
Subject:

Data Code Consultation Submission

OFFICIAL

Good afternoon,

Thank you for the opportunity to comment on the *Data Availability and Transparency Code – Exposure Draft and Consultation Paper – Draft Data Code*. It is great to see the DATA Scheme taking form. Comments are provided on selected questions only. [Please publish this response anonymously]

People principle: conflicts of interest

7. Are the requirements of this element of the people principle clear and unambiguous? What, if any, further details or guidance could assist?

8. Is the example provided under this section helpful? Why, or why not?

The Code states "an accredited entity must identify any actual, potential or perceived conflicts of interest of those designated individuals for the entity who are permitted by the data sharing agreement to access the output, or ADSP-enhanced data, of the project". Does this mean that conflicts of interest **only** apply to the outputs, not the process of creating those outputs, eg complex data integration or de-identification activities? It is not clear whether the example of a researcher accessing data which includes family members' information would also apply to a data linker in the same situation. A linker or analyst may see the identifying information of someone they know during linkage or de-identification. The separation principle reduces the information that the linker can access, ie information about the service episode or other content information is kept separately so would not be accessed, and legislative and code of conduct controls provide additional protection.

A researcher working with linked data may recognise a family member in identified data (if this access is permitted) or de-identified data if there are unique combinations of data which are known to the researcher. It is not clear in the Code what action would be expected in these circumstances. Removal of the researcher from the project may be of limited value after the fact.

The example also seems to blur the line between privacy concerns and conflict of interest.

The setting principle

12. Would this section benefit from an illustrative example provided as a note? If yes, what are some proposed examples?

Yes, examples of relevant security standards would be very useful here including a case where the higher level standards would likely be required and what those standards would be (eg IRAP assessment, ISO 27001, essential 8).

Privacy principles - consent

16. One of the objects of the Act is to enable the sharing of data consistently with the Privacy Act and appropriate safeguards. Does this part of the draft data code strike the right balance between holding data custodians accountable to seek consent, and providing data custodians with an exception to collect consent in circumstances where it is genuinely unreasonable or impracticable to seek consent? How could the draft data code be improved to achieve the right balance? For example, could the National Health and Medical Research Council waiver of consent guidelines be used here?

It would be useful to include further guidance or examples on when seeking consent from a large number of individuals (which would be time consuming and incur costs) would be considered 'excessively burdensome'?