

# PRINCIPLES FOR ACCESSING PUBLICLY- FUNDED DATA FOR HEALTH RESEARCH

Response to the NHMRC's Targeted Consultation  
Draft

February 2015

**RESEARCH  
AUSTRALIA**

AN ALLIANCE FOR DISCOVERIES IN HEALTH



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Research Australia's mission is to make health and medical research a higher priority for the nation. We have four goals that support this mission:

- A society that is well informed and values the benefits of health and medical research.
- Greater investment in health and medical research from all sources.
- Ensure Australia captures the benefits of health and medical research.
- Promote Australia's global position in health and medical research.

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# PRINCIPLES FOR ACCESSING PUBLICLY- FUNDED DATA FOR HEALTH RESEARCH

## RESPONSE TO THE NHMRC'S TARGETED CONSULTATION DRAFT

### INTRODUCTION

In December 2014 the National Health and Medical Research Council undertook a targeted consultation on a draft of the *Principles for Publicly-Funded Data for Health Research* (the Principles).

The consultation invited the electronic submission of responses to a number of specific questions. The questions, and Research Australia's responses, are reproduced below. Only those questions to which Research Australia provided a response are reproduced.

Research Australia is of the view that the Principles could do more to support the linking of data from different datasets and the submission addresses this matter. It also provides some comments on the specific wording of the Principles and proposes an addition to the Glossary.

## RESPONSES TO THE QUESTIONS

### **‘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?’**

While individual datasets can be valuable, much greater value can be derived from the linking of two or more datasets. While the Principles make reference at 2a. to having processes in place that cover the use of data for future research purposes, no specific reference is made to facilitating future data matching and linking with other datasets. Research Australia submits that the following paragraph should be added to Principle 1. ‘Data should be collected, structured and stored in ways that optimise the opportunity for linking to other datasets for future research purposes.’

The linking of data requires the manipulation of datasets to facilitate the linking process. This activity takes time and effort and may require specific skills and tools. In many cases the data custodian is best placed to undertake the manipulation of the data and the provision of the dataset to the researcher in a format that enables the linking to be undertaken. (In some cases the data custodian may be the only person or entity capable of doing this.) Research Australia submits that Principle 2 should be expanded to include a requirement that where relevant to the research being undertaken, data custodians should endeavour to provide researchers with datasets in a format that facilitates data linking with other specified datasets.

### **‘Do you have any other comments or concerns on particular sections of the document?’**

#### **Other**

In the heading on Principles 1 and 3 the expression ‘Publicly held...’ is used rather than the expression ‘Publicly-Funded’, which is used throughout the rest of the document. (The expression ‘Publicly-funded data’ is included in the Glossary but not ‘Publicly held data’.)

Research Australia submits that if the two terms are intended to have different meanings they should both be included in the Glossary and the distinction between the two terms made clear. If the terms are being used interchangeably, Research Australia submits that the expression ‘Publicly held’ should be replaced in both instances with ‘Publicly-funded’.

### Appendix C- Publicly-funded data

The definition of 'Publicly-funded data' in the Glossary consists of two sentences. The first sentence is '***Data whose collection and maintenance rely on funding from the government at relevant jurisdictional levels.***' It is not entirely clear what the underlined expression means. (It is clear from the text of the Principles that the Principles are intended to apply to '***...data sets whether held at national, state/territory or local level.***'('Scope and Target audience', page 2 )

The first sentence also fails to address the question of whether it is data wholly or partially funded by governments that is to be included. The Purpose section at the start of the Principles makes it clear that it is both: '***The Principles are a guide for researchers who are seeking access to wholly or partly publicly funded datasets.***' ('Purpose', p.2)

Research Australia proposes replacing the first sentence with 'Data whose collection and maintenance rely wholly or partially on funding from Commonwealth, State/Territory, or local government/s'.

The second sentence in the definition is '***Datasets established through publicly funded modes, for example publicly funded health services.***' While we note the reference to 'data' in the first sentence and 'datasets' in the second, the significance of this is not apparent. Furthermore, the expression 'publicly funded modes' is unclear, and is not assisted by the example of 'publicly funded health services'.

Research Australia submits that the second sentence of the definition be reworded so that its meaning is clearer. Alternatively, consideration could be given to deleting it.

### Appendix C- Data Custodian

The expression 'data custodian' is used throughout the Principles but is not defined. Research Australia submits that a definition of data custodian should be included in the Glossary

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