

Keeping the Community Well

INFORMATION FOR PARTICIPANTS

Introduction

You are invited to take part in a student research study that will investigate how Aboriginal community members and families keep well. You have been invited because you work with community members and may have ideas for how we can improve services to keep the community healthy. This project is being run by researchers from the University of Sydney and Hunter New England Local Health District. The student researcher Christina Gonzalez is using this research for the partial fulfilment of the requirements of a Masters of Genetic Counselling.

What is the research about?

This research is part of a project looking at Aboriginal community views of cancer. This research aims to explore some of the reasons you believe prevent members of the Aboriginal community from seeking genetic counselling when they have a family history of cancer. This study will also explore what you think are some of the views of cancer in the Aboriginal community.

We are interested in your views on:

- What are the things that we need to do to keep the Aboriginal community well
- What do you think causes the Aboriginal community to be unwell
- What the community thinks causes illnesses, for example conditions such as cancer.
- Why the community thinks this happens to some families and not others
- What the community knows about genetic counselling services and what they think about them.

By finding out this information, we may develop a better understanding of the barriers preventing Aboriginal people from going to genetic counselling. Understanding these barriers may help us provide better genetic counselling services to the Aboriginal community.

Where is the research being done?

The study is being conducted by:

Clinical Team

- Melissa Buckman, Senior Genetic Counsellor, Tamworth Community Health.
- Rose Wadwell, Aboriginal Chronic disease development officer, Tamworth Population Health
- Rachel Williams, Senior Genetic Counsellor, Prince of Wales Hospital, Randwick

Research Team

- Associate Professor Kristine Barlow-Stewart, Director and Senior Genetic Counsellor, University of Sydney Medical School - Northern
- Dr Jane Fleming, Lecturer, University of Sydney Medical School – Northern
- Christina Gonzalez, Master of Genetic Counselling Student, University of Sydney Medical School – Northern.

Christina Gonzalez's involvement in the research is part of the requirements for a Masters of Genetic Counselling degree under the supervision of Melissa Buckman, Rachel Williams, Kristine Barlow-Stewart and Jane Fleming.

Who can participate in the research?

This research is suitable for you if you are an Aboriginal Health Worker in NSW who has contact with an Aboriginal community group.

What choice do you have?

This is a telephone interview based study. Participation in this study is entirely voluntary. You do not have to take part in it. If you do take part, you can withdraw at any time without having to give a reason. After the telephone interview, the interview will be written down (transcribed) and you will be given a copy to review. You can tell the research team if you do not want things you said in the interview to be used in the study.

Whatever your decision, please be assured that it will not affect your work or relationship with the Hunter New England Local Health District, South Eastern Sydney Local Health District or the University of Sydney.

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 complete a short telephone interview with Christina Gonzalez. The interview will go for ~30 - 45 minutes and will be audio recorded. You can stop the interview at any time or refuse to answer questions during the interview if you wish. After the interview, a copy of the transcript will be provided to you for you to check. After you have given your feedback, the transcript will be de-identified and analysed.

What are the risks and benefits of participating?

Risks

Although unlikely, you may find talking about illness and cancer uncomfortable or distressing. If you become distressed, we encourage you to speak to your GP about a Mental Health Plan or referral to see a psychologist. Alternatively, you can contact one of the following organisations:

Anglicare

240 Birrell St
Bondi Junction NSW 2022
Ph: 9798 1400

Relationships Australia

Level 7, 10 Barrack Street
Sydney NSW 2000
Ph: 1300 364 277

Benefits

While we intend that this research study will help develop better health services for the Aboriginal community, we cannot guarantee that you will receive any direct benefits from being involved in the study.

Will the study cost you anything?

Participation in this study will not cost you anything, nor will you be paid.

How will your privacy be protected?

All the information collected from you for the study will be treated confidentially, and only the research team named above will have access to it. The clinical team will not know who has participated. The study results may be presented at a conference or in a scientific publication, but individual participants will not be identifiable in such a presentation. If you choose to withdraw from the study after you have given your comments on the written interview, it will not be possible for your data to be removed from the study as it will be de-identified.

Further Information

When you have read this information, Rachel Williams will discuss it with you further and answer any questions you may have. If you would like to know more at any stage, please feel free to contact her on 02 9382 5214.

This information statement is for you to keep.

Thank for considering this invitation. If you have any questions about the study you can contact Rachel Williams on 9382 5214 or Christina Gonzalez at cgon7400@uni.sydney.edu.au.

Signatures



Rachel Williams



Christina Gonzalez

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 HREC/16/HNE/197.

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, 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