

# Queensland Aboriginal and Torres Strait Islander Women's Cervical Screening Strategy

2006 - 2010



Francis J. 93

Painting entitled:

**Strong Aboriginal Women**

*“The beauty of a weak woman is her strength to survive her struggle”.*

By Barbara Mundraby (Artist) 03/06.

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# Foreword

Cancer of the cervix continues to be a major health issue for Aboriginal and Torres Strait Islander women who experience a disproportionate burden of illness from this cancer. Cervical cancer is the second leading cause of cancer death for Aboriginal and Torres Strait Islander women in Queensland.

Queensland Health has undertaken a number of initiatives to ensure the maximum number of eligible women are screened for cancer of the cervix and have follow up treatment after an abnormal Pap smear. These include the employment and support of designated Aboriginal and Torres Strait Islander women's health workers.

This strategy builds on the work commenced with the implementation of the Queensland Indigenous Women's Cervical Screening Strategy 2000 - 2004 and will guide future activities aimed to reduce the burden of cervical cancer experienced by Aboriginal and Torres Strait Islander women in Queensland.

I commend the Queensland Aboriginal and Torres Strait Islander Women's Cervical Screening Strategy to you and invite your participation in improving the health and wellbeing of Aboriginal and Torres Strait Islander women in Queensland.

**Stephen Robertson**  
**Minister for Health**



# Acknowledgments

This strategy builds on the work of Ms Maureen Kirk before she passed away on April 23 2001 from cancer. It acknowledges Maureen for the research she undertook with passion and her strong commitment to make a difference to the health status of Australia's Aboriginal and Torres Strait Islander peoples.

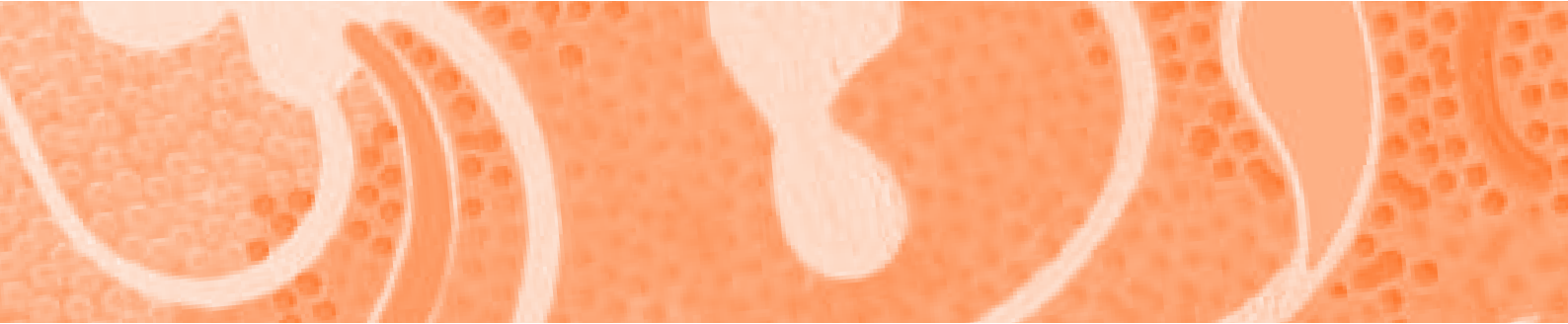
The development of this strategy was undertaken with guidance and feedback from Aboriginal and Torres Strait Islander health workers, key community women and Elders, key partners and key stakeholders (see Appendices 2-4). Their input has shaped the Queensland Aboriginal and Torres Strait Islander Women's Cervical Screening Strategy 2006 - 2010 which builds on the undertakings from the previous Queensland Indigenous Women's Cervical Screening Strategy 2000 - 2004.

## Use of terms throughout the document:

- The term 'culturally appropriate' has been used in the past to abbreviate, replace, represent or combine the terms 'culturally-effective, culturally-relevant, culturally-safe, culturally-specific, culturally-viable, culturally-sensitive, culturally-attuned, culturally-friendly'. The term 'culturally appropriate' has frequently been misunderstood and/or trivialised and the true meaning has been lost and/or become insignificant and un-descriptive. For this reason, the term culturally appropriate has rarely been used in this document. Other terms such as 'culturally safe' and those listed here are the preferred terms and have been used to reflect the intent of cultural appropriateness throughout the document.
- The term 'activities' are used throughout the document to describe programs, services, strategies or resources.
- The longer and separate term 'Aboriginal and Torres Strait Islander people/women', refers to Aboriginal people and Torres Strait Islander people as two quite distinct and separate races of people, as each have their own history, identity, spirituality, culture and traditions.
- The term 'Health Workers' is used throughout the Strategy to refer to Aboriginal and Torres Strait Islander health workers.
- The term 'Women's Health Workers' is used throughout the Strategy to refer to female Aboriginal and Torres Strait Islander Health Workers who work in women's health.
- The term 'cancer prevention and control services' encompasses services relating to the prevention of cervical cancer. This encompasses services that provide -
  - community education
  - the provision of cervical screening services
  - Pap smear reading services (cytology and pathology)
  - follow-up and treatment services including colposcopy, the management and treatment of cervical abnormalities or invasive cancer
  - palliative care services
  - monitoring and evaluation activities.

## Recognising South Sea Islander People:

The Queensland Government formally recognises Australian South Sea Islanders as a distinct group of people, unique to that of Australia's Aboriginal and Torres Strait Islander people (Department of the Premier and Cabinet, 1999). South Sea Islander People did not migrate to Australia voluntarily, but were bought to Australia as a source of cheap labour for Queensland's primary industries. Some were tricked into coming, some were kidnapped or 'black birded' and some came to earn money for their families. South Sea Islander people were forced to work long hours at exhausting manual work for low wages while living in very poor conditions. Many were treated cruelly and in the early 1880s the death rate among South Sea Islanders was five times higher than the European population. South Sea Islanders experienced discrimination, racism and restrictions introduced by the Government on their right to work and living conditions. The descendants of South Sea Islanders still continue to experience and suffer the consequences of this history. Many South Sea Islanders work and live in Aboriginal and Torres Strait Islander communities. However, for the purpose of this document consultation with South Sea Islanders was not undertaken and the issues of South Sea Islanders and their descendants have not been identified or addressed.



### **Acronyms used in this document (listed alphabetically)**

AHS	Area Health Services
AMS	Aboriginal (and Torres Strait Islander) Medical Service
ATSIHU	Aboriginal and Torres Strait Islander Health Unit
CDU	Communicable Diseases Unit, Population Health Branch Queensland Health
CSSU	Cancer Screening Services Unit, Population Health Branch, Queensland Health
DGPs	Divisions of General Practice
FPQ	Family Planning Queensland
FROGS	Flying Rural Obstetrics & Gynaecology Service, Queensland Health
GPs	General Practitioners
HPV	Human Papilloma Virus
HSD	Health Service Districts, Queensland Health
MWHS	Mobile Women's Health Service, Queensland Health
NATSIWF	National Aboriginal and Torres Strait Islander Women's Forum
NGO	Non-Government Organisation
NQWU	North Queensland Workforce Unit
QAIHC	Queensland Aboriginal & Islander Health Council
CCQ	Cancer Council Queensland
QCSP	Queensland Cervical Screening Program
RFDS	Royal Flying Doctor Service, Queensland Branch
SHS	Sexual Health Services

# Preamble

The Aboriginal and Torres Strait Islander Women's Cervical Screening Strategy 2006 - 2010 (the strategy) aims to promote strategies to reduce morbidity and mortality from cancer of the cervix among Aboriginal and Torres Strait Islander women in Queensland. This strategy was developed to progress the initiatives outlined in the Indigenous Women's Cervical Screening Strategy 2000 - 2004. The 2000 - 2004 Strategy was developed as an outcome of a research project undertaken in Queensland in 1998 that explored barriers women face in accessing cervical screening and follow-up services (Kirk et al, 1998). The strategy recognises the diversity of Aboriginal and Torres Strait Islander peoples and their connection to the land in rural, urban, remote or traditional communities. It recognises the Aboriginal and Torres Strait Islander holistic health model and the unique culture, traditions and spirituality of these people. In addition, it reflects on past and present policies and practices and the history of colonisation which continue to impact on the lives and health of all Aboriginal and Torres Strait Islander Australians.

The development of the strategy has been undertaken in consultation with the Aboriginal and Torres Strait Islander Health Policy Unit, Queensland Health and Health Workers across Queensland. In addition, the strategy includes input from women and key stakeholders from the Torres Straits who are also involved in the delivery of cervical cancer prevention and control services in Queensland. While Queensland Health has a significant role in implementing many of the strategies proposed in this plan, it is recognised that other parts of the health sector, and indeed other sectors such as education and training, also have a key role. Where other organisations and/or sectors have been identified as accountable for implementing strategies, it is proposed that Queensland Health provide a support, facilitation and advocacy role, primarily through the Cancer Screening Services Unit (CSSU), Population Health Branch.



## Implementation and resources

The time-frame for implementation of this strategy is over a five year period. However, annual implementation plans will be developed to clearly identify when specific projects or activities will be implemented and when specific resources will be available for each project or activity.

## Process

The strategy is underpinned by the strategic direction of the Queensland Cervical Screening Program State Plan Phase III, 2002 - 2006 and the principles identified for cervical cancer prevention and control. These are outlined in the Cancer Prevention and Control Outcome Area Plan, Queensland Health (Population Health Branch, 2006). A process of participatory action for the development of the 2006 - 2010 Strategy began midway through 2004. This involved a review process with key partners and stakeholders to reflect on the key actions identified in the 2000 - 2004 strategy as outlined in Appendix 1.

The review process involved feedback and input from key partners and stakeholders through a questionnaire and a state-wide participatory action workshop. This informed the development of the strategy and feedback from these activities are incorporated throughout the document.

The development of the 2006 - 2010 strategy was undertaken through:

1. The establishment of a reference group for review of the draft strategy and endorsement of the final strategy.
2. Dissemination of the draft strategy and questionnaire to key partners and stakeholders.
3. Collection of feedback from key partners and stakeholders.
4. A state-wide participatory action workshop.
5. Endorsement of the final strategy.

## Aboriginal and Torres Strait Islander definition of health

Aboriginal and Torres Strait Islander health initiatives must be holistic in nature. As in the 2000 - 2004 Queensland Indigenous Women's Cervical Screening Strategy, the 2006 - 2010 strategy recognises the Aboriginal and Torres Strait Islander definition of health (Queensland Health, 1994). This definition underpinned each stage of the development of the strategy. The definition states:

*“Health does not just mean the physical well-being of the individual but refers to the social, emotional, spiritual and cultural well-being of the whole community. This is a whole of life view and includes the cyclical concept of life-death-life. Health services should strive to achieve the state where every individual can achieve their full potential as human beings and thus bring about the total well-being of their communities.”*

# Introduction

Aboriginal and Torres Strait Islander women suffer a disproportionate burden of illness and death from cancer of the cervix. In Queensland the disparity is clear, with data indicating that incidence rates amongst Aboriginal women are 4.7 times higher than the State average, and mortality rates 13.3 times higher than the State average. In the Torres Straits the differentials are greater, where incidence is 5.3 times higher and mortality rates 21.5 times higher than the rest of the State (Coory et al, 1999).

