

Original Article

Computerised emotional well-being and substance use questionnaires in young Indigenous and non-Indigenous Australian adults

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Abstract

Background: Mental health disorders rank among the most substantial causes of morbidity and mortality worldwide. Almost half of Australian adults experience mental illness at some point in their lifetime, with Indigenous Australians disproportionally affected. Thus, it is imperative that effective, acceptable screening tools are used, which are tailored to the target population.

Objectives: This research investigates the methodology of computerised questionnaires in assessing the emotional wellbeing and substance use in Indigenous and non-Indigenous young adults.

Methods: Cross-sectional data from young adults (21–28 years) in the Life Course Program, Northern Territory, Australia, are presented. Through an extensive consultation process, validated questionnaires were adapted to a computerised format suitable for both remote and urban residing Indigenous and non-Indigenous adults.

Results: Of the 576 participants (459 Indigenous, 117 non-Indigenous) available for assessment, high consent rates were seen, with completion rates >86%. One in three young adults in this cohort were highlighted as 'at risk' of psychological distress, and one in five as 'at risk' of suicidal ideation or self-harm.

Conclusion: The target population of this study were at a critical age with high levels of psychological distress and suicidal ideation reported, particularly in Indigenous young adults. This simple, user-friendly, pictorial programme allowed assessment of a sensitive topic anonymously, while simultaneously collating data and identifying those at high risk, irrespective of literacy level or cultural background.

Keywords

Young adult, Indigenous, non-Indigenous, psychological distress, suicidal ideation

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Introduction

Mental health disorders rank among the most substantial causes of morbidity and mortality worldwide. 1,2 Often beginning in childhood or adolescence, they can lead to considerable disability and contribute to adverse health behaviours, subsequently increasing the risk of developing adult chronic diseases. Approximately half of all Australian adults experience mental illness (psychological distress, affective or substance use disorder) at some point during their lifetime. Aboriginal and Torres Strait Islander Australians (hereafter respectfully referred to collectively as Indigenous Australians) fare worse than other Australians on almost every measure of physical and mental health. 4-7 Indigenous

Australians experience high rates of psychological distress, an increased number of stressful life events⁴ and have high rates of suicide.⁸

Measuring emotional distress is challenging, particularly in populations with low literacy, and in differing cultural

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contexts. Traditional face-to-face (FTF) interviews are an important tool both in mental health research and clinical care. Interviews related to emotional distress and substance use, involve sensitive topics that people can find embarrassing or be reluctant to disclose FTF. While self-administered questionnaires offer a high level of privacy, 9-11 they also require a level of literacy and reading comprehension for participants to be able to provide accurate answers. Questionnaire structures can be complex and rely on the participants having form literacy; the ability to select consistent responses, follow instructions and to correctly follow branching or skip instructions. 12 Increasingly, computers have been used to create an atmosphere that is perceived as impersonal and non-judgmental, thereby promoting a greater sense of privacy. 11 Computer anxiety, attitudes, confidence and experience can impact on the acceptability and reliability of computerised questionnaires.

Although there is substantial population diversity, on average Indigenous Australians have lower education levels and higher rates of illiteracy compared to non-Indigenous Australians. Aboriginal languages are traditionally oral, with no written component. Pictorial aided paper-and-pencil questionnaires using plain English, Aboriginal English or local language have been previously used in the assessment and treatment of mental health disorders in this population. While personal computer ownership and access to a reliable Internet connection is improving, it remains restricted in remote Indigenous communities. There is a paucity of information currently available on the use and acceptance of computerised questionnaires in this population.

To understand the disparities in mental health between Indigenous and non-Indigenous Australians, it is essential that appropriate tools are used. These need not only to be culturally appropriate, but also allow comparability with other populations. ¹⁶ In assessing an individual's emotional well-being, it is critical to consider the cultural contexts and the environment in which the people live. ¹⁷ Measures developed within a given cultural group can provide comprehensive information on Indigenous well-being, ¹⁸ with a formal cross-cultural adaptation process then allowing validated questionnaires to be used across cultural groups and geographical locations. ¹⁸

The aims of this study were threefold: (a) to describe the process of consultation and adaptation of emotional well-being and substance use questionnaires to a computerised format for use in Indigenous and non-Indigenous young adults; (b) to develop a programme capable of immediately highlighting those at increased risk of psychological distress and/or suicidal ideation; and (c) to report the use and internal validity of this method in Indigenous and non-Indigenous young adults.

Methods

Recruitment and retention

The Life Course Program is a prospective longitudinal study examining the effect of early life factors on later health and disease in Indigenous and non-Indigenous Australians. Based in Darwin, Northern Territory (NT), it encompasses two distinct but complementary cohorts: The Aboriginal Birth Cohort (ABC) and the non-Indigenous Top End Cohort (TEC).

