











Executive Summary

This report shares healthcare providers' insights into the barriers and recommendations for addressing congenital syphilis within Aboriginal and Torres Strait Islander communities in New South Wales. Providers identified practical challenges and solutions based on their experiences, highlighting gaps in resources, service accessibility, and cultural competencies. These insights are essential for designing responsive, culturally safe, and effective public health interventions.

1. Introduction

Congenital syphilis is a significant and preventable condition that disproportionately affects Aboriginal and Torres Strait Islander communities. As it progresses through a number of clinical stages, untreated syphilis infection can lead to significant morbidity over a number of years, including cardiovascular and irreversible neurological complications.1 If untreated during pregnancy, congenital syphilis causes adverse outcomes such as stillbirth, neonatal death, prematurity and low birth weight in over 50% of cases.^{2,3} Congenital syphilis can also cause lifelong morbidity in infants born to untreated or inadequately treated mothers.1

In New South Wales three co-design workshops with healthcare providers were conducted in September 2024 across rural and metropolitan areas. Healthcare providers are central to its prevention and treatment, often serving as the primary link between communities and health services. This report consolidates providers' perspectives, gained from co-design workshops with NSW Health services, ACCHOs, and NGOs to enhance patient-centred and culturally safe care delivery.

Collaboration for this project was led by The Kirby Institute (UNSW Sydney) in partnership with the Centre for Social Research in Health (UNSW Sydney), and the New South Wales Ministry of Health. Financial support for this project was provided by the New South Wales Ministry of Health BBV & STI Research, Intervention and Strategic Evaluation (BRISE) Program.

Hook EW. Syphilis. Lancet 2017; 389: 1550-1557.

2. Background

- Current Situation: Overview of congenital syphilis prevalence among Aboriginal and Torres Strait Islander communities. emphasising healthcare providers' concerns regarding the urgent need for preventive interventions.
- Purpose of the Report: This report outlines healthcare providers' feedback on barriers they face in delivering care and their recommendations for improving access, service quality, and cultural alignment in congenital syphilis prevention and treatment

3. Methodology

Healthcare providers in three New South Wales sites were invited to participate in co-design workshops. Providers from diverse roles and services contributed, with representatives from Mid North Coast Health District (Aboriginal Health Worker, Sexual Health Worker, Nurse Unit Manager, Clinical Nurse Specialist, Public Health Aboriginal Program Coordinator, and GP & Midwife from the Aboriginal Medical Service); Sydney Local Health District (Aboriginal Health Population team, Health Promotion Officer, Priority Prep Program, Senior Policy Analyst, and Program Manager); ACCHOs (Sexual Health Nurse and AHP/Manager); ACON (First Nations Coordinator); Western Health District (Medical students; Aboriginal Maternal & Infant Health Service (AMIHS); AMS (Social Emotional Wellbeing Officer); and Sexual Health Population Health Unit. The workshops aimed

² Gomez GB, Kamb ML, Newman LM, et al. Untreated maternal syphilis and adverse outcomes of pregnancy: a systematic review and meta-analysis. Bull World Health Organ 2013; 91: 217-226.

³ Hawkes SJ, Gomez GB, Broutet N. Early antenatal care: does it make a difference to outcomes of pregnancy associated with syphilis? A systematic review and meta-analysis. PLoS One 2013; 8: e56713.



to identify service gaps, resource needs, and practical solutions based on the healthcare providers' perspectives.

The methodology incorporated a yarning approach, which provided a culturally safe and respectful space for participants to share their experiences, ideas and insights. Yarning was used as a conversational tool to foster open dialogue and allow participants to engage with issues from a professional and patientfocused care perspective. This approach encouraged a collaborative environment where everyone's voices, especially those of Aboriginal and Torres Strait Islander healthcare providers, were valued, allowing participants to draw on both their professional expertise and lived experiences of providing care in culturally sensitive ways.

