
Report of focus group consultations
November 2012

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This project was funded by Alzheimer’s Australia Vic
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1) Background

Dementia has become a growing public health issue in an ageing population. Efforts to address dementia in Indigenous populations have been hampered by a lack of culturally appropriate cognitive assessment tools. Current questionnaires that assess dementia (such as the MMSE) have been shown to have considerable cultural, educational and language bias which impairs their application in the Indigenous community. The KICA was developed to address this problem and is an instrument used to assess dementia in older Indigenous people in remote settings. The KICA includes client assessment and informant report of cognition, behavioural and psychological symptoms of dementia, medical history, and alcohol and smoking use.

In an effort to address this issue, in 2010 Alzheimer’s Australia Vic. (AAV) commenced discussions with the Victorian Aboriginal Health Service (VAHS), the Victorian Aboriginal Community Controlled Health Organisation (VACCHO), the Aboriginal Community Elder Service (ACES), the Department of Health (DoH) and Dr. Dina LoGiudice, to discuss the Victorian communities’ needs for both an accessible Elders assessment service and a validated cognitive screening tool. As a result of these discussions it was agreed that there was a need for a culturally appropriate service and also a cognitive screening tool that aboriginal health workers could utilise. As a result of Dept. of Health funding, an older person’s clinic was established in collaboration with the Aboriginal Health Service.

Alzheimer’s Australia Vic were already working collaboratively with a range of aboriginal communities as well as providing education to aboriginal health workers in collaboration with VACCHO. Drawing upon these existing relationships, an approach was made to the National Ageing Research Institute (NARI) to undertake the first phase of a project that would review the suitability of the KICA for use with Victorian Aboriginal communities in both regional and urban contexts. AAV funded this project and provided a key liaison role between NARI and the various Aboriginal communities and organisations involved in the study.

To date, the KICA has been validated for remote and rural areas of Australia including the Kimberley region of Western Australia and parts of the Northern Territory, whilst a version of the KICA-cog has been validated in Cape York and the Islands of Torres Strait in far north Queensland. The ‘Koori Growing Old Well’ study (Neuroscience Research Australia) is currently undertaking a survey of older Indigenous people in the urban Sydney region, and includes a modified form of the KICA. Preliminary data indicates its usefulness in urban regions. However the utility of the KICA in Victorian indigenous populations has not yet been demonstrated. As such, this 2-phase project will determine the acceptability, validity and reliability of the KICA for older Indigenous people in regional and urban Victoria (referred to herein as the KICA Regional Urban). Focus groups will discuss the KICA and advise an expert panel on appropriate changes for a Victorian setting. Those focus group consultations are detailed in this report.
1.1) **Objectives**

There are two phases in this project, each with a complimentary aim.

Phase 1: To adapt the components of the Kimberley Indigenous Cognitive Assessment (KICA) to reflect differences between its original use (remote areas) and proposed use (urban and regional Victoria). Focus group consultations in regional (Mildura) or urban (Carlton, Melbourne) Victoria were conducted to test face validity of the modified KICA.

Phase 2: To evaluate the validity of an adapted KICA in Indigenous people aged over 50 years, with any level of cognitive impairment and residing in Victoria.

This report details the findings of the focus group consultations for Phase 1 of this project.
2) Method

An expert panel adapted the original KICA (suitable for remote areas) for use in urban and region areas (modified KICA). Community representatives and health workers then reviewed the questions of the modified KICA to ensure that any changes were appropriate for administration in urban and regional Victorian communities. Two communities were selected as representative of Victorian – inner Melbourne to represent the urban regions, and Mildura to represent regional areas.

The format of testing was focus group interview. There were 2 focus groups (one urban and one regional) of 2 hours duration each. These consultations involved interviews with community representatives and allied health staff.

2.1) Interview topics

Themes explored were dementia, access to information and services, and most importantly, views on the proposed changes to the KICA for suitability in Victorian settings. A series of questions was developed to encourage discussion (see Attachment 1). Opinion on each question of the KICA was sought, with particular emphasis on questions regarding orientation and pictures.