The recruitment of the ABC¹⁹ and TEC²⁰ studies have been described elsewhere. In brief, between 1987 and 1990, 686 babies (54% of those eligible) born to Indigenous mothers at the Royal Darwin Hospital, the main referral hospital for the NT, were recruited to the ABC study. Subsequent follow-up has occurred at the participant's residences, in over 40 urban and remote communities across the NT, at age 11 (1999–2002)²¹ and age 18 (2006–2008). Between 2007 and 2009, 196 non-Indigenous people residing in Darwin and born there between 1987 and 1991, were recruited to the TEC study. TEC participants were matched to participants of the ABC study according to age and birth location.²⁰

Cross-sectional data obtained between September 2013 and June 2015, when Life Course Program participants were aged 21–28 years, are presented. As in previous follow-ups, participants were invited to have a comprehensive health check involving various physical (anthropometric, cardiovascular, respiratory and renal) and emotional (lifestyle, cognitive and emotional well-being) components.

All participants provided written informed consent to participate in this study, and all procedures were approved by the Human Research Ethics Committee of the Northern Territory Department of Health and the Menzies School of Health Research. The ABC study also obtained approval from the Aboriginal Ethical Sub-committee, which has the power of veto (ABC HREC 2013-2022; TEC HREC2013-1986).

Geographical setting

The NT has the third largest area of the states and territories in Australia (1,346,200 km²). It has a small (244,300), relatively young (median age of 31.8 compared to 37.3 nationally) population, with the highest proportion of Indigenous people in Australia (approximately 30%), of whom 4 out of 5 reside in remote or very remote areas.²³ Remote communities vary in population size from 200 to 2000 people, with many small family groups living in outstations (<50 people). Across the NT, many (100+) varied dialects are spoken, with English often the second or third language.^{24,25}

Process of adaptation

The adaptation of validated questionnaires to a computerised format was developed through a process that considered factors relevant to the target population, such as the age of participants, cultural considerations, literacy levels, user friendliness and method acceptability. Participants of both the ABC and TEC studies encompass a broad spectrum of education levels (from 'left school in year 8' to 'tertiary

educated') and language and literacy groups (from 'fluent in written English' to 'English is a second, or third language'). A questionnaire suitable for use both in Indigenous and non-Indigenous young adults, across all education and language groups, was required.

As the questions were asked as part of a comprehensive physical and emotional health assessment, particular attention was given to maintaining the careful balance between the research areas to be covered and ensuring minimal burden was placed on participants. To enable this, preference was given to the shortened versions of questionnaires when available, for example, the Kessler-5 (5 questions) was used to assess psychological distress in preference to the Kessler-10 (10 questions), and the 4-question Perceived Stress Scale was used as opposed to the 10-question.

Consultation with expert, Indigenous and cohort reference groups occurred on the areas of priority and development of the draft tools. Pilot testing resulted in refinement, further consultation and additional pilot testing. The Expert Reference Group (ERG) facilitated access to expert consensus opinion and determined content validity of the tool. The ERG was comprised of Indigenous and non-Indigenous researchers and clinicians, including a psychiatrist, who together have over 30 years combined experience with Indigenous health in the NT. The group met on a monthly basis over an 18-month period. Further consultation with mental health experts, including the Darwin and remote mental health team, facilitated additional access to expert consensus opinion, determined content validity of the tool and ensured the correct referral pathway was established.

Advice on the questionnaire content, administration method and feedback, and any cultural considerations, was obtained through consultation with the Menzies School of Health Research Child Health Indigenous Reference Group (CHIRG), primary healthcare services, Aboriginal organisations, key service providers and the cohort reference group.

Although the translation of questionnaires into Indigenous languages would be the most suitable method, it is very time consuming and costly. Participants of this study reside in over 40 geographically, culturally and linguistically diverse urban and remote communities. The communities involved cover over 50 language groups; therefore, translation into each Indigenous language was not feasible. Recommendations from the Indigenous consultation process highlighted the need for participants to feel safe in answering questions by ensuring a high level of privacy. Their suggestions included ensuring a private area was used, and that gender matched, or older, researchers conducted the interviews (e.g. a male researcher to ask the questions with male participants). To assist with language barriers, the recommendations were to: simplify the questionnaire by displaying a single question at a time; use additional explanations in simple plain English to provide clarification of questions; supplement answers with pictures or pictorial images; and to use local interpreters when required. Refinement of the guide developed for use with the Strong Souls questionnaire in the previous followup of the ABC study was conducted, and reviewed by Indigenous researchers and the cohort reference group. This guide provided standardised alternate wording for the questions if the participants were having difficulty following the original question. Training was provided to all researchers in conducting interviews and communication skills, particularly in relation to mental well-being and suicidal ideation via Lifeline workshops. Local Indigenous community member(s) were also identified and employed in each community to assist in contacting participants and to act as interpreters as required.

The cohort reference group, involving Indigenous and non-Indigenous young people, participated in the pilot testing. Opinions on the overall content, appearance, user friend-liness, format and style were obtained. Resulting from this feedback, the size and depth of colour of the pictorial boxes were increased, and changes were made to the font style and text size for ease of reading. Further pilot testing resulted in the refinement of text font, colour and display style.

