TITLE PAGE

**Title**

Asking young Aboriginal people who use illicit drugs about their healthcare preferences using audio-computer assisted self-interviewing

**Short title**

Health needs of vulnerable Aboriginal youth

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**ABSTRACT**

**Introduction and aims:** Substance use significantly contributes to increasing the disease burden experienced by young Aboriginal and Torres Strait Islander (Aboriginal) Australians. Little is known about the primary healthcare needs of young Aboriginal people who use drugs. The aim of this study was to pilot Audio Computer Assisted Self Interviewing (ACASI) as a method of asking young Aboriginal people who use illicit drugs about their health concerns and service preferences, in inner-Sydney, New South Wales.

**Design and methods:** We employed a sequential mixed methods exploratory study design. Qualitative data was collected using a focus group and in-depth interviews. These findings informed the development of the ACASI survey, which trialled questions on substance use, health concerns, health service usage, barriers and preferences for services. Recruitment sites included youth and health services. Qualitative results were analysed thematically, and survey results using descriptive statistics.

**Results:** Eight people participated in the focus group and two in in-depth interviews. Of the 38 survey respondents, 68% reported illicit drug use. Reported barriers to service access included waiting time, services seeming unfriendly or not understanding Aboriginal people. Participants expressed preferences for Aboriginal-friendly health services that provide internet access, literacy skill development and opportunities to learn about Aboriginal culture. Participants found the ACASI survey user-friendly.

**Discussion and conclusions:** This is the first report of the health concerns and service preferences for young Aboriginal people who use illicit drugs. The ACASI survey appears to be an appropriate and efficient approach to giving a voice to young Aboriginal people.

**KEY WORDS**

Youth

Aboriginal

Substance use

Health service needs

Technology

Survey methods

**INTRODUCTION**

For young Aboriginal and Torres Strait Islander (Aboriginal) Australians, adolescence and young adulthood can be complicated by experience of trauma, poverty and discrimination [1, 2]. Young Aboriginal Australians have significantly higher rates of psychological distress, symptoms of serious mental illness, and rates of suicide than their non-Aboriginal peers [1] [2]. This is accompanied by an increased risk of substance use disorders, and these, together with mental health disorders and injuries, contribute the greatest burden of morbidity and mortality (77%) for young (15-24 years) Aboriginal Australians [3]. Household survey data on substance use by Aboriginal young people (aged 15-24) are limited, but suggest just under a third (32.5%) report illicit drug use (including petrol sniffing) in the last 12 months [4]. Aboriginal young people who inject drugs are more likely to share needles and to contract hepatitis C than their non-Indigenous counterparts [5]. The youth of other indigenous peoples who have experienced colonisation [6, 7] are also at increased risk from mental health and substance use.

Two thirds of Aboriginal Australians aged under 30 in 2014-5 live in major cities [4],. However, healthcare is often underutilised by young urban Aboriginal people, who may prefer to seek help from extended family or friends [8-10]. Aboriginal young people have reported a number of barriers to accessing primary health care including confidentiality and anonymity concerns that are also described by Non Aboriginal youth [8, 9, 11-14]. In particular, young Aboriginal people note issues being identified accessing specialised services that may shame themselves or their family [8, 9, 14].In addition, lengthy wait times, a lack of service availability, transport issues and cost have all been noted as obstacles to accessing health care [15]. Primary healthcare is often the first point of contact Aboriginal youth have with the health system [16] that aims to provide access to early interventions and the coordinated ongoing management of mental health and substance use disorders [17]. However, there is la lack of data on how primary healthcare services meet the needs of young Aboriginal people who use illicit drugs.

A study examining specialised drug treatment services (rather than primary care), found that 46% of Aboriginal drug user clients were aged 16-25 years. Respondents reported a preference for services that were Aboriginal-controlled or for culturally appropriate non-Aboriginal specific services [18]. However, there appears to be a lack of young Aboriginal voices in drug and alcohol research.

