



An Australian Government Initiative



**Validation of the  
Kimberley Indigenous Cognitive Assessment Tool  
(KICA)  
in rural and remote Indigenous communities  
of the Northern Territory**

A joint collaboration between Alzheimer's Australia NT, University of Western Australia and National Ageing Research Institute



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## List of terms and acronyms

AA	Alzheimer's Australia
AANT	Alzheimer's Australia Northern Territory
ABS	Australian Bureau of Statistics
ACAT	Aged Care Assessment Team
CVA	Cerebral Vascular Accident
DSM – IV	Diagnostic and Statistical Manual of Mental Disorders (4 <sup>th</sup> Edition)
FORWAARD	Foundations of Rehabilitation with Aboriginal Alcohol Related Difficulties
HACC	Home and Community Care
KACS	Kimberley Aged and Community Services
KAMSC	Kimberley Aboriginal Medical Service Council
KICA	Kimberley Indigenous Cognitive Assessment
KIS	Kimberley Interpreting Service
NARI	National Ageing Research Institute
NHMRC	National Health and Medical Research Council
NOS	Not otherwise specified
OT	Occupational Therapist
PBS	Pharmaceutical Benefits Scheme
UWA	University of Western Australia
ROC	Receiver-Operator Characteristic curves
TOPPS	Territory Older Persons Support Service



# 1. Introduction

There are many complex needs of older Indigenous people with dementia and other health related issues. The determination of the extent of dementia and other cognitive impairment in this group has been hindered by lack of a culturally appropriate assessment tool. The Kimberley Indigenous Cognitive Assessment tool (KICA) has been developed and validated in a number of Indigenous communities in the Kimberley region of Western Australia (WA). The principal researchers of this tool sought to replicate the validity and reliability of the KICA in another group of Indigenous older people from different regions and language groups i.e. the Northern Territory (NT). This was to determine whether the KICA is applicable to the majority of older Indigenous people living predominantly in remote and rural regions of Northern Australia.

This report discusses a study undertaken to validate the KICA tool in the NT. Using the KICA tool, fifty older Indigenous people over the age of 45 years, across a vast geographical region of the Northern Territory. This was followed by cognitive assessments blinded to KICA results. The outcome of the study and recommendations are also included. Additionally the study identifies the significance of a robust cognitive tool which will assist in highlighting the needs of older Indigenous people who have cognitive impairment and dementia, and their families.

# 2. Background

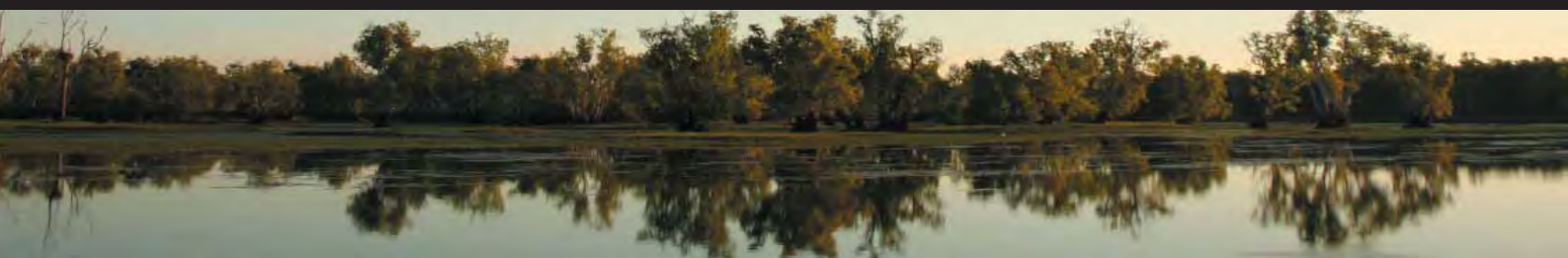
Twenty five percent of the NT population are Indigenous (Australian Bureau of Statistics, Northern Territory 2005), yet these statistics do not reflect the prevalence of dementia within this population group. To understand this, in 2002 Alzheimer's Australia Northern Territory (AANT) initiated the Indigenous Dementia Research Project. The final report of this project was released in December of the same year and highlighted the problem of dementia within Indigenous communities and the unmet needs for Indigenous people living with dementia. AANT, the Australian Government and Northern Territory Government jointly funded this project. A copy of 'The Indigenous Dementia Report' is available from [www.alzheimers.org.au](http://www.alzheimers.org.au) (click on the NT map of Australia).

