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Participant Information Statement

Mothers and their Children's Health study (MatCH 2)

You are invited to take part in the second survey of the **Mothers and their Children's Health study (MatCH 2)** being conducted by the Women's Health Australia team. You may have completed the first MatCH survey in 2016 or you could be receiving this information for the first time.

Before you decide whether you would like to participate, it's important to understand why the research is being conducted and what it involves. Please take the time to read the following information carefully and discuss it with others, if you wish.

Why have you been invited to join the study?

You have been a member of the Women's Health Australia project since 1996 – thank you! We have collected a wealth of data about Australian women. We would now like to find out more about you and your children, particularly about their health and healthcare experiences.

Who can participate in MatCH 2?

You are eligible to take part in MatCH 2 if you are a member of the 1973-78 cohort and have at least one biological child aged 0-12 years or have a teenager aged 13-19 years of age.

Why are we doing the research?

Mothers and their children's health is closely linked. This study will help us understand how the health of one generation influences the next as well as understanding the important health and healthcare experiences of children and adolescents growing up in Australia today.

Who is running MatCH 2?

MatCH 2 is being run by the Women's Health Australia team at The University of Queensland and the University of Newcastle. The project is funded by the Australian Government Department of Health and Aged Care.

What will you be asked to do?

- If you agree to participate, you'll be asked to complete an online survey for any child/ren you have aged 0-12 years old. The survey will take around 20-30 minutes to complete for each child. You will only see questions that are relevant to you and your child/ren, so some women may complete more questions than others depending on their circumstances. You will be asked to complete questions related to your child's physical and social development, diet, physical activity and health problems. You don't have to complete the survey all at once. You can save your answers and return to the survey up until the survey closes.

- If you have a teenage child aged 13-19 years old, you will be asked to provide consent for us to contact your child/ren via email (you can opt to add your own email address if you prefer). Your teenage child/ren will then be invited to complete their own survey and will be directed to the Teen Participant Information Statement so they can decide whether to take part. A copy of the teen Participant Information Statement can be viewed [here](#). If they decide to take part, they will then be given their own participant identification number once they start the survey.
- The teen survey will cover topics relevant to their lives including school/work, health problems, healthcare use, mental health, diet, physical activity and body development (including puberty). Please note, your child will only see questions relevant to their personal circumstances and age, with more sensitive topics such as sexual activity being asked only of those aged 16 and over. If your teen completes a survey, their answers will remain private and cannot be shared with you.
- You will also be asked whether researchers can access and use your child/ren's data from the Medicare Benefits Schedule (MBS), Pharmaceutical Benefits Scheme (PBS), Australian Immunisation Register (AIR), Australian Early Development Census (AEDC), National Assessment Plan (NAPLAN) and other health databases. You can still participate in MatCH 2 if you don't consent to the researchers accessing your child/ren's data from these databases. Alternatively, you can consent to the researcher's accessing these databases without consenting to complete the MatCH 2 surveys. The choice is yours.
- We intend to repeat these survey every 2-3 years (subject to ongoing funding) and to update external linked datasets annually so we can see how children and adolescent health and healthcare experiences change over time.

Do you have to take part in this research study?

No. Your participation in MatCH 2 and that of your child is completely voluntary and there will be no cost to you or your child. If you do not want to take part in this study, you do not have to. Choosing not to take part in MatCH 2 will not affect your or your child's current or future medical care in any way. Your participation in Women's Health Australia will not be affected by whether you decide to take part in MatCH 2. If you consent to linkage of your teenage child's health data, they still have the right to decide whether they want to consent.

Withdrawing yourself and/or your child from MatCH 2

You are under no obligation to continue with MatCH 2. You may change your mind at any time about participating in the project. People withdraw from studies for various reasons, and you don't need to provide a reason. If you decide to withdraw yourself and/or your child from MatCH 2, please contact Women's Health Australia on 1800 068 081 (freecall) or email: alswh@newcastle.edu.au.