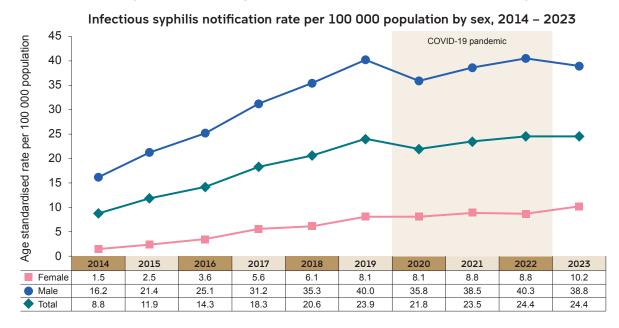
Qualitative data collected during the workshops were systematically organised and analysed using a thematic approach.4 Facilitators documented participants contributions through detailed notes and audio recordings. The transcripts were coded to identify recurring themes, patterns, and unique insights. Data were categorised into barriers and solutions, ensuring alignment with the perspective shared by the diverse healthcare providers. This structured approach facilitates the synthesis of practical recommendations of the professional lived experiences of participants.

Braun, V., & Clarke, V. (2012). Thematic analysis. In H. Cooper, P. M. Camic, D. L. Long, A. T. Panter, D. Rindskopf, & K. J. Sher (Eds.), APA handbook of research methods in psychology, Vol. 2. Research designs: Quantitative, qualitative, neuropsychological, and biological (pp. 57–71). American Psychological Association

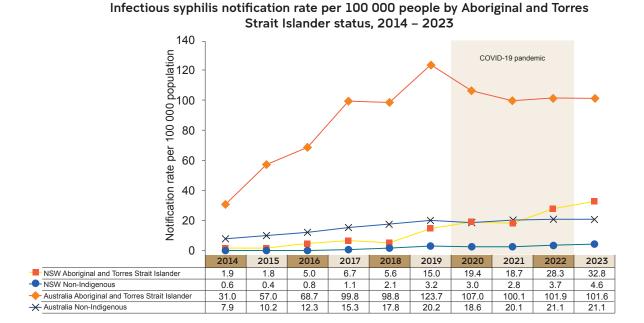
Epidemiology Data

National data: 5

- > Between 2014 and 2023, the infectious syphilis notification rate more than doubled from 8.8 to 24.4 per 100 000.
- > Among women, there has been a six-fold increase in the infectious syphilis notification rate from 1.5 to 10.2 per 100 000. Among men rates, more than doubled from 16.2 to 38.8 per 100 000.

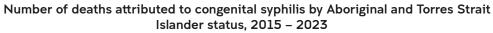


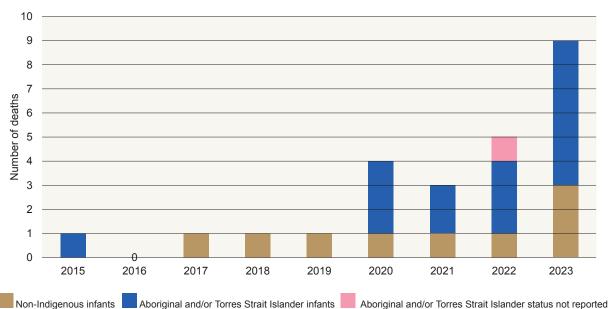
> Between 2014 and 2023, the infectious syphilis notification rate among Aboriginal and Torres Strait Islander people increased more than threefold from 31.0 to 101.6 per 100 000.



King, J., McManus, H., Kwon, J., Gray, R., & McGregor, S. (2024). HIV, viral hepatitis and sexually transmissible infections in Australia: Annual surveillance report 2024. Kirby Institute, UNSW Sydney.

- > In 2023, the infections syphilis notification rate was almost five times as high as among non Indigenous people at 21.1 per 100 000
- > Since 2014 there has been a large increase in the number of infant deaths due to congenital syphilis with 10 infant deaths in 2023 and 26 infant deaths since 2015.
- > Of the 10 infant deaths in 2023, seven were Aboriginal and/or Torres Strait Islander infants.





> From 2014 to 2023 the percentage of all infectious syphilis notifications in Aboriginal and Torres Strait Islander people ranged from 3.0% to 6.4%.

