



# My Diabetes and Me Study

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# Diabetes in people with a learning disability

**Children with Down Syndrome are four times at increased risk of developing T1DM** due to the trisomy of genes on chromosome 21 and increased defects of the immune system (Aslam et al 2022)

**T2DM is reported to be 2-3 times higher in adults with a learning disability** compared to the general population (McVilly et al 2014, MacRea et al. 2014)

Reasons include: **poorer lifestyle factors (diet, restricted physical activity, sedentary behaviour, medication, obesity), lack of access to health promotion/screening** (Emerson & Hatton, 2013; Taggart & Cousins, 2014)

**Diabetes in adults with a learning disability occurs at an earlier age and are 2.6 times more likely to be hospitalized** thereby making the management of this condition more complex (Taggart et al 2013; Balogh et al 2015; Aslam et al 2022)



# Management of diabetes in people with a learning disability



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## Management and quality indicators of diabetes mellitus in people with intellectual disabilities

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Journal of Intellectual Disability Research

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## Improving diabetes care for people with intellectual disabilities: a qualitative study exploring the perceptions and experiences of professionals in diabetes and intellectual disability services

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Taggart et al (2013) within N Ireland reported that individuals with a learning disability were found to have **poor glycaemic control**, were statistically more likely to have T2DM and be younger and be obese

Results also illustrate that the **inter/national standards for good diabetes management were only partially being met** (Shireman et al 2010; Taggart et al 2013; Balgoh et al 2015)

Brown et al (2017) in the UK interviewed learning disability and diabetes nurses and reported that there was an identified need for initial and ongoing **diabetes education for staff, family carers and service users**


People with a learning disability and T2DM were **not routinely offered structured education to self-manage** their condition (Slowie et al 2010; Taggart et al 2014; Tripp et al 2015; Brown et al in 2017) despite this being identified by NICE guidelines (2003) as 'best practice'



