

WELL WOMEN'S EVALUATION – CONSULTING 'THE RIGHT WAY'

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The Well Women's program, a strategy of the Northern Territory Women's Cancer Prevention Program (WCPP), supports holistic health screening as a means to promote cervical screening for women living in rural and remote areas of the NT. The program primarily targets Aboriginal women and is committed to improving two-way understanding of women's health in all aspects of the program, and to strengthen the capacity of communities to address health issues. An impact evaluation was conducted in 1999-2000, five years after the program commenced. It was essential that the evaluation gain the views of Aboriginal women across the Territory.

This paper focuses on issues of consulting 'the right way' with Territory Aboriginal women, and details the challenges of the innovative and empowering approach that was taken in this evaluation. Key features included: an Aboriginal WCPP worker as key member of the project team; an Advisory Committee of five Aboriginal women; 17 Aboriginal women Facilitators who consulted in 14 remote communities across the Territory; and other creative partnerships. Participation far exceeded expectations, with a few surprises and strongly consistent results.

Challenges included: the highly sensitive and private nature of women's health; 'the right way' to seek community participation; and translating concepts and thoughts between traditional Aboriginal languages and English. The evaluation recommended a greater role for Aboriginal women in the program as educators and women's health workers, with education grounded in Aboriginal culture.

Key words: Aboriginal, cervical screening, consultation, evaluation, women's health

1. INTRODUCTION

Northern Territory (NT) Aboriginal women designed and implemented consultations with more than 250 Aboriginal women and Aboriginal Health Workers (AHWs) across the Territory in the recent impact evaluation of the Well Women's program¹. The program coordinator supported this bold approach in order to ensure the best opportunity for Aboriginal women in rural/remote communities, the primary target group of the program, to share their experiences and views of women's health screening.

This paper describes the Well Women's program and decisions regarding an appropriate consultation process with Aboriginal women. While non-Aboriginal women were also consulted and there were other components to the evaluation, including analysis of cervical screening data over time and detailed descriptions of program implementation, the paper focuses on the special issues of consulting with NT Aboriginal women 'the right way'.

2. WELL WOMEN'S PROGRAM

Aboriginal women in the NT have the highest rate of cervical cancer in Australia and are 12 times more likely to die from cervical cancer than other NT women (Markey, 1999). Yet cervical cancer is one of the most preventable and curable of all cancers, and regular two-yearly screenings are a critical factor in detection and treatment. International research shows that regular cervical screening is an effective way to reduce morbidity and mortality from cervical cancer (National Cervical Screening Program, 1998).

The Well Women's program aims to 'decrease preventable illness and death among women in rural and remote communities through promotion of women's screening including breast and cervix using a primary health care approach' (Territory Health Services, n.d.). The program intends to be culturally appropriate for Aboriginal women with principles of education rather than coercion,² a commitment to work with Aboriginal women to increase two-way understanding of women's health³ and community ownership of women's health screening.

The innovative program actively commenced in 1993/94. It incorporated aspects of well women's screening using a 'whole woman' approach developed by Aboriginal community-controlled health services in Central Australia in the late 1980s (Campbell with Kurnoth, unpublished), specific strategies recommended by the National Aboriginal Health Strategy (1989), and practical principles from a pilot women's health project in the Darwin Rural health district (Duquemin, 1996).

¹ The program is a strategy of the Women's Cancer Prevention Program (WCPP) in Territory Health Services (THS) and is jointly funded by the Northern Territory Government and the Commonwealth.

² Screening can be conducted with participants who have little understanding of its purpose and consequences. An educative approach is based on informed participation and genuine choice.

³ One Grandmother in the Nyrripi Grandmothers' program describes 'two-way learning': 'The women on our community worked very hard to teach young women and old women about breast cancer and cervical cancer. But we did it the right way, teaching culture, too' (Campbell with Kurnoth, unpublished). Two-way learning also means that Aboriginal and non-Aboriginal women share their cultural understanding and knowledge of women's health.

Women's Health Educators (WHEs) are the core component of the program. They work in partnership with Aboriginal Health Workers (AHWs), Remote Area Nurses (RANs), other medical practitioners, public health staff and Aboriginal women to establish and maintain local community well women's screening 'programs' or services. There is only one WHE in each of the five remote districts that cover the entire NT outside the Darwin and Alice Springs urban areas. One WHE is an Aboriginal Health Worker.

