

Deed poll for 45 and Up CUPL data access

From: The person identified as the Researcher in the Contract Details below (Researcher)

In favour of: The Sax Institute ('the Institute'), ABN 68 095 542 886, of Level 3, 30C Wentworth Street Glebe NSW 2037 (the Institute).

RESEARCH PROJECT

Researcher details:

Name:	Professor David Breyer
Organisation and role:	Head Dept of Gerontology Concord Hospital
Address	Hospital Rd Concord
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Email	david- breger breger@health.nsw.gov.au

Recitals:

- A. The Institute operates SURE, in which Project Workspaces and Virtual Desktop computing environments are established for the purposes of data analysis using the Chronic conditions Umbrella Program Linkage (CUPL).
- B. As a precondition for access to any Project Workspace and/or Virtual Desktop provided by the Institute, the Researcher must agree to be bound by the terms and conditions of this Deed Poll.
- C. Any breach of the terms and conditions of this Deed Poll may compromise the Researcher's capacity to access data under the Chronic conditions Umbrella Program Linkage for the purposes of the current project and for future projects. Such a breach may also prohibit the Researcher from publishing any findings arising out of the project approved under this Deed Poll.
- D. Serious or repeated breaches of the terms and conditions of this Deed Poll will be notified to all data custodians. Data custodians including the Institute may then determine to prohibit the Researcher from accessing for the current project and/or for future projects.
- E. Execution of this Deed Poll does not of itself give Researchers a right of access to any Researcher Virtual Desktop or Project Workspace or data. The Institute reserves the right to refuse access to the CUPL if provision of data to the Researcher would violate its or Data Custodians' governance conditions and/or Conditions of Data Disclosure.

1. Definitions

In this Deed Poll, the following terms have the following meanings:

Term	Definition
Author Guidelines	The 45and Up Study guidelines prepared by the Institute and available here with instructions and conditions for the preparation and publication of papers, reports, abstracts, presentations and any other publications arising from use of the 45 and Up Study Cohort data, as amended from time to time.
Business Day	A day that is not a Saturday, Sunday or a public holiday in New South Wales, Australia
Conditions of Data Disclosure	<p>The Conditions of Data Custodian authority under:</p> <ul style="list-style-type: none">i. Instrument/s of Data Disclosure; and/orii. Agreement/s for Data Disclosure; and/oriii. Authority/ies for Data Disclosure; <p>to provide the Institute with access to datasets and data variables for linkage and use under the Chronic Conditions Umbrella Program Linkage. Schedule 2 of the CUPL Institutional Agreement [‘The Agreement’] sets out the Conditions of Data Disclosure binding the Lead Research Organisation, Participating Institution/s and Researcher/s in order to authorise the release of Cause of Death Unit Record Files and/or other data sets accessed under CUPL. Schedule 2 must be signed and executed at the same time as the Agreement for access to data to be provided.</p>
Confidential Information	<p>All unit record data made accessible to the Researcher under this Deed Poll, and also:</p> <p>Any information which:</p> <ul style="list-style-type: none">a) By its nature or circumstances of its disclosure, is, or could reasonably be expected to be regarded as, confidential; orb) Is designated by the Institute as confidential; orc) the Researcher knows, or ought to know is confidential. <p>Note that ‘confidential information’ does not include information that is:</p> <ul style="list-style-type: none">a) In the public domain prior to the date of this Deed Poll or which comes into the public domain after the Deed Poll (otherwise than because of a breach of confidentiality obligations); orb) In the Researcher’s possession or otherwise known by the Researcher prior to the date of this Deed Poll, as shown by

contemporaneous records, without violation of any obligation of confidentiality; or

- c) Disclosed to the Researcher by a third party otherwise than in breach of an obligation of confidence; or
- d) Independently developed by the Researcher without use of or reference to any of the Confidential Information and without any breach of any obligation of confidence.

Credential	A physical or electronic token or information that is used to establish authority to access a Researcher Virtual Desktop. Credentials typically consist of a username and password and a second factor of authentication.
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Laws	Any statute, regulation, order, rule, subordinate legislation or other document enforceable under any statute, regulation, order, rule or subordinate legislation.
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Project Workspace	A virtual workspace on the SURE service operated by the Sax Institute.
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Research Organisation	The Lead Research Institution or Participating Institution named on Page 1 of this Deed Poll by which the Researcher is employed or contracted or affiliated for the purposes of this Research Project
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Research Project	The research project listed on Page 1 of this Deed Poll and the body of research work to be undertaken using the Project Workspace for that Research Project.
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Researcher Virtual Desktop	A virtual desktop within a Project Workspace.
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Standards	<p>The standards of research governance, management and practice set out in the following guidelines, codes and statements:</p> <ul style="list-style-type: none">• National Statement on Ethical Conduct in Research Involving Humans (NHMRC, 2007, as updated in 2018) or any replacement versions• Australian Code for the Responsible Conduct of Research (NHMRC, 2018)• Values and Ethics: Guidelines for ethical conduct in Aboriginal and Torres Strait Islander health research (NHMRC, 2003)• Guidelines for Genetic Registers and Associated Genetic Material (NHMRC, 1999)
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- Guidelines issued and/or approved under sections 95, 95A or 95AA of the *Privacy Act 1988* (Cth).

