Discover Health Systems

Case Study

"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

Paula Binks[1] · **George Garambaka Gurruwiwi**[1] · **Roslyn Gundjirryirr Dhurrkay**[1] · **Sarah Mariyalawuy Bukulatjpi**[1,2] · **Cheryl Ross**[1] · **Kelly Hosking**[1,3] · **Jaclyn Tate-Baker**[3] · **Catherine Marshall**[1,3] · **Melita McKinnon**[1] · **Emily Vintour-Cesar**[1] · **Richard P. Sullivan**[1] · **Joshua S. Davis**[1,4] · **Marita Hefler**[1] · **Jane Davies**[1,3]

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Abstract

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 research 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.

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.

Conclusions 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.

Keywords Hepatitis B · Aboriginal and Torres Strait Islander People · Cultural safety · Health outcomes · Empowerment · Self-determination · Education · Equity · Engagement in care

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✉ Paula Binks, paula.binks@menzies.edu.au; George Garambaka Gurruwiwi, gurruwiwigeorge59@gmail.com; Roslyn Gundjirryirr Dhurrkay, mpz5@bigpond.com; Sarah Mariyalawuy Bukulatjpi, sarah.bukulatjpi@miwatj.com.au; Cheryl Ross, cheryl.ross@menzies.edu.au; Kelly Hosking, kelly.hosking@nt.gov.au; Jaclyn Tate-Baker, jaclyn.tate-baker@nt.gov.au; Catherine Marshall, Catherine.Marshall@nt.gov.au; Melita McKinnon, melita.mckinnon@menzies.edu.au; Emily Vintour-Cesar, emily.vintour-cesar@menzies.edu.au; Richard P. Sullivan, richie.sullivan@menzies.edu.au; Joshua S. Davis, joshua.davis@menzies.edu.au; Marita Hefler, marita.hefler@menzies.edu.au; Jane Davies, jane.davies@menzies.edu.au | [1]Global and Tropical Health Division, Menzies School of Health Research, Charles Darwin University, Darwin, NT, Australia. [2]Miwatj Health Aboriginal Corporation, Nhulunbuy, NT, Australia. [3]Northern Territory Health, Darwin, NT, Australia. [4]John Hunter Hospital, Newcastle, NSW, Australia.

Abbreviations

CHB	Chronic hepatitis B
PAR	Participatory action research
NT	Northern territory
HCC	Hepatocellular Carcinoma

1 Background

Chronic hepatitis B (CHB) is a significant global public health concern, affecting 296 million people worldwide [1]. The Northern Territory (NT) bears the highest prevalence of CHB in Australia (1.78%), with Aboriginal and Torres Strait Islander people disproportionately affected (6%) [2, 3]. Left untreated, CHB can lead to fatal outcomes, with 25% of CHB patients succumbing to cirrhosis or liver cancer [4]. In 2010, our research highlighted alarmingly high rates of hepatocellular carcinoma (HCC) in the NT's Aboriginal population, with hepatitis B virus as the primary cause [5]. In response, the NT Health Viral Hepatitis Unit initiated a clinical outreach service, initially targeting two high-prevalence remote NT Aboriginal communities. Over the subsequent decade, the viral hepatitis clinical outreach service transformed into what we now refer to as the "liver one-stop shop." This specialised model of care involves a team consisting of a specialist physician, ultra-sonographer, clinical nurse consultant/nurse practitioner, and local Aboriginal Health Practitioner [6]. Each client receives a comprehensive care package, including an ultrasound, FibroScan®, CHB education in their preferred language, and consultation with a specialist physician or nurse practitioner [7]. Presently, the liver one-stop shop visits more than ten remote communities several times each year. In 2012, a senior Aboriginal Health Practitioner identified a profound lack of CHB knowledge within remote Aboriginal communities, particularly in explaining CHB to clients utilising the health service who did not primarily speak English. This observation led to the development of the "Hep B Story" app, a collaborative effort between the Menzies School of Health Research (Menzies), the local community, and healthcare staff [8, 9]. The "Hep B Story" was the first educational tool on hepatitis B created in an Aboriginal language (Yolŋu Matha) and has since been translated into an additional ten Aboriginal languages [10].

