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First-Stage Development of the Pitjantjatjara Translation of the World Health Organization's Alcohol, Smoking and Substance Involvement Screening Test (ASSIST)

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Abstract

Substance use is a leading contributor to global disease, illness and death. Compared with non-Indigenous Australians, Aboriginal and Torres Strait Islander Australians are at an increased risk of substance-related harms due to the experience of additional social, cultural, and economic factors. While preventive approaches, including screening and early interventions are promising, currently there are limited options available to healthcare workers that are culturally appropriate for use in Aboriginal and Torres Strait Islander populations. Therefore, the aim of this research was to translate and culturally adapt the World Health Organization endorsed, Alcohol, Smoking and Substance Involvement Screening Test (ASSIST) into Pitjantjatjara. This paper first describes the process of translation and adaptation of the instrument (Phase 1). The process of focus-group testing the translated instrument for accuracy and cultural appropriateness is also discussed (Phase 2). Key findings from both phases are presented in the context of how the research team worked with key stakeholders in the community to identify facilitators and work through barriers to implementation. The findings from this paper will be used to inform the development of a digital, app-based version of the instrument for the purposes of pilot-testing and validation.

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Keywords

Pitjantjatjara, Indigenous Health, Substance use disorders, Prevention, Screening, ASSIST

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Substance use is a leading contributor to the global burden of disease, illness, and death (Degenhardt et al., 2018). Aboriginal and Torres Strait Islander people living in Australia experience additional social, cultural, and economic disadvantages compared to Australians of other descent. Many of these issues, including the burdens of multigenerational trauma, stigma and discrimination, and reduced access to adequately resourced health services, are either maintained or exacerbated by the use of alcohol or other drugs. As a result, while Aboriginal and Torres Strait Islander people are less likely to consume alcohol or other drugs in general, they may be more likely to engage in riskier levels of substance use than other Australians (Gray et al., 2008; MacRae & Hoareau, 2016). This places Aboriginal and Torres Strait Islander people at an increased risk of experiencing harms associated with intoxication and longer-term use. Recent surveys have shown substance use and mental health disorders contribute to 23% of the burden of disease for Aboriginal and Torres Strait Islander people, compared with 13% nationally (AIHW, 2021a, 2021b). Identifying and responding to potential risks and harms from substance use – through screening and early intervention for example – is a necessary step in closing that divide. As yet however, culturally valid and acceptable approaches to screening and early intervention for substance use either do not exist, or are limited in their scope.

Accurate and reliable estimates of the prevalence of substance use are difficult to establish. Among Aboriginal and Torres Strait Islander communities in Australia, an overreliance on self-report questionnaires and limited access to representative communities, have called into question the validity of much of the research (MacCrae & Hoareau, 2016). To date, the most informative estimates have been obtained through the 2014-15 National Aboriginal and Torres Strait Islander Social Survey (NATSISS). According to that survey, around 40% of Aboriginal and Torres Strait Islander people surveyed smoked daily, and around 20% exceeded the previous low-risk alcohol guidelines set out by the National Health and Medical Research Council (NHMRC), which at the time was two standard drinks per day. Notably however, in both cases rates have been in decline since 2002 (NATSISS,

2015). In addition, around 30% of Aboriginal and Torres Strait Islander people reportedly used illicit substances in the prior 12-months. Among those reporting using alcohol or other drugs, higher levels were found among men, and in remote areas (NATSISS, 2015).

More recently, the National Drug Strategy Household Survey (NDSHS) found Aboriginal and Torres Strait Islander people were more vulnerable to risky substance use behaviours than other Australian populations – a trend consistent since the 2010 survey (AIHW, 2020). It should be noted however that the NDSHS surveys have been criticised for the underrepresentation of Aboriginal and Torres Strait Islander people (MacCrae & Hoareau, 2016). That aside, the 2019 survey found Aboriginal and Torres Strait Islander respondents were 2.5 times as likely to smoke daily compared to Australians of other descent; and although the proportion of those abstaining from alcohol was higher, those that consumed alcohol did so at higher risk levels. While there are concerns around the high-risk nature of substance use in certain contexts, the survey also identified the emergence of other, more encouraging trends. For example, reductions in rates of both single-occasion and lifetime risk from alcohol consumption. Among Aboriginal and Torres Strait Islander Australians, the rates of those exceeding single-occasion high-risk drinking (defined in NDSHS as more than 11 standard drinks at one time) has decreased since 2016, down to 17.7% (from 28%). Similarly, the proportion of Aboriginal and Torres Strait Islander to other Australians exceeding the lifetime-risk guidelines narrowed from 1.5 times in 2010 to 1.2 times in 2019. It should also be noted that since publication of the NDSHS and NATSISS surveys, the NHMRC has since updated the lifetime low-risk guidelines, from 14 standard drinks per week to ten (NHMRC, 2020) which may distort those figures.

While there are encouraging reductions in higher-risk alcohol use among some Aboriginal and Torres Strait Islander communities in Australia, the rates of illicit single and poly-substance use among these communities are a continued source of concern. Although rates of alcohol and tobacco consumption appear to have reduced from 2016, the use of illicit substances appears to have remained stable (AIHW, 2020). Aboriginal and Torres Strait Islander people still appear to engage in higher rates of illicit drug use – particularly

methamphetamine – than Australians of other descent (AIHW, 2020). Other studies of Aboriginal and Torres Strait Islander people have found cannabis, analgesics, and sedatives used for non-medical purposes are also common (MacRae & Hoareau, 2016). Illicit substance use increases the risk of developing adverse health outcomes. This is particularly true in the case of Aboriginal and Torres Strait Islander populations, given the other additional historical trauma and socioeconomic burdens they have experienced. According to the recent Australian Burden of Disease study in 2018, illicit substance use contributed to almost 7% of the total preventable burden of disease, behind tobacco smoking (11.9%), alcohol consumption (10.5%), and obesity (9.7%). Based on higher rates of illicit substance use and associated health and social risks, there is a clear need for preventive approaches to reduce the harm for Aboriginal and Torres Strait Islander populations.

