COMMUNITY CONSULTATION RAPID SCOPING PROJECT AMONG ABORIGINAL PEOPLE WHO INJECT DRUGS

FOR THE NEW SOUTH WALES USERS AND AIDS ASSOCIATION (NUAA)

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NUAA
NSW USERS AND AIDS ASSOCIATION

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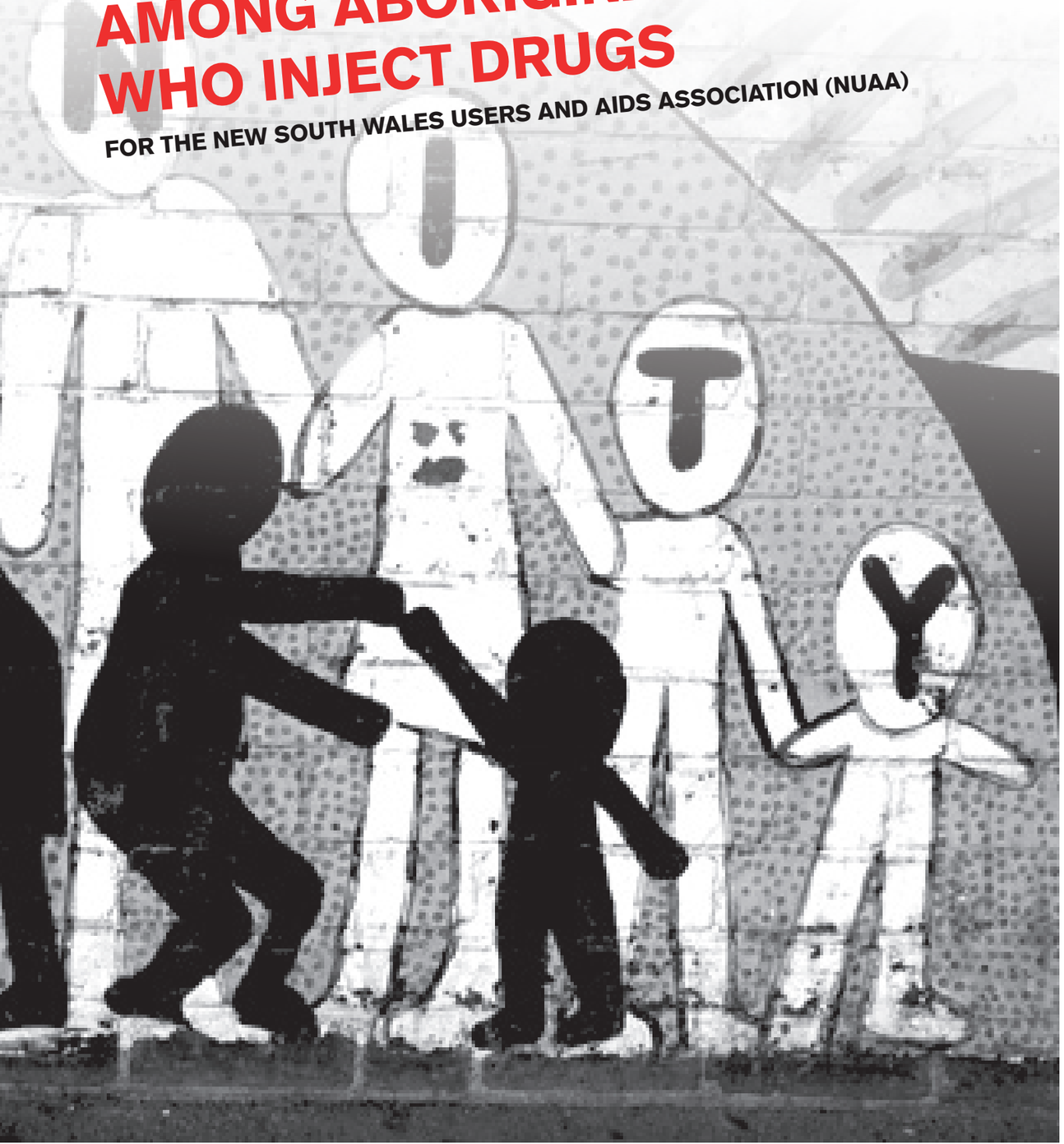

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EXECUTIVE SUMMARY

The main purpose of the Community Consultation Rapid Scoping Project (the RISE Project) is to inform the New South Wales Users and AIDS Association (NUAA) about the needs of Aboriginal people who inject drugs. NUAA is the primary 'voice' for people who inject or use illicit drugs (PWID) in NSW. Established in 1989, NUAA continues to provide government, services, media and the broader community with a 'drug users' perspective on a range of issues in relation to illicit drug use and the prevention of the transmission of blood borne viruses (BBVs), including HIV and hepatitis C. In addition to providing this 'user perspective' and advocating for its members, NUAA is engaged in a range of programs and services that impact directly on the treatment, care and support for those living with BBVs. The findings of the Project will also be useful in informing decision makers in both government and non-governmental sectors in order to improve service delivery for this population.

This Project responds to the dearth of information available about Aboriginal PWID. The commonly held view conveyed in recent reports and peer reviewed professional conferences is that injecting behaviour is increasing among Aboriginal people and among Aboriginal youth in particular. There is also evidence to suggest that the prevalence of injecting drug use is greater among the Aboriginal population compared with the non-Aboriginal population, and that pharmaceutical opiates, heroin and methamphetamines are the most commonly injected drugs. Time spent in prison, personal networks and knowledge on BBVs transmission are important factors for consideration in further study among Aboriginal PWID.