Patterns of hospital usage have been used as an indicator of morbidity from cancer of the cervix for Aboriginal and Torres Strait Islander women. Total public hospital separation rates for conditions of the cervix were 11 times higher in the discrete Aboriginal and Torres Strait Islander communities than the total Queensland rate (Epidemiology and Health Information Branch, 1996). At the time of publication of this strategy, data concerning participation in cervical screening by Aboriginal and Torres Strait Islander women throughout Queensland was not available, except for the above data which relates to discrete communities.


Studies in Queensland and in other states have demonstrated that a higher proportion of Aboriginal and Torres Strait Islander women present with advanced cervical cancer with a correspondingly poor prognosis than would be expected in the general population. As cancer of the cervix is essentially a preventable disease, this situation is unacceptable. Even in the absence of credible screening participation data, it can be assumed that in general, screening rates are lower among Aboriginal and Torres Strait Islander women.

These figures are unacceptable and Queensland Health is working to redress these imbalances. This strategy aims to facilitate collaboration between Queensland Health, Aboriginal and Torres Strait Islander communities and non-government organisations with the aim of enhancing cervical cancer prevention and follow-up-care for Aboriginal and Torres Strait Islander women.

## Background

Cervical cancer was the 13th most common form of cancer in women during 2003. In that year 153 Queensland women were diagnosed with cancer of the cervix and 39 women died as a result of this disease. There is overwhelming evidence that cervical cancer is caused by Human Papillomavirus (HPV). Whilst the vast majority of women with HPV infection do not develop cervical cancer, it is thought that other co-factors, such as smoking, need to be present in addition to HPV to promote the development of cervical abnormalities.

To date there has been a significant reduction in cervical cancer incidence and mortality in Queensland. Between 1999 and 2003 the incidence decreased from 10.7 to 8.0 (per 100,000 women). However the incidence of cervical cancer in Queensland is higher than all other Australian states and territories, except for the Northern Territory. Mortality due to cervical cancer has also fallen from 2.5 to 2.0 (per 100,000 women) over the period 1999 to 2003. Queensland's mortality rate of 2.2 (per 100,000) women during the period 2001 - 2004 was consistent with the national average mortality rate over the same period of 2.1 (per 100,000 women) (Australian Institute of Health and Welfare, 2006).



The most effective proven method of intervention to reduce the incidence of and deaths from invasive cervical cancer is through regular screening of women at risk using Pap smears. Cancer of the cervix is a condition where there is a recognisable pre-symptomatic stage that can be treated and cured in most cases. Early cell changes on the cervix can be detected by a Pap smear before developing into cancer. Hence, the objective of population screening for cervical cancer is to identify cell changes at an early stage so that appropriate management can be instigated to prevent progression to cervical cancer.

Evidence states that three out of four women who develop cancer of the cervix have not had regular two-yearly screening, or have never had a Pap smear (Commonwealth Department of Health and Family Services, 1998). Regular participation in cervical screening is the key to the prevention of cervical cancer and as such is the primary indicator used in monitoring the success of the program.

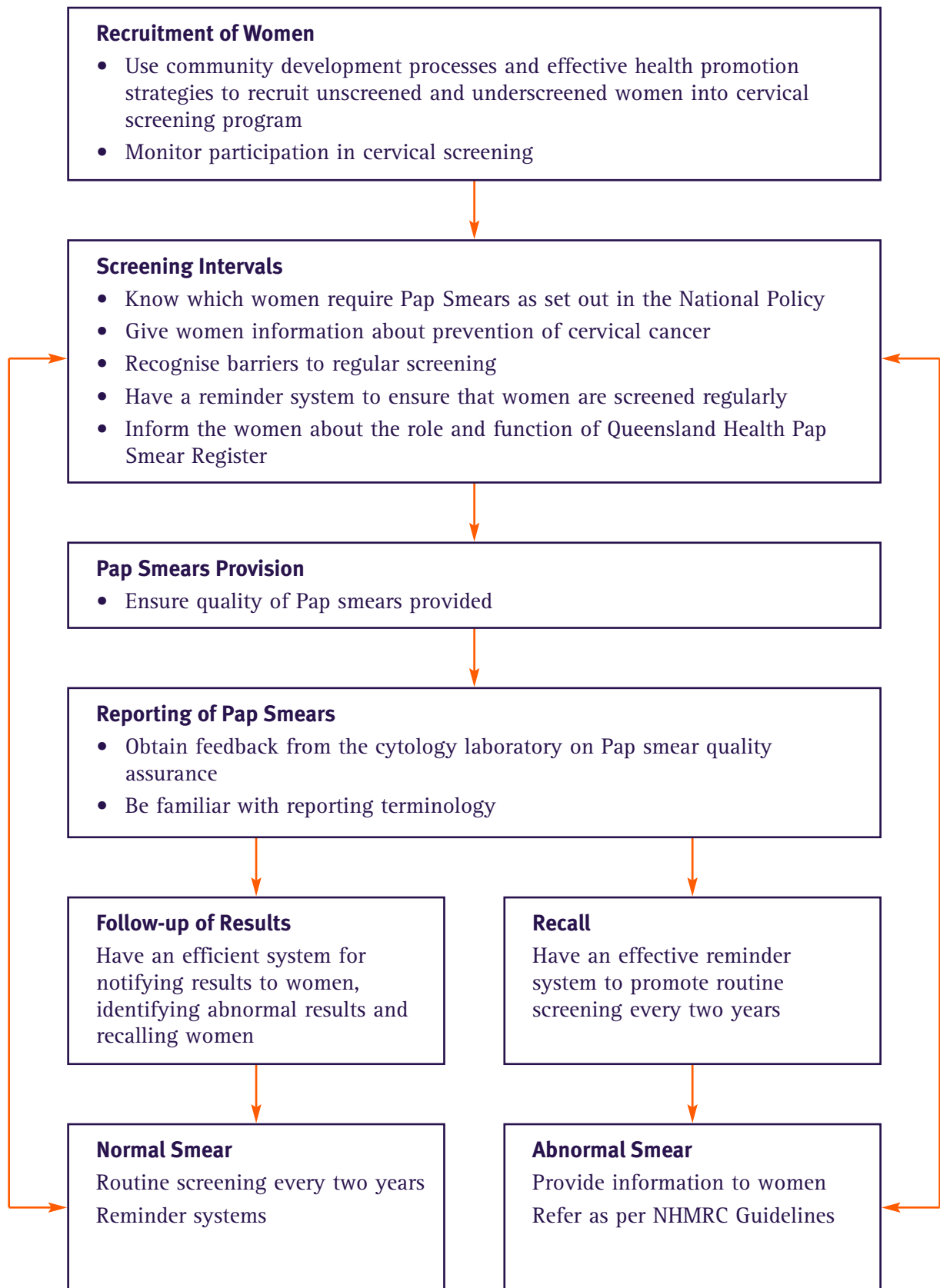
Cervical screening, however, involves more than just a Pap smear. It involves a range of activities that collectively form the cervical screening pathway (see Figure 1). These activities include educating and recruiting eligible women to participate in regular screening, the provision of high quality and appropriate screening services, high quality systems for the reading and reporting of Pap smears, mechanisms to provide women with their results, appropriate follow-up and management of women with screen-detected abnormalities, and monitoring of the screening program.

### **The Queensland Cervical Screening Program**

The Queensland Cervical Screening Program (QCSP) is the State component of the joint Commonwealth/State National Cervical Screening Program (NCSP). Through the provision of cost effective, accessible and high quality cervical screening, management and treatment services, the NCSP aims to reduce the incidence and associated morbidity and mortality attributed to cervical cancer.

The current policy is that women should participate in screening once every two years, with participation measured by rates. The participation rate is calculated as a count of the participation of eligible women aged 20 to 69 who have had a Pap smear within a two-year period and who choose to be registered on the Queensland Health Pap Smear Register as a proportion of the eligible population. The state-wide participation rate for the target age group of women aged 20 to 69 in 2004/05 was 58.3%. This is the lowest participation rate of all the States and Territories and below the 2003 - 2004 Australian rate of 60.7% (Australian Institute of Health and Welfare, 2006).

**Figure 1: The Cervical Screening Pathway**



## **Factors Affecting Women's Participation in Cervical Screening**

There are multiple contributing factors that impact on women's participation in cervical screening in Queensland. These include -

- the geographical distribution of Queensland's population
- a rapidly growing Queensland population and subsequent increase in the number of women eligible for screening
- medical workforce issues including;
  - a shortage of general practitioners (GPs) in rural and remote areas, particularly female GPs
  - decreased availability of or access to GPs who bulk bill
  - the relatively high number of international medical graduates in rural and remote areas, many of whom are from countries where there is limited or no training in cervical screening because these programs are not available in their country of origin
- the percentage of the population in Queensland who are Aboriginal and Torres Strait Islander peoples.

Women who are less likely to participate in regular cervical screening include -

- women living in rural and remote areas including Aboriginal and Torres Strait Islander women
- Aboriginal and Torres Strait Islander women
- women from culturally and linguistically diverse backgrounds
- older women (55-69 years of age)
- women from low socio-economic or rural and remote areas.

## **Barriers Affecting Aboriginal and Torres Strait Islander Women's Participation in Cervical Screening**

The Queensland Cervical Screening Program commissioned the University of Queensland to undertake a research project titled 'Barriers to and Appropriate Delivery Systems for Cervical Cancer Screening in Aboriginal and Torres Strait Islander Communities in Queensland' during 1997/1998 (Kirk et al, 1998). This project explored access barriers faced by Aboriginal and Torres Strait Islander women, reviewed existing service models in Queensland and interstate and made recommendations for action. This research involved comprehensive consultation and collection of qualitative information from Aboriginal and Torres Strait Islander women in urban, rural and remote Queensland and Aboriginal and Torres Strait Islander and non-Indigenous service providers. Major barriers affecting access to screening for Aboriginal and Torres Strait Islander women were identified and informed the development of the 2000 - 2004 strategy. The same or at least similar barriers were identified in the review of the 2000 - 2004 strategy.

### **Client-related barriers**

Findings from the above research revealed the following client-related barriers that impact upon Aboriginal and Torres Strait Islander women's participation in cervical screening in Queensland:

- a lack of knowledge about the screening process and the concept of prevention
- confusion about Pap smears and tests for detecting sexually transmitted infections
- fear of the procedure itself
- feelings of shame and embarrassment when having a Pap smear
- preference for a female provider (for screening and follow-up/treatment services)
- fear about the lack of confidentiality with test results
- fear of having an abnormality detected
- lack of choice of services and/or providers in some geographical areas
- a lack of culturally effective and culturally safe resources
- lack of formal support networks for men who encourage and support Aboriginal and Torres Strait Islander women through screening and/or upon diagnosis.

Aboriginal and Torres Strait Islander women have stated that they are not always able to put into words the nature of their fears or concerns about having a Pap smear to service providers or their male partners, family members or siblings. Aboriginal and Torres Strait Islander women are, in general, reluctant to be screened or treated by non-Indigenous people who are perceived as having limited or no prior knowledge/understanding about past policies and practices (Kirk et al 1998).

