



“WHILE YA DOWN THERE”

A HOLISTIC APPROACH TO INDIGENOUS FEMALE SEXUAL HEALTH

ADVOCACY PROJECT REPORT

FOR SUBMISSION TO THE AUSTRALIAN WOMEN’S COALITION

SUBMITTED ON BEHALF OF DURRI ABORIGINAL CORPORATION MEDICAL
SERVICE

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EXECUTIVE SUMMARY

The 'While Ya Down There' program report provides evidence that a holistic and culturally appropriate women's sexual health service can improve health behaviours and outcomes for Aboriginal women in regional NSW. The program gave Indigenous women regular access to a female sexual health nurse, and resulted in:

- 90 women accessing the program over the 12 month pilot period;
- 34% of these women had never had a Pap smear before or were overdue for screening;
- Follow up rates of 100% were achieved for the 5% of women with cervical abnormalities;
- The program provided an opportunity for screening and treatment of sexually transmitted infections as well as health promotion to improve women's control over their own sexual health;
- There were 57 referrals to other medical services, including treatment of cervical abnormalities detected, breast checks and other general health issues; and
- Women indicated they were comfortable with the examination and consultation, however further consultation to optimise cultural safety is recommended.

INTRODUCTION

In 2008 the Durri Aboriginal Corporation Medical Service (Durri ACMS) initiated a pilot Indigenous women's health program titled "While Ya Down There" (WYDT), supported by the Australian Women's Coalition (AWC).

BACKGROUND

The mortality rate from cervical cancer in Indigenous women is five times greater than that of Non-Aboriginal women in Australia.¹ It is estimated that over 90% of cervical cancer can be prevented with cervical screening.² Despite this, less than 50% of Indigenous women in Australia undergo regular Pap screen tests.³ Rates of sexually transmitted infections (STIs) are also far greater in Aboriginal people compared with non-Aboriginal Australians. Rates of Chlamydia are 10 fold higher, with gonorrhoea being 40 times more common and syphilis nearly 100 times more common in Aboriginal people.⁴

The WYDT program is a project designed to try and prevent cervical cancer and provide screening, treatment and knowledge about the importance of prevention of STIs for Indigenous women.

PROGRAM AIMS

- To determine the attitudes of Indigenous women towards a holistic model of female sexual health care;
- To provide improved access to sexual health services for Indigenous women living in a regional district;
- To provide women the opportunity to take control of their sexual and general health in a gender and culturally appropriate manner;
- To increase the number of Indigenous women screened by Pap smear to detect early precancerous changes;
- To improve follow up and treatment rates following Pap smear detection of abnormalities;
- To encourage women to undergo a Sexually Transmitted Infection (STI) screen; and
- To provide an opportunity to discuss health promotion strategies to reduce the incidence of STIs and cervical cancer, and other general health issues.

TARGET POPULATION

Participation in the program was completely voluntary. Women were eligible to participate if they were:

1. Resident in the Macleay and Nambucca Valleys of the Mid North Coast of New South Wales;
2. Aboriginal or in a direct relationship with a partner identifying themselves as Aboriginal; and
3. Age 18 years or greater.

ETHICAL CONSIDERATIONS

Informed consent was obtained from all women in the WYDT program for the collection, use and reporting of the data.

All data were collected, stored and reported in accordance with current privacy legislationⁱ and the *Health Records and Information Privacy Act 2002 (NSW)*.ⁱⁱ

All data was de-identified for reporting.

No incentives or monies were paid to any of the participants in the program.

Clients had the right to refuse their data being included in the evaluation of the program with no detrimental effect on their access to best practice clinical care.

ⁱ *Privacy Act 1988 (Cmth)*.

ⁱⁱ *Health Records and Information Privacy Act 2002 (NSW)*.

WYDT EVALUATION METHODS

WYDT was established as a program for women requesting or referred for sexual health services.

Women were offered a consultation with a sexual health nurse, who discussed with them the need for cervical screening as well as other women's health issues including sexual health.

