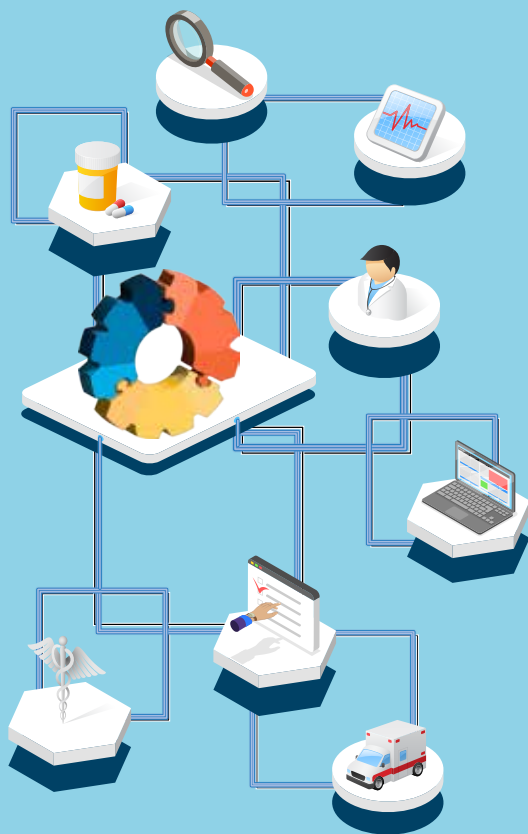


Ten to Men: The Australian Longitudinal Study on Male Health

Data Linkage



What is data linkage?

Data linkage brings together information from several data sources to produce a more complete picture of what has been happening in your life. Linking your responses with existing data also means we can make the survey shorter because we can ask fewer questions and save time for you.

Linked data improves and adds to *Ten to Men* survey data. When your survey data is linked with government data, such as Medicare, Centrelink, and death registers, it is better able to help improve health and healthcare services. These records provide administrative and classification information on health events, medical conditions, treatments and medications, and welfare data, such as Centrelink payments received, and the types of health services you have used. This wider perspective allows us to examine your entire journey through the health system, finding answers which we could not get from survey data alone. For example, when government data is combined with demographic, social and health information in *Ten to Men*:

- Researchers can determine how men's access to health services is affected by where you live by putting Medicare data together with survey data. This means they can investigate why some people might not access health services and treatments available.
- Information about prescription medicine subsidised by the Australian Government allows researchers to understand how many prescriptions and the type of medicines have been filled over an individual's lifetime. This means researchers can examine associations between specific medicines and health conditions amongst Australian men.
- Information on parenting payments obtained from Centrelink can be used to examine the impact of payments. This helps us understand whether policies such as welfare payments are addressing intergenerational disadvantage.

To learn more about why data linkage is important and how it supports the study, you can watch this short video at aifs.gov.au/about/our-services/data-linkage/study-participants



What data is being linked?

The *Ten to Men* study asks about a range of topics including education, employment, and wellbeing. To enhance this information, we are seeking permission to link:

- Medical Benefits Scheme (MBS)
- Pharmaceutical Benefits Scheme (PBS)
- National Death Index (NDI) – Cause of Death
- Centrelink data

If you have already consented to certain linkages in past waves of the study, we will not ask you to consent again. We will only ask you to consent to linkages you have not consented to before.

Your privacy is a priority. Records provided to the *Ten to Men* study are subject to strict privacy policies and procedures and confidentiality regulations. A digital copy of the privacy and confidentiality brochure is available on our website: aifs.gov.au/tentomen/participants/privacy.

Linking your Medicare (MBS) and Prescription (PBS) data

Linking MBS and PBS data to your *Ten to Men* survey responses has the potential to strengthen the impact of *Ten to Men*. This is good for both you and the research and policy community to help understand the health and health care service needs of Australian males and how they might be improved in the future. This also means that researchers and policy makers have strong evidence for better health policy.

We will be asking your permission to link your survey data to MBS and PBS data. Medicare collects information on your medical visits and procedures and the associated costs. The PBS collects information on the prescription medication you have filled at pharmacies.

Linked data is used for **research purposes only** and will have **no impact on your Medicare or prescription services**.

Your contact details are removed **BEFORE** the Medicare or prescription records are attached to your *Ten to Men* survey responses. This means you **WON'T** be identified from the linked data.

Ten to Men data linkage works in **one direction only**. Medicare or prescription records are attached to the Ten to Men survey responses, but Ten to Men survey responses **WON'T be shared** with Medicare.

Linking National Death Index (NDI) data

Because data and cause of death are essential in the analysis of health outcomes, we are seeking your permission to link your Ten to Men data to the NDI – cause of death data.