NSW data: 6

- > Reflecting national data, the infectious syphilis notification rate in NSW increased from 10.3 in 2014 to 24.8 per 100 000 in 2023.
- > Whilst the number of infectious syphilis notifications in females is relatively small, notification rates have been increasing since 2014, from 0.7 to 5.6 per 100 000.
- The highest notification rates in females were in those aged 20-24, with 15.6 per 100 000 in 2023, with 28 cases in pregnant women, an increase of 27% compared with 2022.
- > Rates of congenital syphilis have steadily increased, with 16 cases of congenital syphilis and 4 associated deaths reported between 2017-2023.

King, J., McManus, H., Kwon, J., Gray, R., & McGregor, S. (2024). HIV, viral hepatitis and sexually transmissible infections in Australia: Annual surveillance report 2024. Kirby Institute, UNSW Sydney.

Regions where workshops were conducted:5

- > Regionally, the highest infectious syphilis rates in 2023 were in metropolitan Sydney (SE Sydney and Sydney LHD, 67.9 and 64.3/100 000).
- > A large increase was seen in Far West LHD in 2023 (17.6 in 2022 to 39.3/100 000 in 2023), with the highest rates in females reported (42.8/100 000).
- > An ongoing outbreak in Mid North Coast LHD saw an overall decrease from 2022-2023 from 25.4 to 18.7 per 100 000, and the second highest rate in females $(14.4/100\ 000).$

⁶ NSW Health. NSW Sexually Transmissible Infections Data Report 2023. Sydney: NSW Health; 2024

Introduction

Preventing and treating congenital syphilis in Aboriginal and Torres Strait Islander communities in New South Wales faces significant barriers, as highlighted by three co-design workshops conducted in September 2024 across rural and metropolitan areas in collaboration with NGOs, NSW Health services, and ACCHOs. These workshops identified a range of obstacles that hinder access to timely and effective sexual health care and antenatal care including geographic, cultural, systemic, and workforce challenges.

Delays in or lack of engagement with antenatal care are significant risk factors for congenital syphilis. In New South Wales, congenital syphilis has had a particularly devasting impact on Aboriginal and Torres Strait Islander infants. Of the 16 reported cases in NSW since 2017, at least four resulted in stillbirths or neonatal deaths. Across Australia, from 2018 to 2022, a total of 18 congenital syphilis-related deaths were recorded, the majority of which occurred among Aboriginal and Torres Strait Islander infants. This disparity highlights systemic failures in antenatal care access and the urgent need for targeted interventions to support Aboriginal and Torres Strait Islander communities. ⁷

Key Barriers Identified:

1. Access to Services

- Distance and Travel: Many Aboriginal and Torres Strait Islander communities live in remote and rural areas, limiting access to health services. Long distances, poor transport infrastructure, and a lack of local clinics make it difficult to seek care, especially for sexual health.
- > Funding: Insufficient funding across the Local Health Districts, along with a lack of dedicated sexual health resources, exacerbates difficulties in accessing testing, treatment, and ongoing care.
- > Workforce Distribution: The healthcare workforce in rural areas is predominantly female, which creates gender-specific challenges for men seeking sexual health services due to cultural practices such as Men's and Women's Business.

Quote from workshop participant

"Not a lot of young people have a licence in remote areas and cannot easily get to appointments."

2. Cultural Sensitivity

- > Cultural and Family Support: Health services often fail to engage Aboriginal and Torres Strait Islander cultural values and practices, resulting in low trust and underutilisation.
- > Co-design: Involving community members in designing and implementing health initiatives is essential. Co-design frameworks ensure that services are culturally safe and tailored to community needs.
- Men's and Women's Business: Gendersensitive health issues, especially regarding sexual health, require culturally appropriate workforce development and service provision.

 $^{^7}$ King, J., McManus, H., Kwon, J., Gray, R., McGregor, S., & Kwon, J. (2023). HIV, viral hepatitis and sexually transmissible infections in Australia: Annual surveillance report 2023. Kirby Institute, UNSW Sydney; Sydney, UNSW.