The service was run one morning a week. During the program there was one sexual health nurse who was funded through a partnership between the Area Health Service, the local Division of General Practice and Durri ACMS. Initially, an Indigenous Women's Health Worker employed by Durri ACMS assisted women to access the service, but she was not present throughout the whole program. The program had the support of the general medical practitioners and other health workers at Durri, as well as local community leaders.

Evaluation data were collected from two sources:

1. The patient's medical file at the Durri ACMS

Basic information on Aboriginality, source of referral as well as clinical information on Pap smear results and STI screening were obtained from the medical file.

2. A survey designed to determine women's previous Pap smear experience and perceptions of the WYDT program

A 28-question survey was used to ascertain women's attitudes and experiences towards their care in the program.

BASIC AND CLINICAL INFORMATION

- **Aboriginality** was determined by self-identification.
- **The source of referral** to the WYDT program was recorded as well as referrals resulting from the program to other services.

Pap smear results were collected from the clinical notes at the Durri ACMS. Pap smear changes were graded as low-grade changes if HPV effect or CIN 1 was present, and high-grade changes if CIN 2, CIN 3 or glandular abnormalities were found. Current National Guidelines⁵ recommend repeat Pap smear in 6 months for low grade abnormalities and referral to a specialist gynaecologist for treatment for all high grade abnormalities.

SURVEY TO DETERMINE WOMEN'S PERCEPTION OF THE WYDT PROGRAM

A survey was issued to a selection of Indigenous women who accessed the program.

The survey was divided into three parts:

1. Women were asked about their experience of pap tests at other services and reasons for coming to the Durri ACMS.
2. Women were asked about their experience of the WYDT program. Specifically:
 - Physical experience of the Pap smear and STI screen;
 - Their attitude towards the program;
 - Whether they felt the consultation increased their feelings of empowerment towards their own health;
 - How they perceived the role of the sexual health nurse; and
 - What they thought of the cultural appropriateness and safety of the program.
3. A final open-ended question gave women a chance for free comments on the program and suggestions for improvement.

The survey was piloted with Indigenous staff at Durri ACMS and appropriate language and format changes were made.

RESULTS

The evaluation of the WYDT program was conducted between 1 April 2008 to 31 March 2009.

A total of 132 appointments were made during this time. Of these, 90 women attended for appointments in the program.

Of the clients who attended, 81% self-identified as Aboriginal / Torres Strait Islander.

The program ran for one session per week, with an average of 2 clients being seen per session.

TABLE 1: PROGRAM ATTENDANCE DATA

	n
Total number of appointments made for program	132
Number of women attending and consented for inclusion in program	90
Total number of new clients	31
Total number of Aboriginal / Torres Strait islander clients	73

All women who attended the program consented for their information to be used in evaluation of the program.

Reasons for non-attendance need to be further explored in this population.

REFERRAL PATTERNS TO THE WYDT PROGRAM

Access to the program was either by self-referral or external referral. Just under one third (30%) of women were self-referred. The remainder were referred to the program by one of the other programs offered by Durri ACMS. No clients were referred to the program from external organisations.

TABLE 2: REFERRAL SOURCES WITHIN DURRI ACMS

Referrals to Program	n	ATSI	Other
		N= 73	N= 17
Durri ACMS General Medical Practitioner	20	15	5
Durri ACMS Care Unit	10	10	0
Sexual Health Worker	2	2	0
Immunisation Team (via General Medical Practitioner)	8	6	2
Total	40	33	7

TABLE 3: REFERRALS GENERATED FROM THE WYDT PROGRAM

Referrals from Program	n	ATSI	Other
Durri ACMS General Medical Practitioner	23	21	2
Other General Medical Practitioner service	1	1	0
Private Gynaecologist	4	4	0
Port Macquarie Base Hospital Gynaecology Clinic	1	1	0
Marsh Street Women's Health Kempsey	2	1	1
Breast Screen New South Wales	21	21	0
Sexual Health Worker	2	2	0
Durri ACMS Alcohol and other Drugs Service	3	3	0
Total	57	54	3

The majority (77%) of these referrals out were to a Durri ACMS General Medical Practitioner and /or Breast Screen New South Wales.

