

PLAIN LANGUAGE STATEMENT AND CONSENT FORM



TO: Participants

Plain Language Statement

Date: 2 April 2025

Full Project Title: ReConnect: Co-design of resources to enhance connection after stroke

Principal Researcher: Associate Professor Alyna Turner

Student Researcher:

Associate Researcher(s): Heather Smith, Saran Chamberlain, Tegan Stevens, Hugh McGovern

You have been given this information as you have either had a stroke, or support or work with people who have had a stroke, and have expressed interest in our study. We plan to create new resources targeting social connection after stroke, as well as related topics – such as emotional adjustment and communication about stroke. We will do this in partnership with people who have had a stroke and their supporters and those who work with them. This process is known as ‘co-design’.

We plan to use these resources as part of our service intervention (known as RESET), which is designed to support people who have had a stroke return to and stay at work. As such, although we will focus on social connection broadly, we will also ensure we consider the needs of stroke survivors who are returning to or maintaining work. We hope the resources can also be used more broadly by clinicians supporting stroke survivors.

What does participation involve?

Your participation will depend on how you wish to contribute. All participants will complete an online demographic survey (asking questions about age, gender, work experience, language, residence, cultural background, and experience with stroke).

Following this, there are two options:

1. Joining the Design and Feedback Network: You will have the opportunity to provide feedback via email on the resources that are created. You will also have the additional option of attending individual meetings with the lead researcher to go through the resources in more detail (1-3 meetings, 1 hours each, via Zoom). You can indicate your interest in meetings on the consent form. Both these options are voluntary and you only need to contribute as much as you wish.

2. Applying for the Co-Design Team: You can apply to join the co-design team. You can indicate your interest in applying on the consent form. The application will involve an initial interview (via Zoom, approximately 1 hour) with the lead researcher, a researcher who has lived experience of stroke, and another member of the research team who has no previous connection to any applicants, to discuss your circumstances and interest in joining the team. If there are more applicants to the Co-Design Team than positions available, people who miss out on a position will be part of the **Design and Feedback Network**.

If you are accepted for a position on the Co-Design Team, you will be invited to attend an additional individual meeting (via Zoom) to further discuss what to expect from the Co-Design Team meetings. We will provide you with written and verbal information about what will be discussed in the team meetings to allow you time to consider the meeting topics.

Following this you will be invited to attend 7 group meetings (up to 10 if the Co-Design Team decide they would like additional meetings; meetings are of one hour duration, with meetings scheduled approximately 2-4 weeks apart). These meetings will also be attended by members of the research team who will all have different roles (e.g. leading discussions, taking notes and so on); this will include a researcher with lived experience of stroke. Each meeting will consist of group activities that aim to: identify preferred words to use when discussing social connection, identify factors that encourage or discourage social connection, possible action items that can support social connection, and creating resources to support social connection after stroke.

Some meetings will be conducted separately, with those lived experience of stroke and carers/support people in one meeting, and those who work with people with stroke (e.g. clinicians, employers, service providers) in a separate meeting. Others will include the full group.

All group Co-Design Team meetings will be video recorded via Zoom. These videos will only be seen by the research team, and will only be used to allow the research team to watch back the video in between group meetings to ensure all the information raised during the group activities has been incorporated in the activity notes (for example, if a group member mentioned a factor that encourages social participation and it was not noted down in the meeting, the research team will realise this has been missed and will add it to the list of factors created during the group).

Total time commitment for involvement in the Co-Design Team is up to approximately 9-12 hours (each meeting will be a maximum of one hour).

Expected risks and benefits to participants.

We do not suspect there will not be individual benefits nor risks/disadvantage from taking part in this study. At times discussing the experience of a stroke can cause people to feel distressed; although we do not anticipate this to be lasting, and we have processes in place if this does arise, for example you can take time out from the meeting/interview to chat privately to a team member and we can provide you with information about support options if needed. Expected benefits to the wider community are the creation of new resources that

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can be used by clinicians to support a stroke survivor to return to a connected and productive life.

Do I have to participate?

Participation in this study is voluntary. If you do decide to take part, indicate this by signing the consent form. You will be able to download the signed information and consent form, or be emailed the document.

If you decide to participate, any participation in meetings and electronic discussions is voluntary. If you do not wish to take part in those discussions, you do not have to. You can decide to take part and later change your mind. You are free to withdraw from the meetings at any stage.

If you no longer want to take part in any capacity, please notify a member of the research team and the research team will not collect any more personal information from you. You can withdraw your demographic data if you wish; please inform the research team if this is the case. Other data cannot be removed as in the co-design process participant contributions are incorporated into the overall design immediately.

Your decision whether to take part or not to take part, or to take part and then withdraw, will not affect your relationship with Deakin University.

Funding and study findings

Funding for the project is from IMPACT, Deakin University (\$19,985). If you attend meetings you will be reimbursed for your time (\$30/meeting for up to 10 Co-Design Team meetings, and up to 3 Design and Feedback individual feedback meetings).