2.2) Recruitment of participants

The managers of the Aboriginal health services at Mildura (Mildura Aboriginal Health Service, MAHS) and Melbourne (Aboriginal Community Elder Service, ACES) were responsible for identifying appropriate focus group members. Invitations to participate in the study were then circulated. An appropriate GP in both regions was invited but did not attend. Recruitment began a few weeks prior to the day of the focus group.

Two focus groups were conducted. Six attended the Melbourne focus group in September 2012, and eight attended the Mildura focus group in October 2012. One invitee canceled at short notice and was replaced.

2.3) Ethical requirements

Prior to recruitment of participants for the interviews, approval was obtained from the Monash University Ethics Committee.

Invitations were sent to participants via email prior to the interviews and at the beginning of the interview, participants were asked to sign a consent form and were also verbally informed that their names and contact details would remain confidential and any quotes used from the
interview would be presented anonymously. Participants were given a copy of the consent form.

2.4) Data recording and analysis

Methods used for recording data from the interviews included note taking and audio recording with permission from participants.

Each interview was transcribed. The transcripts were thematically analysed by evaluating the individual transcripts and drawing out major themes.

2.5) Profile of participants

Six community and health professionals attended the consultation at the Melbourne focus group, and eight attended at Mildura. The table below outlines the composition of the two groups:

<table>
<thead>
<tr>
<th>Focus group</th>
<th>Composition</th>
</tr>
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<tbody>
<tr>
<td>Melbourne (n=6)</td>
<td>1 Coordinator of an Aboriginal Aged Care Program</td>
</tr>
<tr>
<td></td>
<td>1 HACC Coordinator</td>
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<tr>
<td></td>
<td>1 Nurse Manager</td>
</tr>
<tr>
<td></td>
<td>1 Elder</td>
</tr>
<tr>
<td></td>
<td>1 Manager of an Aboriginal Aged care Service</td>
</tr>
<tr>
<td></td>
<td>1 Aboriginal Liaison Officer</td>
</tr>
<tr>
<td>Mildura (n=8)</td>
<td>1 HACC Worker</td>
</tr>
<tr>
<td></td>
<td>1 Counsellor</td>
</tr>
<tr>
<td></td>
<td>5 Health workers</td>
</tr>
<tr>
<td></td>
<td>1 Elder</td>
</tr>
</tbody>
</table>

The next section reports on qualitative data collected from consultations with the focus group communities.
3) Results

This section reports the focus group interviews from both the Melbourne and Mildura communities. For specific responses to the modified KICA questions, the information is presented in question order. All other information from the discussions is presented thematically.

3.1 Specific KICA Questions.

The focus groups were shown the instructional KICA DVD to complement their understanding of how the KICA is used. The focus groups were then asked to discuss each question from the modified KICA in sequential order.

**KICA. Q1 What month is it?**

The Melbourne group felt that month was appropriate for an urban community. They identified some potential issues concerning asking this question at the end of the month, for example:

‘if it is the 2nd of September and they say August, kind of right but it’s not.’

The Mildura group said it was reasonable for everybody to know what month it is in a regional setting, though one responded that ‘what day is it?’ would also be a good alternative.

**KICA. Q2 What season is it?**

A member from the Melbourne Group said that this question is at times difficult to administer. Their experience was that someone once responded with ‘it is wattle season’, as the person recognised six seasons. The group suggested the question ‘what year is it?’ as an alternative, though one person commented that maybe year was too broad. Another alternative offered was ‘what weather is it?’ Consensus was reached that asking either the season or weather would be sufficient, but without providing assistance by asking leading questions such as ‘is it summer or autumn?’

The Mildura group agreed that ‘what season is it?’ wouldn’t work in a regional setting. There was considerable discussion concerning what would be a suitable alternative. ‘Picking season’ was offered as a suggestion as most people would know when it is picking season. This idea had some support. Difficulties with picking season were identified though, as the season runs from January to March and there would be issues with what to say during winter time (cold time or
cooler time was suggested without firm opinion from the group). ‘Footy season’ was also suggested but with minimal support from the group. ‘What is the weather?’ was also suggested. Consensus was finally reached that ‘what is the season?’ is appropriate to begin with and if no answer is forthcoming then ‘is it hot weather or cold weather?’ would be an appropriate follow-up question.