This Project utilised a peer-led focus group methodology to consult with Aboriginal people who inject in urban (n=2) and regional (n=5) sites across NSW. In total 70 Aboriginal PWID participated in the focus groups. A number of non-Aboriginal PWID also participated in the focus groups, demonstrating that networks of PWID particularly for Aboriginal people encompass non Aboriginal people as well.

Analysis of the focus group results yielded a number of findings broadly grouped into three main themes:

Drug use and local contexts: Participants were generally concerned with a perceived escalation in injecting drug use within Aboriginal communities, particularly among younger Aboriginal people. Concerns of increases in emerging drugs and their effects, particularly methamphetamine/'ice' and Fentanyl were raised in every group. A concern about the opportunistic nature of drug use related to sporadic accessibility of drugs was also a common theme, predominantly in regional areas.

Knowledge, information and support: Participants demonstrated a generally good level of knowledge of their local health services, and the strengths and limitations of each service. Among some groups there was a surprisingly low level of knowledge regarding blood borne viruses risk associated with injecting drug use. The use and reliance on informal peer networks and natural peer leaders within communities was a strong recurring theme across all sites. Aside from Users News there was limited knowledge of NUAA and its programs, particularly for those resident in regional areas of NSW.

Improving existing health and health related services: Participants provided suggestions for how NUAA could advocate for improvements in service delivery, including timely access to detoxification and other alcohol and other drug (AOD) specialist services as well as improved reach and access to needle and syringe programs (NSP). Included within this area was the need for advocacy for increased safe disposal options within communities, improved service delivery that was mindful of confidentiality while simultaneously addressing shame, stigma and discrimination for PWID when accessing health services and an increase in health promotion activities addressing BBV risk for Aboriginal PWID in communities.

Fitting with NUAA's Strategic Plan, five high level recommendations are provided in this report for the consideration of NUAA and its partners:

1. NUAA should work strategically to increase visibility and awareness of NUAA to Aboriginal PWID, particularly in regional NSW but not at the expense of metropolitan areas.

2. Funding should be sought to increase the scope of harm reduction activities for Aboriginal PWID in NSW.

3. NUAA should advocate for trialling the use of key and influential peers in selected communities to increase reach and visibility of NUAA but to also promote safer injecting practices, harm reduction techniques and broader awareness of injecting risk.

4. NUAA should continue to strengthen partnerships with key stakeholders and organisations to increase the scope of harm reduction activities in Aboriginal communities.

5. NUAA should advocate and work with the NSW Ministry of Health to identify funding for an Aboriginal state-wide coordinator to implement the findings of this report.

PURPOSE

The Community Consultation Rapid Scoping Project was commissioned by NUAA in 2013. Based on community consultations across seven NSW sites, the purpose of the Project is to inform programmatic responses of NUAA to the needs of Aboriginal PWID. The Project contributes valuable information about this population.

The specific aims of the Project were to:

1. Conduct peer facilitated focus groups with Aboriginal PWID across NSW;
2. Explore and understand issues regarding prevention of BBVs with this population;
3. Explore and understand health care needs of Aboriginal PWID in NSW;
4. Explore and understand other health, social and emotional wellbeing issues and needs with this population; and
5. Provide support to Aboriginal staff employed within NUAA in undertaking community consultations.

This report was prepared for the use of NUAA, including tailored recommendations linked to the NUAA Strategic Plan 2011-2014. The findings of the Project are also pertinent to decision makers in both government and non-government organisations providing services to Aboriginal PWID.

BACKGROUND

INJECTING DRUG USE AMONG ABORIGINAL AND TORRES STRAIT ISLANDER PEOPLE

Injecting drug use among Aboriginal and/or Torres Strait Islander people is a critical emerging issue. Historically drug dependence among Aboriginal peoples has been related to alcohol and cannabis use with much of the focus of harm reduction programs being steered to these two issues. However there is evidence and growing concern about a rise in injecting drug use within the Aboriginal community. Most compelling are the higher rates of notifications of hepatitis C infection among Indigenous Australians, the higher levels of participation in needle syringe programs by Indigenous Australians and the higher proportions of HIV incidence due to injecting drug use among Indigenous Australians compared to non- Indigenous Australians – leading to the potential for HIV infection to rapidly increase within the community because of unsafe injecting drug use [1-5].

The report, *Injecting Drug Use and Associated Harms among Aboriginal Australians* (2011), commissioned by the Australian National Council on Drugs highlights strategies to address injecting drug use in Aboriginal communities. One set of recommendations in this report refers to the need to increase research to better understand risks for Aboriginal communities and among Aboriginal PWID [6].

Injecting drug use and its associated harms has also been recognized among service providers and other stakeholders who work in the Aboriginal and Torres Strait Islander substance use area. At the inaugural National Indigenous Drug and Alcohol Conference in 2010, the following resolution was made: *"That as injecting drug use is increasing at a concerning rate in Aboriginal and Torres Strait Islander populations there is a need for increased attention to address the risk of HIV/AIDS and hepatitis C transmission amongst Aboriginal and Torres Strait Islander people* [7]."

While national information is scant on patterns of injecting drug use among Aboriginal people, the Annual Australian Needle Syringe Program survey consistently recruits around 10% of participants who identify as Aboriginal, and the sample recruited in the 2009 NSW Needle Syringe Program pharmacy project included 18% of participants who identified as Aboriginal [8, 9]. Furthermore, there are concerns that while the injecting drug user population is generally an ageing cohort, this may not apply for Aboriginal people [10].