A significant finding of the report highlighted the cultural inappropriateness of the existing screening tools, for cognitive assessment of people from Indigenous groups in the Northern Territory. An outcome from this research project was that further work was proposed to support the development of an appropriate cognitive assessment tool for Indigenous people.

The Kimberley Indigenous Cognitive Assessment (KICA) was developed by Dr Dina LoGiudice (geriatrician, National Ageing Research Institute) and Ms Kate Smith (occupational therapist, Kimberley Aged and Community Services), in collaboration with the University of Western Australia.

The KICA was validated in older Indigenous people of the Kimberley to assess cognitive status (LoGiudice et al, 2005). (See Appendix for copy of tool)

The KICA tool comprises a number of sections to aid in dementia assessment. It includes both client assessment and carer reports of medical, alcohol and smoking history, cognition, behavioural and psychological symptoms, and an informant section to assess activities of daily living. The KICA was adapted from cognitive assessment tools in current use and refined after extensive consultation with community members of the Kimberley, including members of the Kimberley Aboriginal Medical Service Council (KAMSC), Kimberley Aged and Community Services (KACS), Kimberley Interpreting Service (KIS), psychologists and linguists. The KICA was translated and back translated into Walmajarri, a commonly used language originating from a desert area of the Kimberley.





The KICA was validated on 70 older people of diverse Kimberley communities ranging from coastal, river, desert and town regions. A deliberate attempt was made to obtain a sample of older people with a wide range of cognitive scores, resulting in over sampling of people with cognitive impairment. The average age of Indigenous people in the sample was 72.0 years and within this group 40 of them were female. Carers who provided the informant history were predominantly children (24%) and spouses (18%) and the majority (77%) were women. Forty three (61%) had no formal education. Interpreters were used in 32 (45.7%) of the interviews. Using DSM-IV (Diagnostic and Statistical Manual of Mental Disorders) (4<sup>th</sup> Edition) criteria 32 (44.3%) were cognitively normal, 27 (38.6%) had dementia, 9 Alzheimer's, 3 vascular, 5 alcohol-related, 2 multiple etiology, 2 "other" dementia, and 6 dementia NOS (Not otherwise specified) and 11 (15.7%) had cognitive impairment other than dementia. Lack of availability of computerised tomography scanning (the closest being in Port Hedland, 800km from Broome) probably resulted in an underestimation of vascular etiology of cognitive impairment.

The KICA results were compared to an independent assessment by a geriatrician and consensus diagnoses performed by Professor's Leon Flicker and Osvaldo Almeida using DSM-IV and ICD-10 (International Classification of Diseases) criteria. Interpreters were used whenever English was not proficient. Inter rater reliability was assessed using Cohen's Kappa (k) and Bland Altman methods in 14 people rated by two independent observers, with good overall results. The mean difference between raters was -0.07 with a standard deviation of difference of 1.83. Further analysis indicated that five items on cognitive score (orientation, naming abilities, registration, recall and free recall) were able to successfully categorise 91.4% of cases. The area under the curve was 0.95. Sensitivity and specificity was 91% and 93% respectively with a cut off score of 31-32 out of a possible 39. (The KICA-Cog, is the section of the tool that comprises direct cognitive assessment tasks, including areas of orientation, recognition and naming, registration, verbal comprehension, verbal fluency, recall, praxis and others). (See appendix for KICA-Cog questions.)

