

### Post-Print

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## Enhancing Aboriginal and Torres Strait Islander young people's resilience to blood borne and sexually transmitted infections: Findings from a community-based participatory research project

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### Abstract

**Issue addressed:** Health services are fundamental to reducing the burden of blood-borne and sexually transmitted infections (BBV/STI) in Indigenous communities. However, we know very little about young Indigenous people's use of mainstream and community-controlled health services for the prevention and treatment of these infections, or how health services can best support young people's efforts to prevent infection.

**Methods:** University-researchers, a site coordinator and peer researchers developed a project and conducted interviews with 45 Aboriginal and Torres Strait Islander people aged 17 to 26 years. Thematic analysis of interviews notes identified key themes around health service use and experiences of Aboriginal Community-Controlled Health Services (ACCHS).

**Results:** Most participants had accessed health services for the prevention or treatment of BBV/STI, with positive experiences characterised by the provision of information and feeling cared for. Participants described the comfort and understanding they experienced at ACCHS; personal relationships and having an Indigenous care provider present were important factors in the overwhelmingly positive accounts. Young people reported strategies for overcoming challenges to prevention and accessing treatment services, including being proactive by carrying condoms, persisting with behavioural intentions despite feeling shame. .

**Conclusion:** Our findings reinforce the important role both mainstream and community-controlled health services have in the prevention and treatment of BBV/STI blood borne and sexually transmitted infections in young Indigenous people. We highlight opportunities to build on young people's strengths, such as their valuing of their health, their persistence, and their offers to support peers, to better prevent transmission of infections and enhance access to treatment.

### So what?

Providing culturally appropriate health services to young Indigenous people is crucial to early detection and treatment of blood borne and sexually transmitted infections. Health services need to listen to young Indigenous people's perspectives and build on their strengths to provide prevention and treatment programs that are designed and delivered with their cultural and health needs in mind.

## Background

National surveillance data show marked differences between Indigenous and other Australians in the rates of most blood borne and sexually transmitted infections (BBV/STI) (1, 2)<sup>i</sup>. Disparities persist in urban populations and, compared to their non-Indigenous counterparts, women and young people bear a higher burden of infection. There are also differences in the primary routes of transmission, most notably for Syphilis, Gonorrhoea and HIV, with heterosexual contact being a significant transmission mode in diagnoses among Indigenous people. Blood borne and sexually transmitted infections are serious public health issues for Indigenous communities and there is a need for targeted and culturally appropriate programs (3-6).

Access to appropriate clinical services, community-based programs and peer education is essential to prevent transmission of blood borne and sexually transmitted infections and reduce the burden of infections in Indigenous communities (4). Yet there is evidence that Indigenous Australians are not receiving health services when they need them or are accessing them late through hospitals and emergency departments (7). Reported barriers that Indigenous people face when accessing health care include a perceived lack of confidentiality, a lack of trust in health care providers, and feelings of embarrassment and discomfort when accessing mainstream services (4, 8, 9). Practical barriers include the absence of services or distance to services in rural and remote communities (10). Plummer and Forrest have argued that “mainstream services generally do not reach out to marginal groups and are not designed with this in mind” (11, p. 51). In particular, a lack of understanding of Indigenous culture, including concepts of health and illness, are seen to reduce the likelihood of Indigenous people accessing health services (10) and serious miscommunications can arise from a lack of shared knowledge and understanding (12, 13). Cultural and social considerations are intensified by the personal and intimate context of BBV/STI transmission (14). Health care providers not taking proper account of gender by separating men’s and women’s business, providing same-gender health providers, or respecting appropriate contexts for discussing sexual health issues are considered particularly salient issues in the prevention and treatment of blood borne and sexually transmitted infections (14, 15). Improving access to health care is considered vital to addressing disparities in health outcomes for Indigenous Australians (4, 10, 16), and integrating culture into the delivery of mainstream health services is a central strategy (9, 16, 17). A parallel strategy involves the provision of health care via Aboriginal Community Controlled Health Services (ACCHS). These are “culturally appropriate, autonomous primary health services initiated, planned and governed by local Aboriginal communities through an elected board of directors” (18, p.189), and are strongly supported by Indigenous people (19).

