

My Diabetes & Me



Participant Information Sheet for Main Study



Please read this information
leaflet



If you are not sure you
understand, talk to a family
member, carer, partner or a
friend that you trust about this



My name is: Scott Taylor

I work at: Astley Ainsley Hospital

I am carrying out a research study

What is a Research Study?



A research study is a way we try to find out answers to questions

This research study is about how we teach people about diabetes.



You have been invited to take part in **My Diabetes and Me** research study

I want to see if you would like to take part

Why are we doing this research?



We have developed an education programme to teach people with learning disabilities who have Type 2 diabetes, how to look after themselves.

We want to find out how well this programme works

The diabetes education programme is called DESMOND-ID

It is for people who have Type 2 diabetes and the people who support them (a family member, a carer, a partner or a friend)



This programme helps people:

- To learn about their diabetes
- To learn how to keep healthy and stay well

Why have you been invited?



We have invited you to take part in the research because you have Type 2 diabetes



We are asking you because someone like a nurse or a doctor has told us you might like to take part



Or, you or a person who supports you has said that we could contact you about the research

Do I have to take part?



You can choose

You can say YES or NO



If you say YES, we will ask you to sign a piece of paper called a consent form

This form says you are happy to take part in the research study.

We will give you a copy of the form to keep

It is OK to change your mind.

If you say NO to taking part in the research study, nothing will change for you or the care you receive.



What will happen if I take part?



If you say yes, a research nurse will arrange to meet you at a place that you know



It is good to ask somebody who knows you well to be with you. This could be a family member, a carer, partner or a friend.



What will happen when the nurse visits you?

This appointment will be for about 2 hours. But the nurse may arrange a second visit

First we will explain about the research study



We will ask you to sign a piece of paper called a consent form. This is a form that says you are happy to take part in the research study.

We will ask you some questions about your life and your health

We will measure how tall you are and how much you weigh



We will measure your blood pressure. We may let your GP know your results



The nurse will also ask you to have a blood test

The blood test might hurt a little

The research nurses who will take your blood test are friendly. They will look after you



The blood will be tested later that day. This blood will be tested for Hb1Ac and cholesterol. We may let your GP know your results



We will also ask you to complete some forms asking about your health. The nurse or your family member, carer, partner or friend who you trust can help you with these forms. We may let your GP know your answers.

If you don't get these forms completed during this visit, the nurse can call out again to collect the forms

What will happen next?



If you agree to take part, you will be put into either Group 1 (Education programme) or Group 2 (Control group). This will be decided by chance or lucky dip



We will ask a computer to decide

We will let you know which group you are in

If you are in Group 1, what will happen?



If you are in Group 1, you and your family member, carer, partner or friend will be asked to attend 8 education sessions at one of several local venues in your own Health & Social Care Trust area.

These will last approx. 2 and a half hours per week

If you are in the Diabetes Education Group we will send you information about when it starts and where it will be held

We would like you and your family member, carer, partner or friend to come to the sessions together, where possible

If you do not have someone to come with you, that's OK, you can still attend

We may also ask you to take part in a face to face or online focus group with other people who took part in the education programme, to tell us how it went



If you are in Group 2, what will happen?

If you are in Group 2, you will NOT be invited to the education sessions



We will send you a booklet on how to look after your diabetes

We will ask you to see your GP or nurse as usual



Other things you need to know?

We will ask you to see the research nurse again for 2 more appointments after 6 months, and after 12 months

This will be like the other appointments:

- We will ask you some questions
- We will measure you and
- We will ask you to have a blood test



Will I get paid for taking part?

To thank you for your time, we will give you a £10 gift voucher after the first visit at the start of the study. We will give you another £10 voucher at the other appointments after 6 months, and 12 months

We can help you with money for travel costs if needed

Will my information be kept private?



We will keep your information safe. We will not tell anyone else it is about you

We will not talk to anyone else unless we are worried about your safety

We may ask you if you will let us look at your medical notes to help us with this research study



We will also ask if you will let us look at this information in the future

Privacy Notice



Ulster University is the sponsor for this study

We are the “data controllers” which means we have to make sure the information you give us is used in the right way

We will keep your information for up to 10 years after the study has ended. You can find out by sending an email to:

data-protection@ulster.ac.uk

After the study?



We would like to use the information we have found out about you in the research study. This could be in reports and presentations. We will not use your name



If you say yes, we will send you a report about the **My Diabetes and Me** research study when it is finished if you ask

We would like to keep your contact details

If you say yes, we might invite you to help with other research studies in the future.



Who is paying for this research?

The government (Dept of Health) is paying for this research study



Who has checked this research?

Before we do a research study, it is checked by a Research Ethics Committee

A Research Ethics Committee is a group of people who make sure:

- It is ok to do the research study
- The research is being done in a good way

What should I do if I want to take part in the My Diabetes and Me research study?



You can choose if you want to take part. It is a good idea to talk to a family member, carer, partner or friend



Please fill out the reply form and post it back to us in the envelope provided. The envelope does not need a stamp.



Thank you for taking the time to read this information and considering to take part

Who can I contact for more information?

Name of Researcher: Scott Taylor

Address: Woodlands House, Astley Ainsley Hospital, 74 Canaan Lane, Edinburgh, EH9 2TB

Tel No: 07976 582310

E-mail address: Scott.Taylor@nhslothian.scot.nhs.uk

Who can I contact if I need advice, support and information on health-related matters?

Your local Patient Advisory Liaison Service (PALS) email address is: NHS Lothian Patient Experience Team - feedback@nhslothian.scot.nhs.uk