Collecting self-identified status from Aboriginal and/or Torres Strait Islander patients and patients from culturally and linguistically diverse backgrounds

Why is it important?
Despite data on women’s participation in cervical screening, and the types and severities of cervical abnormalities they experience being widely available, it is not possible to accurately measure participation rates for sub-groups of the population such as Aboriginal and/or Torres Strait Islander women and women from culturally and linguistically diverse backgrounds.

One study found that Aboriginal women have up to an 18% lower participation rate than non-Aboriginal women. Aboriginal women are 2.8 times as likely to develop invasive cervical cancer and 3.9 times as likely to die from cervical cancer than non-Aboriginal women. They are also less likely than non-Aboriginal women to survive five years once they are diagnosed with cervical cancer.

Despite approximately 20% of Australians speaking a language other than English at home, there is limited information on culturally diverse women’s cervical screening participation. The Australian Bureau of Statistics released some information in 2001, collected as part of the National Health Survey. Among the nearly 10,000 women aged 18 years and over surveyed, lowest participation rates were recorded for women who:
- spoke Mandarin, Cantonese, Vietnamese, Arabic, Italian, Greek or German as the main language at home
- were born in South East Asian countries or Italy, or
- were born overseas and arrived in Australia since 1991.

The disparity in the cervical cancer morbidity and mortality rates of Aboriginal and/or Torres Strait Islander women and culturally diverse women, compared to the average female population, indicates that these groups of women are under-screened, and that this is leading to health inequality.

Collecting data on the cervical screening participation of Aboriginal and/or Torres Strait Islander and culturally diverse women would enable a greater understanding of their screening behaviour and inform targeted strategies to increase their participation in screening.

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2 AIHW, Cancer Australia 2013. Cancer in Aboriginal and Torres Strait Islander peoples of Australia: an overview. Cancer series 78. Cat. no. CAN 75. Canberra: AIHW; 14
3 Ibid
Definition of Aboriginal and Torres Strait Islander

This is the definition given by the High Court of Australia:

An Aboriginal or Torres Strait Islander is a person:

1. of Aboriginal or Torres Strait Islander descent, and
2. who identifies as an Aboriginal and/or Torres Strait Islander, and
3. who is accepted as such by the community in which he or she lives.

How to collect Aboriginal and/or Torres Strait Islander identification data

The ONLY effective and accurate way to identify someone of Aboriginal and/or Torres Strait Islander origin is to ask the question. Health providers are encouraged to ask each patient the following questions in relation to Aboriginal and Torres Strait Islander identification and to record responses on their cervical screening pathology request forms:

“Are you of Aboriginal or Torres Strait Islander origin?”

- Aboriginal
- Torres Strait Islander
- Aboriginal and Torres Strait Islander
- Not Aboriginal or Torres Strait Islander

If the patient answers yes to this question, it is important that it is clarified with the patient whether they are Aboriginal, Torres Strait Islander, or Aboriginal and Torres Strait Islander.

The exact wording of the question has been developed by the Australian Bureau of Statistics and has been adopted as the national standard for collecting Aboriginal and Torres Strait Islander status in administrative datasets, such as hospital collections; the Census; Registry of Births, Deaths and Marriages; education; and many more.

If a patient refuses to answer or cannot answer the question, the response to the question is considered incomplete. Responses that are incomplete MUST NOT be recorded as ‘Not Aboriginal or Torres Strait Islander’, but should be left blank/unanswered.

Why is it important to ask the question to every patient?

Many Aboriginal and/or Torres Strait Islander people are not visually identifiable and through incorporating the question in a non-judgmental way into your practice you may identify Aboriginal and/or Torres Strait Islander women that you were not aware of. Additionally, it is equally important to collect the status of women who do not identify as Aboriginal and/or Torres Strait Islander.

While you may know the patient’s family background, especially if you work in a small country town, this should NOT be a reason to not ask the question. Not all members of the same family may wish to identify themselves as Aboriginal or Torres Strait Islander.

Definition of a culturally and linguistically diverse background

‘In the Australian context, individuals from a CALD background are those who identify as having a specific cultural or linguistic affiliation by virtue of their place of birth, ancestry, ethnic origin, religion, preferred language, language(s) spoken at home, or because of their parents’ identification on a similar basis.’ (Department of Human Services Multicultural Strategy Unit, 2002)

Culturally and linguistically diverse people are generally defined as those people born overseas, in countries that are not classified by the Australian Bureau of Statistics as ‘main English speaking countries’.

How to collect culturally diverse identification data

Health providers are encouraged to ask each patient the following questions in relation to cultural diversity identification and to record responses on their cervical screening pathology request forms:

1. In which country was the patient born?
2. Does the patient speak a language other than English at home?

The exact wording of the questions has been taken from the Australian Bureau of Statistics.
What do I say if a woman wants to know why they are being asked these questions?

Some possible questions and responses include:

“Why do you need that information? I have never been asked this during a consultation before.”
- These questions are now asked of all patients who attend a health service for cervical screening.
- Currently there is no reliable data on the screening rates of culturally diverse and Aboriginal and/or Torres Strait Islander groups in Australia.
  It is important for us to get reliable statistics on screening rates, so programs can be developed to increase participation.

“How is my information going to be used?”
- Your information will be collected by the National Cancer Screening Registry and is protected by the Privacy Act. Your information will be used to develop programs aimed at reducing the rate of cervical cancer in the community.

What other things do I need to remember when collecting identification information?

- Women have the right to refuse to disclose their Aboriginal, Torres Strait Islander or culturally diverse status.
- Women have the right to change their status.
- Some people may be sensitive about disclosing their Aboriginal, Torres Strait Islander or culturally diverse status.
- Before asking the questions, it may be beneficial to explain why you are now asking about Aboriginal, Torres Strait Islander or culturally diverse status.
- It is important to ask all women the cultural diversity questions even if they have previously identified as being of Aboriginal and/or Torres Strait Islander descent. This will help ensure accurate data records, as well as identify those women with an Aboriginal and/or Torres Strait Islander heritage that may have been born overseas.
- It is important to ask the questions in the same way each and every time.