You are under no obligation to continue with the consented release of your child's MBS, PBS, or AIR information. You may change your mind at any time about releasing this information to the study. You can withdraw your consent to release your child's MBS, PBS, or AIR information by completing and signing the '**Services Australia Child Study Withdrawal Form**'. 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 later. 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 information it has collected about your child.

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

Please note that data about you and/or your child 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.

What are the possible benefits and risks of taking part?

We can't promise you any further personal benefit from participating in this research. 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 their children.

If you complete the MatCH 2 survey for your child/ren aged under 13 years, you will receive a **Prezzy Smart eGift card** via email as a thank you. Likewise, if you have a teenage child and they complete the teen survey, they will receive a **Prezzy Smart eGift card** via email. As questions are personalised based on your specific circumstances, the value of the gift card will vary depending on the number of questions asked. You will receive \$20-\$30 for your time.

There are some potential risks associated with this project. Some of the questions are a bit personal. We ask about your child/ren's diet, physical activity, feelings, health problems, family relationships and your home. There's a slight risk that you may find a question uncomfortable or upsetting. You do not have to answer any question that you do not want to answer or feel uncomfortable answering. It is important to note that there are no right or wrong answers however if you start to feel uncomfortable or upset at any time, you can choose to end the survey (with the option of returning later, if you want to). You can also choose to skip questions that you are uncomfortable answering. You can contact the following support services should you wish to seek support regarding any of the issues raised within the survey:

- Lifeline provides 24-hour crisis support by calling 13 11 14. Lifeline online chat is available from 7pm to midnight AEST through the following website: <https://www.lifeline.org.au/crisis-chat/>
- 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>
- 1800RESPECT provides 24-hour confidential information, counselling and support services for people impacted by sexual assault, domestic or family violence and abuse, by calling 1800 737 732. An online chat can be accessed at any time through the following website: <https://www.1800respect.org.au>

How will your information be used?

The survey data collected in MatCH 2 and your child/ren's linked data from health databases (if you consent to these being used) will be linked with the other data held by Women's Health Australia. 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 and in conference presentations and seminars. A summary of results will be made available in the annual participant newsletter for Women's Health Australia. Individual participants will not be identified in any reports, publications, or presentations arising from MatCH 2.

As with your regular Women's Health Australia data, your MatCH 2 data will be securely stored and may be made available for future research. All researchers who wish to use Women's Health Australia data, including MatCH 2 data, will need to apply to the Australian Longitudinal Study on Women's Health (ALSWH) Data Access Committee and agree to their terms and conditions for use of the data.

How will your privacy be protected? Storage, retention and destruction of your information

We have strict procedures to protect your privacy and that of your child/ren. This also applies to external record linkage.

- All personal and survey information collected remains confidential in accordance with the National Health and Medical Research Council ethical guidelines and the Australian 1988 Privacy Act. Your personal information will be securely stored separately from your survey answers and linked data from health databases on servers, or hosted through cloud computing providers, physically located within Australian borders. These locations will be isolated from the internet by firewalls.
- Access to any identifiable data (such as names and contact details) will be restricted to members of the research team and those outlined in this information statement (including those involved in verifying your data in the linkage process), unless you have consented otherwise; or disclosure is required by law in order for us to comply with our regulatory obligations. Furthermore, access to identifiable data requires user authentication for logging into the databases with a username/password combination. All database edits and data entries completed by each user are logged in the database's audit trail. Researchers conducting analyses do not have access to personal information.
- The survey will be completed online through REDCap (Research Electronic Data Capture), a secure web-based database system. REDCap is a purpose-built software application for the conduct and management of medical research surveys and case report forms for clinical trials. The REDCap application is hosted within Australian borders on Hunter Medical Research Institute secure servers, which are both physically and virtually secured. User authentication is required for logging into REDCap. All database edits and data entries completed by each user (including REDCap Administrators) are logged in the project's audit trail.
- The de-identified survey data captured from the online survey will be stored in the research database, separately from participant contact information. For extra privacy protection, different ID numbers will be assigned to these two databases, with the key between the two sets of IDs limited to a small number of staff. Click [here](#) to see the way this works. Copies of de-identified survey datasets are also archived electronically at the Australian Data Archive (a national repository for the curation of research data assets).
- Due to the ongoing nature of the study, the data will be securely retained for at least five years after the study finishes, and stored in accordance with the University of Newcastle's Research Data and Materials Management Guideline (<https://policies.newcastle.edu.au/document/view-current.php?id=72>) or any successor Guideline, The University of Queensland Policy and Procedures (including: [1.60.02 Privacy Management](#), [4.20.06 Research Data Management](#), and [6.40.01 Information Management](#)), and applicable University of Newcastle policy provisions (as amended from

