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Participant Information Statement

Mothers and their Children's Health study (MatCH)

The **Mothers and their Children's Health study (MatCH)** seeks to understand how maternal and lifestyle factors influence the health, development and wellbeing of children. MatCH is a substudy of the Australian Longitudinal Study on Women's Health (ALSWH) run by Women's Health Australia and is funded by the Australian Government Department of Health and Aged Care. ALSWH surveys women every few years to understand their health, and how this changes over time.

The MatCH study asks mothers of children aged 0-12 years to complete a survey about their child's health and development. For adolescent aged 13-19, they are asked to complete a survey themselves.

As part of this study, we are asking parents' permission to link their child's health records with survey data. You have been contacted because the mother of your child (identified in the email you received) is participating in the MatCH study. Your child's mother has given her consent for us to contact you about linking your child's health records.

What am I being asked to do?

We are asking for your consent for your child's health records from Services Australia, which are linked to your Medicare card, to be shared with the study. This includes records from the Medicare Benefits Schedule (MBS), Pharmaceutical Benefits Scheme (PBS), and the Australian Immunisation Register (AIR).

The consent form will authorise the study to access your child's Medicare Benefits Schedule (MBS), and/or Pharmaceutical Benefits Scheme (PBS), and/or Australian Immunisation Register (AIR) data linked to your Medicare card from Services Australia. Medicare collects information on your child's doctors' visits and the associated costs, while the PBS collects information on the prescription medications filled for your child at pharmacies. The Australian Immunisation Register is a national register that records vaccines given to people of all ages in Australia.

Why do you need my consent?

As MatCH is asking to access health records for children under the age of 14 years, a parent must provide consent. As your child is on two separate Medicare cards, both primary card holders must provide consent. If only one parent/carer has provided consent, Services Australia will only provide data that is related to the consenting parent/carer. To help us get a complete picture of your child's health, it's important for the study to access your child's health records linked to both Medicare cards. ONLY records for your child named in the email will be shared with this study, NOT your own records, nor those of anyone else on your card.

If a child turns 14 years of age during the recruitment process, the child will be required to complete and sign a separate consent form.

How do I consent?

If you agree, please follow the link in the email invitation we sent you and fill out the short online form to let us know whether you consent to your child's records linked to your Medicare card being shared with our study. If you have more than one child in the study, you will receive a separate email for each child. You need to complete a form for each child.

Do I have to share my child's Services Australia health records?

No, it is your choice. Sharing your child's health records from Services Australia is completely voluntary and there will be no cost to you or your child. If you do not want to consent to the release of your child's information, you do not have to. You should feel under no obligation to consent to the study. Choosing not to share your child's record with MatCH will not affect your or your child's current or future medical care or their participation in this study in any way.

What are the possible benefits and risks of taking part?

We can't promise any personal benefit to you or your child if you consent to share their Services Australia health records. However, your contributions will help us to deliver detailed, up-to-date evidence and recommendations that are needed to enable a more tailored, collaborative, and integrated approach to healthcare for women and children.

How will my child's information be used?

Your child's records will be linked with survey data collected from their mother as part of MatCH. Data from all participants will be pooled and analysed to examine issues related to childhood healthcare, and women and children's health. The findings from the study may be reported in publications in scientific journals, reports to the Department of Health and Aged Care and in conference presentations and seminars. Individual participants will not be identified in any reports, publications, or presentations arising from MatCH.

Data will be securely stored and may be made available for future research. All researchers who wish to use MatCH data will need to apply to the Australian Longitudinal Study on Women's Health Data Access Committee and agree to their terms and conditions for use of the data.

How can I withdraw my child's Services Australia health records from MatCH?

You are under no obligation to continue with the consented release of your child's Medicare Benefits Schedule (MBS), Pharmaceutical Benefits Scheme (PBS), or Australian Immunisation Register AIR information linked to your Medicare card. You may change your mind at any time. People withdraw from studies for various reasons, and you do not need to provide a reason.

You can withdraw your consent to release your child's MBS, PBS, or Australian Immunisation Register (AIR) information linked to your Medicare card by completing and signing the '[Services Australia Parent /Guardian Withdrawal of Consent Form](#)' and sending it to Women's Health Australia by email alswh@newcastle.edu.au or call on 1800 068 081 (freecall). You can access this form here. You must supply this form to the Women's Health Australia research team, if you choose to withdraw your consent for the release of your child's MBS, PBS, or AIR information. If you withdraw your consent to release your child's 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 your child. 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 health record information it has received about your child.

If you do withdraw your consent from the study and your child's health record information has already been analysed and/or included in a publication, your child's health record information will not be able to be withdrawn. In such circumstances, your child's health record information will continue to form part of the project study records and results. Your child's privacy will continue to be protected at all times.

How will my child's privacy be protected?

We have strict procedures to protect the privacy of your child. All personal information collected remains confidential in accordance with the National Health and Medical Research Council ethical guidelines and the Australian 1988 Privacy Act. Your child's personal identifying information will be securely stored separately from survey answers and linked data from health databases. This information will be stored on servers, or hosted through cloud computing providers, physically located within Australian borders. MatCH is bound by Commonwealth and State privacy laws and must protect you and your child's anonymity and the confidentiality of your information to the fullest extent possible.

Your child's personal identifying information within the consent form will be sent securely to Services Australia to authorise the release of your child's Medicare Benefits Schedule (MBS), Pharmaceutical Benefits Scheme (PBS), and/or Australian Immunisation Register (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 child's 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 child's MBS, PBS, and/or AIR information will not be sent outside of Australian jurisdiction and is governed by the Privacy Act 1988.

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

However, you can request the destruction of your child's MBS, PBS, and/or AIR information, provided it has not previously been provided to researchers or policy makers (see above 'How can I withdraw my child's Services Australia health records from MatCH?'). All information will be securely destroyed at the completion of the study in a manner appropriate to the security classification of the record content.

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.

Have concerns?

If you have a privacy complaint in relation to the use of your child's 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

Email: enquiries@oaic.gov.au

Telephone: 1300 363 992

Mail: GPO Box 5218, Sydney NSW 2001

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

Should you have concerns about your child's 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.

Where can I get more information?

If you would like further information, please see our [Data Linkage FAQs](#) or contact the Women's Health Australia team via email (alswh@newcastle.edu.au) or phone (1800 068 081).

Thank you for considering this invitation.

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