Surprisingly, there is little rigorous quantitative data describing patterns of injecting drug use and risk behaviours among persons identifying as Aboriginal. Results of the 2004 National Drug Strategy Household Survey (NDSHS) show 10.4% of the

Australian population aged between 20 and 29 had used amphetamines in the previous 12 months [11]. These results indicate that illicit drug use constitutes a significant public health issue, particularly in regard to young adult populations in Australia. The 1994 Urban Aboriginal and Torres Strait Islander Peoples Supplement of the NDSHS (the last time data was collected in this manner), which collated responses from 2993 Aboriginal participants, did not generate a large enough sample of people who use drugs to make any definitive conclusions. However, there was some indication that Aboriginal people may have higher levels of illicit drug use compared to the general population [12].

The Aboriginal Drug and Alcohol Council (ADAC) of South Australia (2002) has conducted a study with one of the largest samples (n=307) of Indigenous people who inject [13], thus providing valuable information about this understudied population. Based in Adelaide, the study used a snowball methodology to recruit participants who were then interviewed by one of seven peer interviewers; the resulting sample had an age range of 14-45 years and a mean age of 32 [13].

The ADAC South Australia study revealed a number of key findings. In this sample heroin was the most used drug; in the previous six months 97% reported using heroin, and 68% used methamphetamines [13]. Heroin was also the most common drug first injected. The average age of first injection was 18. The majority of participants had received assistance the first time they injected from a close friend, partner, or relative. Of the sampled individuals 12% reported that in the last 3 months they had shared a needle after someone else had used it [13]. Participants had more inconsistencies in their knowledge about hepatitis C than other BBVs and while most participants believed they were at a low or very low risk of contracting BBVs, the majority of participants had been tested for hepatitis B virus (HBV), hepatitis C virus (HCV) and Human Immunodeficiency Virus (HIV) (90%) [13]. In regards to overdose, 21% of participants had overdosed with 37% of those reporting to have intentionally overdosed [13]. A large proportion of the sample had been in prison (53%) and of those who had been incarcerated, 44% had injected [13] while in prison. Sharing injecting equipment in prison was common with 52% of those who shared 'always' and only 24% 'never' sharing injecting equipment [13].

The recently completed GOANNA survey 2011-2013; a national cross sectional study of Aboriginal and Torres Strait Islander people aged 16-29 (n=2877) highlights issues for injecting drug use among this population. A total of 95 (3%) participants reported injecting drug(s) in the last year, comprising 5% and 2% of male and females respectively. By age; 3% of participants aged 16-19 and 20-24 years and 4% of people aged 25-29 years reported injecting drugs in the last year [14].

Among those who reported injecting drug(s) in the past year, meth/amphetamine (37%) and heroin (36%) were the most common drugs injected by participants followed by methadone (26%), morphine (19%) and cocaine (15%). A higher proportion of males reported injecting meth/amphetamine (45%) and or heroin (38%) compared to females (29% both); similar proportions of males and females reported injecting methadone and cocaine (~25%). Meth/amphetamine and methadone (38% both) were the most commonly injected drugs, followed by heroin (30%) among participants aged less than 20 years, while heroin was the most common drug (43%) injected among the oldest participants (25+ years) [14]. Lastly, 11% of male participants reported injecting steroids compared to 3% of females [14].

It is also important to note the international context especially among populations with similar colonised histories and contemporary health service delivery contexts such as First Peoples of Canada, USA and NZ. In Canada at the end of 2012, Canadian Aboriginal peoples comprised 23.3% of all HIV diagnosed despite representing only 4% of the total Canadian population [15]. Furthermore 60% of all Aboriginal cases of HIV diagnosis in Canada have been attributed to injecting drug use and 60% of all cases have been diagnosed among women [16]. Moreover a comparison of HIV diagnoses among Indigenous peoples of Canada, Australia and New Zealand highlights the discrepant rates of newly diagnosed HIV between the three countries with 178, 31 and 12 per 100,000 populations respectively [17]. Clearly if Australia is not to follow the same path as Canada then now is the time to act.

Sampling limitations can partially explain why we know so little about Aboriginal people who inject.

PWID constitute a hidden population, which means that the boundaries of these populations are unknown and there are strong privacy concerns of the group members due to the illicit or stigmatized behaviour that they engage in [18]. Accordingly, hidden populations are very hard to sample through traditional population based approaches [18]. Aboriginal PWID represent a hidden population within an otherwise marginalised population, making recruiting of a substantial number of people through population-based methods difficult.

INJECTING DRUG USE AMONG THE ABORIGINAL POPULATION OF NSW

The 2006 census estimated the Aboriginal population within New South Wales as 153 000, representing 2.4% of the entire NSW population and approximately 29% of the total Aboriginal and Torres Strait Islander population of Australia [19].

Due to both lack of inquiry into injecting drug use in the Aboriginal population of NSW, and because of the hidden nature of injecting drug using population in general, it is uncertain how many Aboriginal people engage in injecting drug use in the state. Using a conservative estimate of 3% injecting rate for all 15-54 year olds in the state would constitute around 2 800 Aboriginal PWID in NSW.

NEW SOUTH WALES USERS AND AIDS ASSOCIATION (NUAA)

NUAA is the NSW drug user organisation, a not-for-profit community body, funded largely by the NSW government. NUAA advocates for the health and human rights of people who use drugs, particularly those who inject drugs.

According to NUAA's Reconciliation Action Plan and Strategic Plan 2011-2014 the overall goal of NUAA is to advance the health, human rights and dignity of people who use or have used illicit drugs. NUAA is guided and informed by a commitment to respect, inclusiveness, self-determination, empowerment, and courage and constructive scepticism.

Within the NUAA Strategic Plan 2011-2014, the four key action areas are:

1. Improving the health and human rights of people who use drugs illicitly, including those with a history of drug use
2. Strengthening alliances and partnerships
3. Advocating for sound public policy and a representative voice in decision-making
4. Maintaining a credible, reflective and focused organisation

This Project and its recommendations are in keeping with NUAA's overall strategic goals in that the Project was developed in partnership with the community and that all activities and processes undertaken were controlled and informed by Aboriginal PWID.

