

PARTICIPANT INFORMATION SHEET

> Out-of-Pocket Healthcare Expenditure

Invitation

If you are reading this information sheet then you have clicked on a link which has taken you to a site on a research study that the following researchers are running:

- Rebecca Ivers, Professor, The George Institute for Global Health
- Andrew Holland, Professor, Westmead Hospital
- Tamara Mackean, Doctor, The George Institute for Global Health
- Kate Hunter, Doctor, The George Institute for Global Health
- Courtney Ryder, PhD Student, The George Institute for Global Health

Firstly thank you for your interest in the study. In this study we are hoping to recruit Aboriginal and Torres Strait Islander families, who have children from 0-16 years of age. We are hoping as a parent/carer of these children that you might be able to participate in a survey that we are testing, which has been created to record much money you have spent out of your own pocket on healthcare for your family. For this study it doesn't matter how much you have spent, you may not have spent anything at all. What we are hoping you will be able to do is answer the survey questions based on your families situation. The results you provide us with will go into testing the tool for use with Aboriginal and Torres Strait Islander families. Because in this study we want to make a tool especially for Aboriginal and Torres Strait Islander families, because currently most survey tool are not made in a way to suit Aboriginal and Torres Strait Islander people.

Before you decide if you want to join this small study, take some time to read over the information in this sheet. Also discuss it with any family members or researchers before you decide.

1. What is the purpose of this study?

We want to make a survey tool that records all the costs you have had to pay out of your own pocket for your family's health care, and learn how this has impacted you and your family.

2. Why have I been invited to participate?

You are a parent/guardian of Aboriginal and/ Torres Strait Islander children 0-16 years of age and have clicked on a link on Facebook or Gumtree showing interest in the study.

3. What if I don't want to participate? Or want to redraw later on?

If you don't want to participate you don't have to. If you do participate and decide later you don't want to you can stop too.

4. What is involved?

If you decide yes, then you will click on another link that will take you to a page with some questions which will access if you are eligible to participate. One of the question in this section will ask you if you want to participate in the study, by clicking yes to this question you are consenting to participate in this study. After this you will then be taken through to the survey. We will then require you to participate in the survey tool two week later. We will send you a reminder to participate with the phone number or email address you provide us with.

Completion of this survey should only take 10-20 minutes the first time, it will be much quicker to complete the second time. After completion of the second study you will provide us details on how best to provide you with a \$30 Coles or Woolworths voucher for participating in the study.

How is the study being paid for?

This study is paid for by a National Health and Medical Research Grant.

5. Are there any risks involved if I participate?

There are no risks to participating in this small study. All the information you provide is de-identified, a process where we remove any information that can identify you.

6. What will I benefit from by participating in the study?

We hope the information you provide can build a great survey tool, which can be used by Aboriginal research organisations in the future and help inform policy and decrease the amount of money you have to pay out of your own pocket for healthcare.

We also provide you with a \$30 Coles or Woolworths Voucher for participating as a thank you. If you are living in an outer regional or remote area which does not have a local Coles or Woolworths shop, at the end of the study there is an area where you can provide us with your postcode and we can find an alternative voucher in your local area, or the nearest town.

7. Are there any costs associated with participating in the study?

No.

8. Will the results be confidential? How am I protected?

All information is de-identified. Only the main researcher Courtney Ryder, will need to know if you participate or not. This is so she can send you reminders and your voucher for participating in the study.

9. What will occur with the results of this sub-study?

The information you provide will make a survey tool to record the costs you have to pay out of your own pocket for your family's healthcare. We will also be looking to publish a research journal article and present this information at a conference. If you would like to know about the results of this small study, let us know so we can tell you.

10. What should I do if I would like to discuss the study further before I decide?

If you read this information sheet or anyone in your family has read it and you have questions, the research Courtney Ryder will be happy to discuss these with you. She can be contacted by email: cryder@georgeinstitute.org.au and you can arrange through email to discuss the study verbally if you wish to.

11. Who should I contact if I have concerns about the conduct of the study?

Research which involves people in Australia is looked at by a group of people called a Human Research Ethics Committee (HREC). Research which involves Aboriginal and Torres Strait Islander communities, is also looked at by Aboriginal Health Research and Medical Councils. The study has had its ethical aspects approved by the HREC of:

1. Aboriginal Health Research Ethics Committee

As part of this process, we have agreed to carry out the study according to the National Statement on Ethical Conduct in Human Research along with meeting specific national guidelines around conducting research with Aboriginal and Torres Strait Islander communities.

If you have bad problems with the way this study is being done or you wish to complain to someone not in the Coolamon study, please contact either of the organisations below. You will need to tell them the study name and number (OOPHE Study, 04-14-572).

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Thank you for taking the time to consider this study.
If you wish to take part in it, please go back to the previous internet page.

This information sheet is for you to keep, so please save a copy.