
Final Report
February 2013

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This project was funded by Alzheimer’s Australia Vic

UNDERSTAND ALZHEIMER’S
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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).
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). This adapted scale is called the KICA Regional Urban. Focus group consultations in regional (Mildura) and urban (Carlton, Melbourne) Victoria were conducted to test face validity of the KICA Regional Urban. A Delphi process amongst experts was used to evaluate its content validity.

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 methodology and findings of Phase 1 of this project.
2) Method

2.1 Ethics
Approval to conduct the project was obtained from the Monash University Ethics Committee.

2.2 Key Expert Panel
An expert panel adapted the original KICA (suitable for remote areas) for use in urban and regional areas (KICA Regional Urban). 12 experts were on the panel and included: a geriatrician, a clinical director of older health services, a clinical neuropsychologist, two psychologists, a professor of geriatric medicine, and a number of research fellows. Most panel experts were strongly familiar with indigenous cognitive assessment. State / Territory division of the panel was: 2 from West Australia, 2 from Queensland, 2 from New South Wales, 4 from Victoria, and 2 from South Australia.

The expert panel conferred on 2 occasions, one before the focus groups and one after. By consensus, the expert panel identified any changes that should be made to the original KICA to adapt it for Victorian urban and regional settings. A smaller 4 person work group then refined the modified KICA further in preparation for the focus groups.

After the focus group consultations, the key expert panel met a final time to discuss the recommendations of the focus groups. Consensus from the expert panel was achieved for all items in the KICA Regional Urban.

2.3 Focus Groups
Community representatives and health workers reviewed the questions of the KICA Regional Urban to ensure that any changes were appropriate for administration in urban and regional Victorian communities. Two communities were selected as representative of Victoria, with inner Melbourne representing the urban regions, and Mildura representing the regional areas.

The format of testing was via focus group interview. There were 2 focus groups of 2 hours duration each. These consultations involved interviews with 6 individuals in Melbourne (September 2012) and 8 in Mildura (October 2012). Focus group members included coordinators of aboriginal health services, nurse managers, counselors, health workers and elders). The focus groups were audio taped and all conversations were transcribed.

Themes explored included dementia in general, access to information and services, and most importantly, the views on the proposed changes to the KICA for suitability in Victorian settings. Opinion on each question of the KICA was sought, with particular emphasis on questions regarding orientation and pictures.
2.4 Delphi Process

After consulting the focus groups and consensus from the key expert panel on the changes made to the KICA Regional Urban, the questionnaire was then sent to a wider range of experts to determine content validity of the new scale. Utilising a Delphi process, experts rated the importance of each item on the KICA Regional Urban and commented on clarity and wording of each question. 15 Delphi questionnaires were included in the final sample size. Content validity of the KICA Regional Urban was assessed using content validity ratios. Lawshe (1975) critical cut-off scores were used at p < 0.05, one tailed.
3) Results

This section reports the key expert panel recommendations, focus group interviews, and Delphi process for the project.

Key Expert Panel

Key experts identified a number of issues with using the original KICA in regional and urban settings. It was agreed that one KICA questionnaire would be sufficient to cover both regional and urban areas, with the original KICA left unmodified for remote regions. Only a few KICA questions were identified as needing changing, and that the focus groups were best placed to recommend the direction of changes. A modified KICA Regional Urban was drafted from the recommendations of the key expert panel and on previous changes made by the NSW group who had experience using the original KICA in urban settings.

Focus Group

The Melbourne and Mildura focus groups recommended a number of changes to the KICA Regional Urban [see Attachment: KICA -Phase1- Report of focus group consultations (Final) with AAV Additional]. In particular they recommended that some of the pictures needed improvement. Also, some questions still needed to be refined. They also suggested that the pre-existing training DVD should be updated to include an aboriginal presenter.

The focus groups also highlighted that health workers needed more training to administer the KICA, and that a clearer pathway on how to proceed after using the screening tool was vital.

