

Information and Consent to allow Linkage of PATH data Medicare Benefits Schedule (MBS) and Pharmaceutical Benefit Scheme (PBS) data

You are being asked to complete this consent form authorising the PATH Through Life study to access to your Medicare Benefits Schedule (MBS) and Pharmaceutical Benefits Scheme (PBS) data as outlined here. Medicare collects information on your medical visits and procedures, and the associated costs, while the PBS collects information on the prescription medications you have filled at pharmacies. The consent form is sent securely to the Department of Human Services (DHS) who holds this information confidentially. Data will be requested for the period from 01/10/2015 to 01/10/2020.

What is the purpose and benefits of this research?

The information provided from Medicare and PBS data will be put together with your data from the questionnaire and face-to-face interview components of the PATH study. By combining this information we can study the health and personal factors associated with different patterns of health service use, how service use and treatment can improve health and wellbeing, and investigate why many people may not access the health services and treatments available. The data does not show the results of medical tests or the content of your medical consultations, just that they have occurred. One benefit of such data linkage is that we need to ask fewer questions in the PATH questionnaire.

The information provided will only be used for approved research projects that are consistent with the aims of the PATH project. The reports produced using this data can help inform health policy and improve health services in Australia.

Your participation is voluntary

Your participation in this study is completely voluntary and there will be no cost to you. If you do not want to take part in this study you do not have to. You should feel under no obligation to participate in this study. Choosing not to take part in this study will not affect your current and future medical care in any way.

Your withdrawal from the study

You are under no obligation to continue with the research study. You may change your mind at any time about participating in the research. People withdraw from studies for various reasons and you do not need to provide a reason.

You can withdraw from the study at any time by completing and signing the 'Participant Withdrawal of Consent Form'. This form is to be completed by you and supplied to the research team if you choose to withdraw at a later date.

If you withdraw from the study, you will be able to choose whether the study will destroy or retain the 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.

Storage, retention and destruction of your information

1. Storage

Initially the information collected in the information sheet and consent forms will be stored in locked suitcases by PATH interviewers when completed during face to face interviews or in locked cabinets in locked rooms at UNSW when returned via postal services. A copy of these files will be made for DHS and then scanned and kept securely on university servers. The data will be access-restricted to the PATH research administrative staff only under direction of the project research committee and chief investigators. The server is protected by a firewall and other protective systems that are designed to minimise vulnerabilities. Following this initial period where we collect consent information, all electronic consent data will be downloaded onto a PATH Study specific network drive hosted on a secure UNSW server located in Sydney, Australia, with access restrictions to PATH research administrative staff only. Hard copies will be shredded and disposed of securely after linkage is complete.

Data provided by DHS that will include participant identifiers will be stored (for a maximum of 7 years) on a secure PATH Study specific network drive hosted on a UNSW server located in Sydney, Australia, with access restrictions to the PATH research staff member who will conduct the linkage, who will access the data through secure VPN.

The de-identified electronic linked dataset for PATH will be stored on a secure PATH Study specific network drive hosted on a UNSW server located in Sydney, and an ANU server located in Canberra, Australia, with access restrictions to approved PATH research staff. The data will be kept in a separate folder from the electronic consent forms and will have different access privileges to any identifiable data (e.g., consent data and identifiable linkage data), and different PATH research staff who will manage and use the de-identified linked data. A database of all approved project researchers will be maintained by the data manager.

2. Retention

Your identifiable data will be kept for a period of 7 years after the final waves' completion, and then securely destroyed.

3. Destruction

The original data collected in the consent forms will be securely destroyed under the direction of the chief investigator and according to UNSW Data disposal policy for sensitive data involving overwriting material with random data (at least 3-pass sanitization).

After the data is linked to MBS and PBS data and only identifiable by participants' PATH study IDs (i.e., made de-identified), and within the expected storage period of 7 years, the original DHS provided data will be securely destroyed according to UNSW Data disposal policy for sensitive data involving overwriting material with random data (at least 3-pass sanitization).