A number of social, cultural and structural features also limit the ability of Aboriginal and Torres Strait Islander people to experience effective health service delivery (McBain-Rigg & Veitch, 2011; NHMRC, 2003). In addition, Aboriginal and Torres Strait Islander people often experience overt and structural racism in these settings, and also have to contend with inadequately funded community-controlled health services, which only exacerbates the challenge (Nolan-Isles et al., 2021). One potential solution might be found through purpose-built and culturally appropriate screening and brief intervention frameworks.

Screening and brief intervention (SBI) is an evidence-based approach to early identification and intervention of substance use disorders (Babor et al., 2000; Heather, 2002). To date however, SBI has been under-utilised in Aboriginal and Torres Strait Islander communities, though its promise has been recognised (Gray et al., 2014). Some have suggested that generalised approaches to SBI (i.e., those designed for use in other populations) may have reduced clinical efficacy when used among Aboriginal and Torres Strait Islander people, due to the nature of sporadic binge-drinking patterns (Anderson, 2007), stigma and shame around substance use, and the sensitive-nature of, and general distrust around discussions of substance use (Lee et al., 2019). Given the history of the Australian Government's involvement in the removal of Aboriginal and Torres Strait Islander

children from their families, Australians are typically wary about disclosing substance use out of fear of reprisal (Lee et al., 2014). From a clinical sense, perceptions around power dynamics can make building a therapeutic alliance challenging. Therefore, an Aboriginal and Torres Strait Islander-population specific SBI approach requires further refinement and consideration that is capable of considering the additional social, cultural, and historical factors contributing to an individual's substance use.

The lack of culturally appropriate and validated screening instruments for Aboriginal and Torres Strait Islander populations is also an area of need. The few currently available instruments tend to capture the risk of dependence, and fewer still are capable of capturing frequency and quantity of use. This presents a challenge because substance-related harms increase directly across larger and more frequent doses, including dependence and overdose. The 'Grog survey' app (Lee et al., 2019), and the AUDIT and AUDIT-C instruments have been developed and utilised for alcohol screening among Aboriginal and Torres Strait Islander populations. But while the AUDIT-C has been developed to capture frequency and quantity of alcohol use, there are no instruments available for other substances. The Indigenous Risk Impact Screen (IRIS) for example, combines drug and alcohol risk, and contains a separate mental wellbeing assessment (Schlesinger et al., 2007). Although the IRIS considers the combined burden of polysubstance use, it is incapable of distinguishing between substances, or capturing polysubstance use. Therefore, there is still a need for screening tools capable of distinguishing severity of risk between multiple drugs, and with the capacity to identify risky use, rather than just dependence (Schlesinger et al., 2007).

The Alcohol, Smoking, and Substance Involvement Screening Test (ASSIST; Humeniuk et al., 2008) is one possible candidate for adaptation. ASSIST is an 8-item questionnaire designed to assess severity of risk for substance-use disorders. Importantly, unlike other screening instruments, ASSIST captures risk of harm for all psychoactive substances, including tobacco and misused prescription medication, as well as for injecting drug use. ASSIST stratifies based on severity of risk, which can be used to inform an

appropriate level of intervention, whether through general advice (low-risk), a brief intervention (moderate-risk), or referral for specialist assessment and treatment (for high-risk cases). ASSIST also allows for the monitoring of risk scores over time. One of the primary benefits of ASSIST over other screening tools is its cross-cultural validity. ASSIST was developed by researchers at the World Health Organization (WHO) in response to the increasing global burden of substance-related morbidity (Humeniuk et al., 2008). Thus, ASSIST was designed to be cross-culturally neutral, and has since been translated and validated in a number of different languages. However, although the English-language version of ASSIST has been used to assess Aboriginal and Torres Strait Islander clients in community health settings (Calabria et al., 2019) as well as correctional settings (Holmwood et al., 2008), as yet, a translated and culturally adapted version for Aboriginal and Torres Strait Islander communities does not exist.

Language barriers often encountered in rural and remote health service settings create significant challenges for clinicians providing healthcare. In the context of substance use, most SBI approaches have limited relevance and applicability to Aboriginal and Torres Strait Islander populations. A potential solution may be found in the use of a digitally administered screening instrument, because it has the potential to characterise more accurate descriptions of substance use behaviours (Chikritzhs, 2021; Lee et al., 2014). The ASSIST has been validated and successfully administered in a computer-based format, and an audio computer-assisted version (ACASI) of the ASSIST has also been validated for self-interview in the primary care setting (McNeely et al., 2016). Importantly, digital self-administered screening may also lead to greater disclosure of substance use, due to the perception of privacy. Concerns about privacy are particularly important for Aboriginal and Torres Strait Islander people due the trauma associated with forced removal of children and the perceptions of consequences associated with illicit substance use (Chikritzhs, 2021; Lee et al., 2014).

Another benefit of self-administered instruments is reduced stigma. Stigmatised behaviours, including illicit substance use, are more likely to be reported during self-

administered instruments (McGregor & Makkai, 2003). In regional Aboriginal and Torres Strait Islander communities, crystal methamphetamine ('ice') use carries considerable stigma and shame, which can inhibit help-seeking (MacLean et al., 2017). A study by Povey and colleagues (2016) examined the acceptability of two Aboriginal and Torres Strait Islander mental health applications ('apps') and reported that these apps had the potential to "get around shame job" – to overcome the stigma of help-seeking for mental health. Important factors in improving acceptability included community involvement in app development, use of regionally-specific language, graphics, and the ability for clients to define their own problems and solutions. A range of mobile apps utilise Aboriginal and Torres Strait Islander languages, for example 'Kulila!' developed with NPY Women's Council, and Smiling Mind meditations both utilise Pitjantjatjara language. However, there are no Aboriginal language apps that can be used to comprehensively assess substance use. Developing resources that outline the risks of substance use as well as the benefits and pathways for slowing down or stopping will be an important part of knowledge translation.