Quotes from workshop participants

"We as Aboriginal workers need cultural supervision."

"We need more Aboriginal staff to care for our communities"

"There are more Aboriginal women in this work, we need more Aboriginal males."

"To make my job easier to engage in the Aboriginal community we need Aboriginal Sexual Health Workers, who is known and trusted in the community. As a non-Aboriginal nurse, it takes time to build trust in the community."

3. Stigma and Discrimination

- > Sexual Health Stigma: Syphilis, as a sexually transmitted infection (STI), carries significant stigma in many communities, deterring individuals from seeking care. Shame and embarrassment surrounding sexual health discussions exacerbate delays in diagnosis and treatment.
- Education Levels in Schools: Inadequate sexual health education contributes to stigma. Sex education often frames sexual health negatively, without promoting sex positivity, leading to misinformation and fear around STIs like syphilis.

Quotes from workshop participants.

"We need to reduce shame around the word, sexual health, there is nothing shame about it."

"We should normalise conversation around condoms as a benefit of pleasure, rather than only focusing on the negative."

4. Cost of Bulk Billing GPs

Cost Barriers: While some GPs offer bulk billing, not all services are free. Hidden costs (e.g., for medications or follow-up tests) can deter patients from seeking or

- completing treatment when accessing mainstream GP.
- > 15-Minute GP Appointments: Short GP consultations often limit the ability to address complex sexual health issues, leading to a "stick to one problem" approach. Additionally, GPs are not always sexual health specialists, further limiting comprehensive care.

Quote from workshop participant

"If our mob can't get into AMS, they can't afford to pay for GP, if there is no bulk billing at the clinic."

5. Community Awareness

- Health Literacy: There is a significant gap in health literacy, which includes understanding health information through culturally safe, accessible communication that respects community values, addresses generational impacts, and builds trust in the healthcare system. This gap is particularly evident in relation to sexual health, syphilis transmission, and prevention strategies, with many individuals unaware of congenital syphilis and the risks it poses to unborn children.
- > Delayed Presentations to Antenatal Care: Pregnant women may present late for antenatal care, delaying syphilis screening and treatment. This is particularly common in transient communities with limited healthcare access.
- Education on Sexual Health: Comprehensive sexual health education is lacking in many communities. Schools and community programs should adopt sexpositive approaches to increase awareness and reduce stigma around testing and treatment.

Quote from workshop participant

"Sexual health is a taboo subject in our communities."

6. Transient Communities

- > Language and Workforce Resources: Many Aboriginal and Torres Strait Islander communities are transient, moving between different towns, sometimes interstate. Language barriers and transient populations make it difficult to establish consistent follow-up and continuity of care.
- > Workforce Development: There is a lack of health professionals trained to address the needs of transient populations. Additionally, the lack of Aboriginal and Torres Strait Islander health workers contributes to service gaps.

7. Clinical Education and Workforce Development

- > GP Training and Support: GPs often feel isolated when managing sexual health concerns, and many lack specialised training in sexual health. They may be unsure of correct guidelines and have limited resources for addressing complex cases.
- Lack of Support: While there are existing specialised training programs and support networks, there is a need to ensure these are accessible and tailored to address the specific challenges of managing congenital syphilis. GPs, particularly in underresourced and high-prevalence regions, require greater support. The experience of some healthcare workers is that not all GPs are specifically trained in sexual health therefore, often leading to misdiagnoses. GPs need more support through networks, partnerships, and specialised training to address sexual health management, especially in under-resourced and high prevalence regions.

