Project title: Development of a sexuality intervention for stroke survivors and their partners: A Delphi study

PARTICIPANT INFORMATION STATEMENT

(1) What is this study about?

We want your opinion for a research study on important topics for a sexuality education package for people who have had a stroke.

Sexuality can mean different things for different people e.g., intimacy, relationships, sexual expression, sexual orientation, identity and roles, communication and reproduction.
Many people experience difficulty with sexuality after stroke.

But less than 20% of stroke survivors in Australia receive information about sexuality after stroke as part of their rehabilitation.

As you have personal knowledge of stroke, we want your opinions on what to include in the education.

We will use the "Delphi technique" (a research process) to gain agreement from different groups of people.

We get you to provide your opinions in two surveys.

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.
- It is formatted to be easy for people with communication difficulties to read.
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.

(2) Who is conducting the study?

Researchers:

Dr Margaret McGrath
Senior Lecturer
University of Sydney

Dr Annie McCluskey
Honorary Senior Lecturer
University of Sydney

Ms Sandra Lever
Clinical Nurse Consultant
Graythwaite Rehabilitation Centre, Ryde Hospital

Dr Emma Power
Senior Lecturer
University of Sydney
(3) **What will the study involve for me?**

You will provide information **two times (rounds).**

You can do this on your **computer online**

or **on a paper survey.**

If you have communication difficulties: we can help you to understand the survey or provide your thoughts.

We can help you **in person if possible OR over video conference.**

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**In round 1 you will be asked to tell us:**

1. **Which topics are important** for sexuality education after stroke
2. **Any further topics** you think are important

You will have **two weeks** to do this.

**In round 2 you will be asked to tell us:**

1. **How much you agree** with the education package we developed from round 1 answers.

You will have **two weeks** to do this.
(4) **How much of my time will the study take?**

<table>
<thead>
<tr>
<th>Time 1</th>
<th>about 20 minutes</th>
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<tbody>
<tr>
<td>Time 2</td>
<td>about 20 minutes</td>
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<tr>
<td>Altogether</td>
<td>about 40 minutes</td>
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(5) **Who can take part in the study?**

Stroke survivors, partners of stroke survivors and professionals can take part in this study.

(6) **Do I have to be in the study? Can I withdraw?**

- You are **not required participate** in this study. Your participation is **voluntary**.
- If you don’t want to participate, you can stop. Stopping will **not affect your relationship with anyone at the University of Sydney**.
- If your survey results have been submitted, we cannot remove your answers because the survey is anonymous.
- When you submit the survey, this is how you show us you consent to be in the study.

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

- There are **no risks** from being involved in this study.
- It will **not cost you anything** to be in this study.

(8) **Are there any benefits associated with being in the study?**
• **You will help us** to create a sexuality education package.
• **But you will not receive the education** yourself at this time.

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

All information will be kept **confidential and secure** at the University of Sydney.

• **Only the research team** can read the information unless required by law.

By agreeing to do the survey, **you are agreeing for us to use the information you provide.**

• It will **not** have your name on it.

• When we **present or publish** the results of the study there will be **no personal information** that can be linked to you (i.e., your name).

**We may use the information from this study for future research.**

• If you provide your information now, you are saying we can also use it in the future.

• If we think the knowledge will be useful for another study, we will ask the ethics committee to approve it **before** using your anonymous information.
(10) Can I tell other people about the study?

Yes. You can tell anyone about the study.

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

Dr Margaret McGrath can discuss the study with you further at any time

61 2 9036 7419
Margaret.mcgrath@sydney.edu.au

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

We will send a report to the Stroke Foundation.
We will do this after the study is 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].

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 not involved with the study, please contact the university using the details outlined below.

- Please tell them the study title and protocol number.

The Manager, Ethics Administration, University of Sydney:

61 2 8627 8176

ro.humanethics@sydney.edu.au

61 2 8627 8177 (Facsimile)

This information statement is for you to keep