The KICA appears to be a reliable and valid tool for the assessment of dementia amongst older Indigenous Australians in the Kimberley region. A copy of the KICA is available on the [www.healthykimberley.com.au/chronicdisease.html](http://www.healthykimberley.com.au/chronicdisease.html) website. This initial phase was funded by a "Healthy Ageing Grant", NHMRC. The second phase of the project addressing the prevalence of aged care issues including cognitive impairment in older Indigenous people of the Kimberley was funded by NHMRC project grant (2005-2006) and is currently in the final phases of completion. Experience in the development and use of the KICA in the Kimberley has been positive, raising awareness of aged care issues at all levels of primary health care.

To date there has been very little formal data available on the health issues of older Indigenous Australians, particularly in the area of cognitive impairment and dementia. It is predicted that higher levels are likely to be found due to rates of risk factors including cerebrovascular disease, diabetes, head injury and alcohol.

There is worldwide research knowledge on all aspects of dementia care and its consequences. Medications to slow the rate of decline are available, family and carer programs ease the burden for relatives, preventative measures assist in minimising deterioration. (Green A & Brodaty H, 2002; Brodaty H et al, 2001.) The extent to which these medications and programs have reached Indigenous communities is unknown.

Determination of the magnitude of dementia in Indigenous communities will be the first step in adequate planning for provision of services e.g. respite care, education, support and counselling and dementia specific residential care.

A number of Indigenous health services and Aged Care Assessment Teams (ACATs) across the NT and other rural regions in Australia have shown interest in the KICA, as a potential assessment tool for their older clients. The need to ensure the KICA is appropriate for other communities is important. Therefore the need for validation of the tool in different regions outside the Kimberley was identified.



### 3. Aim of the Project

The aim of the project is to validate the KICA in a group of older Indigenous people from the Northern Territory, and describe its usefulness as an assessment tool for older people with cognitive impairment and dementia in this region.

## 4. Design and Methodology

### 4.1 Project Team

The proposal to validate the KICA in a Northern Territory sample of older Indigenous people was initiated by Dr Dina LoGiudice (NARI), Professors Leon Flicker and Osvaldo Almeida and Associate Professor Nicola Lautenschlager from the University of Western Australia, an experienced team in the assessment, management and research of older people. Ms Kate Smith (OT) is undertaking her PhD on the development of the KICA and prevalence study of aged care issues in the Kimberley. This team collaborated with Alzheimer's Australia NT to undertake this project, providing academic input with regards to methodology, statistical analysis and formulation of the project. The protocol followed that carried out in the Kimberley.

The Project Team in the Northern Territory comprised of AANT staff, Gail Marsh, Project Officer, who provided valuable links across the NT with Indigenous groups and Aged Care services, Marilyn Inglis Education Manager, Project Supervisor and Marianne Fitch, Executive Director.

Dr Sadhana Mahajani, Geriatrician from ACAT provided valuable time and expertise to the project.

Kate Smith provided training of the use of the KICA to the Project Team by teleconference in November 2004 and also face to face during a visit to Darwin on 19 – 23 September 2005. During this visit she discussed the use of the KICA with Darwin ACAT members, allied health at the Royal Darwin Hospital and also at the Guardianship Board in Darwin.

### 4.2 Methodology

Fifty two older Indigenous people over the age of 45 years were approached. For validation purposes this number was adequate for comparison of normal versus those with dementia (as seen in the primary project phase). The participants were selected to provide a relevant cross section for comparison. The only exclusion criteria was lack of family member or those who had been acutely unwell in recent days or weeks. The mix of participants included a range of older people with normal cognition, mild cognitive impairment and dementia over the age of 45 years. Included in the mix were those with acquired brain injury as a result of alcohol.