### **Cultural and historical barriers**

Culturally specific reasons for low participation in screening have been identified. Past policies and practices still impact on Aboriginal and Torres Strait Islander women and their families as these acted to separate Aboriginal and Torres Strait Islander women from their children, their family connections and from their culture and specific traditions. Aboriginal and Torres Strait Islander women have expressed a fear that, by having an abnormality detected, they would need to travel away from their own community for follow-up care or treatment, leaving their family to look after themselves.

Another identified factor is that access to services by Aboriginal and Torres Strait Islander women is dependant upon the provision of a culturally safe environment for women. A culturally safe environment is one where people feel safe enough to be themselves, are not afraid to speak their mind and/or talk about their own culture and or use their own language and are able to express their own views without fear of recrimination, being frowned upon or being humiliated.

## **Structural barriers**

Workforce issues also impact upon service provision for Aboriginal and Torres Strait Islander women. The need for designated Women's Health Workers has been identified.

Another significant issue is a lack of service integration (coordination and liaison) between service providers in the cervical cancer prevention and control area and community members. This includes public and private sector services as well as community follow-up-care services and non-government agencies.

## **Principles and strategies underpinning the Queensland Aboriginal and Torres Strait Islander Women's Cervical Screening Strategy 2006 - 2010**

The Strategy has been underpinned and informed by the previous research conducted by Ms Kirk, the National Aboriginal Health Strategy (National Aboriginal Health Strategy Working Party, 1989), the Indigenous Women's Cervical Screening Strategy 2000 - 2004 and is to be used in conjunction with the National Aboriginal and Torres Strait Islander Sexual Health Strategy 2005 - 2008 and the Queensland Cancer Control Strategic Directions 2005 - 2010.

## **Key action areas for the Queensland Aboriginal and Torres Strait Islander Women's Cervical Screening Strategy 2006 - 2010**

The key actions for the Queensland Aboriginal and Torres Strait Islander Women's Cervical Screening Strategy 2006 - 2010 are:

1. Culturally effective and culturally safe policy and practice.
2. Community education for Aboriginal and Torres Strait Islander women.
3. Screening and follow-up services.
4. Work-force development and cross-cultural awareness for both Aboriginal and Torres Strait Islander and non-Indigenous health service personnel.
5. Cancer support services for Aboriginal and Torres Strait Islander women.
6. Recognising and supporting the role of men.
7. Monitoring and evaluation.

These key action areas aim to improve service provision and women's participation in cervical screening and are described further in the following sections.

## Identifying key partnerships

The successful implementation of the strategy is dependant on building partnerships and requires collaboration across a range of sectors working towards the common goal of reducing incidence, morbidity and mortality from cancer of the cervix amongst Aboriginal and Torres Strait Islander women in Queensland. Key partners in this process include -

- Aboriginal and Torres Strait Islander women and Aboriginal and Torres Strait Islander men
- Aboriginal and Torres Strait Islander Medical Services
- Queensland Health - in particular Area Health Services, Health Service Districts, the Aboriginal and Torres Strait Islander Health Unit, Population Health Branch and Population Health Networks, Communicable Diseases Unit
- Pap smear and colposcopy service providers in public, private and non-Government sectors
- Divisions of General Practice and general practitioners
- Peak bodies representing Aboriginal and Torres Strait Islander peoples
- Peak bodies representing community-controlled Aboriginal and Torres Strait Islander Health Services
- Commonwealth Department of Health and Aged Care (Office of Aboriginal and Torres Strait Islander Health Services)
- Universities and other training institutions
- Aboriginal and Torres Strait Islander Health Service Training Institutions (TAFE, North Queensland Work force Unit)
- Professional, medical and nursing colleges
- Royal Flying Doctor Service (RFDS)
- Medical/nursing training institutions
- Cancer Council Queensland (CCQ).

## **Culturally Effective and Culturally Safe Policy and Practice**

### **Rationale**

This key action area aims to promote the implementation of the 'Principles of Practice, Standards and Guidelines for Providers of Cervical Screening Services for Indigenous Women' to guide strategic planning processes for Aboriginal and Torres Strait Islander women's cervical screening services.

This key action has been included in the 2006 - 2010 Strategy in response to feedback from key stakeholders to ensure the strategy underpins individuals' work plans. This key action area also outlines strategies to guide the implementation of the 'Principles of Practice, Standards and Guidelines for Providers of Cervical Screening Services for Indigenous Women'.

### **Principles of Practice, Standards and Guidelines for Providers of Cervical Screening Services for Indigenous Women**

An outcome of the research conducted by Ms Kirk (1998) was the development of the 'Principles of Practice, Standards and Guidelines for Providers of Cervical Screening Services for Indigenous Women'. These standards and guidelines will be referred to from this point forward as the 'Principles of Practice'. Written in a broad context, these Principles of Practice are suitable for use in other services and settings besides cervical screening.

The Principles of Practice were introduced nationally to provide a framework for action and are supported by Health Workers across Australia. Implementation of the Principles of Practice is on-going.

### **How the Strategy and the Principles of Practice will guide us in the future**

The 2006 - 2010 strategy and the Principles of Practice are both considered to be working documents to effect positive change in the planning, development, implementation, evaluation, monitoring and maintenance of cervical cancer prevention and follow up care services.

The 2006 - 2010 strategy is intended to provide a state-wide framework for action that will guide individual work plans and practices. In particular, it is expected that the strategy will contribute to Queensland Health's commitment to reducing the incidence, morbidity and mortality from cancer of the cervix among Aboriginal and Torres Strait Islander women. This can best be achieved by implementing a multi-disciplinary team approach whereby Health Workers form an integral part of the team.

## Key Action Area 1. Culturally Effective and Culturally Safe Policy and Practice

**Goal** To increase knowledge of key strategies and guidelines among key partners and stakeholders involved in Aboriginal and Torres Strait Islander cervical screening/cancer service provision.

**Objectives** To implement and evaluate the Queensland Aboriginal and Torres Strait Islander Women's Cervical Screening Strategy 2006 - 2010. To continue the implementation and to evaluate the Principles of Practice, Standards and Guidelines for Providers of Cervical Screening Services for Indigenous women.

Strategies	Process and Quality Indicators	Timeframe	Key Partners
1.1 Encourage and support the establishment of Aboriginal and Torres Strait Islander networks within each Area Health Service to promote the Queensland Aboriginal and Torres Strait Islander Women's Cervical Screening Strategy 2006 - 2010.	1.1 Evidence of networks that communicate both formally and informally.	January 2006 - 2010.	CSSU, AMSs, Elders and community members, AHS, PHU, HSD and other identified networks as appropriate.
1.2 Disseminate and promote the 2006 - 2010 Strategy to other local and State/Territory key partners.	1.2 Number of Strategy documents disseminated throughout Queensland and other jurisdictions.	April 2006 - June 2009.	CSSU, Reference group members, IHWs, AHMs, DMs, other key partners.
1.3 Promote the 2006 - 2010 Strategy as a guide for individual work plans and practices.	1.3 Evaluation feedback indicates the use of the Strategy to guide work plans.	May 2006.	CSSU, Reference group members, IHWs, AHMs, DMs, other key partners.

## Key Action Area 1. Culturally Effective and Culturally Safe Policy and Practice

**Goal** To increase knowledge of key strategies and guidelines among key partners and stakeholders involved in Aboriginal and Torres Strait Islander cervical screening/cancer service provision.

**Objectives** To implement and evaluate the Queensland Aboriginal and Torres Strait Islander Women's Cervical Screening Strategy 2006 - 2010.  
To continue the implementation and to evaluate the Principles of Practice, Standards and Guidelines for Providers of Cervical Screening Services for Indigenous women.

Strategies	Process and Quality Indicators	Timeframe	Key Partners
1.4 Monitor and report on the implementation of the 2006 - 2010 Strategy.	1.4 Implementation plan developed and disseminated to key partners.	May 2007 and December 2010.	CSSU SPOI, AHS, DMs and other key stakeholders.
1.5 Encourage and support the development and maintenance of a key contact list of support persons or networks involved in the implementation and dissemination of the 2006 - 2010 Strategy.	1.5 Evidence of a register of people or networks that is regularly maintained.	June 2007 and updated annually.	CSSU SPOI, Health Workers and other key partners.
1.6 Disseminate copies of the Principles of Practice to all cancer services, other Pap smear providers and key partners/ stakeholders throughout Queensland.	1.6 Number of Principles of Practice disseminated throughout Queensland.	June 2006 ongoing.	CSSU SPOI, members of the NATSIWF, AGDOHA.
1.7 Evaluate the usefulness of the Principles of Practice with cervical screening and follow-up service providers throughout Queensland.	1.7 Evaluation report completed.	July 2006 and July 2007.	CSSU SPOI, members of the NATSIWF, AGDOHA.

## Key Action Area 2

### **Community Education for Aboriginal and Torres Strait Islander Women.**

#### **Rationale**

This key action area aims to increase the knowledge of Aboriginal and Torres Strait Islander women about cancer and in particular their understanding of the importance of having regular Pap smears. Increased participation of Aboriginal and Torres Strait Islander women in cervical screening is imperative to reduce the incidence, morbidity and mortality of cervical cancer in Indigenous communities.

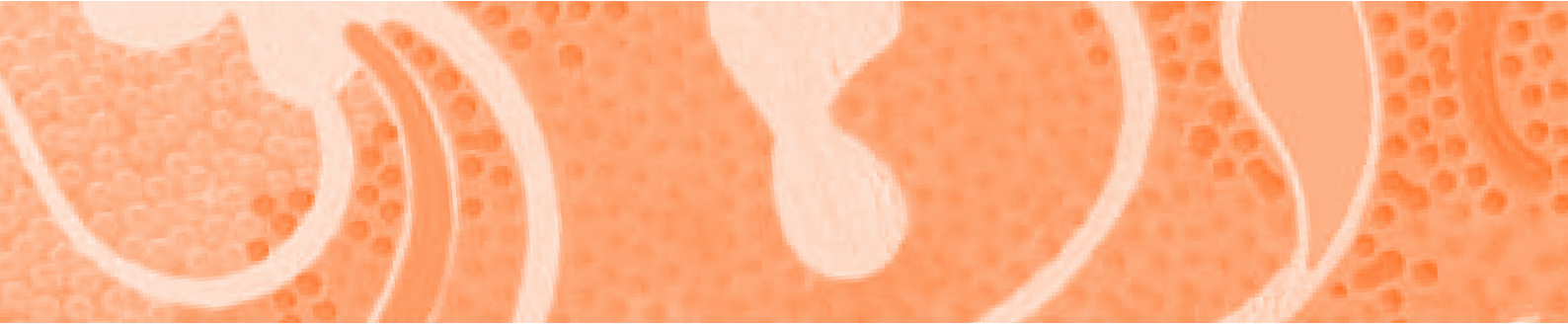
Community education about risk factors, risk factor modification, and the screening itself, is therefore an important first step in encouraging women to participate in cervical screening. The importance of providing health promotion messages to women in a way that is culturally appropriate and culturally safe cannot be overlooked. It is essential that educational programs or activities are planned, developed, implemented, evaluated and maintained by Aboriginal and Torres Strait Islander women themselves or in an equal partnering relationship with non-Indigenous women.

