

national



---

NHMRC National Breast Cancer Centre

# Breast cancer and Aboriginal and Torres Strait Islander women

Sue Carrick  
Kathleen Clapham

Christine Paul  
Aileen Plant

Sally Redman

NHMRC National Breast Cancer Centre  
Yooroang Garang, the Centre for Indigenous Health  
Studies, University of Sydney  
Consultant  
Department of Public Health,  
University of Western Australia  
NHMRC National Breast Cancer Centre

National Library of Australia Cataloguing-in-Publication data:

Breast cancer and Aboriginal and Torres Strait Islander women

ISBN 0-9586732-2-5

1. Breast - Cancer - Australia.
  2. Aborigines, Australian - Women - Health and hygiene.
  3. Torres Strait Islanders - Women - Health and hygiene.
  4. Aborigines, Australian - Women - Medical care.
  5. Torres Strait Islanders - Women - Medical care.
- I. Carrick, Sue. II National Breast Cancer Centre (Australia).

616.99449

© 1996

NHMRC National Breast Cancer Centre  
PO Box 572  
KINGS CROSS NSW 1340

Ph: (02) 9334 1700

Fax: (02) 9326 9329

email: [director@nbcc.org.au](mailto:director@nbcc.org.au)

*homepage:* <http://www.nbcc.org.au>

The NHMRC National Breast Cancer Centre is funded by the Commonwealth Government

---

## Contents

|  |           |
|--|-----------|
| List of tables and figures   | ii        |
| Acknowledgments  | iii       |
| Executive summary  | iv        |
| Introduction   | vii       |
| <b>1 Demographic characteristics and risk profile</b>  | <b>1</b>  |
| <b>2 Incidence of, and mortality from, breast cancer</b>   | <b>7</b>  |
| <b>3 The early detection of breast cancer</b>  | <b>15</b> |
| <b>4 Knowledge, attitudes, and perceived needs in relation to breast cancer</b>                              | <b>20</b> |
| <b>5 Conclusions and recommendations</b>   | <b>31</b> |
| References   | 34        |
| Appendices   |           |
| 1 Key Aboriginal and Torres Strait Islander organisations and individuals consulted in preparing this report | 38        |
| 2 Cancer registries contacted  | 40        |
| 3 Unpublished small studies or reports identified  | 41        |
| 4 List of resources for Aboriginal and Torres Strait Islander women on breast cancer                         | 44        |

## **Tables**

|   |  |    |
|---|--|----|
| 1 | Aboriginal and Torres Strait Islander population: proportion in capital city and rest of state                                   | 2  |
| 2 | Observed and expected incidence of breast cancer in Aboriginal and Torres Strait Islander women for three states and territories | 10 |
| 3 | Self-reported participation in early detection: a comparison of Aboriginal and Torres Strait Islander and non-Aboriginal women   | 16 |

## **Figures**

|   |  |    |
|---|--|----|
| 1 | Female Aboriginal and Torres Strait Islander population aged 30-69 by Aboriginal and Torres Strait Islander Council region   | 3  |
| 2 | Age profile of Aboriginal and non-Aboriginal women in Australia  | 5  |
| 3 | Age-standardised incidence rates of breast cancer per 100,000 woman-years in Aboriginal and Torres Strait Islander women in the Northern Territory in 1987-1993 and in Western Australia in 1987-1992                    | 9  |
| 4 | Age-standardised mortality rates of breast cancer per 100,000 woman-years in Aboriginal and Torres Strait Islander women in the Northern Territory in 1987-1993 and in Western Australia in 1987-1992                    | 11 |
| 5 | Northern Territory age-standardised hospital separation, breast cancer, by Aboriginality, 1979-1988  | 13 |
| 6 | The proportion of eligible Aboriginal and Torres Strait Islander women and eligible non-Aboriginal and Torres Strait Islander women participating in BreastScreen Australia, the national mammographic screening program | 18 |

---

## Acknowledgments

The NHMRC National Breast Cancer Centre would like to thank the following individuals and organisations for their assistance in the preparation of this report:

- Congress Alukura, Alice Springs, for hosting two consultative workshops on behalf of the NHMRC National Breast Cancer Centre and undertaking to commission the painting used for the cover.
- The women who took part in the NHMRC National Breast Cancer Centre consultations.
- Lynore Geia, Congress Alukura, for her comments on the manuscript.
- John Condon, Epidemiology Branch, Northern Territory Department of Health and Community Services, for permission to reproduce Figures 3 and 4.

---

## Executive summary

This report summarises all of the available information about Aboriginal and Torres Strait Islander women and breast cancer on a national basis for the first time.

There is very little existing information about breast cancer in Aboriginal and Torres Strait Islander women, and that which is available may be biased, inaccurate and incomplete. However, within these limitations, it appears that:

- the crude incidence rates of breast cancer (ie the absolute numbers of cases per number of women in the population) may be lower among Aboriginal and Torres Strait Islander women than non-Aboriginal women primarily because of differences in the age structures of the populations. It is estimated that there may be approximately sixty new cases of breast cancer per year among Aboriginal and Torres Strait Islander women;
- from the limited available data the age-standardised rates of breast cancer among Aboriginal and Torres Strait Islander women are similar to or slightly less than those of non-Aboriginal women;
- data from the Northern Territory suggest that age-standardised mortality rates for Aboriginal and Torres Strait Islander women from breast cancer are the same as those among non-Aboriginal women. However, non-Aboriginal women in the Northern Territory are four times more likely to be hospitalised for breast cancer than Aboriginal and Torres Strait Islander women;
- data from South Australia indicate that age standardised cancer mortality rates for all cancers are higher among Aboriginal and Torres Strait Islander residents of South Australia than other Australians. The data also shows that Aboriginal and Torres Strait Islanders in South Australia are found to have lower primary cancer survival rates.
- data from the Australian Bureau of Statistics' Aboriginal and Torres Strait Islander Survey and from BreastScreen Australia indicate that Aboriginal and Torres Strait Islander women are less likely than non-Aboriginal women to participate in all early detection programs. Among Aboriginal and Torres Strait Islander women, 52% report regularly examining their breasts, 57% report ever having had their breasts examined by a health care professional and 26% of eligible women aged between 50-69 years had received a screening mammogram within the national program in the previous two years;

