T1D-DAB

The Diversity of Type 1 Diabetes Across Bristol

Study Information Sheet: 12-15 Years

Hello!

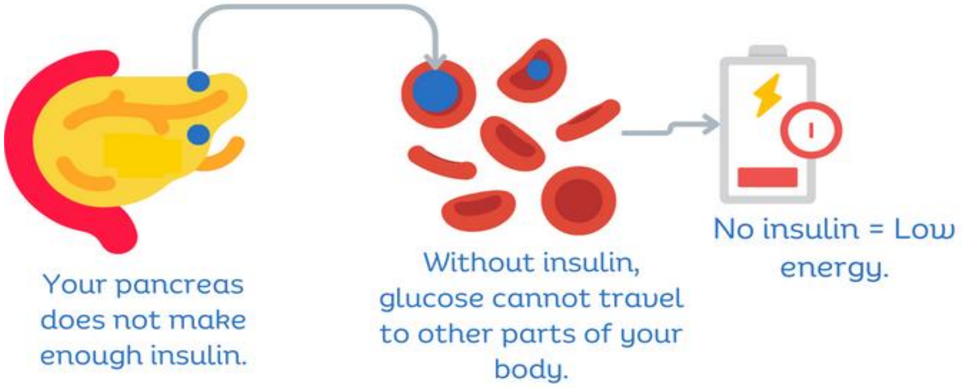
We would like to tell you about a study called T1D-DAB that will help us learn more about Type 1 Diabetes.

Before deciding if you will or will not join our study, take the time to read the information below. Please get in touch with us if you have any questions.

What is Type 1 Diabetes?

The pancreas in our body digests (breaks down) the food we eat. It also produces a hormone called insulin. We need insulin to help change the glucose (sugar) in our food into energy. In Type 1 Diabetes, our pancreas does not make enough insulin. This makes us feel exhausted and unwell because we have less energy.

People with Type 1 Diabetes are treated with insulin injections to give them more energy. Anyone can have Type 1 Diabetes, even babies, and it is not their fault.



Alt text picture caption: There is a picture with three images linked to one another. The first image displays a pancreas and how not enough insulin is produced. The second image displays how due to the lack of insulin, glucose is not able to travel in the red blood cells to other parts of the body. The final image shows a low battery to explain how low insulin is linked to lower energy levels.

When someone has Type 1 Diabetes, their body's defence system, called the immune system, gets confused. It mistakenly thinks that the cells that make insulin are harmful. Their immune system attacks the insulin-producing cells in the pancreas. Proteins called antibodies show this attack is happening.

These antibodies can be found in your blood years before you develop Type 1 Diabetes, from as early on as when you were a baby.

Why am I being asked to take part?

Your doctor has told you that you have Type 1 Diabetes

You live in Bristol.

Your help can make a difference in understanding and treating Type 1 Diabetes.

Why is the T1D-DAB study important?

We have a good understanding of Type 1 Diabetes in White children. However, we know little about Type 1 Diabetes in adults and people from other heritages.

We want to find out if age and ethnicity affect Type 1 Diabetes.

This information could help everyone with Type 1 Diabetes, no matter their age or ethnicity.

Who can join T1D-DAB?

We are asking people aged over 3 years who have Type 1 Diabetes and live in Bristol to take part in our study.

What would I need to do?

If you decide to take part in our study, you will need to follow these steps:

Step-1: Collect samples at home:

We will post sample collection kits to your home.

These collection kits will also include instructions on how to collect your urine, mouthswab, finger-prick blood, and saliva samples.

You might need help from your parents or guardians to collect these.

We also have sample collection instruction videos on our study website here: https://tinyurl.com/T1D-DAB-sample-collection

Step 2: Complete Questionnaires

We will ask you and your parents/ guardians to answer questions about:

- Your age and ethnicity
- When were you told you had Type 1 Diabetes
- How do you feel about having Type 1 Diabetes

Alt text picture caption: There is a picture where a young person is standing over a table, and two older people are sitting at the table studying what looks like a document. A young person thinks, what would I need to collect if I decided to help with this study? The older person explains that the following items would be collected: 1) Urine in a pot, 2) a Mouthswab (to look at your genetic information, called Deoxyribonucleic acid -DNA) by rubbing a small brush in my mouth, 3) saliva in a collection tube, and a finger prick blood sample. The older person also says that a completed would need to be completed on their behalf.

What is going to happen to my samples?

Alt text picture caption: There is a picture of two scientists working in a lab with lab clothing on and equipment surrounding them. Scientist 1 says they can check how well your insulin-producing cells are working by testing your urine samples. Scientist 2 says they will analyse your finger-prick blood and saliva samples for antibodies and look at the genetic information (called DNA) inside your mouthswab sample.

Antibody testing:

Our scientists will test your finger-prick blood and saliva samples for antibodies.

We know these antibodies can be found in blood, but we are also interested in seeing if they are in saliva.

Antibodies help us to see if there have been any changes to your immune system.

DNA testing:

We will also look at the genetic information code (called DNA) in the cells of your mouth swab sample.

This will help us to learn more about your Type 1 Diabetes.

Urine testing:

We will assess your urine samples for a substance called C-peptide, which is made at the same time as insulin.

A C-peptide test will help us to see how well your pancreas makes insulin.

How can I take part?