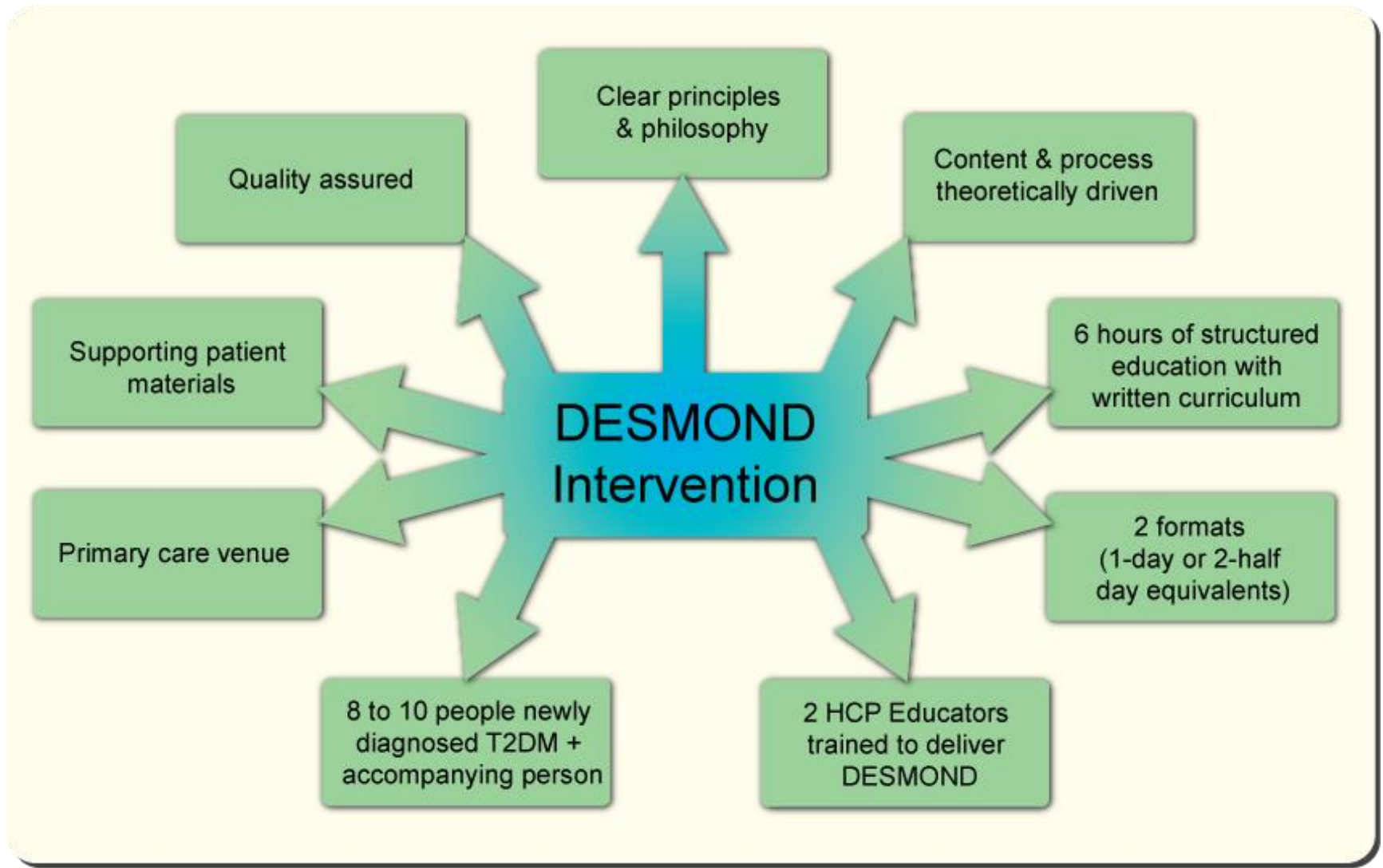
# DESMOND

**DESMOND stands for 'Diabetes Education  
and Self Management for Ongoing and Newly Diagnosed'**

More simply...

- It's a way of finding out more about Type 2 diabetes
- It's a resource to help people manage the changes diabetes will bring to their lives (self-manage)
- It's an opportunity to meet and share experiences with others
- DESMOND is a family of education modules 

# DESMOND Programme



## STUDY PROTOCOL

## Open Access

## A study protocol for a pilot randomised trial of a structured education programme for the self-management of Type 2 diabetes for adults with intellectual disabilities

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### Abstract

**Background:** The need for structured education programmes for type 2 diabetes is a high priority for many governments around the world. One such national education programme in the United Kingdom is the DESMOND Programme, which has been shown to be robust and effective for patients in general. However, these programmes are not generally targeted to people with intellectual disabilities (ID), and robust evidence on their effects for this population is lacking. We have adapted the DESMOND Programme for people with ID and type 2 diabetes to produce an amended programme known as DESMOND-ID.

This protocol is for a pilot trial to determine whether a large-scale randomised trial is feasible, to test if DESMOND-ID is more effective than usual care in adults with ID for self-management of their type 2 diabetes, in particular as a means to reduce glycosylated haemoglobin (Hb1Ac), improve psychological wellbeing and quality of life and promote a healthier lifestyle. This protocol describes the rationale, methods, proposed analysis plan and organisational and administrative details.

**Methods/Design:** This trial is a two arm, individually randomised, pilot trial for adults with ID and type 2 diabetes, and their family and/or paid carers. It compares the DESMOND-ID programme with usual care. Approximately 36 adults with mild to moderate ID will be recruited from three countries in the United Kingdom. Family and/or paid carers may also participate in the study. Participants will be randomly assigned to one of two conditions using a secure computerised system with robust allocation concealment. A range of data will be collected from the adults with ID (biomedical, psychosocial and self-management strategies) and from their carers. Focus groups with all the participants will assess the acceptability of the intervention and the trial.

**Discussion:** The lack of appropriate structured education programmes and educational materials for this population leads to secondary health conditions and may lead to premature deaths. There are significant benefits to be gained globally, if structured education programmes are adapted and shown to be successful for people with ID and other cognitive impairments.