**KICA. Q3 What is the name of this community or place?**

The Melbourne group re-iterated that ‘Place’ was an important part of the question

‘I think they all need to be there. I am [a particular community] elder living on [a particular place] land and all that information I know. You have young people who were taken away and who are trying to find their people, they might still have that in their heads at this age. Of course a lot of people aren’t found until they are old so they don’t know that they’ve had a community all these years and they are just finding them at the end of their lives.’

The Mildura group had no comments with this question.

**KICA. Q4, Q5, Q6  What do you call this? (Comb, Cup, Matches) What is it for? Rename objects.**

The Melbourne group said that matches are harder to buy, and questioned if lighter was a better alternative. They did agree that everyone would recognise matches. Another alternative suggested was water bottle instead of matches.

The Mildura group expressed no concerns with asking this question in a regional environment.

**KICA. Q7, Q8. Shut your eyes. Point to the ceiling and then the floor.**

The Melbourne group felt that ‘Close your eyes’ was better than ‘Shut your eyes’ for ease of understanding.

The Mildura group has no concerns with the question.

**KICA. Q9 Name in 1 minute as many different animals as you can.**

The Melbourne group felt that prompts would aid answering this question. They suggested the prompt of ‘name all your favourite animals’ would be appropriate.

The Mildura group had no concerns with ‘name as many animals as you can’.
KICA. Q10 Where did I put the cup, comb, matches?

Both Melbourne and Mildura groups had no concerns with this question

KICA. Q11 Name pictures.

The Melbourne group felt that either boomerang or guitar was fine in an urban setting. They also felt that emu was appropriate for an urban group so there was no need for the alternate horse picture. They suggested that kangaroo could be used instead of crocodile, or that kangaroo could be used first, with dog as a backup picture if needed. The group saw no problem with the bike or boy pictures.

The group did feel that billy could look like a handbag. One comment was,

“That would be quite acceptable [billy picture] up Mildura and the country. I can’t see any kids today [in Melbourne], not many at all would know what a decent billy can was.’

Another question was whether ‘fire’ was an acceptable answer when showing the billy picture. An alternative picture of a football was suggested, but did not gain much support. It was queried whether it was possible to just use fire as the picture, removing the billy entirely. Final consensus was that the picture needed to be modified, possibly by making the logs more prominent,

“You would need to make it visually ok, maybe more logs hanging up on the top of the fire or something.’

The Mildura group agreed that boomerang was appropriate for a regional area, and that it was not offensive to show it. They had no issues with boy, and that emu and horse were also fine to use. Crocodile and bicycle were not seen as problematic.

A variant picture of a billy on a tripod over larger logs was shown to the group, alongside the original picture shown originally to the Melbourne group, and an alternate billy viewed from a slightly more top-down angle. Consensus was that the preferred billy picture was the variant picture of the billy on a tripod over larger logs. However the Mildura group firmly believed that the tripod should be removed from the picture so that it was less confusing.

KICA. Q12 Draw crosses and circles.

Both Melbourne and Mildura groups expressed no concerns with the appropriateness of this question.

KICA. Q13, Q14 Recall pictures. Or identify pictures shown from sets of three.
The Melbourne group suggested that piano would be a better alternative to keyboard. They thought that keyboard could be a bit confusing and agreed that it could be mistaken for an ironing board. They felt that guitar was a good picture to show.

The Mildura group felt that drums would be appropriate to show, but felt the picture was a ‘bit busy’. They felt that piano was more recognisable than keyboard.

**KICA. Q15, Q16. Use bottle, cup and comb.**

Both Melbourne and Mildura groups expressed no concerns with the appropriateness of this question.

**3.2) Other related Questions.**

**DVD instructional video for using the KICA**

There was strong opinion from the Melbourne group that the DVD should be introduced by an aboriginal person, possible one that the community knows. As it currently is, they felt it was ‘White people telling black people what to do.’