The relative youth of the Australia Indigenous population (a median age of 21 years compared to a non-Indigenous median of 36 years (10)) has potential implications for the provision of health care. Yet, we know very little about young Indigenous people’s experiences of mainstream and community-controlled health services, and even less about services specific to BBV/STI prevention and treatment (22). This is particularly significant as early detection of these infections is a key principle in prevention strategies; the Queensland Aboriginal and Islander Health Council endorses routine screening of all 15 to 30 year olds (23). There is a lack of research on how this population group, who bear a disproportionate burden of blood borne and sexually transmitted infections, currently use health services to prevent and treat infections, and how health services can best support young people in their prevention efforts.

The Indigenous Resiliency Project utilises community-based participatory research (CBPR) to bring Aboriginal and Torres Strait Islander young people, three participating ACCHS and university-based researchers<sup>ii</sup> together to develop and conduct qualitative research on what protects young Indigenous people from BBV/STI . The research was approved by the Human Research Ethics Committees of the Aboriginal Health and Medical Research Council of NSW and by the University of New South Wales; the project was developed with and approved by each ACCHS Board of Directors. We have reported elsewhere on the nature of the collaboration that conducted the research, the development of the project and the community consultation and ethics processes we followed (24, 25). In this paper, we focus on “Sexual

health through the eyes of Indigenous youth”, the project conducted through the Townsville Aboriginal and Islanders Health Service (TAIHS). Our project’s central aim is to identify, assess and enhance the BBV and STI resilience capability of Aboriginal and Torres Strait Islander people. We understand resilience to mean how young people make use of individual and community strengths to protect themselves against adverse health outcomes and enhance their health and wellbeing. We report on qualitative data concerning young Indigenous people’s use of mainstream and community-controlled health services, and identify how health services can build on young people’s strengths to better prevent transmission of infections and enhance access to treatment.

## **Methods**

Five young Aboriginal and Torres Strait Islander men and women (peer researchers) and a site coordinator (author WE) worked under the guidance of two university-based researchers (JMS, LM), to recruit young people at malls, parks, and homeless drop-in centres and shelters. Interviewers explained the aims of the study and the involvement of TAIHS to all participants and consent processes were followed. During their interview young people were asked to talk about their background and knowledge of BBV/STI, and describe personal experiences of accessing sexual health services and ACCHS, preventing the transmission of infections, and talking to a sexual partner about sexual health. They were also asked what they would advise a friend who suspected they had an infection, and finally what suggestions they had for making services better to reduce rates of BBV/STI among Indigenous young people in Queensland. Interviews were usually conducted at the time and place where recruitment took place, and data was recorded as hand written field notes that were subsequently typed up by the peer researchers or the site coordinator as soon as practical. This paper draws on 16 short interviews and 29 in-depth individual interviews collected around Townsville in 2008. A thematic analysis of this data identified a major theme around health services, made up of sub-themes: type of service provider, treatment, screening, resources, problems with access, and cultural safety and comfort.

An extensive consultation process involving TAIHS and community stakeholders identified young people experiencing or facing homelessness as a priority population, and sampling focused on this population (25). Our study sample consists of 45 people, 17 men and 28 women, aged between 17 and 26 years who self-identify as Aboriginal or Torres Strait Islander. The average age was 22 years, with nearly 40% around the upper age limit (25/26). At the time of interview, over two thirds described themselves as homeless, living in temporary accommodation with friends or relatives, or in hostels. We did not ask young people if they had ever had a blood borne or sexually transmitted infection, however, a significant proportion of the young people disclosed a previous diagnosis.

## **Results and Discussion**

Young people’s use of health services fell into three categories with TAIHS the most commonly mentioned service, followed by dedicated sexual health services (usually Townsville Sexual Health Service), GPs and hospitals.

### *Sexual health checks and screening for blood borne and sexually transmitted infections*

Most participants reported that they have had a sexual health check (SHC) or screening for blood borne and sexually transmitted infections, with routine SHC being the most common. For example, “*Every time I go to TAIHS I go for a sexual health. I make sure that everything is clear*”<sup>iii</sup> (Rachel, 23, recently arrived in Townsville, living in temporary accommodation). Participants also described SHC prompted by symptoms or an event such as a condom break, and some reported using SHC to confirm their own or a partner’s status prior to starting a sexual relationship.

### *Diagnosis and treatment of blood borne and sexually transmitted infections*

Participants reported using health services for the diagnosis and treatment of blood borne and sexually transmitted infections, with many giving detailed personal experiences. In these treatment stories,

participants often described receiving information to help them avoid contracting these infections in the future.