#### **Models of Health promoting education and training, peer education and resource development**

##### **1. The Healthy Women's Initiative**

A common feature of the most successful cervical screening educational activities with Aboriginal and Torres Strait Islander women is when they have been based on the principles of community development. This is where the women themselves have identified the need for programs or resources, proposed potential solutions, then acted upon these to develop programs or resources which meet identified needs.

A recent example of a health promotion project that involved extensive community engagement, development and partnerships is the Healthy Women's Initiative. The Healthy Women's Initiative (HWI) Project (2003/05) investigated several agreed models of women's health services that encouraged participation in the cervical screening pathway within Aboriginal and Torres Strait Islander communities in Cape York. This project aimed to improve health outcomes for women by implementing an integrated healthy women's initiative. This included education and health promoting information on cervical screening and sexual health services, and access to services upon diagnosis, treatment and follow up care and ongoing support. The impact of the project on screening was an 11.9% increase in Pap smears and a 61% increase in PCR testing in the pilot communities during the life of the project. The HWI has been expanded to areas of identified need in Queensland and will continue to be monitored over the life of this strategy.

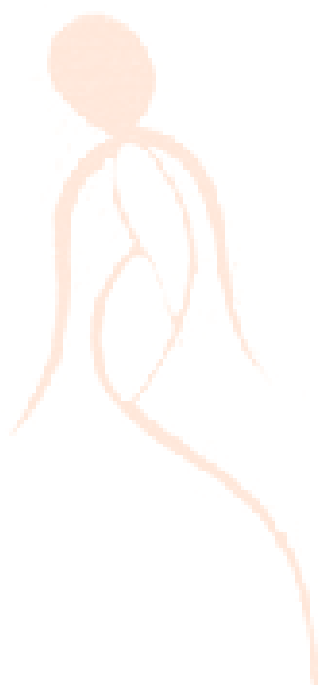


## **2. Aboriginal and Torres Strait Islander Cervical Screening Community Education Kit**

The Aboriginal and Torres Strait Islander Cervical Screening Community Education Kit was finalised in 2006 in partnership with Health Workers, community women, non-Indigenous QCSP staff and other key partners. The resource contains culturally effective information to assist Health Workers develop and deliver cervical screening education sessions for women in the community. It is designed to provide a clear understanding of cervical screening and cancer in general. The information is presented in a range of different formats and at various levels to allow each individual Health Worker to choose the workshop activities and materials that are conducive to the learning needs of their individual audience and includes principles for providing culturally safe learning environments. The kit is to be implemented across Queensland through train-the trainer workshops and health worker education.

## **3. Screening Reminder (Material) Resources; State-wide resources - QCSP**

Resources to prompt and remind Aboriginal and Torres Strait Islander women to participate in regular screening have been developed through community engagement and a genuine community development process. Two culturally effective and culturally safe cervical screening resources, a fridge magnet and a prompt-and-reminder card were developed in 2005 after the need was identified by Health Workers, clients, other key community people and mainstream and community-control services providers.



<b>Key Action Area 2. Community Education for Aboriginal and Torres Strait Islander Women</b>			
<b>Goal</b>	<b>To increase knowledge of the prevention of cervical cancer among Aboriginal and Torres Strait Islander women.</b>		
<b>Objective</b>	<b>Develop cervical screening community education activities and resource materials in partnership with Aboriginal and Torres Strait Islander women and partner organisations, which are based on identified community needs and through appropriate protocols and procedures.</b>		
<b>Strategies</b>	<b>Process and Quality Indicators</b>	<b>Timeframe</b>	<b>Key Partners</b>
2.1 Use existing women's community groups and services including Aboriginal Medical Services and Health Workers and other appropriate networks to support and encourage the collaborative development, dissemination and evaluation of culturally effective and culturally safe resources.	2.1 Number of collaborative resources available or developed and/or implemented and evaluated which have involved input from Health Workers and other appropriate networks.	Ongoing.	QSCP, CSSU, Health Workers and other key community members, DHS, DGPs, GPs, FPQ, QCF.
2.2 Develop and disseminate cervical screening information to Health Workers, Hospital Liaison Officers and women's health service providers.	2.2 Information disseminated in a timely manner to all.	As required.	SPOI.
2.3 Promote links between Health Workers, Aboriginal Medical Services, Mobile Women's Health Service, Sexual Health Services and other key contacts involved in community education programs/ services in rural/remote areas.	2.3 Evidence of collaborative health promotion activities.	Ongoing.	HSD, QCSP, MWHNs, SHS & Health Workers, AMSs, QCF and other key stakeholders as appropriate.
2.4 Disseminate the Aboriginal and Torres Strait Islander Cervical Screening Community Education Kit.	2.4 Number of kits disseminated and health promotion activities conducted as identified during evaluation of the kit.	2006 - 2008.	CSSU, NQWU Health Workers.

### Screening and Follow-up Services

The provision of cervical screening and follow-up services are a critical aspect of the screening program. Many Aboriginal and Torres Strait Islander women use mainstream services for cervical screening and other 'Women's Business' issues, however these services do not always meet the diverse needs of Aboriginal or Torres Strait Islander women. Often there is no other choice of service available, as many communities do not have access to community-controlled health services. However for some women the use of mainstream services is an individual choice.

As highlighted by Kirk et al (1998), some services are culturally insensitive, ineffective, alienating or assimilating in nature. The report indicated that there remains a certain degree of distrust between Aboriginal and Torres Strait Islander women and non-Indigenous Pap smear providers and sexual health workers. Significant progress has been made to increase women's access to female Pap smear providers. Services such as the Mobile Women's Health Service (MWHS) and the Rural & Remote Women's Health Program provided by the Royal Flying Doctor Service (RFDS) operate in many rural/remote communities and significantly enhance women's access to a female provider.

Cervical screening services are available in Queensland through a range of providers including general practitioners, registered nurses (predominantly in rural/remote areas), sexual health clinics, family planning clinics, antenatal services, outpatients services in local hospitals, and community-based Aboriginal and Torres Strait Islander medical services. Because of the inter-relatedness of these services and the need for referral networks to be established within and between services, it is imperative that coordinated and integrated approaches to cervical cancer prevention are established locally as promoted within the Healthy Women's Initiative. This ensures that Aboriginal and Torres Strait Islander women have access to appropriate care at all stages of the screening pathway. However, it should be noted that women, including Aboriginal and Torres Strait Islander women, may decide to travel to another district or geographical location altogether to access screening. This choice can sometimes be attributed to kinship or cultural reasons, or alternatively their screening might take place ad hoc in another location. This might be due to opportunistic screening if they attend a health service for another health issue when visiting a different location other than their usual place of residence. This demonstrates the benefits for women, including Aboriginal and Torres Strait Islander women, being registered on the Queensland Health Pap Smear Register for recall and follow up.

### Factors impacting on screening and follow-up services

From the research conducted through the Queensland Cervical Screening Program, the following factors are known to impact upon women's participation in cervical screening in remote communities and in particular for Aboriginal and Torres Strait Islander women:


- Historically it is an issue for members of the Aboriginal and Torres Strait Islander community (including women) to be seen entering a sexual health service as this causes concern that other community members will assume that the Aboriginal and Torres Strait Islander client may be seeking advice about a sexually transmitted infection (STI). Visible access can also sometimes contribute to the eruption of domestic violence and/or cause other friction within partner or family relationships.

- Access to a female Pap smear provider is essential.
- Services should be provided in a location or environment that is seen to be as 'female friendly' and where possible located in a venue which is seen as a 'well place' rather than a place for treating sick people, such as a hospital environment.
- For women requiring follow-up or treatment for abnormalities, there may be limited choice of gender in relation to service provider. In rural/remote areas where access to specialist services may be further compromised, the gender of the specialist has been demonstrated to be a barrier to many women including Aboriginal and Torres Strait Islander women accessing recommended follow-up or treatment (Kirk et al, 1998).
- Integration of cervical screening into a broader women's health service for Aboriginal and Torres Strait Islander women (eg. through the Well Person's Health Check, Sexual Health Services, Aboriginal and Torres Strait Islander medical services and antenatal services), is a cost-effective way of maximising participation in screening. It also provides opportunities for maximising the referral process and in minimising the number of women who are lost to follow-up.
- Information on stage of cancer at diagnosis and how Aboriginal and Torres Strait Islander cancer patients are affected by co-morbidities has been limited to date. Diabetes type 2, chronic renal disease and hypertension, for instance, are much more common in Aboriginal and Torres Strait Islander people than non-Indigenous people and the presence of co-morbidities may predict even poorer treatment outcomes particularly in respect to cancer treatment and ultimately survival. (Valery, Stirling, Coory, Green, 2005).
- In many cases, there may not be an Aboriginal and Torres Strait Islander person or a provider who has established community trust who can act as a liaison between women and the screening or follow-up service. Health Workers know their community and as such are in a good position to work with service providers to assist them to assess their own service and how well it meets the needs of the local community.

### **New Technologies**

New technologies have been introduced into cervical screening including computer-assisted screen reading devices, liquid-based slide preparation devices and HPV testing. The impact of new technologies on Aboriginal and Torres Strait Islander women needs to be fully explored in consultation with women, communities and health service providers prior to their introduction.

An example of a new technology that has had a positive impact for Aboriginal and Torres Strait Islander women is the use of Thin Prep® in accordance with the Queensland Health Thin Prep Policy.



A trial by the Queensland Cytology Service of a liquid based slide preparation system (ThinPrep®) in Far North Queensland indicated the potential for this technology to enhance screening outcomes for women with persistent unsatisfactory smears (Shield et al, 1999). Unsatisfactory smears may be difficult to assess due to the presence of inflammation or infection (due to sexually transmitted infections, for example) obscuring the cervical cells. Through a filtration process, liquid-based slide preparation devices produce a slide that contains a representative, well preserved sample of cervical cells that are free from obscuring background material, allowing more reliable screening by pathology laboratory staff.

It is recommended that a patient with an unsatisfactory smear have a repeat smear (usually within 6-12 weeks). With persistent unsatisfactory smears, women are referred for colposcopic assessment. For women in remote areas, the need for more regular screening and further tests creates difficulties, particularly where screening services may be provided by visiting service providers or where specialist services are located in major centres. The social and financial costs for women to access follow up can be significant, and in some cases may reduce their compliance with recommended treatment or follow-up.

### **The HPV vaccine**

There is overwhelming evidence that Human Papilloma Virus (HPV) is necessary for the development of cervical cancer. Vaccines for preventing infection with HPV 16 and 18, the most common types of HPV found in cervical cancers have been developed. The vaccines are primarily intended to be given before exposure to HPV (that is before any sexual activity takes place).

The National HPV Vaccination Program will commence in April 2007. All girls aged 12 to 18 years will receive the free vaccine through a school-based vaccination program. The vaccine will also be available at no cost to women aged 18 to 26 years from their GP, or community immunisation provider in 2007 and 2008.

The implementation of the HPV vaccine in Aboriginal and Torres Strait Islander communities needs to be incorporated into community education programs in consultation with Aboriginal and Torres Strait Islander peoples to maximise its uptake.

