

# One size fits all? The national bowel cancer screening experience in one remote Aboriginal community

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Following a short stint as a nurse and midwife, Kay Coppa undertook postgraduate studies in both primary health care and public health. She has worked in a variety of health, hospital and community settings for both government and NGOs.

After working in Newcastle and Sydney for 20 years and the kids leaving home, Kay decided the time was right to build on her experience and move to remote Australia. She took a new position as Public Health Coordinator in north-east Arnhem and it's her experiences in Milingimbi that prompted this paper.

Kay's presentation has taken in her experiences where she quickly learned that the best work could be done 'accidentally' by walking the community, singing in the choir and hunting with the local women. And definitely more fun! While she's always had a passion for community engagement, in north-east Arnhem communities this means leaving the desk behind, talking under trees and hanging out with the locals.

One of the most rewarding aspects in Kay's role is working alongside the Aboriginal community workers who play a pivotal role in cultural brokering to improve their people's access to appropriate health services. Kay's presentation is possible due to the generous knowledge-sharing of the Milingimbi Aboriginal community workers.

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## Background

Bowel cancer is the third most common cancer for Indigenous Australians, after lung and breast cancer in women, and lung and prostate cancer in men. It accounts for around 10% of all cancers. It is rarely noted as a significant health issue for Indigenous people with incidence and deaths from bowel cancer much lower than in the non-Indigenous population. However, under-ascertainment of Indigenous status in cancer registries and other factors may mean Indigenous cancers are significantly underestimated.<sup>1</sup>

In 2002 a pilot program for bowel cancer screening commenced in Australia in Melbourne, Adelaide and Mackay. The Final Evaluation Report of the Bowel Cancer Screening Pilot Program showed that a national bowel cancer screening program would be feasible, acceptable and cost effective in Australia. After the pilot program completed in 2004, screening was extended to all people who were turning 50, 55 or 65 years. In 2008 the program was suspended due to a problem with the sampling kits giving false negative results when exposed to too much heat. A new kit was developed and the program restarted in 2009.<sup>2</sup>

Milingimbi is an Aboriginal community on an island in the Arafura Sea, 400km east of Darwin and approx 200km west of Nhulunbuy. It is only ½ km off the mainland and part of the Crocodile Island Group in the northeast Arnhem region of the Northern Territory. It has a tropical climate. There are approximately 1500 Yolngu people resident on Milingimbi.

Prior to moving to the NT, I worked for 5 years in the prevention area of the NSW Cancer Council. I have since been working in a regional public health role and live in Milingimbi. I work alongside the Aboriginal Community Workers and together we form the public health and community team. The Community Worker role is relatively new in the NT and focuses on community liaison, cultural brokering and health promotion. The Community Workers enrich the relevance and contribute to the effectiveness of the health service.

Chronic conditions such as diabetes, renal disease, rheumatic heart disease, pulmonary disease and heart disease pose the biggest threat to the health and wellbeing of Milingimbi residents. Many children have skin infections and growth faltering. Significant issues that continue to contribute to ill health are smoking, poor housing and overcrowding. In East Arnhem the adult smoking prevalence is 76%.

## Our problem

In June 2010 about 30 very large packages arrived at the Milingimbi Health Centre, addressed to people in the community, care of the Health Centre. There is a post office in Milingimbi but no postal delivery service. The opening hours are intermittent and unpredictable. No one in the Health Centre knew what the packages were

when they arrived so they just stayed in boxes and kept getting moved out of the way. Finally a staff member gave one of the Aboriginal Community Workers one of the packages which was addressed to them so we could see what they were.

No one at the Health Centre had seen a bowel cancer screening kit before. It contained lots of components and lengthy and complicated instructions written in English. The boxes of packages created a dilemma for the Health Centre. What do we do with them? Where do we put them (in a very old and crowded building)? Should we wait until these people next come to the Health Centre? Are we supposed to deliver them all (bearing in mind there's no postie)? Should we just throw them out or perhaps ignore them a bit longer and keep moving them out of the way? I'm told that over 90% of the kits sent to remote NT communities were destroyed and not used.