Please talk to your parents or guardians if you want to join the T1D-DAB study.

We also have a separate information sheet for parents/guardians to read.

Your parents or guardians must complete a consent form to state that they agree to allow you to participate.

You will also be given a form (called an assent form) to sign to state that you are happy to take part.

Both forms are on REDCap. Researchers use this web-based tool to manage and collect clinical data.

If your parents or guardians would prefer the forms sent by post, please ask them to contact us.

Alt text picture caption: There is a picture of a tablet and a laptop with the research study's logo and website on them.

You will also receive a record of the signed consent and assent form.

What are the benefits of taking part?

You will not personally benefit from taking part in T1D-DAB.

However, the information from this study and others could help to produce better tests to predict who might develop Type 1 Diabetes.

Our study will collect samples to see if your age and ethnicity affect Type 1 Diabetes.

What are the risks of taking part?

Your finger might be sore from the finger-prick blood test, but it will not last long.

What will happen to the results of T1D-DAB?

It is important to know that we will not share the results with you or your parent/guardian. However, we will update our study website with a summary of the results.

The study results will be published in scientific journals, which other researchers will read to learn more about our work.

The results will also be shared at conferences. This will help to educate other healthcare staff and researchers.

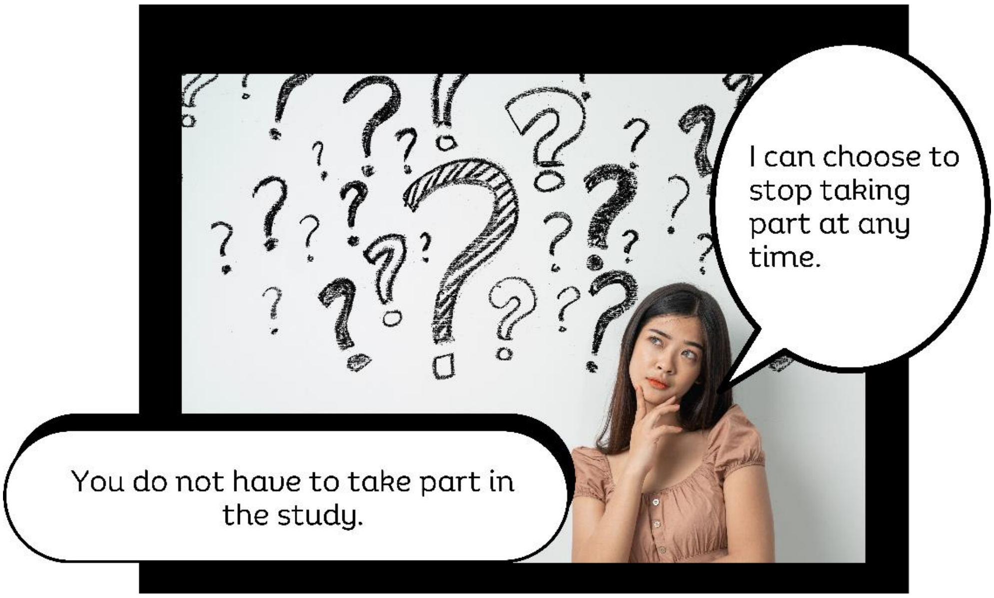
Alt text picture caption: There is a picture of a scientist standing up and speaking with the research study logo displayed on a flip chart behind them. The scientist from the T1D-DAB study team is presenting the results at a conference. The scientist thinks, " The study results will be presented at conferences to help educate other healthcare staff and researchers." The scientist tells the audience: "So what we learned in the T1D-DAB study was that Type 1 Diabetes is affected by….." On the top of the image, there is a bubble explaining that 'the study results will be written up in scientific journals and…'

Do I have to take part?

No, you do not have to take part in T1D-DAB if you don't want to.

If you change your mind about taking part:

- No one will mind. It will not change your medical care.
- Just ask your parents or guardians to contact Dr. Anna Long, who leads our study.



Alt text picture caption: There is a picture of a white square surrounded by a black border. In the white square there are lots of different questions marks. In front of the white square, you can see a young person standing and saying 'I can choose to stop taking part at any time." At the bottom of the image, there is a bubble saying, 'You do not have to take part in the study'.

How will my personal information and data be protected?

We are committed to protecting your privacy and promise to keep all the information collected about you and your parents/guardians safe. We will follow strict guidelines to protect your personal information, such as the General Data Protection Regulation (GDPR) and the Confidentiality Act.

We will ensure that any information that leaves our research centre will not include your name or any other information that can be used to identify you.

You can learn more about how we will take care of your data here:

http://www.bristol.ac.uk/secretary/data-protection/policy/research-participant-fair-processing-notice/

Who do I contact if I have any questions?

Please ask your parents or guardians to visit our study website: https://tinyurl.com/T1D-DABStudyHomepage

We are happy to answer any questions you or your parents or guardians have.

Contact us:

T1D-DAB Study **Address:** **Diabetes and Metabolism** **Level 2, Learning and Research** **Southmead Hospital** **Bristol** **BS10 5NB**	**T1D-DAB Study** **E-Mail:** **diabetes-study@bristol.ac.uk** **Telephone:** **0117414 7915**

Chief Investigator: Dr Anna Long

E-Mail: Anna.long@bristol.ac.uk

Thank you for taking the time to read this!