This study

Currently, there exists no culturally appropriate screening instruments capable of identifying risk of harm for all substances. This paper presents the process and findings from a participatory action research (PAR) framework, which aims to actively engage and involve members of an Aboriginal community in Adelaide as stakeholders in the research outcomes. In collaboration with members of the community, the primary aim of this study was to adapt the ASSIST for use within the Pitjantjatjara-speaking populations. Although the language targeted in this adaptation is Pitjantjatjara, the future aim of this project will be to build in capacity for additional Aboriginal and Torres Strait Islander language adaptations as required. Pitjantjatjara is recognised as a prominent language commonly spoken in central Australia; it remains the first language spoken by the majority of Pitjantjatjara people and is spoken across generations. A high proportion of the population are literate in Pitjantjatjara, and the language is commonly understood by neighbouring Aboriginal and Torres Strait Islander groups. This makes Pitjantjatjara an ideal candidate for the pilot project.

The secondary aim of this study was to identify patterns and features of substance use common to the Pitjantjatjara community. The goal of this step was to inform the future development of a culturally-adapted and nuanced brief intervention. This adaptation presented here will build upon the existing electronic versions of the ASSIST, including the smartphone app (*ASSIST Checkup*), which in addition to screening for risky substance use, also provides educational and self-help resources for individuals to manage ongoing use. This paper describes the process of translation and adaptation of the instrument and subsequent focus-group testing. The paper also discusses important key findings from each stage, as well as barriers and facilitators to the process.

Method

Aboriginal Australian leadership

This paper outlines the process of working with the community to develop a cultural adaptation and translation of the ASSIST for use in Aboriginal and Torres Strait Islander populations. The methodological approach for this research draws on principles from Participatory action research (PAR) framework. PAR is a methodological approach to research that promotes participation and action through collaborative engagement of the intended population (i.e., those directly affected by its outcomes; Whyte et al., 1991). The guiding principle of PAR is the recognition that individuals are experts in their own lives, and involving those individuals as stakeholders in decision-making, planning, reviewing and implementing action is key to meaningful empowerment and change (McTaggart, 1991; Tsey et al., 2002). PAR methodologies have a number of advantages for health research with Aboriginal and Torres Strait Islander populations (Hecker, 1997; Henry et al., 2002; Pyett, 2002). As such, members of the Aboriginal and Torres Strait Islander community were both involved in, and led the research at all levels of the project, from conceptualisation, planning and delivery.

The process of translation and adaptation was led by a Pitjantjatjara researcher (DB), and a non-Pitjantjatjara researcher (SB) at Flinders University. An Aboriginal and Torres Strait Islander researcher (MT) at Drug and Alcohol Services South Australia (DASSA) was

also involved in the project, including the design of the research and collaboration with community leaders on its appropriateness, as well as direct connection to carrying out the wishes and desires of community. Also involved at various stages of translation and adaptation were Pitjantjatjara and non-Pitjantjatjara men and women who served as a key stakeholder group, comprising of linguists, translators and research assistants (see Acknowledgements). Finally, the artwork for the digital app-based version of the instrument will also include artwork from a prominent Aboriginal graphic designer**.**

Ethical approval

The initial phase of the research was to be carried out among individuals currently residing in Port Augusta Prison, in South Australia. Ethics approval was obtained from the Department of Corrective Services (CEN/20/0201). However, due to restrictions on access in response to the lockdowns from the COVID-19 pandemic, alternative sources of participants were required. The study protocol was amended and resubmitted to the AHREC, DASSA and SALHN ethics committees for approval. Approval of initial protocol and amendments were granted by Drug and Alcohol Services South Australia (DASSA/2021/1); Aboriginal Health Research Ethics Committee (AHREC: 04-19-849); and Southern Adelaide Local Health Network (SALHN) Human Research Ethics Committee (HREC: 19/SAC/310).

Phase 1: Translation and Adaptation

The process of translating the ASSIST into Pitjantjatjara language followed the protocol recommended by the WHO, which has been described in detail elsewhere (WHO, 2016). A schematic representation of each of translation, including the individuals responsible for undertaking the process is outlined in Figure 1.

Stage 1: Translation into Pitjantjatjara

The first stage of adaptation involved translating the questionnaire items from English into Pitjantjatjara. Translation was undertaken collaboratively by three individuals: a first-language Pitjantjatjara speaker with previous experience in translation/adaptation (the ‘original translator’); a Pitjantjatjara linguist; and a non-Pitjantjatjara researcher with experience working with the Pitjantjatjara community (‘the researcher’). The role of the

researcher in this stage was to provide additional explanations of the clinical intent of the items to those responsible for the translation process, working collaboratively to maximise the accuracy and cultural comprehensiveness of the instrument.

Stage 2: Back-Translation into English

Upon completion of an initial working translation (Stage 1), an independent expert panel of first-language Pitjantjatjara speakers were convened and tasked with providing a back-translation from Pitjantjatjara into English (Stage 2). The purposes of back-translation was to ensure robustness of the initial translation, and to identify any areas of discrepancy between the forward and back-translated items. The independent expert panel were also required to have knowledge and experience in the field of substance use, to ensure that the language was consistent with the target audience. During this stage, the original translator and researcher from Stage 1 were present to help clarify any situations where the translation was unclear or had been misinterpreted. To resolve these issues, the original translator worked with the independent expert panel members to amend and refine the translation, until all parties came to a consensus on style and content. In situations of discrepancy, the task of the researcher, translator and linguist was to identify language that most closely matched the intent of the original items.

Stage 3: Refinement and Audio-Recording

The third stage of translation and adaptation involved refining the items for clarity. This process included two additional first-language Pitjantjatjara speakers tasked with providing advice and technical guidance to the researcher on translating some of the more difficult items. This iterative process of refinement led to the development of a working slide-deck of all questionnaire items for the purposes of pre-testing among a small group of first-language Pitjantjatjara speakers (Stage 4). In this stage, items were displayed in written word Pitjantjatjara, and a male (original translator) and female (first-language Pitjantjatjara speaker) were tasked with recording spoken word readings of each item. The purposes of this stage was to enable future participants to listen to an audio recording while reading the text.

