Author reply

Dharmenaan Palamuthusingam, David W. Johnson, Carmel M. Hawley, Elaine M. Pascoe & Magid Fahim

Health data linkage in Australia remains challenging¹ as reflected in our recent experience of multi-jurisdictional data linkage. We welcome the Population Health Research Network (PHRN) collaborative's initiatives in establishing a streamlined and unified application process in multi-jurisdictional data linkage projects, and we fully support their vision. We acknowledge the concerns raised by Flack and Smith² and take this opportunity to elaborate.

First, Flack and Smith² refer to the coordinated online application process. However, even at the time of writing this reply, this application process is not universally accepted by several large jurisdictions who still require their own application to be completed. We would strongly welcome a centralised process to streamline applications, but unfortunately this is still not yet a reality.

Second, pertinent to our experience was the use of hospital admission datasets and hence the article by Tew et al.³ was the most relevant as this was the dataset of interest in their systematic review. Flack and Smith² identify a more recent review by Young and Flack⁴ demonstrating a positive trend in research output when considering all other datasets. This is a promising finding but was published well after submission of our narrative reflection.

Finally, we do not dispute that human research ethics committee (HREC) approval is essential when undertaking data-linkage projects and we advocate that all researchers undertaking data-linkage seek ethics approval for the reasons outlined in our narrative.¹ Our intention was to highlight the inconsistency between different jurisdictions' review processes, whereby custodian consultation could only occur after HREC approval running the risk that custodians modify research requests resulting in HREC amendments that would have been avoided had the custodian consultation occurred earlier in the process. We also wished to highlight the national mutual acceptance memorandum is inconsistently applied across

jurisdictions and we welcome the PHRN's ongoing contribution to achieving national acceptance.

With an ever-increasing emphasis on data-linkage research, we support the sentiments of Flack and Smith² that comprehensive ethical and legal frameworks are equally as important in creating effective data-linkage infrastructure. We also wish to emphasise that a unified consistent process is essential to maximise the utility of this valuable resource. The PHRN's leadership in harmonising the currently fragmented approval process for multi-jurisdictional data-linkage is greatly appreciated and welcomed.

References

1. Palamuthusingam D, Johnson DW, Hawley C, Pascoe E, Fahim M. Health data linkage research in Australia remains challenging. *Intern Med J* 2019; 49: 539– 44.
2. Flack F, Smith M. Access to linked data: challenges and progress. *Intern Med J* 2019; 49: 1335–6.
3. Tew M, Dalziel KM, Petrie DJ, Clarke PM. Growth of linked hospital data use in Australia: a systematic review. *Aust Health Rev* 2017; 41: 394– 400.
4. Young A, Flack F. Recent trends in the use of linked data in Australia. *Aust Health Rev* 2018; 42: 584– 90.