

An analysis of resources for Indigenous women in NSW about cervical screening

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Introduction

There is international consensus that screening of the cervix every two years can prevent over 90%¹ of cases of squamous cancer of the cervix. However, Aboriginal* women have lower rates of participation in cervical screening than non-Aboriginal women.² The incidence for cervical cancer in Aboriginal women ranges from 28 to 52 per 100,000,² some two to five times higher than that for non-Aboriginal women.³ Aboriginal women have a six to ten fold greater mortality from cervical cancer compared with non-Aboriginal women.³

In 1996, there were 1507 Aboriginal or Torres Strait Islander women, aged between 15 and 75 years, living in Central Sydney.⁴ Central Sydney has a high age standardised incidence of cervical cancer of 13.2 per 100,000.⁵ Only 53.3% of women are screened biennially.⁵ This rate is well below the target of 75% of all women at risk to be screened every two years.¹

The National Cervical Screening Program (NCSP) acknowledges that Aboriginal and Torres Strait Islander women are to be targeted in its recruitment initiatives.¹ The Situational Analysis of the NSW Cervical Screening Program suggests

three major cultural barriers specifically discouraging their participation in cervical screening, namely:

- that screening is 'women's business',
- that many associate cervical cancer with sexually transmitted diseases which adds to the stigma of screening and potentially, ostracism for those with abnormal smears, and
- that most service providers performing screening are male.¹

In an effort to improve population-based screening, written brochures have been used to support public health messages,⁶ although not always achieving behaviour change.⁶ Readability and content of printed resources must be appropriate to the audience targeted.⁷ Before the launch of the NCSP, there was little consistency in the content of brochures about cervical screening.⁸ In the case of resources for Aboriginal women, the purpose and reasons for cervical screening must be clear, with reassurance that smears are not tests for sexually transmitted diseases (STDs) nor a means of contact tracing.⁹ We conducted this study to describe the content, readability and acceptability of brochures about

ABSTRACT

OBJECTIVE: To examine resources about cervical screening made available to Indigenous women in NSW.

METHOD: An Aboriginal woman, on behalf of another Aboriginal woman, telephoned 47 NSW based organisations in May 1998 for information about cervical screening. Received materials were analysed for format, content and readability and then submitted to a panel of Indigenous women for their feedback.

RESULTS: Of those 34 organisations agreeing to send resources, only 20 (59%) did so. After removing duplicates, 12 cervical screening resources were available for review of which six were designed and printed in NSW and the other six originated outside NSW. Of the six resources developed in NSW, two (33%) were for Aboriginal women. Of the six resources originating from outside of NSW, another two (33%) also were for Aboriginal women. The Flesch readability scores for resources ranged from 58.6 to 87.27. Those developed in NSW had a significantly lower readability score than those from outside of NSW ($p = 0.025$). Despite lower education levels among the target group, there was no difference in the readability scores of resources designed for Indigenous women ($p=1$).

CONCLUSIONS: Most resources obtained by us were not tailored for Indigenous women.

IMPLICATIONS: This study has set a base line for resources available for Indigenous women. Our method could be replicated in the future to evaluate and monitor improvement.

* For many years the Commonwealth used the following points to determine Aboriginality:²

- The person must be of Aboriginal descent.
- The person must self identify as Aboriginal.
- The person must be accepted in the community in which they live as Aboriginal.

This definition has since been simplified by the Aboriginal and Torres Strait Islander Commission Act (1989)² to being:

- A person who is a member of the Aboriginal race of Australia.

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TABLE 1: ANALYSIS OF 12 PAMPHLETS ABOUT CERVICAL SCREENING

C	Place of resource origin	Type of Resource	Reading Ease score	Reading Ease ¹¹	Initiation of screening			Cessation of screening		NSW Pap Register
					Age	Onset of sexual intercourse	Interval	Age	Pap OK 2*	
1	NSW	ATSI	77.54	f. easy	nm	nm	12m	nm	nm	nm
2	NSW	ATSI	77.3	f. easy	nm	y	2yrs	nm	nm	y
5	NSW	General	61.83	standard	18	y	2yrs	70	Y	y
6	NSW	General	83.77	easy	nm	y	2yrs	nm	nm	y
8	NSW	General	77.64	f. easy	nm	nm	2yrs	nm	nm	nm
10	NSW	General	58.6	difficult	nm	y	regular	nm	nm	nm
65	SA	ATSI	84.22	easy	nm	y	2yrs	70	nm	na
68	Qld	ATSI	80.58	easy	nm	y	2yrs	nm	nm	na
9	J	General	79	f. easy	18	y	2yrs	70	Y	na
60	NT	General	83.35	easy	18	y	2yrs	70	Y	na
63	NT	General	87.27	easy	nm	y	2yrs	70	nm	na
67	SA	General	80.31	easy	nm	y	2yrs	nm	nm	na