Cause of death is usually the last relevant information that can be collected about a person's health. By combining information about date and cause of death with the extensive health and wellbeing data collected in Ten to Men throughout a man's life, we hope that our research will discover more about how men can live longer, healthier lives.

Linking your Centrelink data

In the past, it has been difficult to determine how changes to Centrelink payments impact on people's lives. The Government needs to understand whether and how Centrelink payments work for the people who receive them. By linking Ten to Men survey data with Centrelink data, researchers can study how and why payments do or don't help.

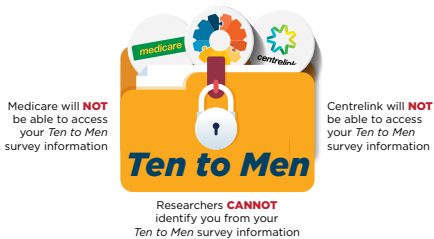
We are hoping that insights provided through data linkage from the Australian Department of Social Services can make better policies in relation to Centrelink payment.

We are asking you for permission to link your survey data to Centrelink data to better understand how these payments work (or don't work) for those who need them.

Linked data is used for **research purposes only** and will have **no impact on your Centrelink payments**.

Your contact details are removed **BEFORE** the Centrelink records are attached to your Ten to Men survey responses. This means you **WON'T** be identified from the linked data.

Ten to Men data linkage works in **one direction only**. Centrelink records are attached to the Ten to Men survey responses, but Ten to Men survey responses **WON'T be shared** with Centrelink.



Do I have to give consent?

Providing consent for data linkage is voluntary. This means it is entirely your choice whether or not you allow your information to be linked with data from other sources.

Can I withdraw my consent?

You have the right to withdraw your consent to link your data at any time by calling 1800 019 606 or emailing info@tentomen.org.au

Any data linked before your withdrawal will continue to be used and form part of the Ten to Men study dataset.

If you withdraw from the Ten to Men study, we will continue to link to any data you have consented to until you specifically withdraw your consent from the linkage.

How is my privacy protected?

Your privacy is very important to us. Your personal information will be handled with the strictest confidence in accordance with the Privacy Act 1988 and the Australian Privacy Principles. A digital copy of the privacy and confidentiality brochure is available on our website: aifs.gov.au/tentomen/participants/privacy or via the QR code.



To ensure that your survey information is kept secure, we use strong encryption technology. This means that the information you send is not able to be read by anyone but those authorised to have access. To protect your stored data, multilevel password protection is used on all electronic storage systems.

Any data received for the study, including your linked Centrelink and/or MBS and/or PBS, and/or NDI and/or address details, is only ever used for research purposes and for maintaining contact with you for the purposes of the study. To ensure security and confidentiality, all survey information will be stored, analysed and reported on with your identifying details removed.

What will happen to my information?

Your personal information (such as your name, date of birth, address, Medicare number and Centrelink Customer Reference Number) will never be used together with your survey responses or linked data. Also, your survey answers will not be analysed on their own but will be combined with those of other participants and analysed as a group.

Your survey data will be securely stored for 7 years at the Australian Institute of Family Studies following the completion of the study. Consent forms will also be stored at the Australian Institute of Family Studies until 20 years after the completion of the study as per National Archives of Australia General Records Authority requirements (see General Records Authority 37 naa.gov.au). After this period, survey data and consent forms will be destroyed in a manner appropriate to the security classification of the record content. If the organisation responsible for future data collection phases of the study changes, the Australian Institute of Family Studies will be required to disclose your information to that organisation.

As Ten to Men has been determined as a nationally significant study, the de-identified research datasets will be stored at the National Archives at the completion of the study.

Further information on privacy in relation to the Ten to Men study can be found at: aifs.gov.au/tentomen/participants/privacy or by calling 1800 019 606.

Want more information?

If you would like more information on the Ten to Men study, please visit: aifs.gov.au/tentomen or call: 1800 019 606

Should you need some support or would like to talk to someone about your health, a range of referral and support services are listed at www.aifs.gov.au/tentomen/participants/services-list

Acknowledgement of Country

The Australian Institute of Family Studies acknowledge the Traditional Owners of Country throughout Australia and recognise their continuing connection to lands and waters. We pay our respect to Aboriginal and Torres Strait Islander cultures, and to Elders past and present.

Australian Government
Department of Health, Disability and Ageing

Australian Government
Australian Institute of Family Studies

Ten to Men has been approved by the Australian Institute of Family Studies Ethics Committee. The Ethics Committee ensures that the Ten to Men study meets the ethical standards outlined in the National Statement on Ethical Conduct in Research Involving Humans. If you have any ethical concerns with the conduct of the study, you may contact the AIFS Ethics Committee Secretariat at ethicssecretariat@aifs.gov.au

1800 019 606

info@tentomen.org.au

aifs.gov.au/tentomen

