Participant Consent Form

Resident Authorised Representative/Guardian

Research Study: Implementation of Pharmacogenomic Testing in Aged Care

Dr. Sophie Stocker (Responsible Researcher)
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Participant Name _____

Guardian Name _____

I agree the person under my care may take part in this research study.

In giving my consent, I confirm that that:

- The details of any involvement have been explained to me, and I have been provided with a written Participant Information Statement to keep.
- I understand the purpose of the study is to investigate the implementation of pharmacogenomics in aged care facilities.
- I acknowledge that the risks and benefits of participating in this study have been explained to me to my satisfaction.
- I understand that in this study the person under my care will be required to
    - i) provide a buccal (cheek) swab for genotyping, and/or
    - ii) participate in an interview about genotyping.

  i) Genotyping-specific participation:

    - I understand that if I choose for the person under my care to participate in the genotyping part of the study, then their participation may involve researchers having access to their existing medical records at Whiddon.

  ii) Interview-specific participation:

    - I understand that if I choose for the person under my care to participate in an interview, then their participation will be audio and/or video-taped.
- I understand that being in this study is completely voluntary.

- I am assured that my decision to let the person under my care participate will not have an impact on any relationship with the research team, the University of Sydney, or the staff at Whiddon.

- I understand that we (myself and/or the person under my care) are free to withdraw from this study at any time and can choose to withdraw any information already provided (unless the data has already been de-identified or published).

- I have been informed that the confidentiality of the information provided by the person under my care will be protected and will only be used for purposes that has been agreed to. I understand that information identifying me or the person under my care will only be told to others with my permission, except as required by law.

- I understand that the results of this study may be published, and that publications will not contain any identifiable information about myself, or the person under my care.

- I confirm the following:

I consent for the person under my care to provide a Buccal (cheek) swab for genotyping	Yes ☐	No ☐
I consent for the person under my care to participate in an interview that is recorded	Yes ☐	No ☐
I would like feedback on the overall results of this study	Yes ☐	No ☐

If you answered **yes** and would like feedback on the results of the study, please provide your preferred contact details (email/telephone):

_____

_____

- I understand that after I sign and return this consent form it will be retained by the researcher, and that I may request a copy at any time.

Guardian Name _____

Signature _____

Date _____

Witness Name _____

Signature _____

Date _____

Australian Government
Services Australia

Study Participant ID:

Participant Consent Form for the release of Commonwealth health information provided by Services Australia

(Participants over 14 years of age only)

Consent to release of my Medicare Benefits Schedule (MBS) and/or Pharmaceutical Benefits Scheme (PBS) Commonwealth health information provided by Services Australia to Dr Sophie Stocker for the purpose of the Implementation of Pharmacogenomic Testing in Aged Care study.

Important Information

Complete this form to request the release of your MBS claims information and/or PBS claims information by Services Australia to the study. The signatory must initial any changes to this form. Incomplete forms may result in the study not being provided with your information.

Rights and Privacy

I understand:

- my MBS and/or PBS health information will be disclosed by Services Australia for the purpose of the study.
- the results of this research may be published in articles or journals.
- my name will never be disclosed by Services Australia, used in the study, or published.
- my participation in the study is completely voluntary.
- I can withdraw my consent to release my Commonwealth health information provided by Services Australia to the study at any time (refer to the participant information sheet and withdrawal of consent form), and I do not have to provide a reason.
- the information provided to me about the study, and I have been given the opportunity to ask questions, and any questions I have asked, have been answered to my satisfaction.

Consent:

☐ I consent to the disclosure of my MBS and/or PBS Commonwealth health information provided by Services Australia to researchers for the purpose of the study.

Participant Details

☐ Mr ☐ Mrs ☐ Ms ☐ Miss ☐ Other

First name

Family name

other given name(s)

Date of birth:

DD / MM / YYYY

Medicare card number (first 9 digits only):

e.g. 123453789

Primary address:

Postal address:

Authorisation:

I authorise Services Australia to provide my:

- ☐ MBS claims history OR
- ☐ PBS claims history OR
- ☐ MBS & PBS claims histories

For the period * 01/10/2024 to: 01/04/2026 to the study.
Date range is to be completed prior to or at the time of signing the consent form.

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

☐ I consent to Services Australia to continue providing my claims information to the study irrespective of treatment outcomes.

Declaration:

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

Sign and date:

DD/MM/YYYY

If signed by a Legal Guardian/POA other than the participant please print name, sign & date below:

First name	Second name
Signature	DD/MM/YYYY

- ☐ Legal Guardian (where the participant is over the age of 14 years old)
- ☐ Power of Attorney
- ☐ Guardianship order/Administration order

Please attach supporting evidence (Power of Attorney document **(medical or enduring)** or legal guardianship)

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

Consent forms will not be processed without the relevant 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/Administration order – A Guardianship/ Administration 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.

Legal guardianship as deemed by a court of Australia for relatives, an authorised carer from an out of home care agency, or other person who has an established relationship with the young person to act on their behalf. A legal guardian may be an individual, two or more people who are appointed or a legal entity such as Public Trustee. Evidence will need to include a certified copy of the order. If the legal guardian is a public trustee, then the letter will need to be on the letterhead from that entity and include the Medicare card number of the participant.

Your MBS claims history will include the following information, below is an example:

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

Date of referral	Rendering Provider postcode	Ordering Provider postcode	Hospital Indicator	Item category
	2300		N	1
20/04/09	2300	2302	N	2

Your PBS claims history will include the following information, below is an example:

Date of supply	Date of prescribing	PBS item code	Item description	Patient category	Patient contribution (this includes under co-payment amounts**)	Net Benefit (this includes under co-payment amounts**)
06/03/09	01/03/09	03133X	Oxazepam Tablet 30 mg	Concessional Ordinary	$5.30	$25.55
04/07/09	28/05/09	03161J	Diazepam Tablet 2 mg	General Ordinary	$30.85	

Pharmacy postcode	Form Category	ATC Code	ATC Name
2560	Original	N05 B A 04	Oxazepam
2530	Repeat	N05 B A 01	Diazepam

** 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 your applications and payments 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 **servicesaustralia.gov.au/privacy**

Feb 2024