



Australian Government

National Health and Medical Research Council

NH|M|R|C

GPO Box 1421 | Canberra ACT 2601
16 Marcus Clarke Street, Canberra City ACT 2600
T. 13 000 NHMRC (13 000 64672) or +61 2 6217 9000
F. +61 2 6217 9100
E. nhmrc@nhmrc.gov.au
ABN 88 601 010 284
www.nhmrc.gov.au

Mr Peter Harris AO
Chairman
Productivity Commission
GPO Box 1428
Canberra City ACT 2601

Dear Mr Harris

NHMRC welcomes the release of the draft report from the inquiry into Data Availability and Use and the opportunity to provide input. The draft report provides further context and supports the direction of NHMRC's current work updating corporate data systems and policies to facilitate greater access to publicly held and funded Health and Medical Research (HMR) related data.

Draft recommendation 3.1 and 3.2 will assist in encouraging both government and research agencies to list data sets and enable access. A framework for data sharing that takes account of the spectrum of risk associated with different types and uses of data will protect more sensitive datasets and still allow access for 'trusted' or accredited users. NHMRC supports the intent of draft recommendations 9.5 to 9.7 to accredit researchers to access sensitive data to ensure identifiable data are only used in environments where privacy and confidentiality are ensured.

Australia's health data are highlighted in the draft report. *NHMRC Principles for accessing and using publicly funded data for health research (2015)*¹ already support and encourage greater access for researchers to publicly held health data. The draft report recommendations would further assist to facilitate access to data sets and support data linkage. Data linkage is an effective way to investigate the outcomes, both positive and negative, of health interventions. For example Gertig et al. (2013)² showed through data linkage that human papillomavirus vaccinations in Australia significantly reduced cervical abnormalities and Mathews et al. (2013)³ successfully investigated cancer incidence rates for people exposed to CT scans.

NHMRC corporate data on research grant expenditure are used by stakeholders to analyse the grant program's allocation of funds from year to year. In the near future more data will be released publicly from the grants administration system. Whether some of these data could only be provided to accredited users is not clear at this stage. The draft report provides useful guidance on this issue for all Government Departments.

NHMRC provides national leadership on the conduct of HMR research, including research ethics, and it is integrally involved in the translation of HMR research. In particular two of the draft recommendations, 3.2 and 9.9, are

¹ <https://www.nhmrc.gov.au/principles-accessing-and-using-publicly-funded-data-health-research>

² Gertig DM, Brotherton JML, Budd AC, et al. 2013. Impact of a population-based HPV vaccination program on cervical abnormalities: a data linkage study. *BMC Medicine* 11:227. doi: 10.1186/1741-7015-11-227.

³ Mathews JD, Forsythe AV, Brady Z, et al. 2013. Cancer risk in 680 000 people exposed to computed tomography scans in childhood or adolescence: data linkage study of 11 million Australians. *BMJ* 346:f2360. doi: <http://dx.doi.org/10.1136/bmj.f2360>.

specific to administrators of publicly funded research and the implementation of these draft recommendations will need careful consideration if adopted by Government. These and other draft recommendations may have significant cost implications, particularly for small Government agencies.

I would welcome the opportunity to meet with you to discuss the draft recommendations in person. My office staff will be able to arrange a meeting time that would be mutually convenient.

I look forward to the final report of this important inquiry in early 2017.

Yours Sincerely

A handwritten signature in dark ink, appearing to read "Anne Kelso". The signature is fluid and cursive, with a small dot at the end.

Professor Anne Kelso AO

Chief Executive Officer

12 December 2016