One person commented that the assessment itself might be more informative if a cognitively impaired person was being assessed in the DVD instead.

The Mildura group identified no concerns with the DVD.

**Anything offensive or gender related (eg male interviewer screening female)?**

The Melbourne group saw nothing offensive with the material. They felt that it would be seen as a general knowledge questionnaire, that those with and without education could answer it, but that it wasn’t so simple as to offend. They also didn’t believe that there were any questions where a female might not want to answer if asked by a male interviewer.

The Mildura group mentioned that they don’t believe people like to be assessed [in general], but it [the KICA] is easy and they’ll do it. They felt there were no issues if a male interviewer was assessing a female. They noted that non-aboriginal people using the tool would need to use non-complicated language and considerable how they approach the person and family.

**Any of these questions too complicated for the urban aboriginal area?**
The Melbourne group felt that the questions were not too complicated. They felt that anyone who couldn’t manage it would say so.

‘They’d be telling you in their own way that they are getting tired.’

The Mildura group believed that an aboriginal who grew up rural should be able to answer all the KICA questions. They should be able to manage.

**Time to administer the KICA**

The Melbourne group estimated 45 minutes to administer the KICA, including lead-up time to get the interviewee at ease. Others guessed at least 30 minutes.

The Mildura group agreed that 30 minutes was sufficient to complete the test.

**Concept of dementia in aboriginal families**

The Melbourne group did not focus on this question.

The Mildura group felt that there was a stigma associated with dementia, and that those with dementia would

‘just hide themselves away. Or they might not even realise it. Or say they are just getting older. Or just think they are confused.’

**Next steps after screening / health services support**

The Melbourne group did not explore this question.

The Mildura group said that they lacked the service support needed once an assessment has been made. Their experience was that once you have got a referral to the doctor, you don’t know where that will go. They also felt that professional people needed to follow up with proper assessments and medications were unavailable.

‘we need someone to be able to do these things [a geriatrician], screening these people, there is a big need in the community, eventually start the medication or make the call to the ambulance.’

They believed there was a lack of specialised health professionals who can follow up after a GP visit. They stated that the only regional service in the area was only interested in late stage dementia. On possibly using Telehealth to video conference medical support, one person said

‘I cannot see a future in the Teleconference, not for Aboriginal people, not for the community.’
The group also expressed the importance of dementia screening in general.

‘It is really important because the aboriginal elders stay in their home longer and if they’re getting Dementia earlier they have not been assessed enough at home.’

**Training for health workers / allied health staff**

The Melbourne group did not reflect on this point.

The Mildura group felt that workers using the KICA could just go through it by themselves. ie self-train. However, they also said at other times that they needed more training. One person felt that

‘it [the instructional DVD] seems easy enough to watch but to do it correctly are two different things.’

More training was a re-occurring theme. The Mildura group felt that training up the nurses or HACC workers was important as they could go out and do the KICA assessments as part of their ADLs. As such, they could just insert the KICA questionnaire. The group suggested that everyone should be trained up to administer the KICA, though one suggestion was to limit it to only HACC and health workers, so as not to cause confusion in the community as to who you would see concerning screenings and early signs of dementia.

**Training for GPs**

The Mildura group firmly believed that more training for GPs was needed, particularly concerning taking more steps when they refer a client. This point was iterated a number of times during the focus group. Someone noted that when training opportunities had been organised previously (in another area, not Mildura), GP attendance was low.

**Wider Education of the KICA or dementia in aboriginal people**

The Melbourne group felt that the health workers would need to be able to educate the carers and families of people with dementia, or to have a system in place to provide this education.

‘Educating the educators, that’s where you’ve got to start’.

They considered it the role of community to provide knowledge about dementia to other community people.

‘So it needs to be community people. It needs to be our workers first, the people who are right at the front line doing the work, and the carers’.
The Mildura group felt that increasing public awareness was vital. They felt that community days were a perfect avenue to inform the community, especially if elders provided the information. Community and fun days were seen as a more acceptable way of providing information to the community. Using commercials on local TV was suggested. Concerning attendance, the area has had previous fun days with all the aboriginal elderly attending, provided it’s based around elderly activities.
4) **Summary of Key Findings**

The Melbourne and Mildura focus groups recommended a number of changes to the modified KICA.