Instrument

The questionnaires were adapted into a computerised format using Microsoft Access. Importantly, for the geographical area covered (where Internet coverage was often limited), this programme was not reliant on Internet access. It had the ability to be directly downloaded into the master database, thereby eliminating data entry errors. Several small, portable touch screen laptops were used, so multiple people could answer the questionnaires at any one time and a constant power source was not required. The identification of participants was restricted to a unique identification number and the researcher's name, with the date of assessment automatically filled in. This ensured a high level of anonymity and privacy while still providing key links with the master database.

Individual questions were displayed on a single screen, with pictorial colour gradient boxes used to depict the possible answers with the wording underneath. These boxes ranged from a small and lightly coloured box representing 'none of the time', up to a larger sized and darkly coloured box representing 'all of the time' (see Figure 1), with the increase in size and deepening of colour used to reflect an increase in frequency. Advice obtained from the Indigenous reference group and cohort reference groups resulted in the use of boxes as opposed to images, as images can have different meanings in different settings and facial expressions can be hard to decipher. Items could be answered by either the touch screen or clicking the mouse pad. Once the answer was selected, one was automatically directed to the next question. After completing the questionnaire, a final instruction screen appeared asking participants to call for the researcher. Answers were automatically saved on closing the programme.

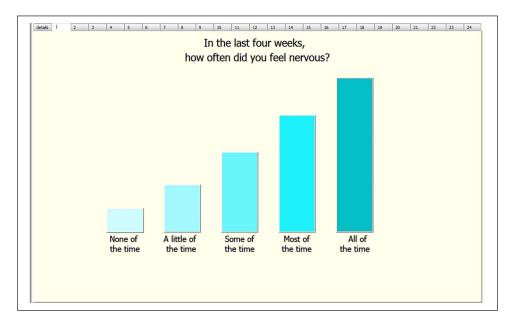


Figure 1. Screenshot of the emotional status assessment.

Emotional well-being assessment. A total of 26 questions were asked, encompassing a broad range of factors recognised as imperative in assessing emotional well-being, including psychological distress, suicidal ideation, positive well-being, perceived stress level, discrimination, connection to culture and additional questions on occurrence of stressful life events. This combination of questionnaires inquired about symptoms related to the previous 4 weeks and used a 5-point Likert-type scoring scale covering none, little, some, most or all of the time.

Psychological distress was assessed by the Kessler-5 questionnaire, which has previously been used with Indigenous and non-Indigenous Australians in state-wide and national surveys. This questionnaire asked how often participants felt: 'nervous? hopeless? restless or jumpy? everything was an effort? and so sad that nothing could cheer them up?'. The scores from each individual question were added together to create a continuous variable, which was categorised into high and low risk of psychological distress.

Positive well-being was assessed by the Short Warwick-Edinburgh Mental Well-being Scale.²⁹ Although there is a scarcity of research from Australia, this scale has been used widely in the United Kingdom and Scotland in teenagers and young adults.³⁰ This questionnaire asked how often participants felt: 'happy about the future? useful? relaxed? dealt with problems well? thought clearly? close to other people? and able to make up their own mind?'. Individual question scores were combined to create a continuous variable as per previously used criteria.²⁹

Subjective stress level was assessed by the Short-Perceived Stress Scale,³¹ which has been previously used in Australian Indigenous and non-Indigenous adults.^{32,33} This questionnaire asked how often participants felt they were

'able to control the important things in their life? handle personal problems? that things were going their way? and that difficulties were piling up so high that they could not overcome them?'. Individual question scores were combined to create a continuous variable.³¹

Risk of suicidal ideation and/or self-harm was assessed by questions from the Strong Souls questionnaire, which was used and validated in the previous follow-up of ABC participants.³⁴ This questionnaire asked how often participants 'felt like giving up, no point in trying? felt that everyone would be better off without them? felt like hurting yourself? wished you were dead? and felt like killing yourself?'.

The occurrence of discrimination and connection to culture were assessed by two questions previously used in the Strong Souls questionnaire. These questions also used a 5-point Likert-type scale, but answers were worded as: none, a little, some, a fair bit and lots. The questions, while covering the same concept, were tailored to cultural identification. Indigenous participants were asked: 'have you been treated unfairly or discriminated against because you are Aboriginal?' and non-Indigenous were asked: 'have you been treated unfairly or discriminated against?'. Connection to culture was assessed by the question 'how much do you know about Aboriginal culture?' in Indigenous participants, and 'how much do you know about your culture?' in non-Indigenous participants.

