PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM

Consumer and Consumer Organisations

Tailoring the reporting of hip fracture information for consumers

Professor Jacqueline Close

1. **What is the research study about?**

   You are invited to take part in this research study. The research study aims to improve the reporting of information about a broken hip by talking to people in Australia who have lived experience of these injuries, as a patient, relative, friend, or carer.

2. **Who is conducting this research?**

   The study is being carried out by the following researchers: Professor Jacqueline Close, Dr Gretchen Poiner, Associate Professor Catherine McDougall, Ms Elizabeth Armstrong, Ms Narelle Payne, Mr James Wright, and Ms Jamie Hallen, from the Falls Balance and Injury Research Centre at Neuroscience Research Australia (NeuRA).

   Research Funder: This research is being funded by the Commonwealth Department of Health.

3. **Inclusion/Exclusion Criteria**

   Before you decide to participate in this research study, we need to ensure that it is ok for you to take part. The research study is looking to involve people who meet the following criteria:

   - An older person (aged 50 years or older) who has had a broken hip
   - A carer or relative of an older person who has had a broken hip
   - An employee of an organisation that advocates for older people, or healthcare consumers, or carer's, or fragility fracture and bone health
   - A consumer member of organisations that advocate for older people, or healthcare consumers, or carer's, or fragility fracture and bone health
   - Health care providers/clinicians directly involved in the provision of care to older people with a hip fracture

4. Do I have to take part in this research study?

Participation in this research study is voluntary. If you do not want to take part, you do not have to. If you decide to take part and later change your mind, you are free to withdraw from the study at any stage.

If you decide you want to take part in the research study, you will be asked to:

- Read the information carefully (ask questions if necessary);
- Sign and return the consent form if you decide to be involved;
- Take a copy of this form with you to keep.

5. What does participation in this research require, and are there any risks involved?

If you agree to participate you will be asked to complete some or all of the following research activities. You may choose which activities to participate in.

Workshop/focus group: Workshop sessions will take place either online (using Microsoft Teams or Zoom) or face to face at [to be confirmed]. Online workshops will take 1-2 hours and face to face groups will take a full day from 9.30am until approximately 2.30pm. During the workshop you will be asked questions about what information should be reported by the ANZHFR, what format and presentation styles should be used, how and when consumer reports should be made available, and what data should be collected by the ANZHFR to measure and report a person's experience of their hip fracture care. With your permission the research team would like to audio record the workshop. If you decide to participate, your comments along with other participants will be recorded during the group discussions. Because of the way in which the workshop discussions are recorded, the research team will not be able to withdraw or destroy individual participant responses. You may also be asked to complete a follow up interview and/or questionnaire/survey. The research team will arrange these at the completion of the workshop. You will receive an initial reminder by telephone and one follow up reminder.

Interviews: Interviews may be face to face, online by video call, or by telephone and will be undertaken in the format most convenient to you and the researchers, considering geographic location and individual

preferences. You will be asked questions about the information provided in the workshops. If only participating in an interview, questions will be about what information should be reported by the ANZHFR, what format and presentation styles should be used, how and when consumer reports should be made available, and what data should be collected by the ANZHFR to measure and report a person's experience of their hip fracture care. Online or telephone interviews will take place using Microsoft Teams or Zoom and will take approximately 30 to 60 minutes. For face to face interviews we will meet you at a place you choose, such as a public place, like a café or library. With your permission the research team would like to audio record the interview. If you do not wish to be recorded but you would like to participate, you can advise the research team and only written notes will be taken. You may be asked to complete a follow up questionnaire/survey, and the research team will arrange this at the completion of the interview.

Survey: An online/email/verbal questionnaire/survey may be provided asking you to answer questions about the information gathered from the workshop and interviews. You will be asked to complete this survey once. The survey should take approx. 20-30 minutes to complete.

The researchers will also ask for your input via email on the recommendations for tailored consumer reporting developed from the consultation process.

Additional Costs and Reimbursement: Consumer participants (patients, carers, relatives) in workshops and interviews will be reimbursed at the 2021/22 hourly rate recommended by Health Consumers NSW of $45.26/hour, and for additional incidental expenses such as parking, travel, light refreshments, where applicable (https://www.hcnsw.org.au/for-health-consumer-organisations/remuneration-and-reimbursement-of-health-consumers/). Reimbursement for workshops and interviews will be inclusive of participation in any questionnaire/survey and review of recommendations.

6. What will happen to information about me?

By signing the consent form, you consent to the research team collecting and using information provided by you for the research study. The research team will store the data collected from you for this research project for:

- A minimum of 5 years after the publication of the research results

The information about you will be stored in a:

- Non-identifiable format where your identity and the data collected will be stored separately.
- Information collected from you in an electronic format will be stored on a NeuRA server in a password protected folder only accessible to the approved research team.
- Information collected from you using paper-based measures will be stored in the Falls Balance Injury Research Centre at NeuRA and only the approved research team will have access to this information.
- Audio recordings will be stored on a NeuRA server in a password protected folder only accessible to the approved research investigators

The information you provide is personal information for the purposes of the Privacy and Personal Information Protection Act 1998 (NSW). You have the right of access to personal information held about you by NeuRA, the right to request correction and amendment of it, and the right to make a complaint about a breach of the Information Protection Principles as contained in the PPIP Act. Further information on how NeuRA protects personal information is available in the NeuRA Privacy Policy.