*I found out that one of the boys I was sleeping with had Chlamydia (...) His sister came round to me and told me to get myself checked out. I didn't know anything and thought I might die. I went to the doctor to get medication [did the doctor give you advice?] The doctor mainly said to wear a condom (Margaret, 17, living with family)*

Participants who described diagnosis and treatment experiences in a positive way noted the information they had received and care they felt the health care professional had shown them. For example:

*"Went and saw the people at the sexual health clinic (...) I found out I had Trichomoniasis (...) Easily treated, the service was great and very informative (Naomi, 26, living in hostel)*

In contrast, a *lack* of information or care featured in the few descriptions of negative or dissatisfying experiences of diagnosis and treatment:

*The doctor at the emergency centre in (clinic name) just blurted out that I have Hepatitis C, have a nice day, see ya later, and did not explain anything to me. I was upset, shocked, this doctor should have told, explained something to me (Edwina, 24, living in hostel).*

Of the few participants who reported negative experiences, most described subsequently seeking out more supportive services. Participants did not describe instances where they had not sought treatment (though we did not specifically ask about this), nor times when previous negative experiences had put them off seeking treatment. Moreover, during the interviews, the majority of participants indicated a willingness to seek screening and treatment if they suspected they had an infection. When we asked young people what they would suggest to a friend who suspected they had an infection, participants overwhelmingly reported they would tell their friend to see a doctor, reinforcing the sense of a generally positive orientation to health services.

Evidence of barriers to treatment seeking came not from participants' personal experiences but from the advice they would give a friend who suspected they had an infection. A third of participants (all women) raised the potential shame a friend may experience at having an infection and having to seek treatment for it. Participants reported they would offer reassures that were oriented to reducing the stigma associated with these infections, such as letting their friend know they were not the only one to have a blood borne or sexually transmitted infection, endorsing their choice to be proactive in looking after their health, and encouraging them not to be shy or shame in seeing a doctor. Participants also reported they would offer reassurance about the health service itself, vouching for the staff and the care they would receive there: *"The people at the clinic are very good they listen to you and they try to help"* (Samantha, moves between Townsville and Palm Island). Four young women indicated they would offer to accompany their friend: *"Don't worry we'll go see a doctor together"* (Jane, 19, living in rented accommodation). Insights into the need for reassurance and support came from participants' own experiences of having had a blood borne or sexually transmitted infection. For example, *"I would tell them to go to a doctor, and support them because I've been through that"* (Margaret, 17, living with family).

Making and keeping appointments was one of the few challenges young people mentioned they had personally faced and this was also identified as a barrier faced by other young homeless people. Distance to health services and a lack of transport are usually cited as potential barriers to access in the context of remote communities (10, 11). For our sample, for whom there were numerous local health care options available, providing transport appeared to facilitate access by addressing challenges beyond sheer distance. This was particularly true of the outreach by health service staff that occurred alongside the provision of transport.

*A lot harder for people that are homeless to get help. They drink too much; they won't go and get help if they get an STI. They don't know how to book appointments, people at TAIHS come here and help them. Sometimes they need transport and help to get them to the doctors. It is hard which is why I think they end up with STI (Morris, 20, moves around, living temporarily in Townsville).*

#### *Health hardware*

The third category of health service use described by participants was accessing free condoms. There was widespread awareness about the availability of free condoms and both men and women indicated that getting condoms was easy. For example, *"It's free medicine at Sexual Health and condoms too. When I visit TAIHS I grab heaps of condoms"* (Ester, 26, living with family). Several young women reported buying condoms.

Despite the widespread availability of free condoms, a few participants did note barriers to access. The supply at health services was not always reliable and issues of timeliness and convenience were raised. A small number of participants reported having sex without a condom because they did not have a condom 'in the moment'. Alcohol was usually implicated in these accounts, and the worry reported by the young man below was common.

*Not always easy to get condoms. Protection is very easy word but is hard to do. I have to always say to myself what next, it is easy to say use the condom but when you are out drinking and forgetting to get a condom you just go ahead and do it right there and then and not bother about protection. I have done this a few times before then I worry after the following day (Fred, 19, living with family).*

To counter these challenges and make sure they were not caught without a condom, both male and female participants in our study reported carrying condoms on them. Young people who described situations involving unsafe sex, including condom breakage, often reported they had subsequently sought screening.