- in summary, the sparse evidence suggests that while the absolute numbers of new cases of breast cancer among Aboriginal and Torres Strait Islander women are not high, Aboriginal and Torres Strait Islander women are dying from the disease *at least* at the same rate as non-Aboriginal women and are less likely to be hospitalised for breast cancer; this may imply that Aboriginal and Torres Strait Islander women are less likely to receive or complete treatment for their disease. It also appears that breast cancer may be less likely to be found early among Aboriginal and Torres Strait Islander women because of their lower rates of participation in early detection programs;
- while no published qualitative or quantitative information about Aboriginal and Torres Strait Islander women was located, consultations with Aboriginal and Torres Strait Islander women described in seven different reports suggest that if programs are to be effective in improving breast cancer control they need to take account of a number of issues including: the perceived importance of local control of health programs; the need for health programs to be holistic and not focus on breast cancer in isolation from other health issues and to be delivered where possible by women as part of women's business; a lack of understanding among Aboriginal and Torres Strait Islander women about their risk of breast cancer and the importance of early detection; and the perception that screening mammography is culturally inappropriate and difficult to access. The perception that Aboriginal and Torres Strait Islander women diagnosed with breast cancer find it difficult to get adequate information about treatment options, feel that their treatment is not culturally appropriate, experience practical difficulties in travelling for treatment, and cannot access adequate supportive care either from within their own communities or from the health system was also identified as needing to be addressed by programs.
- programs should be targeted geographically at areas where most Aboriginal and Torres Strait Islander women live or where there are particular regional difficulties. The demographic data indicate that New South Wales and Queensland have the greatest numbers of Aboriginal and Torres Strait Islander women, particularly in the regions of Sydney, Coffs Harbour, Brisbane and Cairns. Women living in remote parts of Australia face particular regional problems in accessing information, screening and treatment.

Based on these findings, this report outlines a number of recommendations which may assist in improving breast cancer control among Aboriginal and Torres Strait Islander women.

**It is recommended that:**

- the state and territory cancer registries be encouraged to systematically record Aboriginal and Torres Strait Islander background;
- an evaluation of the accuracy of registration of Aboriginal and Torres Strait Islander background on breast cancer records be undertaken;
- an exploration of the needs of Aboriginal and Torres Strait Islander women with breast cancer be undertaken using a cohort design;
- a widespread community information program be implemented in consultation with Aboriginal and Torres Strait Islander women and Aboriginal Medical Services to ensure that Aboriginal women understand their risk of breast cancer and the importance of early detection. The campaign should use audiovisual resources and consider involving the Aboriginal media;
- the campaign be supported by the development of locally produced resources about breast cancer and early detection fostered through state and regional agencies;
- special training programs be developed for Aboriginal and Torres Strait Islander health workers to develop skills in clinical breast examination and an understanding of its importance;
- an examination of the costs and benefits of different strategies for increasing the early detection of breast cancer among Aboriginal and Torres Strait Islander women, particularly those living in rural and remote areas, be undertaken. This may include the collection of information about the accessibility and acceptability of mammographic screening to urban, rural and remote Aboriginal and Torres Strait Islander women;
- culturally appropriate resources be developed to provide Aboriginal and Torres Strait Islander women with information about management and support options;
- undergraduate and continuing medical education programs include material on the special needs of Aboriginal and Torres Strait Islander women and culturally appropriate management and support strategies;
- innovative support options be trialed, such as a help line for Aboriginal and Torres Strait Islander women or specially trained support staff in hospitals with higher numbers of Aboriginal and Torres Strait Islander women with breast cancer; and
- Aboriginal and Torres Strait Island Breast Cancer Support Service volunteers be recruited and trained to assist Aboriginal and Torres Strait Islander women diagnosed with breast cancer.

---

## Introduction

### Background

The Commonwealth Government, in establishing the NHMRC National Breast Cancer Centre (NBCC), requested that it address the needs of Aboriginal and Torres Strait Islander women in relation to breast cancer. This report draws together existing information about breast cancer in Aboriginal and Torres Strait Islander communities, with the aim of developing priorities for action. In preparing this report, there has been full consultation with key Aboriginal and Torres Strait Islander groups and individuals as detailed in Appendix 1.

At the outset, it must be acknowledged that little is known about breast cancer in Aboriginal and Torres Strait Islander women, and the disease has largely been seen both by Aboriginal and Torres Strait Islander and non-Aboriginal people as a ‘white woman’s disease’. Historical accounts of health issues among Aboriginal and Torres Strait Islander people did not identify cancer or breast cancer as important; for example, early this century J Burton Cleland noted in a series of articles about Aboriginal health that ‘*The records of neoplasms in natives are few in number*’ but that of these few, the malignant ones included probable breast tumours.<sup>1</sup> Breast cancer was not mentioned at all by the other major series of articles about Aboriginal health published around the same time by Basedow.<sup>2</sup>

Little or no information is available about cancers in Aborigines prior to white settlement or in the first 100 years after white settlement, although it is likely that Aborigines recognised cancer as a wasting syndrome and had a specific name for it. During this century and until very recently the literature about Aboriginal and Torres Strait Islander health remained preoccupied with infectious diseases such as tuberculosis, pneumonia and diarrhoeal disease. Reviews of autopsies and of causes of hospitalisations among Aboriginal people did not mention breast cancer.<sup>3,4</sup> In 1973, an examination of causes of death among Aboriginal people reported that neoplasms accounted for 6-8% of all deaths, although breast cancer was not specifically mentioned.<sup>5</sup>

## **Aim and outline of the report**

The aim of this report is to collate and critically appraise all existing information about breast cancer and Aboriginal and Torres Strait Islander women for the first time on a national basis. It is intended that the information included in the report assist in the identification of priorities for breast cancer control among Aboriginal and Torres Strait Islander women.

