



UNIVERSITY OF
BIRMINGHAM



ELSA-1 Study

Children's information leaflet

Who is this information leaflet for?

This is for children and young people aged 5-13 years who would like to find out more about the ELSA-1 study.



Part 1 - Summary of the ELSA-1 study

We want to know how you and your parents and carers would feel if you were told you may get type 1 diabetes when you are older.

We also want to know how you would feel about being monitored for type 1 diabetes if you were at risk.

We will just be talking to you and your parents and carers to find out your thoughts and feelings. We will not be doing any other tests on you.

If you would like to find out more about the study, please read Part 2.



Part 2 - About the ELSA-1 study

What is type 1 diabetes?

Type 1 diabetes is an illness that affects how the body uses the food that you eat. Type 1 diabetes is not because you ate too many sweets!

In young people with type 1 diabetes, not enough insulin is made in their body. Insulin allows your body to use the food that you eat and turn it into energy.

If your body cannot use your food as fuel, this makes people feel very poorly.

They may then need to see the doctors in the hospital to get some medicine called insulin.

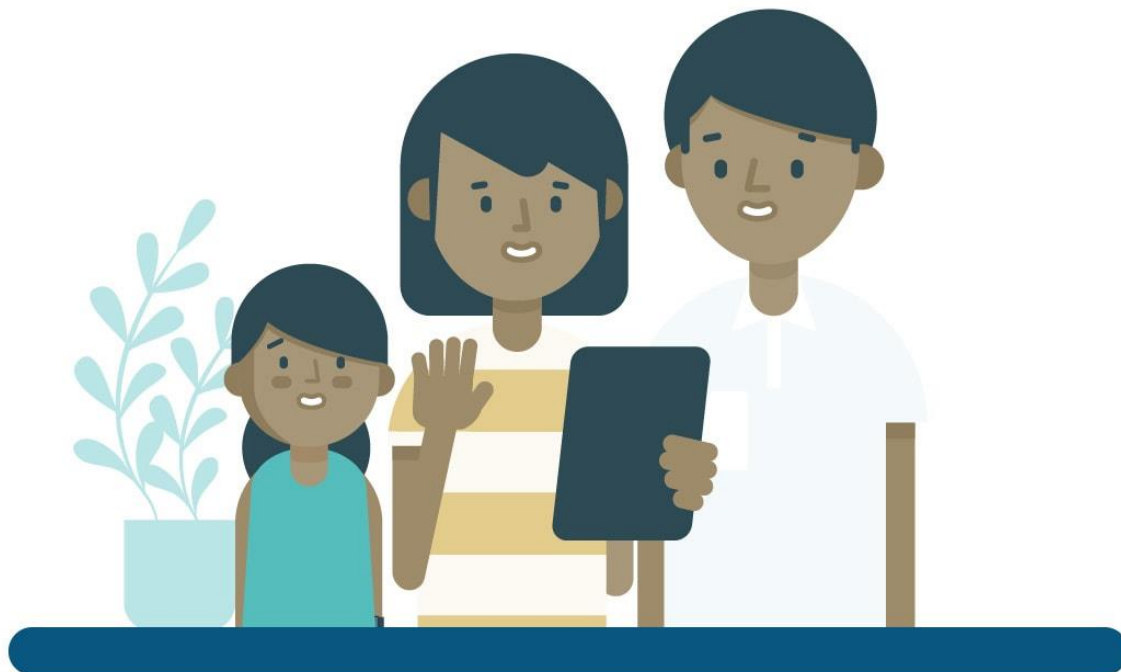
Children who have diabetes, will need to take this medicine for the rest of their lives.



What is the ELSA-1 study?

The ELSA-1 study wants to know how you would feel about knowing if you will get type 1 diabetes in the future.

We want to talk with you and your family to find out if you would or would not like to know, and the reasons for this. There is no right or wrong answer, we just want to hear what you have to say.



What do I need to think about before I take part?

We know that talking about your health in the future could make you and your family feel sad. But we will look after you and your carers and you can take a break anytime.

Remember that we are not testing you for type 1 diabetes in ELSA-1 and you can choose to stop talking to us at any time.

ELSA-1 and ELSA-2 studies:

The ELSA-1 study is leading onto the ELSA-2 study.

The ELSA-2 study is where children can choose to get tested for type 1 diabetes. The test is a simple blood test to tell us if you are at risk of getting type 1 diabetes when you are older.

