

Empowering First Nations Leadership in Hepatitis B Research: The Role of the Infectious Diseases Indigenous Reference Group.

Authors:

Bailey A¹, D'Antoine H^{1,2}, Gurruwiwi G¹, Bukulatjpi S^{1,3,4}, Dhurrkay R¹, De Santis T⁵, Nelson S⁵, Wurrawilya S⁵, Ross C¹, Riley K⁶, Alley T¹, Vintour-Cesar E¹, Hosking K^{1,5}, Binks P¹, Davies J^{1,5}

¹Menzies School of Health Research, ²University of Queensland, ³Miwatj Health Aboriginal Corporation, ⁴Marthakal Homelands Health Service, ⁵NT Health, ⁶Tingkabee Cultural and Interpretation Services.

Background:

The Northern Territory has some of the highest liver cancer rates in Australia, disproportionately affecting First Nations people, with chronic hepatitis B identified as the main cause. In response, the Menzies School of Health Research established the Infectious Diseases Indigenous Reference Group (IRG) in 2014, comprising fourteen members from seven remote communities. The IRG was formed to provide cultural guidance and advice on hepatitis B research initiatives. However, early participation revealed that many members lacked sufficient knowledge about hepatitis B, highlighting a broader knowledge gap within the community and the need for targeted education.

Argument:

Guided by two-way learning principles, the IRG recognised the importance of hepatitis B education to enhance members' ability to provide well-informed advice. In remote communities, hepatitis B is often perceived as a new condition, compounded by stigma and shame. Acknowledging this, the IRG requested dedicated education sessions before meetings to empower members to contribute effectively to research discussions.

Outcome:

Annual education sessions have been instrumental in enhancing IRG members' hepatitis B knowledge and fostering confidence in their advisory roles. These sessions ensure that the research aligns with community priorities. The IRG plays a pivotal role in guiding non-First Nations researchers to approach research respectfully, ensuring cultural safety and promoting First Nations leadership. Amplifying First Nations voices in health research and decision-making ensures respect for cultural practices, values and traditions, guaranteeing traditional knowledge is part of the research process.

Conclusions:

Hepatitis B education should be provided to IRG members to enable them to offer well-informed advice on research projects in First Nations communities. The IRG's Cultural brokerage has been integral to the success of the Menzies hepatitis research program, ensuring that research aligns with cultural protocols and community needs. In 2024, the IRG celebrated its 10th anniversary, marking a decade of strengthening First Nations involvement in hepatitis B research.

Disclosure of Interest Statement:

The Authors of this work recognise the considerable contribution that industry partners make to professional and research activities. We also recognise the need for transparency of disclosure of potential conflicts of interest by acknowledging these relationships in publications and presentations. The Authors of this work have no conflicts of interest to declare. We also wish to thank the people living with viral hepatitis who participated in this research".