

“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

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Acknowledgement of Country

Background

- CHB is a leading cause of liver cirrhosis and liver cancer globally.
- Prevalence of CHB in the Aboriginal and Torres Strait Islander population of NT is 6%.
- Aboriginal and Torres Strait Islander people of the NT are 6 times more likely to get liver cancer.
- NT Health Viral Hepatitis Unit initiated a clinical outreach service, which evolved into the “liver one-stop shop”.
- Lack of CHB knowledge in the community, leading to the development of the “Hep B Story” app.
- Unique hepatitis B sub-genotype, C4, with markers of aggressive disease and exclusive to the Aboriginal population.

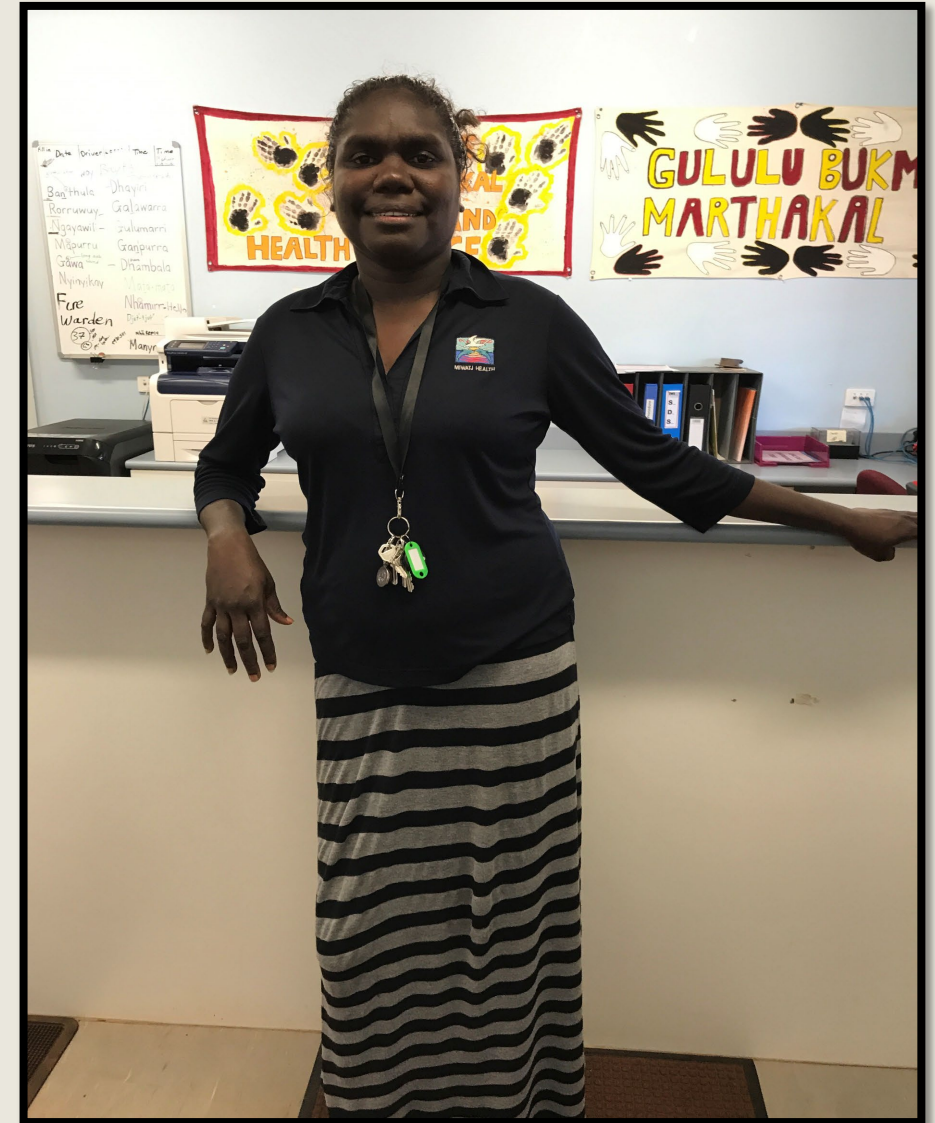
Background

- Began in community research, and the response from the community was surprising.
- Many participants reluctant to participate and visibly uncomfortable talking about hepatitis B.
- Projects encountered apprehension and delays unlike other projects.
- Feedback from community members, hep B projects not well received.
- Prompted a review of project methods and hepatitis B phenomenon.
- Six-month educational program conducted by Community Based Researchers.

Background



Essential role of the Aboriginal Health Workforce and Community Based Researchers





“When Balanda (non-Aboriginal person) tells the story, Yolŋu (Aboriginal person) doesn’t understand whole story, they don’t know about hep B, don’t hear story right, and get confused”.