## Our plan

After several weeks of moving the boxes around, the Aboriginal Community Workers and I decided it was a good opportunity for them to learn about bowel cancer and screening, and then they could deliver the kits and explain to people how to use them. We talked about:

- What a cell is and how bad cells can spread
- What screening is
- Why we screen for some things and not others
- Why there is screening for bowel cancer
- How to use the kit

## Our findings

The Community Workers went out into the community to the various camps to deliver and explain the kits. Gordon the male Community Worker spoke with the men and Elizabeth with the women. When they returned, they'd only delivered a few each and had found it very difficult to explain. People struggled to understand:

- Why they needed to do this
- How important it was in the scheme of things (there are many health problems and imperatives)
- How to do it
- What cancer is

Perceptions of what cancer is:

- It's related to a body part like the breast or brain
- It's mysterious
- It's connected to women's business (pap smear)
- It's when people go into Darwin and don't come back
- It's when people don't get better (you don't keep living when you have cancer)

The next day, a man arrived at the front of the health centre with his specimen causing quite a scene. The Community Worker explained that the specimen didn't need to come to the health centre and reiterated the postal process. Apparently, this person then took the specimen to the post office but was very quickly told to return to the health centre.

Following this experience and not giving up easily, the Community Workers decided to go back out into the community and provide more detail about the collection process. However despite our efforts, we don't believe any of the screening kit recipients successfully participated in the screening program.

During this time, there had been a lot of interest in the kits with broad discussion generated. The Community Workers had talked with many groups of people throughout the community and collected important information, including barriers to participation and suggestions on how to improve the process. Overall people felt that the whole thing wasn't a good idea and didn't feel inclined to participate.

## Feedback

Feedback on the **collection** process included:

- Written instructions were very long and much too complicated. Most people have poor literacy and English as their 3<sup>rd</sup> or 4<sup>th</sup> language.
- Not many houses have fridges and specimens have to be kept cool.
- People won't put faeces in their fridges. There has been a lot of successful community education around germ theory, the faecal/oral route of disease transmission, the importance of washing hands, etc.
- Men and women can't see or know about each other's private business which includes going to the toilet. They definitely can't see each others' faeces specimens.
- Houses are very crowded and not all houses have functioning toilets. A housing audit we conducted in August 2010 indicated that 28% of the Indigenous houses didn't have hot water and/or a toilet that was working at that time.
- The accompanying paperwork and specimen labels didn't provide enough space for their very long names are large handwriting.

Feedback on the **postal** process included:

- It is not possible to keep the specimens cool throughout the postal process.
- Mail only goes into Darwin on the plane 3 times a week.
- The mail bag sits at the airport and on the tarmac in the hot mid afternoon sun before being loaded on the plane.

**Recommendations for future rollouts** include:

- The specimens should be returned to the health centre instead of the postal system. This would build on existing practices and be consistent with collection of other samples and specimens for testing.
- Health centre staff could complete the accompanying paperwork, ensuring correct name spelling and identification.
- The specimens should be sent by the health centre (in cool storage containers) to a local pathology provider.
- Consideration of issues related to access and participation by Indigenous Australians.

If these suggestions were implemented, there could be:

- Increased compliance/participation
- Increased accuracy of documentation/identification
- Improved quality assurance—specimens stay cool until tested

- Increased efficiency by removing unnecessary steps

### The NT program

Due to the low participation rate in the screening program in remote and regional areas across Australia and particularly in the NT, consultations were held in many remote communities. As a result, the NT program began in late 2010 with an alternative screening procedure.

The plan is to allow and encourage opportunistic screening as people over 45 years present at a health centre for any reason. People over 45 years could also be invited to participate. A recall system for checkups and disease management is already part of the NT primary health care system. Bowel cancer screening kits will be kept on hand at health services and can be re-ordered from normal supply systems. Information on the bowel cancer screening process is now available in paper and audio form, with the content and format developed by consultation with communities across the NT.

### Conclusion

Significant socio-cultural, geographic and language barriers prevented Indigenous people in Milingimbi from participation in the national bowel cancer screening program. Our experience is consistent with the findings of a recently published literature review indicating that the population-based approach to implementing bowel cancer screening unintentionally excludes vulnerable minorities, particularly Indigenous people; potentially further widening the gap in cancer outcomes. The review recommends program modifications to facilitate access and participation by Indigenous Australians.<sup>3</sup> It would appear that the NT program is currently implementing this recommendation.

### References

- 1 Australian Institute of Health and Welfare: The Health and Welfare of Australia's Aboriginal and Torres Strait Islander Peoples, 2008. Edited by Pink B, Albon P: AIHW/ABS; 2008.
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- 3 Christou A, Katzenellenbogen J, Thompson SC. Australia's national bowel cancer screening program: does it work for Indigenous Australians? BMC Public Health [Internet]. 2010 [cited 2011 Jan 24]; 10(373). Available from URL: <http://www.biomedcentral.com/1471-2458/10/373>