Although free condoms were available in a range of venues, embarrassment and shame remained an issue for some young people. For example, *"Pretty shame, even if I wanted to grab a free condom at TAIHS I still feel too shame but if I need to use them I would definitely use them"* (Finn, 18, living in hostel). Most young people who described feeling shame also described alternative strategies they employed to access condoms, such as getting them from a friend. For example:

*It's embarrassing trying to buy condoms at stores, its feels like everybody watching, that's why I just get them off a friend or my boyfriend (Jane, 19, living in rented accommodation)*

Experiences of community-controlled health services for sexual health were described by over two thirds of the in-depth interview participants. Participants reported accessing sexual health checks, treatment, advice on prevention, and free condoms, as well as a range of non-sexual health services. The range of services and the sense of care evident in the following quote evoke the holistic approach to health taken by ACCHS; the quote is also indicative of the high levels of satisfaction reported by most participants.

*It's very helpful, like they understand what I go through. The doctors listen to you and understand what I got. And they give you free condoms so you don't have to pay for them. Yeah it was easy, the service is easy, there you can talk to a doctor, health worker or youth worker on a daily basis (Karen, 24, living in hostel)*

According to participants, TAIHS was well known in the community. Many reported a family member had introduced them to the service, with some using the service since childhood. For example, *"My grandmother takes me there when I was small and I now know the place very well"* (Finn, 18, living in hostel). Personal relationships with members of staff were important, and some participants described

relationships they had with individual health care providers at TAIHS. For example, *“I know and get on well with (staff member). He understands me a lot (...) I think he knows what he is doing and talking about because he works at TAIHS”* (Jase, 24, living in hostel). Almost half the participants mentioned the comfort and understanding they felt when using an ACCHS.

*Alright feeling about Indigenous medical centres. It's good, I feel more comfortable explaining to doctors, great service. It feels good having Aboriginal and Torres Strait Islander workers makes me feel very comfortable. They understand me and I can understand them* (Morris, 20, moves around, living temporarily in Townsville).

Understanding and comfort appeared to stem from the health worker caring for the participant being Indigenous or simply to the service itself being 'Indigenous' (20), which we understand to mean community-controlled. In this context, several participants mentioned a shared cultural identity and being able to relate better to each other. For example, *“I feel comfortable because they are black people like you and me”* (Margaret, 26, living in hostel). This contrasts strongly with the following description of the shame experienced when speaking to a non-Indigenous health care provider: *“I don't like going to any other doctor or medical centre, if they are white I won't talk, I get shame and feel very uncomfortable”* (Vince, 21, living in rented accommodation). Respecting cultural protocols around gender is a common theme in the literature (4, 16) but did not emerge as a strong issue in our study. This may be because it is taken for granted and participants had not experienced difficulties accessing a same-gender health care provider. Indeed, two young women reported satisfaction with TAIHS because they could see a female doctor and nurse.

The participants' experiences of ACCHS were not uniformly positive. Four described a dissatisfying or negative experience, from the relatively mundane (waiting times) to unhappiness with staff-patient interactions. All but one of the participants continued to utilise the service because the incident had not overshadowed their general satisfaction with the particular ACCHS. However, one young woman gave a detailed description of an ACCHS visit that she perceived to be a waste of time, as she had not received important information before her consultation. Her description of a lack of care and feeling of being a burden is framed as a particular disappointment that her expectations of an *Indigenous* health service were not met.

*I felt like no one there was able to assist me (...) Every time when I go to this previous medical centre they give me this look like I, oh here we go, what does she want now (...) It was easy for me to use this centre thinking that it is Indigenous, they would be helpful, but they are not really helpful, I feel like I like I was taking up their time with my issues* (Naomi, 26, living in hostel).

It has been suggested that perceptions of a lack of confidence and privacy are a significant issue for Indigenous people accessing services for sexual health (4), including ACCHS (28) and a recent qualitative study found that privacy and confidentiality concerns were significant barriers for young Indigenous people seeking screening at ACCHS (29). Concerns about confidentiality and privacy did not emerge in our study. While some participants reported using mainstream services for screening and/or treatment, it is not possible to determine whether this stemmed from a particular discomfort using a health service staffed by members of their community or extended family (20). This is not to say that confidentiality was not important. The absence of concerns in our study may reflect the level of confidence and comfort participants had with ACCHS, notably TAIHS and its staff. Indeed, the earlier descriptions of TAIHS as part of the community and the emphasis on personal relationships with staff, suggest being personally known is highly valued. Moreover, this personal and community connection may give Indigenous health care providers permission to chastise (“growl”) an individual about their health, an act that was experienced as genuine care for the individual's wellbeing.

