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Participant Information Sheet

Study title: Developing consensus on speech and language therapy best practice for patients in prolonged disorders of consciousness

Principal Investigator: Hannah Roberts **Research Supervisor:** Dr Nan Greenwood

You are being invited to take part in a research study. Before you decide whether to participate it is important for you to understand why the research is being done and what it will involve for you. Please read the following information carefully. It should take about five minutes to read. Please contact Hannah Roberts if there is anything that is not clear (see contact details below).

1. What is the purpose of the study?

This study is a project being undertaken as part of a Masters in Clinical Research funded by the National Institute of Health Research. The purpose of the study is to ascertain the degree of consensus amongst speech and language therapists (SLTs) regarding speech and language therapy best practice for patients in prolonged disorders of consciousness (PDOC). The research evidence regarding SLT management of patients in PDOC is currently very limited, therefore we feel it is important to consult SLTs with experience of working in this area in order to inform clinical practice.

2. Why have I been invited to take part?

You have been given this information sheet because you may have appropriate experience to take part in the study. Specifically, we are looking for SLTs who either:

- are currently employed in a *static post* on a *neurosciences, neurosurgery or neurorehabilitation ward/unit* that accepts adult PDOC patients or
- have *three or more years' past/current experience* of working with adult PDOC patients as a regular part of their caseload

We understand that the regularity of seeing PDOC patients will depend on the setting in which you are working/have worked but this should not affect your taking part in the study. We are hoping to recruit as many SLTs as possible who fit the inclusion criteria.
If you have experience only with a paediatric population, then unfortunately you are not eligible to take part.

3. Do I have to take part?

It is completely up to you to decide whether or not to take part. Please contact the researchers (see contact details below) if you have any questions that you would like answering in order to help you to decide whether or not to participate.

4. What will happen in the study?

The research will be carried out using the Delphi technique, a research method which aims to ascertain the degree of consensus on a topic. If you meet the inclusion criteria and decide to take part, you will be asked to complete two questionnaires (also known as Rounds 1 and 2), about one month apart.

You will have about two weeks in which to complete each questionnaire. The amount of time to complete each questionnaire will vary between participants but should range from about 15-30 minutes. There are no right or wrong answers to the questions. The study is just seeking your professional opinion.

For the first round, you will be asked to email your completed questionnaire to the researcher. For the second round, you will be emailed an anonymised summary of how you, and the group of participants as a whole, responded, and you will also receive the second questionnaire. You will then have the opportunity to review the group responses and comments and appraise your previous answers to decide if your opinion remains the same. You will then email back the second round questionnaire to the researcher.

You will not be required to meet the researcher or other participants in the study face-to-face. Consent will be inferred through completion of the questionnaires.

5. What are the possible benefits of taking part?

There are no immediate benefits. However, it is hoped that information from this study will help to develop SLT guidelines for patients in PDOC in the future.

Unfortunately, there are no funds available to reimburse your time, however a summary of the results can be sent to you at the end of the study on email request.

6. Are there any potential risks in taking part?

There are no anticipated risks in taking part.

7. What if there is a problem?

If you have a concern about any aspect of this study, please speak to Hannah Roberts (07472056098) or her research supervisor Dr Nan Greenwood (020 8725 4756).

8. Will my taking part in the study be kept confidential?

Yes. We will follow ethical and legal practice and all information will be handled in confidence. You will remain anonymous to the other participants throughout the study and only the researchers will be able to identify your specific answers. However, as this is a small field it is possible that you will know other people taking part in the study. In order for the Delphi technique to be effective we ask that you do not discuss your responses with your work colleagues until after the study is completed.

Each participant will be allocated a unique participant ID. The document which links each participant to their unique ID will be password protected and kept on a password protected personal university network drive only accessible by the researchers. All research data will be kept in on a password protected personal university network drive and backed up on the password protected university OneDrive for Business. Your data will only be used for the purpose of this study. In line with University policy, all data will be kept for 10 years after the research is completed after which it will be destroyed.

The questionnaires will be emailed using NHSmail. If you wish to have the extra privacy this offers, please provide your nhs.net email account for correspondence.

9. What will happen if I don't want to carry on with this study?

You are free to withdraw from the study at any time without giving a reason and without penalty. If you withdraw from the study, we would use any data that you had so far provided to the study unless you contacted us to explicitly state you do not want your data to be used. Given the nature of the study, data can only be withdrawn at two time points – Round 1 data can only be withdrawn up until the deadline for receipt of the Round 1 questionnaire and Round 2 data can only be withdrawn up until the deadline for receipt of the Round 2 questionnaire.

10. What will happen to the results of the study?

The research will be written up in a thesis to be submitted in partial fulfilment of a Masters in Clinical Research. If possible the research findings will go on to be submitted to a suitable journal or conference. You will not be identified in any report, publication or presentation.

11. Who has reviewed the study?

This study has been reviewed by the Faculty of Health, Social Care and Education Research Ethics Committee, Kingston University and St George's University of London to protect your safety, rights, and dignity. They have given a favourable opinion. Reference number: FREC 2017-02-007.

12. Further Information and Contact Details

If you have any further questions regarding the study (or if you have questions during the study), please contact:

Hannah Roberts: Email p1606116@sgul.ac.uk Work Tel. 07472056098

Or in the case of a concern or complaint:

Dr Nan Greenwood: Email nan.greenwood@sgul.kingston.ac.uk Tel. 020 8725 4756