support collaboration and shared thinking across CSGs and ensure that the specific needs of children and young people are embedded in their work.

A number of healthcare professional members of CSG7 have been asked to help recruit people newly diagnosed with Type 1 diabetes onto immunotherapy studies that are part of the Diabetes UK and JDRF funded [UK Type 1 diabetes immunotherapy consortium](#).

CSG7 is closely linked to the [National Paediatric Diabetes Audit](#) (NPDA). This database can be used to see how well children and young people are managing their Type 1 diabetes, alongside other information about their condition. They have invited Dr Justin Warner, the Chair of NPDA, to discuss how this database could be used to look at variations in diabetes care.

CSG7 has a strong link with another CSG, known as the NIHR CRN Clinical Studies Group for Endocrinology. This CSG is supported by NIHR, reviews the progress of studies funded by the NIHR and provides advice. The group is currently looking at several areas of research that are important to CSG7, including the effects of obesity on children's health and puberty-related conditions.

CSG7 is also collaborating with the British Society for Paediatric Endocrinology and Diabetes (BSPED), the professional society for paediatric endocrinologists and diabetologists, and the Association of Children's Diabetes Consultants (ACDC). This society includes many of the consultants looking after children with diabetes who are not members of BSPED. This collaboration aims to raise awareness of the importance of research and bring the children's diabetes community together.

Next steps

The group will continue to study the priorities they have identified so far, to better understand the research areas in more detail. This will help them find 'roadblocks', such as why more research hasn't been done, and set out a plan for moving these priority areas forward.

They will also gather more insight from children and young people with diabetes, and plan to recruit additional members with expertise in clinical psychology and dietetics.

Find out more

To find out more about the work of the CSG, please contact csgs@diabetes.org.uk to be put in contact with the group.

CSG members

Current CSG membership, including affiliations.

Name	Affiliation	Role on group
Professor Timothy Barrett	Birmingham Women's and Children's Hospital	Chair (until June 2018)
Dr Carlo Acerini	University of Cambridge	Deputy Chair (taking up Chair position from July 2018)
Dr Hasan Basarir	University of Birmingham	Member
Sr Sara Bennett	Stockport district hospital	Member
Dr Fiona Campbell	St James's Hospital Leeds	Member
Mr Peter Davies	Lay member	Member
Professor David Dunger	Addenbrooke's Hospital	Member
Ms Viv Gill	Lay member	Member
Dr May Ng	Southport and Ormskirk Hospital NHS Trust	Member
Dr Vijith Puthi	Northwest Anglia NHS Foundation Trust	Member
Dr Tabitha Randell	Queen's Hospital Nottingham	Member
Sr Angela Waktare	Lancashire Teaching Hospitals NHS Foundation Trust	Member
Dr Christina Wei	St George's Hospital London	Member
Dr Jarod Wong	Glasgow Children's Hospital	Member