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| USY_MB1_RGB_Standard_Logo.tif | |  | **Discipline of Occupational Therapy Faculty of Health Sciences** |
|  | ABN 15 211 513 464 | |  |
|  | **Margaret McGrath**  *Senior Lecturer* | | Room J112  Cumberland Campus C42  The University of Sydney  NSW 2006 AUSTRALIA  Telephone: +61 2 9036 7419  Facsimile: +61 2 9351 9197  Email: Margaret.mcgrath@sydney.edu.au  Web: <http://www.sydney.edu.au/> |

**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?**

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| Image result for relationships | 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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|  | **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 describ**ed. |

1. **Who is conducting the study?**

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| **Researchers:** |  |
| Dr Margaret McGrath | **Dr Margaret McGrath**  Senior Lecturer  University of Sydney |
| http://api.profiles.sydney.edu.au/AcademicProfiles/profile/resource?urlid=annie.mccluskey | **Dr Annie McCluskey**  Honorary Senior Lecturer  University of Sydney |
| https://www.aci.health.nsw.gov.au/__data/assets/image/0005/278474/Sandra-Lever.jpg | **Ms Sandra Lever**  Clinical Nurse Consultant  Graythwaite Rehabilitation Centre, Ryde Hospital |
|  | **Dr Emma Power**  Senior Lecturer  University of Sydney |

1. **What will the study involve for me?**

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

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| You can do this on your **computer online** | http://www.buffalocomputerconsulting.com/images/computer.jpg |
| or on a **paper survey**. | https://thumbs.dreamstime.com/t/paper-survey-card-pencil-68485256.jpg |
| **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.** | Guiding person-centered, evidence-based aphasia services |

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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. |

1. **How much of my time will the study take?**

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| Image result for clock | **Time 1** about 20 minutes  **Time 2** about 20 minutes  **Altogether about 40 minutes** |

1. **Who can take part in the study?**

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

1. **Do I have to be in the study? Can I withdraw?**

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| * 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. |

1. **Are there any risks or costs associated with being in the study?**

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

1. **Are there any benefits associated with being in the study?**

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| * **You will help us** to create a sexuality education package. * But **you will not receive the education** yourself at this time. |

1. **What will happen to information about me that is collected during the study?**

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| 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. | Image result for locked filing cabinet |
| 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). | http://mpoverello.files.wordpress.com/2013/02/confidential.jpg |
| **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. | http://images.clipartpanda.com/magnifying-glass-clipart-transparent-background-9i4LRa6iE.jpeg  **RESEARCH** |

1. **Can I tell other people about the study?**

**Yes**. You can tell anyone about the study.

1. **What if I would like further information about the study?**

|  |  |
| --- | --- |
| Dr Margaret McGrath | **Dr Margaret McGrath can discuss the study with you** further at any time |
| alt= | 61 2 9351 9213 |
| http://www.activecamps.com/lets-talk-camp/wp-content/uploads/2014/08/Email-icon.png | [Margaret.mcgrath@sydney.edu.au](mailto:Margaret.mcgrath@sydney.edu.au) |

1. **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. | Stroke Foundation logo |

1. **What if I have a complaint or any concerns about the study?**

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| 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.** |

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| **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:** | |
| alt= | 61 2 8627 8176 |
| http://www.activecamps.com/lets-talk-camp/wp-content/uploads/2014/08/Email-icon.png | [ro.humanethics@sydney.edu.au](mailto:ro.humanethics@sydney.edu.au) |
| http://brigadoonfitness.com/wp-content/uploads/2013/02/fax_icon.jpg | 61 2 8627 8177 (Facsimile) |

# This information statement is for you to keep