The Project Team worked closely with the Aged Care Assessment Team (ACAT) and allied health workers, who referred potential participants for assessment. (See appendix for consent forms and plain language statements)

Gail Marsh, AANT Project Officer, performed the KICA assessment, following which Dr Mahajani, ACAT Geriatrician, performed cognitive assessments. The evaluation involved determination of past and present history, medications, informant report and cognitive assessment assessing the main domains required for dementia assessment. No specific tool was used, but assessment relied on clinical judgement of an experienced clinician. Dr Mahajani's



assessment was performed blinded to KICA results, to allow validation of the process. Written results were then subjected to consensus criteria by other members of the research group (Professors Flicker, Almeida and Lautenschlager). Those identified with dementia were referred to the ACAT's for further follow up with treatment options supplied by the Geriatrician.

Analysis of the results included determination of basic demographic data and sensitivity and specificity of the KICA in a population of the NT, as compared to Kimberley data. Further information included qualitative descriptions of whether the KICA tool was suitable to use across various Indigenous groups, as compared to original data from the Kimberley, and any difficulties noted.

It was anticipated that the KICA would prove culturally appropriate and useful for older people in the Northern Territory region, available for health professionals and aged care workers to assess older clients in an appropriate manner, and provide beneficial management plans.

Feedback on the results of the assessment and any recommendations were made to local health service providers after consent of the individual participating. Verbal feedback was given to all individuals and family members. A written summary of findings was also provided to community council members.

The project was approved by the Central Australian Human Research Ethics Committee, NT and they were provided with regular progress reports on the project.

### **4.3 Project Activities**

Aged Care Facilities and providers in centres identified to participate in the study, which are listed below, were contacted to advise of the Project and pending visit. Information explaining the project was sent to providers of potential clients that were earmarked to participate in the study. Contact was made via email, mail and a phone call, ensuring everyone involved was fully informed. The feedback from service providers was very encouraging.

The Aged Care Assessment Team (ACAT) in Alice Springs provided AANT with a list of people willing to take part in the study. A staff member from the ACAT in Alice Springs travelled to Tennant Creek to coincide with AANT's visit and provide a list of people to speak to about the KICA. ACAT also had a worker in Tennant Creek based at the local Hospital. This enabled AANT to work collaboratively with the people involved for best outcomes.

The Project Officer had established links in the aged care arena, having previously worked and lived in Alice Springs, Katherine and Jabiru. These links assisted greatly with the willingness for participants to take part in the project.

The Aboriginal Interpreter Service and the Institute for Aboriginal Development was contacted to engage their service for the study. In both Tennant Creek and Alice Springs, professional interpreters were used from either one of these organisations. This proved to be hugely successful. Individual consent was obtained by each participant or their carers, taking part in the assessment. Individual communities were also approached to obtain their consent. Professional Indigenous interpreters were utilised where necessary. Education was given to family members and the interpreter prior to conducting the assessment. For example, they were told the importance of not assisting the subject with the answers, particularly with the recall questions.

Dr Mahajani, ACAT Geriatrician and Gail Marsh, AANT Project Officer visited the following regions of Darwin, Alice Springs, Tennant Creek, Katherine, Nhulunbuy, Jabiru and Bathurst Island.



***Subjects were assessed in the following communities:***

Community	Location
15 Mile Camp	Darwin
Illparpa Camp	Alice Springs
Amoonguna Community	Alice Springs
Oenpelli Community	Via Jabiru – 60km
Patonga Community	Via Jabiru – 65km
Beswick	Katherine
Bullman	Katherine
Yilapara	Gove/Nhulunbuy
Yirrkala	Gove/Nhulunbuy
Kapalga Station	Via Jabiru
Harts Range	Via Alice Springs