Delphi Process

15 questionnaires were sent to experts in the field to content validate the KICA Regional Urban. A Delphi process was used to determine the importance of each item on the adapted KICA (from ‘Not at all important’, ‘Slightly important’, ‘Moderately important’, ‘Very important’, ‘Absolutely important’). Each question of the KICA Regional Urban was evaluated, with two additional questions establishing the importance of adopting new ‘Billy’ and ‘Guitar / Drums / Piano’ picture sets. Table 1 collates the results.
Table 1: Delphi process questionnaire results

<table>
<thead>
<tr>
<th>Question</th>
<th>Not at all Important</th>
<th>Slightly Important</th>
<th>Moderately Important</th>
<th>Very Important</th>
<th>Absolutely essential</th>
<th>Content Validity Ratio (CVR)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Q1. What month is it?</td>
<td>1</td>
<td>3</td>
<td>4</td>
<td>7</td>
<td>0.467</td>
<td></td>
</tr>
<tr>
<td>Q2. What season is it?</td>
<td></td>
<td></td>
<td>4</td>
<td>6</td>
<td>5</td>
<td>0.467</td>
</tr>
<tr>
<td>Q3. What is the name of this community or place?</td>
<td></td>
<td></td>
<td></td>
<td>4</td>
<td>11</td>
<td>1</td>
</tr>
<tr>
<td>Q4. What do you call this? Comb, Cup, Matches</td>
<td>1</td>
<td>4</td>
<td>10</td>
<td>0.867</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Q5. What is this one for? Comb, Cup, Matches</td>
<td>1</td>
<td>4</td>
<td>10</td>
<td>0.867</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Q6. Tell me those three things I showed you. Comb, Cup, Matches</td>
<td>1</td>
<td>1</td>
<td>4</td>
<td>9</td>
<td>0.733</td>
<td></td>
</tr>
<tr>
<td>Q7. I’d like you to do some things for me: SHUT YOUR EYES</td>
<td>2</td>
<td>5</td>
<td>8</td>
<td>0.733</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Q8. (if indoors) First point to the ceiling and then the floor. OR (if outdoors) First point to the sky and then the ground.</td>
<td></td>
<td></td>
<td>7</td>
<td>8</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Q9. 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 that you can. We’ll see how many different animal you can name in one minute. Are you ready? (repeat if necessary)</td>
<td></td>
<td></td>
<td>5</td>
<td>10</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Q10. Where did I put the comb? Where did I put the cup? Where did I put the matches?</td>
<td>1</td>
<td>3</td>
<td>11</td>
<td>0.867</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Q11. I’ll show you some pictures. You tell me what they are. Remember the words for later on.</td>
<td>1</td>
<td>1</td>
<td>13</td>
<td>0.867</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**INTERVIEWER NOTE:** Point to each picture and ask ‘What is this?’ (Show boomerang as an EXAMPLE by stating, ‘This is for practice. What is this?’ (do not count in score);

Then **TEST on:** boy, emu, bill/fire, crocodile,
& bicycle. If the person has poor vision, name each picture for them to remember. Dog and Horse can be used as alternative pictures for emu and crocodile if appropriate. Boomerang can be replaced with guitar when appropriate.

<table>
<thead>
<tr>
<th>Q12. Look at this. Now you copy it.</th>
<th>1</th>
<th>2</th>
<th>5</th>
<th>7</th>
<th>0.6</th>
</tr>
</thead>
<tbody>
<tr>
<td>INTERVIEWER NOTE: Show alternating crosses and circles (XOXO...) (If poor vision, omit this question)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Q13. Do you remember those pictures I showed you before? What were those pictures? Tell me.</th>
<th>3</th>
<th>12</th>
<th>1</th>
</tr>
</thead>
<tbody>
<tr>
<td>INTERVIEWER NOTE: Show boomerang (or guitar if used previous) as a prompt (do not count in score), score TEST items only.</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Q14. Which one did I show you before?</th>
<th>2</th>
<th>13</th>
<th>1</th>
</tr>
</thead>
<tbody>
<tr>
<td>INTERVIEWER NOTE: Choice of three pictures (recognition); use boomerang (or guitar if used previous) as example – point to boomerang (out of 3) and indicate this was shown before (do not count in score); administer all 5 TEST cards. (If the person has poor vision, tell them the 3 options that they can choose from. For example, &quot;Which one did I tell you to remember: boomerang... bush tomahawk... clapping stick.&quot;)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Q15. (Give the bottle and cup to the person). Open this bottle and pour water into this cup. (Use screw-top bottle; not closed too tightly).</th>
<th>2</th>
<th>4</th>
<th>8</th>
<th>0.6</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Q16. (Give the comb to the person). Show me how to use this comb.</th>
<th>1</th>
<th>7</th>
<th>7</th>
<th>0.867</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>ADD Q1. Please rate the appropriateness of including the following pictures for urban / regional regions: Replacing Billy/fire picture with new version (new version shown). See Question 11.</th>
<th>1</th>
<th>1</th>
<th>3</th>
<th>10</th>
<th>0.733</th>
</tr>
</thead>
</table>