**Trial registration:** Registered with International Standard Randomised Controlled Trial (identifier: ISRCTN93185560) on 10 November 2014.

**Keywords:** Intellectual disability, type 2 diabetes, self-management, structured education

## Diabetes UK Grant (2015-17)

### Adapt DESMOND for adults with a learning disability and T2D

### Feasibility RCT



# Making Reasonable Adjustments to the DESMOND education programme for adults with a learning disability



## Heterogeneity / Different learning styles

- Level of learning disability (borderline, mild, moderate and severe / profound)
- Cognitive deficits / processing information / recall / re-appraisals of beliefs and behaviours
- Communications difficulties / comprehension / acquiescence
- Low levels of literacy skills and different learning skills
- Engagement with family and paid carers / or lack of this
- Variation in supports provided to monitor Hb1Ac, aid with managing a healthy diet, exercising / becoming less sedentary, medication compliance, eye examinations, foot care, etc.

# DESMOND-ID education programme for adults with a learning disability and T2DM:

## MAKING REASONABLE ADJUSTMENTS

A 7-week education programme, 2½hrs each, plus two booster sessions, for approx. 6-8 adults with a learning disability & T2D

1<sup>st</sup> session held only for family member/carer/partner/friend to prepare them for their role

Held in a health centre/day centre, community centre, church hall

Delivered by a trained health professional in learning disability and a DESMOND lay educator (trained in the DESMOND-ID programme).

Cost of transport paid for adults if needed

Adults with a learning disability offered a £10 voucher each time they complete the data collection



Desmond

Intellectual  
Disabilities

ARTICLE

## Working with people with people with intellectual and developmental disabilities who have diabetes

Laurence Taggart, Maria Truesdale-Kennedy, Jillian Scott

Citation: Taggart L, Truesdale-Kennedy M, Scott J (2014) Working with people with people with intellectual and developmental disabilities who have diabetes. *Journal of Diabetes Nursing* 18: XX-XX

### Article points

1. People with intellectual and developmental disabilities are thought to be at greater risk of developing diabetes, compared to people without these disabilities.
2. Despite this, little attention has been paid to improving health promotion, screening and structured education

There is growing evidence to highlight that people with intellectual and developmental disabilities develop diabetes, with prevalence rates being reported to be higher compared to those without these disabilities. Despite this, it is population that is frequently forgotten and little attention has been given to diabetes health prevention and promotion, diabetes screening and structured education in this group. There is also a great importance to educate family and paid carers to support them to help manage their diabetes. Furthermore, the question of whose responsibility it is to manage the person's diabetes within primary care should be discussed. This article will outline some exemplars of user-friendly diabetes educational resources and one specific structured type 2 diabetes education programme that has been adapted for adults with intellectual and developmental disabilities. Gaps in our understanding and clinical practice will be discussed, and readers will be offered practical solutions where they can tailor diabetes education for this group.



**Making Reasonable  
Adjustments to the  
DESMOND education  
programme for adults  
with a learning disability**



- Time (7 x sessions plus 2 booster sessions)
- Core concepts simplified
- Pictorial representations (visual, photos, pictures, symbols)
- Repetitious learning / interactive sessions
- Development of skills / developing 'self-efficacy'
- Support for carers, partner or friend (education of carers; 1 session)
- Health action plans / goal setting
- Celebration and fun

