**Participation Information Statement**

**Project title:** Co-designing a psychoeducation package to enhance psychosocial wellbeing for young adults living with stroke

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| 1. **What is this project about?** | |
| We are developing **resources and methods of providing information to young stroke survivors and their support people** about common **invisible difficulties** (such as difficulties with fatigue, mood and thinking skills).  **We want your opinion** on what **topics the resources should cover**, and **how it might be helpful to receive this information.**  **We aim to include people from all over Australia.**  You are invited to participate because you had a stroke in the last 5 years, and were aged 18-45. | **Question Mark with solid fill**  **A person with a lightning bolt on their head  Description automatically generated** |

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| This **Participant Information Sheet and Consent Form tells you about the research project**. You can then decide if you want to take part.  Please **read this document**. It is formatted to be easy for people with communication and cognitive difficulties to read and understand.  **Ask questions** about anything that you don’t understand or want to know more about. You might want to **talk about it with a relative, friend or local doctor.**  Participation **is voluntary.**  **If you want to take part** in the research project, you will be asked to **sign the consent form**. By signing it you are telling us that you:   * Understand what you have read * Consent to take part in the research * Consent to the project discussions described |  |

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| 1. **Who is conducting this study?** | |
| **Associate Professor Dana Wong**  La Trobe University |  |
| **Ms Michaela Grech**  La Trobe University | **A person smiling at camera  Description automatically generated** |
| **Dr Toni Withiel**  Royal Melbourne Hospital |  |
| **Associate Professor Emma Power**  University of Technology, Sydney |  |
| **Professor Ian Kneebone**  University of Technology, Sydney |  |
| **Associate Professor Rene Stolwyk**  Monash University |  |
| **Dr Eirini Kontou**  University of Nottingham, United Kingdom |  |
| **Mr Adrian O’Malley**  Physical Disability Council of New South Wales |  |
| The project has been **funded** by the **Tim Glendinning Memorial Grant** through the **Stroke Foundation**. |  |

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| 1. **What will this study involve?** | |
| **There are 2 stages in this project.**  In **Stage 1** you will **attend an online discussion**. You will help to decide what things are important to include in an information package to support young stroke survivors.  After this discussion, the researchers will develop examples of these resources.  In **Stage 2**, you will attend another online discussion to talk about these examples.  **If you have communication difficulties:** we can help you to understand the survey or provide your thoughts.  Each stage will take around **90 minutes.**  **We will record these conversations** with your permission.  You can **continue with your usual lifestyle and care** throughout this project.  You will be **paid $50 per hour** for the time you spend on this project. | **Online meeting with solid fill**  **Vlog outlineDocument with solid fill**  **Online meeting with solid fill**    **Clock with solid fill**  **Radio microphone with solid fill**  **Dollar with solid fill** |

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| 1. **Do I have to take part in this study?** | |
| Participation in this study is **voluntary** and you can **withdraw at any time** |  |
| Stopping will not affect your current or future treatment, research involvement or relationship with your care team. |

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| 1. **Are there any risks or costs associated with this study?** | |
| There is a **risk** that you may find some of the questions **stressful or upsetting**. You can skip these questions, take a break, or stop immediately. If this happens, we will offer you support.  **There are also several services you can contact for additional support:**   |  |  |  |  | | --- | --- | --- | --- | | **Helpline** | **Helpline phone number** | **Hours available** | **About the helpline** | | **Stroke Foundation** | **03 9670 1000** | Monday to Friday, 9am to 5pm | First point of call when dealing with a distressed stroke survivor or relative. | | **Stroke Foundation StrokeLine** | **1800 787 653** | Monday to Friday, 9am to 5pm. | Information and advice on stroke prevention, treatment, recovery, and support. | | **Carers Australia** | **1800 242 636** | Monday to Friday, 8:30am to 4:30pm | Provides information and counselling to carers. | |  |

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| 1. **What are the possible benefits?** | |
| **We cannot promise you any benefits from this research.**  But you **may feel good** after talking with others and helping to improve the resources that are provided to other young stroke survivors in the future. |  |

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| 1. **What will happen to information about me?** | |
| We will **store your information securely for at least 7 years**. Only the research team can read the information.  The information you provide will **remain confidential**. We **will not use your name or identify you** in any way.  You have the **right to access your information**.  If you **withdraw**, any **information that you have provided will be retained.** | **A computer and file cabinet with lock icons  Description automatically generated**  **A person in a suit giving a presentation  Description automatically generated** |

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| 1. **Will I hear about the results of the study?** | |
| We will send you a **summary of the results after each group discussion** to **check that it is accurate**.  **We will send you a copy of the project report** at the end of the project. |  |

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| 1. **Research compliance** | |
| Research involving humans in Australia is reviewed by an independent group of people on a Human Research Ethics Committee (HREC).  **This study has been approved by the HREC of La Trobe University.**  **If you are concerned** about the way this study is being conducted or you wish to **make a complaint** about any part of this study, please contact the La Trobe Human Ethics Committee:  Ethics and Research Governance Manager Phone: 03 9479 1443 Email: [humanethics@latrobe.edu.au](mailto:humanethics@latrobe.edu.au) |  |

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| 1. **Further information and who to contact** | |
| **Michaela Grech** can discuss the study with you at any time.  Phone: 0426 267 177  Email: m.grech@latrobe.edu.au | **A person smiling at camera  Description automatically generated**  **Speaker phone with solid fillEmail with solid fill** |
| **Associate Professor Dana Wong** can also discuss the study with you  Phone: 03 [9479 5079](tel:+61394795079)  Email: d.wong@latrobe.edu.au | **A close-up of a person smiling  Description automatically generated**  **Speaker phone with solid fillEmail with solid fill** |

**Declaration by Participant**

**Yes**, I would like to participate

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| Name of Participant: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  Signature: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ Date: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ |

**I am happy for information collected for this research to be used in future related studies**

* **Yes**
* **No**

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| Name of Participant: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  Signature: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ Date: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ |

**Declaration for participants unable to read the information and consent form**

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| Witness\* to the informed consent process.  Name (please print): \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  Signature: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ Date: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_   * Witness is not to be the investigator, a member of the study team or their delegate. Wittness can be a support person (e.g., family member, friend or paid carer) aged 18 years or older. |