



Participant Information Sheet for Children (10 – 15 years)

To be read by parent/carer if required.

We would like to ask you to take part in a research study. Before you decide, it is important to understand what the study is about and what will happen if you take part. Please read this leaflet carefully and ask us about anything you are unsure about or do not understand.

What is Spectrum 10K?

Spectrum 10K is a research study that is trying to improve understanding of autism. We are working with doctors and researchers to gather information from autistic people and their relatives. The results of this work may help us understand autism better and improve quality of life for autistic people in the future.

Why Me?

You have been chosen because you are autistic, or you have an autistic family member who is already in the study. We want to understand how autism has affected you or your family member.

What will happen if I take part?

We will ask you and your parent to provide details about you and to complete questionnaires about your health online. We may also ask you to complete a few questionnaires if possible (such as a memory test). We will also send you a spit kit and ask you to give a saliva sample. We ask that you do not eat, drink or chew gum for 30 minutes before you give the sample. If you and your parent agree, we would like to link your data with your medical records. This will help us fully understand autism and medical care and how it can be improved.

What will happen to my information?

The information we collect about you will be labelled only with your study number. Your name will be stored separately and safely. Only the Spectrum 10K research team will know who you are. Other people may look at the information from the tests but they will not know it is about you. We will not talk to anyone else about you, it is **confidential**.

Do I have to take part?

No, you do not have to take part. It is your choice if you would like to join and you can change your mind whenever you like. If you say **no**, it will **not** change the care you get. Talk to your parents or the person who looks after you about the study.

What else happens?

Your parent can opt in to our newsletter, which we will send out twice yearly to tell you what we have found out about autism. We will not be feeding back individual results about you or your family. We will also ask your permission to contact you about other studies and ask if you would like to join in the future.

If you are unsure about anything, talk to your parent, your carer or doctor. If you have any questions, you can contact us at any time. Our email address is info@spectrum10k.org

Thank you for your time!

Spectrum 10K Team

