

20th December 2021

Data Requests Relating to Patient Ethnicity

ANZDATA has updated its policy on the approval process for data requests relating to ethnic groups living within Australia and New Zealand. We continue to frequently receive requests for data extracts including ethnicity, where the relevance of this is not clear to analyses.

Specific ethnic populations may experience health inequities due to historical factors including colonisation, socioeconomic factors including poverty, educational attainment, housing and employment, institutional racism, and other factors. Potential genetic variation relevant to disease prevalence and severity, and treatment responsiveness may be associated with ethnic identity. Therefore, research that includes patient ethnicity data may be valuable in addressing ANZDATA's mission to improve the understanding of kidney disease and outcomes of treatment for patients with kidney failure. However, ethnicity is a complex personal and cultural identity and research that includes information collected by the Registry on ethnicity should engage meaningfully and respectfully with the relevant concepts.

Therefore, when ethnicity data is requested but the primary focus of the research is not related to patient ethnicity (Group 2 in policy 2.9 Guidance on data requests relating to patient ethnicity) a clear and appropriate description of the planned use of this data is required prior to request approval. We would strongly discourage researchers from treating ethnicity as a confounder and adjusting for this within analyses without careful consideration. Instead, we would encourage adjusting for the determinants of health or risk factors that may be differentially and inequitably distributed. Please read the ANZDATA policy document for more details on this process and how to request this data for projects.

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