



The ELSA Study:

Children's Information Sheet: 11-15 years

Who is this information leaflet

for?

The ELSA study is screening children for type 1 diabetes.

This leaflet is for children and young people aged 11-15 years who would like to find out about the ELSA Study.

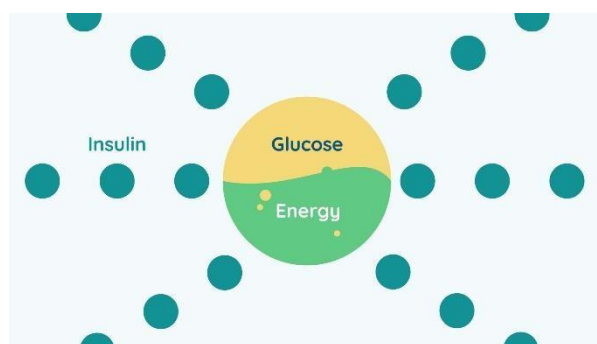


You can also read the online information here if you prefer:

www.elsadiabetes.nhs.uk

What is type 1 diabetes?

In type 1 diabetes, not enough insulin is made in the body. Insulin is a natural hormone. We all need insulin to get energy from the glucose (sugar) in the food we eat. Without insulin, children become very unwell. Children with type 1 diabetes need to take insulin injections for the rest of their lives.

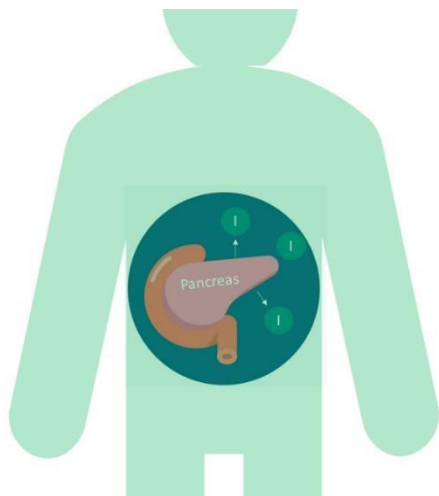


Antibodies are found in the blood. Antibodies tell us if a child may develop type 1 diabetes in the future.

This is because antibodies can attack the pancreas and stop the pancreas from producing insulin. We do not know why some children have these antibodies and other children do not.



This is where the pancreas is in the body. The pancreas makes insulin.




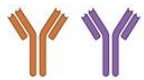


In children with type 1 diabetes, the pancreas stops working and stops making insulin.

What is the ELSA study testing for?

The ELSA Study is screening children for type 1 diabetes. We take a small sample of blood to look for these antibodies. We are testing for 4 different antibodies in the ELSA Study.

If the blood test is negative, this means there are no antibodies, so the risk of developing type 1 diabetes is low.

If the blood test is positive, this means antibodies are present, which could lead to type 1 diabetes in the future. Children with two antibodies or more have a high chance of developing type 1 diabetes in the future.

Number of antibodies positive	Risk of type 1 diabetes
	Lower risk
	High risk
	Higher risk
	Higher risk

Why is the ELSA Study important?

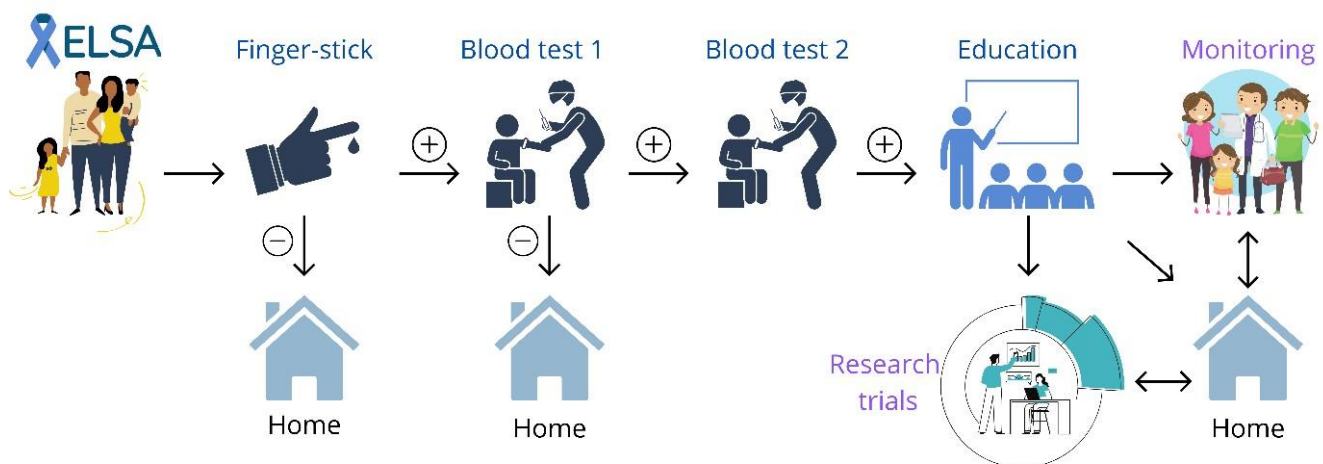
We want to help children who are at high risk of developing type 1 diabetes, by getting them the treatment they need sooner and stop them from becoming too unwell. We also want to let them know about studies they could take part in to check-up on them or test new treatments.