Highlighting those at risk. Answers to individual questions were allocated a score of 1 to 5 and grouped into the appropriate questionnaire (psychological distress, perceived stress, positive well-being or self-harm). For those related to the psychological distress or self-harm questionnaires, additional calculation of scoring occurred to highlight those at

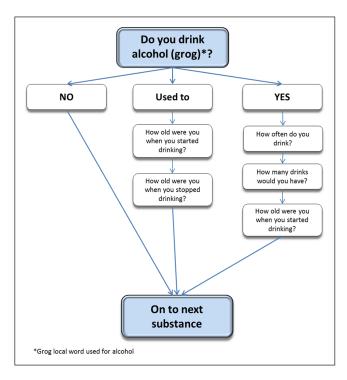


Figure 2. Substance use questionnaire flowchart.

risk of psychological distress and/or self-harm. The researcher was alerted to those at risk by a subtle change in final instruction screen colour as outlined below:

- 1. Risk of psychological distress (Kessler-5 scores 12–25):³⁵ a blue screen was displayed.
- 2. Risk of self-harm: a positive response to 'felt like killing yourself' or three out of the four other questions; 'felt like giving up, no point in trying; hurting yourself; wished you were dead; and everyone would be better off without them', an orange screen was displayed.
- 3. Risk of both psychological distress and self-harm: an orange screen was displayed.
- 4. If no risk was determined a yellow screen appeared.

For those at risk of self-harm, an additional screen then became visible containing further questions related to the immediacy of intent, method of harm, availability of support networks, previous harm and previous use of mental health services. Consenting to participation in this study included obtaining consent for referral to appropriate services for any abnormal results. For those who were categorised with high psychological distress and/or at risk of self-harm, the referral process was revisited, and the specific pathway and immediacy of referral agreed on. Referral occurred by the local health centre and/or relevant mental health service.

Additional questions. Questions were also asked regarding the occurrence of 13 major life events (yes/no), adapted from the

Negative Life Events Scale.³⁶ The questions used in this study were adapted as part of the consultation process to cover areas pertinent to this population, such as the separation of the drug and alcohol questions, and the addition of a question on gambling. The occurrence in the past 6 months of the following events was assessed: 'a close family member has been in an accident; has been in hospital; has been arrested; is in prison; has an alcohol problem; has a drug problem; needs their care most days; has passed away; they didn't have enough money to buy food or pay bills; them or someone in the house gambles a lot and it gives them money problems; they felt their house doesn't have enough space for all the people who live there; they were scared by other peoples' behaviour; and physically hurt by someone'.

Substance use questionnaire. Questions on consumption of alcohol, tobacco and marijuana use were obtained, including frequency and quantity. Each substance appeared on a single screen. Participants were first asked if they currently used each substance, with the possible answers: yes, no or used to. Dependent on the answer they were automatically directed to the next question requiring an answer. This process ensured accurate skipping of non-relevant questions and correct direction to the next question. Figure 2 depicts the flow chart for each of the substance questions. The question format was the same for each substance. An error message would appear if an answer was provided outside of the pre-set guidelines. Directing to the next substance occurred by clicking the next button in the bottom right corner of the screen, or automatically if the first answer was no.

Data collection method

As previously stated, the questionnaires were incorporated into the larger FTF health assessment which occurred in the participant's community of residence. These questionnaires were conducted in a quiet, private area separate from the main study. To comply with cultural requirements, questionnaires were administered by either a gender matched or an older researcher. Local interpreters were also used when required. English and literacy level as well as comfort with using the computer was assessed. The questionnaire delivery method was then tailored to the individual's requirements. The questionnaire was completed either *unassisted*, with a researcher close by to answer any questions, partially assisted with a research sitting next to them but the questionnaire completed by the participant, or assisted with the researcher asking the questions and either completing the questionnaire or guiding the participant to select an appropriate answer. The variance in questionnaire administration method allowed participants to choose the option they felt most comfortable with, while having the researcher available for further explanation and clarification of individual questions. When clarification was needed, the researcher used alternate wording which was provided as a supplementary

sheet refined in conjunction with Indigenous researchers and the cohort reference group. For example, the Kessler-5 asks how often they felt hopeless, which was clarified by how often they felt 'no hope'. The Perceived Stress Scale asked how often they felt that difficulties were piling up so high that they could not overcome them, which was clarified by 'how often they felt they had too many problems and they could not get on top of them'. This clarification process was often necessary in remote residing participants.

Participant's interactions, verbal and non-verbal communication, and specific behavioural events throughout and following the interviews were noted by the research team and discussed at the end of the clinic and in monthly team meetings.

Statistical analysis

All statistical analysis was performed using STATA 15.1. Participants were categorised into three groups according to Indigenous status and area of residency: remote Indigenous, urban Indigenous and urban non-Indigenous. Differences between the three groups were assessed through Pearson chisquare test for categorical variables and two-sample t-test for continuous variables, with the reported p-values unadjusted. Significance was accepted at p<0.05. Cronbach's α was used to determine internal consistency for each of the four emotional well-being scales. Cronbach's α value>0.70 is considered a minimum measure of internal consistency.³⁷

Results

Participants were young adults aged 21–27 years. Of the 576 participants available for assessment, over half were remote Indigenous (61%; n=351) with the remainder urban Indigenous (19%; n=108) and urban non-Indigenous (20%; n=117). Non-Indigenous participants were younger than the remote and urban Indigenous participants. There was a significantly higher number of women in the urban non-Indigenous group. For full details of the participant demographics, see Table 1.