***Facilities, Hostels and Health Centres where assessments were undertaken are as follows:***

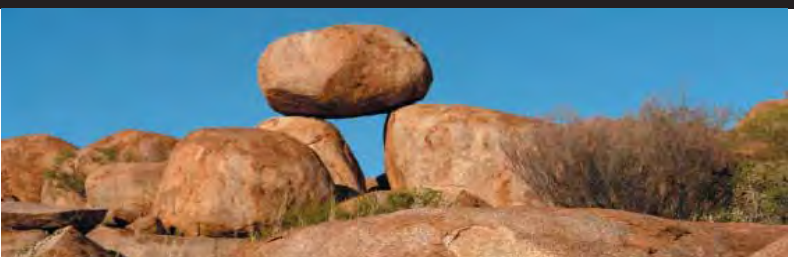
Facility	Location
Juninga Aged Care Facility	Darwin
Retirement Care	Darwin
Hetti Perkins Home for the Aged	Alice Springs
Old Timers Nursing home	Alice Springs
Pulka Pulka Kari Aged Care Facility	Tennant Creek
Jululakari HACC House	Tennant Creek
Amoonguna Aged Care HACC House	Via Alice Springs
Topsy Smith Hostel	Alice Springs
Jabiru Health Clinic	Jabiru via Darwin
Kakadu Aged Care	Jabiru via Darwin
Oenpelli Aged Care	Oenpelli via Darwin
Kalano Hostel	Katherine





## 5. Findings

- The project aims were achieved, with the successful outcome of validating the original KICA in a region outside the Kimberley. Further descriptions of the process and outcomes are described below.
- The KICA was validated in the Northern Territory on 52 participants and their carers.
- 47 participants were assessed by a geriatrician (Dr Mahajani) blinded to the KICA results. These 47 geriatrician reports were reviewed by Professors Flicker, Almeida and Associate Professor Lautenschlager who completed the consensus diagnoses using DSM-IV and ICD-10 criteria.
- The majority of participants assessed were female (73%). Participants aged from 47-87 years were assessed, the largest age group being 65-74 year olds (38.5%). Carers who provided the informant report were predominantly children (25%) or formal carers (21%). 50% of those assessed had no formal education. An interpreter was present for 23 (44%) of the KICA assessments. The place of interview was varied with 30.8% assessed at home and 21.2% in residential care settings; other places included a variety of health and community centres.
- Using the DSM-IV consensus diagnosis provided 21 (34%) participants were cognitively normal, 17 (36.2%) had dementia, and 14 (29.8%) had cognitive impairment not dementia.
- For the Northern Territory study a goanna puzzle for visuospatial skills (worth 1 point) was added to the KICA survey tool. However this will not be added to the final KICA tool as it was found not to accurately discern dementia from non-dementia. The KICA cognition total score remains at 39.
- Internal consistency that estimates how consistent individuals respond to items within the scale was alpha 0.81, which was high. Three items on the cognitive scale (season orientation question, verbal fluency, and free recall) correctly categorised 90.9% of cases. Using 'dementia versus normal' DSM-IV consensus diagnosis (as was used in the Kimberley validity data analysis) the area under the curve of the ROC (Receiver Operator Characteristic), that indicates the ability of a test to correctly classify those with and without the disease was 0.95 with sensitivity of 82.3% and specificity of 87.5%, for a cut off score of 31-32/39.
- The area under the ROC and ideal cut off score is similar to the original KICA validation study, which would support the use of this tool outside the Kimberley region. Although sensitivity and specificity scores were lower than the previous study, it would indicate reasonable suitability in screening for dementia in this population. The result may be explained by the relatively high numbers of those with visual impairment and lack of informant information for geriatrician assessment in some circumstances. As there is no other comparable culturally specific tool, these results indicate an important step in assessment of dementia in this group of people.
- The free recall questions, and orientation questions in both studies were shown to be the most discriminating between those with dementia and normal clients. This is valuable information in developing a short version for GPs in the near future.
- The KICA will be re-validated in those currently assessed for the Phase 2 prevalence study being carried out in the Kimberley, adding further information to the utility of this cognitive tool.