Taking part in the ELSA Study means you are helping children at risk of type 1 diabetes.

What would I need to do in the ELSA Study?

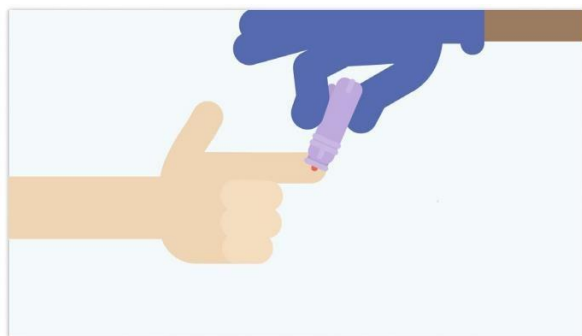
This diagram shows a summary of the ELSA Study.



Step 1 - Finger stick test

First, we will need a drop of blood for a finger stick test. Your parent, or one of our study nurses can do this for you, at home, at school or in the community.

For most children, this will be negative. This means these children are currently at low risk of developing type 1 diabetes and do not need to have any more tests in our study.



Step 2 - Venous blood tests

If the finger stick test is positive for antibodies, we will need to do another blood test to confirm this. This blood test will be into a vein, but we can use creams to help reduce the pain. If this comes back positive, more blood tests are needed to



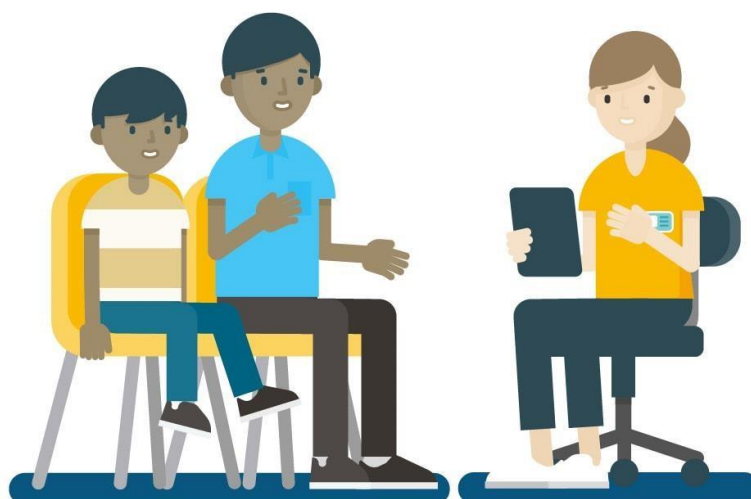
see if insulin needs to be started straight away. These blood tests will be done at the hospital.

Step 3 – Education session and next steps

Children who test positive for antibodies will be invited to an education session, with their family. We will explain what the risk of developing type 1 diabetes is and what we can do next.

For example, children at high risk of developing type 1 diabetes will be offered checkups to see if they need to start insulin, so that they do not become too unwell.

Children at high risk could also go into research studies, testing new treatments to try and delay when the type 1 diabetes starts.



What information will you be collecting about me?

We will ask your parent/carer for your name, age, ethnicity, gender, and if you have any health problems. This helps us to understand your test results. Your data will be kept safely under general data protection regulations (GDPR).

You can find out more about how we look after your data here:
<https://elsadiabetes.nhs.uk/privacy-notice-cookie-usage/>



Who can take part?

Any child aged 2-17 years who does not have type 1 diabetes can take part.



What are the benefits of taking part?

By taking part, you will find out your risk of getting type 1 diabetes and you will be helping us to understand more about type 1 diabetes.

What are the risks of taking part?

We know that blood tests can be sore, but we will look after you and it will only be sore for a moment.

If the blood tests show you have antibodies, the ELSA Study team will support you and explain what we can do to help you.

No test is 100% accurate, but we are using the best possible tests we have. You may need more tests in the future to look at your risk again, because this can change over time.

Where can I take part?

We can send you a finger stick test to your home, and your parent/guardian can do this for you and post it back to us. You can also do the finger stick test at school, at your general practice surgery or in the community.

If you need a venous blood test, these will be taken at a hospital near you.



How can I take part?

If you would like to take part, you can do this online, by post or face-to-face:



Step 1 - Your parent/guardian needs to fill in the eligibility form.

Step 2 -Your parent/guardian will need to complete a consent form for you. You can also sign the assent form to say you are happy to take part.

Step 3 - Your parent/guardian will fill in the medical details form.

How to find out more information about the ELSA Study?

Check out our website to find out more information: www.elsadiabetes.nhs.uk

We are happy to answer any questions you have.

Thank you for reading this information leaflet.