Medicare Benefits Schedule (MBS) and/or Pharmaceutical Benefits Scheme (PBS) Consent Form

You will be asked to sign a consent form authorising the study to access your complete Medicare Benefits Schedule (MBS) and/or Pharmaceutical Benefits Scheme (PBS) data as outlined in the consent form.

Medicare collects information on your doctor visits and the associated costs, while the PBS collects information on the prescription medications you have filled at pharmacies.

The consent form is sent securely to the Department of Human Services who holds MBS, PBS data confidentially.

What about confidentiality?

We will provide the Department of Human Services with your personal information in a secure manner to allow accurate matching with your Medicare and PBS data. However, we will not share any of the information you have provided through the PATH study or your unique PATH ID number. Only the PATH research management staff will be able to link the data provided from the Department of Human Services with your PATH data. No identifying information is kept with the data used for analysis, and research staff working with the data will not be able to identify any participant within the dataset.

Our management of the data from Medicare and PBS complies with privacy laws and other ethical guidelines established by the National Health and Medical Research Council. All information will be stored securely and information will be kept for seven years after the time of the last publication using the data. At the end of this period, this information will be destroyed. Similar to the PATH data, the Medicare and PBS information will not be published in any way that could identify you or any other PATH participant.

Your MBS/PBS data will not be used in any future or unspecified research outside of the approved study.

In collecting your personal information within this research, UNSW must comply with the Privacy Act 1988. The UNSW Privacy Policy is available at <https://www.unsw.edu.au/privacy> and it contains information about how a person can:

- Access or seek correction to their personal information;
- Complain about a breach of an Australian Privacy Principle by UNSW, and how UNSW will handle the complaint.

Can I withdraw at a later time, and how will withdrawing effect my participation in the PATH Project?

The linkage with Medicare and PBS data is an important part of the PATH Project, but your participation is completely voluntary. Your decision will not affect your participation in the rest of the PATH Project. If you decide to take part but change your mind, you can withdraw consent to use your Medicare and PBS data at any time until the data is prepared for publication. To withdraw your consent for Medicare and PBS linkage at a later point in time, please contact **Tanya Price** on tanya.price@unsw.edu.au or 02 6268 8020 and your data will be deleted.

Participant ID:

PARTICIPANT CONSENT FORM

Consent to release of Medicare Benefits Schedule (MBS) and/or Pharmaceutical Benefits Scheme (PBS) claims information by the Department of Human Services (DHS) to UNSW for the purposes of the Path Through Life Study

Important Information

Complete this form to request the release of your personal Medicare claims information and/or your PBS claims to the PATH Through Life Study.

Any changes to this form must be initialled by the signatory. Incomplete forms may result in the study not being provided with your information.

Rights and Privacy:

I understand that:

- my MBS and/or PBS information will be disclosed by DHS for the purposes of the study.
- the results of this research may be published in articles or journals.
- my real name will never be disclosed by DHS, used in the study or published.
- my participation in the study is completely voluntary.
- I can withdraw my participation in the study at any time (refer to participant information sheet and withdrawal of consent form).

Consent:

- I understand the information provided to me about the study I am participating in.
- I have been given the opportunity to ask questions, and any questions I have asked have been answered to my satisfaction.
- I consent to the disclosure by DHS of my MBS and/or PBS information to researchers for the purposes of the study.

PARTICIPANT DETAILS

1. Mr Mrs Miss Ms Other

Family name: _____ First given name: _____

Other given name (s): _____

Date of birth: ___/___/___
DD / MM / YYYY

2. Medicare card number: _____

3. Permanent address: _____

Postal address (if different to above): _____

AUTHORISATION

4. I authorise the Department of Human Services to provide my:

- Medicare & PBS claims history OR
- PBS claims history OR
- Medicare claims history

For the period* 01 / 10 / 2015 to: 01 / 10 / 2020 to the PATH Through Life Study.
DD / MM / YYYY DD / MM / YYYY

*Note: As the Department of Human Services can only extract 4.5 years of data (prior to the date of extraction), the consent period above may result in multiple extractions.