To prioritise these voices in research so that they can inform the improvement of primary health care services, recruitment and data collection techniques may need to be tailored [14, 19, 20]. Recruitment via traditional methods (phone, post, email) may be difficult due to issues accessing to mobile phones or email [14]. Young people may be reluctant to take part in face-to-face research regarding sensitive topics, such as substance use, due to confidentiality concerns, shame, and/or fear of legal or disciplinary repercussions [19, 21, 22]. Substance use is believed to be under-reported in surveys of Aboriginal Australians [23]. This may be the result of perceived lack of anonymity [20, 23], culturally inappropriate interviewer-led or pen-and-paper data collection approaches, and/or social desirability bias [20, 23, 24].

Various approaches have been trialled to reduce social desirability bias and improve confidentiality, including computer based self-report [4]. However, these approaches can exclude individuals who are not comfortable with written English. This barrier can be particularly challenging for young people who may have had disrupted education [25, 26]. ‘Audio-computer assisted self-interviewing (ACASI)’ has been developed to overcome such barriers [27]. ACASI allows participants to hear the questions and potential answers, and confidentially select a response. Surveys can be undertaken using local language(s) [19, 21]. ACASI has been shown to reduce social desirability bias in self-reporting of drug use-related behaviours [22, 28] and to be acceptable to Aboriginal respondents [14, 21].

**Aim**

Concerned staff at a local needle syringe service who identified that the health needs of young Aboriginal clients were not met by local primary health care services initiated the current study. As the first step towards addressing this gap it was necessary to gain a more in-depth understanding of these needs form the perspective of young people themselves using the most appropriate tool. Here we describe the development and pilot results of an ACASI survey to provide insight into the (self-) perceived healthcare needs and preferences of young (aged 16-25 years) urban Aboriginal people who use illicit drugs, including comparing to those who had not used illicit drugs in the last 12 months.

**METHODS**

A sequential mixed-methods exploratory study design was employed with the aim of developing a structured survey to explore the health needs of young Aboriginal people (aged 16-25) who use illicit drugs in inner-city Sydney. While the Aboriginal population is approximately two percent [29], further details of the setting are not provided to protect community confidentiality.

Qualitative data was collected using a focus group discussion and two in-depth, one-on-one interviews with young Aboriginal people who use illicit drugs. The findings of this phase informed the development of the quantitative survey delivered on a tablet-based ACASI platform, and quotes are presented to provide context for responses to the quantitative survey items.

Study methods were guided by an advisory group comprised of a representative from the local Aboriginal Medical Service (AMS; an Aboriginal community-controlled health service), a Needle Syringe Program (NSP; a program offering free clean injecting equipment which can be collected anonymously), staff of non-Aboriginal specific drug and alcohol services ( ie. local hospitals) and research personnel. The Human Research Ethics Committees of the Aboriginal Health and Medical Research Council of New South Wales (NSW) and of Sydney Local Health District approved the study.

**Focus group and interviews**

Following consultation with the study’s advisory group, issues were selected to explore with both the focus group and one-on-one interview participants, including: health issues of most concern, sources and trusted providers of health information and advice, factors facilitating healthcare seeking, involvement in planning and delivering health programs, and improvements needed in health services.

Young Aboriginal Australians were recruited via local youth services, and health services designed for youth who use illicit drugs in inner-city Sydney. Participants with known drug use were invited to the focus group by health service staff. Participation was voluntary and, following a discussion about the study, the provision of a participant information statement and the opportunity to ask questions, all participants provided written informed consent. Food was provided along with reimbursement for participation ($30). Due to recruitment difficulties, only one focus group was conducted (male and female combined). This was supplemented by in-depth, face-to-face, individual interviews with two males who were known to inject drugs, recruited from a drug treatment service. An experienced Aboriginal focus group facilitator (TJ) with no local healthcare delivery involvement led the two-hour group discussion and conducted the one-on-one interviews, using the same framework for discussion. Two non-Indigenous researchers (CG, and AW) were present as observers and assistants at the focus group, but did not participate. Focus groups and interviews were audio-recorded and transcribed verbatim.

*Qualitative data analysis*

Focus group and interview transcriptions were analysed thematically. Two researchers (KL, AD) independently coded the data line-by-line to identify health concerns, service needs and health-seeking behaviour. Transcripts were read and re-read and coding compared across and within each transcript. Following a process of refining and consensus, codes were assigned to categories and then merged into key themes and sub-themes. Concept mapping was used to summarise the themes and sub-themes and the relationships between these.