METHODS

FOCUS GROUPS

Seven focus groups were conducted in February, March and April 2014. Two focus groups were conducted in urban sites (greater Sydney metropolitan area) and five occurred at regional sites ranging from 260kms – 700kms away from Sydney. The focus groups were used to elicit participant perspectives on the ways that government and non-government organisations can improve prevention and treatment services for Aboriginal PWID. The groups were facilitated by James Ward (Baker IDI Aboriginal Health) and Fiona Poeder (NUAA) for all sites with co-facilitation provided by Ms Bonny Briggs (Aboriginal Health and Medical Research Council, AH&MRC) at two sites and Mr John Van Den Dungen (Australian Injecting & Illicit Drug Users League, AIVL) at five sites. The facilitators' role was to guide the discussion and ensure that all participants had an opportunity to express their views. With the co-facilitators role being to elicit, verify and validate peer perspectives and support individuals who might require confidential advice or further information.

Focus groups are an effective method to elicit information from groups and to verify the information within groups, to find explanations for diverging or contradictive information, and importantly to reach consensus on appropriate and feasible interventions. A guide was developed as well as prompts and probes for each question to guide the group to a more in-depth discussion for each question. Prompts are defined as a question that can facilitate a discussion if there is not an adequate response to the initial question and a probe is a question that will explore an issue in more depth. The focus group Guide/Framework is attached at Appendix 1.

Each focus group opened with the offer of light refreshments and opportunity for participants to mingle. At the opening of the session, the peer facilitator welcomed participants and informed them of the purpose of the discussion, gave participants information regarding confidentiality, and identified the outcomes that were expected to be generated. Notes were taken by the co-facilitator and facilitator and any issues raised by participants were clarified by the facilitators as they arose. At the end of each focus group the facilitators summarised the discussion for participant verification. Participants were advised about the development of a report for NUAA which would be available for their viewing following endorsement. The focus group discussions did not exceed 120 minutes in each group.

At the end of each focus group, lunch was provided and afterwards NUAA and the peer facilitator provided training in hepatitis C education using a resource developed through AIVL for Aboriginal PWID by Aboriginal PWID to ascertain levels of knowledge among the group of HCV education. The results of this activity are not included in great detail within this report, however, the overall reflection of the intervention's outcomes supports this report's finding that a greater level of BBV education – developed within a culturally appropriate peer-driven framework - is urgently required to meet the gaps in knowledge and levels of misinformation held by many participants.

PARTICIPANT RECRUITMENT AND PROFILE

Focus group participants were recruited through networks known to NUAA. A peer contact in each site engaged other Aboriginal PWID to participate in the focus group discussions. Participants who have injected non-prescription and prescription drugs more than once in the last 12 months were invited to participate in this focus groups. Participants were all over the age of 16 years and identified as Aboriginal. As it turned out, in some sites non Aboriginal friends and peers of Aboriginal PWID participated in the focus groups, however it was made clear that the specific needs of Aboriginal PWID were to be the focus of the group.

Participants were paid $30 to offset the cost of travel and time to participate in the focus group discussions. An additional $30 was paid to participants who participated in the NUAA HCV education session.

A total of 70 Aboriginal PWID participated in the focus groups. Sex, age and location of participants are identified in Table 1 below.

Table 1. Participant Profile

Participant Characteristics	Total
SEX	
Females	33 (47%)
Males	37 (53%)
AGE	
<25 Years	12 (17%)
25 - 34	18 (26%)
34 - 44	22 (31%)
>45	18 (26%)
LOCATION ON FOCUS GROUP	
Urban Areas	22 (31%)
Regional Area	48 (69%)

ETHICS

The project was approved by the AH&MRC Ethics Committee in December 2013.

Prior to participation in the focus groups, participants were provided with a written consent sheet explaining their participation and the purpose of the focus groups. Participants were advised that they were free to leave the meeting at any time, and that any information provided by them would not be attributed to them, and identifying information about the sites would be omitted from this report. Participant consent was sought prior to each focus group.

The confidentiality of participants was paramount throughout the Project. All venues used for focus groups were determined appropriate in consultation with NUAA and a representative(s) of the group from each site. Signs at the venue identified the focus group as "Invited Health Consultations".

Matters related to confidentiality were also discussed at the commencement of each focus group. Participants were notified that names of persons were not to be used in reporting, that aliases for participants could be used if needed or requested, and that all documentation arising from the consultation would remain non-identifiable by site. Participants learned that the final report would generically discuss the issues affecting Aboriginal people who inject drugs and put forward recommendations based on their input which would be available to them via the NUAA website and the NUAA magazine 'Users News'.

ABORIGINAL REFERENCE GROUP

An Aboriginal Reference Group was established to guide this project (see attached 'Terms of Reference' at Appendix 2). Reference group members are members of the AH&MRC and their member services. The Reference Group were consulted at the commencement of the project, midway through the project and will be provided with the draft and final reports for comment. The Aboriginal Reference Group provided technical advice on all matters related to recruitment, focus groups and interpretation of findings as well as input into draft and final reports.

ABORIGINAL FACILITATORS

Consultation focus groups were all held with at least two facilitators, James Ward and either Bonny Briggs, John Van den Dungen or Fiona Poeder in attendance. In each consultation and where appropriate facilitators identified as peers with participants. This was important in building rapport with participants, to aid in their comfort, and most importantly so that participants understood that what was being discussed was understood and contextualised as relational to the facilitators.

DATA ANALYSIS

Data management of focus groups began immediately upon completion of each focus group. The facilitators summarized each focus group discussion into a more manageable concept map. Key ideas and themes were identified across sessions.