### **NHMRC Guidelines**

The NMHRC guidelines, Screening to Prevent Cervical Cancer: 'Guidelines for the Management of Asymptomatic Women with Screen-detected Abnormalities' was implemented 3 July 2006 in all states and territories. These guidelines reflect the most recent evidence relating to the natural history of cervical cancer and Human Papilloma Virus (HPV). This information is relatively new and all women, including Aboriginal and Torres Strait Islander women need to be provided with information about HPV and changes to follow-up procedures following an abnormal result to ensure they are well placed to make informed choices.

<b>Key Action Area 3. Screening and Follow-up Services</b>			
<b>Goal</b>	<b>To increase access by Aboriginal and Torres Strait Islander women to cervical screening and follow-up services.</b>		
<b>Objective</b>	<b>To ensure that all cervical screening and follow-up services are culturally effective and culturally safe for Aboriginal and Torres Strait Islander women.</b>		
<b>Strategies</b>	<b>Process and Quality Indicators</b>	<b>Timeframe</b>	<b>Key Partners</b>
3.1 Promote the employment of designated Aboriginal and Torres Strait Islander Women's Health Workers.	3.1 Proportion of services that have Health Workers employed directly or indirectly who work specifically in women's health.	Ongoing.	HSDs, CSSU, CDU, AMSs.
3.2 Promote integrated community-controlled and mainstream women's health services through the provision of combined clinics/services and established referral networks.	3.2 Number of integrated clinics/services that are positively evaluated by the community and health service providers.	Ongoing.	HSD, AMSs, CSSU, FPQ, DGPs.
3.3 Encourage visiting colposcopy/treatment services in rural/remote areas to employ and/or build partnerships with Aboriginal and Torres Strait Islander female support staff.	3.3 Evidence of outreach/visiting colposcopy services working in collaboration with appropriate female support staff.	Ongoing.	HSDs, FROGS.
3.4 Implement the Healthy Women's Initiative in targeted areas across Queensland.	3.4 Increases participation rates of women in areas where the Healthy Women's Initiative is implemented.	2006 - 2010.	CSSU, Area Health Services, HSDs.
3.5 Disseminate culturally appropriate information relating to the NHMRC guidelines to health providers to support the care of Aboriginal and Torres Strait Islander women with abnormal Pap smears.	3.5 NHMRC resources are disseminated to health providers.	December 2006.	CSSU, AMSs, AHS, HSDs, Health Workers.

### Work-force Development

- a) **Education and training for Aboriginal and Torres Strait Islander health personnel**
- b) **Acknowledgement and respect for the histories, culture and traditions for both Aboriginal and Torres Strait Islander and non-Indigenous health personnel**

### Rationale

This section encompasses two important areas - education and training for Aboriginal and Torres Strait Islander health personnel; including both clinical and non-clinical training, and cross-cultural awareness.

### Cross-cultural awareness

Cross-cultural awareness aims to ensure that there is acknowledgement and respect for the histories, cultures and traditions for all people including Aboriginal and Torres Strait Islander peoples and health personnel, and for all non-Indigenous people and non-Indigenous Health personnel.

### Education and training of the Aboriginal and Torres Strait Islander health workforce

Health Workers play a vital role in cervical screening across the cervical screening pathway.

Historically, Health Workers have been employed as multidisciplinary workers under the guise of Generalist Health Workers. Their role is complex and compounding, particularly as Health Workers have to deal with multifaceted issues within their community. Cancer Screening Services Unit, Population Health Branch has funded designated Women's Health Worker positions. These positions have clear roles and responsibilities and will be supported to participate in relevant training and professional development activities.

The role of the designated Women's Health Worker is to:

- support women to access screening by providing community education
- assist in recruiting women to attend cervical screening services
- advocate for culturally safe and culturally effective service provision
- encourage women to attend follow-up and minimise the number of women who are lost to follow-up
- support the woman and her family through follow-up and treatment including palliative care when required, and in the event of death and the associated stages of grief and loss.

From the feedback received during the Strategy evaluation process and findings from the Healthy Women's Initiative project, there are a number of workforce issues that impact upon Health Workers and their capacity to function effectively in their role. These include:

- Confusion about the role and scope of the health worker
- Access to appropriate training and professional development
- Local issues, such as other staff who are often temporary or working in the service short-term dictating what and how services should be provided, gate-keepers and lack of recognition of Health Workers' knowledge and skills, despite completing appropriate education and training.

### **Training needs**

Research has revealed that Aboriginal and Torres Strait Islander Health Worker training is successful when provided as 'on the job' training, or relates specifically to the Health Worker's role in their own particular community. Additionally, having a nominated peer support person or identified mentor from the outset and during training is also a preferred model for the delivery of training (National Health & Medical Research Council, 1996).

Training must be competency-based and provided in an environment where trainees can receive immediate feedback and where clinical support mechanisms and referral networks are in place (National Health & Medical Research Council, 1996). Study or training that requires Health Workers to travel away from family and community is not always recommended and this mode of study has mostly been found to be unsuccessful. Therefore community-based practical assessment should be considered. Recognition of prior learning and experience should also be taken into account (National Health & Medical Research Council, 1996).

### **Pap smear provision**

Ideally, Aboriginal and Torres Strait Islander women should be able to choose a Pap smear provider who best suits their individual needs. The role of Health Workers as Pap smear providers has been identified as an appropriate strategy to increase screening participation in some areas. Research has shown that there is a strong desire for local female Women's Health Workers to be trained as Pap smear providers in some communities whereas in other communities, kinship relationships may not always make it appropriate for workers to provide clinical services.

There are limited numbers of Aboriginal and Torres Strait Islander Pap smear providers who have been trained and are currently providing Pap smears, however their role is important as it provides women with another choice of provider. The role of Health Workers as Pap smear providers requires further acknowledgement and recognition through their inclusion in existing Queensland Health Registered Nurse Pap smear provider policies and processes such as the Policy, Protocols and Procedures for Registered Nurse Pap Smear Providers and the Authorisation Process to enable access to the Queensland Health Pap Smear Register.

## **Supporting Women and their Families during Treatment and Follow-up Care**

To date, there has been limited training available on how to support the client (and their family when appropriate) during treatment and follow-up care. Provision of education about treatment options, the impact of co-existing conditions and palliative care will provide Health Workers with a strong knowledge base with which to support women who are diagnosed with cervical cancer.

## **Education and Training for Aboriginal and Torres Strait Islander Health Workers**

### **- North Queensland Workforce Unit Women's Health Cervical Screening Course**

The North Queensland Workforce Unit has been funded to develop a competency-based course for Health Workers that will be offered from 2007. This course aims to provide Health Workers with background knowledge about cervical screening and cervical cancer within the context of women's health. Health Workers who want to become Pap smear providers can then progress to the Women's Health Course which involves clinical training in the provision of Pap smears and cervical screening consultations.

### **- The Cancer Council Australia and the Cancer Council Queensland Cancer Care Program for Aboriginal and Torres Strait Islander Health Workers**

Cancer Council Queensland has made a commitment to provide culturally appropriate and culturally safe education and scholarships that would support Health Workers to attend this training.

A Queensland-wide Aboriginal Reference Group advised on the development of a Queensland-based course 'Cancer Care Program for Aboriginal and Torres Strait Islander Health Workers' which was conducted in November 2005 and November 2006. Further courses are planned for 2007. An equivalent course has been offered for more than twenty years to nurses from all over Queensland.

This course focuses on the clinical and health promotion aspects of cancer, including cancer incidence, cancer treatments and side effects, the impact of cancer, cancer prevention and early detection, palliative care and grief and loss.

## Key Action Area 4.1. Education and Training of Aboriginal and Torres Strait Islander Health Personnel

**Goal** To increase the knowledge of Aboriginal and Torres Strait Islander Health Workers about the practices and procedures of cervical screening, follow-up-care, treatment and support services.

**Objective** To support the development and implementation of culturally effective education, training and on-going support for Aboriginal and Torres Strait Islander Health Workers.

Strategies	Process and Quality Indicators	Timeframe	Key Partners
4.1.1 Support the development of a competency-based cervical screening education and training program for Health Workers.	4.1.1 Competency-based programs developed and provided.	December 2006 and ongoing.	CSSU, NQWU, Health Workers.
4.1.2 Develop Queensland Health Policy and Protocols for Health Workers as Pap Smear Providers.	4.1.2 Policy and protocols for Health Workers as Pap smear providers developed and endorsed.	December 2006.	CSSU-SPOI, CNC, FPQ, ATSI HU, HSD, AMS.
4.1.3 Facilitate the development of clinical support and referral networks for existing and newly trained Women's Health Workers and Health Worker Pap smear providers.	4.1.3. Evidence of well-established support networks for designated Women's Health Workers and Health Worker Pap smear providers.	Ongoing.	SPOI & CNC SPO CSSU, HSD, AMSs, FPQ.
4.1.4 Support the development of appropriate career structures that recognise the advanced practice role of Women's Health Workers.	4.1.4 Career structures developed that recognise the advanced practice role of Women's Health Workers.	December 2006.	ATSIHU, IRU, CSSU, NQWU.
4.1.5 Develop processes to encourage employment of Aboriginal and Torres Strait Islander women within cervical cancer prevention and control services.	4.1.5 Increased number of Aboriginal and/or Torres Strait Islander women employed in cervical cancer prevention and control services.	Ongoing.	All stakeholders.
4.1.6 Develop and provide links to on-going training, education and professional advice/support for Women's Health Workers.	4.1.6 Satisfaction (as reported by key partner and stakeholder organisations and IHWs) with level of advice and support provided by CSSU Senior Project Officer (Indigenous).	Ongoing.	CSSU-SPOI and key partner and stakeholder organisations.

## Key Action Area 4.2. Cross Cultural Awareness Training for Aboriginal and Torres Strait Islander and non-Indigenous Health Personnel

**Goal** To instil in all staff, knowledge about the cultural diversity and significance of Aboriginal and Torres Strait Island history, culture, spirituality and traditions.

**Objective** To ensure that cervical cancer prevention and control services are culturally effective and culturally safe for Aboriginal and Torres Strait Islander women.

Strategies	Process and Quality Indicators	Timeframe	Key Partners
4.2.1 Promote the inclusion of the Principles of Practice and Aboriginal and Torres Strait Islander Women's Cervical Screening Strategy 2006 - 2010 in cervical screening education programs.	4.2.1 Evidence of the inclusion of the Principles of Practice and Aboriginal and Torres Strait Islander Women's Cervical Screening Strategy 2006 - 2010 in cervical screening education program course readings.	December 2006 and ongoing.	CSSU, cervical screening course providers.
4.2.2 Promote the inclusion of cross-cultural awareness in cervical screening education programs for medical students/practitioners, MWHS, registered nurses and health service providers.	4.2.2 Evidence of the inclusion of cross-cultural awareness in cervical screening education program curricula.	Ongoing.	SPOI, CSSU, QCSP CNC, NQWU, FPQ, QCF.
4.2.3 Participate in the provision/review of cross cultural awareness programs to ensure 'Women's Business' and cervical screening issues are appropriately addressed.	4.2.3 Level of involvement in cross cultural awareness programs.	Ongoing.	All stakeholders.