DECLARATION

I declare that the information on this form is true and correct.

5. Signed: _____ (participant's signature) Dated: ___/___/___ OR
DD / MM / YYYY

6. Signed by _____ (full name) _____ (signature) on behalf of participant

Dated: ___/___/___
DD / MM / YYYY

- Legal guardian**
- Power of attorney**
- Guardianship order**

* Once a young person has turned 14 years old, they must consent to their own information being released

** Please attach supporting evidence

Power of attorney – A power of attorney is a document that appoints a person to act on behalf of another person who grants that power. In particular, an enduring power of attorney allows the appointed person to act on behalf of another person even when that person has become mentally incapacitated. The powers under a power of attorney may be unlimited or limited to specific acts.

Guardianship order – A Guardianship order is an order made by a Guardianship Board/Tribunal that appoints a guardian to make decisions for another person. A Guardianship order may be expressed broadly or limited to particular aspects of the care of another person.

A sample of the information that may be included in your Medicare claims history:

Date of service	Item number	Item description	Provider charge	Schedule Fee	Benefit paid	Patient out of pocket	Bill type
20/04/09	00023	Level B consultation	\$38.30	\$34.30	\$34.30	\$4.00	Cash
22/06/09	11700	ECG	\$29.50	\$29.50	\$29.50		Bulk Bill

Scrambled ordering Provider number*	Scrambled rendering Provider number*	Date of referral	Rendering Provider postcode	Ordering Provider postcode	Hospital indicator	Item category
	999999A		2300		N	1
999999A	999999A	20/04/09	2300	2302	N	2

* Scrambled Provider number refers to a unique scrambled provider number identifying the doctor who provided/referred the service. Generally, each individual provider number will be scrambled and the identity of that provider will not be disclosed.

A sample of the information that may be included in your PBS claims history:

Date of supply	Date of prescribing	PBS item code	Item description	Patient category	Patient contribution (this includes under copayment amounts**)	Net Benefit (this includes under copayment amounts**)	Scrambled Prescriber number*	Pharmacy postcode
06/03/09	01/03/09	03133X	Oxazepam Tablet 30 mg	Concessional Ordinary	\$5.30	\$25.55	9999999	2560
04/07/09	28/05/09	03161J	Diazepam Tablet 2 mg	General Ordinary	\$30.85		9999999	2530

Form Category	ATC Code	ATC Name
Original	N05 B A 04	Oxazepam
Repeat	N05 B A 01	Diazepam

* Scrambled Prescriber number refers to a unique scrambled prescriber number identifying the doctor who prescribed the prescription. Generally, each individual prescriber number will be scrambled and the identity of that prescriber will not be disclosed.

** Under co-payments can now be provided for data after 1 July 2012

Privacy and your personal information

The privacy and security of your personal information is important to us, and is protected by law. We need to collect this information so we can process and manage your applications and provide services to you. We only share your information with other parties where you have agreed, or where the law allows or requires it. For more information, go to humanservices.gov.au/privacy

PARTICIPANT WITHDRAWAL OF CONSENT FORM

PATH Through Life Project

I wish to WITHDRAW my participation in the study effective from the date below. I request that the study handles the information they have collected about me in the following way (choose one option):

- DESTROY all information collected about me so it can no longer be used for research
 RETAIN all information collected about me so it can continue to be used for research

I understand that:

1. no further information about me will be collected for the study from the withdrawal date;
2. information about me that has already been analysed and/or included in a publication by the study, may not be able to be destroyed; and
3. choosing to withdraw from the study will not affect my access to Health Services or Government benefits.

.....

Signature

.....

Date

.....

Please print full name

This form should be forwarded by email to: tanya.price@unsw.edu.au

Alternatively, forms can be posted to:

Tanya Price

PATH Through Life Study

Building 36, UNSW Canberra at ADFA

PO Box 7916

Canberra BC ACT 2610