**ACASI survey**

*Development and questions*

Development of survey questions was informed by the focus group and interview responses. The survey covered: demographics, substance use, health and life worries, current health service use, barriers to health service use and preferences for delivery of health services. For questions about health worries, barriers to healthcare, preferences for healthcare services and acceptability of the ACASI survey, quasi-continuous responses were recorded using a visual analogue scale, where participants dragged a marker continuously along a line to demonstrate their answer [30]. The ends of each line were labelled with plain language descriptions. For example, the extent of different health worries (such as lung problems or skin problems) could range from ‘none’ to ‘heaps’, potential issues with getting help for a health worry (such as needing a booking) could range from ‘no problem’ to ‘huge problem’, or factors that make you want to keep going back to a service (such as there are Aboriginal staff) could range from ‘not important’ to ‘very important’; whether you like using ACASI was labelled from ‘No, I don't like it at all’ to ‘Yes, I like it a lot’. In keeping with advice received from Aboriginal (and other) representatives on the steering group, the survey length was capped at 20 minutes to maximise. engagement.

*Substance use questions*

Questions used street drug names and asked about use in the last 12 months. Information was sought about: tobacco, alcohol, cannabis, heroin, stimulants, synthetic cannabis-like/LSD-like/methamphetamine-like drugs (some of which were legal at the time of the survey), performance and image enhancing drugs (PIEDs; such as steroids to increase muscle bulk) and prescription medications. For alcohol and cannabis, the question specified use on at least six days in the last 12 months. Alcohol-related short-term harm was assessed by asking participants whether they consumed five or more standard drinks per occasion, referred to as “risky drinking” [31]. For prescription medications, the source of supply (a doctor or the street) could be selected.

*Participant recruitment*

Recruitment occurred between January 2014 and November 2015 in locations where young Aboriginal people who use illicit drugs may be more likely to be found (e.g. youth services, drug treatment services and NSPs). To avoid people providing false information to ensure inclusion (and so, financial reimbursement), participants were not screened for Aboriginality, age and substance use history. Although this increased the chance of recruiting people outside the target group, it was deemed likely to increase the accuracy of information collected and to reduce the risk of participant stigmatisation. In selected locations, where larger numbers of non-Aboriginal people were present (e.g. a health stall at a public event) some informal screening (age and Aboriginal status) was necessary. Following an explanation of the study and that participation was voluntary, a written information statement was provided. The young person had the opportunity to ask questions. Focus group or interview participants signed a written consent, while survey participants were presented with a consent page by the ACASI.

*Survey administration*

The tablet computer was handed to the young person by a project research assistant (a staff member, student, or a volunteer), who then waited nearby. All three research assistants were non-Aboriginal. Two had considerable experience working with Aboriginal Australians. The survey was completed, where possible in a quiet location, on a tablet computer with headphones attached. Survey duration was around 10 (without audio) to 20 minutes (with audio), based on observation. Reimbursement for participation was provided ($20).

*Analysis of survey data*

Survey responses were downloaded from the tablet-computer and uploaded to IBM SPSS Statistics Version 24. Ineligible responses were excluded (participants aged outside 16-25 years or not identifying as Aboriginal). Visual analogue scale responses were computer-coded as a number (0-79) and then adjusted to a score out of 100. Median scores were calculated. Subgroup comparisons included by gender and illicit drug use where appropriate. Due to the small sample, only descriptive analysis was conducted. Results were communicated to local AMS and drug health service staff for comment.

**RESULTS**

**Overview**

The focus group comprised eight participants who identified as non-injecting drug users (n=4 male, n=4 female; aged 16-25 years). Two one-on-one interviews were conducted with men aged 18-23 (exact ages not provided to protect confidentiality) with recent history of injecting drug use. ACASI survey responses were recorded for 44 individuals. Three were excluded due to age, and another three as they did not identify as Aboriginal, leaving 38 individuals. Qualitative findings were primarily used to inform survey development, and as described selected quotes have been presented to provide context to ACASI survey findings.

**Survey participant characteristics**

Participants’median age was 18 years, and two-thirds (68%) were male (Table 1). Almost one-third of all participants reported that reading was not easy. No internet access was reported by 16% of participants, with others reporting either public (41%) or private (59%) access. Of the 11 (29%) respondents without access to a mobile phone, four reported no internet access.