SURVEY KEY FINDINGS

Sixteen surveys were submitted. Of these 14 were used for analysis, as one survey was very incomplete and the other contained contradictory information making interpretation difficult. Women were permitted to answer more than one answer in each section. Some women chose not to answer some questions, and the number of responses is indicated.

1. Perceptions of Previous Pap Test Experiences

Of the fourteen responses, 12 had experienced a Pap smear at a service other than Durri ACMS. One women stated this was her first Pap smear.

Four of these women described their previous experience in positive terms ranging from 'very good' to 'okay'. One woman felt their previous experience was 'comfortable and non-confronting'.

Eight women whom had had a Pap test at another service described their previous experience in negative terms. Two women indicated they felt rushed, whilst one woman felt that the procedure took too long. Two clients described their previous experience as producing physical pain whilst three clients expressed their previous experience in terms which suggested psychological discomfort, with words like 'embarrassed', 'paranoid' and 'worried' used.

Reasons for accessing the Durri ACMS service were as follows:

- Reputation of women's health nurse and /or program General Medical Practitioner;
- Referral to service;
- Pap test is 'women's business'; and
- Convenience.

2. Experience of the WYDT program

TABLE 4: THE PHYSICAL COMFORT OF THE EXAMINATION

Statement	N = 7
It really hurt	0
It hurt a bit	1
It was uncomfortable	2
It pinched	0
I did not feel any discomfort	4

TABLE 5: THE PSYCHOLOGICAL EXPERIENCE OF COMFORT

Statement	N =14
It was embarrassing	2
I was not embarrassed	5
I found it to be a distressing experience	0
It was no problem at all	4
I felt comfortable the whole time	4
I was relaxed	3
It was okay	7
I am glad it is over	3
I did not feel rushed	7

Seven women felt that they were not rushed during their consultation.

TABLE 6: THE CONCEPT OF PERSONAL RIGHTS AND EMPOWERMENT

Statement	N = 8
I felt that I was in control of how my Pap test was done	4
I felt I had the right to say “no”	6
I felt that I had the right to say “stop”	7

Eight women indicated positive responses in towards the statements on empowerment.

Of these, three indicated positive responses towards all three statements. One client circled only the statement relating to their feeling in control of their Pap test.

Three clients indicated both the right to say ‘no’ and right to ‘stop’ the procedure but did not indicate that they felt in control of how their Pap test was done.

Only one client indicated they felt they had the right to say ‘stop’ but did not select the statement pertaining to their right to say ‘no’.

TABLE 7: THE RELATIONSHIP BETWEEN CLIENT AND HEALTH CARE PROFESSIONAL

Statement	N = 10
The nurse took a general interest in my health, not just in my Pap test	6
I feel free to discuss other issues about my sexual health with my health worker	6
I feel free to discuss other issues about my general health with my health worker	7
I trust my health worker	5

Five women felt free to discuss both general and sexual health matters with their health worker. This is in comparison to two clients who indicated by their statement selection that

they could discuss general but not sexual health matters with their health worker and one client who could discuss sexual but not general health matters with their health worker.

Only five clients felt strongly enough to indicate that they trusted their health worker.

TABLE 8: ISSUES PERTAINING TO ABORIGINALITY

Statement	N = 5
I felt free to discuss culturally sensitive issues	1
I felt that the nurse understood my needs as an Aboriginal or Torres Strait Islander woman	4

In terms of issues pertaining to Aboriginality, five women answered questions in this section. Whilst only one woman indicated she felt free to discuss culturally sensitive reasons, the reasons for not answering these questions need to be further explored in this population.

Four women were positive about the nurse's understanding of their needs as an Aboriginal or Torres Strait Islander woman.