Stage 4: Focus group evaluation

The fourth stage of translation and adaptation involved the pre-testing of the items among a small focus group of first-language Pitjantjatjara language speakers. The members of this group were previously unexposed to the instrument. The intent of this stage was to present both written and spoken-word Pitjantjatjara translations of the items to the group with a view to ensuring a robust translation of the items across both language and intent.

Stage 5: Final Refinement and Audio-Recording

Once all parties involved in the translation were satisfied with the translated version, the instrument was passed to a linguist who worked in collaboration with the original translator to ensure that the most recent language protocols were applied. This led to very minor changes and both male and female spoken word readings were sent for final recording.

Phase 2: Focus Group Pilot-Testing

Subsequent to the development of the translated ASSIST instrument, the research team went into the community to conduct a series of focus groups for feedback. The aim of focus-group testing was to assess whether the finalised translated questionnaire items at stage 5, were accurate and culturally appropriate among the target population. In addition, the purpose was to inform the future development of an app-based version of the instrument and any requisite features (e.g., culturally relevant help services).

In addition to assessing the overall accuracy of the translated instrument, the role of the focus groups during testing was to provide advice on patterns and characteristics of substance use within the Pitjantjatjara community. Such insights were needed to assist in developing a culturally-specific brief intervention. Therefore, each focus group aimed to provide information regarding: a) which drugs were commonly used within the Pitjantjatjara community; b) the common names, routes of administration, and paraphernalia associated with each identified substance, and; c) general attitudes, beliefs and knowledge associated with the use of various substances within the Pitjantjatjara population. This final aspect involved discussions about the risks and harms of each substance (both immediate and

longer-term), the positive aspects for use, and emotions tied to use (e.g., words used to describe intoxication, pleasures and discomforts).

During the focus groups, interpretations of the ASSIST items were evaluated conceptually, and hypothetical patterns of use (e.g., frequency of use) were coded into answer categories by participants. Features for the digital app-based version of the instrument were also tested, including preferences for imagery (e.g., cartoon images or photographs) and presentation of questions and response option formats (e.g., radio buttons). Finally, questions were asked in relation to help-seeking avenues for someone with substance use, including what level of help was thought to be important and what kinds of harm reduction strategies should be promoted.

Participants

Focus group participants comprised individuals at least 18 years of age and identified as Aboriginal, or working in a health or community services setting with Aboriginal clients. The focus group recruitment did not exclude participants on the basis of substance use, but prioritised Pitjantjatjara-speaking Aṉangu participants where possible. No exclusion was based on the literacy of participants. The use of audio recordings was applied in cases where participants were either not confident with literacy, or displayed a preference for audio. Participants were recruited from the Flinders Wellbeing Centre and Iwiṟi. The Flinders Wellbeing Centre provides therapy to address mental health and addiction among Aboriginal people with direct support for the Pitjantjatjara-Yankunytjatjara people and families living in Adelaide. Iwiṟi is a member-based Aboriginal Corporation for Pitjantjatjara-Yankunytjatjara people living in Adelaide. They have extensive connections with this community, through language and cultural maintenance activities, enterprise development and advocacy. Focus groups occurred among nine separate groups, totalling 20 participants, with each group consisting of at least two participants. In total, there were 16 female and 4 male participants, aged between 18 and 65 years. All participants were informed of their right to withdraw at any time, but all consented and agreed to participate.

Recruitment

Recruitment of focus group participants took place through primary places of residence. Participants were approached and given information pertaining to the study aims and objectives. In some cases, given the sensitive nature of substance use among members of the community, it was not always possible to engage members in discussions at their residence. In those cases, an alternative location was sought where the individual participants felt most comfortable discussing substance use. Two sessions occurred at primary residences, one at a city-based gallery, one at a college, one at a fast-food restaurant, and four inside a vehicle parked in front of residences. In all cases, prior to commencement of the focus group, the study was explained in more detail with the aid of the translator, and consents were either signed or withdrawn. The translated versions were then presented to participants for feedback. Two groups were held at community places, when the researchers came across small gatherings.

Key Findings

Phase 1: Translation.

Discussions with key Aboriginal and Torres Strait Islander stakeholders throughout the translation process identified that the clinical nature of the language would not translate effectively in a literal sense, and therefore would be unlikely to resonate with the target audience. To accommodate, the language across all questionnaire items underwent subsequent transformation by the non-Pitjantjatjara researcher and original Pitjantjatjara translator in order to allow for a more meaningful translation. Special care and attention was made to ensure that the intent of the items was not lost during the rephrasing. Table 1 presents a summary of all translated items.

Aside from language, one of the key sources of difference between the original instrument and the translated version was differences in conceptualisations of time. A section of the original ASSIST questionnaire asks participants to think about their substance use over the previous three-month period. Three months is chosen for purposes of recency for recall, and salience. However, in Pitjantjatjara language, the concept of '*in the past three*

months' is not necessarily as literal as it is in English; Pitjantjatjara people do not tend to think in calendar months in the same way. As such, the researchers worked with Aboriginal and Torres Strait Islander stakeholders to identify a way to convey the time period without the need for literal translation.

Another key modification was made to the structure of one of the items of the original instrument. Item 4 of the original ASSIST asks participants about their experiences of impaired function in other areas of life (e.g., health, social, legal or financial). It was suggested during the translation process that the harms indicated in this particular item would not be straightforward, since many of the harms may be more social and emotional in nature, and therefore may not be captured in the same way. Discussions with key Aboriginal and Torres Strait Islander stakeholders during stage 4 of the translation process led to the splitting of item 4 into several parts; with each part focused on a separate domain of function, each with examples (see Table 1). The purposes of this approach was two-fold. First, by splitting the item up into parts, it allowed for more clarity – individuals taking the test would be able to identify the areas which applied to them. Importantly, second, it also allowed the opportunity to capture some more nuanced person-specific details, which could be used for the purposes of brief intervention. By splitting the question up, the brief intervention feedback can be tailored to the specific harms that the individual experiences. Crucially however, the additional introduced items are non-scoring, so there are no changes to the scoring algorithm or risk stratification.