## Key Action Area 5

### Cancer Support Services for Aboriginal and Torres Strait Islander Women

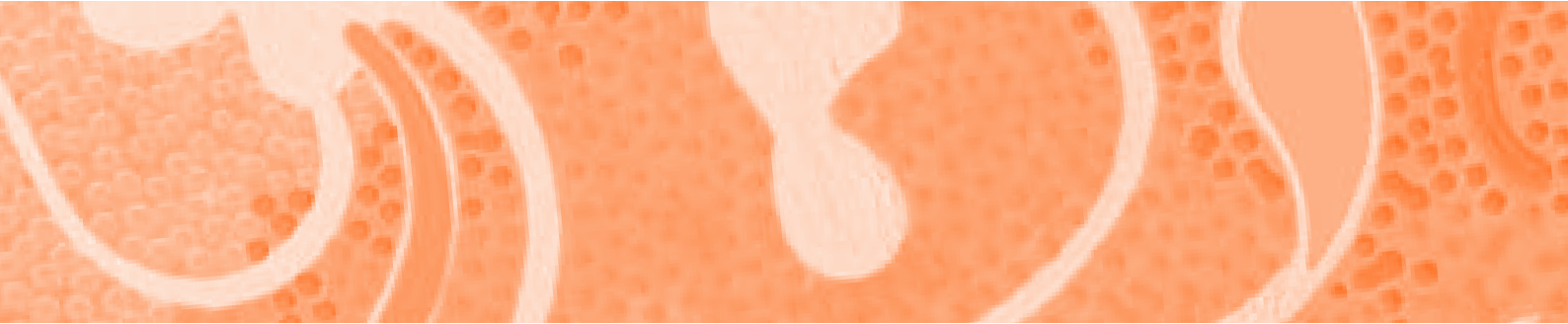
#### Rationale

Women experience a range of emotions when diagnosed with cervical cancer or a cervical abnormality, including fear, embarrassment (shame), confusion, denial or anger. Aboriginal and Torres Strait Islander women experience compounded feelings and reactions which relate to their cultural, community, spiritual, traditional and historical belief systems. Cervical abnormalities are often asymptomatic; that is, there are no physical symptoms that women can see that would lead them to believe they have an abnormality or, indeed, cancer. Historically and traditionally, almost all Aboriginal and Torres Strait Islander women still have genuine fears when hearing the word 'cancer'. When receiving results which indicate an 'abnormal' smear they almost always, regardless of the support and information available, fear the worst.

Although it is imperative that women diagnosed with an abnormality, particularly a high-grade abnormality, have appropriate follow-up, Aboriginal and Torres Strait Islander women often want to retreat back into the family unit and their respective community to allow time to reflect on the information given. However, after this occurs it is often then extremely difficult for the woman to prioritise her own health needs or weigh up how critical it is to access follow up, further treatment or make other decisions to improve health. It is essential that the continuum of care extends beyond diagnosis and that management plans address not only follow-up but the provision of appropriate advice, counselling and on-going care. For this reason, women require support from Health Workers, family and community members to assist and encourage them to access the health system for follow up treatment and care. It is crucial that this 'support' recognises the Aboriginal and Torres Strait Islander concepts of health, illness, wellbeing and healing so that Aboriginal and Torres Strait Islander women can recover culturally and spiritually as well as medically within their own family network and community frameworks. The duty of care for Aboriginal and Torres Strait Islander Health Workers in supporting roles to these clients is an enormous task.

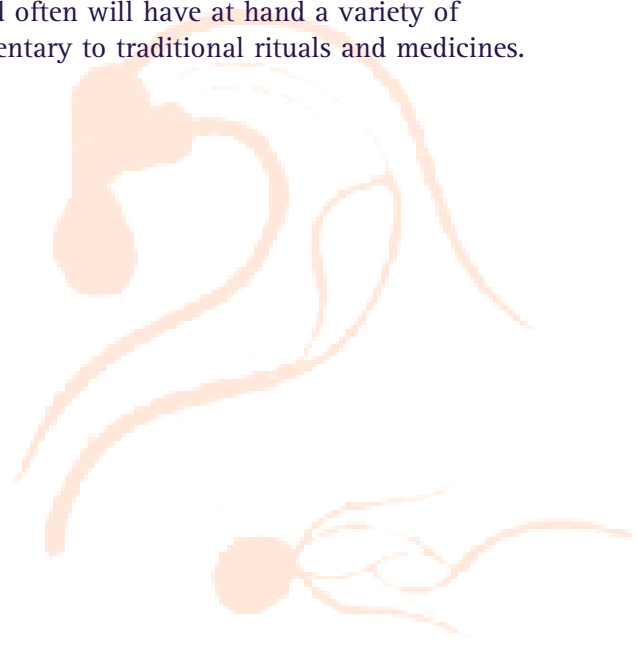
Assistance schemes such as the Patient Transit Scheme must recognise the role of support persons and escort officers in the provision of cancer support services to Aboriginal and Torres Strait Islander women when they need to leave their family network, the familiarity of their own community framework and the familiar and trusted infrastructure and geographical and other environments within their own community. This is important irrespective of whether the community is urban, rural, remote or traditional.





The Queensland Cervical Screening Program has provided funding to two Health Service Districts (Royal Brisbane and Women’s Hospital and Townsville) to establish Aboriginal and Torres Strait Islander Women’s Cancer Support Officer positions within the two major hospital complexes to support women from adjoining or remote communities. These unique positions are dedicated to the critical provision of hands-on support for Aboriginal and Torres Strait Islander women diagnosed with breast or cervical cancer and support for families when required.

A range of government and non-government agencies, including Queensland Health, the Cancer Council Queensland, private hospitals and hospices, provide cancer support, counselling and palliative care services to women. All cancer support and palliative care agencies have a responsibility to ensure services meet the needs of Aboriginal and Torres Strait Islander people. The most effective way of achieving this is to ensure that Aboriginal and Torres Strait Islander people are involved in a meaningful way in advising, developing, planning, implementing, evaluating, maintaining and supporting these service providers. The employment of peer educators and mentors who might be Elders or Aboriginal and Torres Strait Islander women who are cancer survivors is a key initiative towards enhancing the cultural sensitivity of such services. These key people bring with them first hand knowledge and experience with the disease itself and often will have at hand a variety of collaborative western medical treatment regimes complementary to traditional rituals and medicines.



## Key Action Area 5. Cancer Support Services for Aboriginal and Torres Strait Islander Women

**Goal** To ensure that cervical cancer support services for Aboriginal and Torres Strait Islander women are accessible and culturally safe and culturally effective and promote Aboriginal and Torres Strait Islander concepts of healing.

**Objective** To ensure that the needs of Aboriginal and Torres Strait Islander women diagnosed with cervical cancer are met physically, culturally, spiritually and medically.

Strategies	Process and Quality Indicators	Timeframe	Key Partners
5.1 Support the involvement of Aboriginal and Torres Strait Islander peer educators and mentors (including Elders and cancer survivors) in cancer support services.	5.1 Proportion of cancer support services that utilise peer educators or mentors as part of their service.	June 2007 and ongoing.	All cancer treatment, support and palliative care service including CCQ.
5.2 Monitor the need for additional Aboriginal and Torres Strait Islander Women's Cancer Support Officers.	5.2 Aboriginal and Torres Strait Islander Cancer Support Officer positions located in areas of need.	May 2006 and bi-annual review.	CSSU, SPOI, HSD.
5.3 Develop culturally effective and culturally safe cervical cancer support resources and educational materials (human and material) in partnership with key partners and stakeholders.	5.3 Culturally appropriate cancer support resources (human and material) developed promoted and/or distributed to Health Workers, educators and trainers.	May 2006 and ongoing.	QCF, AMS, DOHA, CSSU, CCQ.
5.4 Encourage the establishment of culturally effective and culturally safe women's healing places/services.	5.4 Support for culturally effective and culturally safe women's healing places/services.	Ongoing.	Cancer treatment, support/palliative care services, hospitals, AMs.
5.5 Encourage cancer treatment, support and palliative care services to disseminate culturally appropriate information regarding services and referral points in local Aboriginal and Torres Strait Islander communities.	5.5 Support for proportion of cancer treatment, support and palliative care services disseminating information to Aboriginal and Torres Strait Islander communities.	December 2007.	All cancer treatment, support and palliative care service including CCQ.


### Recognising and Supporting the Role of Men

#### Rationale

Traditionally, culturally and historically, Australian Aboriginal and Torres Strait Islander peoples have had a clear division between 'Men's and Women's Business'. Research categorically states that it is often the male partners (or other male family members), of Aboriginal and Torres Strait Islander women who support Aboriginal and Torres Strait Islander women through the cancer screening pathway. This occurs specifically upon diagnosis and afterwards during treatment and follow up care. Therefore education must be developed to increase men's knowledge and skill in this area (Kirk et al, 1998). As there are very few material resources available to support and educate men about what Aboriginal and Torres Strait Islander women deal with upon diagnosis and during treatment and follow up care, health promotion resources must be designed in consultation with men to enhance and improve the knowledge and skills of carers and support people, including male partners or family members.

In all education sessions, educators and participants should be mindful and respectful of the 'Men's and Women's Business' cultural concept and be respectful of the feelings of each participant to ensure that the teaching environment is at all times culturally effective and culturally safe. This is particularly so if the only educator available is a female. As a further safety net, throughout any education sessions, regardless of whether the educator is male or female, individual participants should be supported if they leave the room at any time should they find that any of the material is confronting or goes against their own belief system about the 'Men's and Women's Business' concept. If such a situation arises educators should ensure that these exits inform the content of future courses to prevent a reoccurrence of confronting, culturally unsafe situations.

Regardless, Aboriginal and Torres Strait Islander women's health must be recognised as women's business and educators, service providers and policy makers should be mindful that male Health Workers or men often will not undertake 'Women's Business', unless a specific need has been identified. This notwithstanding, it is important that male Health Workers and men recognise that cancer screening is an important preventative action and that they can offer crucial support for their Aboriginal and Torres Strait Islander partners, family members and friends. Therefore, the need for men to be involved in any business considered 'Women's Business', whether it be in developing education and training or material resources for men and male Health Workers, must be assessed on an individual and/or community needs basis. This must occur in strict collaboration with Aboriginal and Torres Strait Islander and non-Indigenous men and with members from each community for which the resources are proposed.



Current research identifies that male partners and/or family members including siblings, are often the main support people who encourage Aboriginal and Torres Strait Islander women to access screening services, or are the main support people or carers of Aboriginal and Torres Strait Islander women when an abnormality or cancer is diagnosed (Kirk et al, 1998). Men and male Health Workers have inquired as to how they can best encourage their partners, or family and community members to access preventative cancer screening and to support them if they need treatment and follow-up-care. There is currently a lack of culturally-safe or culturally-effective information available that has been specifically developed to inform or guide men or male Health Workers in this area.

Aboriginal and Torres Strait Islander women also need information to pass onto their carers. Often their carer is their male partner. Aboriginal and Torres Strait Islander women are struggling with the consequences of their diagnosis and concern for their families and carers. However, it is often too difficult to talk about their feelings when appropriate avenues such as culturally effective and culturally safe counselling and healing services are not available.

