**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.