

# Diabetes Clinical Studies Groups

## Annual progress report

April 2018-March 2019

## Executive Summary

Diabetes UK established the UK's first Clinical Studies Groups (CSGs) for diabetes in 2017. Their key roles are to identify priority research areas for people living with diabetes and the research studies needed to move forward our understanding of the condition and improvements in care.

Each CSG unites leading thinkers in seven key research areas with people living with diabetes and healthcare professionals (HCPs). This brings together expertise in both research and the lived experience, to effectively identify and prioritise areas for research. The first CSG annual reports<sup>1</sup> published last year outlined initial areas of research focus identified by the CSGs.

Significant progress has been made in refining priorities and identifying new areas of concern within the research landscape. This report outlines the priority areas identified. Diabetes UK and the CSGs are working together in three main ways:

1. **Hosting 'research workshops'**: events focussed on a specific research area with the aim of developing a set of recommendations to shape future research in the field. The first report has focused on [Diabetes and Mental Wellbeing](#).
2. **Launching 'strategic calls'**, in which research funds are offered for research projects in a specific topic identified by the CSGs as an area of urgent need. Diabetes UK launched its first strategic call in eating disorders and diabetes following the publication of the Diabetes and Mental Wellbeing report.
3. **Implementing 'highlight notices'** on Diabetes UK project grant rounds: calls for projects to answer a specific research question identified by the CSGs. Diabetes UK's first highlight notice called for qualitative research projects to identify the issues faced by women with diabetes during the menopause.

The diabetes CSGs have actively sought to collaborate with researchers, research funders and other organisations where the opportunity has arisen. This has led to a wide range of activities, including providing advice for researchers' grant applications and collaborating with other CSGs on shared areas of importance, such as Kidney Research UK's CSGs and the UK Diabetes in Pregnancy CSG group.

Diabetes UK would like to thank the 105 participants of the CSGs, the chair of the oversight CSG Management Committee, Professor Sally Marshall, the individual CSG chairs and in particular, the lay experts without whose tireless enthusiasm, drive and dedication this initiative would not have made such progress to date.

The CSGs want to make sure the priorities they identify are aligned with those of people living with or at risk of diabetes. To do this, they are reaching out to the wider diabetes community to find out if these areas matter to them. If you would like to provide feedback on the priorities here, or give new ideas for potential new research priorities, please contact [CSGs@diabetes.org.uk](mailto:CSGs@diabetes.org.uk).

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<sup>1</sup>\*For more information, see [the CSG webpages](#).

## Research priorities and progress

### Effects of hormones on diabetes

Diabetes can often become more difficult to manage during times of changing hormone levels, such as puberty, the menstrual cycle and menopause. However, there is little research in this area, or evidence-based advice for people with diabetes.

In 2018, a subgroup of CSG members worked together to better understand this evidence gap, resulting in Diabetes UK's first highlight notice for research proposals to identify the issues faced by women with diabetes going through the menopause. Applications will be reviewed by Diabetes UK's Research Committee in late 2019, with successful applicants announced in early 2020.

Puberty can also increase the risk of diabetes complications later in life, and make diabetes management more challenging in the short term. The need to explore why this happens and how to prevent it has also been identified as a priority area.

### Diabetes and Mental Wellbeing

The CSGs have identified research into mental health as a clear priority, including:

- improving the diagnosis and treatment of eating disorders, particularly in young people.
- better understanding how the 'emotional burden' of diabetes can be reduced.
- identifying the best models of care for people with diabetes and mental health conditions.

Diabetes UK held a two-day international research workshop in February 2019, bringing together research experts in diabetes and in mental health, people living with diabetes and healthcare professionals to identify the current gaps in research and provide recommendations on how best to address them. The workshop resulted in eleven recommendations for future research into diabetes and mental wellbeing, published in [Diabetic Medicine](#).

In order to begin to drive research forward in these areas, Diabetes UK has launched a strategic call for research projects focused on improving our understanding of eating disorders or how to manage them effectively in people with diabetes. Successful applicants will be selected in December 2019.

## Mental wellbeing research: a summary of priorities from the February 2019 workshop



### **Eating disorders**

We need to understand how and why people with diabetes develop eating disorders, and how to best care for them if they do.

### **Depression**

People with diabetes are twice as likely to have depression. We need to understand why, so that we can find the best ways to care for them.