Literature about soothing, painless and calming environments and material resources about palliative care and caring environments or facilities that are seen to be culturally effective and culturally safe are essential. Cancer support and palliative care services must take responsibility for ensuring that culturally appropriate and culturally safe resource materials, palliative care centres and formal support networks are available for not only the woman but for male partners and carers and developed in consultation with Aboriginal and Torres Strait Islander and non-Indigenous men.

A 'train-the-trainer' module about cervical screening and cancer for men has recently been developed by a respected male Aboriginal Health Worker. The resource aims to educate men and Health Workers who support Aboriginal and Torres Strait Islander women through the screening pathway from diagnosis to treatment and follow up care. This resource was recognised as an appropriate culturally effective and culturally safe health promoting resource by Aboriginal and Torres Strait Islander men and participants at the Strategy Workshop in May 2005. This resource has the potential to be adopted as a state-wide resource and will hopefully be followed up and supported by appropriate organisations and departments.

## Key Action Area 6. To Recognise and Support the Role of Men in Cervical Cancer Prevention and Control Services

**Goal** To develop and support mechanisms that recognise and support the role of Aboriginal and Torres Strait Islander men in cervical screening, prevention and control services.

**Objective** To develop in participation with key Aboriginal and Torres Strait Islander men and support culturally safe and culturally effective education, training and on-going support activities to inform men who act as support people to women with cervical cancer.

Strategies	Process and Quality Indicators	Timeframe	Key Partners
6.1 Identify male Health Workers and other key men in the community to provide advice to CSSU on appropriate projects, services or resources for men who support Aboriginal and Torres Strait Islander women with cervical and other cancer.	6.1 Local networks established and/or existing men's groups supported.	Advisory Group established by June 2007 and ongoing.	CSSU SPOI, HSD, AMS, GPs, Community Health Centres, QBCSP.
6.2 Facilitate the development of culturally effective and culturally safe cervical cancer education, training and support resources for Aboriginal and Torres Strait Islander men.	6.2 Resources developed in consultation with Aboriginal and Torres Strait Islander men.	June 2008.	CSSU, HSDs, Male HWs, CCQ, QBCSP.
6.3 Investigate the possibility of training Aboriginal and Torres Strait Islander men to be skilled as peer educators for other men who are supporting Aboriginal and Torres Strait Islander women diagnosed with cancer.	6.3 Feasibility of an education program for Aboriginal and Torres Strait Islander men explored with relevant organisations as identified.	January - December 2007.	CCQ, HSD, SPOI CSSU, QBCSP.

## Key Action Area 7

### Monitoring and Evaluation

#### Rationale

Monitoring and evaluation is a critical part of a population-based screening program, as it allows an objective assessment of whether the screening program is achieving its intended outcomes. Queensland Health reports to the Australian Government Department of Health and Aged Care through the Australian Institute of Health and Welfare against a number of performance indicators relating to cervical screening and cervical cancer.


Two Queensland Health data sources provide this information - the Queensland Cancer Register, which collects data on incidence and mortality from cancer, and the recently established Queensland Health Pap Smear Register, which is a population-based register of Pap smear and related cervical histology results.

Indicators cover the areas of participation in screening (ie. in line with the biennial screening policy), early re-screening (ie. earlier than two yearly where the previous smear result was normal), low and high-grade abnormality detection, incidence and mortality from cancer of the cervix (Australian Institute of Health and Welfare. 1998).

The Queensland Cancer Register receives data under the Health Act from hospitals, nursing homes and pathology laboratories. Ethnic origin (including Aboriginality) has been collected since 1991 by the Queensland Cancer Register, however the completeness and accuracy of this data relies on service providers collecting this information at the time of providing the service.

Improving the health and well-being of Aboriginal and Torres Strait Islander people in Queensland is a key priority for Queensland Health. Crucial to achieving this goal is having information systems that accurately identify Aboriginal and Torres Strait Islander people. A report on Aboriginal and Torres Strait Islander Identifiers in Queensland Health's Public Health Systems (Communicable Diseases Unit, 1998) made a number of recommendations, including that all new information systems and data collections conform to the standards set out in the Queensland Health Data Dictionary (Health Information Centre, 1999) and include an Aboriginal and Torres Strait Islander identifier. It was acknowledged in this report that concern remains among some representatives of the Aboriginal and Torres Strait Islander community about the potential misuse of health data, which includes a person's Aboriginal and Torres Strait Islander status.

A person's Aboriginal and Torres Strait Islander status cannot and should not be determined by observation alone yet feedback from the distribution of the initial draft strategy confirmed that this happened often. Therefore appropriate mechanisms must be developed to assist all Pap smear providers to ask women in an appropriate way if they identify as Aboriginal, Torres Strait Islander or both. Such mechanisms must be developed and promoted in consultation with Aboriginal and Torres Strait Islander women. In addition, Aboriginal and Torres Strait Islander women must be made to feel safe to self-identify as being Aboriginal and/or Torres Strait Islander.



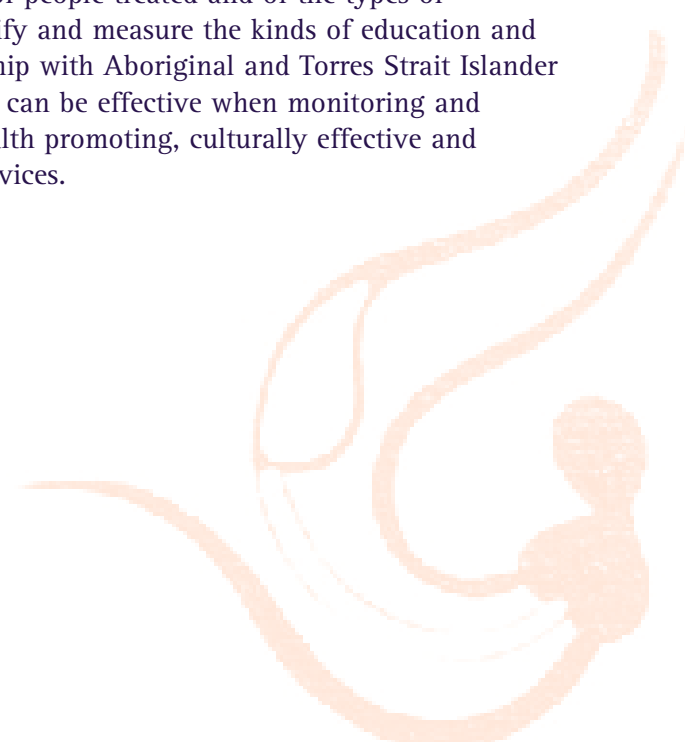
Because of the incompleteness of data held on the Cancer Registry in terms of ethnic origin, indications of incidence and mortality from cancer of the cervix amongst Aboriginal and Torres Strait Islander women have instead been provided by analysing data based on Statistical Local Areas (SLAs) that have a significant Aboriginal and Torres Strait Islander population (Coory et al, 1998).

In 2002, a study was conducted to investigate the extent of participation in cervical screening among women who live in discrete rural and remote Indigenous communities in Queensland (Coory et al, 2002). This research highlighted that the biennial participation rate in Indigenous communities was 41.1% which was 30% lower than the rest of Queensland at that time. The study revealed significant variance in participation rates among communities, with biennial participation percentages ranging from 19.9% to 63.5%. This analysis highlighted areas of need for targeted programs aimed at increasing Aboriginal and Torres Strait Islander women's participation in cervical screening and is to be repeated in 2006 to determine the effectiveness of strategies that have been introduced since 2001.

Program monitoring and evaluation is a valuable way of measuring the effectiveness of services and service delivery and is often used in determining the allocation of program resources. However, Aboriginal peoples and Torres Strait Islander peoples often regard this as research. There is continuing concern among Aboriginal and Torres Strait Islander peoples about the amount of research undertaken in their communities, particularly by non-Indigenous people.

Self determination for Aboriginal and Torres Strait Islander people also extends to the areas of monitoring, evaluation and research, allowing Aboriginal and Torres Strait Islander people to undertake their own research and to use the information as seen to be appropriate and/or beneficial to the Aboriginal and Torres Strait Islander community.

Often because of the way services are funded, priority in terms of monitoring and evaluation is for quantitative measures such as throughput - the number of people treated and of the types of individual services provided. It is often difficult to quantify and measure the kinds of education and health promotion services provided. Working in partnership with Aboriginal and Torres Strait Islander peoples, other service providers and general practitioners can be effective when monitoring and evaluating strategies that measure women's access to health promoting, culturally effective and culturally safe cervical cancer prevention and control services.



## Key Action Area 7. Monitoring and Evaluation

**Goal** To use an evidence-based planning process, based on accurate and reliable data, to plan, monitor and evaluate the Queensland Cervical Screening Program.

**Objective** In participation with Aboriginal women, Torres Strait Islander women and service providers, develop mechanisms for monitoring and evaluating cervical cancer prevention and control services.

Strategies	Process and Quality Indicators	Timeframe	Key Partners
7.1 Enhance the capacity of the Pap Smear Register, to collect Aboriginal and Torres Strait Islander status through incorporation of an Aboriginal and Torres Strait Islander Identifier on pathology request forms, or mechanisms for self-identification.	7.1a) Aboriginal and Torres Strait Islander Identifier included on both public and private pathology request forms. 7.1b) Mechanisms for self-identification established.	Progress towards identifier on private forms by December 2006.	QHPSS, CSSU, SPOI, ATSIHU, Private pathology laboratories, AGDOHA.
7.2 Facilitate and support the development of culturally sensitive mechanisms for collecting Aboriginal and Torres Strait Islander status during a cervical screening consultation.	7.2 Guidelines for the collection of Aboriginal and Torres Strait Islander Identifiers developed and implemented.	Guidelines developed by December 2007.	CSSU, ATSIH, professional colleges, health service providers and the community.
7.3 Conduct research on cervical screening participation in discrete Indigenous communities.	7.3 Reports produced and disseminated widely, particularly to key stakeholders.	June 2007.	CSSU.

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## **Strategies used to review the 2000 - 2004 Strategy and develop the 2006 - 2010 Strategy**

The review of the previous Strategy and development of the 2006 - 2010 Strategy was undertaken through:

1. The distribution of a strategy review questionnaire to key stakeholders
2. Written and telephone feedback received from key partners and key stakeholders
3. A state-wide participatory action workshop
4. The establishment of a reference group for consultation and review of the draft strategy and endorsement of the final strategy
5. Dissemination of the draft strategy to key partners and key stakeholders, including reference group members
6. Endorsement of the final strategy
7. Official launch of 2006 - 2010 Strategy.

## **Strategy Review Questionnaire**

An evaluation survey in the form of a written questionnaire was circulated by both land mail and email to key stakeholders to gain feedback to evaluate the effectiveness of the 2000 - 2004 Strategy, including its implementation and inform the development of the 2006 - 2010 Strategy.

