

**Participant Information Statement and Consent (PISCF) Data Banking Form
for the Health Insight Pilot Study**

The study is being carried out by the following researcher:			
Role	Name	Title	Organisation
Data Custodian	Dr Martin McNamara	Deputy CEO; Head, Research Assets	Sax Institute
Databank Name	Health Insight Pilot Study		
Research Funder	This research is being funded by the Bupa Health Foundation.		

1. Invitation

Following on from your consent to participate, we ask that you also consider giving your permission for storage of your contact details in the above databank for the following:

- To be recontacted by the Sax Institute to provide you with summarised results of the Health Insight Pilot Study
- To be recontacted by the Sax Institute to let you know whether or not a large-scale version of the Health Insight Study will go ahead. If it is going ahead, we would invite your participation in a future full-scale study on the health of privately-insured Australians.

This form provides you with information to help you decide whether you will allow this. If you do not give permission then you can still fill in the questionnaire but we will not contact you again afterwards. Please take the time to read the following information carefully and discuss it with others if you wish.

2. What type of data will be stored in this databank?

With your permission the Sax Institute would like to securely store the following types of data (contact information) with the intention to use it if this study proceeds to a future full-scale study.

Identifiable Contact Information (not to be shared)

- Title
- Given, middle and family names
- Date of birth
- Postal Address
- Home phone number
- Mobile phone number
- Email address

3. What will happen to my data (contact information)?

If you provide your permission the research team at the Sax Institute will securely store your contact information in a databank. Your identifying personal information (contact information) will be stored separate from any non-identifiable responses you give to questionnaires.

The information you provide is personal information for the purposes of the Privacy and Personal Information Protection Act 1998 (NSW). You have the right of access to personal information held about you by the Sax Institute, the right to request correction and amendment of it, and the right to make a complaint about a breach of the Information Protection Principles as contained in the PPIP Act.

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4. Who will have access to my data (contact information)?

Only the custodian listed in the table above will ensure that your data is stored and managed appropriately and according to the relevant privacy laws.

5. How long will you store my data (contact information) for?

The Sax Institute intends to store your data for 7 years from the completion of the Health Insight Pilot Study (mid 2019).

6. Can I withdraw my information from this databank?

If you no longer wish to have your data stored or do not wish to be contacted for the future full-scale study, you can withdraw your information at any time by completing the withdrawal of consent form that is provided at the end of this document or by phoning the data custodian and letting them know.

7. Data Custodian Contact Details

Name	Dr Martin McNamara
Position	Deputy CEO; Head, Research Assets, Sax Institute
Telephone	1300 45 11 45
Email	martin.mcnamara@saxinstitute.org.au

8. Research Team Contact

Name	Alison Cowle
Position	Cohort Manager, Sax Institute
Telephone	1300 45 11 45
Email	healthinsightstudy@saxinstitute.org.au

9. What if I have a complaint or any concerns about this databank?

If you have any complaints about any aspect of the project, the way it is being conducted, then you may contact:

10. Complaints Contact

Position	Human Research Ethics Coordinator
Telephone	+ 61 2 9385 6222
Email	humanethics@unsw.edu.au
HC Reference Number	HC180524

Please choose one of the following options:

- I provide my consent for the information collected about me to be used for the Health Insight Pilot Study and **to be re-used for a future full-scale Study.** ➔ **Please complete the consent form on the following page**

OR

- I provide my consent for the information collected about me **to be used for the Health Insight Pilot Study only.** ➔ **Please complete questionnaire**

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Consent Form

Declaration by the participant

- I have read the Participant Information Sheet or someone has read it to me in a language that I understand;
- I understand that this consent is separate to the study that I am agreeing to participate in and understand that providing my consent to have my data stored for a future full-scale study is optional;
- I understand that I am providing my consent for the Sax Institute to store my data for a future full-scale study;
- I understand that I am consenting to provide my details and agree to be invited to participate in the large-scale study;
- I understand that I may be able to have my data deleted. I understand that I am free to withdraw at any time during the project and withdrawal will not affect my relationship with any of the named organisations and/or research team members;
- I have had an opportunity to ask questions via the Study Helpline and I am satisfied with the answers I have received;
- I freely agree to participate in this research study as described.

Signature

Signature	
Date	

Personal details

Title	
Given name	
Middle name	
Family name	
Date of birth	

Contact details

Street address	
Suburb/Town	
State	
Post code	
Home phone	
Mobile phone	
Email address	

Please complete questionnaire

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Form for Withdrawal of data from the Health Insight Pilot Study

I wish to **WITHDRAW** the data from the databank listed above and understand that such withdrawal **WILL NOT** affect my relationship with the Sax Institute, Bupa or the Bupa Health Foundation.

Participant Signature

Name of Participant (please print)	
Signature of Research Participant	
Date	

The section for Withdrawal of Participation should be forwarded to:

CI Name:	Professor Emily Banks
Email:	healthinsightstudy@saxinstitute.org.au
Phone:	1300 16 34 26
Postal Address:	The Health Insight Pilot Study, GPO Box 5289, Sydney NSW 2001