

PROJECT REPORT

Marrying research, clinical practice and cervical screening in Australian Aboriginal women in western New South Wales, Australia

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A B S T R A C T

Introduction: Research shows that Australian Aboriginal women experience a significantly higher rate of mortality from cervical cancer than non-Aboriginal women. We now understand that infection with human papillomavirus (HPV) is a necessary prerequisite for cervical cancer. This knowledge, together with the development of prophylactic vaccines against the HPV types most commonly associated with cervical cancer (16 and 18), made it vital to gain nationally representative HPV genotyping data for Australian women, including Aboriginal and Torres Strait Islander women. A research project, the 'Women, Human papilloma virus prevalence, Indigenous, Non indigenous, Urban, Rural Study' (WHINURS) was designed to obtain the HPV status of Aboriginal and non-Aboriginal women when they presented for their routine cervical screen. Family Planning NSW (FPNSW), an organisation that had previously worked in community based projects to increase Aboriginal participation in cervical screening, provided an investigator site in western NSW with the intention to recruit 50 Aboriginal women and 100 non-Aboriginal women.

Methods: The method was a consultative approach, including national and local frameworks for Aboriginal and Torres Strait Islander recruitment. The FPNSW Dubbo team devised a series of strategies to maximise recruitment when this did not progress according to plan. Strategies were developed to meet this challenge, including street walks, attendance at community forums, flexible appointments, drop-in times and assistance with travel and babysitting.



Results and Conclusion: As a result of the activities listed above, 43 women were recruited to WHINURS, just seven short of the target. Collaborative community-based consultation, as well as the research study itself increased the number of Aboriginal women accessing cervical screening at the family planning clinic. This was sustained a year after the conclusion of the study.

Key words: Aboriginal women's health, cervical screening, HPV genotyping, HPV vaccination, research, women's health.

Introduction

Australian Aboriginal women experience a significantly higher rate of mortality from cervical cancer than non-Aboriginal women. This has not changed with the introduction of the national cervical screening program in 1991, as it has for non-Aboriginal women. The national age-standardised mortality rate for Aboriginal and Torres Strait Islander women aged 20–69 years in the 2001–2004 period was 9.9 per 100 000 women and was 4.7 times higher than the mortality rate for other Australian women in the same age range¹. In New South Wales (NSW), mortality rates for Aboriginal women were more than three times that of the NSW population for the period 1994–2002². The reason for this disparity is thought to be low screening rates in Aboriginal women. It is believed that the majority of women who present with established cancer have either never been screened, or only screened many years previously³. Determining true screening rates for Aboriginal women can be difficult because the data are unreliable; some Australian states do not collect Pap test data that also captures Aboriginality. In the Northern Territory where data are available, during the period 1999–2004 participation rates were approximately 44% for Aboriginal and Torres Strait Islander women aged 20–69 years⁴. This compares with an overall screening rate of 61% for Australian women aged 20–69 years in the period 2004–2005¹.

In the past 20 years a large body of scientific evidence has been collected on the cause and progression of cytological abnormalities that may develop into cervical cancer. Research has revealed that infection with human papillomavirus (HPV) is a necessary pre-requisite for

cervical cancer⁵. Genotypes 16 and 18 alone are responsible for 70% of cervical cancers worldwide. The Australian experience mirrors this global prevalence of genotypes 16 and 18 being responsible for close to 80% of these cancers⁶. However, although 16 and 18 are the most common types detected in cervical cancers, there is a lack of data about the most prevalent types in otherwise healthy women in Australia, particularly Aboriginal and Torres Strait Islander women. There is only one published study on the prevalence of the various HPV genotypes in Aboriginal women⁷.