time to time). After the closure of the study and the mandatory retention period, all personally identifying information (such as names, dates of birth and contact details) will be securely destroyed.

- De-identified survey data will continue to be maintained in the Australian Data Archive. Arrangements will also be made at this time about the linked health record data provided to us, for the duration of the study, by national and state governments. At the discretion of the agency which provided the data, it will either be included in the non-identifiable archive, or securely destroyed.

What do you need to do to participate?

Please make sure that you have read this information statement and that you understand its contents before you consent to participate.

To participate, please click on the survey link in your email invitation. Before you begin the survey, you will be provided with a list of your children's dates of birth and asked to check them for accuracy. You will then be asked whether you consent to participate in MatCH 2 and whether you give consent for any of your teenage children to be invited. Finally, depending on your child's age, you will be asked whether you consent to researchers accessing and using your child/ren's data from health and education databases.

Consenting to data linkage for your child

If you consent to the researchers accessing and using your child/ren's data from health and education databases, you will be asked to sign a consent form. Depending on your child's age, they may also need to give their consent.

- Services Australia data: If your child is under 14 years old, you need to complete a consent form for us to access this data. If they are 14 years or older, only your child can give consent - your child will need to complete a consent form.
- Hospital data: If your child is under 14 years old, you need to complete a consent form for us to access this data. If they are 14 years or older, you AND your child need to complete a consent form.
- Education data: If your child is under 18 years old, you will need to give consent for us to access this data. Your child does not need to sign a consent form.

For children aged 13 years and over who complete the survey themselves, we will ask for their assent to access their health data as well.

This consent form will authorise the study to access your child's 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 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.

Your child's personal information within the consent form will be sent securely to Services Australia to authorise the release of your child's 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 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. 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 child's MBS, PBS, and/or AIR information, provided it has not previously been provided to researchers or policy makers (see 'Withdrawing yourself and/or your child from MatCH 2'). 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 or you are consenting for someone over the age of 14 years, 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.

As our study is asking for consent for external data linkage for children under the age of 14 years, you as the parent must provide consent for your child. If your child is on two separate Medicare cards, both primary card holders must provide consent. The consent form must include both Medicare card numbers for the two cards the child is on and both parent's signatures. Services Australia will only provide data to the study in instances where the primary card holder of that card has consented.

Within this consent form, you will also be able to authorise the study to access your child's AEDC, NAPLAN, hospital, and emergency department data. The AEDC collects information about early childhood development at the time children commence their first year of full-time school, and occurs every 3 years. NAPLAN collects annual assessment data for students in Years 3, 5, 7, and 9. Linkage will be conducted by the Australian Institute of Health and Welfare for AEDC, and state-based Data Linkage Units for hospital, and emergency department data. Linkage for NAPLAN will be conducted by the relevant state education authority themselves, or by an external Accredited Integrating Authorities (as directed by the responsible data custodian). Linkage will be conducted by State-based Data Linkage Units for hospital, and emergency department data.

The study is bound by Commonwealth and State privacy laws and must protect the confidentiality of you and your child/ren's information to the fullest extent possible.

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

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

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

Where can I get more information?

If you would like further information, please see our [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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The University of Queensland

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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 (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.