NELFT NHS
NHS Foundation Trust

PARTICIPANT INFORMATION SHEET FOR SERVICE USERS

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

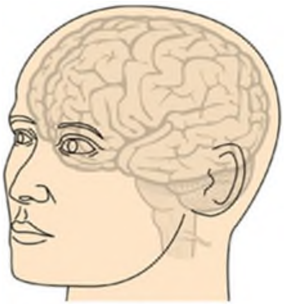
photo of researcher	My name is ….
	I am a researcher
	I am writing to ask if you want to help me

To help you understand this letter you can

- Ask someone to read it for you

- Talk to your carer about it

- You can ask me a question

What is my work about?	
	I want to find out if group Cognitive Stimulation Therapy (CST), helps people with learning disabilities who have memory problems
	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 think
	I want to find out if playing these games can help slow down memory loss

I am looking for 50 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 can help to make things better for people who have problems with their memory

What will happen to me if I take part?

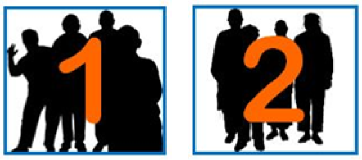
You do not have to take part

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 they usually do (usual care group)
	If you are in the CST group you will join a group of up to 5 people and you will play puzzles and games

You will do this 2 times a week for forty five minutes

You will do this for 7 weeks

After 8 or 9 weeks we will ask you and your carer some questions.

These questions will be about

- your memory

	• how you get on with day to day activities
	• your quality of life
	At the end of the study we may invite you to take part in a short interview about the study This will be recorded If we use any quotes (things that you say in the interview), we will not use your name or personal information so no one will know it is you.
	The health professionals in the learning disabilities team will get a copy of the manual at the end of the study so that they can run their own group.

If you are in the group that did not get the therapy, the health professionals in your learning disability team might let you join a therapy group at the end of the study. But it is possible that you might not get to join a therapy group.

Do you have to take part?

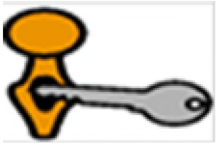
No, you do not have to take part

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

<table>
<tr><td>
</td><td>If you say Yes, I will ask you to sign a consent form
You can stop taking part at any time</td></tr>
<tr><td colspan="2">What information about me will you take?</td></tr>
<tr><td></td><td>We will need to use information from about you in this research. This information will include your;
• Name
• Age
• Gender
• Ethnicity
• Contact details (address and telephone numbers)
• Diagnosis
• NHS number
We will use this information to do the research or to check your</td></tr>
</table>

 1234   	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 an ID number instead. We will keep all information about you safe and secure. 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 happens after you have seen me?	
 	If you agree to take part in this research

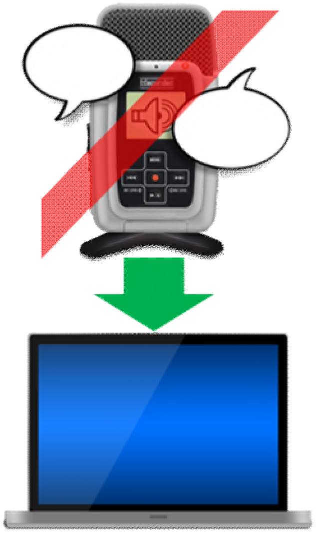
I will let your GP (doctor) know you are taking part

- The information you give will be private and kept in a locked cupboard for up to year. Then stored away by your local NHS team.

- I will not talk to anyone else about you.

Although what you say to us is not going to be shared, If you say anything to us which puts you or anyone else in danger, we may need to report this to the right person to help

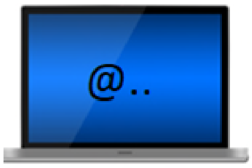
- The recordings of the groups and any interviews will be put on a computer and deleted from the digital recorder



- I will not use any information with your name and address when writing any reports, or when any other research team member needs to look at results.

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

You can call our research team to ask any questions on …



You can find out more information on this website:

	www.hra.nhs.uk/information-about-patients/ You can email our data protection officer Robert Paley on robert.payley@nelft.nhs.uk
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 My phone number is

Thank you for looking at this

This research project has been reviewed by (insert ethics committee) who are there to make sure you are treated well.