Further research by our team unveiled a unique hepatitis B sub-genotype, C4, marked by indicators of more aggressive disease progression [11–13]. This sub-genotype was exclusive to the Aboriginal population, increasing the urgency for both further research into its natural history and the need to provide holistic care to those living with CHB. As the Menzies hepatitis B research program expanded beyond clinic-based care, an initial surprising response was observed within the community, with many members exhibiting adverse reactions such as reluctance to participate in the research and displaying visible discomfort when broaching the subject of hepatitis B. This manuscript explores the rich tapestry of experiences, insights, and lessons gleaned over a decade of working on hepatitis B-related initiatives in Aboriginal communities. Drawing from the participatory action research (PAR) framework, we delve into the complexities of addressing the hepatitis B phenomenon and the modifications we applied to our approach while maintaining cultural safety and efficacy in research and clinical service delivery.

2 Methods

Given the timeframe and the necessity to retrospectively comprehend and reconstruct processes, we adopted a case study design based on Stake's methodology [14]. This constructivist approach offers a flexible and pragmatic approach to unravelling the enigmatic elements of the hepatitis B phenomenon, thereby facilitating a holistic understanding deeply embedded in the real-life perspectives of the involved parties. We analysed and synthesised information from various sources, enabling a thorough and multifaceted exploration of the challenges surrounding the delivery of clinical services and research pertaining to hepatitis B in remote communities. Instead of adhering to a pre-existing framework, we were guided by our experiences, discussions, observations, and data analysis to adapt our approach to create a culturally safe hepatitis B clinical service and research program.

2.1 Setting

This case study analyses data from several remote communities in the NT from 2010 to the present. The NT is a vast and sparsely populated region covering approximately 1.34 million square km [15, 16]. Numerous remote communities are accessible by road only during the dry season, becoming isolated during the wet season. Air travel is the primary means of access. The provision of a viral hepatitis outreach clinic service extends to more than ten communities spanning the NT, encompassing the tropical Top End to the arid Central region. Frequent movement between communities and strong familial and community connections often transcend the boundaries of neighbouring communities, contributing to the complexity of healthcare delivery and research in this region.

2.2 Researcher reflexivity

The team comprises Aboriginal members (GG, RD, SB, CR) representing diverse language and cultural groups across the NT. They bring a wealth of experience as Aboriginal Health Workers, and Researchers and have extensive family connections throughout communities in the NT. The non-Aboriginal team members (PB, KH, JTB, CM, MM, EVC, RPS, JSD, MH, JD) possess extensive experience in Aboriginal clinical service delivery and/or research. The team upholds Participatory Action Research (PAR) principles to ensure a respectful and inclusive work environment. It is committed to continuously reflecting upon their biases and working together to eliminate them.

2.3 Ethical approval

Ethical approval for the study protocol was obtained from the Human Research Ethics Committee of the Northern Territory Department of Health and Menzies School of Health Research (NTHREC 2018-3240) and (NTHREC 2018-3242). This study was conducted in accordance with relevant guidelines and regulations, including the Declaration of Helsinki and the NHRMC ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: Guidelines for Researchers and Stakeholders and the Australian Institute of Aboriginal and Torres Strait Islander Studies Code of Ethics. Informed consent was obtained from all participants in this study.

