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Participant Information Statement

Mothers and their Children's Health study (MatCH)

You are invited to join the **MatCH study**. We need your help to find out about teenagers' health and wellbeing, so we can help improve services, policies and programs that affect the lives of young people in Australia.

Before you decide to join our study, it's important you understand why we are doing it and what we are asking you to do. Please take some time to read through this information and discuss it with someone else, if you want to.

Why have I been invited to join the study?

Your mum is part of the Women's Health Australia project and has been completing surveys for 28 years! About 8 years ago, we asked her to complete a survey about her children. Now, we are asking you to tell us how you are going. This next survey is called **MatCH 2**.

We would like you to join MatCH 2 so we can hear about the experiences of teenagers and what it is like to be a teenager growing up in Australia. We are asking older kids and young adults aged 13-19 years to complete their own surveys.

What will I be asked to do?

- If you agree to be in the study, you will be asked to do a 20–30-minute online survey about your health. We would like to do this once every 2-3 years, but you don't have to say yes to future surveys, you can do this survey now, and decide later if you want to keep doing more.
- You will also be asked to let us use your immunisation and other health records from when you take medication, go to a doctor, or go to hospital. This lets us get a bigger picture of how you are going, without asking you more questions.

Who is running the study?

This study is being run by Women's Health Australia who have researchers at The University of Queensland and the University of Newcastle. The project is funded by the Australian Government Department of Health and Aged Care.

Why should I take part?

By taking part in this study, you are helping us gather important information to improve the health and wellbeing of teenagers and their families in the future. The findings from this study will help us find ways to help young people access existing health services or identify new

services that are needed. The findings can also guide the development of new programs, resources and services.

Do I have to take part in MatCH 2?

Your mother has agreed for us to invite you to join the study, but you can still say “**No**”. Your participation in MatCH 2 is completely voluntary and there will be no cost to you. If you don't want to take part in this study, you don't have to. Your mother will not be told if you don't choose to take part and will also not be told if you do choose to take part in the survey. However, she may learn of your decision if she has access to your emails or other ways that we might get in touch with you. Choosing not to take part in MatCH 2 will not affect your current or future medical care in any way. You can let us know your decision if you click on the link to the survey in the email we sent you.

What are the benefits of taking part?

We can't promise you any personal benefit from taking part in the study. Those who complete the survey will receive a **Prezzy Smart eGift card** sent to your email as a thank you. As the questions are specific to you, such as your age or sex, some people will see more questions than others. This means that the amount you receive on your gift card will depend on how many questions we ask you. Whether or not you decide to link your data will not affect us giving you a gift card for completing the survey. You will receive \$20-\$30 for your time.

What are the risks of taking part?

Some of the questions we ask are a bit personal. We ask you about your diet, exercise, your feelings, any health problems you might have and about how your body is developing as you get older (puberty). Older people (aged 16 and over) will also get asked some questions about topics such as sex and contraception. There is a small risk that you might find that a question makes you feel uncomfortable or upsetting. You do not have to answer any question that you do not want to answer or feel uncomfortable answering. You can skip questions without giving a reason. You can also stop the survey and go and talk to someone you trust. You can contact the following support services should you wish to seek support regarding any of the issues raised within the survey:

- Kids Helpline provides 24-hour crisis support by calling 1800 55 1800. Kids Helpline online chat is available 24 hours a day, 7 days a week through the following website: <https://kidshelpline.com.au/get-help/webchat-counselling>
- Youth Beyond Blue provides mental health support through calling 1300 224 636. They also offer an online chat on the following website: <https://online.beyondblue.org.au/#/chat/start>

You can always come back to the survey later if you want to.

What will happen to my information?

It will be stored securely at the University of Newcastle and The University Queensland. Your survey answers will be separated from your personal details. Your personal details will not be passed on to anyone (including your parents).

Will my mum see my survey answers?

We won't pass on anything from your survey to anyone else unless we are required to by law. Your survey links are sent via email to the email address provided to us. Links for surveys that

have been started but not finished may also be sent to the email address provided for you. Only the person who clicks this link in your email will have access to your survey responses. Once the survey is completed, it cannot be accessed in this way.

What do I need to do to participate?

Please make sure that you have read this information statement and that you understand what this study is about and what we are asking you to do. If you decide you want to do the study, click on the link in your email. Before you begin, we will ask you to agree/consent to participate in the study. You don't have to do the whole survey at once, you can save it and finish it later.

We will also ask you to consent to our researchers accessing your linked health records. You can complete the survey without letting us link your health records and you can also consent to us linking your health records without completing the survey. It's your choice. You don't need to answer every question in the survey. If you don't like the question, you can leave it blank and move on.

What is data linkage?

Data linkage is where we join together data that has already been collected through different sources. There are 2 data sources we are asking your permission to link:

1. Services Australia data: Medicare (MBS - Medicare Benefits Schedule), PBS (Pharmaceutical Benefits Scheme) and Australian Immunisation Register (AIR).
2. Hospital data: Hospital admissions and Emergency Department visits.

How do I consent to data linkage?

