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***Development of a sexuality intervention for stroke survivors and their partners: A Delphi study***  
**PARTICIPANT INFORMATION STATEMENT**

**(1) What is this study about?**

You are invited to take part in a research study which aims to develop an intervention to address sexuality after stroke. Sexuality can mean different things for different people. It may include reproduction and sexual expression but can also include relationships, intimacy, and communication as well as identity and sexual orientation. Many people experience difficulty with sexuality after stroke yet less than 20% of stroke survivors in Australia receive information about sexuality after stroke as part of their rehabilitation. We want to know what stroke survivors, their partners and health professionals or researchers believe are important things to include in a stroke sexuality educational package (intervention).

You have been invited to participate in this study because you are a stroke survivor, a partner of a stroke survivor, or a professional or researcher with an interest in this topic also known as an 'expert'. As a person who has direct experience and knowledge, 'an expert', we are keen to hear your views regarding what topics should be included, who should provide the intervention, when and how the intervention should be delivered.

We will use the "Delphi technique" (a research process) to gain consensus from experts such as yourself. The experts will be sent a survey and the results will then be summarised and returned as feedback. Experts will then be asked to respond to a second questionnaire (i.e. two 'rounds' of structured questionnaires).

When we have completed the study we will use the information to guide us in developing a stroke sexuality educational package (intervention) which can be offered to stroke survivors and partners of stroke survivors.

This Participant Information Statement tells you about the research study. Knowing what is involved will help you decide if you want to take part in the research. Please read this document and ask questions about anything that you don't understand or want to know more about.

Participation in the study is voluntary.

By giving your consent to take part in this study you are telling us that you:

- ✓ Understand what you have read.
- ✓ Agree to take part in the research study as outlined below.
- ✓ Agree to the use of your personal information as described.

You will be given a copy of this Participant Information Statement to keep.

## **(2) Who is conducting the study?**

The study is being carried out by the following researchers:

- Dr Margaret Mc Grath, Senior Lecturer, The University of Sydney
- Dr Annie McCluskey, Honorary Senior Lecturer, The University of Sydney
- Ms Sandra Lever, Clinical Lecturer, The University of Sydney/ CNC Rehabilitation, Graythwaite Rehabilitation Centre, Ryde Hospital, NSLHD
- Dr Emma Power, Senior Lecturer, The University of Sydney

## **(3) What will the study involve for me?**

You will be asked to complete two questionnaires, either online or as a printed survey. If you require support to complete the survey because of communication impairment then a researcher will support you in providing your answers either in person if possible or over videoconference.

In the first round, you will be asked questions about the importance of topics, and to suggest topics as part of a sexuality intervention for stroke survivors early after stroke. You will also be asked to provide information about yourself including some details about your stroke experiences, relationship status etc. This information is gathered so that we can ensure a diverse group of respondents.

In a second round, you will receive a summary of responses, and a draft outline of an intervention to address sexuality including topics to be covered, details of timing, professionals involved and methods of delivery. A second questionnaire will be used to assess your agreement with this intervention model.

In order to allow timely conclusion of the study we would respectfully request your response within 2 weeks for each round.

## **(4) How much of my time will the study take?**

The survey will take approximately 15-20 minutes to complete on each occasion (30-40 minutes total).

## **(5) Who can take part in the study?**

Stroke survivors, partners of stroke survivors, professionals with an interest in the topic of sexuality can take part in this study.

## **(6) Do I have to be in the study? Can I withdraw from the study once I've started?**

Participation in this study is completely voluntary and you do not have to take part. Your decision whether to participate will not affect your current or future relationship with the researchers or anyone else at the University of Sydney.

Submitting your completed questionnaire is an indication of your consent to participate in the study. You can withdraw your participation any time before you have submitted the survey. Once you have submitted it, your responses cannot be withdrawn because they are anonymous and therefore we will not be able to tell which survey is from you.

**(7) Are there any risks or costs associated with being in the study?**

Aside from giving up your time, we do not expect that there will be any risks or costs associated with taking part in this study.

**(8) Are there any benefits associated with being in the study?**

We cannot guarantee that you will receive any direct benefits from being in the study.

**(9) What will happen to information about me that is collected during the study?**

Information collected about you during this study will be stored at The University of Sydney. Only members of the research team will have access to this information.

By providing your consent, you are agreeing to us collecting personal information about you for the purposes of this research study. Your information will only be used for the purposes outlined in this Participant Information Sheet, unless you consent otherwise.

Your information will be stored securely and your identity/information will be kept strictly confidential, except as required by law. Questionnaires will be anonymous. Study findings may be published, but you will not be individually identifiable in these publications.

We will keep the information we collect for this study, and we may use it in future projects. By providing your consent you are allowing us to use your information in future projects. We don't know at this stage what these other projects will involve. We will seek ethical approval before using the information in these future projects.

**(10) Can I tell other people about the study?**

Yes, you are welcome to tell other people about the study.

**(11) What if I would like further information about the study?**

When you have read this information, Dr Margaret McGrath will be available to discuss it with you further and answer any questions you may have. If you would like to know more at any stage during the study, please feel free to contact. **Dr Margaret McGrath, Senior Lecturer** by email [Margaret.mcgrath@sydney.edu.au](mailto:Margaret.mcgrath@sydney.edu.au) or by telephone 61 2 9036 7419

**(12) Will I be told the results of the study?**

We will share the overall results of the study in a summary report to the Stroke Foundation of Australia. This summary will be provided after the study has been completed.

**(13) What if I have a complaint or any concerns about the study?**

Research involving humans in Australia is reviewed by an independent group of people called a Human Research Ethics Committee (HREC). The ethical aspects of this study have been approved by the HREC of the University of Sydney [2017/079]. As part of this process, we have agreed to carry out the study according to the *National Statement on Ethical Conduct in Human Research (2007)*. This statement has been developed to protect people who agree to take part in research studies.

If you are concerned about the way this study is being conducted or you wish to make a complaint to someone independent from the study, please contact the university using the details outlined below. Please quote the study title and protocol number.

The Manager, Ethics Administration, University of Sydney:

- **Telephone:** +61 2 8627 8176
- **Email:** [ro.humanethics@sydney.edu.au](mailto:ro.humanethics@sydney.edu.au)
- **Fax:** +61 2 8627 8177 (Facsimile)

*This information statement is for you to keep*