NSW Youth Health Access Survey
ADULT, PARENT & CARER INFORMATION STATEMENT

1. What is this study about?
Young people aged 12 to 24 living in NSW are invited to take part in a research study about how young people access health services and find their way around the NSW Health system. The study will tell us more about how services can make it easier for young people to find the help they need when they need it.

This Participant Information Statement tells you about the research study. Knowing what is involved will help you and young people take part in the research. Please read this sheet carefully and ask questions about anything that you don’t understand or want to know more about. Participation in this research study is voluntary.

2. Who is running the study?
The study is being carried out by the following researchers:

- Dr Melissa Kang, Department of General Practice, University of Sydney
- Fiona Robards, Department of General Practice, University of Sydney
- Professor Tim Usherwood, Department of General Practice, University of Sydney
- Professor Kate Steinbeck, Academic Department of Adolescent Medicine University of Sydney
- Associate Professor Lena Sanci, Department of General Practice, University of Melbourne
- Professor Stephen Jan, The George Institute, University of Sydney
- Associate Professor Catherine Hawke, School of Rural Health, University of Sydney
- Dr Marlene Kong, The Kirby Institute, University of New South Wales

Fiona Robards is conducting this study as the basis for the degree of Doctor of Philosophy (PhD) at The University of Sydney. This will take place under the supervision of Dr Melissa Kang.

The study is funded by NSW Kids and Families, NSW Health.

3. What will the study involve?
To participate in the study young people need to go to the survey website, open the survey and complete their answers. The survey asks about:

- Themselves, where they live and their cultural background
- Their digital media use
- Their perceptions and experiences of accessing healthcare
- Any health problems they may be experiencing

Young people can ask their parent to help them complete the survey if they want to.

At the end of the survey young people will be invited to enter a prize draw. In order to receive the prize, the young person will need to provide their contact details. If the young person does not wish to go into the draw they do not need to provide any contact details.

At the end of the survey your young person will also be invited to be contacted about another study, which involves being interviewed about their experience accessing healthcare. It’s completely up to
you and your young person if they are willing to be contacted. Being contacted does not commit them to participating in the second study.

If needed, interpreters can be used by workers to facilitate young people answering the survey.

4. **How much time will the study take?**
The survey will take about 20 minutes to complete.

5. **Who can take part in the study?**
The study is open to young people aged between 12 and 24 years old who live in NSW.

The researchers are keen to include young people from a diverse range of backgrounds, including:
- Aboriginal and/or Torres Strait Islander
- Refugee and asylum seekers
- Young people living in rural and remote areas
- Young people who are homeless or not living anywhere permanently
- Young people who are sexuality and gender diverse

The reason these groups have been chosen is because they may have unique healthcare needs, which are not currently well known.

6. **Does my young person have to be in the study? Can they withdraw from the study once they’ve started?**
Being in this study is completely voluntary. Young people do not have to take part. Your/their decision to participate will not affect your/their relationship with the researchers or anyone else at the University of Sydney now or in the future.

If young people decide to take part in the study and then change their mind later (or they no longer wish to take part), they are free to withdraw from the study at any time. Young people or parents can let us know by emailing fiona.robards@sydney.edu.au.

Your young person is free to stop the survey at any time.

7. **Are there any risks or costs associated with being in the study?**
The survey will involve young people talking about their experience of accessing healthcare. If this causes any distress young people are provided with a list of services they can contact.

8. **Are there any benefits associated with being in the study?**
By participating in the survey young people will be helping us do our research. This study will help health services know how they can be better at helping young people access health care.

To show appreciation for young person’s time they will have the opportunity to enter a draw to receive on of 20 vouchers valued at $50 each. Young people can choose between a JB Hi-Fi gift card, movie tickets, Myer or Dymocks voucher.

9. **What will happen to information that is collected during the study?**
The survey will be conducted online, and is confidential. We won’t tell anyone else what a young person says, except if they talk about a threat to their own or another’s safety. Under these circumstances, we will be required by law to act on this to keep the young person and other people safe.
The survey will be analysed for broad level findings. Publications may directly quote young people’s words but will not include any identifying details. The study results may be published in journals, reports, books or via conference presentations.

The data will be stored electronically on a secure server by the Department of General Practice and will be password protected and will only be accessed by the researchers. The data will be kept for a minimum of 5 years or until all participants are 25 years old.

Personal information will only be used for the purposes outlined in this Participant Information Statement, unless you consent otherwise.

10. Can I or my young person tell other people about the study?
Yes, you are welcome to tell other people about the study.

11. What if we would like further information about the study?
When you have read this information, Melissa Kang and Fiona Robards will be available to discuss it with you further and answer any questions you may have. If parents, carers or young people would like to know more at any stage during the study, please feel free to contact Fiona Robards, Senior Research Officer on phone 9845 9214.

12. Will we be told the results of the study?
Feedback about the overall results of this study will be in the form of a brief easy to read summary will be available on the survey website: http://sydney.edu.au/medicine/general-practice/access. You will not receive feedback about any young person’s personal situation or experiences.

13. What if we have a complaint or any concerns about the study?
Research involving humans in Australia is reviewed by an independent group of people called a Human Research Ethics Committee (HREC). The ethical aspects of this study have been approved by the HREC of the University of Sydney [protocol number 2015/874]. As part of this process, we have agreed to carry out the study according to the National Statement on Ethical Conduct in Human Research (2007). This statement has been developed to protect people who agree to take part in research studies.

If you (as a parent, carer or young person) are concerned about the way this study is being conducted or wish to make a complaint to someone independent from the study, please contact the university using the details outlined below. Please quote the study title and protocol number.

The Manager, Ethics Administration, University of Sydney:
- Telephone: +61 2 8627 8176
- Email: ro.humanethics@sydney.edu.au
- Fax: +61 2 8627 8177 (Facsimile)

You can also write to the Chairperson, AH&MRC Ethics Committee, Aboriginal Health & Medical Research Council of NSW, PO Box 1565, Strawberry Hills, NSW 2012.

This information sheet is for you to keep.