The final aspect of the translated and culturally-adapted version that differs from the original instrument will be used to frame the brief intervention. During stage 4 of translation, it was determined that the clinical focus on the brief intervention component would similarly lack resonance with the target audience. Therefore, an alternative approach taking a 'yarning-style', with story-based feedback was conceptualised for the brief intervention. It was also identified by the Aboriginal and Torres Strait Islander members that the feedback should take on a strengths-based approach, focusing on raising awareness of areas identified by the individual in item 4 to promote and encourage behaviour change.

Phase 2: Focus-group discussions

Once a working translation of the instrument had been developed, the research team conducted the focus-group testing, using the instrument as the basis of discussions. The primary aim of the focus groups was to check the accuracy of the translated instrument. The secondary aim was to provide qualitative insights into patterns, characteristics, attitudes and beliefs of substance use within Pitjantjatjara community.

The substances most commonly identified during focus group testing were alcohol, tobacco, cannabis, methamphetamine and inhalants. These five substances were agreed upon during focus groups as the prominent drugs used in the community, and will therefore form the basis of the first iteration of the digital app-based instrument. Additional, albeit limited information was obtained for other substances including sedatives, stimulants (other than methamphetamine), and opioids. Key findings and beliefs around each substance are detailed in turn.

Alcohol: 'Wama'

Alcohol was the most commonly reported substance used. Alcohol is used by a broad range of demographics including mainly younger people, both men and women. In Pitjantjatjara, alcohol is known as '*wama,'* although a number of alternate spellings and pronunciations of *wama* exist, including *woma* or *womma*, depending on the location of the community. People also referred to the cask red wine or port, as '*maru'* or 'monkey blood'. In Pitjantjatjara, *maru* means 'black' (which may refer to the colour of the box, or the wine itself). The price of cask wine (both red and white) makes it an attractive option for drinkers, though mixing bourbon with cola was identified as becoming increasingly common. There was a commonly reported belief that young people will escalate from alcohol use to other drugs.

The consumption of alcohol typically occurs in groups, which can lead to disputes. There were no indications of individuals consuming alcohol alone. Alcohol can sometimes be associated with violence, with arguments over supply a possible occurrence. As such,

alcohol tends to have a polarising effect on the Pitjantjatjara community. There are those who abstain from use altogether, and those engaged in heavier levels of consumption. Provided there is sufficient supply, some members of Pitjantjatjara communities may consume alcohol until the point of significant intoxication. These findings are consistent with nationally reported trends of alcohol use among Aboriginal and Torres Strait Islander populations (AIHW, 2019; NATSISS, 2014).

Alcohol use within the Aboriginal and Torres Strait Islander communities may also be associated with increased rates of transient living. Regular consumption of alcohol was reportedly common among individuals sleeping rough, or in temporary unsupported accommodation, mostly within the parkland areas surrounding the city. There were reports of individuals turning up at family members' homes, with many such houses becoming overcrowded and unsafe as a result. It was also reported that individuals who otherwise may have housing, but due to lack of social supports or unfamiliar surroundings, often choose to visit areas where other individuals are gathered to drink to meet those social needs.

The welfare and the impact of alcohol use on children was also expressed as a primary concern. Those who did not consume alcohol were reportedly worried about the effects on younger children, but were conflicted about the possibility of turning family members and friends away. Some individuals expressed concern and anxiety about intoxicated individuals walking in uninvited, and were considering the need for higher fencing, but reported an obligation to invite others in regardless. In some cases, there were reports of residents placing signs on doors to discourage those who had been drinking from entering. The need for temporary accommodation for those under the influence of substances was also identified.

Tobacco: 'Tjikita'

Aside from alcohol, tobacco was the other most commonly reported substance used in Pitjantjatjara communities. Tobacco is primarily called '*tjikita'*, derived from the word 'cigarette', although it is also sometimes referred to as *puyu, rolly* or sometimes just *tobacco.* Smoking is reportedly common among both men and women, with age of onset typically

starting in middle adolescence. There were also reports of younger adolescents taking up smoking, with tobacco smoking widely viewed as a gateway drug to cannabis.

The recognition of physical harm from smoking was widespread, which may be why rates have been in decline recently. It was reported that smoking leads to illness – *kata kura* (meaning bad head, thick head or headaches) and is something that only younger people can reportedly 'get away with' due to the physical health repercussions. The younger members of families with older individuals who smoked were particularly concerned about the health and wellbeing of their elder family members, and would often encourage them to stop smoking. There was also a clear appreciation of the cardiorespiratory effects of smoking, and the negative effects for both pregnant women and their unborn children.

Cannabis: 'Ukiṟi'

In terms of illicit drugs, cannabis was the most widely reported substance. Cannabis is commonly referred to as '*ukiṟi*', though is also known as *marijuana, gunja,* or *joints*. Cannabis is most commonly smoked through home-made 'bongs', with garden hoses and plastic bottles and pipes. The typical age of onset is around mid-to-late adolescence, and is common among both young males and females. Onset can occur much earlier however, with some members of the Pitjantjatjara community as young as 10 years reportedly engaging in use.

Like alcohol, cannabis consumption is a social phenomenon; individuals reportedly smoke together in groups rather than alone. Relaxation, and aiding sleep and/or comedown from other substances were the typically reported motivations to use cannabis. In the community context, mixing cannabis with tobacco is seen as enhancing the experience by increasing the amount of smoke-able material to make it last longer. The tobacco also provides a level of 'head spin' effect prior to the THC from cannabis taking effect. When mixed with tobacco, it is also believed that cannabis can help increase energy, and is often used to aid the completion of household tasks. Pitjantjatjara families are more tolerant of cannabis compared to other substances, due to its calming effect on younger people and its

natural occurrence. This has the potential to broaden the proportion of individuals who may use it.