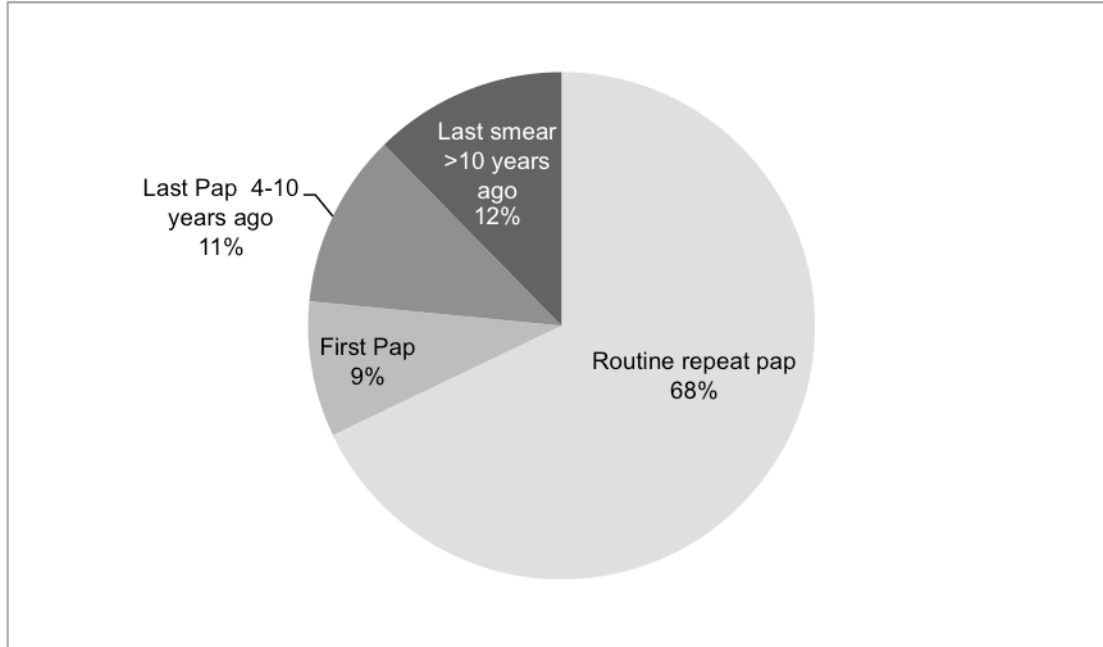
4. General comments

Four respondents had suggestions on how the service could be improved. These suggestions are quoted below:

- *'Maintain current practice.'*
- *'Have appointments for workers. Not just sit and wait.'*
- *'More women to do women's business.'*
- *'Take the service to the women; especially those isolated without transport.'*

CLINICAL RESULTS

CHART 1: PAPER TEST REGULARITY OF WOMEN PARTICIPATING IN PROGRAM



Of the 90 women seen by in the WYDT program, 81 had Pap smears taken. Reasons for not having a Pap smear were not explored.

Seven women underwent their first Pap smear. Nineteen (19) women were significantly under screened, with 9 of these women having their first smear over 10 years.

TABLE 9: PAPER TEST RESULTS

Item	N = 81
Normal Pap test results	64
Low Grade cervical abnormalities	1
High Grade cervical abnormalities (requiring referral to Gynaecologist)	3
Number of STIs / BV	13

5% of Pap smears were abnormal and 16% of women were diagnosed with bacterial vaginosis or an STI.

DISCUSSION

Although the total reach of the program may appear low with only 90 women participating, the following factors should be considered:

- Participation in the program was voluntary;
- No formal marketing strategy was used to promote the program;
- Not all women will present annually for a Pap smear; and
- The reasons (cultural and personal) for non-presentation for a Pap smear have not been confirmed in this population.

It was very encouraging that over one third of women presented to Durri ACMS for the first time, suggesting that the project generated a positive reputation through word of mouth.

Other studies have suggested a number of reasons why Aboriginal women have lower cervical screening rates than the general Australian population. These include, but are not limited to, cultural, linguistic and geographical barriers as well as a lack of culturally safe and effective counselling and follow up services.⁶

High rates of non-attendance are an issue for many ACMS programs. The reasons for this are complex and multi-factorial, including the availability of transport^{7,8}, acceptability of the service⁹, pressing family and community issues, cultural issues¹⁰ and socioeconomic factors.¹¹

The number of women participating in the program could be improved by targeted 'marketing' of the program through local Indigenous women's groups. This approach would allow consultation on what women would like to see included to make the program culturally safe and appropriate for them. It was also of concern that no clients were referred from external organisations, indicating a need for initiatives to improve external awareness of the program.