(Insert Table 1 about here)

**Patterns of substance use**

Two-thirds (68%, n=26) of participants smoked tobacco sometimes or daily. Half (50%, n=19) consumed alcohol on more than six days in the last 12 months. Of those who consumed alcohol, most (84%, n=16) drank at risky levels (five or more drinks per occasion) and were mainly male (69%, n=11) and aged 18 years and over (75%, n=12).

Two-thirds of participants (68%, n=26) reported using illicit drugs in the last 12 months (participants who reported illicit drug use; hereon abbreviated as PRID), most commonly cannabis (55%, n=14), followed by stimulants (31%, n=12) and heroin (13%, n=5). Four reported use of benzodiazepines and two of painkillers, while two people (5%) reported having ever injected substances. PRID were mainly male (73%, n=19), aged 18-years or older (65%, n=17), and half were also daily tobacco smokers (50%, n=13; versus 25% of non-PRID, n=12).

Only 58% (n=15) PRID indicated that reading is easy, compared to 100% of non-PRID. PRID had similar access to the internet and mobile phones as non-PRID. One-third (35%, n=9) of PRID reported using other psychoactive substances, most commonly cannabis-like substances. Only one person reported using PIEDs. All individuals who described use of other psychoactive substances were PRID.

Of participants reporting any substance use, half (46%, n=12) used only one substance, most commonly cannabis (67%, n=8) or stimulants (33%, n=4). One-quarter (23%, n=6) of participants reported using two substances, and one-third (31%, n=8) three or more substances.

Survey participants aged under 18 years (n=15) more commonly reported cannabis use than alcohol in the last 12 months (60%, n=9 versus 33%, n=5). All participants aged less than 18 years (n=9) using illicit drugs reported cannabis use. In comparison, those aged over 18 (n=23) more commonly reported using alcohol than cannabis (61%, n=14 versus 52%, n=12). Of the 16 participants who were risky drinkers, most (88%, n=14) were also PRID. In contrast, just over half (54%, n=14/26) of PRID reported risky drinking.

**Issues of concern**

*Health worries*

Health worries with the highest median score were ‘teeth or gum problems’ and ‘lung problems’ (median score=66). The lowest score was for ‘things about how I look (like how thin or fat I am or how big my muscles are)’ (median score=49). Median scores for females were, on average 33 points higher than males for all health worries (Figure 1a). PRID reported higher health worry scores (Figure 1b):

*“Skin infections and stuff like that [worry me] … also the flu and that and your lungs and stuff like that. I've had trouble with my liver. I come up with Hep C and that when I was locked up. I think I've cleared it. But it's just you've got to be careful with stuff like that, especially at my age.”* [male interviewee 2 (I2)]

(Insert Figure 1 about here)

*Other worries*

Of the other worries explored (‘sorry business’ [i.e. events or grief associated with death and dying], relationships, health of family and friends, feeling down or stressed, and ‘life and your future’) median scores were highest for worry about the health of family and friends (96), and life and your future (96):

*“Now, it's like you've got to pay bills and this and that. Not necessarily now, but in the future. I worry about what I've got to do, if I want to get a home on my own and stuff like that. I've been thinking really like that.”* [male I2]

PRID had higher median scores than non-PRID for all these ‘other’ worries, except sorry business. Females had higher median scores for each of these ‘other’ worries than males, particularly for relationships (score of 92 versus 51) and feeling down or stressed (100 versus 62). Both females and males indicated a high level of worry about the health of family or friends (92 and 96 respectively).

**Current health care use**

PRID most commonly reported attending a youth service (58%), whereas non-PRID more often visited an AMS (58%) (Figure 2a). Approximately one-third of both groups (33% and 35%) reported visiting an emergency department (ED; Figure 2a). Around one third of respondents reported seeing a counsellor in the last 12 months, irrespective of whether they used illicit drugs (33% and 35% respectively, Figure 2b). PRID were more likely to use specific drug and alcohol (D&A) services, whether at the AMS, residential or via a needle syringe program. In total, one-quarter (26%) of participants had received past treatment for a drug or alcohol problem.

