

Supporting Young Stroke Survivors Through Engaging Messaging Advisory Group Member



Position: Supporting Young Stroke Survivors Through Engaging Messaging (SYSSTEM) Advisory Group Member

Program: Utas PhD project

Manager: Dr Marie-Louise Bird

External liaisons: World Stroke Organization Future Leaders Young Stroke Group, Funded by TasCare

Term and hours: Term for 3 years
Meetings up to 90 minutes, 2 times a year, and out of session involvement up to 5 hours (reading and responding to documents). Meetings conducted via zoom.

Location: Anywhere around Australia

About the project

Stroke is a high priority public health concern as its impact extends beyond the individual domains to family. The section of the community affected by young people having stroke is increasing. Young stroke is defined heterogeneously among many studies depending on the scope of research. The incidence of stroke in the young age group is high and the outcomes devastating, as it affects productive years due to the disability that comes with it. Our study aims to determine how best to improve participation and quality of life for young stroke survivors (under 25 years) while reducing the development of secondary chronic diseases.

Project Outline

The project will have input from this advisory group, that will provide valuable direction to the scope of the following phases of the project

Phase 1.

- The first phase will be the exploratory stage eliciting the needs of young stroke survivors and how these needs can be met to improve the quality of life through interview or focus group. We will conduct interviews and focus groups with people with lived experience of stroke (people who had a stroke under 25 years of age and their families) and health professionals and then develop a survey to more broadly gather information on the questions identified in the first part of Phase 1, including the prioritization of solutions to meet the identified needs.

Phase 2

- Development of one (or several) technological solutions to improve quality of life of young stroke survivors and test the feasibility of these solutions

Phase 3.

- This phase involves the evaluation of the technological solution in improving quality of life of young people with stroke

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Role of Advisory Group Members

Provide expert knowledge, advice and guidance to the project team and represent the interests of young people with stroke and their families by:

- 1. Reading papers and provide direction to the researchers on
 - study questions
 - study design
- 2. Where possible meet with other members of the advisory group twice a year for a maximum of 90 minutes in business hours (Australia) to discuss the study progress and have input into materials (e.g. surveys)
- 3. Assist with participant recruitment for this project including young stroke survivors and their families, and health care professionals working with young stroke survivors to participate in the various phases within the project.

Compensation

- The project team will provide compensation for the time of advisory group members in both attending meetings and reading and replying to documents out of session at the rate of \$50 per hour for a maximum of 8 hours a year for those members who are not compensated as part of their employment
- This honorarium may be provided by gift card.

Eligibility and Suitability

If you are;

- a person under the age of 30 years who had a stroke when less than 25 years of age, or their family member, or a health professional (any age) with experience and interest in young people after stroke (under 25 years of age)
- have good written and verbal communication skills (people who require assistance with communication will be supported)
- ability to complete projects in a timely manner
- experience in consumer representation, advocacy or volunteering

then please contact

the project manager, Dr Marie-Louise Bird marie-louise.bird@utas.edu.au

or

PhD student lead Mrs Dinah Amoah dinah.amoah@utas.edu.au