8. Standardisation and Clinical Guidelines

Pathology Listing Algorithms: While national STI testing guidelines exist, challenges arise from variations in how these guidelines are applied or interpreted across different regions, organisations, and clinical settings. Participants noted

- that inconsistencies in local protocols, workplace policies, and regional practices can result in differences in testing and treatment approaches. Syphilis diagnosis involves a complex process, including treponemal and non-treponemal testing, PCR when available, and consideration of the patients' medical history. However, the absence of a standardised testing algorithm can lead to variability in diagnostic processes, treatment thresholds, and follow-up practices. While this doesn't necessarily affect diagnostic accuracy, it can cause confusion or delays, particularly for clinicians who are less experienced or working in resource-limited settings.
- > Electronic Data Sharing: Fragmented data systems across health services limit the ability to track patient records, particularly for transient populations. Current electronic recording systems, such as maternity eMR, sexual health databases, hospital systems, and GP data platforms, do not communicate with one another, creating significant barriers to continuity of care.

9. Follow-up Treatment

Inconsistent Follow-up: Patients, especially those from transient or remote communities, often face challenges in attending follow-up appointments, resulting in incomplete treatment. Improved tracking systems and outreach are needed to ensure full treatment courses are completed.

10. Health Burden in Antenatal Care

> A health burden in antenatal services in Aboriginal and Torres Strait Islander communities exists because of systemic inequities, including limited access to timely care, and barriers to culturally safe services, compounded by social determinants of health, workforce gaps, stigma, and the impacts of generational trauma. These factors present barriers to the prevention of congenital syphilis because they lead to delays in diagnosis and treatment, resulting in serious health complications for newborns.

11. Sexual Health and Closing the Gap

> Sexual Health is Not Prioritised: Despite the risks posed by congenital syphilis, sexual health remains under-prioritised in national efforts to close the gap in health outcomes between Indigenous and non-Indigenous Australians. More investment is needed to address this issue.

12. Language Barriers

Young People's Engagement: Language barriers, especially among young Aboriginal and Torres Strait Islander individuals, hinder engagement in testing and treatment for syphilis. Programs should be designed to be accessible and inclusive of language terms that young people use.

13. Lack of Partnerships and Collaboration

- > Fragmentation: There is a lack of collaboration between healthcare providers, community organisations, and government agencies, limiting the effectiveness of syphilis prevention and treatment initiatives.
- Networking: Increased partnerships between Aboriginal health organisations, government bodies, and other stakeholders are needed to strengthen service delivery and outreach efforts.
- > Stereotyping and Misinformation: Cultural practices and a visual style of knowing often lead to the belief that serious health concerns would be physically obvious. The importance of conversations with Aboriginal staff is vital in ensuring individuals understand that internal health issues may not always have visible symptoms.
- Cultural Safety: Aboriginal health staff are sometimes used as token representatives in research projects. It is crucial that these staff are empowered to engage with communities in culturally safe and respectful ways.

14. Workforce Challenges

> Aboriginal health workers can feel isolated or unsupported if not provided with

- expanded scopes of practice or the necessary resources. If their roles do not align with community expectations, they may be labelled "9-5 blacks," meaning they are seen as failing to provide culturally appropriate services.
- Mainstream services often prioritise building the capacity of others, but it is just as crucial to invest in the development of Aboriginal health staff. Aboriginal Sexual Health and BBV workers need to do more than communicate effectively and advocate for their communities (talk the talk). They must also embody cultural values, demonstrate genuine commitment through meaningful actions, and lead by example in both their professional and personal conduct (walk the walk). This approach builds trust, credibility, and capacity within their communities.
- > Long waiting periods for Appointments: Services themselves can create barriers to care. For instance, there is often a long waiting period for a 715-health check appointment, and there are not alternative pathways for patients to receive similar care. This creates further delays in accessing necessary health services, including sexual health checks.
- Outreach limitations and the inability for clinical staff to engage effectively in community-based outreach restricts access to care.
- > Frontline staff often lack essential cultural sensitivity training.
- > Workforce are left to undertake contact tracing with limited specialised skills, which are crucial for effective service delivery.

Quote from workshop participants

"There's long wait for appointments, like for the 715 health checks, and no alternatives. That just creates more barriers for our mob."