SURE

The Secure Unified Research Environment – the remote-access computing environment operated by the Sax Institute that allows researchers to access and analyse linked health-related data files for approved studies.

2. Accessing the Project Workspace

- 2.1 The Researcher agrees to access and use the Project Workspace only:
- a) In accordance with any and all policies imposed by the Institute in respect of use of the Project Workspace or SURE from time to time, including policies relating to ethics, ongoing training, data disclosure and publications. Such policies will be notified to the Researchers or are available to Researchers on the SURE website.
 - b) In accordance with any and all applicable conditions required by data custodians in relation to the use, disclosure, publication, storage and disposal of data made available by them under this linkage
 - c) In accordance with the terms of this Deed Poll
 - d) To perform duties associated with their association with the Research Organisation.
- 2.2 Except as expressly authorised in writing by the Institute, the Researcher must not under any circumstances, allow any person to access or view any Researcher Virtual Desktop allocated to a Researcher.

3. Confidentiality and Infringement

- 3.1 Researcher must keep confidential any Credential or Confidential Information provided to the Researcher in relation to the Researcher's access to the Project Workspace.
- 3.2 In respect of any Credential provided to the Researcher, the Researcher must:
- a) At all times, keep those Credentials secret and secure; and not share the Credentials with any other person
 - b) Comply with any reasonable instructions from the Institute in respect of their use of SURE or the Project Workspace;
 - c) Notify the Institute within one Business Day of any breach of security relating to the Credential or the Researcher's access to the Project Workspace of which the Researcher becomes aware; **and**
 - d) Return to the Institute or destroy any such Credentials on the earlier of request by the Institute or expiry of the Project Workspace.
- 3.3 The Researcher agrees to:

- a) Not disclose Confidential Information to any person (other than to fellow researchers who have signed a deed poll on the same terms as this Deed Poll); **and**
 - b) Take all steps and do all things that are necessary or prudent to safeguard the confidentiality of Confidential Information.
- 3.4 If the Researcher is required by Law or court order to disclose any of the Confidential Information, the Researcher must immediately notify the Institute and the Research Organisation in writing of the requirement. The Researcher must, as directed by the Institute:
- a) Assist or permit the Institute to oppose or restrict disclosure; **or**
 - b) To the extent allowed by Law, make disclosure on terms which will preserve the confidentiality of the Confidential Information.
- 3.5 The Researcher must not use the Project Workspace or any part of SURE in a manner which:
- a) Infringes any intellectual property right (including copyrights, patents and trademarks) of any person
 - b) Is in breach of any law relating to privacy; or
 - c) Is in breach of any other obligation on the Researcher, **including**:
 - i. Ethical obligations, relating to the Research Project
 - ii. Conditions imposed by the Institute and/or data custodians on access, use, disclosure, publication, storage and disposal of data made available within a Project Workspace as part of this linkage.

This includes requirements for statistical disclosure control (SDC) techniques and minimum cell size.

- 3.6 The Researcher agrees to comply with any and all disclosure and publication requirements of all data custodians whose data is supplied via this linkage for use in their approved Project, including:
- a) Compliance with all requirements for Researchers detailed in the Agreement executed by the Lead Research Organisation or Participating Institution under whose auspices they are conducting the Project
 - b) Compliance with specific agreements for data disclosure for data sets where this is a requirement of the data custodian. Where applicable, these agreements constitute schedules to the Agreement
 - c) Accessing the data dictionary pertaining to the data set or sets and data variables approved to be used in their sub-study and familiarising themselves with the limitations, caveats and characteristics of those data sets and variables prior to accessing them in SURE (NSW Data dictionaries are [at this link](#) and dictionaries pertaining to the 45 and Up Study, MBS, PBS are [at this link](#))
 - d) Submitting all publications, including papers, reports, abstracts and conference presentations, to the Institute for review in accordance with the requirements set out in the Authors' Guidelines, at least 30 Business Days (6 weeks) prior to the date of intended submission for publication or release
 - e) Compliance with any and all specific conditions for publication, including but not limited to, those required by the Institute and Data Custodians

- f) Submission to the Institute no less than 21 Days (3 weeks) prior to publication or release, of a copy of all publications approved after review by the Institute in accordance with clause 3.5d The Institute will forward a copy of all publications to the data custodian/s whose data have been used in the Project
- g) Submission to the relevant Ethics Committee, in accordance with the relevant Ethics Committee approval..