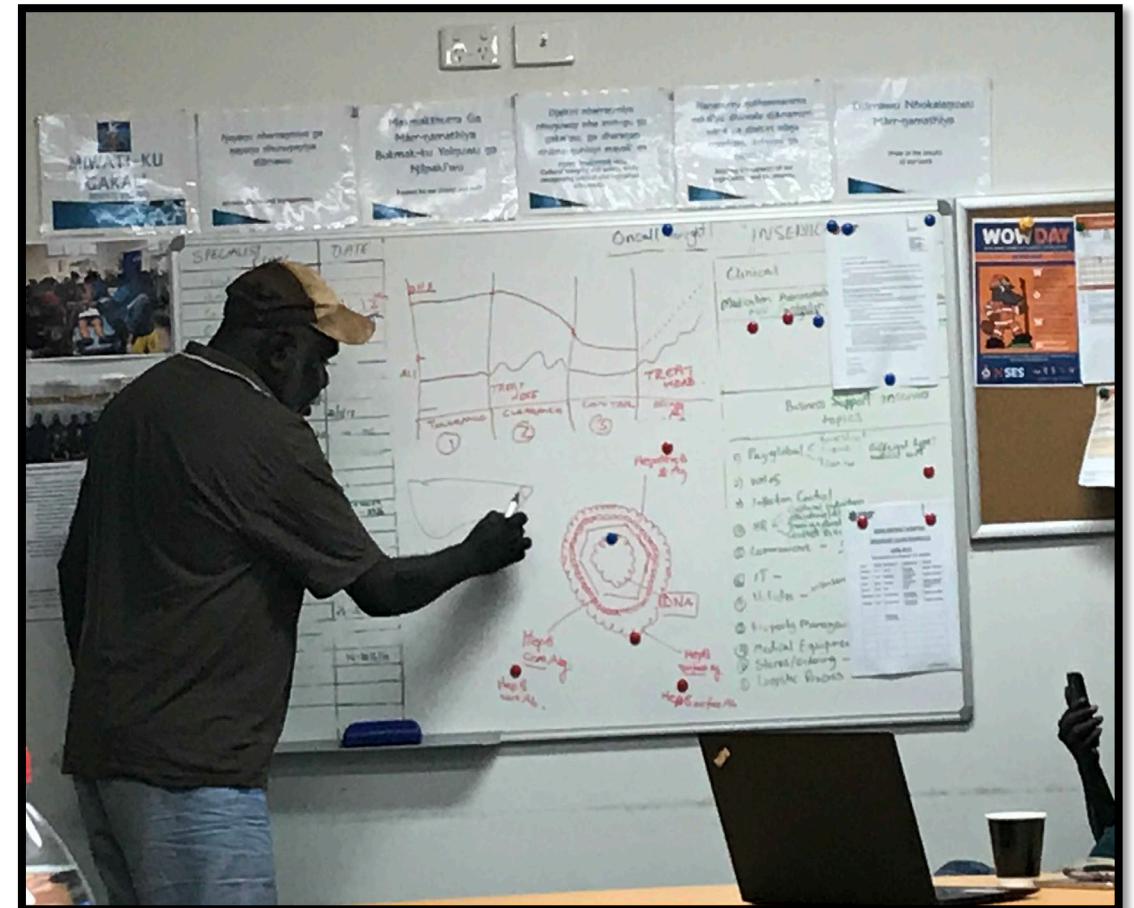
Community Based Researcher

The importance of providing hepatitis B education in a person's preferred language



“I will never forget the way his eyes lit up (person living with chronic hepatitis B whom I had been seeing for a number of years) when he heard the story in his own language facilitated by a Community Based Researcher, it was a very humbling moment for me”.

Non-Aboriginal specialist physician



Addressing shame stigma and blame



Addressing shame stigma and blame

“People need the full information to make their own decisions to have hep B check without shame.”

Community Based Researcher

“Need to be very careful that we don’t make mothers feel guilty of blame.”

Community Based Researcher



Respecting cultural norms and kinship relations



“He just got up and walked out in the middle of the mother-to-child transmission section (of the education session). That was the first time it really struck me that these rules are not a guide. They are non-negotiable”.

Non-Aboriginal doctor

“Not have yapa (sister) and wawa (brother) together hearing the story.”

Community Based Researcher



The necessity of building trust and respect

“At first, I found it hard and confronting to take and incorporate the advice that was fundamentally so different to my Western biomedical training, but as I did and observed the results, I gained confidence and trust in our equal and respectful working relationship to achieve the best outcome for the patient”.

Non-Aboriginal doctor

“We stand together and share knowledge and do research in proper way”.

Community Based Researcher



The value of taking time and avoiding rush

“Must be patient, give proper time to think, don’t push them. When we started this project, people felt uncomfortable; we just leave those people; they not ready, we walk away and say OK. Sometimes they hear from other people and then come back and ask us”.

Community Based Researcher

“Recognising the profound truth that, as a highly trained specialist, one’s effectiveness hinges entirely on access to information conveyed in the appropriate language and the trust and support of Aboriginal Health Practitioners and Community Based Researchers is a compelling insight. This awareness underscores the significance of relinquishing power imbalances and levelling hierarchies, leading to a transformative shift in dynamics”



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