2.4 Data collection and analysis

In our research approach, no strict demarcation existed between the data collection, analysis, and interpretation phases. Instead, we embraced an iterative process wherein the ongoing analysis and interpretation of data played a pivotal role in shaping our practices. We engaged participants through inquiries and keenly observed their surroundings and behaviours. Throughout this journey, we fostered a culture of continuous dialogue within our team meetings, allowing us to collectively refine our comprehension of providing clinical service and conducting hepatitis B research in remote Aboriginal communities. Adhering to PAR principles [17–19], we maintained a cyclical rhythm, consistently moving through data collection, analysis, interpretation, and the application of findings to refine clinical and research methodologies. This iterative approach was fortified by member checking, a crucial step that bolstered our confidence in the validity of our results. By seeking confirmation from participants, we ensured that our findings genuinely reflected their sentiments and experiences.

Throughout the PAR process, the authors achieved consensus on the themes elucidated in this paper. These themes serve as the cornerstone of our ongoing work approach. Although we have been operating within these principles for several years and steadily refining them through iterative processes, this is the first time they have been explicitly presented.

All data collection spanned a decade and aimed to maximise richness and validate findings through diverse sources, including individual and group discussions, observations from study participants and researchers, and field experiences and notes. Key informants for this data collection effort were Community Based Researchers and Aboriginal Health Workforce members (consisting of Aboriginal Health Practitioners, Aboriginal Health Workers and Community Health Workers) engaged in hepatitis B research and working at the local medical clinic. Additionally, insights were sought from patients attending the viral hepatitis clinic, family and community members, and non-Aboriginal medical practitioners.

2.4.1 Discussions with Community Based Researchers and Aboriginal Health Practitioners

Comprehensive discussions were held with the Community Based Researchers and Aboriginal Health Practitioners actively engaged in the research and clinical service. The primary objective was to discern distinctions between hepatitis B and other health conditions present within the community. The most valuable dataset emerged from these interactions. These discussions were characterised by their informality, deliberately avoiding audio recordings to foster a relaxed atmosphere conducive to open and candid conversations on hepatitis B. Notes were meticulously taken during these discussions and subsequently reviewed with participants to ensure their accuracy. Interpretations drawn from the data were later presented to the participants, further reinforcing the credibility and integrity of the information obtained.

2.4.2 Observations of participants, hepatitis B patients, and Aboriginal Health Practitioners

Verbal and behavioural reactions from community members approached for study participation, and those observed during clinical consultations were meticulously documented and subjected to discussion. Incidents, actions, spoken words, and dialogues were carefully observed and noted during interactions with hepatitis B patients and local Aboriginal Health Practitioners.

2.4.3 Researcher and clinician field notes and experiences

The dataset encompassed field researcher notes from an individual well-versed in study recruitment and a senior clinician. It further incorporated personal reflections, experiences, and guidance from Community Based Researchers and Aboriginal Health Practitioners, all duly documented and integrated into the analysis. Visual materials such as photographs and video recordings were also part of the dataset.

3 Results

The research team initiated the recruitment of participants for hepatitis B projects in 2010. These participants were individuals under the care of the viral hepatitis unit, well-informed about their hepatitis B status, and willingly participated in the research project [11, 12]. In 2014, the team embarked on "in-community research" projects [20, 21] involving the collection of biological specimens from participants residing in various remote communities. This necessitated study staff to visit potential participants at their homes. The consent process involved providing information about the project's requirements and hepatitis B, with this communication conducted by Community Based Researchers in the local Aboriginal language, supported by non-Aboriginal team members. However, the recruitment rate was below expectations, and these projects encountered significant resistance and apprehension, leading to substantial delays in progress. Although the community had previously engaged in other health research projects, the newfound reluctance was unexpected. Community members provided feedback to the Community Based Researchers, revealing that hepatitis B research projects were not well-received within the community. Many community members had little to no prior knowledge of hepatitis B and were overwhelmed by the new information. Even those who had some awareness of hepatitis B felt uncomfortable discussing it. It became evident that the traditional study approach was not proving successful.

