Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

Progressive Vision RESEARCH

Examining retinal health in people with Down Syndrome (DS)

Study Information Booklet

What is this research about?

We are trying to find out more about aging and the eyes.

To do this, we want to examine the eyes in detail.

We are trying to find out more about how the eye works in people with Down syndrome

We also want to understand if your extra chromosome affects how your eyes age

Why is this important?

This research is important because it could help us to understand more about diseases of the eye

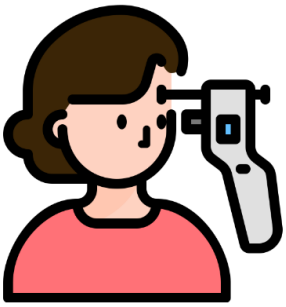
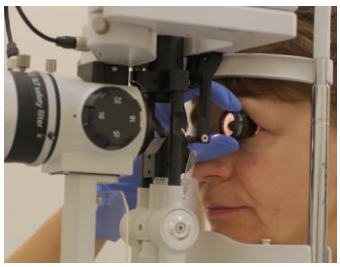
	This research could help us know **how we prevent people getting eye diseases as we age**

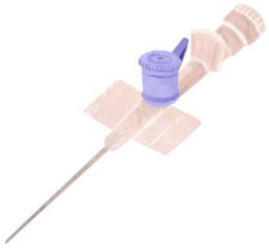
Why are you contacting me?

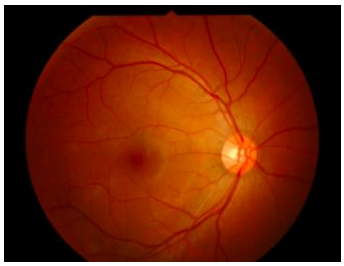
	We would like to include you in the study because: You have Down syndrome You are over 25 years old
	We want to make sure that people with Down syndrome are included in this type of research

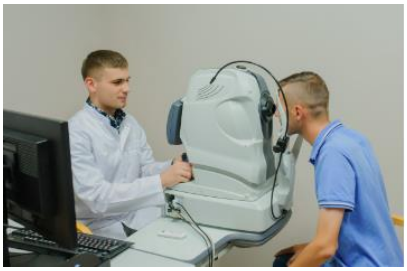
What will I have to do?

	We will ask you to come to Progressive Vision Research Clinic

	We will ask you some questions about your life
	We will also do some tests – these tests will take about 1.5 - 2 hours You can take breaks if you want or if you become tired we can organize another time to finish the tests
	We will check what you are able to see on a chart of letters, numbers or pictures
	We will put drops into your eyes to check your eye pressure A small machine will come close to your eyes but will not hurt you
	We will look at the front of your eye with a small lens The lens will come close to your eyes but it will not hurt you

	We will put a second drop into your eyes to make your pupil, the black part of your eye, bigger This will give us a better look into your eye
	The drops can make your vision blurry The blurry vision should go away within three hours of leaving the clinic
	We will put a small needle into your arm A small plastic tube will stay in your arm for about twenty minutes
	We will ask you to have a **blood test** through the tube The blood test may hurt a little You may also have some mild bleeding or bruising after the test. If you had problems before with having a blood test, please let us know

	We will do a test on the blood to find out more about how your extra chromosome affects your immune system
 W	We will also ask you to have an OCT scan
	This is a machine that takes a picture of the back of your eye
	You will also have a yellow dye, called fluorescein, injected into your arm This will show us how the blood vessels at the back of your eye are working

	You have to stay still at the machine for about five minutes but you will have breaks It will not hurt and the scanner won't touch you

What will happen with my information?

	We will save your information on a secure computer in the eye clinic and in Trinity College Dublin We will take your name out first before we save it on a computer
	We will send your blood to a laboratory to do tests
	This laboratory will be in Trinity College Dublin We will send it here because they have a special machine to test your blood

	The blood samples will not be stored with your name This means that no one will know it is yours
	We will store the samples of blood to use in the future as part of this research project In the future there might be new ways to examine the blood to find out more information
	We will save the pictures of your eye from the OCT and dye test on a computer in Progressive Vision Research
	If we see anything that is worrying on the picture of your eye, we will send a letter to your family doctor

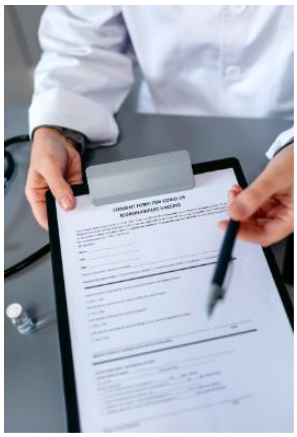
Who will see my information?

	We will share your information with a group of people who are doing research with people with Down syndrome in Trinity College Dublin
	We will share this information because the more people that do research, the more we can find out
	Students may also use the information for their projects
	But no one will know it is about you – we will take out your name and where you live (personal information) before it goes on the computer

	The information you give will be confidential
	We will not use any information with your name and address
	We would like to keep your name and address on a list This is so we can contact you if we need more information or to do more research in the future

Do I have to take part?

	No you don't. It is ok to say 'no' if you don't want to take part in the research

	If you say no it will **not** change the care you get
	If you decide to take part, we will ask you to sign a **consent form**
	You can stop taking part at any time
My rights about what people know about me	
	You have a right to get a copy of any information that we have about you

	You have a right to fix any of your information so that it is correct
	You have a right to tell us to get rid of any identifying information we have about you
	You have a right to stop us from using any of your information
	You have a right to access any of the information we hold on you
	Contact Dr Sarah Doyle or Katie Robb about any of these rights

Who do I contact if I have questions?

If you have any questions, you can contact Dr Sarah Doyle or Katie Robb

By email at:

Sarah Doyle: sarah.doyle@tcd.ie

Katie Robb: katier@tcd.ie

Thank you for taking the time to read this information