Legend:

C: NAHOU Code number
 J: Joint Commonwealth/State/Territory design
 NSW: Materials were designed in NSW
 QLD: Materials were designed in Queensland
 NT: Materials were designed in the Northern Territory
 SA: Materials were designed in South Australia
 ATSI: Resources identified as being for Aboriginal and Torres Strait Islander women

General: Resources identified as being for the general Australian population
 f. easy: Fairly easy (see Box One)
 nm: Not mentioned in the resource examined
 na: Not applicable
 y: Yes
 Pap OK*2: If the resource mentions 2 consecutive clear cervical screens in the last 5 years

cervical screening for Aboriginal and Torres Strait Islander women living in NSW.

Method

In 1998, we generated a list of 47 organisations in NSW (appendix A) and contacted each by telephone. The caller (LJ) truthfully advised she was calling on behalf of her sister, also an Aboriginal woman, asking to be sent information about cervical screening. At that time, her 35-year-old sister had never had a cervical smear.

Resources about cervical screening were examined for:

1. format;
2. content;
3. the Flesch readability score (box 1), since the National Aboriginal and Torres Strait Islander Survey¹⁰ had found that nearly half of Indigenous people over the age of 15 either have had no formal education, or have not completed year 10 at school. Two researchers independently calculated Flesch readability scores for each resource. Inter-rater reliability was calculated using kappa;
4. appeal to Aboriginal women.

Each resource also was submitted to a panel of seven Aboriginal women and one Torres Strait Islander woman. Each resource was viewed in full by panel members. If the resources had clearly identifiable Aboriginal images and colours, phone numbers of Aboriginal Health Workers or Aboriginal words such as Murri, Goori, Koori, it was considered to be designed explicitly for Aboriginal women.

Results

RESPONSE RATE AND DESCRIPTION OF RESOURCES

Of the 47 organisations on the list, 13 stated they did not distribute cervical screening materials. Of these, eight referred the caller to another organisation, (all of which were included on our original list) while three organisations referred us to individual doctors. The remaining two did not refer the caller elsewhere.

Of the 34 organisations agreeing that they distributed cervical screening material, only 20 (59%) actually forwarded resources to LJ. Six of the organisations' responses were accompanied by hand written notes urging the caller's sister to attend their service, including names of specific individuals and their contact numbers. Of the 20 organisations replying, eight (40%) also sent other health related materials. However, two sent information on screen-detected cervical abnormalities while the other six sent 15 other resources, related to breast screening, safe sex,

BOX 1: GUIDE TO INTERPRETING FLESCH 'READING EASE' SCORES¹¹

Flesch Reading Ease Score	Description of style	Typical magazine
0 - 30	Very difficult	Scientific
30 - 50	Difficult	Academic
50 - 60	Fairly difficult	Quality
60 - 70	Standard	Digests
70 - 80	Fairly easy	Slick fiction
80 - 90	Easy	Pulp fiction
90 - 100	Very Easy	Comics

women's health services or information about cancer counselling. We also excluded four resources sent about Pap test registers and an educational resource about the Northern Territory Pap Test Register designed for Aboriginal Health Workers.

After excluding duplicates, the final sample of 12 cervical screening resources comprised one card, three booklets, six brochures, one plastic wallet folder and one post card. Six resources had been developed within NSW while another six originated outside of NSW, although mailed to us by a NSW service. Of the six resources from NSW based organisations, four were designed for the general (non-Aboriginal) population. Only four (33%) of the 12 resources were identifiably designed for Aboriginal women.

While three resources mentioned the age to initiate screening (25%), 10 resources mentioned onset of sexual activity as an indicator to commence screening (table 1). All resources (100%) mentioned the necessity of repeat screening, although recommendations ranged from 'regularly' (n=1), '12 months' (n=1) and '2 years' (n=10). The cessation of screening at age 70 was mentioned in only five resources (42%) although only three clearly advised the need for two normal smears in the preceding five years before cessation. The NSW Pap Test Register was mentioned in three of the six resources created in NSW (50%).