(Insert Figure 2 about here)

*Preferences for discussing health worries*

Focus group participants expressed a wish to seek help from family or friends:

*“Friends or family. They're the only ones or on yourself, I don’t know. I don’t want to go and ask someone random one of those types of questions. That’s why it’s people that you can trust, someone that’s close to you.”* [male focus group participant (FGP)]

For some health issues (e.g. needing counselling, or help with lungs or liver) participants preferred seeking professional help, and having a service with an easy process to access the help required:

*“[The AMS] that’s the only one that people actually feel comfortable enough to walk in. They’re like, if you don’t want to see a doctor, you don’t have to see a doctor. Everywhere else you go, if you go to see a doctor or if you think about going to see a doctor, you’re more worried about needing ID and if you’ve got enough ID, or if someone could prove that they know you to actually get into the place.”* [male FGP]

Focus group participants also preferred services that were considered youth-friendly and offered a range of help:

*“At the youth centre at [suburb], they had this nurse that will come in every week and just talk to the boys that were in there. Just if you have any personal issues, just come downstairs, talk to her and can get you the blood tests or an STD [sexually transmitted disease] check. Everyone used to go down there on their own time.”* [male FGP)

Survey participants indicated they would often discuss their health worries with family (median score 100) or an Aboriginal health worker (100). Median scores were also very high (90-99) for some other people or services (hospital ED, youth services, friends, someone you know who works in health, someone with the same problem and Elders). Other options (AMS, GP clinic, community or sports centre and other health staff like doctors or nurses) had median scores of 62-89, except talking to religious clergy (13).

**Likelihood of future health service need or use**

Overall, participants rated the likelihood of wanting drug or alcohol treatment in the next 12 months as relatively low, with only 13% (n=5) indicating that ‘for sure’ they would want to use these services, and one-third (34%, n=13) indicating ‘no way’. The median score for PRID was much higher than for non-PRID (53 vs 3), however there was some polarisation: three people indicated their likelihood of wanting treatment as ‘for sure’ and seven as ‘no way’.

**Barriers to getting help**

The three barriers to health service use with the highest median scores were waiting around before seeing someone (81), the service not being friendly (78), and the service not understanding Aboriginal people (66) (Table 2):

*“They’ll try and [work out quickly why you are here] … Then they do it as fast as they can just to get you out so they can see the next person. You show no interest that you care. You’re meant to care, I’m your patient.”* [female FGP]

All other barriers, including lack of anonymity, had median scores between 48 and 58. Although lack of anonymity scored the lowest, there was some polarisation; most of the nine participants with a score greater than 90 were PRID (7/9; 78%). Conversely, seven of the 11 PRID scored less than 10.

Overall, PRID reported barrier scores that were higher by an average of 12 points. Median scores were also higher for females than males, on average by 33 points. Most participants (84%, n=32) thought there were enough local services for young people to attend. All of those who thought there were not enough services were PRID.

(Insert Table 2 about here)

**Preferences for health services**

When asked how close health services should be located to where young people ‘hang-out’, most participants thought either within walking distance (47%, n=18) or near public transport (42%, n=16). Only four participants (11%; all PRID) preferred a mobile service.

Approximately equal numbers of participants reported preferring youth services (37%, n=14) or services for all ages (40%, n=15). Responses were similar between PRID and non-PRID. Participants overall indicated they liked to see staff that they know from community (median score 84); however, for PRID median scores were lower (76 versus 91).

*What is important in making you want to keep going back to a health service?*

Overall, the highest median score (97) was for health services that can also assist with psycho-social supports such as housing, training, jobs and money (Table 3). This was the highest rated category for PRID (median=100) but the lowest for non-PRID (median=61):

*“More Indigenous stuff, more training for Indigenous people to help get more jobs for Indigenous people, to help out the community and bring the community closer.”* [female FGP)

Participants who reported illicit drug use had higher median scores for all factors which were important in a service. For those not reporting illicit drug use, the highest median scores were for good reputation, being organised and having Aboriginal staff (all 78).

