A study about how parts of the brain work in people with Down syndrome

Our names are Carla and Ros

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 possible reasons for this
**Why do we want to see you?**

We want to talk to you
because you have Down syndrome
because you are 16 years old or older

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 put a special band on your head to make brain traces
You will play some games on our computer
The meeting will last for about **2 hours**

We will meet at our **work**

Your carer or support 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 me?

If it is **OK** with you we will

tell your doctor about the tests we did
tell your care team about the tests we did

We will also put the test results on a computer

other people can then look at the information

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 small gift to say thank you

We will also give you any travel expenses from taking part
<table>
<thead>
<tr>
<th>![Image]</th>
<th>If you take part in our study</th>
</tr>
</thead>
<tbody>
<tr>
<td>![Image]</td>
<td>the information you give will be confidential</td>
</tr>
<tr>
<td>![Image]</td>
<td>we will not talk to anyone else about you without asking you first</td>
</tr>
<tr>
<td>![Image]</td>
<td>we will not use any information with your name and address</td>
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<tr>
<td>![Image]</td>
<td>We might have to tell someone if we are worried about your health or care at all though</td>
</tr>
</tbody>
</table>
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

020 7679 9314

our email address is
downsindrome@ucl.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.