Attachment 3

Hunter Stroke Research Volunteer Register

INFORMATION FOR PARTICIPANTS
Version 4 – 21 April 2017

Introduction

You are invited to become a volunteer for the Hunter Stroke Research Volunteer Register. The purpose is to develop a register of people with stroke or transient ischaemic attack (TIA) who are willing to take part in research at a later date.

What is the Register about?

The Register will be a centralised database of people with stroke or TIA, living in the Hunter region, who are willing to be contacted to participate in stoke research at a later date.

Where is the Register operating?

The Register will be operating out of the Hunter Medical Research Institute and is a partnership between the University of Newcastle Priority Research Centre for Stroke and Brain Injury and Hunter Stroke Services (Hunter New England Health District).

Other investigators include:
A/Prof Coralie English, University of Newcastle (UON) Priority Research Centre for Stroke and Brain Injury
A/Prof Rohan Walker, UON Priority Research Centre for Stroke and Brain Injury
Prof Michael Nilsson, Hunter Medical Research Institute
A/Prof Michal Pollack, Hunter Stroke Service
Ms Monique Hourn, Hunter Stroke Service
Ms Gillian Mason, UON Priority Research Centre for Stroke and Brain Injury

Who can participate in the research?

We are seeking people with stroke or TIA who are willing to participate in research at a later date. If you are a person with stroke or TIA who is willing to add their contact information to a Register, and is willing to be contacted about research at a later date then this Register is suitable for you.

What Choice do you have?

Participation in the Register is entirely voluntary. You do not have to take part in it. If you do take part, you can withdraw from the Register at any time without having to give a reason.

Whatever your decision, please be assured that it will not affect your medical treatment or your relationship with the staff who are caring for you.

What would you be asked to do if you agree to participate?

If you agree to participate in this study, you will be asked to sign the Participant Consent Form. You will then be asked to provide contact information for you, your carer and information about the date and type of TIA or stroke you suffered (bleed or blockage, if known) and if you are participating in any other research or clinical trial (if known).

Your contact details will then be added to the Register. The Register Coordinator may contact you at a later date if a suitable clinical trial for stroke arises that may be of interest for you. Until such a time, there is nothing else you need to do.

What are the risks and benefits of participating?

Risks
There are no known risks to adding your information to the Register.

Benefits:
By being part of the Register you are more likely to hear about opportunities to be involved in research projects that may interest you. Individual research projects may or may not be of direct benefit to you.

While we intend that the Register will further medical knowledge through supporting high quality clinical trials which may lead to improvements in the treatment of stroke in the future, it will not be of direct benefit to you.

Will the study cost you anything?

Participation in the Register will not cost you anything, nor will you be paid. A reply paid envelope will be provided for you to return any relevant documents.

How will your privacy be protected?

All the information collected from you for the Register will be treated confidentially, and only the Register Coordinator and members of the Registry project team will have access to it. Researchers will apply to the Register Coordinator for access to the Register participants for the purposes of inviting people with stroke to take part in research.

The Register Coordinator will contact you by phone or via email or mail in the first instance to see if you are interested in participating in a particular research project. If you indicate that you are willing to participate the Register Coordinator will send you further information about the study via email or mail and the option to return a signed consent form. Only with your permission will your contact information be passed onto other researchers for follow up.

All personal information added to the Register will be accessed, used and stored in accordance with Commonwealth Privacy Laws and the NSW Health Records and Information Privacy Act 2002.

You can choose to withdraw from the Register at any time and all your information will be removed and destroyed. You can do this by phoning (02) 4042 0093 or strokeregister@hmri.org.au

Further Information

If you would like to discuss this further at any time, please contact the Hunter Stroke Research Volunteer Register Coordinator on (02) 4042 0093.

This information statement is for you to keep. Thank you for considering this invitation.

Complaints about this research

This research has been approved by the Hunter New England Human Research Ethics Committee of Hunter New England Local Health District, Reference 16/09/21/5.06.

Should you have concerns about your rights as a participant on the Register, 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, to Dr Nicole Gerrand, Manager, Research Ethics and Governance Unit, Hunter New England Human Research Ethics Committee, Hunter New England Local Health District, Locked Bag 1, New Lambton NSW 2305, telephone (02) 49214950, email Hnehrec@hnehealth.nsw.gov.au

For independent stroke support services please contact the Stroke Foundation's National helpline StrokeLine 1800 787 653

For HNELHD (for single site or site specific information statements done at HNELHD Sites)
The conduct of this study at the John Hunter Hospital has been authorised by Hunter New England Local Health District. Any person with concerns or complaints about the conduct of this study may also contact Dr Nicole Gerrand, Manager Research Ethics & Governance Unit on 4921 4950 and quote reference number **LNRSSA/16/HNE/376.**