Recommendations to the Prevention and Treatment of Congenital Syphilis for Aboriginal and Torres Strait Islander People in New South Wales

Congenital syphilis poses a significant threat to the health and well-being of Aboriginal and Torres Strait Islander communities. Addressing this issue requires a multifaceted approach, starting with prevention efforts at a population level to reduce rising rates of syphilis in both men and women. This must be tailored to cultural sensitivities, community engagement, and practical implementation. Below are the key strategies suggested by workshop participants that may support the prevention and treatment of congenital syphilis in these populations.

1. Incentives for Engagement in Care

Incentives, such as baby bundles or car seats, can encourage pregnant women and families to engage in care. Providing tangible rewards for attending antenatal visits and sexual health check-ups could increase participation and enhance the prevention of congenital syphilis.

2. Utilising Technology and Social Media

Placing ads on dating apps like Tinder, Grindr, and Bumble can target sexually active populations, promoting syphilis testing and treatment in a discreet, stigma-free manner. In addition, promoting screening and testing via social media platforms like TikTok, YouTube, and Apple Health can increase awareness, especially among younger demographics.

3. Targeted Men's Outreach

Developing outreach programs aimed at men, particularly through culturally relevant events like sporting events (e.g., Knockout games), can foster engagement. Testing teams could set up before events to make screening accessible, normalising syphilis testing among men.

4. Normalisation and Education

Syphilis education should be integrated into schools, focusing not only on reproductive health but also on pleasure and consent, to shift the narrative from diseasefocused discussions to healthy sexual behaviour. School nurses should also be allowed to perform screenings to enhance early detection. Additionally, community awareness and champions could be trained to disseminate information within their circles. reducing stigma and normalising discussions about syphilis.

Quote from workshop participant

"We need to look at how we educate in schools around sexual health through a sex-positive lens, not one that shames and stigmatises."

5. Holistic, Community-Based Approach

A holistic, community-based approach focuses on meeting people where they are, rather than expecting them to seek out services centred on a single health issue. This means bringing health consultations, screenings, and education to places like festival, sporting events, or community gatherings, where people naturally come together. By moving away from a disease-centred model, this approach

considers the wider cultural and social needs of the community, recognising that health is influenced by many interconnected factors. It also empowers individuals to address other social health issues, creating a supportive environment for the overall wellbeing and resilience.

Quote from workshop participant
"We need to meet the people where
they are at."

6. Co-Designing Services with the Community

Community consultation and co-design are essential to ensure that solutions are culturally appropriate and effective. Aboriginal and Torres Strait Islander communities should be involved in the design and implementation of prevention and treatment strategies, ensuring that the framework is holistic rather than siloed.

Quote from workshop participants

"It's vital that we co-design services with the community to ensure they're culturally appropriate and reflect our needs."

7. Peer Support and Health Literacy

Patients could benefit from peer navigation, where trained individuals from within the community guide others through the healthcare system, enhancing health literacy and building trust. Empowering peers to support patient navigation can ensure people know where to go and whom to contact for testing and treatment.

Quote from workshop participants

"Having people from our own mob guides us through the health system builds trust and helps us understand the process better."

8. Workforce Capacity and Professional Development

Increasing Aboriginal and Torres Strait Islander workforce capacity is essential to upskill staff

and provide more male and female clinicians to meet the demand. Reviewing the scope of practice for Aboriginal Health Practitioners in NSW could ensure they are working towards the whole scope of practice. Funded pathways for professional development and caregiver roles should also be enhanced, ensuring adequate care and community representation. To enhance care and outreach effectiveness, sexual health and antenatal workforce training should incorporate in-depth cultural sensitivity and community-focused contact tracing practices, specifically tailored to sexual health and antenatal care. Through partnership with Aboriginal Medical Services, culturally safe training on sexual health, and networks that provide guidance on syphilis prevention, treatment, and contact tracing, these initiatives can be further strengthened to support effective and culturally appropriate care delivery.

9. Streamlining Clinical Services and Sharing Records

Sharing responsibility among all healthcare workers, including GPs, sexual health nurses, and community health workers, can streamline the care process. Utilising reflex testing, where pregnant women are automatically tested for syphilis with informed consent, and digital record sharing can improve coordination between services. Digital systems that prompt opportunistic screening and flag missed tests can further ensure comprehensive care. Review and implementing a standardised electronic health record would improve information sharing and ensure seamless care for patients across different health settings.

