**Attachment A**

***Principles for accessing and using publicly funded data for health***

***Research*: Implementation suggestions**

NHMRC conducted targeted consultation on the Principles and the following ideas

were suggested by the varied stakeholders. As NHMRC does not have a role or

mandate to implement the Principles, these ideas are being provided to agencies

during dissemination to encourage and facilitate greater uptake and use of the

Principles.

This complete suite of suggestions is being provided to all stakeholders so everyone

is aware of the recommendations complied during targeted consultation.

***Research sector ideas***

* Training of researchers regarding the Principles, and how to correctly refer to

their proposed use of data in their ethics and/or grant applications. Current

legislation has good protections of privacy in place, and researchers do not need

to shy away from how they intend to use the data if these provisions are adhered

to.

* Developing and adopting improved practices in research data management,

including: provisions for data sharing and reuse in ethics and clinical trial

protocols; developing data repositories and information technology infrastructure;

and developing policy and advisory services.

* Training of researchers regarding systems or processes for managing research

data, for example http://libguides.library.curtin.edu.au/research-datamanagement

, http://datalib.edina.ac.uk/mantra/ ;

<http://www.lib.umich.edu/research-data-services/nsf-data-management-plans>

***Systems improvements***

Custodians, universities and research institutes could consider:

* Embedding the Principles in the “application for data” process provided online.
* Aiming for consistency of data access policies and procedures across

government (and the research sector).

* Streamlining information systems and access arrangements within the agency,

including: standard operating procedures, application processes, access

agreements and any privacy and confidentiality agreements.

* Incorporating the Principles into accreditation frameworks for organisations that

collect, house or facilitate access and linkage to health and health-related data.

* National technology solutions enabling efficient and secure storage and data

transfer facilities, to help facilitate institutional / researcher compliance with

Australian Privacy Principles.

* Developing repositories that provide a secure unified research environment for

health related data sets where the primary research is completed.

* Developing a tiered access to data, where researchers with extensive track

records who are monitoring safety and benchmarking outcomes in areas

fundamental to provision of quality healthcare, may be provided an expedited

acknowledgment of the validity of their access request.

* Developing template consent forms (universities and research institutes) with

appropriate wording to ensure:

o use of data is made clear

o suitable consent is obtained, and

o clarity of potential future use of data, including any restrictions or

limitations.

***Tips regarding forming Agreements between custodians and researchers***

* Data sharing agreements should clearly state the terms and conditions of use for

the data. Examples of agreements include memorandums of understanding,

contracts, deeds, letters, undertakings, licences, and head of agency

agreements.

* The National Statistical Service and the Australian Bureau of Statistics has

information on the critical elements of these arrangements at

http://www.nss.gov.au/nss/home.nsf/NSS/E6C05AE57C80D737CA25761D002F

D676?opendocument

* Agreements should include information on:

o any restrictions on re-use of data, including commercial use,

o expectations regarding acknowledgement or citation of the material used,

and

o ownership of data and Intellectual Property.

***Agency training opportunities***

* Training of custodians by agencies regarding the Principles, and in the

Appropriate interpretation of relevant legislation.

***Research funders***

* Consider a new funding scheme to attract upgrading and improvements to health

data systems.

* Consider including in relevant funding policies, asking researchers to

acknowledge addressing the Principles in funding applications.