KEY FINDINGS

The findings of the community consultations are broadly grouped into three main areas:

- Drug use and local contexts;
- Knowledge, information and support; and
- Improving existing health and health related services.

These three areas encompass a number of sub themes as described below.

DRUG USE AND LOCAL CONTEXTS

Supporting what is thought to be occurring and what is already known about Aboriginal PWID, participants described the trends of injecting drug use in their local communities including the types of drugs used.

a) Increasing levels of injecting drug use.

One of the main issues identified by Aboriginal PWID is the increasing prevalence of drug use, particularly among younger Aboriginal people. Older more experienced injectors felt that injecting was on the increase in communities and often expressed, that young people had little support. More experienced PWID were concerned about younger injectors' levels of knowledge, their behaviours - particularly related to unsafe disposal of used equipment - and general knowledge of safer injecting practices.

b) Emerging drug issues drugs.

Participants felt methamphetamine/'ice' was especially prevalent in communities and among young people with smoking strongly associated with it. Participants discussed in length the potential for young people to transition to injecting drug use, with concerns related to how to deal with this in communities expressed.

The use of Fentanyl was raised in almost all consultations and was generally related to personal stories of loss of loved ones or peers from overdose resulting from the use of the drug. Many focus group participants suggested that information should be provided so that people knew of the risks associated with its use, the particular issues pertaining to the drug's formulation that contribute to overdose and what to do in overdose situations.

c) Opportunistic and poly drug use

In many focus groups, participants explained the use of drugs was often driven by their availability within communities and that for many Aboriginal PWID poly-drug use, including the use of non-injectable drugs was the norm.

KNOWLEDGE, INFORMATION AND SUPPORT

Participants described where they normally sourced information and support in relation to injecting issues.

a) Good knowledge of relevant health services.

Most participants understood the context of health care delivery in their local areas and communities, including the limitations and strengths of local health care provision and most particularly services related to injecting. This knowledge of services and their delivery ranged from where NSPs operated, for instance; operational hours, and what equipment can be accessed at different points in the community, in addition to where and when alcohol and other drug (AOD) doctors were in town [if ever] and who were the "injecting drug user friendly GPs" to see regarding AOD health care issues. Many participants expressed concern in regard to difficulties in accessing specialist AOD doctors particularly in regional areas – where it may often be weeks or months to get an appointment and the need for a better system for detoxification services. In this regard an often repeated story within the focus groups was that if a person wanted to detoxify and presented to a health service [which required both internal conviction and courage], they were often sent away disappointed with an appointment date weeks in to the future.

b) Reliance on informal peer networks.

In each site participants described the informal peer network in operation. However these networks appeared to be limited to older and more established PWID, and it was felt that younger PWID were often injecting in small groups or alone. In every group a natural peer 'leader' was identified. These people were usually older, more established PWID, who many in the community sought out for advice on injecting health issues, other drug and alcohol issues, what to do in the case of an overdose and was generally someone they could trust to seek advice from. This natural leader knew the drug using context of their own community very well, including; who was using, what drug(s) they were using, how and where to access information and they were often advocating for health services to be more appropriate. These leaders were highly connected individuals within their community and their peer-to-peer influence was observed to be a very powerful means of networking within community. Aside from the leaders within the community, the participants were all familiar to each other which appeared to be over and above cultural or familiar linkages suggesting that injecting networks within communities are well linked.

c) Limited knowledge of NUAA among young Aboriginal PWID.

Participants were asked about their knowledge of NUAA. Those linked with NUAA and those residents in Sydney or having a previous history of living in Sydney, generally knew of NUAA and had a better understanding of NUAA's role and functions. However for many younger participants and particularly among rural and regional participants there was limited knowledge of NUAA, if any in some instances. However many participants knew of, had read, seen or receive Users News – ironically this was more likely for people who had been previously incarcerated.

d) Limited knowledge of blood borne virus risk.

Overall during our discussions we were surprised of generally low levels of knowledge exhibited by participants on BBV risk and other drug-related issues. Many people in the hepatitis C transmission sessions facilitated by NUAA categorized risks wrongly. It appeared that more was known about hepatitis C than HIV in the focus groups and it appears that HIV has been moved to the backburner as a low risk if it is considered at all. This is not surprising given the ubiquitous nature of HCV in Aboriginal communities; it lends itself to more knowledge and discussion within the population.

IMPROVING EXISTING HEALTH AND HEALTH-RELATED SERVICES

Focus group participants commented on the limitation of current services and how these could be improved to better meet their needs.

a) Access to needle syringe programs (NSPs).

Many participants raised concerns in relation to inadequate NSP access – too often located in one central site and away from where people live, limited after-hours access, vending machines in high traffic throughput locations, confusing vending machine instructions (people not sure what they were accessing and in some cases purchasing) and pharmacies dispensing sterile equipment were diminishing.

b) Confidentiality at health services.

Confidentiality of patients' information within health services was raised as an issue for participants. Many felt a level of discomfort and untrustworthiness of health services and how their health data might link to other agencies such as housing, child and other welfare groups.

c) Access to safe disposal sites.

Participants, in almost every site raised disposal of used equipment as an important issue. Many participants felt that aside from where people access sterile injecting equipment there were too few places to safely dispose of used equipment within the community.

d) Health promotion strategies.

Many participants suggested that there should be safe drug use information available in waiting rooms of health services, including information on the importance of testing and knowing your status in relation to BBVs. These should ideally be located on posters in waiting rooms so people could read while they were waiting and then prompt a discussion with their doctor or clinician. Similarly, participants felt that posters promoting health seeking behaviour could be posted in courts and agencies accessed by the community, for instance Centrelink in addition to drug treatment services. Many felt the use of smart phone applications could be useful particularly in relation to location and accessibility of services.