Example 1. Unexpected reactions to research visits At the outset of our hepatitis B community study visits, household members would assemble in a group, initially eager to learn about the study's purpose. However, as research staff delved into discussions about hepatitis B, individuals would gradually disperse from the group. By the end of the discussions, only a few individuals would remain engaged, as many felt uncomfortable continuing the conversation and were hesitant to participate further.

Furthermore, it came to our attention that not all members of the Aboriginal Health Workforce possessed awareness of hepatitis B, and the additional burden of understanding another chronic medical condition affecting Aboriginal communities was understandably overwhelming.

Example 2. Aboriginal Health Practitioner at morning meeting On the initial day of our scheduled 6 week stay in a particular community, we attended the morning staff meeting at the local health clinic as a courtesy to inform them of our presence in the community and discuss our upcoming hepatitis B research project. However, it swiftly became evident during the presentation that people were experiencing discomfort when the topic of hepatitis B was broached. One Aboriginal Health Practitioner expressed strong displeasure, remarking, "Why this hep B, another disease affecting Aboriginal people."

We were genuinely surprised to learn that this Aboriginal Health Practitioner had never encountered information about hepatitis B, despite the ancient nature of the virus [22]. Hepatitis B surface antigen was first identified in blood samples from Aboriginal people and was initially referred to as "The Australian Antigen" [23]. This lack of awareness was particularly striking, considering their role in a health clinic in a community with a high prevalence of hepatitis B.

The community and local health staff's response prompted our team to conduct a comprehensive analysis of our project methods and the hepatitis B phenomenon itself. Concurrently, we initiated an intensive community education program focussed on hepatitis B. For six months, two Community Based Researchers stationed themselves outside the medical clinic in one community, equipped with the educational app "Hep B Story" [9], and offered to share it with community members as they awaited their appointments (Fig. 1). Simultaneously, the viral hepatitis outreach service continued its clinical visits to the community, with the same Community Based Researchers delivering hepatitis B education to the clients.

Gradually, community members became increasingly acquainted with the "Hep B Story." Even those who had initially declined to engage were now more comfortable approaching the Community Based Researchers and requesting to hear the story. What we uncovered was genuinely unexpected. There was a noticeable surge in the number of regular CHB clients seeking consultations at the one stop shop specialist outreach clinic. These clients began arriving at the medical clinic even before it opened, and some were present even before the medical specialists' plane had landed, eagerly anticipating their "Hep B check-up with the liver doctor." Some clients were so keen to engage that they presented to the clinic even when they were not on the list to be seen, but purely because they knew the liver one-stop shop was in the community. Additionally, the response to the hepatitis B research took a positive turn. Community members exhibited a genuine interest in the research, leading to a significant improvement in consent rates for study participation.

We have identified six significant themes that account for the shift in the community's response. These themes, detailed below, are crucial considerations in all hepatitis B-related work, especially within remote communities.

Fig. 1 Community Based Researcher (and co-author) sitting outside local health clinic delivering hepatitis B education in language as part of the six month community-wide education campaign

3.1 The essential role of Community Based Researchers and Aboriginal Health Workers in all hepatitis B-related work

> *"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 employment of local Community Based Researchers is essential when conducting studies in remote Aboriginal communities, particularly when the research topic is considered sensitive or "risky." Community Based Researchers serve as the communities' local experts and are ideally positioned to engage with potential participants. They also provide invaluable guidance to non-Aboriginal team members on cultural matters. It is paramount that they assume a leadership role on the ground, especially when the research project involves approaching individuals in their own homes. In our specific case, tasks such as conveying the "Hep B Story," explaining study commitments, and conducting the consent process, were most effectively carried out by the Community Based Researchers. They can share the story in a culturally sensitive manner and the participant's preferred language.