**Recommended Changes to the KICA**

The focus groups identified a number of questions that may need further modification for suitability in Victoria.

Q2 ‘What season is it?’ would remain unchanged. If the response is inadequate then, ‘Is it hot or cold weather?’ or ‘What weather is it?’ should then be asked.

Q7 ‘Shut your eyes’ should be replaced with ‘Close your eyes’.

Q11 The billy picture should be replaced with a version with larger logs (see attachments). The other pictures are all appropriate.

Q13 The piano picture should replace with the keyboard picture (see attachments). The other new pictures were appropriate (guitar, drums).

The presenter in the instructional DVD should be an aboriginal person.

**Training and Support**

Health workers should be trained in administering the KICA. Providing more training for GPs on how to proceed with a referral is also vital, particularly in regional centres.

Regional areas in particular may need more support and services, and a clearer pathway on how to proceed after using the screening tool.

**Wider education of the community**

Community programs may help raise awareness of dementia in aboriginal people.

**4.1) Concluding remarks**

This report has outlined participants’ responses across both urban and regional Victoria regarding appropriate changes to the KICA for a Victorian setting. In particular, each question of the KICA was discussed. Findings from this consultation will be used by an expert working panel to inform the development of the KICA for a Victorian setting.
5) Attachments

Interview Protocol – Focus Group (Urban Melbourne, ACES)

(ACES) Use the word Kooris, Aboriginal people, or Aborigines. People tend to avoid the word ‘Indigenous’.

Acknowledgment: NARI, Monash University, and Alzheimer’s Australia Vic acknowledges and pays respects to the Traditional Owners of this land – Wurundjeri people of the Kulin Nation and pays respects to Elders Past and present.

Purpose: Focus group interviews will gather opinion on using a dementia screening tool (KICA) in Victoria. We want to know whether the Kimberly Indigenous Cognitive Assessment (KICA) questionnaire is suitable for use in Victorian communities. This focus group will talk about what changes are needed to use the KICA in an urban Victorian area.

Participants: Focus group interviews will be conducted with selected members of staff at ACES, and possible with some community members (such as elders).

Time: Total focus group time: 1.5 hr – 2 hr (including 10 min break)

Audio-taping and Confidentiality: As discussed, we will be tape recording the discussion, because we don’t want to miss any of your comments. The transcripts will be subject to content analysis – that is, they will be examined for their responses to the discussion points listed below. A summary of the responses to the discussion points listed below will be provided to the Expert Working Panel. Individual responses will be de-identified and any reference to people by name will be deleted. Some anonymous direct quotes may be used to illustrate the points made by the focus group.

Before we start, we’d like to show you a video on how to use the KICA. Show video (12 mins)

Discussion Points: You will be asked to comment on the following:

1. The initial question and general questions about the KICA:
   - Today we are here to talk about the KICA questionnaire. What comes to mind when you look at the questionnaire? What are your opinions about the questions? Are the questions relevant to aboriginal Victorians, especially for urban areas like Melbourne?

2. Particular questions about specific questions in the KICA (Most important). With slides
   - Is it reasonable to expect an urban Melbourne aborigine to know the month?
   - There is a concern that a task ‘naming all animals’ is too easy (we used to ask ‘name animals you hunt’). Which one is more appropriate for urban areas? How much easier is naming all animals?
• What about the pictures? Would an elderly urban aborigine have seen that animal before? Does ‘billy’ look like a handbag? Is dog and horse more appropriate than emu and crocodile?
• We used to use boomerang but thought it may be too stereotypical. Would it offend some?
• What about the guitar, drums and keyboard? Would an elderly aborigine have seen this before? We thought the keyboard looked like an ironing board? What do you think?