4. Warranty

4.1. The Researcher warrants that they:

- a) Have not been subject to any sanctions in relation to the use, analysis and reporting of data
- b) Have not engaged in any research misconduct or been investigated for any breach of the Australian Code for the Responsible Conduct of Research; **and**
- c) Have clearly and accurately stated the source and relationship of funding for the Research Project specified in this Deed Poll.

5. Acknowledgements

5.1 The Researcher acknowledges and agrees that:

- a) Execution of this Deed Poll does not give the Researcher any rights to access any Researcher Virtual Desktop
- b) The Institute may decline to provide the Researcher access to any Researcher Virtual Desktop without notice, and has no obligation to provide reasons to the Researcher where it does so; **and**
- c) The Institute has no liability to the Researcher as a result of failing to provide access to any Researcher Virtual Desktops to the Researcher.

5.2 The Researcher acknowledges and agrees that:

- a) In order to access SURE, a user must meet various technical requirements nominated by the Institute from time to time
- b) The Research Organisation which is responsible for a Project Workspace has the power to access, delete or modify the contents of any Researcher Virtual Desktop within its Project Workspace
- c) In some circumstances, third parties will also have rights in respect of a Project Workspace (arising for example out of an election by the Research Organisation to use that third party's data in the Project Workspace) such as rights to:
 - i. Suspend the Researcher's access to the Project Workspace
 - ii. Delete data from the Project Workspace
 - iii. Review or audit of the Research Virtual Desktop and the files it contains
 - iv. Review or audit of data being imported to or exported from the Researcher Virtual Desktop; **and/or**

- v. Prevent data being imported to or exported from a Researcher Virtual Desktop.
- d) A third party may have such rights in relation to multiple Project Workspaces; **and**
- e) The Institute has no liability to the Researcher in the event a third party (including a research organisation) exercises rights in relation to a Project Workspace, even where that exercise results in the deletion of the Researcher's data, or the prevention of the Researcher's access to data.

5.3 On expiration of the Project Workspace, the Researcher must:

- a) Cease using SURE and the Project Workspace immediately
- b) Return all of the Institute's Confidential Information and Credentials within their possession or control to the Institute or the Research Organisation
- c) Except where Confidential Information and Credentials are stored electronically within SURE, comply fully with any conditions of data storage and erasure required by any or all data custodians and in accordance with the undertakings set out in Clause 3.6 and associated schedules; and
- d) To the extent that Confidential Information and Credentials are stored electronically (except where stored within SURE), permanently and verifiably erase or destroy any other Confidential Information or Credential, except for any materials which the Institute agrees in writing that the Researcher may retain.

5.4 Nothing in this Deed Poll requires the Researcher to return or destroy any Confidential Information which they or the Research Organisation is legally required to retain.

5.5 The Researcher agrees that their obligations under this Deed Poll are continuing obligations and survive the termination of any employment, contractual relationship or association with the Institute or the Research Organisation.

6. General

6.1 Except as set out in this Deed Poll to the contrary, nothing in this Deed Poll:

- a) Gives either party the ability to act or incur liability on behalf of the other party; **or**
- b) Creates a relationship of joint venturers, principal and agent or employee and employer between the parties.

6.2 This Deed Poll is governed by the laws in force in the State of New South Wales, Australia. Each party submits to the exclusive jurisdiction of the courts of that State.

6.3 Notifications under this Deed Poll must be given in writing.

Acknowledgements and signatures

I understand and agree to the following conditions in order to be granted access by the Institute to the SURE platform and CUPL data:

Please acknowledge each item by ticking the relevant box, and then sign in front of a witness.