This lack of data is of new importance in the wake of the development of the highly effective prophylactic bivalent and quadrivalent vaccines that protect against infection and disease caused by HPV types 16 and 18⁸⁻¹⁰. To gain nationally representative data on all Australian women, the research project 'Women, Human papilloma virus prevalence, Indigenous, Non indigenous, Urban, Rural Study' (WHINURS) was designed to recruit 1000 Aboriginal and 2000 non-Aboriginal women when they presented for their routine cervical screen. Family Planning NSW (FPNSW), an organisation that had previously worked in community based projects to increase Aboriginal participation in cervical screening, was invited to become an investigator site^{11,12}. Family Planning NSW ultimately agreed to recruit 350 women to WHINURS; 200 non-Aboriginal women at an urban clinic in southern Sydney, and 100 non-Aboriginal women and 50 Aboriginal women at the Dubbo clinic in rural western NSW.

Objectives

This article describes the challenges of recruiting Aboriginal women to WHINURS in Dubbo and the strategies used to



overcome these challenges. The article also describes how implementation of the strategies led to a secondary gain: an increase in the number of Aboriginal women presenting for cervical screening at the FPNSW Dubbo clinic.

Methods

National Consultation Framework for Aboriginal and Torres Strait Islander recruitment

Research into Aboriginal health issues is vital but must be tempered by a culturally sensitive approach that involves in-depth consultation and collaboration with Aboriginal people. Cultural safety is an important concept that allows the recipient of health care (or the person invited to participate in a research study) to feel safe in the interaction. In addition, cultural competence, the ability to integrate culture into the delivery of health services (or recruitment to a research study) is understood to be a critical element in the interaction of healthcare services with people of a culture different from the prevailing mainstream health service¹³⁻¹⁵. To integrate these important principles into the study the 'Indigenous Health Coordinator', a Jamitji woman employed by the National Centre for Immunisation Research and Surveillance, was appointed to the WHINURS team to provide consultancy services on Aboriginal and Torres Strait Islander recruitment processes to the various WHINURS investigator sites throughout Australia. Her role was to ensure cultural safety, respect and appropriate research resources for the Aboriginal and Torres Strait Islander participants. Steering committees with representation from local communities were also established for each of the investigator sites aiming to recruit Aboriginal and Torres Strait Islander women. The role of these committees was to oversee the conduct of the project for local Aboriginal women, including feedback about the appropriateness and endorsement of information materials, consent procedures, training processes and the follow up of results. A primary issue that was identified early was the communication of difficult and sensitive information about a sexually transmissible infection (HPV), the potential consequences of

HPV infection and the need to have a genital examination for cervical cytology screening.

A colourful and informative flip chart was developed in central Australia in collaboration with one local steering committee and this was later modified to suit other Aboriginal communities. The flip chart was used by the doctor or nurse when recruiting and gaining the consent of women. An additional and important part of the 'consenting process' was to work alongside an Aboriginal health or Aboriginal community liaison worker who would ensure cultural safety for the potential research participants and provide cultural mentoring for the doctors and nurses involved.

Consultation with the Aboriginal community in Dubbo

Family Planning NSW already had good connections with the local Aboriginal community and since 2003 had convened the FPNSW Aboriginal Women's Advisory Committee. This group of women, which includes local Elders, Aboriginal health workers, an Aboriginal education officer, representatives from the Aboriginal medical service (AMS) and community members meets on a quarterly basis with the Dubbo Family Planning team to provide advice, support and mentoring on cultural issues. The concept of the research project was discussed with the advisory group initially and, with their support, a broader group was identified to consult with the WHINURS Study Indigenous Health Coordinator and to form a local steering committee.

Once convened, the steering committee included the chief executive officer and team at the AMS, members of the Dubbo Aboriginal Women's Alliance, committee members from the Aboriginal Maternal and Infant Health Strategy as well as representatives from the Dubbo/Plains Division of General Practice, Aboriginal Women's Circle Sentencing and Sexual Health and Greater Western Area Health Services. The concept of the study was warmly embraced by the steering committee who openly expressed concern that local women were not accessing mainstream providers for



cervical screening. They were enthusiastic about the prospect of a vaccine against HPV and saw the research project as a way to encourage more women to be screened, as well as to add to their knowledge about women's health issues. Ethics approval was given by the Aboriginal Health and Medical Research Council and the Family Planning NSW Ethics Committee.