It was encouraging that the program resulted in the identification of general health problems and 57 referrals to appropriate services. The program extended beyond performing Pap smears and gave an opportunity for women to access other services, which included drug and alcohol, smoking cessation and other general health services.

Whilst distribution of the survey was small, it does provide information on the experiences of the Indigenous women who completed it. Over all, women responded positively to the program and gave useful comments about how it could be improved. These ideas included making the program available in communities and having more appointments available. Another improvement suggested was that more women should be engaged in the doing of 'women's business'. In Queensland, women stated standard Pap smear screening programs often show a lack of respect for the protocols surrounding Indigenous women's business.¹²

There is some evidence that Indigenous women would prefer to have the Pap smear included in a more general women's health check^{13,14}, which was achieved in this project. Community consultation is vital in designing an appropriate service¹⁵, and if this program is to be expanded an ongoing free and open consultative process is essential.

The Pap smear can be an emotionally and psychologically difficult procedure for some women.¹⁶ Negative experiences may affect the willingness of clients to present again.¹⁷ Encouraging feedback from clients allows women to be more in touch with their body¹⁸ as well as enabling the health professional to gauge the quality of their technique.

The National Cervical Screening Program recommends that all women over the age of 18 and who have ever had sexual intercourse should present for a Pap smear every two years.¹⁹ A more frequent Pap smear is usually only recommended if a previous smear demonstrated cellular changes of concern or if symptoms such as bleeding after intercourse arise. This program highlighted the problems with under screening in this population. Women presenting to Durri ACMS have a far higher rate of high grade abnormalities on Pap smear compared to the general Australian population. The incidence of high-grade cervical changes on Pap smear at Durri ACMS is extrapolated to be 12.3 per 1000 women, compared to the Australian national figure of 7 per 1000 women.²⁰ Delayed screening and significant under screening are likely to be important factors to the high rates of advanced abnormalities in this population. Programs such as this are an important way for Indigenous women to access cervical screening and prevent the development of cervical cancer.

KEY RECOMMENDATIONS

STRATEGIES TO IMPROVE THE REACH OF THE PROGRAM

- Targeted 'marketing' of the program through local Indigenous women's groups.
- The program could be taken to the women rather than expecting women to come in from rural and regional areas to centralised health services.
- The employment of community-trusted Indigenous women to work with the Health Professional is essential.

IMPROVING THE PAP SMEAR EXPERIENCE

- Physical discomfort can be reduced if clients are given appropriate and accurate information and explanations regarding the procedure.
- Specific education programs run through Indigenous Women's groups pertaining to patients' rights and autonomy are required to reduce the tendency to passive unempowered submission to clinical procedures.
- The integrated nature of the program needs to be communicated to current and potential clients so that clients understand that they are encouraged to discuss

broader health issues with the health care professional during their Pap smear test appointment.

IMPROVING PROGRAM CULTURAL SENSITIVITY AND SAFETY

- Community specific consultation should take place during the design and implementation of an integrated Pap smear and sexual health program.
- Health care professionals engaged in integrated Pap smear programs should receive regular training and updates on local community cultural issues.
- There should be greater engagement with local Indigenous women's groups about cervical and STI screening.

THE NEED FOR ADVOCACY

- The current national approach to Pap smear and STI screening is not working for Indigenous women.
- There is a need to advocate nationally for a change in the approach to Pap smear and STI testing for Indigenous women to one is more integrated and holistic.
- Indigenous women must be afforded the right, nationally, to be seen by appropriately clinically skilled women's health workers and supported by Indigenous Female Health Workers for 'women's business' health matters.

CONCLUSION

The "While Ya Down There" program illustrates the acceptability of a women's sexual health worker working in a regional Aboriginal medical corporation. This program gives a sense of the value of this service to Indigenous communities, as evaluated by Indigenous women. This program merits ongoing financial support to continue building a culturally appropriate service for Indigenous women to improve their sexual health.

By creating culturally appropriate health services for 'women's business', sexual health care and access to cervical screening can be greatly improved for Indigenous women, which will lead to a reduction in diagnosis and deaths from cervical cancer in the future.

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