

Long-term self- management & Glycaemic Control Clinical Studies Group

Annual progress report

April 2017-April 2018

In brief

This Clinical Studies Group (CSG) aims to improve our understanding of the long-term self-management of diabetes. It covers a range of topics, including diet, exercise, blood glucose control, structured education, peer support, other informal learning and support options, mental health, psychological and emotional support, and behaviours related to taking medication.

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

The group have 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 identify five particular research areas that need more attention. They then focused in on two priority areas.

"I was pleased that the priorities identified by CSG5 so accurately reflect the concerns expressed by the many people with diabetes and their carers with whom I regularly mix, both online and in person. It was no surprise that research in these areas is lacking, but I now feel hopeful that with time and when research is completed, lives will truly benefit from the work of the CSGs." **Lis Warren, London**

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

Together, they used this information to identify topics where little research was underway, or gaps, and then prioritised them. Topics were prioritised initially by the CSG itself, before the results were presented to and endorsed by the Lay & Healthcare Professional Forum (lay and healthcare professional members of all CSGs together).

The group initially identified five areas that would benefit from more research:

1. Managing diabetes in the context of changing hormone levels
2. Managing eating disorders in people with diabetes of all types
3. How to manage the burden placed on the families of people with diabetes
4. Lack of services and health inequalities in children & young adults with Type 2 diabetes
5. New technology

The group carried out an initial review of the published research in each of these five areas, along with any funded research grants currently underway. Based on this, the group focused in on two priority areas:

Managing diabetes in the context of changing hormone levels; the menstrual cycle and menopause

This priority area originated from the James Lind Alliance Priority Setting Partnership for Type 1 diabetes. When carrying out the review, the group included research into managing diabetes in the context of the menstrual cycle, menopause and pregnancy.

While there is substantial published research in pregnancy, there is a lack of evidence into diabetes and the menstrual cycle or the menopause. As a result, there is little evidence based advice for women living with diabetes who experience these hormonal changes.

The group agreed that there is a need for research in this area, to improve our understanding of the scale of this issue for women living with diabetes.

Managing eating disorders in people with diabetes

When carrying out the review, the group found that the research publications on this topic mainly relate to the number of people with diabetes experiencing eating disorders, and the causes. There are limited studies aiming to help people manage these conditions.

The group agreed that there is a clear need for research to:

- better understand the psychology behind eating;
- find treatments for eating disorders in those with diabetes;
- find ways to support people with diabetes and eating disorders to manage their blood glucose levels.

Analysing the research landscape

Moving forward, the group plan to carry out a more robust and thorough review of ongoing research in their area. Using UberResearch, they plan to create a set of categories for research in their CSG area and map those categories against research projects happening across the world. This will help them identify research gaps and build a future plan of action for research in this area.

Engaging with communities

The CSG presented their emerging ideas at the Diabetes UK Professional Conference and at the Lay and Healthcare Professional Forum.

The group also invited expert speakers in the areas of diabetes, hormones and eating disorders to attend a CSG meeting and provide insight on the current status of the field.

Links and collaborations

Members of CSG5 have teamed up with members of other CSGs to look more closely at the issue of managing diabetes in the context of changing hormone levels. They'll then be able to recommend what to do next.

Next steps

Now that the CSG has identified these two research priorities, they need to understand both areas in more detail. For example, looking at why more research hasn't been done, or what questions need to be asked by future studies.

Once they have completed their robust review of ongoing research across the world, they will also be able to identify additional priorities to form part of their research roadmap.

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
Dr Mark Evans	University of Cambridge	Chair
Dr Nick Oliver	Imperial College London	Deputy-Chair
Professor Stephanie Amiel	King's College London	Member (stepped down 2018)
Dr Craig Beall	University of Exeter	Member
Professor Vivien Coates	University of Ulster	Member
Dr Nicky Conway	University of Dundee	Member (stepped down 2018)
Dr Clare England	University of Bristol	Member
Professor Jörg Huber	University of Brighton	Member
Dr Manyee Li	Queen Elizabeth Hospital Birmingham	Member
Charlotte Massey	Lay representative	Member
Robin (Bob) Swindell	Lay representative	Member
Dr Anthony Tasker	Ninewells Hospital	
Lis Warren	Lay representative	Member
Dr David Webb	Leicester University	
Dr Kyle Wedgewood	University of Exeter	
Dr Kirsty Winkley	King's College London	Member