The program works along two paths simultaneously with WHEs taking a lead role to:

- work with local women to provide information to increase their knowledge and understanding in order that they can make informed choices about well women's screening and other women's health issues; and
- work with local health staff to provide information, training and support to increase their skills in order to increase holistic well women's screening services.

An earlier evaluation of the Well Women's program examined the assumptions underpinning the program design and concluded that, '...evidence suggests that the current program is a realistic and achievable way in which to promote women's health in remote areas and should be continued and expanded' (Duquemin, 1996). Aboriginal women were not consulted at that time.

3. EVALUATION DESIGN

3.1 Cross-cultural issues

A number of complex issues need to be resolved when evaluating cross-cultural programs (Westwood and Brous, 1993). The National Aboriginal Health Strategy highlighted concerns that many standard research and evaluation practices are impractical and inappropriate:

Cross-cultural research, and in particular, cross-cultural research in Aboriginal affairs, has difficulties which have remained largely ignored by researchers... The framework, the cultural and the philosophical value system within which the research is conceived, designed and conducted come into question in the cross-cultural situation... The model within which research is conducted reflects the values of the dominant culture (National Aboriginal Health Strategy, 1989).

There is increasing demand from and recognition that Indigenous people should not only participate in, but shape and control research with their people (Humphery, 2001; Nissanka et al, 2000; Garrow, 1994). Mainstream methods often fail to take into account the intellectual understanding and culture of the group (Chambers, 1999; Trudgeon, 2000), and results of these methods are open to question.

3.2 Evaluation model

A participatory action research model was chosen for the evaluation. A cross-sectional, non-probability design was used to collect the experiences and views of women living in remote communities through consultation. The design was explorative and descriptive, and provided a ‘group portrait’ of the program and the target group at one point in time (Fink, 1995). The evaluation process supported Aboriginal women to shape the consultation. They planned, advised, facilitated, reported and interpreted processes and results.

The consultations with Aboriginal women were primarily intended to provide insights into:

- whether and why/why not they participated in Well Women’s activities and screening; and
- their concerns about women’s health and suggestions for improving the program.

The impact evaluation was conducted in 1999-2000, five years after the program actively commenced. The consultation component with Aboriginal women was complicated by a number of factors in addition to the issues in Section 3.1 Many of the women speak traditional languages in addition to or instead of English, and ‘women’s business’ is highly sensitive, culturally important and very private. The Minymaku Kutiju Tjukurpa Women’s Business Manual provides a valuable introduction to these issues (Congress Alukura and Nganampa Health Council Inc, 1994). Appropriate consultation methods needed to take account of these complex issues.

The major evaluation questions and methods used are summarised in Table 1.

Table 1. Major evaluation questions and methods used

Key evaluation question	Methods used
Program implementation	<ul style="list-style-type: none"> • Analysis of program documents • Comparison with early evaluation • Interviews with key stakeholders
Program achievements Barriers and factors critical to success	<ul style="list-style-type: none"> • Interviews with key stakeholders • Consultation with women and health centre staff in remote communities • Analysis of data from NT Pap Smear Register and NT Cancer Register
What it would be like if there were no program	<ul style="list-style-type: none"> • Consultation in remote communities

3.3 Creative partnerships

The consultation process relied on a number of partnerships, including community council consent for consultations within their community and partnerships with employers to enable appropriate Aboriginal women to serve as Facilitators. Community council commitment was strong, and every invitation to participate in the consultation was accepted. Employer partnerships included an agreement with an Aboriginal community-

controlled health organisation for one of their staff to conduct consultations in two remote communities, and several arrangements with Territory Health Services managers.

3.4 Consultation process

The Aboriginal Project Officer in WCPP worked with the external evaluator on all aspects of the evaluation: participant in both⁴ advisory groups; primary liaison with the Facilitators; co-interviewer of key stakeholders; Facilitator in several communities; and sounding board for the many issues that arose. The consultation process with Aboriginal women would not have been possible without her continuing and committed involvement.

