Yarning up After Stroke

Participant Information Statement
V3_24012025
Phase II Stroke Navigator Group

Project Title: Yarning up After Stroke Phase II
HREC Number: **2020/ETH02782**
Principal Researcher: Dr Heidi Janssen

You are invited to take part in this research project. Please read this information carefully and ask questions about anything. Before deciding if you want to agree to be involved (consent), you might want to talk about it with your family or a friend.

What is the project about?

Working with your Community to develop a culturally safe stroke care approach for Aboriginal and/or Torres Strait Islander people who have had a stroke.

Who is involved in the project?

Aboriginal people are on the research team which include people who have had a stroke and there will be ongoing involvement from Aboriginal people. The lead researchers are Dr Heidi Janssen (Physiotherapist and Researcher) and Professor Chris Levi (Neurologist).

Why have I been invited to be involved?

You have been invited to participate because you are an Aboriginal and or/Torres Strait Islander living on Gamilaraay/Gomeroi lands within the Hunter New England Local Health District area and you have had a stroke within the last 6 months.

Why is the research being done?

To understand if a stroke care approach built by your Community is helpful after a stroke. We need two groups of people in this project so that we can understand if this approach is beneficial and hear what people thought about it.

Group 1: The first group are people who have had a stroke but who have not used the stroke care approach.

Group 2: The second group is people who have used the stroke care approach – this being support from a **Stroke Navigator**. **This is your group**.

We will then have a look at the results of the two groups to see if support from a Stroke Navigator is helpful.

We are inviting you to join in the second group (Group 2) where you will be able to receive the support from the Stroke Navigator for 12 weeks. The Stroke Navigator will work with you during your stroke recovery as little or as often as you like.

This Stroke Navigator role was **designed by members of the Gomeroi/Gamilaraay Community** including people with lived experience of stroke (stroke survivors and carers of people with stroke), health professionals, and members of the Yarning up After Stroke Research Project Team.

What would you have to do?

If you agree to be involved in this project your involvement will be 3 months.

You will be asked to:

1. **Yarn with a member of the project team** at a time and place that suits you to answer questions (in 2 surveys) about how you are **feeling** and **how you think your life is going after stroke** at **two different times**;

(a) Once when **you start in the project**, and

(b) **12 weeks (3 months) later**, this is when you will be finished in this project.

Your yarn will be a relaxed social yarn with a researcher before the session where you can ask questions that you might have.

The yarning session will be in person or over the phone or computer video.

This yarn can occur at a location that suits you and the researcher. A place that you feel safe and relaxed.

This yarn will take about 30 minutes to complete.

2. Agree to a researcher **reviewing your medical records** and **contacting your GP or Specialist** if further information is needed about your stroke.

3. Agree to a researcher **collecting information about what health services** you have used during your time in the study.

4. Meet with the Stroke Navigator as much as you want or need throughout the 12 weeks. You can decline support from the Stroke Navigator at any time you want.

What choice do you have?

You have a choice to take part in this project. If you do take part we need your permission (informed consent). If you decide to take part in the research you may leave the project at any time without giving a reason. If you do decide to leave the research project, all the information that has been collected for this study about you will be destroyed. If you decide not to be involved this will not have any impact on the health care you receive from Hunter New England Health.

How will your privacy be protected?

All information you give will be kept private (confidential). Your records are kept private by a using a code instead of your name. All personal health information you provide will be used and stored in accordance with Commonwealth Privacy Laws and the NSW Health Records and Information Privacy Act 2002. All research records will be kept in a secure place and only the researchers have access. No information that identifies you will be reported.

How will the information collected be used?

Your information will be secure. Your personal information such as your name will never be used by the researchers. Results from the project may be published in research reports (they are called journals by researchers) or at health education gatherings but your name will not be used at any time. Information collected may be used by other researchers working with this research team who also do research related to stroke. Information obtained from this project will be kept by the Hunter Stroke Service for fifteen (15) years, after which it will be destroyed.