10. Innovative Testing Approaches

Online consultations with local services, mail-in testing kits, and point-of-care testing (POCT) can make testing more accessible, especially for those in remote or regional areas. Repurposing mobile labs, such as COVID-19 testing buses, for sexual health outreach can expand access to testing in underserved areas.

11. Support for Clinicians and **Patients**

Educating clinicians on comprehensive screening methods, including serology and PCR testing for chancre or rash, will improve diagnostic accuracy. Additionally, introducing GP billing items for STI checks and flexible consultation times will also encourage more patients to seek care. Proving incentives such as free education and testing, could further support engagement.

12. Cultural Sensitivity and Support

Incorporating cultural sensitivity into healthcare delivery is critical. Offering cultural loading on top of wages for Aboriginal and Torres Strait Islander workers and ensuring continuous relationshipbuilding with communities fosters trust. Clinicians need training in culturally appropriate care to provide non-stigmatised, discreet services. Additionally, access to cultural supervision for Aboriginal and Torres Strait Islander health workers is essential to support their well-being, strengthen their practice, and ensure that culturally safe care is maintained across all healthcare settings.

13. Nurse-led care model

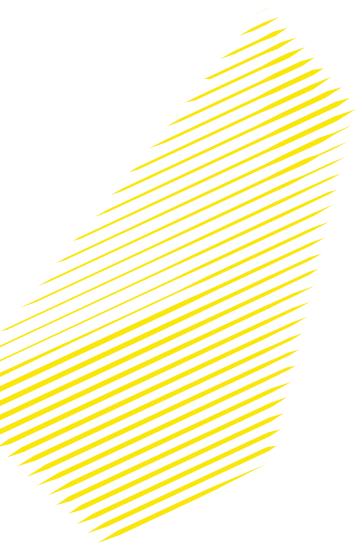
Investing in a mobile testing services, such as clinics, and enhancing online sexual health consultations can increase accessibility for people living in remote areas. A nurse practitioner in regional settings that lack access to medical services can be funded and supported to provide care more effectively. Nurse-led care models in Australia have proven effective, enhancing quality, safety and client's outcomes.8 A study conducted at Sydney Sexual Health Clinic highlighted the success of a nurse-led results management approach, showing faster notification and treatment times and cost saving for the healthcare system.9

Quote from workshop participant. "I dream of the bus."

14. Education, Media, and Visual Awareness Campaigns

Community awareness can be raised through visual campaigns, social media, and television advertisements. These initiatives should be developed through co-design with youth and the target population, focusing on the importance of testing and prevention, highlighting the ease and confidentiality of testing.





Suggested citation:

Walker M, Lorch R, Treloar C, Monaghan R. (2024). Report on Healthcare Providers Perspectives on Barriers and Recommendations for Congenital Syphilis Prevention and Treatment in Aboriginal and Torres Strait Islander Communities in New South Wales. Kirby Institute, UNSW Sydney.



Conclusion

Feedback gathered from three co-design workshops with key healthcare providers working across rural and metropolitan areas in NSW suggests that prevention and effective treatment of congenital syphilis in Aboriginal and Torres Strait Islander communities requires a comprehensive, culturally sensitive approach, that combines incentives, education, community engagement, and workforce development. Given the significant impact of congenital syphilis, a substantial investment is needed to expand the scope and capacity within sexual health and antenatal workforce. Healthcare plays a vital role in this effort, and as demonstrated by our findings, healthcare providers offer essential insights to existing barriers and possible solutions that form the foundation for meaningful, sustainable improvements in care access and quality. Additionally, there is a critical need for innovative health promotion and awareness campaigns, utilising accessible platforms to educate and engage these communities effectively. Co-designing solutions with the community and adopting innovative testing methods can improve health outcomes, ultimately enhancing healthcare quality and reducing the incidence of congenital syphilis in these communities.