> *"Some think if hep B story told by Balanda, they can get disease."*
> *Aboriginal Health Practitioner*

Conversations about hepatitis B with patients in the health clinic are best facilitated with the support of a member of the local Aboriginal Health Workforce. This is closely tied to the worldviews and beliefs regarding how Aboriginal individuals may have contracted hepatitis B. Traditional and modern Aboriginal beliefs about the origins of illness can significantly differ from biomedical explanations [24, 25]. Including Aboriginal staff during these consultations is crucial in dispelling misconceptions or falsehoods about disease transmission.

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

> *"Education is very important, so people know what hep B is, how to prevent passing it on, how to stay on treatment if needed."*
> *Aboriginal Health Practitioner*

Example 3. Hepatitis B client A young male client had initiated antiviral treatment for his hepatitis B. On a subsequent follow-up consultation, it became apparent that the young man had not been adhering to his medication regimen. When a Community Health Worker inquired about this in language (Yolŋu Matha), he thought the medication was only for a limited duration, akin to taking antibiotics for an infection. To address this misconception, the young man received education using the chapter from the "Hep B Story" app, explicitly focussing on treatment. The combination of this resource and the Community Health Worker's expertise in addressing the man's questions in his language led to a clear understanding by the client of the importance of continuing his treatment.

Before the initiation of the research projects, the community had minimal knowledge about hepatitis B. When asked, only 30% (69/231) of research participants had prior knowledge of hepatitis B. In contrast, other chronic conditions like kidney disease, heart disease, and diabetes were well-recognised within the community. However, hepatitis B was perceived by many as a "novel" or unfamiliar condition.

> *"Need translator to give more information and answer questions. Probably never heard about it."*
> *Aboriginal Health Practitioner*

This underscored the urgent requirement for hepatitis B education within the community, emphasising the critical importance of delivering it in an individual'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*

Example 4. Indigenous reference group In 2014, we founded an Indigenous Reference Group, with members representing communities throughout the entire NT, to offer advice, guidance, and prioritise our hepatitis B research initiatives [26]. We presented our research projects to the group and hoped to receive feedback. Despite their enthusiasm to participate, it became evident that many members were unfamiliar with hepatitis B and didn't feel sufficiently informed to contribute to the discussions.

This experience highlighted the significance of delivering hepatitis B education. Before each annual meeting of the Indigenous Reference Group, we now conduct educational sessions to ensure that all members are well-prepared to provide informed advice. These sessions educate new members and refresh the knowledge of existing ones about hepatitis B, empowering them to offer well-informed guidance in their advisory role.

3.3 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

Among the very few individuals with prior awareness of hepatitis B, the prevailing assumption was that it primarily spread through stigmatised behaviours like IV drug use or having multiple sexual partners. Given the distress caused by the revelation of a perceived "new" health condition impacting Aboriginal communities, coupled with the deep-seated shame and stigmatised behaviours associated with hepatitis B, it was unsurprising that people were reluctant to engage in the research and numerous community members exhibited visible discomfort when the subject of hepatitis B was broached with them. Engaging in discussions with the hepatitis B research team in a public setting could inadvertently suggest to other community members that the participant was personally affected by hepatitis B. Consequently, it became imperative to identify secure and discreet locations for these conversations to safeguard the privacy and confidentiality of the participants.

"Need to be very careful that we don't make mothers feel guilty of blame."
Community Based Researcher

Conversations regarding transmitting hepatitis B from mother to child were approached with sensitivity and a high degree of care. The content of these discussions needed to be conveyed in a manner that ensured a comprehensive understanding, preventing any undue blame from being attributed to the mother.

"Sometimes family reacts badly, we will educate family, sometimes father can react violently towards mother, and we have to make sure we are aware and keep things confidential to protect mother."
Community Based Researcher

Minimising stigma, shame, and blame is intimately connected to providing education in one's first language and engaging Aboriginal health and research personnel in the conversations [27]. A Community Based Researcher noted that "people need hope" and stressed the significance of conveying positive messages in education. This includes emphasising the role of vaccination as a tool to prevent transmission of hepatitis B and highlighting the availability of antiviral medication for those with chronic infections. Additionally, it was crucial to acknowledge that hepatitis B was a global health concern, not limited to the Aboriginal community alone.

