






Participant Information Sheet for Service Users (3)

A trial of cognitive stimulation therapy in people with learning disabilities who have memory problems

 A portrait of a young woman with long brown hair and glasses, wearing a patterned top.	<p>My name is Emma Brown</p>
 An icon showing a woman pointing at a bar chart with a magnifying glass over it, symbolizing research.	<p>I am a researcher</p>
 A photograph of two women sitting at a table, looking at a document together. One woman is wearing a red jacket and the other is wearing a grey jacket.	<p>I am writing to ask if you want to take part</p>

   	<p>To help you understand this letter you can...</p> <ul style="list-style-type: none">• ask someone to read it for you• talk to your carer about it• you can ask me questions
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What is my work about?

	<p>I want to find out if Cognitive Stimulation Therapy (CST) can help people with learning disabilities who have memory problems</p>
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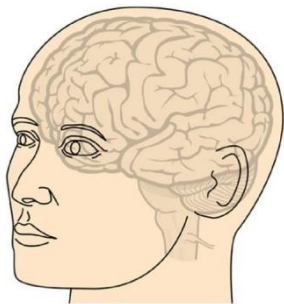
Having memory problems means sometimes not remembering where you put things or the names of people



It means you can't do some things you used to do and need more help



In **CST** we play games and puzzles to help us to think



I want to find out if playing these games may help slow down memory loss



I am looking for **40** people to take part

Why do I want to see you?



I want to see you because

- you have problems with your memory



- you have a mild or moderate learning disability



- the information you give may help to make things better for people who have problems with their memory

What will happen to me if I take part?



You do not have to take part

It is up to you



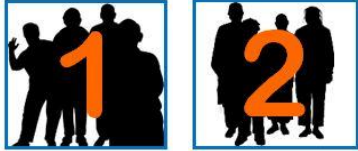
If you say **Yes** to taking part



I will ask your carer some questions about you



I will ask you some questions to test your memory



You will be put in one of two groups



You will not choose which group you will be in. That will be decided by chance, like a lucky dip



Half the people who take part will be in the CST group



The other half will carry on with the things that they usually do (usual care group)



People in the CST group

If you are in the **CST** group you will play puzzles and games with your carer at home



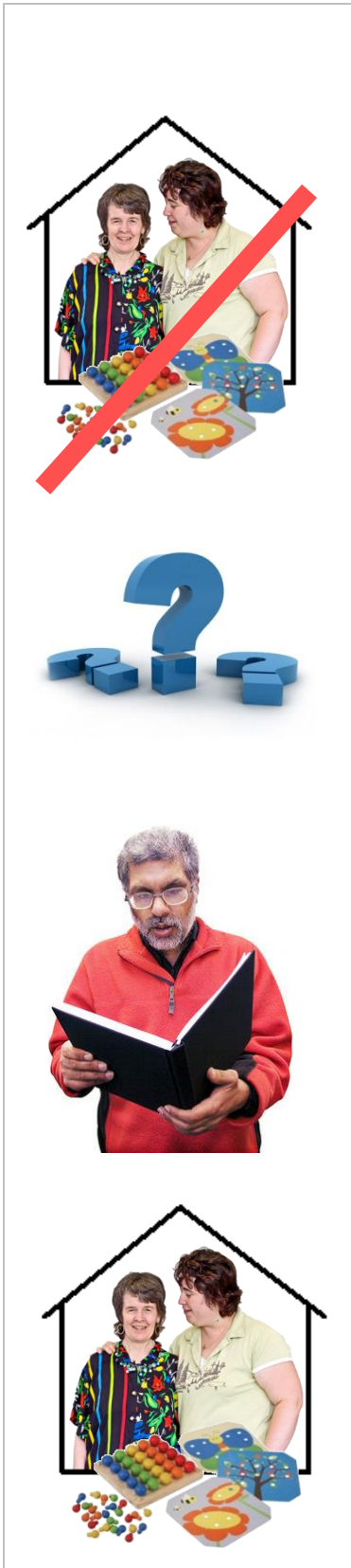
You will do this 2 times a week for half an hour



You will do this for 5 months (20 weeks)



We will ask you to answer some questions and do some tests (see below)



People in the Usual Care Group

If you are in the **usual care group**, you **will not** take part in the puzzles and games

You will carry on with your usual activities

We will also ask you to answer some questions and do some tests (see below)

You and your carer will get a copy of the manual at the **end of the study**

And you will be able to take part in the puzzles and games with your carer



1			
5			
9		11	
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21			



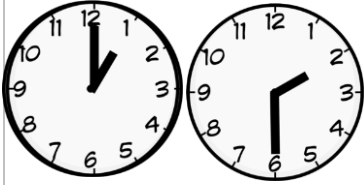
Questions and tests

We will ask **everyone** in the study some questions

We will ask you and your carer some questions at **11** weeks and **21** weeks

These questions will be about

- your memory
- how you get on with day to day activities
- your quality of life



This will take up to one and a half hours to do each time



If you are in the **CST** group, we will ask your carer to audio record you playing games and puzzles with your carer on two days



Everything will take place at home



At the end of the study we may invite you to take part in a short interview about the study

This will be recorded

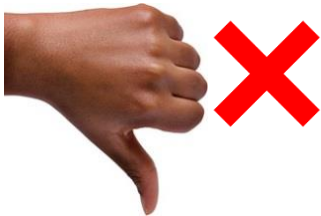
You do not have to take part in this

Do you 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 **No** it will not change the care you get



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 and this will not change the care you get

What happens after you have seen me?



If you agree to take part in this research



- To thank you for your time, we will give you a £10 gift voucher after answering the questions at 11 weeks and 21 weeks (£20 in total)



- If you chose to do the extra interview at the end of the study you will receive another £10 gift voucher

- I will let your GP (doctor) know you are taking part



- the information you give will be **confidential** (private)

  	<ul style="list-style-type: none">• I will not talk to anyone else about you • the recordings will be put on a computer and erased from the digital recorder • I will not use any information with your name and address
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If you want to talk to me



- 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 you can speak to Dr Afia Ali, who is the Chief Investigator for this study, at University College London.

My telephone number is:
07525 279810 or 020 3108 6978

Or my email address is:
Emma.Brown@ucl.ac.uk

Dr Afia Ali can be contacted by:

Telephone: **0208 928 8300**
Email: Afia.Ali@ucl.ac.uk

Thank you for looking at this

This research project has been reviewed by the Harrow Research Ethics Committee who are there to make sure you are treated well.