In terms of availability, cannabis is reportedly easy to obtain in city areas, but participants noted limited availability in the lands. As a result, price distortions are common in the community, with goods sold for up to four-times the price compared to suburban areas.

Methamphetamine: 'Ice'

Crystal methamphetamine has become a primary concern for Aboriginal and remote Australian communities. As is common throughout Australia, methamphetamine is commonly referred to as *ice*, though Pitjantjatjara-speakers residing in west coast communities sometimes refer to it as '*wada*' which literally translates from the Wirangu language as "*you know, that thing."* Methamphetamine is typically smoked, though *ice* was the only drug in the list mentioned by focus group participants in relation to needle use. Intravenous administration of methamphetamine is widely viewed as an indication of more severe involvement.

Physical harm to the self and others are the primary area of concern among community in relation to methamphetamine use. Participants in the focus groups reported that methamphetamine-use could be identified by physical symptoms, with typical indicators include shaking, weight loss, and robotic gait. It was suggested that women who used *ice* are motivated to stop use when pregnant. People also reported using methamphetamine for purposeful reasons, including to stay awake, to escape certain harmful situations, or in anticipation of physical violence that can be common among some drug-using environments. *Ice* use brings an additional dimension of confidence to physical fighting, which broadens the appeal for use.

The other issue related to methamphetamine is its tendency for use with other drugs. Polysubstance use, where methamphetamine is used, is commonly encountered during assertive outreach programs among those living on the streets around Adelaide. There is also a belief that taking methamphetamine will cause individuals to use any drugs available,

and that the use of methamphetamine will escalate problems. The beliefs and attitudes towards methamphetamine identified during focus groups reflect similar findings from other studies of Aboriginal and Torres Strait Islander people (Clough et al., 2015; MacLean et al. 2017).

Inhalants: 'Pantilpai'

The final class of substances recognised as commonly occurring were inhalants, though there were fewer variations of inhalant substances than anticipated. The most common inhalants were glue and sprays. Many participants recognised nitrous oxide canisters, though no participants were able to recall what they are referred by in in Pitjantjatjara or English, leading researchers to refer to inhalants collectively as *mulyangku pantilpai tjuta*.

Petrol and AV Gas were recognised, though are less common nowadays. Previous research has found a similar trend with respect to the decreasing use of volatile substances for inhalation (d'Abbs et al., 2019; Australian Indigenous Health*InfoNet*, 2021). During discussions, it was reported that inhaling substances occurs mostly among younger people (i.e., those under 25), and is more common among females. Inhaling was also reported as more common in remote townships, such as Alice Springs and Port Augusta, compared to metropolitan areas. Other research has estimated prevalence rates of adult inhalant use at less than 1% (d'Abbs et al., 2019), though likely higher among younger populations and more remote communities. Individuals typically fill a plastic bag or a bottle with a volatile substance and inhale – though nowadays nitrous oxide inhalation is becoming more widespread, with discarded cannisters reportedly an increasingly common sight.

Pharmaceutical medications

Participants were able to provide some insights around the non-medical use of pharmaceutical medications, although responses and information was limited. In general, there was no recognition of the use of pills, except in the case of codeine, which some participants indicated was sometimes crushed and injected. However, the rescheduling of codeine on the PBS is likely to reduce the rates of codeine injection in Australia. Suboxone

strips were also identified as potential substances, however participants indicated that use of Suboxone was more common in prison settings or among people living near prison communities (e.g., around Port Augusta). Suboxone strips are typically cut up and lit using a light bulb. These were sometimes referred to as orange peel, and *kunya* (an Adnyamathanha word meaning *poison*). Prices were approximately $25 per strip at the time of asking.

Traditional Tobacco: 'Mingkulpa'

During the course of discussions, it was also clear that traditional tobacco (*mingkulpa*) was a substance commonly used by Pitjantjatjara community members, primarily among young women. However, given the cultural status among Aboriginal people, *mingkulpa* was not included in the list of substances for the final instrument. The knowledge of the effects of *mingkulpa* potentially could be used to explain the effect of other substances (e.g., tolerance and dependence).

The findings here related to *mingkulpa* reflect similar findings in other studies (Ratsch et al., 2017). *Mingkulpa* is regarded as relatively weak in potency, so it is commonly mixed with loose tobacco and chewed. The process of chewing *mingkulpa* is similar to that of chewing other tobacco; individuals will chew the leaf before placing it under the lower lip or behind the ear (for mucosal or transdermal absorption respectively) during sleep at night (see also Latz, 1995; Ratsch et al., 2017). The leaf is also mixed with the ash from gum tree (commonly red river gum) in a practice that appears to enhance the potency pharmacokinetically by increasing the pH levels. At higher pH levels, nicotine can travel more freely across cell membranes located within the mouth (Pickworth et al., 2014), leading to a faster rate of absorption.

The issues around availability of *mingkulpa* were also identified and discussed. *Mingkulpa* used to be seasonal, with the harvest following the summer rains. However, now that more individuals are mobile and able to travel greater distances, individuals are willing to pay larger sums of money for *mingkulpa* when they run out locally. When supply of *mingkulpa* is constrained, individuals will often turn to tobacco, though the preference is

generally for *mingkuḻpa*. It is common for individuals travelling from APY lands to Adelaide and other regions to bring *mingkuḻpa* down to sell. However, though *mingkuḻpa* is regarded as an accepted cultural practice and is commonly consumed by young people, especially women, its use in schools is banned where Pitjantjatjara children attend.

Other research with Aboriginal communities, including Pitjantjatjara speaking groups have also identified a similar challenge with the culturally-accepted nature of chewing *mingkuḻpa* compared to smoking tobacco. Western notions of the harmful nature of tobacco smoking are not seen to apply to *mingkuḻpa*. *Mingkuḻpa* is regarded as a cultural practice, and thus when individuals undertake health assessments they are unlikely to report the consumption of *mingkuḻpa* (Ratsch et al., 2017). Respondents in our study were also likely to deny negative health consequences of *mingkuḻpa*. It is therefore important that potential risks and harms associated with *mingkuḻpa* use, including elevated glucose during pregnancy (Ratsch et al., 2021), are researched and discussed among Aboriginal communities.