Significant differences in socioeconomic status (SES) were seen between Indigenous and non-Indigenous participants. The majority of Indigenous participants were either married or in a *de facto* relationship and had one or more children. They had lower rates of employment and lower levels of educational attainment. These rates were similar between the remote and urban Indigenous groups; however, the urban Indigenous participants had higher rates of employment than the remote.

Response rates

Of the 576 participants who were available to participate, the majority consented to completing the substance use questionnaire (97%; n=556), with slightly lower numbers

consenting to the emotional well-being questionnaire (93%; n=534).

Emotional well-being assessment: Higher completion rates were seen in urban non-Indigenous (95%; 110/116) compared to their Indigenous counterparts, both remote (85%; 274/321) and urban (84%; 81/97). Four Indigenous remote participants were classified as non-completion due to commencing but not completing all questions. Similar to the original cohort, more women than men completed the questionnaire in all three groups (remote Indigenous 54%, 149 vs 125; urban Indigenous 53%, 43 vs 38; urban non-Indigenous 63%, 69 vs 41). Response rates are presented in Table 1.

Substance use: Higher completion rates were seen overall for the substance use questionnaire than for the emotional well-being questionnaire. Within group completion rates were higher in urban non-Indigenous (91%; 107/117) and Indigenous urban (90%; 97/108) young adults compared to their Indigenous remote counterparts (84%; 292/347). Similar to the original cohort, more women than men completed the questionnaire (remote Indigenous 54%; 159 vs 133, urban Indigenous 51%; 49 vs 48; urban non-Indigenous 62%; 66 vs 41). Response rates are presented in Table 1.

When stratified by Indigenous identification, no significant differences in sex, relationship status, employment status or education attainment were seen between those who completed either of the questionnaires and those who did not.

Team reflections: The majority of non-Indigenous participants completed both questionnaires unassisted, with approximately half of urban Indigenous and the majority (~90%) of remote Indigenous participants requiring researcher assistance. Although some of the Indigenous participants (particularly in remote communities) showed initial hesitancy towards using the computer, they often became more comfortable during the questionnaire and assisted by answering questions on the touch screen once questions were asked.

The most common reason for consenting to participate but not completing the questionnaires was related to the time restrictions of participants. The questionnaires were conducted towards the end of the larger health assessment which often took 1.5–2 h to complete.

Internal consistency

Cronbach's $\alpha > 0.7$ was used to measure the acceptable internal consistency of the scales. Overall, the psychological distress (0.78), self-harm (0.81) and positive well-being (0.76) scales had acceptable internal consistency. When

Table 1. Participant demographics, and questionnaire completion rates and frequencies, by Indigenous identification and residence.

	Remote Indigenous n = 35 I	Urban Indigenous n = 108	Urban non- Indigenous n = 117	p-value remote Indigenous versus urban Indigenous	p-value remote Indigenous versus urban non- Indigenous	p-value urban Indigenous versus urban non- Indigenous
Mean age	25.29 ± 1.16	25.60 ± 1.14	23.80 ± 1.46	0.076	<0.001	<0.001
Men	45.6% (160)	51.6% (56)	36.8% (43)	0.84	0.14	0.18
Employed	24.9% (87)	38.3% (41)	89.7% (105)	0.005	<0.001	< 0.001
Married or de facto	64.7% (227)	57.6% (61)	39.3% (46)	0.16	<0.001	0.006
Attended year 10	84.4% (292)	81.3% (87)	99.1% (114)	0.89	<0.001	<0.001
With children	68.6% (216)	61.8% (63)	7.8% (9)	0.08	<0.001	<0.001
Emotional status	, ,	, ,	. ,			
Consented to participate	n=321	n = 97	n=116			
Completed all questions	84% (274)	84% (81)	95% (110)	0.89	0.004	0.007
Psychological distress	31.0% (85)	35.8% (29)	34.5% (38)	0.42	0.50	0.89
Positive well-being	25.42 ± 4.68	24.49 ± 4.65	23.00 ± 3.86	0.17	<0.001	0.016
Perceived stress	4.42 ± 2.97	5.09 ± 2.69	4.92 ± 3.08	0.07	0.15	0.69
Risk of self-harm	23.7% (65)	19.8% (16)	15.5% (17)	0.45	0.07	0.44
Substance use						
Consented to participate	n = 334	n = 105	n=117			
Completed all questions	87.4% (292)	92.4% (97)	91.5% (107)	0.16	0.24	0.80
Smoke tobacco	74.7% (218)	58.8% (57)	13.1% (14)	0.003	<0.001	<0.001
Drink alcohol (≥ I week)	28.4% (83)	45.4% (44)	52.3% (56)	0.002	<0.001	0.32
Smoke marijuana	34.6% (101)	34.0% (33)	5.6% (6)	0.92	0.002	<0.001

Percentage (number) presented for categorical variables and mean \pm standard deviation for continuous variables. Psychological distress was defined as a Kessler-5 score of \ge 12. Risk of self-harm defined as a positive response to 'felt like killing yourself' or three out of the four of the following questions; 'felt like giving up, no point in trying; hurting yourself; wished you were dead; and everyone would be better off without them'.

stratified by Indigenous identification and residency, all three groups had acceptable internal consistency for psychological distress (remote Indigenous 0.83; urban Indigenous 0.75; urban non-Indigenous 0.83) and self-harm (remote Indigenous 0.73; urban Indigenous 0.87; urban non-Indigenous 0.95). Positive well-being was marginal for urban Indigenous (remote Indigenous 0.80; urban Indigenous 0.69; urban non-Indigenous 0.88). The Perceived Stress Scale Cronbach's α for the cohort was low at 0.49. However, it did exceed 0.8 in the urban non-Indigenous group (0.81) but was low in the Indigenous population irrespective of area of residency (remote Indigenous 0.45; urban Indigenous 0.37).