### **Social stigma**

We need to understand how stigma impacts people with diabetes emotionally and socially, and the knock-on effect this could have on how someone manages their diabetes, so we can reduce it or prevent it from happening.

### **Language**

We need to improve the language used by healthcare professionals, so that consultations don't negatively impact wellbeing.

### **Supporting people who find it difficult to engage with their diabetes**

We need new ways to help people who find it difficult to engage with their condition to keep their blood sugar levels safe, without negatively affecting their emotional wellbeing.

### **Supporting friends and family members**

Diabetes can impact friends and family members emotionally too, which can come full circle and affect the person with diabetes. We need to support everyone affected by diabetes.

### **Learning from best practice**

We need to learn from those who are already successfully incorporating care for people with diabetes with mental wellbeing support, so that we can share their practice across the UK and internationally.

### **Diabetes distress**

We need consistent and effective UK-wide services to find people with diabetes distress and support them. This needs to be part of everyday diabetes care.

### **Emotional wellbeing when you're diagnosed**

Being diagnosed with diabetes can come as a shock. We need to find ways for healthcare professionals to diagnosis people and support them emotionally – both at that moment in time and in the future.

### **The effect of Type 2 diabetes medications on mood**

Some research has suggested that medications we already prescribe to people with Type 2 diabetes might positively boost your mood – we need to find out more.

### **Diabetes technology**

We need to understand how and why technology can affect the mental wellbeing of people with diabetes, so we can maximise the benefits of diabetes tech.

## **Finding ways to prevent or slow the progression of diabetes complications in people with Type 1 or Type 2 diabetes at extremely high risk**

People with diabetes are at risk of developing certain complications, such as sight loss or heart disease. But some people, such as those who develop Type 2 diabetes at a young age, have a higher risk. The CSGs have written a call for research proposals to find effective ways to slow the development of complications, or ensure they don't occur, in groups of people at very high risk.

Diabetes UK will be launching a strategic call in this area in 2020, in partnership with another funder.

## **Improving the technology made to support diabetes management**

Technology such as blood glucose monitors and insulin pumps are a vital tool to help people manage their diabetes, and advances in the field could improve lives even further. The CSGs are concerned that technological developments may not reflect the needs of people living with diabetes.

As such, CSG members are developing a project asking people with diabetes and parents of young children with diabetes what they want to see next from technology and how it could be improved

Many forms of technology exist today to help people manage their diabetes, but different people have different needs. The CSGs propose that we need to better understand who will benefit from individual devices the most, and why.

The CSGs also hope to bring together experts across the technology sector, to better understand how to move research forwards, in the near future

## **Glucose monitoring technology in hospitals**

The CSGs advise that new technologies used to monitor blood glucose levels could be better used in hospitals to improve care for people with diabetes who may find it difficult to manage their condition in hospital. Research is needed to establish which technologies work best in this setting and how to implement these changes.

Diabetes UK will have a 'highlight notice' in this area on its next research funding round, for projects testing the effectiveness of technology (such as web-linked glucose meters or continuous glucose monitoring) in hospitals. The round will open in December 2019 and more details will be made available soon.

## **Restoring insulin secretion**

Scientists are looking for ways to restore the function of insulin-producing beta cells in people with Type 1 diabetes. They are exploring a range of methods that might be successful in achieving this, ranging from islet cell transplantation through to islet cell regeneration. The CSGs believe that collaboration and knowledge sharing between scientists in the field could lead to more progress.

To drive this forward, CSG members would like to organise meetings at international diabetes research conferences, to bring together the world's experts to agree the direction for future research in this area.

### **Measuring the success of trials to restore insulin secretion**

HbA1c – a measure of long-term blood glucose levels – is often used to test if new treatments can restore insulin production in people with Type 1 diabetes.

Other factors, such as blood glucose variability, time in range or the function of insulin-producing beta cells could have a significant impact on the lives of people with Type 1 diabetes, but these often aren't measured. The CSGs believe research to understand the long-term impact of these factors on health, and how to measure them and use the information gained to help people with diabetes, is needed. They are working towards potential calls for research focussed on the improved measurements being developed.

### **Improving the classification and diagnosis of diabetes**

Diagnosing diabetes isn't currently a completely accurate process. This means that some people have received the wrong diabetes diagnosis, resulting in them being given the wrong treatments – potentially increasing their risk of diabetes complications and leading to emotional distress.