## 6. Challenges and Issues

### 6.1 Barriers Identified by the Project Officers

- Inaccessibility to areas due to seasonal rains and flooding, and difficulties trying to coordinate with aged care providers during the wet season.
- Due to the importance of using an interpreter with non English speaking subjects, when assessing cognition, the timeframe to conduct assessments was longer. As part of the study the subject had to be assessed by the geriatrician immediately after their KICA assessment. This led to the subject at times not wanting to talk to the doctor as they were tired following their KICA assessment.
- Due to referrals from interested agencies there was an over representation of subjects assessed in residential care and HACC settings.
- Only 31% of subjects were assessed at their home so it was difficult at times to find family members to provide informant information to the researchers.
- Unable to access communities due to cultural reasons, for example funerals, Men's and Women's Business and other community priorities.
- A large percentage of Indigenous people in Central Australia and Northern Top End of Australia have vision impairments to some degree. It was interesting to note that the facility in Tennant Creek, Pulka Pulka Kari Aged Care Facility, had 19 residents and 85% of them were visually impaired. Glaucoma is one of the main diseases affecting these people.
- Although there are visual barriers when using the KICA for some people, the tool provides options to overcome these. For example tactile measures (i.e. feel the object if you can't see it), naming the objects and pictures for them, and large pictures to potentially overcome visual barriers. The people assessed were easily (in most cases) able to identify the objects that were placed in their hands.
- The perseveration (frontal executive function) task is the only question of the tool that cannot be used with those who have significant visual impairment, although can be utilised by many with mild to moderate visual impairment.

### 6.2 Examples of Problems and Limitations Encountered in the Study

#### *Assessing an Indigenous Lady Post CVA using the KICA Tool Scenario 1*

I (Project Officer Gail Marsh) was approached by the Manager of an Aged Care Facility to assess a lady who was sent in from a remote area who had recently had a CVA. The ladies' right side had been affected and she had lost movement, this also included her speech, she was unable to speak.

I tested her cognition by using the KICA tool in such a way that I discovered that she understood what was being said to her, however, she could not respond verbally. I showed her a series of the animal pictures in the KICA tool. I



showed her a picture of a crocodile. I asked her “Is this a tree?” She nodded “No”. “Is this a boy?” She nodded “No”. “Is this a crocodile?” She nodded “Yes” and smiled.

Using the 3 items for the “Recognition and Naming” section, the person being assessed with no speech, was able to perform the actions for each object, identifying that she could understand and perform the command when asked.

The “Verbal Fluency” section was assessed by asking the participant to identify animals that people hunt in the community. This was again asked of the lady. She proceeded to point to a bird that was nearby in the bush, and point out the animals that were in the KICA tool, leaving out the pictures that were not relevant to the question, once again proving her understanding of the question being asked of her.

## *Assessing a Participant with Vision Impairment Using the KICA Tool*

### *Scenario 2*

Using the KICA tool to assess a participant it was noticed they had some vision impairment after the test was commenced.

I (GM) explained what I was doing and proceeded to use the tactile measures to assess this person.

I placed each article under the C4 and C5 section in the persons hand to “feel” the object. I asked if they could tell me what each object was, one by one.

Instead of hiding the object as per C5 I asked the person to tell me what those things were as part of the recall exercise. I then asked the participant to identify the pictures using the large drawings of the KICA tool.

This technique of assessment was focussing on using the “tactile measures” for someone with vision impairment.