The report addresses the following issues:

- 1 demographic characteristics and risk profile;
- 2 incidence of, and mortality from, breast cancer;
- 3 the early detection of breast cancer;
- 4 knowledge, attitudes, and perceived needs in relation to breast cancer; and,
- 5 conclusions and recommendations.

The definition of ‘Aborigine’ used in this report is that used by the Australian Bureau of Statistics.<sup>6</sup> That is, an ‘Aboriginal and Torres Strait Islander’ person is one who self-identifies as a person of Aboriginal or Torres Strait Islander origin.

---

# 1 Demographic characteristics and risk profile

## Geographic location of Aboriginal and Torres Strait Islander women aged 30-69

The 1994 Australian Bureau of Statistics' (ABS) survey of Aboriginal and Torres Strait Islanders estimated that there were 46,334 Aboriginal and Torres Strait Islander women aged between 30 and 69 years of age living in Australia in 1994.<sup>6</sup>

Table 1 shows the numbers of Aboriginal and Torres Strait Islander people living in each state, based on data from the ABS.<sup>7,8</sup> It is evident that the largest numbers live in New South Wales and Queensland, both of which have approximately 80,000 Aboriginal and Torres Strait Islander people.

Figure 1 shows the numbers of women living in each of the thirty-six Aboriginal and Torres Strait Islander Council regions.<sup>6</sup> The Sydney region has the largest number of Aboriginal and Torres Strait Islander women (4,078 women), with large communities also in the Coffs Harbour region (2,953), Brisbane region (2,767), Cairns region (2,034), and Perth region (2,042). Smaller populations are resident in other regions.

**Table 1**  
**Aboriginal and Torres Strait Islander population:**  
**proportion in capital city and rest of state**

|                           | Capital city region |             | Rest of State  |             | Total          |
|---------------------------|---------------------|-------------|----------------|-------------|----------------|
|                           | Number              | Percent     | Number         | Percent     | Number         |
| <b>New South Wales*</b>   | 25,340              | 31.5        | 55,100         | 68.5        | 80,440         |
| <b>Victoria**</b>         | 9,370               | 48.9        | 10,040         | 51.1        | 19,180         |
| <b>Queensland</b>         | 18,800              | 23.5        | 61,040         | 76.5        | 79,840         |
| <b>South Australia</b>    | 11,020              | 59.8        | 7,410          | 40.2        | 18,430         |
| <b>Western Australia</b>  | 14,100              | 29.8        | 33,150         | 70.2        | 47,250         |
| <b>Tasmania***</b>        | 10,140              | 100         |                |             | 10,140         |
| <b>Northern Territory</b> | 8,140               | 17.7        | 37,900         | 82.3        | 46,040         |
| <b>AUSTRALIA</b>          | <b>96,910</b>       | <b>32.1</b> | <b>204,640</b> | <b>67.9</b> | <b>301,550</b> |

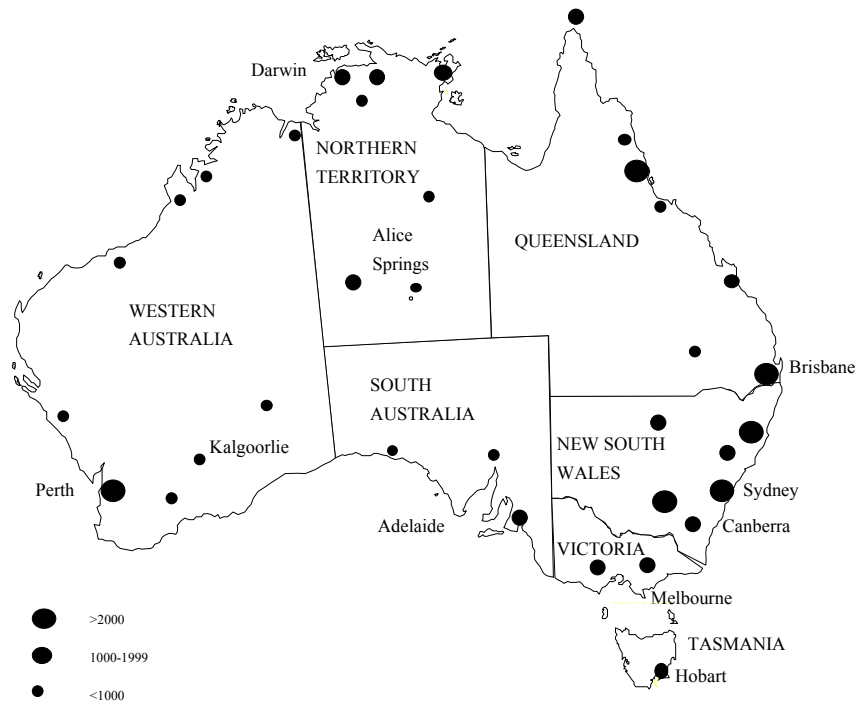
\* NSW figures include the ACT. The 1995 ABS<sup>6</sup> recorded the Aboriginal and Torres Strait Islander population as 1,775.

\*\* Victorian capital city region includes the Wangaratta region.

\*\*\* Tasmanian capital city region includes the whole of Tasmania.

Source: *The Health and Welfare of Australia's Aboriginal and Torres Strait Islander Peoples, 1997*. Canberra: Australian Bureau of Statistics; 1996f, 1991 Census, unpublished data.