*“[With Aboriginal services] It’s like they’re happy to have Aboriginal people there. It’s like you’re glad to be an Aboriginal person there.”*  [male FGP]

*Other important aspects of a health service*

PRID had stronger preferences (i.e. higher median scores) for a range of factors to encourage young people to attend a health service compared to other respondents, particularly for ‘getting help with other things’ and counselling (both 100 versus 61). All participants indicated that learning about traditional culture would be important to encourage young people to attend. It was the only category where the median score was 100 for both PRID and non-PRID (Table 3).

(Insert Table 3 about here)

**ACASI acceptability**

Participants indicated that they liked the ACASI method of survey delivery (median score 100). Only three participants indicated dissatisfaction with it (score <50). Verbal feedback provided spontaneously to research assistants at the time of survey was also favourable.

**DISCUSSION**

This is the first study to recruit young Aboriginal Australians who use illicit drugs and report their healthcare preferences. The study provides insights into how to refine recruitment and research methods to gather data from young people. Despite the challenges, a group of young Aboriginal people were successfully recruited for the ACASI survey, of whom two-thirds reported illicit drug use in the last 12 months – twice that of the national prevalence in Aboriginal Australians aged 15-24 years [4]. Consistent with other surveys, cannabis was the most commonly used illicit drug, and those who reported drinking any alcohol tended to consume at a risky level [32].

**Reported concerns**

The health of family and friends was a priority for these young people. Worries about ‘life and your future’ were prominent. While this reflects the relative social disadvantage of participants, this response also suggests these young people are actively considering the future.

**Sources of advice and health service use**

Both focus group and survey participants saw family or friends as a source of support about health worries. This is consistent with other studies of young Australians, both Aboriginal and non-Aboriginal [8, 9, 11]. Survey participants largely preferred Aboriginal health services or youth services, which were also referred to favourably by focus group and interview participants. The flexibility of a youth service where young people could attend and speak with a health worker on their own terms was favourably discussed in the focus group, and has been previously reported by young Aboriginal people [14].

**Barriers to health service use**

The three greatest barriers to health service access were waiting times, services not being friendly or not understanding Aboriginal people. The desire for prompt and flexible service is consistent with a past study of Australian adults who inject drugs, which raised the importance of not having to make appointments [33]. Respondents generally indicated satisfaction with the number of services in their area; however PRID were more likely to report that there were not enough. While this inner-city area has far greater service availability than other regions, those using illicit drugs are more likely to be marginalised with complex health and social needs. Additionally, nationally consultations have reflected a shortage of specialised alcohol and drug treatment services for young people [34]. The relative lack of concern about transport may also reflect the inner-city setting.

**Health service preferences**

Holistic services which offer ‘help with other things’, such as literacy or computer use, were favoured by survey participants, particularly PRID. Similarly, Canadian Aboriginal youth needing treatment for HIV express a preference for a ‘one-stop shop’ for healthcare, which includes services such as drug treatment and laundry facilities [35]. Almost half of PRID indicated reading difficulties, consistent with the vulnerable nature of young people who use illicit drugs [25, 26]. Participants’ poor access to mobile phones and internet is a reminder of the limitations of internet-based health promotion. It may also have increased the attraction of services that provide internet access. Participants reported a desire for health services to have a counsellor. This suggests insight and desire for support and/or change in relation to substance use, mental health, or both.

Services aimed specifically at Aboriginal people were rated highly by survey participants. Aboriginal community-controlled health services (ACCHSs, such as an AMS) and Aboriginal health staff play a key role in ensuring culturally appropriate and accessible services and can act as positive role models [36]. However, family or kinship ties can reduce anonymity or, in remote regions, can pose challenges where cultural constraints limit who can talk to an individual [37]. In our study, several focus group participants mentioned the comfort they felt in attending an AMS. However, there was a tension between a desire for familiar Aboriginal staff and for anonymity, particularly among PRID. This is consistent with clinical observations that, some adult Aboriginal clients who inject drugs strongly prefer to attend an AMS for substance use disorder treatment, whereas others strongly prefer the anonymity of a non-Aboriginal specific service.

Learning about Aboriginal culture was the highest rated ‘preference’ for an additional service. The importance of learning about culture is reported in studies involving Aboriginal illicit drug users or (separately) in Aboriginal young people more broadly [5, 18, 37-39]. Culture can have a potential healing role and ‘connectedness’ to community may protect against substance use disorders [38, 40-42]. It is encouraging that these vulnerable young people were seeking this connection.

