



## Yarning up After Stroke

### Participant Information Statement Control

V2\_10112023

Phase II Group 1

**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 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/Gomeri 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 community is helpful after a stroke. We need people who **have not** used this community built stroke care approach so we can understand the possible benefits seen in people who do use the community build stroke care approach.

## What would you have to do?

If you agree to be involved in this project your involvement will be at least 3 months, but no longer than 9 months long.

.

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 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** your stroke, and

(b) **12 weeks (3 months) later**, this is the end of your involvement.

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 computer video. With your permission we will video record or record the session on the computer.

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.

### **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 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 and surveys 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 a password protected computer and on 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.

**Complaints about this research:** If you are concerned about your involvement in this research, or you have a complaint about the research you can yarn to the researcher, or, if you want to talk with someone else, please contact the **HNE Research Office**, Hunter New England Local Health District, Level 3, POD, HMRI, Lot 1 Kookaburra Circuit, New Lambton Heights NSW 2305. Telephone: 02 4921 4140. Email: [HNELHD-ResearchOffice@health.nsw.gov.au](mailto:HNELHD-ResearchOffice@health.nsw.gov.au) and quote the reference number: STE04901.

Or The Chairperson

Aboriginal Health & Medical Research Council Ethics Committee

35 Harvey Street

Little Bay, NSW, 2012

[ethics@ahmrc.org.au](mailto:ethics@ahmrc.org.au)



**Yarning up After Stroke  
 CONSENT FORM  
 Phase II Group 1  
 V2\_10112023**

**Project Title:** Yarning up After Stroke

**Principle Researcher:** Dr Heidi Janssen

**Organisation:** Hunter New England Local Health District

I,  
 .....  
 .....  
 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](mailto:ethics@ahmrc.org.au)

-----

Name: .....

Signature .....

Date.....

Witnessed by .....

Date .....

-----

Researcher's signature: .....

Date .....