

## What will happen to what I tell you and my results?

The information you tell us will be stored at The Children's Hospital at Westmead in a secure, password protected database. Paper records will be stored in a locked cabinet. The information could be used with information from other young people in reports or papers about the research. You will not be able to be identified in these reports or papers.

ARDAC study data belonging to Aboriginal participants will remain the property of participating Aboriginal communities. Communities will receive local area reports about screening results and are asked to review reports or papers before they are published or presented. The researchers will have ownership of study data belonging to non-Aboriginal participants.



## Questions? Contact Us:

Aboriginal Study Manager: (02) 9845 1472

Research Nurses: (02) 9845 0119 or (02) 9845 0137

Freecall: 1800 005 846 (leave a message)

Email: [ardac.SCHN@health.nsw.gov.au](mailto:ardac.SCHN@health.nsw.gov.au)

**This project has been approved by the Sydney Children's Hospital Network, and the Aboriginal Health and Medical Research Council of NSW, Ethics Committees. If you have any concerns about the conduct of this study, please contact the following Ethics Committees and quote our approval number.**

The Secretary, The Sydney Children's Hospitals Network Ethics Committee: (02) 9845 3017, *reference no. HREC/13/SCHN/354*

The Chairperson, AH&MRC Ethics Committee: (02) 9212 4777, *reference no. 597/07*

# The Kidney Health Study (ARDAC Phase 3)



## CHILD/YOUNG PERSON INFORMATION SHEET

This is a booklet that has been put together to help you decide if you would like to take part in our research study about the early signs of kidney and heart disease in Aboriginal and non-Aboriginal children and young people.

### Investigators

Professor Jonathan Craig, University of Sydney, SCHN

Dr Elisabeth Hodson, Centre for Kidney Research

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### **What is the study about?**

ARDAC stands for **A**ntecedents (markers) of **R**enal **D**isease in **A**boriginal **C**hildren. The ARDAC study is finding out about the kidney and heart health of Aboriginal and non-Aboriginal children and young people who are living in NSW. This study will help us to understand why Aboriginal adults are more likely to develop kidney and heart disease than non-Aboriginal adults. It may also tell us how we can prevent or delay this from happening.

### **Who is doing the study?**

The ARDAC Study is directed by the Centre for Kidney Research at the Children's Hospital at Westmead. The Centre for Kidney Research is working toward improving kidney health and the care of patients with kidney disease.

### **What will I have to do if I take part?**

If you decide to participate in the ARDAC study we will ask you to take part in a screening to check your kidney and heart health. This screening will measure your height, weight, blood pressure, waist and test a sample of urine. The screening takes about 5 minutes and will be done privately at your school, home or health service. There are no blood tests and none of the measurements are painful. There will be two study nurses who will do your screening. We would like you to be screened every two years.

Study participants will be asked to complete a questionnaire. This questionnaire will ask participants to answer questions about their own health, family history of health problems, education and access to health care. The questionnaire should take about 10 minutes to complete.

Participants will also be asked to give permission to link their screening results to routinely collected health data which is called data linkage.

### **Do I have to take part in the research?**

No you don't. If you say no, that is ok. It is up to you. You can take part at the beginning and change your mind later on. You may also choose to participate in all or part of the research (screening, questionnaire and data linkage).

### **Will anyone hear about what I tell you?**

Your results will remain confidential at all times and no-one else will be given screening results unless you request so. We may provide Aboriginal Education Officers, Aboriginal Health Workers or health services working in your community with your name so they can help us find you for screening visits. We will not be requesting any details about your health from them – this will remain confidential.

### **What is data linkage?**

An important part of the ARDAC study is observing your health over time. With your permission we will link information from your screening results and questionnaire with routinely collected health data. We would like to know information from when study participants were babies, and also about their mother's health during pregnancy to see if they affect the risk of kidney and heart disease. In the future, we would also like to be able to track whether they have developed kidney failure, heart disease or have unexpectedly passed away.

This is called data linkage and we wish to link data to the NSW admitted patient data collection, NSW birth deaths and marriages, NSW perinatal data collection and the Australian and New Zealand Dialysis and Transplantation registry (ANZDATA). We do not send screening results to the government.

There is a small risk to your privacy because personal information is used in the record linkage process. This risk is minimised by separating the processes of record linkage and data analysis. All safety measures have been put in place to ensure that your confidentiality is maintained.

Participation in data linkage is optional and you will be asked to give your permission on the participant consent form. Data linkage will happen when you are enrolled and then further linkage happens every two years until after the end of the study in 2020.

### **What if you find something wrong when you check me?**

If the screening shows any worrying results we will send a letter explaining the results and ask you or your parent/guardian to make a follow up appointment with your family doctor. With your permission the results can be sent to your doctor, Aboriginal Medical Service or other health provider that you have named on your consent form. If the results are urgent, the study doctor or nurse will contact you by phone.

### **Is there anything that might make me upset if I take part in the research?**

If anything you talk about during the research does make you upset you can stop the research. Your parents/carers will be told and you will be given the names of people you can talk to about what is making you upset, if that is what you want to do. The researcher can help you do that.