3.4 Respecting cultural norms and kinship relations

"Women's business not good for men to hear about."
Community Based Researcher

"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

Flexibility is critical when working with the Aboriginal Health Workforce and Community Based Researchers, as they may encounter limitations in engaging with certain participants due to kinship laws. To ensure culturally appropriate interactions, it is advisable to have both male and female Aboriginal Health Workforce and researchers available for hepatitis B-related work, facilitating male-to-male and female-to-female conversations as needed. It is imperative to respect cultural norms and confidentiality by discussing women's business, such as pregnancy and childbirth, exclusively with females, as these topics are not meant for men to be privy to.

Similarly, exercise care and consideration for kinship dynamics when broaching the topic of hepatitis B in a mixed-gender group. It is essential to refrain from discussing hepatitis B when brothers and sisters are present together.

> *"Not have yapa (sister) and wawa (brother) together hearing the story."*
> *Community Based Researcher*

3.5 The necessity of building trust and respect

> *"We stand together and share knowledge and do research in proper way".*
> *Community Based Researcher*

> *"Trust, thoughtful, encouraging right way."*
> *Community Based Researcher*

Establishing trust with community members is a crucial cornerstone for delivering successful hepatitis B-related clinical services and research projects. It is imperative to allocate sufficient time for cultivating these relationships before commencing recruitment into research projects, allowing the community to become acquainted with the study staff. Moreover, trust and respect between Aboriginal and non-Aboriginal research personnel are fundamental to the project's success. A partnership founded on trust and respect facilitates honest knowledge exchange in both directions, fostering a "two-way learning" process [28]. In situations where Community Based Researchers, Aboriginal Health Workforce, and participants all perceive the research project as "risky," exercising additional caution in the study's conduct is essential.

> *"We correct each other; we are all advisors."*
> *Community Based Researcher*

> *"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*

Establishing trust within the clinical environment is achieved through the consistent delivery of care and the cultivation of long-lasting collaborative relationships with the local Aboriginal Health Workforce. A significant contributing factor to the effectiveness of the liver one-stop shop is the regular presence of the same staff, ensuring continuity through familiar faces and routine visits [7].

3.6 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*

Recruiting participants for hepatitis B studies involved an additional time commitment, wherein each potential participant received hepatitis B education before proceeding with the consenting process (Fig. 2). This educational step was supplementary to the standard participant information process specific to the research project and significantly extended the duration of each participant's consent process.

Our team deliberately invested this extra time in providing hepatitis B education, even if it did not necessarily lead to study participation. The primary objective was to ensure that people were well-informed about hepatitis B and could visit the local medical clinic for a blood test on their own terms. We allowed ample time for thorough discussions and

Fig. 2 Community Based Researcher (and co-author) providing hepatitis B education before enrolling participants in the research project

explanations about hepatitis B. We encouraged individuals to return home, contemplate the information, discuss it with family members, and then contact the research team if they were interested in participating. This approach, combined with the Community Based Researchers' six month educational period, culminated in a comprehensive community-wide hepatitis B education effort.

We recognised the importance of adopting a realistic approach to the study timeline, allowing for the additional time dedicated to community consultation and education. This was essential to ensure that participants could acquaint themselves with the topic on their terms through comprehensive education provided to all interested parties.

Example 5. Community Health Worker advice The outreach clinic plane was to leave in 30 min to fly back to Darwin. A member of the viral hepatitis outreach team was in consultation with a client whom they wished to commence on antivirals for chronic hepatitis B. The clinician felt pressured by the time constraints of getting to the airstrip to make the flight home. When asking the Community Health Worker what would be best to do, the Community Health Worker advised it was best not to rush the consultation but instead discuss with the client the need to go on antivirals and then wait until the next outreach clinic visit to the community to commence the client on the medication. They felt it was important not to rush the client but to give them time to think and discuss with their family.