**Figure 1**  
**Female Aboriginal and Torres Strait Islander population**  
**aged 30-69 by Aboriginal and Torres Strait Islander Council**  
**region**



*Source: Australian Bureau of Statistics. Australia's Aboriginal and Torres Strait Islander population: census of population and housing 6 August 1991. Canberra: Australian Bureau of Statistics; 1993.*

## Risk profile

The major risk factors for breast cancer established in non-Aboriginal populations are increasing age and family history.<sup>9</sup> Reproductive factors such as late menopause, late age at first birth (over 30), low parity and childlessness make a small contribution to increased risk, which may alter incidence rates at a population level.<sup>10,11</sup>

There have been no studies exploring risk factors for the development of breast cancer among Aboriginal and Torres Strait Islander women.

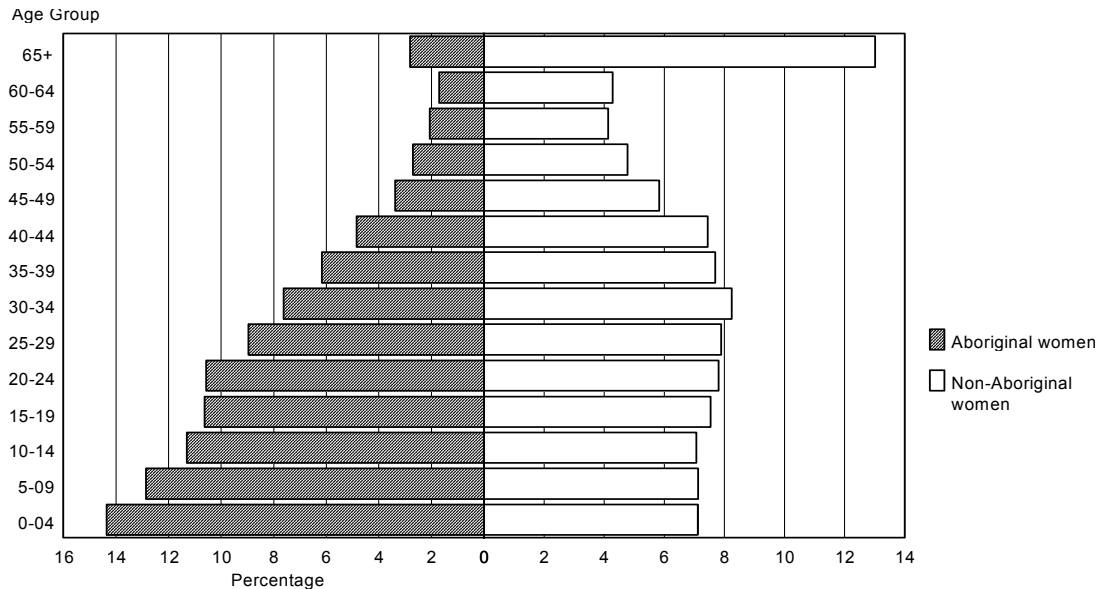
### **Age profile and life expectancy as a risk for breast cancer**

As shown in Figure 2, the age structure of the Aboriginal and Torres Strait Islander female population is quite different to that of the non-Aboriginal female population in Australia.<sup>6</sup> Only 2.9% of Aboriginal and Torres Strait Islander women are aged 65 years and over, compared to 13.3% of the non-Aboriginal population. Similarly, 9.4% of Aboriginal and Torres Strait Islander women are aged 50 years and over, while 26.7% of non-Aboriginal women are aged 50 years and over.<sup>6,12</sup>

Estimated life expectancies are much lower for Aboriginal and Torres Strait Islander women than for non-Aboriginal women.<sup>13</sup> Estimated life expectancies for Aboriginal and Torres Strait Islander women range from 58 to 65 years.<sup>13</sup> Eighty-nine percent of non-Aboriginal girls can expect to live to age 65, as compared to 54% of Aboriginal and Torres Strait Islander girls.<sup>14</sup> An investigation of mortality rates in Western Australia among people aged 50-69 years found that, in Aboriginal and Torres Strait Islander women, the main causes of death were circulatory diseases, diabetes, respiratory diseases, and injury and poisoning. Except for neoplasms, deaths from these causes occurred among 50-54 year olds at rates that were experienced by non-Aboriginal people ten to thirty years later in life.<sup>15</sup>

It is often claimed that the age profile of the Aboriginal and Torres Strait Islander population is such as to reduce the importance of breast cancer, as it is a disease primarily of older women. However, there remain significant numbers of Aboriginal and Torres Strait Islander women in the age groups most at risk of developing breast cancer; in total, there are estimated to be 11,030 Aboriginal and Torres Strait Islander women aged 40-49 years; 6,378 aged 50-59; and 6,055 aged over 60 years. This represents a total of 23,463 Aboriginal and Torres Strait Islander women aged 40 and over.<sup>6</sup>

**Figure 2**  
**Age profile of Aboriginal and non-Aboriginal women in Australia**



Source: D. Carson, Australian Bureau of Statistics, personal communication, November 1995.

### Family history

Known inherited genetic mutations (BRCA1, BRCA2, ATM and HRAS1 genes) are estimated to explain between 5-15% of all breast cancers among Australian women.<sup>16</sup> However, there is no information about the prevalence of the identified genetic mutations among Aboriginal and Torres Strait Islander communities. The role of family history in breast cancer in Aboriginal and Torres Strait Islander women is unknown.