Challenges and opportunities

Timing and recruitment

The timing of recruitment for eligible participants for focus-group testing presented the most significant methodological challenge. For context, prior to recruitment, two members of the community had passed away, which resulted in an extended period of mourning. This was an upsetting and challenging time for the community, and advice was sought from various key Aboriginal stakeholders about how to find alternative means to collect data. It was suggested, in consultation with members of the Pitjantjatjara community, that the ideal time to recruit participants from the community was in the morning; this approach was taken where possible. In other cases, advice from the community was to defer recruitment until a more culturally appropriate time could be established.

Participant recruitment was also impacted by living arrangements. Subsequent to the initial grieving period, the research team sought potential participants among members of the community known to be living rough in Adelaide (i.e., homeless or sleeping in parklands).

However, the ability to locate participants proved challenging in some cases due to the colder weather, ultimately leading the research team to visit houses in local areas. Though in most cases, individuals were enthusiastic to participate, the presence of other individuals either at the same location or nearby led to some hesitancy among participants that required a change in location. For example, during one focus group, a participant expressed a preference to talk away from others, so opted to be interviewed at a local restaurant nearby. In other cases, focus group discussions were interrupted by other individuals or by other events. As a result, not all participants were able to complete both phases of the focus-group testing.

Cultural Sensitivity

Revealing information about the consumption of alcohol and other drugs to others living in the same community is a sensitive cultural issue among many Aboriginal groups. In almost all cases, there was some hesitancy with revealing drug-related information for this reason. However, with the help of key Aboriginal and Torres Strait Islander stakeholders, adequate explanations about the purpose of the research and the roles of the researchers in the community resulted in the majority of participants warming to discussions. In fact, in the majority of cases, participants were more comfortable discussing substance use with the non-Pitjantjatjara researcher due to their status as an 'outsider' among the community, though this did present an additional challenge for interpretation. The presence of an additional interpreter, an Aboriginal person fluent in Pitjantjatjara, but from a different cultural group, aided this process. The additional interpreter was well-known within the community, having married into a Pitjantjatjara family. However, since the individual had married into the community, he was considered an 'outsider', which meant participants seemed less concerned about disclosing sensitive information in his presence.

Language

An additional and important challenge related to differing conceptualisations of time between English and Pitjantjatjara languages. Specifically, the original ASSIST refers to substance use '*in the past three months'*. Although '*in the past three months*' can be

translated literally, suggestions were that it was not a period of time (or concept) which would ever be referred to literally. Therefore, it was anticipated to cause some confusion. In order to avoid difficulties in understanding the concept, key Aboriginal and Torres Strait Islander stakeholders suggested two alternate conceptualisations for testing. First, visual representations of three moons, with a person looking over their shoulder was conceptualised and tested. The second, was the inclusion of a function in the app that uses the current date to automatically calculates three months prior, so that the person would be asked "*since* [*month*] …" using terms that would try to imply recent past rather than distant past. However, after testing among the focus groups, it was determined that the most efficient and adequate solution was to ask '*looking back on the past three months*.'

Variations in individual levels of literacy was also identified as a potential opportunity. While many individuals are fluent speakers or writers in one or both languages, there are many who may speak or read one, but not the other. Therefore, to increase the likelihood of comprehension and limit potential misunderstanding, collaboration with key Aboriginal and Torres Strait Islander stakeholders identified the need to include a capacity for both audio and visual representation of both Pitjantjatjara and English languages.

Finally, the use of hand signals as a way of referring to various substances was also identified through the course of focus-group testing as a possible way to overcome language and interpretation issues. For example, while hand signals for nitrous oxide canisters were immediately recognisable to participants, there was no recollection of a common name. The incorporation of hand signalling has the possibility in some cases to provide a visual aid to comprehension, but future research will be needed to identify and validate any such signals.

Facilitators of Future Research

The concerns among community about the impact of ice and other drug use on young men and women is likely to be an important facilitator for future research. While many Aboriginal and Torres Strait Islander communities have established self-declared dry areas as a result, there has been a growing concern recently among the Anangu population about the use of methamphetamine and its impact on young men, women and their families. There

are specific concerns about the widespread availability, use and consequences of crystal methamphetamine, including unpredictable and scary behaviour, and increased incidence of mental health problems. There are also concerns about the earlier age of onset of substance use in general, and the increased level of alcohol consumption among young men and women. Throughout the course of this research, there was a palpable sense of relief that efforts were being made to identify and respond to some of these concerns.

Significant concerns about the social and emotional impacts of community substance use on families may also be an important facilitator to preventive approaches going forward. Increased concern about the social impact of regular substance use on younger children, and the burdens of care it places on already overburdened parents was also expressed. Despite these concerns however, participants were steadfast in their commitment to family, and the need to show empathy and compassion in difficult times. One participant noted: "*if no one comes, they will keep doing it*", and "*family need to show love and respect*", because "*people feel very lost if they have no family*". Clearly, Aboriginal and Torres Strait Islander people feel a deep sense of duty to their community in difficult times, regardless of the personal toll it may take.

Active presence within community also helped to curate a number of key relationships and connections with people living within Pitjantjatjara community. These relationships were built upon trust and came about as a result of objective and non-judgmental attitude towards substance use. In many cases, participants indicated a willingness to engage in future phases of the research, and expressed intention to invite other community members to participate. In some cases, individuals who had previously reported problems with alcohol or other drugs, but had since recovered, were more open and motivated to participate in the study during subsequent phases. The spirit of collaboration and objectivity will help to facilitate future research and implementation within the community.