If the answer is yes, these children and their families will go into a monitoring programme. You can choose to be part of ELSA-1, or ELSA-2, or both, but ELSA-2 will not open until 2022.

What would I have to do for the ELSA-1 study?

One of our friendly study team will talk to you and your family, by video call using Zoom, by phone or at the university.



We want to ask you and your family:

- What you think the good and bad things could be about having the tests and knowing the results.
- How you and your carers would feel if you were told you may get diabetes when you are older.

Why?

The ELSA-1 study will help us to understand if setting up a testing programme for type 1 diabetes is the right thing to do. By talking to young people and their families, we will learn more about their thoughts and ideas to help adapt a future type 1 diabetes monitoring programme.

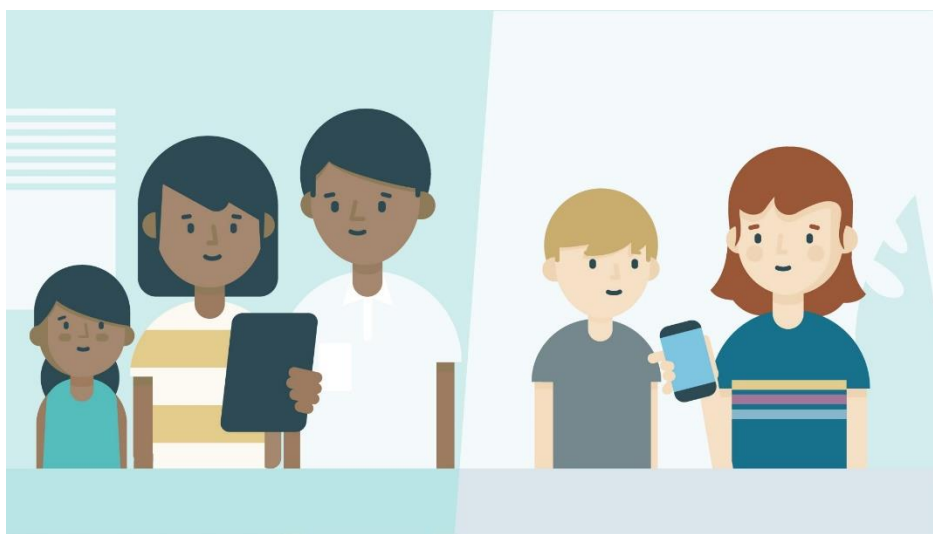


Where?

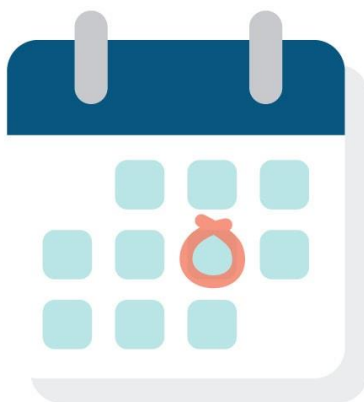
The ELSA-1 study is COVID-19 friendly meaning that you can take part in the study from your own home, using your phone or computer.

You can read about the study online and can complete the online consent form. You can take part in the meeting with the research team by video call.

You can also choose to take part in the interviews by coming to see us in person if that would be better.



When? If you and your parents agree to take part, we will contact your parents to hold an interview. The interviews will last about one hour and can be done in the daytime or in the evening time after school. We will ask your family what is the best time for them to do this with you.



Who?

The ELSA-1 study is open to children and young people aged 5-13 years and their families, living in the West Midlands. If you already have type 1 diabetes, you can still take part.



What information will we be collecting for this study?

We will ask you for your name, age, gender, and ethnicity. This is to help us to gather as many thoughts from as many different children as possible. We will keep this information safe. Your data will be under general data protection regulation (GDPR). You can find out more about how we look after your data here: <https://elsadiabetes.nhs.uk/privacy-notice-cookie-usage/>

How do I join the ELSA-1 study?

1. You need to have read and understood the ELSA-1 children's study leaflet (this document) and/or online tool.
2. You or your parent can then sign the children's online or postal assent form to take part in the study.
3. Your parent or carer will also need to have read the ELSA-1 study parents / carers leaflet or online tool, and signed the online or postal parents / carers consent form.

How to find out more information about ELSA study?

Check out our website to find out more and how to contact us about the ELSA-1 study. You can email the study team on elsa@contacts.bham.ac.uk.



Thank you for reading this information leaflet.