The median Flesch readability score for the six NSW based resources was 77.4, (range 58.6 - 83.77) (table 1). The lowest readability score of 58.6 would be considered 'difficult' to read and suitable only for an 'academic' publication.¹¹ By contrast, the median Flesch readability scores for the six interstate-based resources was significantly higher, at 81.9 (range 79 - 87.27) ($z = -2.2$, $p = 0.025$).

The median Flesch readability scores for four Aboriginal resources was 79.0 (range 77.3 - 84.22), while the median Flesch readability scores for the eight general resources was 79.65 (range 58.6 - 87.27). There was no significant difference in the readability scores of general population compared with Aboriginal specific resources ($z=0$, $p=1$).

Our kappa value of 0.64 ($K=0.64$, $z=3.24$ $p<0.001$) indicated 'good' inter-rater reliability.¹²

VIEWS OF THE ABORIGINAL AND TORRES STRAIT ISLANDER PANEL

Images that were easily recognisable as being for Aboriginal and Torres Strait Islander women were considered by our Indigenous panel as more acceptable to the target audience. Only four (two NSW based and two other) resources met this criterion.

Statements endorsed by the panel included:

- "By having a regular two-yearly test, early changes can be treated before cancer develops"
- "Pap tests are a test for well women"
- "A Pap test is not used for the detection of STDs"
- "Having a Pap test can feel uncomfortable, but it should not hurt"

Statements about 'optional extras' made the panel feel less comfortable however. For example, ThinPrep technology, for which an additional fee is charged, was promoted for reducing "unsatisfactory and inconclusive diagnosis".

Furthermore, the panel noted statements that were inaccurate, for example:

- "The Pap smear is a test taken by your doctor"
- "a small metal instrument....."
- "It is done gently and does not hurt or even feel uncomfortable....."
- "Women avoid having Pap smears because they are shy....."

Finally, one member of the panel member noted the low response rate from contacted organisations agreeing to send information, stating: 'What if this was a *real* enquiry?'

Discussion

The evaluation of materials on cervical screening using a simulated caller strategy was an effective way to obtain resources likely to be sent in response to genuine caller inquiries. Others also have used similar strategies to evaluate cancer information.^{8,13,14}

This study had hoped to obtain resources designed for Indigenous women specifically, however little seems to be available. What are readily available however, are resources designed for the 'general' population. The four resources (33%) designed specifically for Aboriginal women are seemingly the only ones available at the time. Therefore, Indigenous women have to rely on resources that do not target them specifically, despite the targeting of Aboriginal women in cervical screening programs.^{1,2,3,5}

This study, like the earlier Australian survey⁸ and a more recent Belgian study,¹⁵ also found that information about eligibility for cervical screening, such as age to initiate screening, differ from one resource to the other. Key advice is inconsistently or inaccurately provided still. This stands in contrast to the philosophy of the NCSP, which seeks to promulgate standardised messages in response to conflicting policies rampant in the 1980s.¹⁶

We also were surprised to find such a wide range of readability scores, despite the desirability of health information in plain English.⁶ Further, any information with a readability score under 70 would likely be difficult for Indigenous women, who have typically not attained high levels of formal education, to read and understand. As there was no detectable difference in the readability scores between resources according to target group, Indigenous women may be especially disadvantaged.

That not all organisations agreeing that they distributed resources on cervical screening did, indeed, respond to our request is disappointing. However, that relatively little information matched the need was alarming. Nonetheless, we anticipate improvements could readily be made in response to this baseline assessment. Our method is a novel way of evaluating equity in the promotion of cervical screening and could be repeated by other Indigenous health workers to monitor improvement.

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Appendix A

Organisations in NSW that were contacted for materials

- Health Promotion Units (n=17)
- Community Health Services (n=9)
- Women's Health Centres (n=4)
- The Aboriginal Medical Services (n=3)
- Family Planning Association
- Natural Family Planning Service
- The State Department for Women
- Women's Referral Service
- NSW Department of Health
- Aboriginal Health Resource Coop
- La Perouse Community Centre
- NSW Cervical Screening Program
- NSW Pap Test Register
- NSW Faculty of the RACGP
- NSW Chapter of RACOG
- NSW office of the AMA
- Doctors Reform Society
- Cancer Info Line

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