Problem solving

Despite the enthusiasm for the research study by the representatives of the local community and their efforts to spread the word about the project, only one Aboriginal woman was recruited to the study in the first 11 months (between January and December 2006), compared with 100 non-Aboriginal women in the same time. One difficulty was that the study protocol required women to have their HPV test at the time they attended for a routine Pap test, and while approximately 6% of the women attending for consultation at the Dubbo centre at that time were Aboriginal, very few presented for a Pap test, and those who did were either outside the 18 to 40 year study age range or refused to take part in the study. In addition, the Aboriginal community liaison worker employed in the centre resigned early in the recruitment period and this limited community outreach activities. The active involvement of the Community liaison worker had been a critical element in previous projects undertaken by FPNSW^{11,12}. Ultimately, one of the advisory group members, a Wiradjuri woman who had been employed by FPNSW as a health promotion officer, agreed to act in a community liaison role for the study in addition to her other responsibilities.

During the time that the Dubbo centre did not have an Aboriginal employee to help with liaison, the FPNSW Aboriginal Women's Advisory Group held meetings with the Thubbo AMS and the Greater Western Area Health Service (GWAHS) and devised a plan to refer and transport women presenting to the AMS to the Family Planning Service for cervical screening and possible recruitment to the study. This proved to be time consuming and difficult to implement and resulted in the recruitment of only one

additional participant. At a subsequent special meeting of the advisory group to consider the recruitment issue it was agreed that an intensely proactive community based approach was required. The Dubbo clinic team, with critical input from the health promotion officer, then devised a series of strategies to take this mainstream service to the community. Four key strategies were developed from January to April 2007:

1. *Street walks*: The Aboriginal health promotion officer accompanied by one of the two family planning nurses to spend approximately an hour walking the Dubbo main street during business hours. They talked to women they knew and introduced themselves to others. They talked and distributed flyers about the services provided by FPNSW and about WHINURS.
2. *Attendance at community forums*: The Aboriginal health promotion officer or a clinic nurse attended mothers' groups and play groups to talk about FPNSW services and WHINURS. Approximately 10 visits were made in the 3 months from February to April 2007.
3. *Flexible appointments and drop in clinics*: The FPNSW clinic operated on a fixed appointment schedule prior to the study. Additional drop-in, nurse-run clinics and flexible appointment times were organised and advertised.
4. *Travel and babysitting*: A small reimbursement for out-of-pocket expenses such as babysitting or travel was negotiated with WHINURS coordinators for Aboriginal women who agreed to participate in the study.

Results

As a result of implementing the strategies, 41 Aboriginal women aged between 18 and 40 years were recruited to the study between the beginning of January and the end of April 2007. This brought the total number recruited to WHINURS



to 43 women, just seven short of the original target of 50 women.

Discussion

Research has an essential role in providing the evidence for medical interventions such as cervical screening and HPV vaccination. Collection of baseline data is essential to determine the prevalence of HPV infection, the consequences of which have been shown to be largely preventable and of critical importance to all women, but particularly to women who may have low cervical screening rates. The study team were aware from the outset that cultural safety and collaboration with Aboriginal and Torres Strait Islander communities would be critical elements in recruitment to the HPV prevalence study. There was an awareness by the team at both the national and local levels of the legacy of mistrust left by past researchers due to poor communication, inadequate consultation, cross-cultural insensitivity and a perception that research outcomes fail to benefit the community¹⁶.