The CSGs believe that research is needed to improve the accuracy of diagnosis, using biological samples (such as blood tests) from people with diabetes to work out how often diabetes is misdiagnosed and why this might be happening. This could lead to further research to develop more accurate ways to diagnose diabetes.

### **Understanding the different ways gestational diabetes can affect women**

The experience of gestational diabetes – from symptoms and diagnosis, through to treatments – can vary greatly for different women, and it is currently difficult to know who will develop the condition during their pregnancy. A better understanding of the causes and risk factors of gestational diabetes, alongside further knowledge of who might develop the condition and why, is needed. This research could provide further insight into why some women develop Type 2 diabetes after gestational diabetes, while others do not.

Several CSG1 members have joined a larger Diabetes in Pregnancy Clinical Studies Group. With experts in gestational diabetes from a number of other organisations, they are working together to develop a research project addressing this question.

### **Medications other than insulin for people with Type 1 diabetes**

Drugs used to manage blood glucose levels in people with Type 2 diabetes (such as SGLT2 inhibitors or GLP-1 agonists) may also help people with Type 1 diabetes. Research in this area has already suggested benefits of SGLT2 inhibitors, and the first SGLT2 inhibitor was licensed for people with Type 1 diabetes in the UK in 2019.

The CSGs believe that further assessment of the effectiveness of these treatments is needed, to understand how and where these medications could have the most benefit for people with Type 1 diabetes.

### **Understanding how best to prevent Type 2 diabetes**

The NHS Diabetes Prevention Programme (NDPP) was set up in 2016 to help prevent people from developing Type 2 diabetes. The CSGs consider that the NDPP could be an excellent platform to address unanswered questions in relation to the prevention of Type 2 diabetes.

CSG members are currently in conversation with the NDPP team to explore this possibility.

### **Choosing the best Type 2 diabetes treatment when metformin isn't enough**

Despite the number of people living with Type 2 diabetes across the world, there is currently not enough evidence to help HCPs choose the next best treatment when metformin no longer works well enough. The CSGs believe that research is needed to help improve this evidence base, to support HCPs decision-making around treatment options.

A group of experts have joined forces with CSG members to design a large long-term trial to directly compare the effectiveness of the most common Type 2 diabetes drugs.

### **Diabetes and healthy ageing**

Managing diabetes in nursing or care homes can be particularly challenging. A better understanding of how to care for people with diabetes and their specific support needs in later life is needed.

People with diabetes in these environments are also frequently referred to hospital due to preventable instances of severe hypoglycaemia or diabetic ketoacidosis (DKA). The CSGs recommend further research into the use of new technology and different treatment strategies that will prevent these instances.

Diabetes UK is planning a workshop for April 2020 to develop research recommendations for the field of Diabetes and Healthy Ageing, similar to that held for Diabetes and Mental Wellbeing.

### **A new care pathway to prevent neuropathy**

Many potential improvements to neuropathy (nerve damage) screening have shown promise in reducing rates of neuropathy in people with diabetes in recent years. These include new devices to detect neuropathy sooner, combining screening for neuropathy and retinopathy, and ensuring that people who show signs of neuropathy receive as much help as possible to stop it progressing any further.

CSG members are working to develop a research project which would bring all of these advances together, to test a new pathway for screening and caring for neuropathy. The

project would test whether these improvements together significantly reduce the rates of neuropathy, as well as the foot ulcers and amputations which can follow.

### **Preventing amputations**

Scientists believe that a large number of amputations which occur as a result of neuropathy could be preventable, if the signs of neuropathy or foot ulcers could be spotted earlier, or through a greater understanding of the best treatments. The CSGs recommend that more research is needed to prevent neuropathy and ensure that amputation rates are reduced, and they have reached out to researchers and healthcare professionals working in this area to build a clearer picture of current research activity?.

### **Transitioning to adult care**

The time at which children with diabetes move from a paediatric clinic to an adult clinic has been identified by the CSGs as a pivotal moment. Many young people stop attending appointments at their new clinic, and consequently experience problems with their diabetes management.

The CSGs plan to hold a meeting in 2020 focussed on this important transition period and how to improve the care people receive, which will include exploring the potential of research into health services.

#### **Find out more**

For more information on the CSGs and their work visit **their webpage** or contact **CSGs@diabetes.org.uk**.