This approach is equally relevant in clinical consultation, particularly when initiating someone on antiviral treatment. Such discussions cannot be hurried, and it is imperative to ensure that the patient is fully informed. Achieving this requires a substantial investment in education, extensive explanation, and ample time to discuss with family. The conventional approach to health literacy often centres on individuals acquiring information to enable them to make personal health-related decisions [29]. However, this perspective is limited in its scope and fails to consider cultures and societies where decisions are made within a family context [30].

Fig. 3 Aboriginal Health Practitioner (and co-author) providing hepatitis B education in language using the "Hep B Story" app during a joint consultation with the specialist physician (and co-author)

The assistance of an Aboriginal Health Practitioner or Community Health Worker is valuable in facilitating clear communication and addressing questions in the participant's preferred language (Fig. 3).

4 Discussion

This paper offers insights gained and adaptations implemented to enhance the effectiveness of clinical service delivery and research practices related to hepatitis B in remote Aboriginal communities. This guide can serve as a resource not only for those engaged in culturally sensitive hepatitis B-related work in such communities but also for addressing other health issues, especially sensitive topics that may evoke feelings of shame. Kinship structures are the foundation of many Aboriginal communities. Understanding and respecting these structures is pivotal to building trust and ensuring the success of our work. We have learned that approaching discussions and research activities involving sensitive topics, such as hepatitis B, with consideration of kinship relationships is essential. Collaborating with the Aboriginal Health Workforce and Community Based Researchers, who possess deep cultural insights, has effectively navigated these dynamics. Trust-building is a continuous process that underpins the success of our work. It necessitates time and effort to cultivate relationships with community members. Trust is about delivering on promises, listening, learning, and showing genuine respect for local customs and traditions. The Aboriginal Health Workforce and Community Based Researchers have played a pivotal role in bridging the trust gap and helping us connect with community members on a deeper level. Providing education in the preferred language is an absolute necessity. It ensures that information is accessible and comprehensible to all community members. The Aboriginal Health Workforce and Community Based Researchers have played an indispensable role in facilitating effective communication and education in a culturally sensitive manner.

Additionally, education is seamlessly integrated into every viral hepatitis outreach clinical visit. Local Community Based Researchers and Aboriginal Health Workforce utilise the "Hep B Story" app to educate patients during these visits. This approach has significantly improved patients' understanding of hepatitis B and the importance of regular check-ups. It ensures that patients are well-informed about the disease and its management, empowering them to take charge of their health. 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 the Aboriginal Health Workforce 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.

Acknowledging the need for realistic research timelines is paramount. Rushing the research process can jeopardise the quality and ethical integrity of the work. Striking the right balance between expediency and thoroughness ensures we allow adequate time for community engagement and education. This applies also in the clinical setting by giving people plenty of time to think and talk with their families. This may mean having multiple instances of contact before any decisions on clinical treatment or research participation are made. Establishing continuity of care is also crucial. The critical aspect of maintaining continuity of care is genuinely caring and demonstrating that care through concrete actions. Many individuals, including institutions, organisations, and researchers, may profess to do the right thing repeatedly. Still, genuine commitment is only evident when consistently translated into tangible actions on the ground. Residing in the community is not a necessity, but regular visits and a familiar presence are essential. This holds particular significance within remote communities, where the frequent turnover of healthcare personnel can create substantial challenges in maintaining continuity of care with patients and building enduring working partnerships with the Aboriginal Health Workforce [31, 32].

Hepatitis B can carry significant shame and stigma within these communities and thus may prevent people from engaging in care [27, 33]. To counteract this, our approach has been one of empathy, education, and non-judgment. We acknowledge that addressing these complex emotions requires patience and tact. By involving the Aboriginal Health Workforce and Community Based Researchers in these conversations, we've been better equipped to create a safe discussion space and reduce the shame and stigma associated with hepatitis. Nonetheless, despite our persistent efforts, there remains a pressing need for substantial research to tackle the stigma and shame associated with hepatitis B, extending beyond remote Aboriginal communities to a global context [34–37].

