First Steering Committee Meeting

The first steering committee meeting for the Indigenous Dementia Services Study was held on the 7th of August in Broome.

The meeting brought together community representatives, carers for people with dementia, workers and aged care service providers from across the Kimberley.

There were several people who couldn’t make the first meeting and a full list of everyone involved in the steering committee is on page 4.

The first meeting was attended by the following people...

- Michelle Skinner, Chairwoman of Looma Community;
- Janet Oobagooma, Heather and Ruth Umbagai, carers from Mowanum Community;
- Dr Nicolette DeZoete a doctor based in Balgo with the Kimberley Aboriginal Medical Services Council Inc (who also did the doctors reports for the older people in Balgo during the prevalence study in 2006);
- Maxine Nixon from the Kimberley Aged & Community Services.

The meeting went for half a day and we all enjoyed a wonderful morning tea of locally prepared sushi by Tadami Tanaka.

A snapshot of what was discussed is given on page 4.

Fast Facts on Indigenous Dementia

Did you know...

- In Australia 2.5% of people over 45 years have dementia
- In the Kimberley, 12.5% of Aboriginal people over 45 years were estimated to have dementia
- That is 5 times more than the National average
- If you are male or a smoker, have had a stroke, epilepsy or a head injury - you are more at risk of getting dementia as you get older
Background

Validating the KICA-cog

In 2003 to 2004 the Kimberley Indigenous Cognitive Assessment tool (KICA) was developed and the cognitive section of the KICA (KICA-Cog) was validated.

Before the KICA there were no appropriate tests to assess dementia with Aboriginal people. Because of this, the number of Aboriginal people with dementia was largely unknown, and many people missed out on treatments.

Working with several local communities and Indigenous health and aged care organisations, the KICA was developed.

First, existing dementia tests were looked at. Then a final list of questions about memory problems were agreed upon by linguists, health workers, elders and other clinicians. These were then adapted for use in the Kimberley by using easily recognized pictures (see Box 1), objects (e.g., comb, pannikin) and activities. To make sure the questions were clear in their meaning, they were also translated into Walmajarri language, and then translated back into English.

The KICA was then trialed with a group of 70 older Aboriginal people in the Kimberley. The KICA-Cog was found to be a valid test of dementia in the region. The KICA-Cog was then trialed in the Northern Territory, and was again found to be a valid assessment tool. A short version of the KICA is to soon be validated in Northern Queensland.

The Prevalence of Dementia

Using the KICA, a second study was conducted over 2005 to 2006 to find out how common dementia is amongst Aboriginal people in the Kimberley. This study also aimed to find out the risk factors for dementia.

363 older Aboriginal people and their families from the town of Derby, and the communities of Mowanjum, Looma, One Arm Point, Junjuwa, Warmun and Balgo took part in the study.

Dementia was found to be very common, with 12.5% of people over the age of 45 years having the condition. It was most striking and concerning that so many young people in the 45 to 59 year age range had dementia. The risk factors for dementia were found to include; being male, older or a current smoker, and having a history of a stroke, head injury or epilepsy.

These findings suggest that dementia may be linked to other health problems, and that the more health problems a person has, the greater their risk of developing dementia as they get older. These findings also suggest that more support and training is needed for people caring for family with dementia. Whilst further raising community awareness of dementia risk factors may assist in reducing the number of people developing the condition.
2003 to 2004

Developing the KICA

This project was completed with the assistance of many community members and organisations. Sincere thanks are extended to the Kimberley Aged and Community Services, Kimberley Aboriginal Medical Services Council, Kimberley Interpreting Service, North West Mental Health Services and Kimberley Language Resource Centre, Kimberley residential aged care facilities, and Naidigurra Cultural Health Service.

Local community councils including One Arm Point, Lombadina, Djarindjin, Beagle Bay, Bidyadanga, Balgo, Malan, Billden, Kalumburu, Kanumarra, Derby, Mowanjum, Junjuwa, Looma, Jarlmadangah, Warmun and Wyndham.

Grateful assistance is acknowledged from local Aboriginal health workers and interpreters, Home Community Care providers, Pat Lowe and Eirly Richards. Sincere thanks to the older people and their families who generously gave their time to answer questions and give valuable feedback.

The study was funded by a Healthy Ageing grant with the National Health and Medical Research Council.

2005 to 2006

Dementia Prevalence Study

Acknowledgment is given for the guidance and support of community members, councils and traditional owners of One Arm Point, Balgo, Derby, Junjuwa, Looma, Mowanjum and Warmun. Also recognised is the assistance and support provided by staff from aged care and health services across the region.

The hard work of the community based workers in this project and all interpreters is also recognised and greatly appreciated. This includes; Yingiy Ngay Oscar, Judith Brooking, Darryl Isaac, Edward Mungulu, Gabriella Dolby, Brenda Green, Wayne Milgin, Kevin Nungatcha, Charlene Carrington, Laurie Churnside, Lorna Hudson, Ronald Mosquito and Melissa Sunfly, Ruth Nagomarra, Michelle Skinner, Henry AhChoo, Shirley Pardo, Kimber Peters, Eileen Brey, Janet Obhogoona and Heather Umbagai.

This study was also funded by a Healthy Ageing grant with the National Health and Medical Research Council.
The Current Study

Developing and Trialing Indigenous Specific Dementia Services

The current study is focused on finding out what the unmet needs of people with dementia and their family carers are in rural and remote Indigenous communities, and together with communities and service providers, trialing new approaches to care. The study will first involve interviewing service providers, workers and family carers. This information will then go to focus groups in several communities, so the communities can determine the best approaches to care for older people with dementia in their community. The study team will then work with services and communities to trial these new approaches and to evaluate if improvements are seen in peoples health and well being.

It is acknowledged that ‘one size won’t fit all’, and that several different models of care will need to be developed and trialed as decided by each community.

This third stage is funded by a NH&NMRC grant to run in the Kimberley over 2007 to 2008, and in the Pilbara over 2008 to 2009. The study is focused on the Kimberley at present, and consultation will begin in the Pilbara early next year.

It is hoped that the communities that were involved in the 2005-2006 prevalence study, will again take part in the current study, pending approval from each community council.

What the Steering Committee Discussed

The steering committee currently has representatives from the following organisations and communities; the Kimberley Aboriginal Medical Services Council, Kimberley Aged and Community Services, Commonwealth Department of Health and Aging, Indigenous Coordination Centre, North West Mental Health Service, Nindillingarri Cultural Health Service, Mowanjum, Looma and Balgo Communities.

The steering committee decided it was important to involve more men, and that representatives could be sought from the pensioner units in Mowanjum and Warmun and from the Balgo and Halls Creek areas.

The steering committee felt that representatives from all 7 communities involved in the earlier study was not necessary (too big a group), but that information must be fed back to everyone.

The steering committee agreed that their role was to guide and advise the current study, and to help pass information on to services and communities.

The steering committee approved the interview process and questions to be used with service providers and community based workers. These were role played.

It was suggested that Police and Wardens, and Arts Centre staff may also be good to interview as they are often involved with older people.

The steering committee decided that face to face meetings in Broome were best, and that the next meeting should be in early November. Permission was given for a group photo to be in this newsletter.

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Who’s working on this project?

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