7. How and when will I find out what the results of the research study are?

The research team intend to publish and report the results of the research. The research results will be reported/published in a report to the funder, the Commonwealth Department of Health, and as a publication in an academic journal. Results will also be made available in presentations at Conferences. All information will be published in a way that will not identify you, unless you tell us you want to be acknowledged by name as a member of the expert Consumer Group consulted.

If you would like to receive a copy of the results you can let the research team know by inserting your email or mailing address in the consent form. We will only use these details to send you the results of the research.

Reports and publications arising from the consultation will also be made available on the ANZHFR website www.anzhfr.org and will be promoted via various media channels (mainstream and social).

8. What if I want to withdraw from the research study?

If you do consent to participate, you may withdraw at any time. You can do so by completing the 'Withdrawal of Consent Form' which is provided at the end of this document or you can ring the research team and tell them you no longer want to participate. Your decision not to participate or to withdraw from the study will not affect your relationship with UNSW Sydney, the ANZHFR, or NeuRA. If you decide to leave the research study, the researchers will not collect additional information from you. You can request that any identifiable information about you be withdrawn from the research project.

9. What if I have a complaint or any concerns about the research study?

If you have a complaint regarding any aspect of the study or the way it is being conducted, please contact the UNSW Human Ethics Coordinator:

Complaints Contact:

Position	UNSW Human Research Ethics Coordinator
Telephone	+ 61 2 9385 6222
Email	humanethics@unsw.edu.au
HC Reference Number	[INSERT HC reference number]

10. What should I do if I have further questions about my involvement in the research study?

The person you may need to contact will depend on the nature of your query. If you require further information regarding this study or if you have any problems which may be related to your involvement in the study, you can contact the following member/s of the research team:

Research Team Contact Details:

Name	Ms Elizabeth Armstrong
Position	Consumer Reporting Project Manager, ANZHFR
Telephone	02 9399 1091
Email	e.armstrong@neura.edu.au

Name	Ms Jamie Hallen
Position	Manager, ANZHFR
Telephone	02 9399 1132
Email	j.hallen@neura.edu.au

Chief Investigator:

Name	Professor Jacqueline Close
Position	Clinical Director, Falls Balance Injury Research Centre, NeuRA
Telephone	02 9399 1055
Email	j.close@neura.edu.au

Consent Form – Participant providing own consent
Declaration by the participant

- ☐ I understand I am being asked to provide consent to participate in this research study;
- ☐ I have read the Participant Information Sheet, or someone has read it to me in a language that I understand;
- ☐ I understand the purposes, study tasks and risks of the research described in the study;
- ☐ Recordings: I understand that the research team will audio record the workshops/interviews; I agree to be recorded for this purpose.
- ☐ I provide my consent for the information collected about me to be used for the purpose of this research study only.
- ☐ I have had an opportunity to ask questions and I am satisfied with the answers I have received;
- ☐ I freely agree to participate in this research study as described and understand that I am free to withdraw at any time during the study and withdrawal will not affect my relationship with any of the named organisations and/or research team members;
- ☐ I understand that I will be given a signed copy of this document to keep.
- ☐ I understand that the results of the research will be made publicly available, including on the NeuRA and the Australian and New Zealand Hip Fracture Registry websites.
- ☐ I would like to receive a copy of the study results via email or post, I have provided my details below and ask that they be used for this purpose only.

Name: _____

Address: _____

Email Address: _____

Optional Consent for reuse of data and future research:

- ☐ I provide my consent to be identifed in publications relating to this research
- ☐ I provide my consent for my name and contact details to be retained in a register so I can be contacted about other research projects in the future.

Participant Signature

Name of Participant (please print)	
Signature of Research Participant	
Date	

Declaration by Researcher*

- ☐ I have given a verbal explanation of the research study; its study activities and risks and I believe that the participant has understood that explanation.

Researcher Signature*

Name of Researcher (please print)	
Signature of Researcher	
Date	

***An appropriately qualified member of the research team must provide the explanation of, and information concerning the research study.**

Note: All parties signing the consent section must date their own signature.

Form for Withdrawal of Participation

I wish to **WITHDRAW** my consent to participate in this research study described above and understand that such withdrawal **WILL NOT** affect my relationship with The University of New South Wales (UNSW), Neuroscience Research Australia (NeuRA), Australian and New Zealand Hip Fracture Registry (ANZHFR).

- ☐ I am withdrawing my consent and I would like any identifiable information collected about me which I have provided for the purpose of this research study withdrawn.

- ☐ I am withdrawing my consent and I understand that any information already published and/or not linked to my identity cannot be withdrawn from the research.

Participant Name

Name of Participant (please type)	
Date	

The section for Withdrawal of Participation should be forwarded to:

CI Name:	Professor Jacqueline Close
Email:	j.close@neura.edu.au
Phone:	02 9399 1055
Postal Address:	PO Box 1165, Randwick NSW 2031