

## **Information Sheet for Participants**

# Research on language in people with Down syndrome and people with learning disability

UCL Research Ethics Committee Approval ID Number: 2693/014



My name is Elisa



I am a researcher



I am writing to ask if you want to take part in research



To help you understand this letter you can:



Ask someone to read it for you

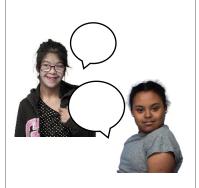


• Talk to your parent or carer about it



• Ask me questions

### What is my work about?



I want to learn more about how people use and understand language

I want to find out how language changes as people get older



I am looking for **40** people to take part in my research

#### Why do I want to see you?



I want to see you because

You have Down syndrome or a learning disability

You are between 15 and 70 years old



I will also talk to your parent or carer

I will ask them questions about you and the things that you do



The information you give may help make things better for other people with Down syndrome and people with learning disability

#### What will happen to me if I take part?



You decide if you want to take part

It is up to you



If you say Yes to taking part

You will meet me 2 or 3 times to take part in different activities online

In these activities, we will



- Look at pictures
- Solve puzzles



- Repeat words and sentences
- Tell a story



The activities will take between half an hour and one hour on each day



We will meet on different days



We will meet on a video call



We may audio record or film some of our activities

#### Do I have to take part?



No, you do not have to take part

You can tell me Yes if you want to take part



You can tell me No if you do not want to take part



If you say **Yes** I will ask you to sign a consent form



You can stop taking part at any time

You do not have to give a reason



If something happens and you can't give consent anymore, we will no longer include you in the study

That is not a problem

We will delete the information we already have unless you tell us not to

#### What happens after you have seen me?



If you agree to take part in this research



We will give you a £10 gift voucher to thank you for your time



The information you give will be **confidential** (private)



We will not talk to anyone else about you

We will only talk to someone else about you if we are worried about your safety



We will not use any information with your name and your address



We will put the audio recordings or videos of the activities on a computer

And we will delete them from the recorder or video camera

# How will we use information about you?



We will need to use information about you in this study

This information will include your

- Name
- Sex
- Date of birth
- Ethnicity
- Contact details (addresses and telephone numbers)



We will ask your parent or carer to give us information about you



Some people from UCL might look at your data to check that we are doing things right



They will **not** see your name and contact details.

We will use a code number

We will keep information about you safe and secure



At the end of the study, we will keep what you told us so that we can check the results.

We will write the report in a way that no-one can tell you took part in the study.



You can stop taking part at any time and we will delete the information about you that we already have



You can find out more about how we use your information by contacting the Data Protection Officer at this email address:

data-protection@ucl.ac.uk

#### If you are not happy about the study



- You can call me if you have any questions about the study
- You can call me if you are not happy with the study or if anything happens in the study that you are uncomfortable about



 If you want to make a complaint you can contact the Principal Investigator (see contact details below)



 If you are not happy with the answer we give you, you can contact UCL Research Ethics Coordinator at this email address:

ethics@ucl.ac.uk

They will check that we do the study the right way





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# Thank you for looking at this