In spite of extensive preliminary preparation and collaboration by the WHINURS team, it was always thought that it might be difficult to recruit the goal of 50 Aboriginal women to WHINURS in Dubbo. In 2005, fewer than 30 Pap tests were performed for Aboriginal women at the Dubbo clinic and a number were for women outside the age range required for the study. The study required women to be attending for routine Pap tests. Although the Dubbo clinic had worked for some years to break down well-known barriers to Aboriginal women accessing mainstream health services (such as our own), the women can experience culturally inappropriate services, incur costs and have to travel some distance with poor access to transport. The women may also desire an Aboriginal point of contact, and be unaware of existing services and preventive healthcare issues^{11,12,17-19}. Due to all these barriers, there was great difficulty in attracting recruits to the study.

A critical issue was the difficulty in accessing the community directly after the resignation of the Aboriginal community liaison worker. This position was not refilled because FPNSW had made a decision to engage an Aboriginal health promotion officer (HPO) for the Dubbo centre to provide general reproductive and sexual health education and information for the community. The new role did not specifically include transport or recruitment of research study participants, although the HPO readily contacted and transported Aboriginal clients for the clinic services. An attempted solution of engaging the community indirectly through other services (such as the AMS) was unsuccessful. The solution lay in taking a far more proactive approach by re-engaging with the community via the HPO and changing her role for a period of 4 months to include recruiting study participants. The nurse role was also broadened from usual clinical activities to include a walk of the main streets of Dubbo with the HPO to engage with the Aboriginal community and encourage women to enroll in the study. The nurses and HPO also worked with the family planning clinic centre manager to provide flexible options for women to attend the clinic, with the provision of 'drop in' and nurse only clinics.

Such an approach is a major challenge for a mainstream health service, where fixed appointments and nurse clinic sessions supported by a concurrent doctor clinic are usual. The FPNSW Clinic at Dubbo, which is 5 hours by road from Sydney, from its inception in 2001 has been managed by a fly-in doctor from Sydney 1–2 days a week. Medical workforce challenges have not allowed for a local doctor to provide the service and this has limited the provision of flexible arrangements. However, the measures introduced (including visits to community centres and help with babysitting and travel) assisted women to feel comfortable with, and develop confidence in, the clinical and non-clinical centre staff, and to achieve a sense of 'cultural safety'. A limitation of this study is that an evaluation of the various recruitment strategies was not conducted. At the time of the study, changes were made 'on the run' and so it can only be concluded that this was a multilayered approach where no



specific strategy was more effective than others in achieving the positive outcome.

A important benefit of the study was that it facilitated the attendance of Aboriginal women at the clinic, often for the first time. There was an increase in the number of women accessing the service and increased community interest in cervical screening. In the 12 months from January to December 2006, 43 Aboriginal women were seen at the Dubbo FPNSW clinic and 29 of these had a Pap test. This number increased during the four-month active recruitment strategy between January and April 2007, with 51 Aboriginal women visiting the clinic and 39 of these receiving a Pap test. The number of Aboriginal women attending the clinic for the whole of 2007 was 108, with 81 women undergoing Pap testing. By 2008 (more than a year after the study completion) these figures were 124 and 41, respectively, representing an 188% increase in the number of attendances and an 41% increase in the number of Pap tests in Aboriginal women attending the clinic prior to the study in 2006.

Other researchers have also found that research interventions can lead to an improvement in health-seeking behaviour and, potentially, health outcomes. Aboriginal health workers in an Aboriginal community controlled health service in Townsville also found that an HPV project increased the number of women having Pap tests²⁰. Manderson and Hoban's publication on cervical cancer services for Indigenous women suggests that the consulting and collaborating with the community in their study resulted in significant changes to health programs and policy¹⁴.

Conclusion

In conclusion, the recruitment of Aboriginal women to this HPV prevalence study was challenging but the difficulties were overcome with collaborative community-based consultation. The recruitment strategies developed through the process of consultation and the study itself increased the number of Aboriginal women accessing cervical screening at

the family planning clinic. This was sustained a year after the conclusion of the study.

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