*I realise they growl you more rather than to you at the Indigenous centre, maybe they care for me, it was maybe easier when they are Indigenous, and I'm Indigenous, easy to growl and know they really do care. And I know most of them there, so I don't really mind because I know they are looking out for me (Katie, 26, living in hostel).*

## **Conclusion**

We drew on qualitative data from a community-based participatory research project in Townsville, Queensland, to describe young Aboriginal and Torres Strait Islander people's use of health services for the prevention and treatment of blood borne and sexually transmitted infections. Almost all of the young people in our study reported contact with health services around their sexual health, and screening and obtaining free condoms were common experiences. A significant proportion reported receiving treatment for a blood borne or sexually transmitted infection; unsurprising given previous reports suggesting a relatively high prevalence of STI diagnoses in the region (27, 30).

Experiences of mainstream and community-controlled services were generally positive. Importantly, young people indicated a readiness to seek health services if they needed them and reported they would suggest medical help to a friend who suspected they had a blood borne or sexually transmitted infection.

Difficulties accessing condoms, screening and treatment services were local and specific, and only a small number mentioned negative experiences. ACCHS were widely used by the young people and there were high levels of satisfaction. While mainstream services remain significant providers of health care (16), our findings emphasise the important role ACCHS have in the development and delivery of blood borne and sexually transmitted infection prevention and treatment services to young Indigenous people (14). A good health service for the young people in our study was characterised by a feeling that the health provider cared; they took time, provided information and prioritised the individual's own concerns. The presence of an Indigenous health care provider was important. Participants repeatedly associated these characteristics with ACCHS.

The findings on the reassurance young people would offer friends needing treatment give valuable insights into the challenges that can face young people, particularly in relation to shame and stigma around blood borne and sexually transmitted infections. Specific recommendations arising from these findings would be developing peer support systems such as advertising that young people can have a friend accompanying them to consultations and engaging 'health service experienced' young people as allies to guide others through screening and treatment services. Finally, providing free condoms so they can be accessed more discretely, i.e. not on the health service reception desk, is a straightforward recommendation that echoes other literature (29).

There are a number of limitations to our study. Clients at an ACCHS are likely to be seen by a non-Indigenous and possibly overseas trained general practitioner (31, 32), while at the same time, an Indigenous health worker or nurse is likely to be involved in their consultation (21). Our data does not allow us to tease out the relative importance of AHW as cultural brokers between clients and non-Indigenous care providers (9), the consultation being conducted in a culturally appropriate way in a community-controlled setting, and the presence of community or extended family members at the service itself. We interviewed a highly mobile and residentially insecure population who live in a regional city with a large well established ACCHS and a dedicated mainstream sexual health service, as well as numerous local general practices. Their experiences overwhelming focused on TAIHS and may not be generalisable to other, particularly smaller, ACCHS. Finally, the lack of reported concerns about confidentiality and privacy may genuinely indicate a lack of concern, but it is important to acknowledge that the project was explicitly connected to TAIHS and participants may have felt some apprehension expressing negative views about the service.

It was clear that health was important to the young people in this study; they acted in ways to prevent BBV/STI transmission, sought treatment when they knew they needed it, and persisted when faced with

barriers. The young people drew on their own experiences and feelings of responsibility to their community when indicating the support they would offer other young people. To “empower people to access services early” (4, p.4), health services need to build on these strengths and engage with young Indigenous people to ensure prevention and treatment programs are designed and delivered with their cultural and health needs in mind.

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<sup>i</sup> Data need to be interpreted with care as there are limitations in the recording of Indigenous status across some jurisdictions and considerable variation between communities, for example, increased testing.

<sup>ii</sup> ACCHS partners are Townsville Aboriginal and Islander Health Service; Aboriginal Medical Service Redfern; Derbarl Yerrigan Health Service Perth. The university partner is the National Centre in HIV Epidemiology and Clinical Medicine, University of New South Wales.

<sup>iii</sup> The following conventions have been used in the presentation of interview extracts: interviewer questions are enclosed in square brackets, clarifying comments or explanations from the interviewer or author are enclosed in parentheses, ellipses in parentheses indicate text has been removed. Punctuation has been added and some repetitious text removed to make extracts more readable.