

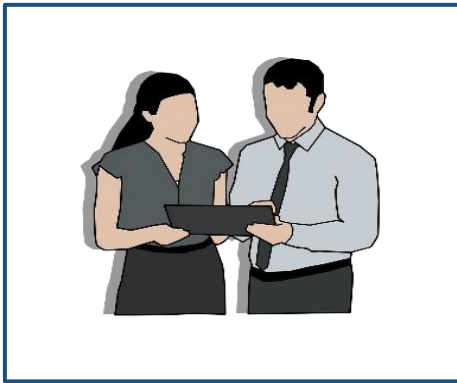


Easier Read Information Sheet

A study about genes and Autism Spectrum Conditions

To be read by carer/family member if required.

What is Spectrum 10K?



We would like to invite you to take part in our research study called Spectrum 10K.

Research is when we ask people questions and do tests to find out things.

Spectrum 10K is trying to find out more about autism.



To help you understand this letter you can:

- Ask your carer or clinician to read it for you
- Talk to your carer or clinician about it.

Why me?



You are invited to take part because you are autistic or have a family member who is autistic.

We want to understand how autism has affected you or your family.

To do this we will ask about your health and look at genes.



Everyone has genes. Genes are recipes (codes).

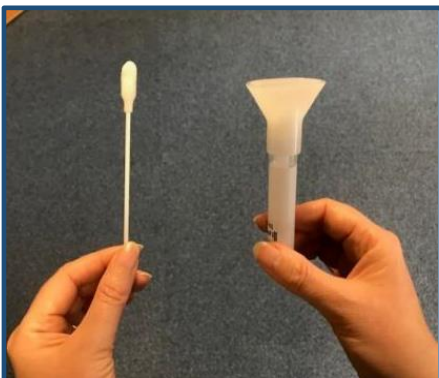
Genes are what make children look like their parents, or some of us tall and some of us short.

We want to find out if understanding genes can help autistic people.

What will happen if I take part?



If you say it is ok, we will ask you or the person who looks after you to answer questions about your health and what life is like for you.



We will send you a tube (spit-kit) and a small sponge.



Your clinician or carer will ask you to put the sponge in your mouth.

This is to soak up some of your spit (saliva). The person who looks after you will help you do this.



We will also ask your doctors what treatment you have had, if any. We will put your medical information in a database (computer).

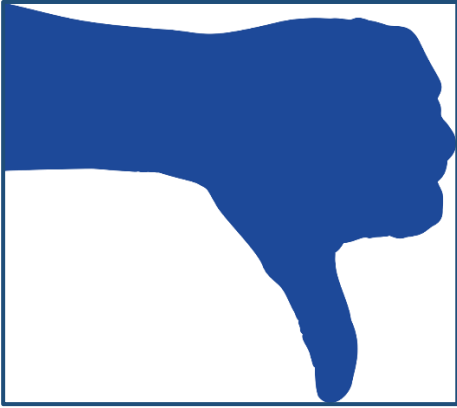
Do I have to take part?



You do not have to take part.

You can say **yes** if you would like to take part.

It is your choice. If you change your mind, that is ok.



You can say **no** if you do not want to take part.

If you say **no**, it will **not** change the care you get.

What happens after I have taken part?



Your spit will be tested in a laboratory.



We will put the test results on a computer.

Only the Spectrum 10K team will be able to see your name and where you live (**personal information**) on the computer.



Other people may look at the information from your tests but they will not know it is about you. We will not talk to anyone else about you, it is **confidential**.



But we would like to keep your name and address on a list.

This is so we can contact you if we need

- more information
- to do more research

We will keep this list locked.

What else happens?



If you are unsure about something tell your clinician or carer.



Or contact us
Our phone number is 0800 0520050



Our email address is info@spectrum10k.org

PALS

Patient Advice and Liaison Service

If you are unhappy about something, you can talk to your local PALS team or make a complaint to the NHS.

- You can ask your GP surgery, hospital or phone NHS 111 for details of your nearest PALS.



Thank you for your time!

This research project has been reviewed by the London Queens Square and Scotland A-REC Research Ethics Committees, who are there to make sure you are treated well.