**Limitations of the focus group**

Some individuals said little in the focus group and deferred to one or two more outspoken participants (one male, and to a lesser extent, one female). This may have been affected by the presence of two observers. A facilitator who was known to the participants and closer to their age (so more like a peer) may have achieved better engagement [43]. While no-participant appeared frankly intoxicated it is impossible to exclude mild intoxication. The ordering and arrival of pizza (intended as an ‘ice-breaker’) proved a distraction. Our experience highlights the challenges of conducting focus groups with Aboriginal Australians [14], and the need for further study of focus group conduct for young Aboriginal people. This may include restricting number, age or sex of participants, carefully considering perceived power balance between facilitators/observers and participants, and considering cultural influences on comfort in speaking-up in the group [43].

**Challenges in recruiting survey participants**

Recruitment was slow for this study. Employing an Aboriginal staff member with good connection with young Aboriginal people who use illicit drugs could have helped engagement and recruitment. However, this was not possible due to the short-term (1-year) pilot funding for the project. The short-term funding affected the retention of study staff/volunteers, which impeded building relationships with local services for recruitment. The research assistants who recruited the young people for the ACASI survey did not know the participants, and did not have strong relationships with service staff. It is not possible to assess if this diminished the effort that young people put into the computer-administered survey. Snowballing recruitment was limited as participants appeared unwilling to suggest others, potentially due to drug and alcohol-related stigma.

In some interview settings (e.g. youth services) noise appeared to distract participants. On one occasion, at a public event, some participants appeared to rush their responses. Having more than one tablet, so that friends could complete the survey at the same time, may help recruitment and engagement.

**Using the ACASI**

The acceptability of using a computer to answer survey questions on a sensitive topic was consistent with past studies [14, 21, 22, 44]. The computer format is interactive, increasing engagement, and may provide a greater sense of confidentiality and anonymity [14, 19, 21, 22]. However, only a simple interface with no visual images was available; a more modern interface may have been more engaging [19].

Young people who use illicit drugs may have lower educational attainment [25, 26, 43] and sometimes lower literacy, as reported by PRID in this study. Because of this, ACASI and other interactive computer-based survey delivery methods, offer promise in providing a voice to this vulnerable population. Finally, the computer program did not record if a participant chose to use audio or the duration of the survey. These could be a useful additions in future electronic surveys.

**Other limitations**

The sample was small, non-probabilistic and urban. While results provide a voice for these young Aboriginal people who use illicit drugs, they may not be generalizable to other parts of Australia. The needs of those most vulnerable young people, who are not connected to services or community events in any way, may be greater or may differ. Recall bias, or deliberate under- or over-reporting is possible. However, allowing participants to enter their responses privately via ACASI may have minimised social desirability bias [22, 28].

**Conclusions**

Interactive computer-based surveys with an audio option appears to be a valuable way of engaging young Aboriginal people who use illicit drugs in research to deepen understanding of the health concerns and service preferences of young people to inform service planning. However, the delivery of such surveys requires close partnerships with Aboriginal staff, ACCHSs and youth services. The participants of this study strongly endorsed health services aimed at young Aboriginal people, and services that address both current health issues and the social determinants of health. The findings highlight the vulnerability of young Aboriginal Australians who use illicit drugs, their strengths and support mechanisms, concerns for the future and their desire to be better connected with their culture. Further research should explore ways that this cultural connection better aligned with health service delivery to improve access to primary health care young Aboriginal people who use illicit drugs.

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**Conflicts of interest**

Bradley Freeburn and Katherine Conigrave are employed in health services which potentially serve Aboriginal young people with alcohol or drug problems. They were not directly involved in the collection or analysis of data, but only in the study planning, data interpretation and reporting. The research was funded by a research grant from the New South Wales Ministry of Health. KC was supported by an NHMRC Practitioner Fellowship (APP1117582) during the later stages of this project.