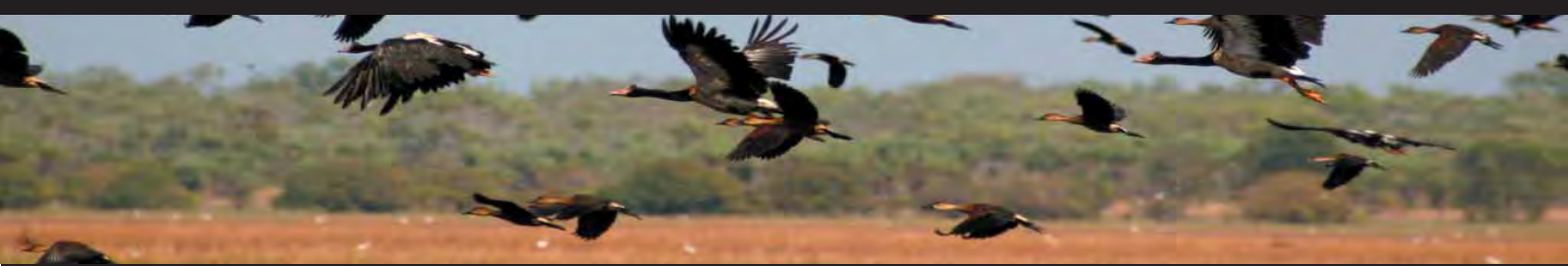
## **7. Conclusions**

The findings of this research indicate that the KICA was a useful assessment tool for older Indigenous people living in the Northern Territory. Statistical results indicate that with a cut point of 31/39, the KICA was able to reasonably discriminate between those with dementia and those without. The results are comparable with other screening cognitive tools used in non Indigenous cultures in the community.

Despite high levels of people with visual impairment, the KICA was able to be utilised in many cases to provide useful information. As with all screening tools, visual impairment, aphasia and hearing impairments limit its usefulness. Some modifications of pictures can be made to allow for cultural differences between regions and states, e.g. different types of animals shown may be more appropriate for specific regions.

The KICA obtains other information on general health, carer perceptions and behavioural issues associated with cognitive impairment. This data will be further analysed in the future to determine utility of carer perceptions in assisting with the diagnosis of dementia.

The KICA was well accepted by health workers, community members and families. The tool was considered long in some cases, but a comprehensive assessment is required for accurate diagnosis, management and planning. The



KICA can be used as part of a generic assessment, that is used for instance by ACAT teams. It is planned in the future a shorter screening tool will be made available for initial screening, following which the more comprehensive assessment can be undertaken if appropriate. An informant questionnaire for family and carer perceptions will be analysed to assess its utility, and compared between regions.

The project facilitated increasing awareness of dementia and assessment techniques, and various education sessions were held to highlight the need for appropriate cognitive assessment in older Indigenous people. Availability of a tool may facilitate a way to approach a person with cognitive impairment, as a tangible means of assessment.

## 8. Recommendations

- The KICA be made available for use in older Indigenous people in the Northern Territory, and current data supports the utility of this measure.
- The KICA has been utilised in two regions of rural and remote Aboriginal Australia. It can be recommended therefore that the KICA be utilised in other remote and regional areas such as Northern Queensland, Pilbara etc.
- The short version of the KICA, currently in development, will be made available to appropriate health services when completed.
- That the KICA be utilised as a measure to assist with longitudinal assessment of those with dementia to determine progress. This will be particularly important with regards to Pharmaceutical Benefits Scheme (PBS) guidelines and prescription of cholinesterase inhibitors.
- That ongoing support in the area of relevant medical assistance and referral to relevant aged care services is provided to participants of the KICA project particularly in remote areas.
- Funding to be made available to provide training in the use of the KICA tool and dementia assessment to aged care services and any health professionals who provide health assessment and services to older Indigenous people across the Northern Territory, rural and remote areas.
- Appropriate educational material be developed on the KICA tool for Indigenous groups.
- That this Final Report be made available on the Alzheimer's Australia website.





## 9. Acknowledgements

AANT would like to thank Dr Mahajani for her support with this project, the Indigenous people and their families who participated in the project and all relevant aged care providers for their support.

The Report was written by Gail Marsh, Marilyn Inglis, Kate Smith and Dina LoGiudice.

This Project is an Australian Government Initiative.

### Also

This project was supported by Alzheimer's Australia and the Northern Territory Department of Health and Community Services.

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