



The Chronic Conditions Umbrella Program Linkage

A guide for researchers

The fast and effective way to access data for chronic conditions research

The Chronic Conditions Umbrella Program Linkage (CUPL) offers a fast and convenient way to use the power of the 45 and Up Study and its linked data assets to drive research into chronic disease – cutting project set-up times by as much as 80%.

CUPL is an enduring linked dataset that gives researchers access to data from 10 administrative datasets, as well as the self-reported survey information from more than 260,000 45 and Up Study participants. Access to CUPL involves a single, convenient approval process that aims to improve the quality, quantity and efficiency of chronic conditions research in Australia.

CUPL will be piloted in 2023 and made available more generally across the research community from early 2024. CUPL has the support of all data custodians and approval from the Population Health Services Research Ethics Committee.

CUPL datasets	Date Range (Earliest)	Date Range (Latest)*	No. of Participants	No. of Records
45 and Up Study	Jul 2005	Feb 2021	266,509	266,509
Medicare Benefits Scheme including Department of Veteran Affairs MBS	Jan 2001	Dec 2021	266,353	129,367,868
Pharmaceutical Benefits Scheme including Repatriation PBS	Jun 2004	Dec 2021	264,705	109,389,600
NSW Admitted Patient Data Collection	Jul 2001	Mar 2022	248,625	3,207,180
NSW Registry of Births, Deaths and Marriages	Jan 2006	Mar 2022	56,259	56,386
NSW Cause of Death Unit Record File	Jan 2006	Dec 2020	49,824	49,844
NSW Emergency Department Data Collection	Jan 2005	Mar 2022	219,410	1,345,685
NSW Cancer Registry	Jan 1996	Dec 2019	68,167	83,828
NSW Mental Health Data Collection	Jan 2001	Dec 2021	16,549	1,558,717
Notifiable Conditions Information Management System	Jan 1993	Mar 2022	23,538	76,167
Notifiable Conditions Information Management System-COVID	Jan 2020	Dec 2021	1,182	1,185

*as of Dec 2022

Key benefits of CUPL for researchers



Fast-tracked access

CUPL offers fast-tracked access to data, reducing wait times for researchers by as much as 80%. A researcher that may have previously waited more than a year to access linked data could gain access through CUPL in a few months.



Unmatched range of healthcare data

The broad scope of linked data in CUPL includes hospital admissions, mental health, ambulatory care, prescription data, notifiable conditions such as COVID, cause of death and much more. Researchers using CUPL can seek answers to an unprecedented range of questions about chronic conditions and ageing in Australia.



More than 15 years of longitudinal data

Since 2005, the 45 and Up Study has been following over a quarter of a million Australians. Participants provide in-depth demographic, lifestyle and health information through a baseline questionnaire and are surveyed every five years. Researchers can see changes over time in lifestyle behaviour, biomedical factors and social determinants of health.



One approval process and fee

Researchers can avoid the administrative burden of liaising with multiple data custodians and linkage agencies. The Sax Institute administers the approval process and access fee for all datasets in CUPL. Successful research proposals will be approved by Scientific Review as well as the Population Health Services Research Ethics Committee.



Secure virtual workspace

Researchers will access data through The Secure Unified Research Environment (SURE), a highly secure virtual workspace that runs on hardware located at, and managed by, the Sax Institute. Researchers can log in remotely and analyse data, without datasets ever leaving SURE.



Up-to-date data

All datasets available through CUPL are updated annually. Researchers will be working with current data immediately and can receive automatic data updates.

FIND OUT MORE

If you're interested in accessing the Chronic Conditions Umbrella Program Linkage or discussing your research needs, please contact us at:

45andUp.research@saxinstitute.org.au

About the Sax Institute

The Sax Institute is an independent, not-for-profit organisation and a national leader in driving the use of research evidence in policies and programs to improve the health and wellbeing of Australians.