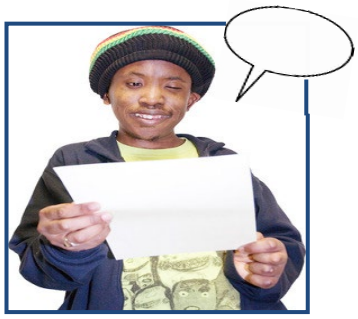
a study about how parts of the brain work in people with down syndrome

	Our names are Anna and Mona.
	We are doing some **research** Research is when we ask people questions and do tests to find out things
	We are writing to ask if you would like to help us



To help you understand this letter you can:

ask someone to read it for you

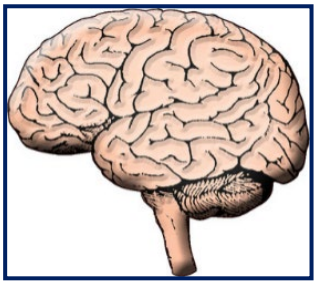
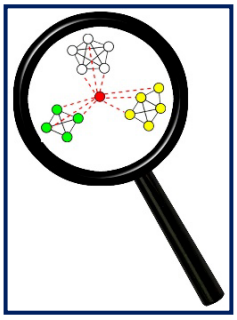


talk to your carer about it

what is our work about?



We are finding out about people with down syndrome

	We want to find out how different parts of the brain work in people with down syndrome
	We want to find out about differences between people with down syndrome
	We want to find out if there are genetic or other reasons for this. genes are like a recipe. they make us who we are

why do we want to see you?



We want to talk to you

because you have down syndrome

because you are 30 – 60 years old.



This research can make things better for people with down syndrome

what will happen if you take part?



If you agree to take part

we will ask you and your carer some **questions**

we will ask your **care team** some questions

	Your carer will fill in some **forms**
	You will do some **tests** – these are like games
	Some of the tests will be on a **computer**

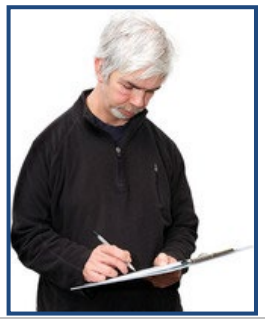
 	Some of the tests will be on a tablet or mobile phone at home
	We will check your **health**. we will take your **blood pressure and weight**
	We will ask you to have a **blood test**

	The meeting will last for about 4 **hours**

	Your carer or worker will also come to the meeting

do you have to take part?

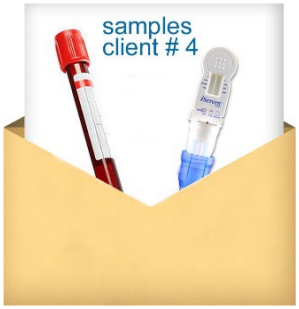
	You can tell us **yes** if you want to take part
	You can tell us **no** if you do not want to take part
	If you say no it will **not** change the care you get

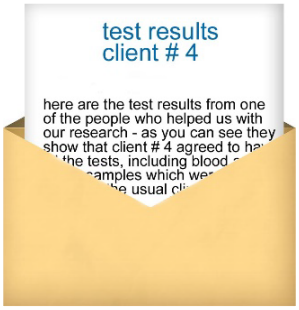
	If you decide to take part, we will ask you to sign a **consent form**
	You can stop taking part at any time

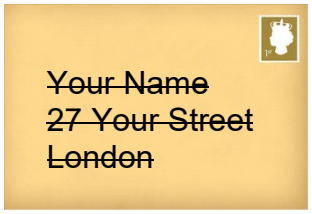
what happens after you have seen us?

	If you tell us it's **ok** we will

	Ask your doctor about you
	Tell your doctor about the tests we did
	Ask your care team about you
	Tell your care team about the tests we did

 	We will test your blood in a laboratory We may keep them in the laboratory for more tests We may need to send them to another place so that they can look at them
	The samples will not be stored with your name
	We will also put the test results on a computer

	Other people can then look at the information
	Students may also use the information for their projects
	but they will not know it is about you – we will take out your name and where you live (personal information) before it goes on the computer
	We will give you a gift voucher to say thank you we will also give you any travel expenses from taking part

	If you take part in our study
	The information you give will be confidential
	We will not talk to anyone else about you without asking you first
	We will not use any information with your name and address

	We might have to tell someone if we are worried about your health or care at all though
	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

if you want to talk to us



you can phone us

or



you can email us



If you would like to take part in the study

	If you have any questions about the study
	If you are unhappy about something
	Our phone number is 02078483626
	our email address is

	downsyndrome@kcl.ac.uk
	If you are unhappy about something, you can also talk to your local PALS team

Thank you for looking at this

This research project has been reviewed by the North Wales West Research Ethics Committee. They are there to make sure you are treated well.

Additional information

How will we use information about you?

We will need to use information from you, from your medical records and your GP for this research project.

This information will include your:

- Your name
- Your NHS number
- Your contact details

People will use this information to do the research or to check your records to make sure that the research is being done properly.

People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.

We will keep all information about you safe and secure.

Some of your information will be sent to other researchers. They must follow our rules about keeping your information safe.

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

What are your choices about how your information is used?

- You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.
- We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.
- If you agree to take part in this study, you will have the option to take part in future research using your data saved from this study.

Where can you find out more about how your information is used?

You can find out more about how we use your information

- At www.hra.nhs.uk/information-about-patients/
- By asking one of the research team