A Survey on the Screening and Diagnosis of Unilateral Spatial Neglect

Participant Information Sheet (PIS)

This PIS should be read in conjunction with The University privacy notice accessed here: http://documents.manchester.ac.uk/display.aspx?DocID=37095

You are invited to take part in a research study. Before you decide it is important to understand why the research is being conducted and what it will involve. Please read the following, discuss it with others if you wish, and ask if there is anything that is not clear or if you would like more information.

Who will conduct the research?

Mr Matthew Checketts (PhD student) will carry out the research supervised by Profs Audrey Bowen and Andy Vail (The University of Manchester, UK) as part of an international collaboration with researchers from The University of Texas, The University of Geneva, Umeå University, The Kessler Foundation, Dalhousie University, and the Tuscany Rehabilitation Clinic, Montevarchi.

What is the purpose of the research?

We want to find out which tools are used to screen for and diagnose unilateral spatial neglect (USN), by which professional groups, in which countries, as well as the reasons for these choices.

Why have I been chosen?

You are a clinician practising in stroke medicine or rehabilitation.

What would I be asked to do if I took part?

To complete a brief online questionnaire hosted by SelectSurvey at The University of Manchester about the methods that you use to screen and diagnose stroke patients for USN in clinical practice.

What will happen to my personal information?

The University of Manchester research team will be responsible for collecting and handling data. We will collect the following information about you:

- Your area of clinical expertise
- The country you work in
- The setting in which you currently work (e.g. inpatient, outpatient, community)
- How long you have worked in your current clinical setting (years and months)
- Approximately how many patients with USN you have seen in the past 12 months
- Whether you are currently active in USN research
- Your responses to questions about screening and diagnosis of USN.

The University of Manchester, as Data Controller for this project, takes responsibility for the protection of the data collected. To comply with legal obligations to protect data the University has

This project has been approved by the University of Manchester’s Division of Neuroscience and Experimental Psychology Research Ethics Committee [2018-3901-7071]
safeguards in place such as policies and procedures. All researchers are appropriately trained and your data will be looked after in the following ways:

We will not collect personal identifiable information. The online survey platform will only collect data you have provided within the questionnaire. Identifiable information such as name, date of birth, email address, IP address, etc, will not be recorded by the online system. Data are fully anonymised by the time they reach the study team.

Data are held initially by the online survey system until downloaded and stored electronically by the study team. Raw data will not be transferred outside of The University of Manchester. Analysed anonymised data will be shared amongst international collaborators at the institutions above. Long-term storage of data will be kept securely for up to five years from the publication of results.

If you wish to contact us about your data protection rights, please email dataprotection@manchester.ac.uk or write to The Information Governance Office, Christie Building, University of Manchester, Oxford Road, M13 9PL at the University and we will guide you through the process of exercising your rights.

You also have a right to complain to the Information Commissioner’s Office, Tel 0303 123 1113

**Will my participation in the study be confidential?** Yes.

**What happens if I do not want to take part or if I change my mind?**

It is your choice whether or not to take part. This information sheet is for you to keep. If you take part you can withdraw at any time without giving a reason and without detriment to yourself. However, it will not be possible to remove your data from the project once it has been anonymised and forms part of the dataset as we will not be able to identify your specific data.

**Will my data be used for future research?**

The anonymised data collected may be provided to researchers running similar research studies. Such research would be compatible with this research project and concern stroke and rehabilitation medicine. These organisations may be universities, NHS organisations or companies involved in health and care research in this country or abroad. Your information will only be used by organisations and researchers to conduct research in accordance with the UK Policy Framework for Health and Social Care Research.

This information will not identify you and will not be combined with other information in a way that could identify you. The information will only be used for the purpose of health and care research, and cannot be used to contact you regarding any other matter or affect your employment.

**Will I be paid for participating in the research?**

No. There is no payment or compensation arrangement for participation in this study.

**What is the duration of the research?**

Completion of one questionnaire is anticipated to take no longer than 20 minutes. There is no follow-up.

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Where will the research be conducted?

The questionnaire is hosted online by SelectSurvey, and data will be collected and stored on servers located at The University of Manchester.

Will the outcomes of the research be published?

The study will be included in Mr Matthew Checketts’s PhD thesis, which will be available upon completion under open access arrangements via The University of Manchester library. The study will also be submitted for publication in an appropriate peer-reviewed, academic journal.

If you would like to receive copies of published manuscripts, please contact the investigators using the details below.

Who has reviewed the research project?

This project has been reviewed by the Division of Neuroscience and Experimental Psychology research ethics committee at The University of Manchester.

What if I want to make a complaint?

Minor complaints - If you have a minor complaint please contact the research team (below).

Formal Complaints - If you wish to make a formal complaint or if you are not satisfied with the response you have gained from the researchers in the first instance then please contact

The Research Governance and Integrity Manager, Research Office, Christie Building, University of Manchester, Oxford Road, Manchester, M13 9PL, by emailing: research.complaints@manchester.ac.uk or by telephoning (+44)0161 275 2674.

What Do I Do Now?

If you wish to take part in the short survey please click this weblink: bit.do/uomsurvey

Thank you for your help

If you have any further queries or would like to register to receive the results of the study then please contact the researcher(s):

Mr Matthew Checketts, G.706 Stopford Building, Oxford Road, The University of Manchester, M13 9PL, or by telephone at (+44)0161 275 7764, or by emailing matthew.checketts@manchester.ac.uk

Professor Audrey Bowen, G.800 Stopford Building, Oxford Road, The University of Manchester, M13 9PL, or by telephone at (+44)0161 275 1235, or by emailing audrey.bowen@manchester.ac.uk

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