Team reflections: It was noted by researchers that Indigenous participants often had difficulty understanding the phrasing of the Perceived Stress Scale. The question 'how often they felt unable to control the important things in your life?' posed particular confusion among participants and often required significant additional explanation to be given.

Discussion

Through a comprehensive consultation process, the successful adaptation of emotional well-being questionnaires to a computerised version was achieved in a geographically challenging and culturally diverse population.²⁵ This adaptation proved to be acceptable, as reflected in the high completion

rates (\geq 85%), in both Indigenous and non-Indigenous participants. Computer access is limited in remote Indigenous communities, and initially concerns were raised on the cultural acceptance of using computer-based questionnaires. However, this potential limitation was not reflected in the completion rates seen or in the reflections noted by the research team.

The inclusion of a simple pictorial image to clarify the possible answers was particularly beneficial in those participants where English was a second or third language. A high level of understanding and acceptance was reflected in high completion rates, with all but four people fully completing the questionnaire after commencement. The option of being self-administrated, or partially assisted with a gender matched researcher, ensured acceptance across all groups. The availability of a researcher, and/or a translator, to provide assistance and further clarification was advantageous for all, but especially in those with low literacy levels, where language or culture may affect their understanding, or where computer anxiety occurred. A high level of confidentiality was obtained, with minimal identifiable data entered, and this was particularly beneficial in those participants who self-administered the questionnaire.

Measuring emotional distress is challenging, often requiring multiple questionnaires covering sensitive topics. The interpretation of questionnaire results and the correct classification of level of distress can be complex and time

consuming. The main benefit of this computerised method was in its ability to collate individual questions into their correct category (i.e. psychological distress, suicidal ideation or self-harm) and correctly categorise the level of risk according to the defined criteria. Thereby, shifting the burden of correctly identifying those who required further counselling and referral to appropriate services away from the researcher. This programme did not require connection to the Internet, ensuring its suitability for use by clinicians and researchers in all geographical areas as a method of identifying young adults at risk of emotional distress.

Given the high rates of suicide in the NT,⁸ particularly in remote areas, it is imperative that questionnaires on mental health are used effectively to highlight people at increased risk. Notably, this programme quickly and accurately highlighted those who were at increased risk of mental health issues. By the simple, non-intrusive changing of screen colour, participants at risk of psychological distress, and perhaps more importantly, of suicidal ideation and/or self-harm could be identified. In a cohort where one in three people reported psychological distress and one in five reporting suicidal ideation and/or risk of self-harm, it was essential that these people were correctly identified.³⁸

Assessment of the internal consistency of each questionnaire used was acceptable for the majority of participants, irrespective of Indigenous identification or gender. The Kessler-10 (K-10) is one of three consumer measures mandated for use throughout all Australian public mental health services to assess psychological distress.³⁹ The shortened Kessler-5 has been used with Indigenous people in statewide and national surveys, 4,5,16 with comparable Cronbach's α reported for the K-5 in Indigenous and non-Indigenous Australians. 16,40 The self-harm questions have also been internally validated in this Indigenous cohort.³⁴ However, neither the perceived stress nor positive well-being scales have been previously validated in this population. The low Cronbach's α results for the Perceived Stress Scale in urban and remote Indigenous participants, may partly be explained by the complex wording of the questions and their relevance in this cultural context. Further research is required to ascertain the suitability of these questionnaires in Indigenous populations.

The main limitation of this study is the lack of comparison data available to assess the acceptability of computerised formats of the questionnaires, as oppossed to traditional paper format. A paper version of the emotional well-being and substance use questionnaires were available if required or requested: However, it was not utilised, largely due to the availability of researchers to assist those with limited computer awareness. No formal data, through an additional questionnaire or interview, was obtained to fully assess the acceptability of this method in the cohort.

The current paucity in information on the emotional status of Indigenous young adults in remote communities of the NT makes it difficult to ascertain if the resulting level of distress seen in this cohort is comparable to those found in other methods of questionnaire administration. However, examination of the questionnaires which have been validated in Indigenous Australians showed comparable internal validity. An additional limitation is the relatively small participant numbers that may have reduced the power to detect statistically significant differences.