Conclusions

The purpose of this study was to develop a translation and cultural-adaptation of the ASSIST. The goal in doing so will be to provide health and wellbeing workers in Pitjantjatjara-speaking communities with an instrument to assist in identifying and responding early to harmful substance use. While the ASSIST questionnaire was translated according to WHO guidelines, the process of community consultation led to a change in the framing of several items within the questionnaire. The subsequent translation was tested during a series of focus groups, in which several key findings related to alcohol and other substances were identified. The findings from this study will inform the next phase of development of an app-based version of the instrument which will require pilot-testing and validation before it can be scaled up into additional Aboriginal and Torres Strait Islander languages, and deployed in community.

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Figure 1.

Process of Translation and adaptation into Pitjantjatjara

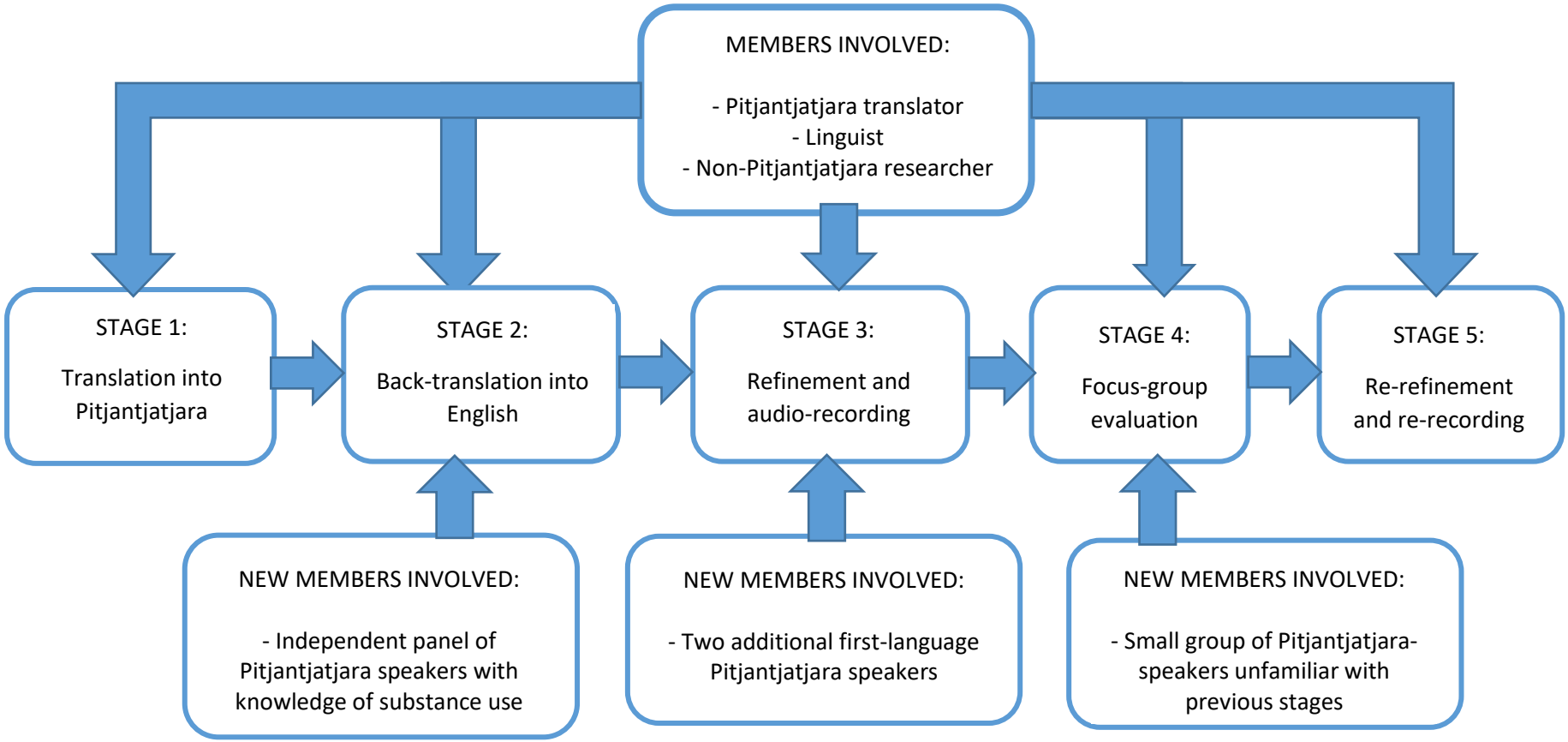

Table 1.

Summary of ASSIST questionnaire items in original English and translated English versions.

ASSIST Item	Original text	New item	Translated item
1	In your life, which of the following substances have you ever used…?	1	From when you were young, think about which of the following substances you have ever tried?
2	In the past three months, how often have you used …?	2	Looking back over the past three months, how often have you been using …?
3	During the past three months, how often have you had a strong desire or urge to use …?	3	Looking back over the past three months, how often have you been crying out for …?
4	During the past three months, how often as your use of … led to health, social, legal or financial problems?	4- preamble	In the past three months, when you were using …, did any of these things happen to you? Perhaps like this …
-	*New item*	4- health	… You got sick in the head or your body got sick?
-	*New item*	4- social	… Your family didn't stay together, perhaps because they were frightened or because of fights or arguments?
-	*New item*	4- legal	… You were not safe or living in a proper way?
-	*New item*	4- financial	… Your money was running out?
-	*New item*	4- scoring	In the past three months, how often have these bad things we were talking about been happening to you?

5	During the past three months, how often have you failed to do what was normally expected of you because of your use of …?	5	Looking back on the past three months, think about and tell me how often using … has caused you to think differently, and because of that, you haven't done some things? Perhaps, you were not looking after your child enough, or you were not turning up for work?
6	Has a friend or relative or anyone else ever expressed concern about your use of …?	6	Has someone talked to you about using …? Perhaps your family, your partner, your friend or your health worker?
7	Have you ever tried to cut down on using … but failed?	7	Have you ever tried to slow down or stop using … but couldn't do it?
8	Have you ever used any drug by injection?	8	When you have previously used drugs, have you used needles?