

Taking part in research – YOU HAVE RIGHTS!

Information Sheet by Linnea Larsson, Tourettes Action's Research Manager



Research is very important because it helps us find cures for diseases and disorders and to make life better for people who are sick.

Research often involves trying out new things. Then new ideas are tried out on humans, we need to make sure that the people involved are kept safe. There are many rules for doctors and researchers to follow when they are doing a research study on humans.

If you want to take part in a research study, you should know your rights first!

Your rights

The World Medical Association (an organisation made up of doctors from all over the world) has written a document containing all these rules that doctors and researchers must follow, and where your rights as research participant can be found. Among many things, this document says that:



YOU decide whether you want to take part in a research study or not. If you are under 16 years old, your parents need to agree to let you take part too.



YOU have the right to know whatever you want to know about the study that is going to be done – why is it needed? What will happen? What do you need to do to take part?



YOU have the right to stop taking part in the study at any time, if you feel that you don't want to be a part of it anymore.



ALL the information that the researcher gets from you through the study will be protected.



YOU have the right to find out the result of the study you have taken part in, once it is finished – just ask the researcher!

If you want to take part

Let your parents know that you want to take part, and make sure you and your parents understand the project before you say if you want to take part .

Why is it done?

What exactly will happen if I take part?

The researcher will be able to answer any questions you or your parents may have.

What happens next?

What happens next depends on what type of research project you have decided to take part in. Some projects involve giving you a different form of treatment, or an extra test, like a scan, or just asking you some questions. When the project is over, you can ask the doctor or researcher what they found out from the study.

If you have any questions about research, you can ask us at Tourettes Action. Call our Research Manager Linnea on 020 7793 2356.