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| **Co-designing a psychoeducation package to enhance psychosocial wellbeing for young adults living with stroke**  The research is being carried out in partial fulfilment of a PhD under the supervision of A/Prof Dana Wong and Dr Toni Withiel. The research team includes: | | |
| **Role** | **Name** | **Organisation** |
| Principal Investigator | A/Prof Dana Wong | La Trobe University |
| Student Investigator | Ms Michaela Grech | La Trobe University |
| Co-Investigator | Dr Toni Withiel | Melbourne Health (Royal Melbourne Hospital) |
| Co-Investigator | A/Prof Emma Power | University of Technology Sydney |
| Co-Investigator | Professor Ian Kneebone | University of Technology Sydney |
| Co-Investigator | A/Prof Rene Stolwyk | Monash University |
| Co-Investigator | Dr Eirini Kontou | University of Nottingham |
| Co-Investigator | Mr Adrian O’Malley | Physical Disability Council of NSW |
| **Research funder** | This research has received funding from the Tim Glendinning Memorial Grant, Stroke Foundation, Australia | |

1. **What is the study about?**

We would like your opinion on what things are important for an information package to support young stroke survivors. This will help us to develop ways to address and prevent psychological and cognitive challenges after stroke.

1. **Do I have to participate?**

Being part of this study is entirely voluntary and you can withdraw at any time. You decision will not affect ongoing or future care, research involvement or professional relationships with the research team. If you want to be part of the study, we ask that you read the information below carefully and ask us any questions.

1. **Who is being asked to participate?**

You have been asked to participate because you are 18 years or older, live in Australia, and you are a support person (i.e., family member, friend, support worker) of a young stroke survivor.

1. **What will I be asked to do?**

If you choose to take part in this study, we will ask you to attend **two online Zoom discussions** with a small group of other support people to help us decide what things are important for a new information package for young stroke survivors. The information package may include tip sheets, videos, and Q&A sessions with clinicians. These will be on topics around “invisible difficulties” such as challenges with thinking, mood and fatigue.

There will be **two group discussions**, each lasting around **90 minutes**. The first group will involve discussing initial ideas about what to include in the package and how it should be delivered. After this group discussion, the researchers will develop prototypes or examples of the resources in the package, which will be discussed at the second group discussion, around 3 months after the first meeting. Similar focus-group discussions will also be held with young stroke survivors and clinicians with expertise working with young stroke survivors.

We will **record these conversations with your permission**.

You will be paid $50/hour in recognition of the time spent participating in these focus groups.

1. **What are the benefits?**

The benefit of you taking part in this study is that it will help us determine the important components of providing information to young stroke survivors and their support people. Designing resources for young stroke survivors and their support people could address high levels of need for support in young stroke survivors, and improve their mood, cognitive functioning (thinking skills), confidence, and quality or life. It could also help families and close others feel more confident and informed about how to support stroke survivors.

1. **What are the risks?**

With any study there are (1) risks we know about, (2) risks we don’t know about and (3) risks we don’t expect. If you experience something that you aren’t sure about, please contact us immediately so we can discuss the best way to manage your concerns.

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| **Name/Organisation** | **Position** | **Telephone** | **Email** |
| A/Prof Dana Wong, La Trobe University | Associate Professor and Clinical Neuropsychologist | 03 [9479 5079](tel:+61394795079) | d.wong@latrobe.edu.au |
| Michaela Grech, La Trobe University | PhD Student | 61 426267177 | m.grech@latrobe.edu.au |

You may feel that some of the questions are stressful or upsetting. If you do not wish to answer the question, you do not have to provide a response. You may take breaks during the group discussion or choose to leave at any point. If you become very distressed while answering the questions, we will arrange appropriate supports for you, with your permission. There are also several services you can contact for additional support:

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| **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. |

1. **What will happen to information about me?**

The information you provide will remain **confidential and we will not use your name or identify you** in any way. We will store your information securely for at least 7 years, and only the research team can read the information. You have the right to access and correct your personal information by contacting the research team.

The storage, transfer and destruction of your data will be undertaken in accordance with the [Research Data Management Policy](https://policies.latrobe.edu.au/document/view.php?id=106/) <https://policies.latrobe.edu.au/document/view.php?id=106/>.

At the end of the project, the results will be published and presented in a variety of forums so that interested people may learn from the findings. In any publication or presentation, information will be presented in a way that does not identify you.

If you withdraw, any information that you provided will be retained.

1. **Will I hear about the results of the study?**

We will send you a summary of the themes generated in our group discussions to check that the themes are accurate and resonate with your experiences. We will also send you a copy of the final project report at the end of the project.

1. **What if I change my mind?**

You can choose to no longer be part of the study at any time. Any information that you have provided up to that point will be retained. You can withdraw from the study by calling or emailing us (see section 10 for contact details). Your decision to withdraw at any point will **not** affect your relationship with the researchers or any organisation listed in this form.

1. **Who can I contact for questions or want more information?**

If you would like to discuss the study at any time, please contact:

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| **Name/Organisation** | **Position** | **Telephone** | **Email** |
| A/Prof Dana Wong, La Trobe University | Associate Professor and Clinical Neuropsychologist | 03 [9479 5079](tel:+61394795079) | d.wong@latrobe.edu.au |
| Michaela Grech, La Trobe University | PhD Student | 61 426267177 | m.grech@latrobe.edu.au |

1. **What if I have a complaint?**

If you have a complaint about any part of this study, please contact:

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| **Ethics Reference Number** | **Position** | **Telephone** | **Email** |
| [HEC24093](https://prime.latrobe.edu.au/portal/s/detail/a1MMn000006Lngd) | Senior Research Ethics Officer | +61 3 9479 1443 | [humanethics@latrobe.edu.au](mailto:humanethics@latrobe.edu.au) |

**Consent Form – Declaration by Participant**

I (the participant) have read (or, where appropriate, have had read to me) and understood the participant information statement, and any questions have been answered to my satisfaction. I agree to participate in the study, and I know I can withdraw at any time. I agree information provided by me or with my permission during the project may be included in a thesis, presentation and published in journals on the condition that I cannot be identified.

I would like my information collected for this research study to be:

Only used for this specific study;

Used for future related studies;

I agree to have the group discussion audio recorded

I would like to receive a copy of the results via email or post.

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| **Name** | **Email** | **Postal address (optional)** |
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**Participant Signature**

I have received a signed copy of the Participant Information Statement to keep

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| Participant’s printed name |  |
| Participant’s signature |  |
| Date |  |

**Declaration by Researcher**

I have given a verbal explanation of the study, what it involves, and the risks and I believe the participant has understood;

I am a person qualified to explain the study, the risks and answer questions

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| Researcher’s printed name |  |
| Researcher’s signature |  |
| Date |  |

\* All parties must sign and date their own signature