

“Talking about something no one wants to talk about” - navigating hepatitis B-related work in remote Australian Aboriginal communities: A decade of learning and growth

Authors:

Binks P¹, Gurruwiwi GG^{1,a}, Dhurrkay RG^{1,a}, Bukulatjpi SM^{1,2,a}, Ross C^{1,b,c}, Hosking K^{1,3}, Tate-Baker J³, Marshall C^{1,3}, Everitt A¹, McKinnon M¹, Vintour-Cesar E¹, Sullivan RP¹, Davis JS^{1,4}, Hefler M¹, Davies J^{1,3}

¹ Menzies School of Health Research, ² Miwatj Health Aboriginal Corporation, ³ Northern Territory Health, ⁴ John Hunter Hospital NSW

^a Yolŋu people, ^b Arrernte people, ^c Kaytetye people

Background: Chronic hepatitis B (CHB) is one of the leading causes of liver cirrhosis and liver cancer globally. In Australia, Aboriginal and Torres Strait Islander people of the Northern Territory (NT) have the highest prevalence of CHB (6%) and are six times more likely than non-Aboriginal people to be diagnosed with liver cancer. In 2010, a “liver one-stop shop” model of specialised care and hepatitis B research program was initiated to address this disparity. Despite many challenges, the program was accepted in NT Aboriginal communities. This study aimed to identify the key elements linked to this success.

Methods: We conducted a retrospective case study using Stake’s methodology to understand the hepatitis B phenomenon. A constructivist approach allowed a holistic understanding from the real-life perspectives of those involved in the hepatitis B work. Information was sourced from the Aboriginal workforce, patients of remote clinics, interested community members and service providers. Adhering to participatory action research principles, we maintained a cyclical rhythm, consistently moving through data collection, analysis, interpretation, and the application of findings to refine clinical and research methodologies.

Results: We identified six elements critical to the successful conduct of our hepatitis B program, which included the essential role of the local Aboriginal workforce, providing health education in a patient’s preferred language, addressing shame and stigma, respecting culture, taking time, and building trust in the community.

Conclusion: Commitment over the long term was crucial for the success of our hepatitis B program. Adhering to the identified elements was essential to create a culturally safe environment and engage more Aboriginal people in clinical care and research. This study provides powerful lessons and insights that can be applied to other programs and comparable settings worldwide.

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