



**MY DIABETES
AND ME STUDY**



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BACKGROUND

The purpose of this booklet is to inform staff about a new study that will be starting in the Autumn of 2022. The study will examine the effectiveness of a structured education programme for adults with learning disabilities and Type 2 diabetes.

People with learning disabilities are more likely to develop Type 2 Diabetes. They tend to develop it at a younger age and are less likely to have access to appropriate education that would help them to manage the condition.

This may make it more likely that they will develop other health problems, such as heart or kidney disease and strokes, and die younger.



WHO IS INVOLVED IN THIS STUDY?

Researchers from Ulster University (Prof Laurence Taggart), University of Leicester (Dr Alison Dunkley) and the University of Glasgow (Dr Maria Truesdale) are looking to recruit 450 adults with learning disabilities and Type 2 Diabetes across Northern Ireland, England (Leicestershire) and Scotland (Glasgow and Lanarkshire) to take part in this study.

We are also working with adults with learning disabilities who have Type 2 Diabetes, their family carers, and community learning disability teams across these three countries to deliver this study.

This is a UK wide study led by Prof Laurence Taggart at Ulster University.



WHAT IS THE DIABETES EDUCATION PROGRAMME?

If you or I were diagnosed with Type 2 Diabetes by your GP today, they would recommend that we attend a self-management diabetes education programme: the programme delivered across the UK is called DESMOND.

DESMOND (Diabetes Education and Self-Management for Ongoing and Newly Diagnosed) is a 6-hour group education programme, delivered by health professionals and lay educators over two half days or one full day.

DESMOND is the collaborative name for a family or group of self-management education modules for people with, or at risk of, Type 2 Diabetes.

A fundamental goal of DESMOND is a more engaged and informed individual living with diabetes, whereby they become the expert. However, DESMOND has not been adapted for adults with learning disabilities.



We now need to do a larger research study to find out if our programme brings about longer health benefits for adults with learning disabilities: this is called a randomised control trial.

A few years ago, we adapted this national DESMOND programme for adults with learning disabilities. The programme is now called DESMOND-ID.

The new DESMOND-ID education programme lasts for 7 weeks, followed by two booster sessions at months 1 and 3 (each lasting 2½ hours), delivered in a health centre / day centre in your local area and delivered by two educators. The adult with a learning disability and their carer/ partner/advocate are encouraged to attend together.

The programme can support adults with learning disabilities to improve their understanding of diabetes, improves diet, increases physical

activity, reduces weight, helps effective smoking cessation and reduces depression.

The education programme provides self-management education including a healthy diet, physical activity and taking medication, which aims to encourage healthy lifestyle behaviour changes thereby potentially leading to better health outcomes (e.g. blood pressure, HbA1c and cholesterol).

We have already completed a small study with 39 adults with learning disabilities which showed that the diabetes education programme can be effectively delivered and is acceptable to the service users and their carer/ partner/advocate.



PURPOSE OF THE STUDY

The purpose of the study is to test whether the adults with learning disabilities who received the diabetes education programme have better health outcomes compared to those who do not receive the education programme regarding their knowledge, diets, physical activity, mood, weight, BP, cholesterol, and HbA1c.

With the permission from the adults with learning disability, half will be randomly selected to receive the diabetes education programme, while the other adults with learning disabilities will continue with their usual diabetes care.

To test the effectiveness of the programme, we would like to recruit 450 adults with learning disabilities who have Type 2 Diabetes from Northern Ireland, Scotland, and England.



IDENTIFICATION & TRAINING OF DIABETES EDUCATORS

We will recruit educators across each health board in each research site, who will consist of a healthcare professional who has experience of working with people with learning disabilities and a lay person.

These staff would receive training in the diabetes education programme and then would be expected to deliver the programme over several times during the study.

The training would last two days and will take place online and in Leicester. It will be agreed that your employer will give you the time to attend training and deliver the diabetes education programme.



WHAT DATA WILL WE COLLECT?

We will need your help to identify adults with mild-moderate learning disability aged 18yrs plus, who have Type 2 Diabetes, living in the community and who could participate in a group education format.

We will measure everyone's HbA1c, blood pressure, cholesterol, and BMI before they start the study and twice more later in the study.

We will also ask some questions about the person's understanding of their diabetes, mood, and general well-being again before they start the study and twice more later in the study.

We will then compare the results for the adults with learning disabilities allocated to the diabetes education programme and those receiving usual care.



We will also carry out an economic evaluation to see if the diabetes education programme is good value for money.

We will hold focus groups where 6-8 educators will meet for approximately one hour to identify what worked well in the education programme.

We would also like to talk to those healthcare professionals who become diabetes educators to ask them about their thoughts on the benefits of the education programme, and any amendments that are needed to the programme in the future.



WHAT ARE THE BENEFITS?

For the adults with learning disabilities and carers...

We have already done a small study which showed that the diabetes programme can be delivered and is acceptable to 39 adults with learning disabilities and their carer/partner/advocates.

The diabetes programme was valued and accepted by the adults with learning disabilities and their carer/partner/advocates.

The study found that we can successfully identify and recruit adults with learning disabilities into such a study, obtain their consent, obtain blood samples, administer questionnaires, and randomise the adults to either the diabetes programme or usual care.

The preliminary study showed that diabetes may be able to decrease HbA1c.



For the healthcare professionals ...

We also found that those healthcare professionals, who received the diabetes training, were able to successfully deliver the seven-week education programme in their local area.

The healthcare professionals also reported that they enjoyed the training, learning more knowledge about Type 2 diabetes and its self-management, as well as finding the programme easy to deliver.



HOW CAN YOU HELP?

If your interested to know more about the study please contact us:

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