If you consent to the researchers accessing and using your data from health databases, you will be asked to sign a consent form. This consent form will authorise the study to access your complete Medicare Benefits Schedule (MBS), and/or Pharmaceutical Benefits Scheme (PBS), and/or Australian Immunisation Register (AIR) data from Services Australia. Medicare collects information on your doctors' visits and the associated costs, while the PBS collects information on the prescription medications filled for you at pharmacies. The Australian Immunisation Register is a national register that records vaccines given to people of all ages in Australia.

Your personal information within the consent form will be sent securely to Services Australia to authorise the release of your MBS, PBS, and/or AIR information to the study. Services Australia will retain the consent form for the life of the study as a record of consent. A copy of the consent form will also be retained by the study for the life of the study. Your MBS, PBS, and/or AIR information will be de-identified and stored securely by the study on servers, or hosted through cloud computing providers, physically located within Australian borders. Your MBS, PBS, and/or AIR information will not be sent outside of Australian jurisdiction and is governed by the Privacy Act 1988.

Your MBS, PBS, and/or AIR information that has been included in de-identified databases will be destroyed after the final publication of the study. As this is a longitudinal study, there is currently no end date for the study.

However, if you withdraw from the study, you can request the destruction of your MBS, PBS, and/or AIR information, provided it has not previously been provided to researchers or policy makers (see 'Can I change my mind'). All information will be securely destroyed at the completion of the study in a manner appropriate to the security classification of the record content.

Power of Attorney, Guardianship and Administration Orders provide people the legal authority to act on behalf of someone else. If you are unable to provide consent for yourself, Power of Attorney, Guardianship, or Administration Order may be accepted. Services Australia will only accept a certified copy of an original Power of Attorney (Enduring or Medical), Guardianship, or Administration order. Services Australia cannot provide the study information without supplied evidence. Statutory declarations will not be accepted.

Services Australia has confirmed that this research and any associated documents have been approved by a Human Research Ethics Committee (HREC) that is registered with the National Health and Medical Research Council (NHMRC) and operates within guidelines set out by the NHMRC.

If you have two separate Medicare cards, you must provide consent for both cards. The consent form must include both Medicare card numbers for the two cards.

Within this consent form, you will also be able to authorise the study to access your hospital, and emergency department data. This linkage will be conducted by State-based Data Linkage Units where your data will remain secure at all times.

The study is bound by Commonwealth and State privacy laws and must protect the confidentiality of your information to the fullest extent possible.

If you have a privacy complaint in relation to the use of your MBS/PBS/AIR information, you should contact the Office of the Australian Information Commissioner. You will be able to lodge a complaint with them.

Website: www.oaic.gov.au

Telephone: 1300 363 992

Email: enquiries@oaic.gov.au

Mail: GPO Box 5218, Sydney NSW 2001

Your personal information Services Australia hold is protected by the Privacy Act 1988 and cannot be given to a third party without your consent or where otherwise permitted by law. For more information about privacy, go to servicesaustralia.gov.au/privacy

Can I change my mind?

Yes, you can change your mind at any time. If you decide you don't want to be in the study anymore, please ring Women's Health Australia on 1800 068 081. It's a freecall. You can also email us at info@alswh.org.au to let us know.

You are under no obligation to continue with the consented release of your MBS, PBS, or AIR information. You may change your mind at any time about releasing this information to the study. People withdraw from studies for various reasons and you do not need to provide a reason. You can withdraw your consent to release your MBS, PBS, or AIR information by completing and signing the '**Services Australia Participant Withdrawal Form**'. You can access this form [here](#). You must supply this form to the research team, if you choose to withdraw your consent at a later date. If you withdraw your consent to release your information to the study, you will be able to choose whether the study will destroy or retain the MBS, PBS, or AIR information it has collected about you. You should only choose **one** of these options. Where both boxes are ticked in error or neither box is ticked, the study will destroy all information it has collected about you.

If you wish to withdraw your consented release of your hospital or emergency department data, please contact Women's Health Australia on 1800 068 081 (Freecall) or email alswh@newcastle.edu.au or info@alswh.org.au.

Please note that data about you that has already been analysed and/or included in a publication by the study will not be able to be destroyed. In such circumstances, your personal information will continue to form part of the project study records and results. Your privacy will continue to be protected at all times.

Where can I get more information?

If there is anything you don't understand, or if you have questions, please contact Women's Health Australia on 1800 068 081 (Freecall) or email alswh@newcastle.edu.au

Thank you for considering this invitation.

Professor Gita Mishra
Women's Health Australia Director,
The University of Queensland

Professor Deborah Loxton
Women's Health Australia Director,
University of Newcastle

This project has been approved by the University of Newcastle and the University of Queensland's Human Research Ethics Committees, Approval H-2014-0246 (University of Newcastle) and 2014/HE001213 (The University of Queensland).

Concerns about this research

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 the Human Research Ethics Officer, Research and Innovation Services, The University of Newcastle, University Drive, Callaghan NSW 2308, Australia, telephone (02) 4021 6333, email Human-Ethics@newcastle.edu.au.