### Reproductive Factors

Studies overseas have shown that reproductive factors including early menarche, late menopause, having fewer or no children, having children later rather than earlier and not breast feeding are linked with higher rates of breast cancer at the population level. However, the increase in relative risk from all of these factors is quite small; for example, the odds ratio for the association between age at first full term pregnancy and breast cancer rises only to 1.5 for women who have their first baby when aged between 32 and 34.<sup>10</sup>

The few data comparing Aboriginal and Torres Strait Islander and non-Aboriginal women in terms of reproductive issues suggest that at the population level Aboriginal and Torres Strait Islander women may be less at risk of breast cancer. Although no information about age of menarche and menopause were located, Aboriginal and Torres Strait Islander women tend to begin having children at a much younger age and have much higher fertility rates under 25 years than do other women in Australia.<sup>17-20</sup> For example, of the women giving birth in Australia in 1991, the average age of Aboriginal and Torres Strait Islander mothers was 23.4 years, while for non-Aboriginal mothers the average age was 27.9 years - a difference of 4.5 years.<sup>17</sup> In South Australia in 1993, 26% of Aboriginal and Torres Strait Islander women who gave birth were aged less than 20 years, compared to 5.6% of all new mothers in South Australia.<sup>19</sup>

Similarly, Aboriginal and Torres Strait Islander women tend to bear more children than non-Aboriginal women.<sup>17,21</sup> For example, of the women giving birth in Australia in 1991, 26% of Aboriginal and Torres Strait Islander mothers had at least three previous confinements, compared with 9.9% of all women.<sup>17</sup> Data from Western Australia suggest that Aboriginal and Torres Strait Islander mothers have on average a much higher parity than Caucasian mothers.<sup>21</sup> The proportion of nulliparous Caucasian women (39.3%) was higher than that for Aboriginal and Torres Strait Islander women (28.8%).<sup>21</sup> A greater proportion of Aboriginal and Torres Strait Islander women were having their fifth or more child (8.5%) as compared to 1.1% of Caucasian women.<sup>21</sup>

## **Conclusions**

In total, in 1994 there were 46,334 Aboriginal and Torres Strait Islander women aged 30-69 years of age, of which 23,465 were aged over 40 years, which is when breast cancer begins to become more common. The majority of these women lived in New South Wales and Queensland and primarily in the major city areas.

There is little information on which to compare risk profiles of Aboriginal and Torres Strait Islander and non-Aboriginal populations. However, since there are proportionally fewer older Aboriginal and Torres Strait Islander women, it is likely that the overall absolute numbers of breast cancer per number of women in the population (crude incidence) might be lower among Aboriginal and Torres Strait Islander women than in non-Aboriginal women. Higher Aboriginal and Torres Strait Islander fertility rates may also contribute to a lower overall crude incidence of breast cancer.

---

## 2 Incidence of, and mortality from, breast cancer

### Data sources

In order to identify information about the incidence of and mortality from breast cancer among Aboriginal and Torres Strait Islander women, a number of sources of information were searched. Two Aboriginal and Torres Strait Islander health bibliographies did not specifically identify breast cancer<sup>22,23</sup> and a computer-based search of the Medline database did not identify any relevant publications. Government reports were retrieved and the state and territory cancer registries were asked for the numbers of Aboriginal and Torres Strait Islander women from the time records were kept until the end of 1994 who:

- had been diagnosed with breast cancer each year; and
- died from breast cancer.

The cancer registries were also asked for age-standardised incidence and mortality rates for the same period.

### Limitations of the data

The limitations of the available incidence and mortality data should be recognised at the outset. The data are clearly incomplete and a number of issues need to be borne in mind in interpreting this section of the report.

Some of the issues include:

- The accuracy of the census data collections and the Aboriginal and Torres Strait Islander Survey (ATSI Survey)<sup>6</sup> used in this report, in recording the numbers of Aboriginal and Torres Strait Islander women living in each area, is unknown.
- No data were available from the majority of states in Australia about incidence or mortality for breast cancer among Aboriginal and Torres Strait Islander women. Cancer registrations in all states have had provision for the identification of Aboriginal and Torres Strait Islander background since 1992, and earlier for some states.<sup>24</sup> It is unlikely, however, that all Aboriginal and Torres Strait Islander

people with cancer are identified as such in notifications to cancer registries.<sup>25</sup> Therefore, information on the occurrence of breast cancer in Aboriginal and Torres Strait Islander women is likely to be under-reported. The identification of Aboriginality in breast cancer mortality data is also considered to be incomplete in most states.<sup>24,26</sup>

- Although all states and territories now have provision for recording Aboriginality on cancer registrations, data for Aboriginal and Torres Strait Islander women were available only from Western Australia, South Australia and the Northern Territory. However, only approximately one-third of the Aboriginal and Torres Strait Islander population live in these states.<sup>6</sup> New South Wales, Tasmania, the Australian Capital Territory, Queensland and Victoria were not able to supply data for several reasons, including that the data had not been coded by the registry due to its poor quality, coding was incomplete or no cases were recorded, as was the case for Tasmania.
- Information from the Northern Territory based on hospital separations was available. These data identified Aboriginal and Torres Strait Islander women, and have been used in framing the conclusions of this report.<sup>27</sup> However, only 15.5% of the Aboriginal and Torres Strait Islander population in Australia live in the Northern Territory.<sup>6</sup> In addition, hospital separation data count events rather than people; one person admitted to hospital three times is counted as three events. Other limitations include the inaccuracies found in all coding of hospital data plus the problem of whether Aboriginal and Torres Strait Islander background is adequately recorded.
- Other factors which limit the usefulness of the available data include: the small number of recorded cases of breast cancer in Aboriginal and Torres Strait Islander women in each state and territory; the lack of comparability of timeframes for those states which had records of breast cancer cases; and possible changes in the number of people self-identifying as Aboriginal and Torres Strait Islander over the last two decades.