DAY 1	DAY 2	DAY 3	DAY 4	DAY 5	DAY 6
Welcome and introduction (25 mins)	Welcome back (20 mins)	Welcome back (20 mins)	Welcome back (20 mins)	Welcome back (20 mins)	Welcome back (20 mins)
My story with diabetes (part 1) (15 mins)	My story with diabetes (part 2) (15 mins)	Knowing what your blood sugar levels mean (35 mins)	Heart and circulation problems: what can I do to keep healthy (part 1) (40 mins)	Food and fats (35 mins)	Diabetes health action plan: what will I work on? (35 mins)
My body and diabetes (20mins)	What diabetes does to your body? (25 mins)	Break (15 mins)	Break (15 mins)	Break (15 mins)	Break (15 mins)
Break (15 mins)	Break (15 mins)	Being active (40 mins)	Other diabetes health problems: what can I do to keep healthy (part 2) (35 mins)	Making healthier food choices (40 mins)	Keeping my plan going (35 mins)
What is diabetes? (35mins)	Food and blood sugar (35 mins)	What did I learn today? (10 mins)	What did I learn today? (10 mins)	What did I learn today? (10 mins)	Important questions and celebration of achievement (15 mins)
What did I learn today and preparing for next week? (10 mins)	What did I learn today and preparing for next week? (10 mins)	What did I learn today and preparing for next week? (10 mins)	What did I learn today and preparing for next week? (10 mins)	What did I learn today and preparing for next week? (10 mins)	
2 hours	2 hours	2 hours	2 hours	2 hours	2 hours

## Research: Educational and Psychological Aspects

### Pilot feasibility study examining a structured self-management diabetes education programme, DESMOND-ID, targeting HbA<sub>1c</sub> in adults with intellectual disabilities

L. Taggart<sup>1</sup>, M. Truesdale<sup>2</sup>, M. E. Carey<sup>3</sup>, L. Martin-Stacey<sup>3</sup>, J. Scott<sup>4</sup>, B. Bunting<sup>5</sup>, V. Coates<sup>1</sup>, M. Brown<sup>2</sup>, T. Karatzias<sup>2</sup>, R. Northway<sup>6</sup> and J. M. Clarke<sup>7</sup>

<sup>1</sup>Institute of Nursing and Health Research, Ulster University, Belfast, <sup>2</sup>Edinburgh Napier University, Edinburgh, <sup>3</sup>Leicester Diabetes Centre, University Hospitals of Leicester NHS Trust, Leicester, <sup>4</sup>Northern Health and Social Care Trust, Coleraine, <sup>5</sup>Institute of Psychology, Ulster University, Derry, <sup>6</sup>University of South Wales, Cardiff and <sup>7</sup>MRC Hub for Trials Methodology Research, Queen's University Belfast, Belfast, UK

Accepted 25 October 2017

#### Abstract

**Aim** To report on the outcomes of a pilot feasibility study of a structured self-management diabetes education programme targeting HbA<sub>1c</sub>.

**Methods** We conducted a two-arm, individually randomized, pilot superiority trial for adults with intellectual disability and Type 2 diabetes mellitus. A total of 66 adults with disabilities across the UK met the eligibility criteria. Of these, 39 agreed to participate and were randomly assigned to either the DESMOND-ID programme ( $n = 19$ ) or a control group ( $n = 20$ ). The programme consisted of seven weekly educational sessions. The primary outcome was HbA<sub>1c</sub> level, and secondary outcomes included BMI, diabetes illness perceptions, severity of diabetes, quality of life, and attendance rates.

**Results** This study found that the DESMOND-ID programme was feasible to deliver. With reasonable adjustments, the participants could be recruited successfully, and could provide consent, complete the outcome measures, be randomized to the groups and attend most of the sessions, with minimal loss to follow-up. The fixed-effects model, the interaction between occasion (time) and condition, showed statistically significant results (0.05 level) for HbA<sub>1c</sub>; however, the CI was large.

**Conclusion** This is the first published study to adapt and pilot a national structured self-management diabetes education programme for adults with intellectual disability. This study shows it is possible to identify, recruit, consent and randomize adults with intellectual disabilities to an intervention or control group. Internationally, the results of this pilot are promising, demonstrating that a multi-session education programme is acceptable and feasible to deliver. Its effectiveness should be further tested in an adequately powered trial.

