

NHMRC Principles for Accessing and Using Publicly Funded Data for Health Research

Maximise the use of publicly funded health and health-related data for research

- Research is an important use of publicly funded health and health-related data and is vital to unlocking their value to benefit Australians by driving improvements in disease prevention and clinical care.
- The value of data lies in its use. Use of datasets for research should be promoted, encouraged and maximised for public benefit, while also protecting privacy and confidentiality.
- To maximise public benefit, health and medical research should develop processes and systems to incorporate and support sustainable consumer and community involvement.
- Public trust in the use of personal data for research should not be compromised.

Data custodians should recognise their responsibilities and accountabilities when providing access to data for research

Custodians of publicly funded health and health-related datasets should:

- Encourage, support and facilitate access to data, including for data linkage, to promote high quality and sustainable research outcomes.
- Ensure that data releases for research purposes protect the privacy of individuals and maintain confidentiality of their data in accordance with relevant legislation, policies and ethics guidelines.
- Specify the conditions of data access and licensing, and provide a description of their data holdings to assist researchers to determine whether the data are fit-for-purpose.
- Provide researchers, whose applications for access have met the required criteria and have been approved, with timely access to data for research on a 'best endeavours' basis.
- Seek wherever possible to harmonise access, approval and data supply processes with other data custodians responsible for similar or related data sets.
- Be transparent and proactive about:
 - requirements for ethics approval (if applicable)
 - how requests or applications for data access are made, assessed, and approved, and how long assessing applications may take
 - timelines for provision of data
 - any charges associated with data provision
 - processes to follow up on outstanding data access requests
 - processes to follow when seeking review of decisions to deny data access
 - how data will be made available, and
 - requirements for researchers to sign confidentiality, data use and/or other agreements.

Researchers should recognise their responsibilities and accountabilities when accessing and using publicly funded health and health related datasets

Researchers using publicly funded health and health-related datasets should:

- Consult with data custodians early in the research project development: be clear about their research intent, and check that the data are appropriate for the intended research purpose.
- Comply with the *National Statement on Ethical Conduct in Human Research (2007)* and be aware of relevant state, territory and Commonwealth legislation relating to privacy and use of data.
- Ensure that the identity of individuals is not disclosed to unauthorised persons, that data are kept secure and only used for the purpose for which their use is approved.
- Meet obligations under legislation and in signed agreements with data custodians for the use of data; including restrictions imposed on the use, sharing and destruction of data; and any requirements for review of research findings and reports.
- Publicly acknowledge in their publications, reports and presentations the data source, and support given by data custodians.
- Be transparent and proactive about:
 - declaring conflicts of interest
 - source/s of funding
 - measures taken to protect and prevent misuse of data
 - the quality of datasets, including identifying any limitations
 - objective reporting of research findings
 - consultation with stakeholders including relevant consumer representatives
 - timeframes for research and publication of findings
 - considerations for research translation
 - compliance with, and the terms and conditions of data provision and usage, and
 - compliance with all relevant legislation, including the *Privacy Act 1988*.