| ADD Q2. Including the following pictures as alternatives in urban/regional regions. See Question 14. Guitar / Drums / Piano | 2 | 1 | 5 | 7 | 0.6 |
Content Validity was computed using the Content Validity Ratio for each item. The formula used was:

\[
\text{CVR} = \frac{n_e - N/2}{N/2}
\]

where \( n_e \) = number of experts rating the item ‘Very important’ or ‘Absolutely Essential’, and \( N \) = number of experts rating the item. Lawshe’s calculated cut-offs suggest that for \( N=15 \), \( \text{CVR} > 0.425 \) is sufficient content validity at \( p < 0.05 \) one tailed significance.

All items of the KICA Regional Urban scored higher than the CVR cut-off, with Q1 and Q2 having the lowest content validity scores. Expert comments from the Delphi questionnaire concerning Q1 (‘What month is it?’) questioned how many days either side of the month would still be considered correct. There was also considerable feedback for Q2 (‘What season is it?) in regards to what constituted a correct answer, and how would it be operationalised. Further comments made by the field experts for all questions in the Delphi questionnaire are in Attachment - KICA Delphi Questionnaire - Final scores and comments.
4) Summary of Key Findings

The expert panel, focus groups, and delphi process suggested a number of changes to the original KICA would be needed to develop a KICA tool suitable for regional and urban Victoria. Called the KICA Regional Urban (see Attachment - KICA-COG REGIONAL URBAN: COGNITIVE ASSESSMENT), these changes include (major changes only):

- Changing Q1 from ‘Is this week pension/pay week?’ to ‘What month is it?’
- Changing Q2 from ‘What time of year is it now?’ to ‘What season is it now?’
- Changing Q9 from ‘Tell me the names of all the animals that people hunt’ To ‘Tell me the names of as many animals as you can. We’ll see how many animals you can name in one minute. Ready?’
- Changing the Billy picture in Q11.
- Adding a Guitar picture as an alternative example picture in Q11. Adding Guitar/Drums/Piano as an example set of pictures in Q13.

A number of minor changes were also made, such as minor word revisions and clearer instructions, etc.

Finally the focus groups identified that training and support was necessary (especially in regional areas). Health workers should be trained in administering the KICA with a clear pathway on how to proceed after using the KICA screening tool. Finally the focus groups recommended that the presenter in the instructional DVD should be an aboriginal person.

4.1 Concluding remarks

This report outlined the development of the cognitive component of the KICA tool for use in Regional and Urban Victoria. Called the KICA Regional Urban, face and content validity was tested using expert working panels, focus groups, and Delphi processes. Though developed for usage in Victoria, the tool should have applicability Australia wide in regional and urban communities. The original KICA would then be an appropriate screening tool primarily for remote settings.
5) Acknowledgements

5.1 Key Expert Panel Members:
Leon Flicker, Stephen Gibson, Heather Jensen, Melissa Lindeman, Dina LoGiudice, Holly Mack, John Price, Kate Radford, Sarah Russell, Steven Savvas, Kate Smith, Edward Strivens.

5.2 Focus Groups
Thank you to all the focus group members who participated and provided feedback. Special thanks to Lauris McCormack and Naomi Aves (Mildura Aboriginal Health Service), and Deborah Deacon (Aboriginal Community Elders Service) for hosting and organizing the focus group sessions.

5.3 Delphi Process
Additional Experts: David Atkinson, Catherine Brown, Lucy Comerford, Marianne Cummins, Emily Hindman, Mary Ingrames, Cecilia Minogue, Linda Skeaf.
6) **Attachments (separate documents)**

- KICA Regional Urban (Cognitive section only)
- KICA Regional Urban Pictures - updated
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- KICA Delphi Questionnaire - Scores and comments
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