Diabet. Med. 35, 137–146 (2018)

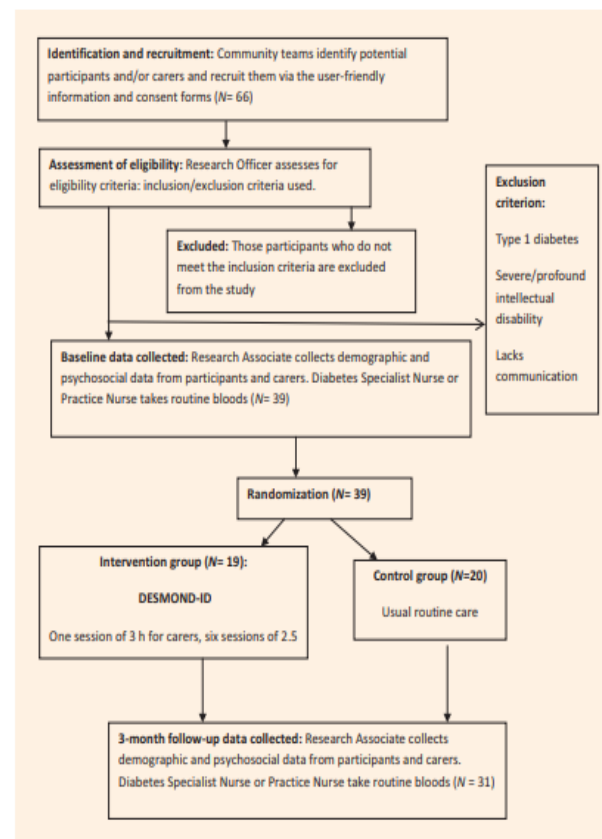


FIGURE 1 Flow chart of the study protocol.

## Learning from research



## Identifying Challenges & Solutions

**Individual Factors:** Heterogeneity, Co-morbidities, Persons' ability to read/write, Use of Self-Report Measures

**Design Factors:** Funder, Ethics, Capacity to Consent, Recruitment, Randomisation, Burden

**System/Organisational Factors:** Funding, Staff as Gatekeepers, Commitment from Staff, Staffs' Research Understanding, Fidelity of Intervention

**Solutions:** Making Reasonable Adjustments, Inclusive Research, Working with our Partners, Recruitment Strategy,

APPLICATION SUMMARY INFORMATION

Programme Name	HTA
Funding Opportunity	HTA Researcher-Led
Call	19/160 HTA Researcher-led call Primary Research
Host Organisation	University of Ulster

Research Title	
The clinical and cost-effectiveness of the DESMOND-ID education programme for adults with intellectual disability and Type 2 Diabetes	

Research Type	Primary Research
Proposed start date, end date (duration)	From: 01/01/2022 to: 31/12/2025 (48 months)
Total research costs (not including NHS Support & Treatment Costs)	£2,334,682.36
Total NHS support & treatment costs	£100,701.00
Total Non-NHS intervention costs	£0.00

LEAD APPLICANT DETAILS & CV

Details of Lead Applicant	Dr Laurence Taggart
Job Position	Reader
Department	Institute of Nursing and Health Research
Email / Phone	l.taggart@ulster.ac.uk 00442890366538
Organisation	University of Ulster

NIHR HTA Open Call / Cost £2.3m

Completed a Diabetes UK feasibility RCT earlier (Taggart et al 2017) / tried and tested the methodology / intervention

Track record / Team Assembled / published papers

Work with DESMOND Centre, Leicester

Three Sites (N Ireland, Scotland, & England): N = 450

Funder Issues:

- Able to recruit participants
- PPI Involvement



# My Diabetes and Me Study

- **AIM:** The clinical and cost-effectiveness of the DESMOND-ID diabetes education programme for adults with LD and T2D
- **Funder:** NIHR HTA
- **Time:** 45-month RCT
- **Where:** N Ireland, Scotland and England
- Ethics obtained / Research Governance obtained