Perhaps the most vital lesson we have learned is the central role that the Aboriginal Health Workforce, Community Based Researchers, and Indigenous Reference Group should occupy in our work [38, 39]. Placing them at the forefront, following their lead on cultural protocols, and seeking their advice on research in the community have been transformative. Their deep understanding of community dynamics, language, and customs has guided our actions, and their cultural brokerage has been instrumental in our success. Recognising the pivotal role of the Aboriginal Health Workforce and Community Based Researchers, we understood the critical need for investing in their education and capacity building. Our experienced Community Based Researchers have completed Certificate II in Community Health Research. This comprehensive program encompassed dedicated modules on hepatitis B, equipping them with the specialised skills essential for their research roles. Furthermore, in collaboration with Aboriginal Health Practitioners, we developed the "Managing Hepatitis B" course tailored for the Aboriginal Health Workforce. This groundbreaking initiative, the first of its kind, has been successfully delivered to more than 150 members of the Aboriginal Health Workforce across the NT. This course has garnered overwhelmingly positive feedback, with participants commending it as "the most culturally safe training" they have ever received [40, 41]. The knowledge and skills acquired through this course have left a substantial and enduring impact, empowering the graduates to autonomously provide hepatitis B care in primary healthcare settings with confidence [41]. A holistic approach such as the values described in Maslow's Hierarchy of human needs (physiological, safety, love and belonging, and self-actualisation) [42] are "critical for participants to be empowered and safe in the learning environment and to maximise critical thinking and learning potential" [40].

5 Conclusion

Our journey of over a decade in hepatitis B-related work within remote Australian Aboriginal communities has been marked by profound lessons. Recognising the significance of kinship, addressing shame and stigma, building trust, providing education in preferred languages, respecting realistic timelines, and, most critically, embracing the leadership of the Aboriginal Health Workforce and Community Based Researchers have collectively enabled us to forge meaningful connections and make a positive impact. As we continue our work, we remain committed to these principles, aiming to advance health outcomes and foster mutual respect and understanding within these communities. This is achieved by promoting meaningful and positive engagement of Aboriginal people in health and healthcare in a manner that nurtures confidence and self-determination [43]. As a team, we consistently reflect on our processes, ask questions, and remain receptive to the answers as we refine and advance our research and clinical service delivery in remote Aboriginal communities, striving for more equitable and impactful outcomes.

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Author contributions PB performed study design, project management, community consultation and education, literature search, data acquisition, analysis and interpretation, main manuscript writing and revision. GG, RD, SB, CR, KH, and MM performed community consultation and education, acquisition analysis and interpretation of data and writing and revision of the manuscript. JTB, CM, EVC and RPS performed acquisition, analysis, and interpretation of data, and writing and revising the manuscript. JSD, MH and JD performed study concept and design, analysis and interpretation, manuscript writing and revision, and supervision. The authors read and approved the final manuscript.

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Data availability The datasets generated and analysed during this study are not publicly available as individual privacy may be compromised.

Declarations

Ethics approval and consent to participate Ethical approval for the study protocol was obtained from the Human Research Ethics Committee of the Northern Territory Department of Health and Menzies School of Health Research (NTHREC 2018-3240) and (NTHREC 2018-3242). This study was conducted in accordance with relevant guidelines and regulations, including the Declaration of Helsinki and the NHRMC ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: Guidelines for Researchers and Stakeholders and the Australian Institute of Aboriginal and Torres Strait Islander Studies Code of Ethics.

Consent for publication Written consent has been obtained from all subjects to use photos in this publication.

Competing interests The authors declare that there is no competing interest regarding the publication of this article.

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