You will be provided with copies of the resources created during the project. In addition, at the end of the project you will be sent the overall study results via email. The resources resulting from the study will be the intellectual property of Deakin University. Finally, the published results will be available to you upon request.

What happens to my information?

By signing the consent form you consent to the relevant research staff collecting and using personal information about you for this study.

If you attend group meetings, we request that you and other group members do not share anything discussed during the group sessions with anyone outside the group. We also request you do not share identifying information about anyone that you know during the meetings. Please note that if you attend group meetings we cannot guarantee complete anonymity or confidentiality in the workshops/focus groups due to the presence of other participants in these sessions.

Any information obtained by the research team in connection with this study that can identify you will remain confidential. All information that is collected about you for the purposes of this study will be marked with a code instead of your name; the list containing the code and your name will be password protected. Your personal information will only be used for the Plain Language Statement & Consent Form to participants
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purpose of this research project and will not be disclosed unless you have given us permission or if disclosure is required by law. Any information obtained during the research project are subject to inspection (for the purpose of verifying the procedures and the data) by the relevant authorities and authorised representatives of Deakin University, or as required by law. By signing the Consent Form, you authorise release of, or access to, this confidential information to the relevant study personnel and regulatory authorities as noted above. The study will be monitored by the Deakin University Human Research Ethics Committee via annual reports and a final project report from the research team.

It is anticipated that the results of this research project will be published and/or presented in a variety of forums. In any publication and/or presentation, information will be provided in such a way that you cannot be identified. With ethical approval, we may also share de-identified data with other researchers, or use for secondary analysis.

After the study has been completed, all study-related documents will be stored securely for 5 years in line with national research guidelines (on a Deakin University server), and then securely destroyed (link to National Statement on Ethical Conduct in Human Research 2023: [National Statement on Ethical Conduct in Human Research 2023 | NHMRC](#)).

Further information and who to contact

Please do not hesitate to contact the research team if you would like more information about the study; if there is any matter about it that concerns you, either now or in the future; or you would like a copy of this plain language statement and consent form:

<p>Dr Alyna Turner: 03 4215 3313 Email: a.turner@deakin.edu.au</p>
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For support:

If any aspects of this research cause you distress, the following websites provide lists of relevant services for people who have experienced stroke:

- **Stroke Foundation support page:** <https://strokefoundation.org.au/About-Stroke/Life-after-stroke/Help-after-stroke>

For further support, ***or if you are extremely distressed***, please contact:

- Your GP, who can organise a mental health plan if required,
- **Lifeline** (13 11 14),
- **The Beyond Blue Support Service** (1300 22 4636), or
- **The Suicide Call Back Service** (1300 659 467),
- If you require **emergency mental health assistance please call 000.**

Complaints

If you have any complaints about any aspect of the project, the way it is being conducted or any questions about your rights as a research participant, then you may contact: Human Research Ethics Office, Deakin University, 221 Burwood Highway, Burwood Victoria 3125, Plain Language Statement & Consent Form to participants
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Telephone: 9251 7129, research-ethics@deakin.edu.au. Please quote project approval number 2024/HE000447.



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Consent Form

Date: 2 April 2025

Full Project Title: ReConnect: Co-design of resources to enhance connection after stroke

Principal Researcher: Associate Professor Alyna Turner

Student Researcher:

Associate Researcher(s): Heather Smith, Saran Chamberlain, Tegan Stevens, Hugh McGovern

I have read, or have had read to me, and I understand the attached Plain Language Statement.

I freely agree to participate in this project according to the conditions in the Plain Language Statement.

I understand that meetings will be recorded.

I have been given a copy of the Plain Language Statement and Consent Form to keep.

The researcher has agreed not to reveal my identity and personal details, including where information about this project is published, or presented in any public form. I understand that meetings will be recorded

I understand I will be a member of the Design and Feedback Team, unless invited to be a member of the Co-Design team (interest to be indicated below).

- As a member of the Design and Feedback Team, I wish to be invited to attend individual meetings to provide feedback on the resources (up to 3 Zoom meetings)
- I wish to apply for membership of the Co-Design Team (up to 12 Zoom meetings)
- I agree for any meetings I attend being videorecorded.

Participant's Name (printed)

Signature Date

For participants who will attend meetings:

I have confirmed consent and confirm this participant meets eligibility criteria for the meetings.

Researcher Name:

Signature:

Date:



PLAIN LANGUAGE STATEMENT AND CONSENT FORM

TO: Participants

Withdrawal of Consent Form

(To be used for participants who wish to withdraw from the project)

Date: 2 April 2025

Full Project Title: ReConnect: Co-design of resources to enhance connection after stroke

Reference Number: 2024/HRE000447

I hereby wish to WITHDRAW my consent to participate in the above research project and understand that such withdrawal WILL NOT jeopardise my relationship with Deakin University

Participant's Name (printed)

Signature Date

Please post or email this form to:

Associate Professor Ayna Turner
IMPACT TRIALS, HERB Building B, Level 3
PO Box 281
Geelong 3220
Email: a.turner@deakin.edu.au