

Fees and Charges Policy

1. Background

- 1.1 The Sax Institute manages the 45 and Up Study (the 'Study'). Researchers can apply to conduct research projects using data from the Study (the 'Main Database'), provided requirements of the Study Access Policy are met.
- 1.2 This policy should be read in conjunction with:
 - a) the Study Access Policy that outlines conditions for conducting a project using data from the Study. All projects conducted using the Main Database must be approved in accordance with the Access Policy; and
 - b) the Data Licence Agreement that outlines conditions for purchasing a licence for projects using the Main Database.

2. Purpose

- 2.1 The purpose of this policy is to define conditions for a Data Licence that must be purchased for all projects accessing the Main Database of the Study.
- 2.2 The 45 and Up Study 'Main Database', means any data collected by the Sax Institute in baseline or follow up questionnaires as well as any data collected by sub-studies (conducted by the Sax Institute or other researchers) when these data are contributed to the collaborative resource.
- 2.3 The Main Database must be accessed to establish the linkages required for extractions of linked data from external datasets, including linkages facilitated through the Centre for Health Record Linkage (the CHeReL) and data provided by Medicare Australia.
- 2.4 There will be additional charges for access to data outside of the Main Database (see Item 7).
- 2.5 This policy does not apply to use of biological samples or information derived from these.
- 2.6 The fees and charges outlined in this policy may be varied under exceptional circumstances and with approval from the Sax Institute CEO or delegate.

3. Principles

- 3.1 This Policy is based on the following principles:
 - The 45 and Up Study is to be used for the purposes of furthering the public good in relation to health.
 - No access to the Main Database is permitted without a current Data Licence.
 - No access to the Main Database is permitted without a current project approval.
 - Data from the Main Database can be used only for the purpose for which approval has been granted.
 - No one can access or use the unit record data of the 45 and Up Study Main Database without signing an Individual Confidentiality Agreement
 - No one can access or use the unit record data of the 45 and Up Study Main Database without relevant ethics committee approval where required for their project.

4. Application

- 4.1 Organisations, research groups or individuals must purchase a Data Licence to access the Main Database.
- 4.2 The Data Licence will be for a set period of time (1 to 3 years) and for a specified number of users.
- 4.3 The users associated with a Data Licence must normally be employed by the same institution as the owner of the Data Licence.
- 4.4 A Data Licence must be active at all times throughout a project where a data extraction from the Main Database is required. This is required for access to additions to the Main Database such as follow up data or data collected through sub-studies as well as for facilitating linkages with external datasets.
- 4.5 At the time of data extraction from the Main Database, the following individuals must be covered by a Data Licence:
 - the responsible lead investigator as nominated on the project approval
 - any other chief investigators who will access unit record data
 - all analysts or biostatisticians on the project who will access unit record data
 - any students who will access unit record data

5. Cost of a Data Licence

5.1 Research Licences

To access 45 and Up Study questionnaire data, a data licence is required by each researcher accessing the data through SURE. There are currently two datasets available: baseline (over 250,000 records) and first follow-up including SEEF (around 137,000 records). The licence fee per researcher per year is:

- \$8,370 + GST for the first questionnaire dataset; and
- 50% + GST for second questionnaire dataset.

Institutional licenses are able to be negotiated for multiple licences from the same centre or Institution.

5.2 Project Data Preparation fees

A data preparation fee of \$3,850 + GST per occasion is charged for projects that require the 45 and Up baseline and/or follow-up dataset/s to:

- be linked with external databases such as emergency presentations, or hospital admissions through the NSW Health data linkage facility CHeReL. This does not include data linkage fees from CHeReL of other linkage facilities
- be linked with Medicare Benefits Schedule (MBS)
- be linked with Pharmaceutical Benefits Scheme (PBS) data
- include geocoded data.

5.3 Project Data Access Fees

Data access for all 45 and Up Study projects is through our secure facility SURE. Current project fees are \$3,465 for establishment and \$2,310 per year for storage and operations. Current user fees are from \$2,310 per user per year depending on the resources required.

For further information see <http://www.saxinstitute.org.au/wp-content/uploads/2016-SURE-Virtual-Workspace-Fee-Schedule.pdf>.

5.3 PhD students do not need to pay licence fees however their supervision will need to have a licence that covers their specific project.

5.4 Under extreme circumstances that are outside the control of the investigators (for example unanticipated delays in gaining ethics approval, staffing issues) an application for a hiatus to the period of the Data Licence may be made to the Sax Institute CEO or delegate.

6. Increasing the number of users covered by a Data Licence

6.1 The names of users, where known, must be nominated on purchase of a Data Licence. The users can be updated over time. Where the number of users increases above the allowance for the Data Licence, the owner will be required to either: 1. increase the level of the Data Licence and the difference in costs paid; or 2. Remove a user from the Data Licence.

6.2 Owners of Data Licences can upgrade their licence to cover more users by paying the difference in costs between the lower and higher user rates.

7. Upgrading a Data Licence to cover sub-studies and linkage projects

7.1 The Data Licence provides access to data contained in the Main Database.

7.2 Additional charges will apply where the Main Database is being linked with external databases (linkage projects) or where Study participants are being recontacted (sub-studies). These additional charges will cover operating costs such as staff time and consumables. A quote will be provided for these charges at the time of project application.

8. Study Partners

8.1 Study Partners are organisations that have entered into a formal agreement with the Sax Institute as a significant financial contributor to the 45 and Up Study.

8.2 At the time of agreeing the financial contribution of the Study Partner, the conditions for fees and charges to access the Main Database will be determined.