The Advisory Committee of Aboriginal women comprised an elder, a staff member of ATSIC, a women's health worker at a major Aboriginal health service and a former Well Women's health worker, all highly respected.

The consultation process depended on locating appropriate Aboriginal women to serve as Facilitators in a number of remote communities across the Territory. These women had to be well known and accepted by the communities they would visit, and capable of undertaking the consultations with minimal supervision. Seventeen Aboriginal women agreed to take on this role.⁵ Facilitators worked in teams of two – one was always a local woman. Community workshops were intended to be the main method of consulting, and Facilitators received standard workshop guidelines and reporting packets. Questionnaires for working women and health services staff were to be delivered and later collected by the Facilitators.

The consultation process itself was also intended to raise awareness of well women's checks. Facilitators reported that Well Women tee shirts, cardholders and calico bags, as well as the meetings with morning or afternoon teas, were very popular.

Through these processes, 256 women in 14 remote communities across the NT contributed to the consultation, including at least 143 Aboriginal women through questionnaires and 83 through community meetings. In addition, 59 health center staff, of whom 32 were AHWs, completed questionnaires.

3.5 Challenges

The highly sensitive and private nature of women's health was a major challenge. The Advisory Committee recommended which questions could be asked in a group meeting and which were only appropriate for written questionnaires. They also advised that a questionnaire was important, and suggested wording and format. Facilitators later reported that some written questions were 'very hard' for the women, but the majority who completed questionnaires wrote additional comments on the forms that helped in 'interpreting' some responses. For example, questions in the past tense were often

⁴ In addition to the Advisory Group of Aboriginal women, there was a Reference Group to advise on evaluation/research issues.

⁵ In several communities, a non-Aboriginal WHE supported an AHW to conduct the consultations, while in two others, local Aboriginal women supported the non-Aboriginal WHE. By far the majority of Facilitator teams were both Aboriginal women.

answered in the present tense. Despite these difficulties, there were strongly consistent patterns of responses across all communities.

One of the greatest challenges was translating concepts and thoughts between traditional Aboriginal languages and English. Not all Facilitators spoke the local language so the local women co-facilitators were invaluable. A video-tape of one community meeting shows the painstaking care taken by the Facilitators to ensure that the evaluation questions were understood and that the women's views were meticulously noted and checked. Women answered the questions in their own way, and raised important questions of their own.

3.6 Surprises

An overwhelming number of women wanted to complete questionnaires. This was surprising as many remote community women, while very knowledgeable and articulate, were not expected to complete questionnaires in English. One Facilitator described how they handled this:

The meeting started at the women's center...had to introduce myself...the questions on the form were then explained to the women...we had to explain each question to them...then we had to interpret the questions for them in English...After lunch, I went to visit some women at the camp, and to sit with them to explain to them and to give them forms to fill in... (Campbell with Kurnoth, unpublished).

Another surprise was a submission prepared by the women of Nyirripi, a small community in remote Central Australia, regarding their highly successful Grandmothers' Program. They not only video-taped much of the group workshop, with personal statements by several Grandmothers and young women, but also a session out bush with traditional dancing and singing to 'show that they do what they say they do'.

4. CONSULTATION FINDINGS

The key findings of this comprehensive consultation process with Aboriginal women that spanned 14 communities from the desert land of Central Australia to island communities off the Top End were strongly consistent. The Aboriginal women consulted said that they value women's health education and activities, and want it grounded in Aboriginal culture. They want a greater role for Aboriginal women in the program as educators and women's health workers, and they want women's health activities to be part of everyday community life. These powerful messages confirmed the intention and approach of the Well Women's program, and led to the recommendation that the program be continued and explicitly strengthened in these ways.

5. CONCLUSION

The Well Women's program supported Aboriginal women to design and carry out an essential consultation process with other Aboriginal women, and the women responded

enthusiastically and well beyond expectations. The large number of women involved increased the pool and validity of information collected.

The consultation process confirmed the issues of cross-cultural evaluation in the literature and yielded strongly consistent themes in every participating community, whether or not that community had previous access to the Well Women's program. The consultations, done 'the right way' for Territory Aboriginal women, provided the information needed for a fair and appropriate assessment of the impact of the program

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