Health promotion information on fit pack boxes was identified by focus group participants as a positive way to disseminate targeted and high impact information to Aboriginal PWID. However, in the past PWID have been questioned and prompted to explore the strategy further; as to whether people would be interested in reading health promotion material on boxes when most are discarded almost immediately after use, most PWID generally agree that this is not a viable and cost effective strategy.

To reach younger people, participants felt that school-based education on drug awareness should be routinely provided. Many participants also felt that younger people engaging in injecting drug use required significant education not only about safe injecting practices but also about safe disposal and in particular what to do in overdose situations and their rights in relation to police questioning and searches.

Many participants felt that much more could be done in regards to the provision of health promotion and safe injecting practices in prisons, including risks associated with BBV transmission and their risks.

e) Input into programming.

Many participants were overwhelmingly pleased about the community consultation, and for many it was the first time they had an opportunity to inform an organisation such as NUAA of the their needs, experiences and ideas. Participants expressed thanks and gratitude for being able to participate in the process: Indeed most want to see real action arise from the project.

f) Exemplary program.

One program was identified by focus group participants as working well and providing benefit: the First Steps program based in the Illawarra/Shoalhaven area of NSW. Established in 1999 by the NSW Ministry of Health, the First Steps Program aims to reduce the incidence of harm associated with drug use.

Focus group participants appreciated First Steps because of the holistic approach it takes. The program assists clients assess risk behaviour, provides assistance with stabilising drug use, community services, legal and financial help and referrals to treatment and health care, as well as extensive outreach to the community. In addition the Program provides access to sterile injecting equipment, particularly in areas where NSP access is limited. First Steps manages this by providing an outreach-based model which ensures the pro-active provision of safe injecting equipment and safe sex products to PWID. While doing this First Steps provides education to PWID about BBV transmission risks. Focus group participants recognised the program's role in reducing the transmission of HIV and other blood borne viruses in the area.

KEY RECOMMENDATIONS

The NUAA Strategic Plan sets out four Key Action Areas on which NUAA will focus its activity for the period of this Plan (2011—2014). With these Key Action Areas in mind, the following five recommendations have arisen from the Project.

NUAA to work strategically to increase visibility and awareness of the organisation to Aboriginal PWID, particularly in regional NSW but not at the expense of metropolitan areas.

1. The development of a comprehensive communications plan would be beneficial in outlining how NUAA could have more reach and impact into Aboriginal communities in NSW, for example:

- Many participants see Users News occasionally but would like to have this mailed to them;
- Many participants did not know that NUAA had a page on their website highlighting the work of NUAA with Aboriginal communities in NSW;
- Many participants did not know of NUAA particularly in regional areas, or make the link to NUAA if they knew of Users News;
- More work needs could be done to promote the NUAA website and specifically the Aboriginal pages within the NUAA website, highlighting activities and news for Aboriginal people in NSW. Suggestions for adding to this page include:
  - » Prevention of BBV information
  - » Information related to safer injecting
  - » Risks associated with injecting particularly with emerging drugs
  - » Vein and other health care issues
  - » Rights with police and other law enforcement agencies
  - » Treatment options for people living with viral hepatitis and/or HIV

2. Funding sought to increase the scope of harm reduction activities for Aboriginal PWID in NSW.

Many participants felt that NUAA could up-scale the amount of work it has underway in Aboriginal communities by establishing a specific Aboriginal reference group. Ideally the group should be made up of predominantly Aboriginal PWID, but it would also be strategic to include key agencies and stakeholders as a minority to ensure the groups is both considered in its focus and in line with what might be possible from policy and programming opportunities. A draft Terms of Reference for the group should this recommendation be adopted is attached at Appendix 2.

Other areas participants felt NUAA could provide assistance to Aboriginal PWID include:

- Brokering or providing first aid training related specifically to overdose to key peers within communities.
- Extending the reach of work to ensure Aboriginal people know their rights with police, transport police, security guards and other agencies. This would include information in regards to carrying injecting equipment and calling an ambulance in overdose situations;
- Advocating for a mechanism within both Aboriginal community controlled health services and LHDs for fast-tracked detoxification services for Aboriginal PWID;
- Consideration of the development of smart phone applications showing NSP and other AOD service provider locations; and
- Advocating for increased reach and expansion of NSP services in all areas.

3. NUAA to advocate for a trial or pilot project which incorporates the use of key and influential peers in selected communities to increase reach and visibility of NUAA, and also promotes safer injecting practices, harm reduction techniques and broader awareness of injecting risk.

It was apparent in each focus group that there were natural peer leaders within each consultation. Characteristics of these peer leaders include: That they were usually longer and established drug users or past users, that they were held with significant regard within the Aboriginal community, that they were usually open about their drug use in the community, and that they were usually people with a high level of knowledge of all matters associated with injecting drug use.

Individual and peer networks of educators have been used extensively overseas among injection drug users [20-25]. However, to date very little formal evaluation or trialling of this model has been conducted in Australia specifically with Aboriginal communities. These programs are guided predominantly by social networks theory, social influence and empowerment frameworks and have trained peer leaders operating in injecting drug user communities. The programs have resulted in significant reductions in risk behaviours for HIV and other blood borne viruses and increased the promotion of HIV prevention among the leaders' risk network members and others at risk of acquiring and/or transmitting HIV.

It seems natural to trial the use of peer led interventions given that we easily identified peer leaders within every community visited. This model may lead to greater reach and impact in Aboriginal communities than a centrally driven program from an organisation like NUAA, however there would be a central role for NUAA in ensuring outcomes from peer leaders and overall objectives of such a program were being met.

