

School of Psychology

Title of Study: Investigating SIGHT as an intervention for community dwelling brain injury survivors with spatial neglect: A feasibility study at people's homes.



PARTICIPANT INFORMATION SHEET FOR CARERS

Name of Researcher: Dr Stephanie Rossit & Amy Jolly

Thank you for your interest in this study. Before you decide whether you want to take part, please read the following information carefully (this sheet is for you to keep). Please ask any questions if you would like more information.

What is this research looking at?

This research is looking at a newly developed computerised intervention for spatial neglect, called SIGHT (which stands for Spatial Inattention Grasping Home-based Therapy).

We are looking to see whether SIGHT is feasible and whether it produces any changes in attention and upper limb function in brain injury survivors. We are also looking for carer feedback on the system. The person you care for has agreed to undergo SIGHT at home for 7 consecutive days. We would like to get your feedback (from a carer perspective) about the strengths and weaknesses of SIGHT. This will help us to make it as user-friendly as possible and improve it further.

What is spatial neglect?

Spatial neglect is a frequent disorder observed after brain injury and consists of a loss of awareness to one side of the body or the world, usually the side where loss of movement is observed (affected side). For example, people with this condition may not notice things on one side of their body.

Do I have to take part?

No, your participation in any of this research is completely voluntary. This information sheet will explain what the study is about and what will happen. Please feel free to ask any questions. You may withdraw yourselves from the study at any time, without giving a reason. Withdrawing does not affect you in any way. If you decide to take part you will be given this information sheet to keep. You will be asked to sign a consent form, but you are still free to withdraw from the study at any time and without giving a reason.

What will happen if I agree to take part?

This study involves your assistance in a rehabilitation program developed for spatial neglect, named SIGHT. If you agree to take part, the researcher will visit the home of the person you care for to arrange an initial neuropsychological assessment. During this assessment you will be asked to fill in a questionnaire relating to your experience as a carer. Within the next seven days the researcher will return to the home of the person that you care for to take these tests again. You will again be asked to complete a questionnaire relating to your experience as a carer.

Once this is complete the researcher will demonstrate how to set up and run SIGHT. The researcher will lead the first session with you and the person you care for and show you how to use the system and carry out the training.

SIGHT requires you to do repetitions of rod lifting with your less impaired arm. This rod lifting involves you grasping a rod until it's balanced. SIGHT involves rods, a mat, a laptop and a small motion-tracking camera. We will leave all this equipment at the home of the person you care for during the duration of the study (7 days).

Rods will be placed on top of mat at a table in front of the television screen. All SIGHT instructions will be shown by your TV screen through a laptop connected to your TV. A portable motion-tracking camera will connect to the laptop and placed on top or below of your TV. This camera will not film at any time, but will only record rod lifting responses when the person you care for is doing SIGHT.

We will ensure that SIGHT is properly set-up during a first session. No cables will be left on the floor and you will be given step by step instructions as well as our contact numbers in case of any problems or questions

After completing the first SIGHT session with the researcher, you will be asked to help the person you care for repeat SIGHT sessions for 30-minutes, twice a day, for 7 consecutive days.

We will ask you (if available) to help set up and run the system for the person you care for. The researcher will call the person you care for on two different occasions during the 7 day training schedule to make sure that you are happy and that everything is running smoothly.

After 7 days, the researcher will revisit the home and carry out the short psychological tests with the person you care for again. You will be asked to complete a questionnaire about your experience as a carer for a final time. The researcher will also dismantle SIGHT. The researcher will then interview you on your thoughts and feedback on the SIGHT training. You will also be asked to fill out a short questionnaire on how usable you found the software. We will also interview the person you care for about what they thought of SIGHT.

You are free to withdraw at any time during or after the study. However, if you wish to withdraw your data after the study has been completed, please contact the researchers within two weeks after the study has ended.

Will it help me if I take part?

Previous research has shown that a non-computerized version of SIGHT may reduce spatial neglect but this may not be the case for everyone. Your participation will help us to improve and update the system to make it more user-friendly in the future.

How will the information I have given you be stored?

All information which you provide during the study will be stored in accordance with the 2018 General Data Protection Regulation and kept strictly confidential. The chief investigator will be the custodian of the anonymous research data. Any identifiable data will be stored separately in a password protected file and will be securely

disposed of as soon as it is no longer necessary, and within 5 years. All anonymized results will be stored indefinitely in order to comply with open practice standards. Any data resulting from your participation will be identified only using anonymised codes, without any reference to your name or personal information. The data will be stored on a secure computer and/or locked drawers in a locked room. After completion of the experiment, data will be archived on storage disks and stored in a locked room.

You will also be asked whether you would like to have your information, such as contact and demographic information, kept in a confidential database so researchers can contact you to give you information on this and future research. Your data will be identified using a participant code. If you are interested in being contacted for future research studies, please let the researcher know and they will provide you with more information. If you decide you would like to be contacted for future research now but change your mind at a later date, you will be able to withdraw your information at any time.

How will the data be used?

This data will be used to help improve our SIGHT rehabilitation software, making it more accessible and user-friendly. The data will be kept anonymous. In case any of the research is presented at conferences and/or written up in reports, your name and personal information will remain confidential.

What happens if I agree to take part, but change my mind later?

You are free to withdraw at any point, without reason or consequence, during the study and up to two weeks following completion of the study. If you choose to withdraw, please contact researchers.

How do I know that this research is safe for me to take part in?

All research in the University is looked at by an independent group of people, called a Research Ethics Committee, to protect your safety, rights, wellbeing and dignity. This research was approved by the Psychology Research Ethics Committee at the University of East Anglia on 1st April 2019 (Reference: 2017-0440-000799).

You are under no obligation to agree to take part in this research. If you do agree you can withdraw at any time without giving a reason.

If you wish to ask any questions about the research please contact:

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