Key stakeholders included:

- Aboriginal and Torres Strait Islander Health Workers
- District Managers, Health Services Districts, Queensland Health
- Australian Society of Colposcopy and Cervical Pathology
- Aboriginal and Torres Strait Islander Community Health Education and Training Centres
- Aboriginal (& Torres Strait Islander) Medical Services
- Communicable Diseases Unit, Population Health Branch, Queensland Health
- Cancer Screening Services Unit, Population Health Branch, Queensland Health
- North Queensland Workforce Unit
- Flying Rural Obstetrics & Gynaecology Service, Queensland Health
- Family Planning Queensland
- Indigenous Health Programs, Queensland Health
- Representatives from the Mobile Women's Health Service, Queensland Health
- National Association of Community Controlled Health Organisations

- National Aboriginal and Torres Strait Islander Women's Forum
- Office of Aboriginal and Torres Strait Islander Health
- Queensland Aboriginal & Islander Health Council
- Cancer Council Queensland
- Royal Australian College of General Practitioners
- Royal Flying Doctor Service, Queensland Branch
- Sexual Health Services

### **Findings the 2000 - 2004 Strategy evaluation survey**


Concerted effort was invested during the review of the Queensland Indigenous Women's Cervical Screening Strategy 2000 - 2004 to encourage and support the participation of key partners and reference group members.

The questionnaire was distributed and received in good faith by respondents and returned with constructive feedback. Feedback was both qualitative and quantitative and was received from people who work at varying levels of the work environment including Health Workers and managers and staff of services, and as well from clients and community members.

### **Content provided from survey participants**

The questionnaire requested voluntary feedback and people were not required to add their name or contact details. However, almost everyone who responded to the survey did attach not only their name but also their title or role and their contact details. This assisted with follow up when required. Some of the responses given were developed collaboratively with input from each staff member of the service or organisation named in the respondent's contact details, thus providing comprehensive feedback and a "whole service" perspective.

Overall the evaluation feedback from the survey questionnaire was extremely constructive and honest and on the whole, very positive. Respondents stated that they were aware of the Queensland Indigenous Women's Cervical Screening Strategy 2000 - 2004 with only five (5) respondents revealing they were not aware of the strategy. Respondents were very supportive of the 2000 - 2004 strategy, of having a strategy for the next five years (2006 - 2010) and of each of the identified key action areas including the goals, objectives and strategies that were recommended for 2000 - 2004 strategy. When respondents weren't supportive about a particular key action identified in 2000 - 2004 strategy they were able to give very constructive feedback about the reasons why and thus there weren't any negative responses that did not give direction about the development of the 2006 - 2010 strategy.



Conversely, some respondents did not complete all of the questions in the questionnaire. However, the lack of answers to some of the questions did not cast any reasonable doubt on, or challenge the need for the development of a 2006 - 2010 strategy. Instead, the lack of answers to some questions seemed to be more a case of not being familiar with the 2000 - 2004 strategy in the first instance. At times, people stated “don’t know” or “not applicable” and/or actually stated that they were not aware of the strategy in the first place, which relates more to the implementation of the 2000 - 2004 strategy and was useful to guide the development and implementation of the 2006 - 2010 strategy. Although several of the returned questionnaires contained responses which were fragmented or ambiguous, additional unobtrusive follow up (via telephone and through the 30th May 2005 workshop) assisted in providing a more comprehensive analysis and guide for the overall 2006 - 2010 strategy.

Evidence suggested that while district and other managers, Aboriginal and Torres Strait Islander and non-Indigenous health practitioners, health personnel and staff at all levels including clients and community members were all aware of and mostly supported and endorsed the Queensland Indigenous Women’s Cervical Screening Strategy 2000 - 2004, a number of gaps have emerged. One gap related to the effectiveness of the Strategy’s implementation and in particular, in relation to the use of the Strategy during and after it was implemented.

Responses confirmed that the majority of respondents had seen and had used the 2000 - 2004 strategy but it was disappointing to receive feedback that they had not used the Strategy to guide their own work plan or individual practice. As a result, the 2006 - 2010 strategy includes another key action area “Culturally Effective and Culturally Safe Policy and Practice” with a view to ensuring specific strategies are incorporated into the 2006 - 2010 strategy to promote its use to guide individual and workplace practices and continue to be used in the work place as a “working” document.

### **The state-wide participatory action workshop**

This workshop was organised by Cancer Screening Services Unit and provided an opportunity for Health Workers and other key partners and stakeholders to work together in collaborative partnerships to identify and develop the key actions for the 2006 - 2010 strategy.

**Survey respondents and workshop participants identified key actions from the 2000 - 2004 Strategy that;**

- had been completed
- were in progress
- were yet to begin or be finalised
- should be on-going
- were either not appropriate or able to be addressed at this point in time.

In addition, participants were asked to identify new key actions that should be included in the 2006 - 2010 strategy.

**Strategy Review Reference Group**

As an outcome of the workshop, a reference group was formed with many self-nominating members making a commitment to provide further feedback and guidance for the development of the 2006 - 2010 strategy. The draft was widely circulated as a strategic planning document and recommendations were based on the outcomes of all research available in Queensland. The strategy was circulated widely for comment throughout Queensland by surface mail and email and follow-up by teleconference or face-to-face meetings was undertaken to gain further comment and endorsement as required.

### Key Stakeholders involved in the development of the 2006 - 2010 Strategy

#### Questionnaire respondents 2005

- Leeanne Baker - SIHW, Charleville Health Service District, Q 4470
- Catherine Swain - Indigenous Health Worker, Community Health, Gladstone Q 4680
- Rosenna Goodwin/David Webber - IHW, Redcliffe-Caboolture Health Service District, Q 4020
- Kym Kilroy - Indigenous Studies Unit, U of Q, St Lucia, Q 4067
- Margot Kingston - Family Planning Brisbane, Q 4000
- Kamille Bligh - IHW, Emerald Hospital, Q 4720
- Dr R.G. Wright - Pathologist, QML 60 Ferry Rd, West End, Q 4101
- Council Clerk - Kubin Is Council, Moa Island Torres Strait via Thurs Island, Q 4875
- Frankie Calleja - MWHN PO Box 221, Longreach, Q 4730
- Registered Nurse - Pap smear provider, Child and Family Health, Cnr Bolsover & Cambridge Sts, Rockhampton, PO Box 501 Rockhampton, Q 4700
- Prof S K Khoo - MO, Director, Div Gynae Teaching & Research, Level 6, Ned Hanlon Bldg, Royal Brisbane Hospital, Brisbane, Q 4006
- Felicity Pollard - IHW (Nutrition), Community Health, PO Box 301, Maryborough, Q 4650
- Dr Noel Hayman - Director, Indigenous Health Service Inala, PO Box 52, Inala Q 4077
- Robyn Chilcott - District Coordinator, Indigenous Health Community Service and Palliative Care Program, Prince Charles Hospital, Chermside, Brisbane, Q 4032
- Ann Cekulis - Maryborough District Community Health Service, Q 4650
- Hughie Kirk Snr - Aboriginal Elder, 3/185 Biota St, Inala Heights, Q 4077
- Registered Nurse Pap smear provider - RRWHP/RFDS PO Box 187, Edge Hill, Q 4870
- Manager - Mackay Health Service District, PO Box 5580, Mackay Mail Centre, 4741
- Leone Smith - A/Team Leader, Indigenous Health Program, PO Box 509, Maroochydore, Q 4558
- Margaret Hegarty - Deputy Director, Community Services, Cancer Council Queensland, PO Box 201, Fortitude Valley, Q 4004
- A/Prof Deryck Charters - Director of Obstetrics & Gynaecology, Gold Coast Hospital, Southport, Q 4215
- Janet Struber - Manager at the Zonal Level, Northern Zone, Q 4870
- Women's Health - Cherbourg Hospital, Q 4605
- AICHS - Woolloongabba, Q 4102
- Mary Coman - Executive Director, Community and Allied Health, Toowoomba, Q 4350
- Nurse Unit Manager - Wide Bay Sexual Health Service, Bundaberg, Q 4670
- Queensland Community Health - Cairns, Q 4870
- Phillipa Cole - Hospital Liaison Officer, PA Hospital, Q 4102
- Manager - North Burnett Health Service District, Mundubbera, Q 4626
- Sue Fatnowna - IHW (Sexual), 12-14 Nelson St Mackay, 4740

## Appendix 3

### Staff and participants of the Aboriginal and Torres Strait Islander Women's Cervical Screening Strategy Workshop 30th May 2005

Thanks to staff from Cancer Screening Services Unit for their timely knowledge and support including for their assistance in organising the travel arrangements of workshop participants and with the workshop venue hire (Ms Robyn Evans) and for their administrative support Ms Margo Deane and Ms Vanessa Cox. Additionally for their knowledge, skill and support and providing information on the day of the workshop.

- Jennifer Muller - CSSU
- Sandy Angus - CSSU
- Helen Suey - Toowoomba
- Michael Veasey - Toowoomba
- Mary Abbot - Toowoomba
- Lori Salam - Bundaberg
- Robert Salam - Bundaberg
- Lesley-Anne Clements - Princess Alexandra Hospital
- Leeann Baker - Charleville
- Christine Buchanan - Gold Coast
- Vera Webber - Eidsvold
- Olivene Youse - Roma
- Nancy Collins - Royal Brisbane & Women's Hospital
- Janet Struber - Cairns
- Wendy Sexton - Cairns
- Maureen Marzak - Redland Bay
- Lyn Gangemi - Biloela
- Laurel Lincolne - Maryborough
- Stephanie Button - Brisbane
- Emily Gordon - Gold Coast
- Dee Wallis - Cairns
- Liela Murison - Townsville
- Kym Kilroy - Brisbane
- Kym Boyes - Weipa
- Eileen Rasmussen - Biloela
- Roslyn Boland - Toowoomba
- Jerom Kirby - CSSU
- Phillipa Cole - Princess Alexandra Hospital
- Debbie Zysk - Bundaberg
- Norah Ansey - Rockhampton
- Cheri Yavu - Kama - Hahthunian, Hervey Bay
- Christine Reynolds - CSSU
- Deryk Charters - Gold coast
- Carmen French - Gold Coast
- Annette Rabbitt - Inala
- Maleta Nona - Thursday Island
- Kerrie Paul - Woolloongabba
- Margot Kingston - Brisbane
- Patsi Maw - Roma
- Raelene Baker - Brisbane
- Bronwyn Fredricks - Rockhampton
- John Brady - CSSU
- Alain Ferre - CSSU
- Leanne Christie - CSSU
- Joanne De Vries - Cairns

### Reference Group Participants

- Leeanne Baker - SIHW, Charleville Health Service District, Q 4470
- Catherine Swain - Indigenous Health Worker, Community Health, Gladstone, Q 4680
- Kym Kilroy - Indigenous Studies Unit, U of Q, St Lucia, Q 4067
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- Dr Noel Hayman - Director, Indigenous Health Service, Inala, PO Box 52, Inala, Q 4077
- Robyn Chilcott - District Coordinator, Indigenous Health Community Service and Palliative Care Program, Prince Charles Hospital, Chermside, Brisbane, Q 4032
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- Margaret Hegarty - Deputy Director Community Services Queensland Cancer Fund, PO Box 201, Fortitude Valley, Q 4004
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- Janet Struber - Manager at the Zonal Level, Northern Zone, Q 4870
- Women's Health - Cherbourg Hospital, Q 4605
- AICHS - Woolloongabba, Q 4102
- Phillipa Cole - Hospital Liaison Officer, PA Hospital, Q 4102
- North Burnett Health Service District - Mundubbera, Q 4626
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