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**1a**

**1b**

**Figure 1:***Median health worry scores by gender (a) and illicit drug use (b) (D&A = drug and alcohol issues)*

**2a**

**2b**

**Figure 2:** Use of health services (2a), and of counselling or drug and alcohol treatment services (2b) by all participants in the past 12 months by drug use status

None = did not select any other option, AMS = Aboriginal Medical Service, GP = general practitioner, ED = emergency department

D&A = drug and alcohol, NSP = needle and syringe program

**Table 1:** ACASI *survey participant characteristics (N=38)*

|  |  |  |
| --- | --- | --- |
|  | n | (%) |
|  |  |  |
| Age (median) | 18 |  |
| Age groups |  |  |
| 16-17 | 15 | (39) |
| 18-25 | 23 | (61) |
| Gender |  |  |
| Male | 26 | (68) |
| Female | 11 | (29) |
| Transgender | 1 | (3) |
| Usual residence |  |  |
| In the interview area (Inner Sydney) | 22 | (58) |
| Other parts of Sydney | 14 | (37) |
| Other NSW | 2 | (5) |
| Literacy |  |  |
| Easy to read | 27 | (71) |
| Bit hard | 9 | (24) |
| Very hard | 1 | (3) |
| Can't read | 1 | (3) |
| Mobile phone access |  |  |
| No | 11 | (29) |
| Sometimes | 8 | (21) |
| All the time | 19 | (50) |
| Internet access |  |  |
| No | 6 | (16) |
| Sometimes | 20 | (53) |
| All the time | 12 | (32) |
|  |  |  |

**Table 2:** *Perceived barriers\* to health service access*

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Barriers | Illicit substance use (n=12) | No illicit substance use (n=26) | Males  (n=27) | Females  (n=11) | All  (N=38) |
| No services close | 51 | 56 | 48 | 73 | 53 |
| Got no money to get there | 53 | 51 | 30 | 68 | 51 |
| No transport | 71 | 48 | 41 | 94 | 51 |
| Not open when needed | 53 | 61 | 53 | 53 | 53 |
| Need booking | 73 | 53 | 58 | 84 | 58 |
| Need ID or Medicare card | 48 | 53 | 46 | 63 | 48 |
| Waiting | 84 | 51 | 53 | 100 | 81 |
| Referred elsewhere | 68 | 38 | 43 | 89 | 58 |
| Not friendly | 81 | 58 | 51 | 100 | 78 |
| Don't understand Aboriginal people | 73 | 56 | 58 | 100 | 66 |
| People I know from community are there and I don't want them to see me | 48 | 41 | 38 | 53 | 48 |

\* Participants were asked “If you want to get help about a health worry, how much of a problem could each of these things be?” The participants scored that issue with a sliding marker on a line, ranging from 'no problem' to ‘huge problem’

**\***The participant was asked to score each characteristic with a sliding marker as ‘not important’ to ‘very important’

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Table 3:** *Health service preferences* | | | | |
| Question | Service characteristic |  | Median scores |  |
|  |  | Illicit drug use (n=12) | No illicit drug use (n=26) | All  (N=38) |
| How important are these things in making you want to go back to a health service? | People say it’s a good service | 91 | 78 | 89 |
| It is organised, I know what will happen when I go there | 94 | 78 | 89 |
| They have an Aboriginal flag or art work [Aboriginal friendly] | 89 | 63 | 81 |
| I can get help for other things (like housing, training, jobs and money) | 100 | 61 | 97 |
| I can understand what the staff say | 97 | 71 | 89 |
| The staff look at me like I know what I’m talking about | 81 | 73 | 78 |
| There are Aboriginal staff | 81 | 78 | 78 |
| If you want more young people to go to a health service, how important is it that a service provides these things? | Learning how to read, write or use computers | 100 | 84 | 94 |
| Internet access | 100 | 91 | 100 |
| Sport or dance groups | 86 | 76 | 84 |
| How important to you are these things in a health service? | Learning about traditional culture | 100 | 100 | 100 |
| Other community activities | 89 | 89 | 89 |
| Help for worries about drinking or drugs | 100 | 78 | 94 |
| A counsellor to talk to | 100 | 61 | 94 |
| A dentist | 100 | 89 | 100 |
| Has lots of services in the one place (health, training, other help) | 100 | 81 | 94 |
| It has lots of health information (classes, booklets, posters) | 94 | 71 | 86 |
| Aimed at Aboriginal people | 100 | 89 | 100 |