## **Incidence**

Cancer registries recorded twenty-two cases of breast cancer in Aboriginal and Torres Strait Islander women in Western Australia in 1988-1992 and 25 cases in 1992-1994. (T. Threlfall, personal communication) There were 25 cases recorded in South Australia in 1977-1995, and 13 cases in the Northern Territory in 1987-1993.<sup>28,29</sup>

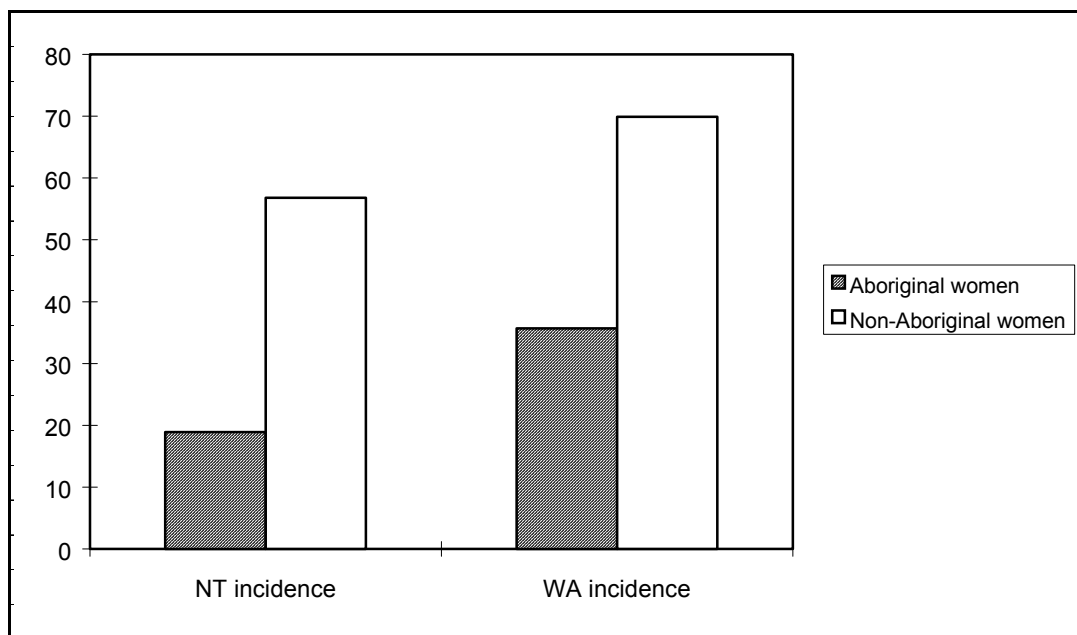
The numbers of Aboriginal and Torres Strait Islander women who would have been affected by breast cancer had they experienced similar age-specific incidence rates to those for all Australian women were

estimated. This analysis suggested that as many as sixty new cases of breast cancer in each year would be expected in this group of women.<sup>30</sup>

Table 2 compares the recorded incidence rates in Aboriginal and Torres Strait Islander women with those which might be expected if the rates were similar to those among non-Aboriginal women. It is evident that the incidence rates among Aboriginal and Torres Strait Islander women were lower in three studies: Northern Territory 1987-1993; Western Australia 1988-1992 (T. Threlfall, personal communication); and South Australia 1977-1995.<sup>28,29</sup> However in Western Australia 1992-1994, the rates among Aboriginal and Torres Strait Islander women were the same as those among non-Aboriginal women.<sup>32</sup> While these data are based on small numbers and not consistent, it appears that incidence is lower among Aboriginal and Torres Strait Islander women than non-Aboriginal women.

Figure 3 compares the recorded incidence rates in Aboriginal and Torres Strait Islander women and non-Aboriginal women in the Northern Territory and Western Australia.

**Figure 3**  
**Age-standardised incidence rates of breast cancer per 100,000 woman-years in Aboriginal and Torres Strait Islander women in the Northern Territory in 1987-1993 and in Western Australia in 1987-1992**



Source: Kricger A, Jelfs P. *Breast cancer in Australian women 1921-1994*. Canberra: Australian Institute of Health and Welfare; 1996.

**Table 2**  
**Observed and expected incidence of breast cancer in Aboriginal and Torres Strait Islander women for three states and territories**

|                                     | Observed <sup>1</sup> | Expected <sup>2</sup> | Rate ratio | Confidence limits |
|-------------------------------------|-----------------------|-----------------------|------------|-------------------|
| <b>NT 1987-1993<br/>ie 7 years</b>  | 13                    | 52.2                  | 0.25       | 0.13, 0.43*       |
| <b>WA 1988-1992<br/>ie 5 years</b>  | 22                    | 38.1                  | 0.58       | 0.36, 0.88*       |
| <b>WA 1992-1994<br/>ie 3 years</b>  | 25                    | 24.9                  | 1          | 0.65, 1.47        |
| <b>SA 1977-1995<br/>ie 19 years</b> | 25                    | 45.5                  | 0.55       | 0.33, 0.76*       |

\* statistically significant

Sources: de Espaignet E, Measey M, Condon J, Jelfs P, Dempsey K. *Cancer in the Northern Territory 1987-1993*. Darwin: Territory Health Services; 1996; *Epidemiology of cancer in South Australia*. Adelaide: South Australian Health Commission; 1997; Threlfall T, Whitfort M, Thompson J. *Cancer incidence and mortality in Western Australia, 1992-1994*. Perth: Health Department of Western Australia; 1996; T. Threlfall, *Cancer Registry of Western Australia*, personal communication, September 1995.