4. NUAA to strengthen partnerships with key stakeholders and organizations to improve scope of harm reduction and other AOD services in Aboriginal communities

NUAA should continue to align itself strategically with the AH&MRC and the Ministry of Health in rolling out projects in NSW Aboriginal communities and LHDs. More works needs to be conducted between these partners, with the first area of work being to ensure health services are responsive and proactive to the needs of Aboriginal PWID. Examples of services which require strengthening include; availability and responsiveness of detoxification services, health promotion initiatives, reducing stigma and discrimination targeted toward Aboriginal PWID within mainstream and Aboriginal community controlled health services and advocating for more NSP services in areas where there are major gaps in services.

Secondly more work needs to occur to ensure NUAA as a peak agency has access to information pertaining to injecting drug user populations in each LHD across NSW.

An issue that became apparent in many consultations was the number of overdoses and loss of lives attributed to injecting drugs within communities across NSW in recent times, particularly related to the use of Fentanyl, with at least half of the groups noted having lost family members or loved ones due to overdose. NUAA should work with the Ministry of Health and other agencies to gather information in a timely manner related to the following by Aboriginal status:

- Number of NSPs operating in NSW at LHD level, total number of NSPs operated by government and community organisations and by type of service provider
- Distribution of fit packs per recording period at LHD level
- Reporting of number of Aboriginal clients accessing NSPs by LHD level and by time periods
- Number of Aboriginal clients accessing opioid substitution programs (OST) by LHD level
- Number of fatal and non-fatal overdose incidents at LHD level to monitor trends in drug use
- Number of HCV notifications
- Number of HIV notifications acquired through injectiog drug use.

At the very least these reports should be aggregated by a central agency and reported to NUAA on a regular basis preferably three monthly but at the minimum by 6 monthly periods.

This data would provide important information on where NUAA should be responsive and proactive in its remit of addressing issues pertinent to Aboriginal PWID.

5. NUAA to advocate and work with the NSW Ministry of Health to identify funding for an Aboriginal state-wide coordinator to implement the findings of this report.

There is much work to be done to improve the health and wellbeing of Aboriginal PWID in NSW. The scope of work outlined in these findings highlights the role that NUAA has in rolling out projects in communities. A fully funded position based within NUAA should be considered to achieve these recommendations. A fully developed work plan including a communications plan and trialling of interventions that reduce risk of BBV transmission as well as increased training among Aboriginal PWID to reduce personal and social risks is required. NSW is home to the highest number of Aboriginal people of any Australian jurisdiction and the state has a considerable sized drug using population, dispersed across communities in NSW. In the absence of a coordinator position within the peak drug user organisation there is little chance that these recommendations can be fully achieved by utilising NUAA's existing resources.

CONCLUSION

There are growing concerns within the Aboriginal community of a rise in the number of Aboriginal individuals who inject drugs. The increase in the use of injectable illicit drugs will have a significant impact on the health of Aboriginal people if aside from needle syringe programs, stringent harm reduction measures are not implemented and complementary to each other. It is well known that a higher rate of HIV occurs among the Aboriginal and Torres Strait Islander population attributable to injecting drug use; an increase in the use of injecting drugs within this community will potentially rapidly increase the number of individuals diagnosed with HIV and viral hepatitis. This study has met and discussed with individuals in communities across NSW some of the issues affecting their daily lives and where health programs and initiatives can be improved upon by an agency such as NUAA.

The information presented within this report reflects the consultations held in communities across NSW. We do not know how generalisable the findings are to other Aboriginal PWID across NSW, nevertheless, we have successfully assembled a sample with a range of demographic characteristics – from all targeted age groups, and from urban and regional areas of NSW. The findings are important as it is the first project in some time to talk directly to Aboriginal PWID. In too many consultations we heard the personal stories of discrimination, stigma and shame caused by health services; that are meant to be serving everyone in our communities. Similarly we heard the personal and distressing stories of the loss of loved ones, attributable to injecting drugs such as Fentanyl. In one group a participant told us they lost their partner of 13 years in the last 6 months, in another group the loss of two siblings, months apart was distressing for the community and particularly the families of these people. These are the stories of people in our communities.

The timing is right for such a report as we continue to witness escalations in hepatitis C notifications and HIV among Aboriginal people attributable to injecting drug use while at the same time witnessing decreases in the non-Aboriginal population. We also continue to see increases in the number and proportion of Aboriginal people accessing needles and syringe programs, well knowing that not all PWID are accessing these programs.

Furthermore the timing is right for this report because we witnessed in many of our focus groups within this project surprisingly low levels of knowledge about transmission risks. While it may seem easy science for those working in the field, the reality is that many people who inject drugs do not understand risk factors associated with injecting drugs, variances in viral hepatitis genes and treatment options for people living with BBVs. These issues make it paramount to do something now, before more transmissions occur. We must act on these recommendations as a matter of urgency. Lack of action is an injustice to Aboriginal people living in NSW who inject drugs, their peers and their families.

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APPENDIX 1:

FOCUS GROUP FRAMEWORK NUAA

1. Introductions, introduce why we are doing this, confidentiality, aliases, no names necessary, process after consultation.

2. Tell me a bit about how you think drug services are provided in this area? (NSPs ACCHS, AOD services, including methadone services/OST, hospital, private GP, all or some). Are these adequate (time to travel, time to get to appointments, judgemental etc.)