Conclusion

The targeted population of this study were at a critical age with high levels of psychological distress and suicidal ideation reported, particularly in Indigenous young adults. This simple, user-friendly, computerised programme allowed assessment of a sensitive topic anonymously, while simultaneously collating data and identifying those at high risk, irrespective of literacy level or cultural background. It eliminated human error related to wrongly categorising a participant's risk of psychological distress or self-harm. It has the potential to be adapted to both clinical and other research settings, thus helping to ensure accurate diagnosis and timely treatment is received.

Authors' note

B.D., J.F. and G.R.S. designed the study, and participated in data collection, analysis, interpretation and write-up. R.L. designed the study and participated in interpretation and write-up. B.D. drafted the manuscript and all authors critically revised the manuscript and approved the final version to be submitted.

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Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Ethical approval

Ethical approval was obtained from Human Research Ethics Committee of the Northern Territory Department of Health and the Menzies School of Health Research. The ABC study also obtained approval from the Aboriginal Ethical Sub-committee which has the power of veto (ABC HREC 2013-2022; TEC HREC2013-1986).

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References

- Kessler RC, Angermeyer M, Anthony JC, et al. Lifetime prevalence and age-of-onset distributions of mental disorders in the World Health Organization's World Mental Health Survey Initiative. World Psychiatry 2007; 6: 168–176.
- Walker ER, McGee RE and Druss BG. Mortality in mental disorders and global disease burden implications: a systematic review and meta-analysis. *JAMA Psychiatry* 2015; 72(4): 334–341.
- Slade T, Johnston A, Oakley Browne MA, et al. 2007 National Survey of Mental Health and Wellbeing: methods and key findings. Aust N Z J Psychiatry 2009; 43(7): 594–605.
- Australian Bureau of Statistics (ABS). Australian Aboriginal and Torres Strait Islander Health Survey: first results, Australia, 2012-13 (Cat. no. 4727.0.55.001), http://www. abs.gov.au/ausstats/abs@.nsf/mf/4727.0.55.001 (accessed 6 September 2018).
- Jorm AF, Bourchier SJ, Cvetkovski S, et al. Mental health of Indigenous Australians: a review of findings from community surveys. *Med J Aust* 2012; 196: 118–121.
- Australian Institute of Health and Welfare (AIHW). Australia's health 2012 (Australia's health series no. 13. Cat. no. AUS 156). Canberra, ACT, Australia: AIHW https://www.aihw.gov.au/getmedia/5fd0fcfe-bac9-4a4c-8128-1152d0ae9d8d/14178.pdf.aspx?inline=true (accessed 6 September 2018).
- Australian Indigenous HealthInfoNet. Summary of Aboriginal and Torres Strait Islander health, 2016. Perth, WA, Australia: Australian Indigenous HealthInfoNet, 2017, https://healthinfonet.ecu.edu.au/healthinfonet/getContent.php?linkid=59082 7&title=Summary+of+Aboriginal+and+Torres+Strait+Isl ander+health+status+2016 (accessed 6 September 2018).
- Australian Bureau of Statistics (ABS). Suicides, Australia, 2010 (Cat no. 3309.0), http://abs.gov.au/AUSSTATS/abs@. nsf/mf/3309.0/ (accessed 6 September 2018).
- KobakKA, GreistJH, JeffersonJW, et al. Computer-administered clinical rating scales: a review. *Psychopharmacology (Berl)* 1996; 127(4): 291–301.
- 10. Lucas R, Mullin P, Luna C, et al. Psychiatrists and a computer as interrogators of patients with alcohol-related illnesses: a comparison. *Br J Psychiatry* 1977; 131: 160–167.
- Lawrence ST, Willig JH, Crane HM, et al. Routine, self-administered, touch-screen, computer-based suicidal ideation assessment linked to automated response team notification in an HIV primary care setting. *Clin Infect Dis* 2010; 50(8): 1165–1173.
- Al-Tayyib AA, Rogers SM, Gribble JN, et al. Effect of low medical literacy on health survey measurements. *Am J Public Health* 2002; 92(9): 1478–1480.
- Bailie RS, Stevens M and McDonald EL. Impact of housing improvement and the socio-physical environment on the