## Mortality

It is not possible to determine the actual number of deaths due to breast cancer that occur among Aboriginal and Torres Strait Islander women on a national basis because there is a lack of Australia-wide data concerning Aboriginal and Torres Strait Islander background on cancer registry and death certificates. The most complete data about mortality from breast cancer among Aboriginal and Torres Strait Islander women are from the Northern Territory, Western Australia and South Australia.<sup>27,30,33</sup>

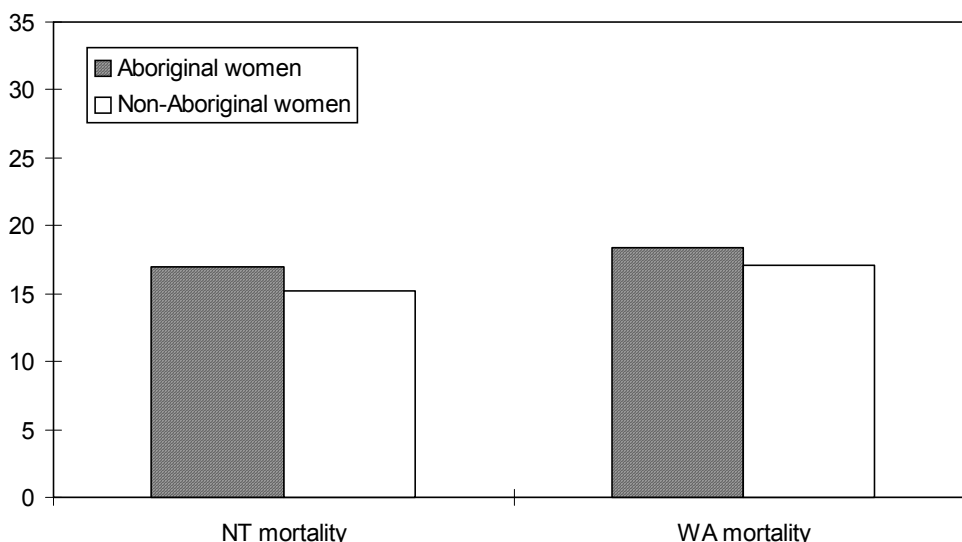
For example, in the Northern Territory, between 1979 and 1986, there were ten deaths from breast cancer among Aboriginal and Torres Strait Islander women.<sup>27</sup> Further data from 1987-1993 published by the Northern Territory cancer registry indicate that there were ten deaths from breast cancer reported.<sup>29</sup> In Western Australia from 1992-1994 there were four reported deaths from breast cancer.<sup>32</sup>

<sup>1</sup> Observed refers to the actual number of breast cancer cases diagnosed among Aboriginal and Torres Strait Islander women.

<sup>2</sup> Expected refers to the number of cases that might have been predicted if the Aboriginal and Torres Strait islander incidence rate was the same as in the Australian population.

Figure 4 compares the recorded mortality rates in Aboriginal and Torres Strait Islander and non-Aboriginal women. A comparison of rates showed that mortality rates were similar for Aboriginal and Torres Strait Islander and non-Aboriginal women in the Northern Territory and Western Australia.<sup>29</sup>

**Figure 4**  
**Age-standardised mortality rates of breast cancer per 100,000 woman-years in Aboriginal and Torres Strait Islander women in the Northern Territory in 1987-1993 and in Western Australia in 1987-1992**



Source: Kricker A, Jelfs P. Breast cancer in Australian women 1921-1994. Canberra: Australian Institute of Health and Welfare; 1996.

However, South Australian data for all cancers show a higher cancer mortality rate for South Australian Aborigines than experienced by other Australians, without a corresponding elevation in incidence.<sup>28</sup> The authors argue that this may be due in part to higher incidence levels amongst Aboriginal and Torres Strait Islander South Australians of cancers with typically elevated case fatality rates such as cancer of the lung, liver and pancreas in association with a more advanced stage of diagnosis for South Australian Aborigines. However the data show an elevated case fatality in Aboriginal and Torres Strait Islander South Australians after adjusting for primary site and stage across all cancers, including breast cancer. The report therefore raises the notion of poorer treatment outcomes for Aboriginal and Torres Strait Islanders with a cancer diagnosis.

Recent data show that the breast cancer mortality rates for Aboriginal and Torres Strait Islander women peaked in 1989-1991 with rates of twenty eight, twenty seven and thirty seven respectively.

The rates fell in 1992 to twelve and remained low through 1994 to eleven. This shows that the mortality rates for breast cancer in Aboriginal and Torres Strait Islander women dropped significantly from 1.1 in 1989-1991 to 0.5 in 1992-1994.<sup>33</sup>

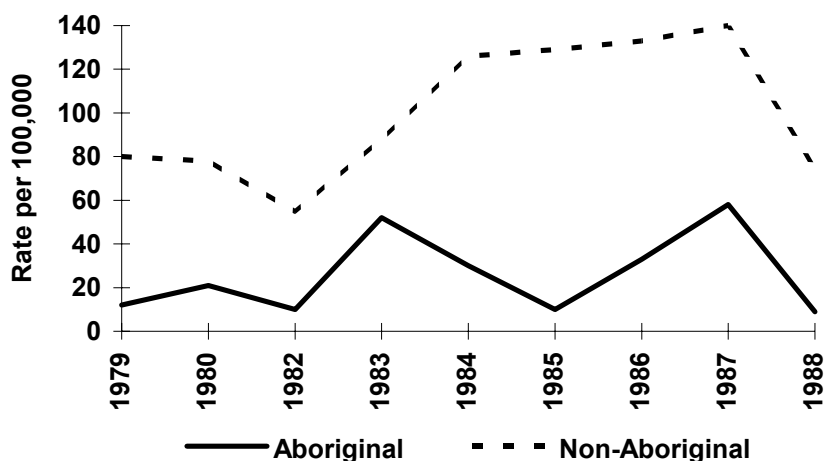
## **Hospital separation data**

Hospital separation data reflect diagnosis at the time a person leaves the hospital, whether the separation be due to discharge home, death or transfer to another hospital. Hospital separation data reflect discrete hospital events and not individual patients. Hospital separation data do not routinely include information about Aboriginal and Torres Strait Islander background in all states and territories, and even when Aboriginal and Torres Strait Islander background has been recorded, the accuracy is generally unknown. Furthermore, medical practice and access to medical care have changed over time, making the data more difficult to interpret.

