of these studies, Hirayama *et al*. reported 13 of 21 (62%) patients with relapsed/refractory or transformed FL obtaining a complete response, many of which were sustained beyond 2 years.[3] We are also heartened by the clinical trial access to CAR-T cells at limited sites in Australia. Nonetheless, the immaturity of data in FL, and its expense, will likely preclude widespread availability of this approach in Australia and New Zealand for some years.

Although we acknowledge that FL is incurable, the prolonged remissions seen following effective first line therapy likely provides a 'functional cure' for many patients (who have a median age at presentation of 60). For younger patients, with an anticipated median PFS beyond 15 years after anti-CD20 antibody-bendamustine chemotherapy, we can anticipate for most patients any CD4 lymphopenia will have resolved at the time of any relapse.[4] Martinez-Calle reported a median time to lymphocyte count recovery ($\geq 1 \times 10^9$/L) following bendamustine of 26 months with rituximab maintenance associated with further delays in recovery.[5] Saito observed recovery of lymphocyte and CD4-positive T-cell counts to those at baseline at 7–9 months after the completion of bendamustine.[6] There is a paucity of data on the 'fitness' of the T-cell compartment over time and the ability to generate CAR-T cells, from bendamustine-treated patients. Whether the small risk (<10%) of early progression and/or transformation of disease within the first 2 years justifies avoiding bendamustine in the first-line treatment is unclear. We lack adequate pre-treatment prognostic factors for FL to inform fully the choice of first line therapy in a given patient. Perhaps the impact of CD4 lymphopenia following bendamustine on T-cell fitness for immunotherapy will be more relevant in subsequent lines of therapy.

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## Access to linked data: challenges and progress

The paper by Palamuthusingam *et al*. describes the challenges faced by researchers wishing to access Australian linked data.[1] We agree with several points they make. Their experience replicates the experiences of others as highlighted in several Government reports.[2,3] We also agree that the Population Health Research Network's (PHRN) role includes advocating for changes that will improve access to linked data for researchers. However, the article included out of date information and misinterpretations that should be clarified.

The PHRN is not a 'central body' but a national collaborative network of government agencies and academic institutions. Despite the challenges described in the article, this collaboration has significantly improved access to linked data. In 2009, two states

(WA and NSW) had data linkage units (DLU) and now all states and territories are serviced by DLU. Access to cross-jurisdictional linked data was restricted to a few special programmes or *ad hoc* arrangements. Today, all researchers can apply for access to cross-jurisdictional linked data through a coordinated online application process.

The authors were critical of the number of publications attributed to the use of the new DLU based on a paper by Tew *et al*.[4] This paper only included publications involving linked hospital data and counted publications up to 2014 when the new DLU were still in their infancy. Many researchers receiving data through these facilities would not have had time to complete their analysis and publish their results. More recent publications data are available and could have been cited.[5]

The legal and ethical frameworks in which data intensive research must be conducted are complicated and overlapping.[6] The authors claim that their example only involves non-identifiable data and can be exempt from ethical review (National Statement 5.1.22).[7] However, it could not be exempt under Section 5.1.22 because it uses existing identifiable data collections and identifiable data are used to create links between the data collections. The detailed clinical data provided to the researchers for analysis may also be identifiable (National Statement 3.1 Element 4).[7] In addition, the waiver of consent to link the data must be approved by a human research ethics committee (National Statement 2.3.9).[7] The authors also imply that data custodians are insisting on ethics review unnecessarily, however, HREC review may also be required to meet legal requirements under the statute governing the particular data collection.[6]

The authors note that projects involving linked data are currently excluded from the National Mutual Acceptance Scheme (NMA) by several jurisdictions. The PHRN participated in the development of a report to the NMA Jurisdictional Working Group which made recommendations about including linked data in the NMA. The report is currently under consideration by the Working Group.

Finally, the authors are supportive of the recommendations in the Productivity Commission Report but fail to acknowledge that the Australian Government has accepted the report and are in the process of implementing the recommendations. The PHRN will continue to advocate for these and other initiatives to improve researcher access to Australian linked data.

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## Author reply

Health data linkage in Australia remains challenging[1] 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