- mental health of children's carers: a cohort study in Australian Aboriginal communities. *BMC Public Health* 2014; 14: 472.
- Phillips A. Health status differentials across rural and remote Australia. Aust J Rural Health 2009; 17(1): 2–9.
- Nagel T and Thompson C. AIMHI NT 'Mental Health Story Teller Mob': developing stories in mental health. Aust e-J Adv Ment Health 2007; 6(2): 119–124.
- McNamara BJ, Banks E, Gubhaju L, et al. Measuring psychological distress in older Aboriginal and Torres Strait Islanders Australians: a comparison of the K-10 and K-5. *Aust N Z J Public Health* 2014; 38(6): 567–573.
- Butler TL, Anderson K, Garvey G, et al. Aboriginal and Torres Strait Islander people's domains of wellbeing: a comprehensive literature review. Soc Sci Med 2019; 233: 138–157.
- Le Grande M, Ski CF, Thompson DR, et al. Social and emotional wellbeing assessment instruments for use with Indigenous Australians: a critical review. Soc Sci Med 2017; 187: 164–173.
- Sayers S and Powers J. Birth size of Australian Aboriginal babies. Med J Aust 1993; 159(9): 586–591.
- Davison B, Cunningham T and Singh G. Engaging adolescents and young adults in a longitudinal health study: experience from the Top End cohort. *Aust N Z J Public Health* 2011; 35(1): 86–87.
- 21. Sayers S, Mackerras D, Halpin S, et al. Growth outcomes for Australian Aboriginal children aged 11 years who were born with intrauterine growth retardation at term gestation. *Paediatr Perinat Epidemiol* 2007; 21(5): 411–417.
- 22. Sayers S, Singh G, Mackerras D, et al. Australian Aboriginal Birth Cohort study: follow-up processes at 20 years. *BMC Int Health Hum Rights* 2009; 9: 23.
- Australian Bureau of Statistics (ABS). 2016 Census QuickStats: Northern Territory (Code 7 (STE)), http://quickstats.censusdata.abs.gov.au/census_services/getproduct/census/2016/quickstat/7?opendocument (accessed 6 September 2018).
- Gruen RL, Weeramanthri T and Bailie R. Outreach and improved access to specialist services for indigenous people in remote Australia: the requirements for sustainability. J Epidemiol Community Health 2002; 56(7): 517–521.
- Lawrance M, Sayers SM and Singh GR. Challenges and strategies for cohort retention and data collection in an indigenous population: Australian Aboriginal Birth Cohort. BMC Med Res Methodol 2014; 14: 31.
- 26. Silburn S, Robinson G, Leckning B, et al. Preventing suicide among aboriginal Australians. In: Dudgeon P, Milroy H and Walker R (eds) Working together: aboriginal and Torres Strait Islander mental health and wellbeing principles and practice. 2nd ed. Australia: Commonwealth of Australia, Canberra.ACT, 2014, pp. 147–164.
- Australian Bureau of Statistics. 2004–2005 National Aboriginal and Torres Strait Islander Health Survey (NATSIHS) (Cat. no. 4715.0). Canberra, ACT, Australia: Australian Bureau of Statistics, 2006, https://www.abs.gov.au/ausstats/abs@.nsf/ mf/4715.0 (accessed 6 November 2019).
- Kessler RC, Andrews G, Colpe LJ, et al. Short screening scales to monitor population prevalences and trends in nonspecific psychological distress. *Psychol Med* 2002; 32(6): 959–976.

Bartram DJ, Sinclair JM and Baldwin DS. Further validation of the Warwick-Edinburgh Mental Well-being Scale (WEMWBS) in the UK veterinary profession: Rasch analysis.
 Oual Life Res 2013; 22(2): 379–391.

- Clarke A, Friede T, Putz R, et al. Warwick-Edinburgh Mental Well-being Scale (WEMWBS): validated for teenage school students in England and Scotland. A mixed methods assessment. BMC Public Health 2011; 11: 487.
- Cohen S, Kamarck T and Mermelstein R. A global measure of perceived stress. *J Health Soc Behav* 1983; 24: 385–396.
- 32. Wiggers J, Radvan D, Clover K, et al. Public housing, public health: health needs of public housing tenants. *Aust N Z J Public Health* 2001; 25(2): 111–114.
- Brown A, Mentha R, Howard M, et al. Men, hearts and minds: developing and piloting culturally specific psychometric tools assessing psychosocial stress and depression in central Australian Aboriginal men. Soc Psychiatry Psychiatr Epidemiol 2016; 51: 211–223.
- 34. Thomas A, Cairney S, Gunthorpe W, et al. Strong souls: development and validation of a culturally appropriate tool for assessment of social and emotional well-being in Indigenous youth. *Aust N Z J Psychiatry* 2010; 44(1): 40–48.

- 35. Australian Bureau of Statistics. *Australian Aboriginal and Torres Strait Islander Health Survey: users' guide, 2012-13* (4727.0.55.002), 2013, https://www.abs.gov.au/ausstats/abs@.nsf/Lookup/4727.0.55.002main+features12012-13 (accessed 6 November 2019).
- Kowal E, Gunthorpe W and Bailie RS. Measuring emotional and social wellbeing in Aboriginal and Torres Strait Islander populations: an analysis of a Negative Life Events Scale. *Int J Equity Health* 2007; 6: 18.
- Nunnally JC and Bernstein IH. Psychometric theory. New York: McGraw-Hill, 1994.
- 38. Davison B, Nagel T and Singh G. Life, lifestyle and location: examining the complexities of psychological distress in young adult Indigenous and non-Indigenous Australians. *J Dev Orig Health Dis* 2017; 8(5): 541–549.
- Nagel T, Robinson G, Condon J, et al. Approach to treatment of mental illness and substance dependence in remote Indigenous communities: results of a mixed methods study. *Aust J Rural Health* 2009; 17(4): 174–182.
- 40. Ferdinand AS, Paradies Y and Kelaher M. Mental health impacts of racial discrimination in Australian culturally and linguistically diverse communities: a cross-sectional survey. *BMC Public Health* 2015; 15: 401.