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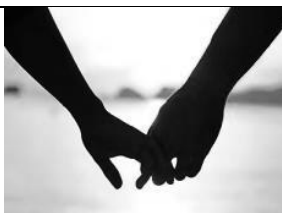
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**Project title: Development of a sexuality intervention for stroke survivors  
and their partners: A Delphi study**

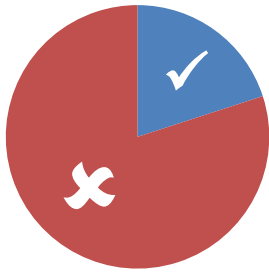
**PARTICIPANT INFORMATION STATEMENT**

**(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 difficult 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**.

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

**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.**



**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

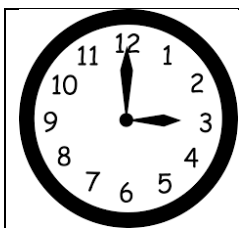
You will have **two weeks** to do this.

**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?



**Time 1** about 20 minutes

**Time 2** about 20 minutes

**Altogether** about 40 minutes

#### (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?

	<b>Dr Margaret McGrath can discuss the study with you</b> further at any time
	61 2 9036 7419
	<a href="mailto:Margaret.mcgrath@sydney.edu.au">Margaret.mcgrath@sydney.edu.au</a>

### (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](mailto:ro.humanethics@sydney.edu.au)



61 2 8627 8177 (Facsimile)

*This information statement is for you to keep*