Yarning up After Stroke

Participant Information Statement

For Implied Consent Stroke Survivor

V2_28012026

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.

What is the Yarning up After Stroke 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 person 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 – Stroke Navigator role built by your Community is helpful after a stroke.

You will be able to receive the support from the Stroke Navigator for 3 months. The Stroke Navigator will work with you during your stroke recovery as little or as often needed.

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.

There are different ways you can participate in this project.

Your participation will help us understand if this Stroke Navigator is helpful for First Nations People after stroke.

Your participation in these activities will **imply your consent.**

These activities include:

1. **Receiving support from the Stroke Navigator**.

Involving:

- You meeting or talking with the **Stroke Navigator as much as wanted or needed** throughout the 12 weeks. You can **decline support from the Stroke Navigator at any time** you want.
- Allowing the **Stroke Navigator and other health employed researchers** in the team access your medical records to document what support is given, and to look up your health information, stroke relevant, to support you in your stroke recovery.
- With your permission, **contact your GP** to support stroke recovery care, which may include asking for further health information, and
- **Review and record other NSW Health services** are used during your stroke recovery. This will help us understand if there are any opportunities to improve your access to services and potentially other stroke survivors in the future.

2. **Yarning with an Aboriginal researcher**

These yarns will be with a member of the project team at **3 different times, and** could be **conducted with yourself or your family member living with stroke –** whichever is the **most appropriate;** based on your **ability and want** to participate. The 3 times will include:

1. At the **start of the time of support** from the Stroke Navigator, and then
2. **3 months later**.

During these yarns the Aboriginal researcher will cover topics to support the completion of 2 surveys, developed for use with First Nations People, about how you are **feeling** and your **well-being after stroke**.

3. **The final yarn is to understand the your experience of working with the Stroke Navigator.** These yarns can be at a time and place that suits you and or your family. You may want to participate in some, all or none of these yarns.

Participation in these yarns will imply your consent to have the information that you share, documented or recorded, and after taking off any information that identifies you, used to understand the potential value of the Stroke Navigator Role.

What choice do you have?

You have a choice to take part in this project.

You may leave the project at any time without giving a reason. If you do decide to leave the research project, you can choose to let us keep the information about your stroke, well-being and experience with the Stroke Navigator, or can you choose for it all to be removed and we will delete it.

If you decide to NOT receive support from the Stroke Navigator OR to not have a yarn with an Aboriginal researcher, 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). All 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 and the name of the person you care for/family member 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 and/or your family member (whomever participates in the yarns) will **receive a $20 gift voucher each time (up to 3 times) the research team yarn with you**.

This is to help cover any costs incurred during these yarns network use/transport. You and your family may also benefit through this support – better mood, well-being and possibly as well, their stroke recovery experience. Your participation may also benefit your Community by helping to develop a stroke care approach that if shown to be helpful, after further consultation with Community and other First Nations groups, could be used in the future with other First Nations People of NSW and possibly even Australia.

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 given a copy of the Information Statement which will include a page that summaries what you participation in the project's activities means.

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

Participant Information Statement and Implied Consent Stroke Survivor

V2_28012026

Phase II Stroke Navigator Group Implied Consent

This Implied consent form has been given to you because:

1. You are an Aboriginal/Torres Strait Islander person living on Gomeroi/Gamilaraay lands within the Hunter New England Local Health District
2. Have had a stroke within the past 6 months, and
3. Have agreed to receive support from the Stroke Navigator.

- The Stroke Navigator is a role within Hunter New England Local Health District services, developed by First Nations Community members within the Gomeroi/Gamilaraay Community, to help First Nations stroke survivors navigate their stroke recovery journey.
- We are evaluating how helpful this role is for First Nations stroke survivors using different research methods – yarning to understand spirit well-being and mood, and, what to hear what was and was not helpful about the role.
- We understand that people may find it difficult, for many reasons, to provide written or verbal consent.
- Understanding this, and the low risk nature of the stroke service we are evaluating (Stroke Navigator Role), we have received approval from the HNELHD Human Research Ethics Committee to use *implied consent*.

What does Implied Consent mean?

Implied consent means that your engagement in our project activities, indicate your willingness to participate in this research.

In this research project your engagement will be through your choice to

(i) Get support from the Stroke Navigator,

AND if wanting,

(ii) Agreeing to yarn with an Aboriginal researcher from the team up to 3 different times about your/your stroke survivor's recovery and your experience of working with the Stroke Navigator.