- For prevention where do you mainly go for clean equipment?
  a. NSP
  b. Primary, or
  c. secondary
- For health related education?
  a. friends
  b. family
  c. internet
  d. drug health services
  e. NUAA

3. What is your understanding of NUAA?

  a. Its role
  b. Services provided by NUAA
  c. Programs provided by NUAA

4. What are the main issues facing people who inject drugs in the region?

5. Thoughts on how NUAA could respond to some of these issues (process, timeliness, outcomes, logistics, training, usefulness)

6. What could NUAA do more of? (is it in education, prevention improving understanding of clinical pathways, training, guideline development, targets for service delivery, health promotion, brokering relationships or resource development)

7. Are there any emerging issues that need to be addressed in the future direction of NUAA?

APPENDIX 2:

MEMBERSHIP AND TERMS OF REFERENCE FOR THE NUAA RAPID SCOPING PROJECT FOR ABORIGINAL PEOPLE WHO INJECT DRUGS

1.0 PREAMBLE

The New South Wales Users and AIDS Association (NUAA) are conducting a rapid scoping project in NSW consulting with Aboriginal people in NSW who inject drugs in seven sites across NSW. The outcomes of this project will assist NUAA in shaping their strategic directions, policy and advocacy for Aboriginal people who inject drugs. Secondary benefits anticipated will be to assist other service providers such as Aboriginal Community Controlled Health Services in their delivery of services to people who inject drugs. Prior to this project very little effort has been given to hear from current injecting drug users. The project will be conducted by James Ward, Deputy Director of the Baker IDI in Alice Springs, an experienced researcher in the fields of drug and alcohol as well as STIs and BBVs and as well as working with ACCHS.

2.0 ACKNOWLEDGEMENT OF ABORIGINAL RIGHT

NUAA and Baker IDI recognize and respect Aboriginal rights and title, including the right of Aboriginal communities to be involved in decisions that impact their health and wellbeing. To this extent we would like to establish an Aboriginal Reference Group to oversee the project.

3.0 PURPOSE STATEMENT

The Aboriginal Reference Group will provide advice to Baker IDI (James Ward) and NUAA on matters pertinent to the improvement of health and health services for Aboriginal people who inject drugs. To achieve this, the Aboriginal Reference Group will support the fostering of a respectful, trusting, responsible partnership on behalf of Aboriginal people to ensure that findings from consultations are interpreted and any strategies are designed inclusive of the needs of Aboriginal people and services are provided in a culturally safe manner.

4.0 MEMBERSHIP

The Aboriginal Reference Group (ARG) is composed of representatives from Aboriginal Community Controlled Health Services in NSW. Nine ACCHS have been invited to represent their organisation on the ARG. Other representatives from the Aboriginal Drug and Alcohol workforce and sexual health and BBV workforce may be invited to participate.

5.0 APPOINTMENT AND TERM OF COMMITTEE MEMBERS

5.1 **Appointment and term of Aboriginal community representatives.**

5.1.1 Representatives of ACCHS and other workforces in NSW are designated after approval of participation by their respective CEO or managers.

5.1.2 The ARG will convene three to four times via teleconference over the first six months of 2014.

6.0 ROLES AND ASSOCIATED RESPONSIBILITIES

6.1 Roles and responsibilities of the ARG

6.1.1 The ARG will provide advice on the consultation framework and focus group framework prior to consultation with Aboriginal people who inject drugs.

6.1.2 Review progress of the project including the outputs of the focus groups used to inform effective strategy development for Aboriginal people who inject drugs.

6.1.3 Assist with the interpretation of findings of each of the focus groups to ensure the findings are relevant to Aboriginal community context and situation.

6.1.4 Review the draft and final reports of the project to ensure cultural relevance and fit to strategy and service delivery situations for Aboriginal people who inject drugs.

6.1.5 Baker IDI and NUAA will convene the meetings and ensure the provision of resources for meeting expenses.

6.1.6 Baker IDI and NUAA will ensure effective facilitation of the ARG meetings.

6.2 **Members.** All ARG members will be responsible for:

6.2.1 Working collaboratively towards the goals of the reference group.

6.2.2 Adequately preparing for ARG meetings.

6.2.3 Attending and participating in ARG meetings.

6.2.4 At least five members must be present in order for a formal ARG meeting to proceed.

6.2.5 Meeting minutes will be recorded by the Baker IDI and NUAA and made available a week after meetings have occurred.

APPENDIX 3:

DRAFT TERMS OF REFERENCE FOR AN ABORIGINAL REFERENCE GROUP FOR NUAA

Background

As a result of the RISE project NUAA would like to establish an Aboriginal Reference group to help guide its activities and scope of work with Aboriginal people who inject drugs (PWID) in communities in NSW.

Purpose of the Committee

To provide leadership and advice to NUAA in developing, implementing and evaluating NUAA activities as they relate to Aboriginal PWID in NSW, in the areas of prevention treatment and care for both drug use and BBVs risk.

Aims and objectives of the Committee

- Provide leadership and advice to NUAA.
- Provide input into the development of a work plan of activities for NUAA.
- Acknowledge and respect cultural groups and diversity within NSW Aboriginal communities and ensure the committee's work reflects this understanding.
- Assist in the development of health promotion and education messages (e.g. testing, know your status, treatment options, provide assistance with addressing shame and stigma campaigns).
- Work collaboratively to devise strategies of allocating limited resources to have maximum effect in NSW.
- Provide advice on how best to reach Aboriginal communities and PWID in NSW.

Meeting Frequency

It is envisaged the "committee" will meet regularly via teleconference and at least annually face to face.

Membership

The Committee is comprised of a majority of Aboriginal PWID as well as membership from NSW Ministry of Health, LHD representative(s) an AH&MRC representative, and a NUAA representative. Others may be co-opted as required.

Duration

The committee will exist and function for a period of two years initially.

CONTACT US

If you have any questions about the information in this peer support worker project manual contact us during business hours using the details below or reach us through our website:

www.nuaa.org.au

NUAA OFFICE PHONE HOURS:

Mon	9.30am – 5.30pm
Tue	1.30pm – 5.30pm
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