3. Using the KICA
• Are these questions too complicated for an urban aboriginal area? What questions do you think would be the most difficult?
• What issues may arise when using this questionnaire?
• How would the questionnaire be received?
• Are there questions that a female may be reluctant to answer if a male interviewer was using the KICA? Or vice versa?
• How long do you think it would take to finish the questionnaire, and could people manage? Could it be used equally well for those with and without an education?

**Interview Protocol – Focus Group (Rural Mildura, MAHS)**

(ACES) Use the word Aboriginal people, People tend to avoid the word ‘Indigenous’.

**Acknowledgment:** NARI, Monash University, and Alzheimer’s Australia Vic acknowledges and pays respects to the Traditional Owners of this land and pays respects to Elders Past and present.

**Purpose:** Focus group interviews will gather opinion on using a dementia screening tool (KICA) in Victoria. We want to know whether the Kimberly Indigenous Cognitive Assessment (KICA) questionnaire is suitable for use in Victorian communities. This focus group will talk about what changes are needed to use the KICA in a rural Victorian area. We would also like to hear your views on more general questions about cognition/memory problems in aboriginal people

**Participants:** Focus group interviews will be conducted with selected health specialists, and community members.

**Time:** Total focus group time: 1.5 hr – 2 hr (including 10 min break)

**Audio-taping and Confidentiality:** As discussed, we will be tape recording the discussion, because we don’t want to miss any of your comments. The transcripts will be subject to content analysis – that is, they will be examined for their responses to the discussion points listed below. A summary of the responses to the discussion points listed below will be provided to the Expert Working Panel. Individual responses will be de-identified and any reference to people by name will be deleted. Some anonymous direct quotes may be used to illustrate the points made by the focus group.
Discussion Points: You will be asked to comment on the following:

1. General questions about the KICA:
Before we start, we’d like to show you a video on how to use the KICA. Show video (12 mins)

- What comes to mind when you look at the questionnaire? What are your opinions about the questions? Are the questions relevant to aboriginal Victorians, especially for rural areas like Mildura?

2. Particular questions about specific questions in the KICA (Most important).
With slides

- Is it reasonable to expect an older Aboriginal person from rural areas to know the month?

- In the original KICA we used the term “all the animals people hunt” and this was modified to “naming all animals”. There is a concern that a task ‘naming all animals’ is too easy. Which one is more appropriate for rural areas? How much easier is naming all animals? The modified version is: I am going to time you for one minute. In that minute, I would like you to tell me the names of as many different animals as you can. We’ll see how many different animals you can name in one minute. Are you ready?

- What about the pictures? Would an elderly person from rural areas have seen that animal before? Does ‘billy’ look like a handbag? Here are a few billy pictures, which one is best? Is dog and horse more appropriate than emu and crocodile?

- We used to use boomerang but thought it may be too stereotypical. Would it offend some?

- What about the guitar, drums and keyboard/piano? Would an older Aboriginal person have seen this before? We thought the keyboard looked like an ironing board? What do you think? What’s better, piano or keyboard?

3. Using the KICA
- Are these questions too complicated for an older Aboriginal person grown up in rural areas? What questions do you think would be the most difficult?
- What issues may arise when using this questionnaire?
- How would the questionnaire be received?
- Are there questions that a female may be reluctant to answer if a male interviewer was using the KICA? Or vice versa?
- How long do you think it would take to finish the questionnaire, and could people manage? Could it be used equally well for those with and without an education?
- What training would be useful to you?

4. General questions about aboriginal people and dementia:
Now that we have talked about the KICA questionnaire, we’d like to talk more generally about aboriginal people and dementia…

- What is currently missing in being able to detect dementia in aboriginal people?
- Are there any things that we need to be aware of when assessing dementia in aboriginal people?
- What should non aboriginal health professionals know before they work with someone with dementia or their families?
• What can we do to better assess dementia/memory problems/cognitive impairment in Aboriginal people with dementia?
• Tell us about how memory problems/cognitive problems/dementia are assessed now? What works? What doesn’t work? (this may lead into a discussion about service providers/access)

5. (Optional, if focus group or John Price wants to talk about it) Service provision
• Why isn’t it working now? How should it work? Who should be involved to improve it?