- That I have read and understood and will comply with the Institute's governance and access policies which can be found at <https://www.saxinstitute.org.au/our-work/45-up-study/governance/> in order to use and access the Project Workspace and Virtual Desktop
- That I have completed all training required by the Institute prior to seeking access to SURE
- That I have familiarised myself with the data dictionary or dictionaries pertaining to the data sets and data variables I have sought permission to access
- That I will conduct all research, use and reporting of data under this agreement in accordance with the Standards
- That I am only authorised to use the Project Workspace and Virtual Desktop for the purposes of completing data analyses as specified and required for the Research Project specified on this Deed Poll
- That I will comply with all instructions issued by the Institute in respect of use of the SURE platform, access to the Project Workspace and Virtual Desktop
- That I will not allow any person to access or view my Virtual Desktop
- That I will make available to the Institute all data analyses, reports, notes and related material arising from use of the Virtual Desktop for audit as required by the Institute, Data Custodians and/or the NSW Ministry of Health and/or a delegate appointed by any of these
- That I will keep all Confidential Information confidential
- That I have familiarised myself with all conditions of ethical approval for my Project and will abide by all conditions
- That I have familiarised myself with the data disclosure conditions and procedures for protecting Confidential Information required by the Institute and any and all Data Custodians whose data I am accessing in accordance with this Deed Poll, and will comply with them
- That I understand that if I am seeking to use Cause of Death Unit Record File (COD URF) data, I will ensure my full compliance with the conditions of data disclosure detailed in Schedule 2 of The Agreement signed by my Research Organisation
- That I will keep all Credentials confidential and secure. This includes a prohibition on sharing Credentials, including with other researchers conducting research on the same Research Project

- That I will advise the Institute immediately (within 24 hours) of any breach of confidentiality or, of security of Credentials
- That I will return or destroy all Credentials to the Institute on completion or cessation of the Research Project
- That on completion or cessation of the Research Project, as directed by the Institute and/or in accordance with the requirements of the data custodians, I will return or destroy all confidential information and files and/or materials containing confidential information
- That I will notify the Institute of any change in my employer
- That I will advise the Institute of any issue that may or has affected the delivery of the agreed research outcomes for this Research Project
- That I will apply statistical disclosure control (SDC) techniques as required by the Sax Institute and Data Custodians in my reporting of all analyses
- That I will not report or present figures with data for small cell sizes – between 1 and 4 inclusively – and will also apply secondary suppression if required to prevent back calculations of small cell sizes to ensure I do not identify any individual or sensitive group in publications, reports, abstracts or presentations arising out of my research. Small cells may be presented as '< 5'
- That I will comply with all conditions of data disclosure and reporting in relation to identification and comparison of facilities and centres
- That I will report at least annually, and more often as required under this Deed Poll, on the status of my project
- That I will acknowledge the Institute in all publications, presentations and reports arising out of the Research Project
- That I will acknowledge all Data Custodians and/or the NSW Ministry of Health as appropriate, whose datasets data are utilised, in any research report, publication or presentation arising out of the Research Project, using the form of words required by each and all of the relevant parties
- That I will include in all publications, reports and presentations, arising out of my use of all data sets and/or data variables for this Project, all required form or words or caveats as required by the Institute, Data Custodians and/or the NSW Ministry of Health. I understand that my compliance with this requirement will be checked by the Institute as part of the Technical Review required before publication
- That I will acknowledge the Centre for Health Record Linkage in any publication or report arising from the use of data under this Deed
- That I will submit for Technical Review to the Institute copies of all draft publications, abstracts, presentations and reports at least 30 Business Days (6 weeks) PRIOR to their intended public release or submission for publication

- That I will provide the 45 and Up Study Coordinating Centre with a copy of any publication, abstract, presentation or report arising from the use of data under this Deed at least 21 days (3 weeks) PRIOR to public release or publication and understand that these copies will be forwarded to all relevant data custodians and/or the NSW Ministry of Health, who retain the right to request changes or delay publication
- That I will provide a copy of any publication or report arising from the use of data under this Deed, to any ethics committee that requested such as a condition of ethical approval and in accordance with the timeframe detailed in the ethics approval, and if no timeframe is detailed, at least 14 days (2 weeks) prior to public release
- That I have clearly and accurately identified my employing or affiliating institution, the relationship and the source of all funding for my research project under this agreement
- That I have not been subject to any sanctions in relation to the use, analysis and reporting of data. If I incur such sanctions after commencement of the Project, I will notify the Sax Institute of such within 3 Business Days of this
- That I have not engaged in any research misconduct or been investigated for any breach of the Australian Code for the Responsible Conduct of Research; and,
- That my obligations under this Deed Poll are continuing obligations and survive the termination of any employment, contractual relationship or association with the Institute or the Research Organisation.

Please print, sign and have witnessed this Deed Poll in duplicate. Retain one signed and witnessed copy for your records, and return one to the Institute.

Executed as a Deed Poll in favour of The Sax Institute (ABN 68 095 542 886)

Signed by the Researcher in the presence of a witness:



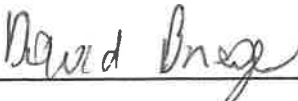
Signature of Researcher

Date: 5/12/22



Signature of Witness

Date: 5/12/22



Full name of Researcher



Full name of Witness