What are the potential risks?

If during yarning you become upset, the researcher can offer to:

1. Talk to your General Practitioner
2. Contact your local Aboriginal Medical Service for support
3. Yarn with Elders in the Community

How will I benefit?

You will receive a $20 gift voucher each time the team yarn with you (twice) to answer the questions. This is to help cover any costs such as transport. You may also benefit your Community by helping to develop a stroke care approach to be used in the future with people who have had a stroke

Do I have to be involved?

If you don’t take part in this research. Your relationship with Hunter New England Local Health District will not change.

If you decide to take part, you will be asked to sign the consent section. Signing tells us you:

- Understand what you have read
- Agree to take part

You will be given a copy of Information Statement and Consent Form.

Data storage

Interview recordings will be kept at Hunter New England Local Health District. Survey data will be collected over the phone, video conference on a computer or through an email link the Redcap data storage platform. All survey data and consent forms will be stored on Redcap. Only the research team will have access to information stored on password protected computer and the Redcap database. Project information will be kept for 15 years and audio recordings for 7 years, then it will be destroyed. Culturally sensitive information will be protected as advised by the Yarning up After Stroke Cultural Advisory Group.’

Contact

If you have any questions please contact Ms Rachel Peake on (02) 67678393 or Dr Heidi Janssen, Lead Researcher on (02) 40420417.

Ethics: This research has been **approved** by the Hunter New England Human Research Ethics Committee of Hunter New England Local Health District, Reference ETH02782.

Governance: The conduct of this research has been **authorised** by the Hunter New England Local Health District to be conducted at the Aboriginal Health Unit Tamworth site.

This project will be carried out according to the National Statement on Ethical Conduct in Human Research (2023), produced by the National Health and Medical Research Council of Australia. This statement has been developed to protect the interests of people who agree to participate in human research studies.

Should you have **concerns about your rights** as a participant in this research, or you have a **complaint** about the manner in which the research is conducted, it may be given to the researcher, or, if an independent person is preferred, please contact the HNE Research Office, Hunter New England Local Health District, Level 4 West, HMRI, Lot 1 Kookaburra Circuit, New Lambton Heights NSW 2305, telephone (02) 49214140, email HNELHD-ResearchOffice@health.nsw.gov.au and quote reference **2020/ETH02782**.

Or The Chairperson
Aboriginal Health & Medical Research Council Ethics Committee
35 Harvey Street, Little Bay, NSW, 2012, ethics@ahmrc.org.au

Yarning up After Stroke
CONSENT FORM
Phase II Group 2
V2_10112023

Project Title: Yarning up After Stroke

Principle Researcher: Dr Heidi Janssen

Organisation: Hunter New England Local Health District

I,
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have consented to participate in the above project:

DECLARATION BY PARTICIPANT

1. I have received the Information Statement and asked questions. I understand what the project is trying to do and my involvement.

2. I have the right to stop my involvement at any time without giving reasons. This will not affect any services that I receive.

3. Any information I provide will remain confidential. Where the results of the research are published, my results and involvement will be anonymous.

4. I understand that interviews may be recorded, secured and destroyed after 7 years.

5. Any complaints or questions I can contact the principal researcher, or the Chairperson of the Aboriginal Health & Medical Research Council Ethics Committee:

Dr Heidi Janssen

Research Fellow, Hunter Stroke Service
Hunter New England Local Health District
Level 1, The Lodge Building.

Rankin Park Campus, Lookout Rd,
New Lambton Heights. Locked Bag 1, HRMC 2310.
(02) 4921 4037
The Chairperson
Aboriginal Health &Medical Research Council Ethics Committee
35 Harvey Street
Little Bay, NSW, 2012
ethics@ahmrc.org.au

Name: ……………………………………………………………………………….

Signature …………………………………………………..…

Date…………….………………..

Witnessed by ……………………………….……………….

Date …………………………...

Researcher's signature: …………………………………………….

Date …..…………………