# RCT Design: Norfolk and Essex

- **Who:** 44-48 adults with mild/mod learning disability and T2D, living in the community, can give consent, communication skills, (need to identify & approach approx. 100-140) in each site
- **Support:** Where possible the person with learning can bring a family member / carer / partner / friend to support, it's the persons choice
- **Where:** Norfolk and Essex
- **When:** Identification and Recruitment: Jan – April 24
- **Data collection:** We will collect bloods (Hb1Ac, cholesterol, lipids), BMI, T2D beliefs and depression data at baseline and 6 and 12-months follow-up (£10 voucher)
- **Intervention delivered** in May – June 24 (flexibility)

# CLINICAL TRIALS RANDOMIZATION



Patient information is entered into a computer



The computer randomly assigns patients to two or more groups, helping to prevent bias



Control group receives standard therapy

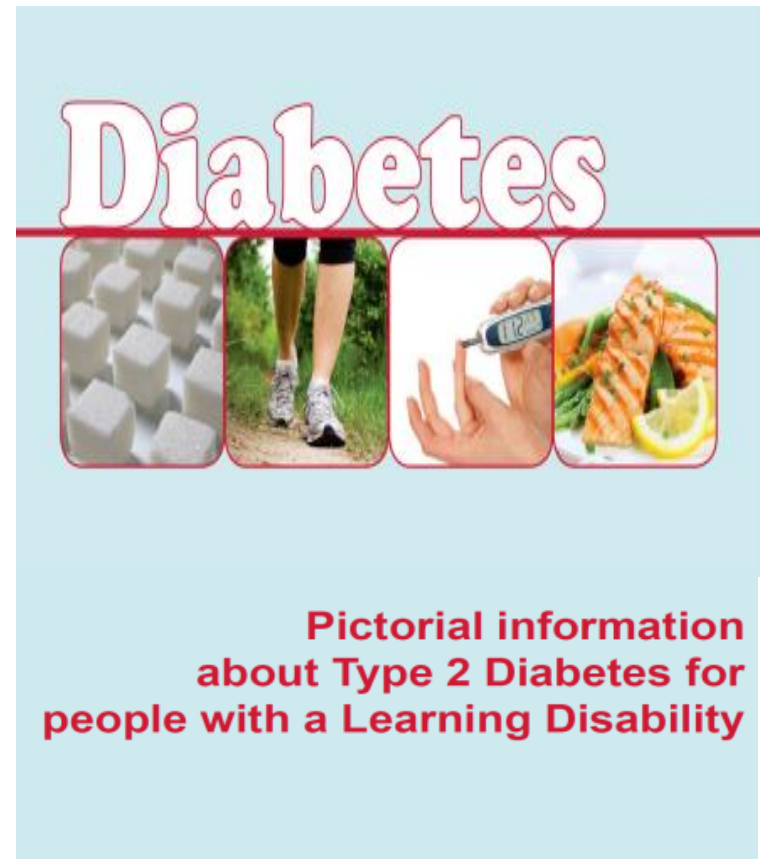


Investigational group receives new treatment



# Control Group

- They will not receive the DESMOND-ID education programme
- They will receive usual care plus a book
  - What is diabetes?
  - Symptoms
  - Management
  - Hypoglycaemia
  - Hyperglycaemia
  - Insulin
  - Diet
  - Exercise
  - Complications
  - Eye Care
  - Foot Care
  - Annual Check up



# Action

- **Identify** potential adults with a mild/moderate learning disability with Type 2 diabetes
- CLDN; LD housing; LD charities; GP practices; and Social Media
- **E-mail:** Dr Rosie Kelly ([r.kelly@ulster.ac.uk](mailto:r.kelly@ulster.ac.uk)) and the CRNs at each site
- When the person returns a positive reply slip/e-mail, then the research team will contact the person to obtain consent and collect baseline date



## Have you got Type 2 Diabetes and a Learning Disability ?



The University of Ulster has developed an education programme for people with a learning disability who have Type 2 diabetes.



This programme could help you to understand and manage your diabetes better.



It gives advice on how to manage your weight and diet, become more active; and control your blood sugars.

**If you or someone you support may be interested, contact Gary McDermott on**

**T: +447873704514 E: [g.mcdermott@ulster.ac.uk](mailto:g.mcdermott@ulster.ac.uk)**

