Targeted consultation on the draft Principles for accessing and using publicly-funded data for health research submission

Targeted consultation on the draft Principles for accessing and using publicly-funded data for health research submission has been updated.

View  Edit

Submission Details

Submission Closure Date: 16 Feb 2015 - 10:00am

This submission reflects the views of

Views: An organisation
Organisation Name: Council of Australian University Librarians (CAUL)
Please identify the best term to describe the Organisation: Other
Please add further information: Peak body for university libraries in Australia

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Disclaimer

Permission to publish on the NHMRC website: Yes, NHMRC may publish my submission on the NHMRC website
Agreement: I agree
Targeted consultation on the draft Principles for accessing and using publicly funded health and health-related data: https://consultations.nhmrc.gov.au/public_consultations/submissions/

Consultation Questions

1. **Would you describe you or your organisation as?**
   - d) other- please specify (please go to question 2)

2. **How could the principles in the draft Guide add value when making a request to access existing health and health-related datasets for the purposes of health research and for your use of the data?**
   - CAUL is a body representing university libraries who act as custodians of publicly funded health and health related data and who support the development of researcher skills in using and managing publicly funded health and health related data. The principles provide an agreed national approach strengthening libraries’ ability to positively influence researcher data management practise and to negotiate access to publicly funded research data to support our research community.

3. **How could the principles in the draft Guide add value (to you or your organisation) when considering an application to access existing health and health-related datasets for the purposes of health research?**
   - 3. Clearly defining principles which support research which maximises the use of publicly held health and health-related data.

4. **What barriers exist in adhering to or achieving the principles in the draft Guide? How could these be overcome?**
   - From the view of research organisations, barriers to adhering or achieving the principles might include: 1. Visibility of the guidelines to researchers and data custodians – concerted communication strategies will be required. 2. Ability to enforce principles outlined in the guidelines - consideration should be given to mechanisms to reward compliance. 3. Possible costs to the organisation to support compliance with the principles – see 2. 4. Support for data custodians in de-identifying data (see suggestion in Q8 for additional resources for Appendix A) – better sharing of current emergent best practise will also assist here. 5. Need for clarity in definition of terms in the Guide e.g. ‘data custodian’ and ‘data quality’ – there needs to be consistency across all government initiatives (open government/open data initiatives and those emanating from the research sector). 6. The principles assume the data custodian is available to respond to requests from a researcher. In some cases, especially where there are large shared datasets, the data custodian may more appropriately be the institution. It would be useful for an organisation to define workflows should the data custodian be unavailable e.g. data custodian has moved to another institution but the institution has been contacted by a researcher interested in the data. Such workflows would be improved through the use of an international agreed unique researcher identifier linked to the data sets (see 7). 7. Advising data custodians to reference a researcher identifier for themselves (in particular, ORCID) in the metadata stored with a dataset would assist in consistent and persistent identification of these individuals, the links to their datasets, and mitigate the risk of researchers being unable to contact them.

5. **Is there other relevant legislation, regulations and/or policies that could be added to Appendix A in the draft Guide? Please specify, including their relevance.**
   - It may be useful to reference the Office of the Australian Information Commissioner Principles on open public sector information http://www.oaic.gov.au/information-policy/information-policy-resources/information-policy-agency-resources/principles-on-open-public-sector-information

6. **If the Guide was co-badged by other Australian Government Departments, would you or your organisation be more likely to implement it? Why? Why not?**
   - Yes. A Guide that was co-badged by the major Australian national and state government departments involved in the collection of publically funded health and health related data would provide better consistency in the treatment of research and research-related data and reinforce its value across all the public sector. It would ensure consistency in definitions, expectations and ideally in the practises developed to collect, maintain and make accessible the data.

7. **What could be done to publicise and disseminate the Guide, and to encourage its adoption and implementation by researchers and data custodians?**
   - Issuing it to key bodies involved in research services and infrastructure support for researchers, such as university libraries, research offices, national bodies such as ANDs, AeRO, NECTAR and to government agencies involved in the collection of publicly funded health and health related data would be a good initial step. Consideration should also be given to ways in which to reward or recognise good practice.

8. **Do you have any other comments or concerns on particular sections of the document? If so, please use the drop down boxes to select the section you wish to comment on:**

   - **Principle 1b**
     - The term “data quality” is a broad term open to interpretation. It would be useful if this were further defined.

   - **Principle 1c**
     - The term “data quality” is a broad term open to interpretation. It would be useful if this were further defined.

   - **Principle 3e**
     - Suggest explicitly mentioning data citation as an international method of attribution. For example: ‘Publicly acknowledge in their reports and presentations the support given by data custodians and cite the dataset(s) used’.
Finalise submission

My submission is complete: yes