Hospital separation data are available for the Northern Territory in relation to breast cancer and Aboriginal and Torres Strait Islander women.<sup>27</sup> The Northern Territory reported a total of twenty-seven hospital separations for breast cancer in Aboriginal and Torres Strait Islander women from 1979-1988 (excluding 1981), an average of three per year. The directly age-standardised hospital separation rate for breast cancer compared with Northern Territory non-Aborigines is shown in Figure 5.

Figure 5 shows that the Northern Territory Aboriginal and Torres Strait Islander hospitalisation rates for breast cancer are about one-quarter that of non-Aborigines. These data are age-standardised, although based on very small numbers.

**Figure 5**  
**Northern Territory age-standardised hospital separation, breast cancer, by Aboriginality, 1979-1988**



Source: Plant AJ, Condon JR, Durling G. Northern Territory health outcomes: morbidity and mortality 1979-1991. Darwin: Northern Territory Department of Health and Community Services; 1995.

## Conclusions

The data on the incidence of, and mortality from, breast cancer among Aboriginal and Torres Strait Islander women are sparse and difficult to interpret. It is not currently possible to know the real incidence, mortality or survival rates of breast cancer in Aboriginal and Torres Strait Islander women. The data that are available reflect the small population of Aborigines and the historically poor documentation of Aboriginal and Torres Strait Islander background in both vital statistics and cancer registry data.

The very limited evidence suggests that breast cancer incidence rates are lower than, and mortality rates similar to or higher than, the Australian rates. Of the four incidence studies located, three reported lower rates among Aboriginal women. There was no difference in mortality rates between Aboriginal and Torres Strait Islander women and non-Aboriginal women in Western Australia or the Northern Territory. Recently reported data show a higher mortality rate amongst Aboriginal and Torres Strait Islander and Torres Strait South Australians than other Australians.

When these very limited results are combined with the fact that Aboriginal and Torres Strait Islander background is likely to be under-recorded on all the relevant forms, then the best conclusion appears to be that while the disease rates from breast cancer may be slightly less or may differ greatly between non-Aboriginal women and Aboriginal and Torres Strait Islander women, mortality appears to be similar or higher and rates of hospitalisation from the disease lower, at least in the Northern Territory.

There are several possible interpretations of these data including:

- the estimates of incidence and/or mortality rates are inaccurate because many Aboriginal and Torres Strait Islander women are not identified as such on hospital, registry or death register records, or because the numbers are so small that the estimates have a high degree of statistical error;
- the incidence of breast cancer among Aboriginal and Torres Strait Islander women is similar to that among non-Aboriginal women, mortality is similar or higher and hospitalisation rates are lower. This would suggest that hospitalisation and treatment does not improve survival for breast cancer patients, or more likely comes too late for Aboriginal and Torres Strait Islander women;
- the incidence of breast cancer among Aboriginal and Torres Strait Islander women is lower than that among non-Aboriginal women, mortality is similar or higher and hospitalisation rates are lower. This would suggest that poorer treatment of Aboriginal and Torres Strait Islander women with breast cancer or later detection of the disease reduces their survival. This possibility that Aboriginal and Torres Strait Islander women have a lower incidence rate but a higher case-fatality rate than non-Aborigines cannot be excluded on the basis of current evidence and while the data are very limited and this suggestion tentative, it clearly warrants further exploration; and
- the incidence of breast cancer among Aboriginal and Torres Strait Islander women may be changing as indicated by the pattern seen in rates in Western Australia. If this is the case, over time it might be expected that mortality from breast cancer among Aboriginal and Torres Strait Islander women will increase.

In conclusion, it must be said that the findings detailed in this report should be interpreted with caution. In order to understand the true incidence and mortality rates of breast cancer among Aboriginal and Torres Strait Islander women it will be necessary to collect better national data including the routine recording of Aboriginality.

---

## 3 The early detection of breast cancer

If breast cancer is detected while it is still small and before it has spread, the chances of survival are greatly improved.<sup>34</sup> Increasing participation in early detection programs is therefore a very effective method of decreasing mortality from breast cancer. There are three methods of early detection: the Australian Cancer Society recommends that women practice monthly breast self-examination from age 35 and receive an annual check or clinical examination of their breasts by a health professional.<sup>35</sup> However, mammographic screening is the best method of detecting breast cancer while it is still small, and has been shown to decrease mortality by 20-30% in populations offered a screening program.<sup>36</sup> Australia has a free national mammographic screening program, BreastScreen Australia.

Some limited information is available about early detection practices by Aboriginal and Torres Strait Islander women as follows:

### Breast self-examination

The ABS conducted a National Health Survey in 1989-1990, a component of which was the Women's Health Questionnaire, including questions on breast self-examination, clinical breast examination and mammography. A small number of Aboriginal and Torres Strait Islander women were included in the sample and a comparison of the Aboriginal and Torres Strait Islander and non-Aboriginal respondents was provided by the ABS (B. Richings, Australian Bureau of Statistics, personal communication, November 1995).

The survey was conducted door-to-door during 1989 and 1990. Of the 26,470 randomly selected households, 22,202 households were surveyed, resulting in 54,576 interviews (96.1% response rate).<sup>37</sup> The Women's Health Questionnaire is a component of the survey which was completed only by women aged 18-64 years. Ninety-seven percent of all eligible women completed the Women's Health Questionnaire. Separate response rates for Aboriginal and Torres Strait Islander women were not available.

The number of Aboriginal and Torres Strait Islander women completing the survey was quite small (151 women). The sample is also likely to be biased; Aboriginal and Torres Strait Islander women with poorer educational status and those living in remote areas may

have been less likely to participate. There is also no information about the cultural acceptability of the survey and this may have led to a lower response rate and/or biased responses to the survey. Due to the small sample size, responses are reported only for the total sample, with no age break down.

Table 3 shows self-reported rates of breast self-examination separately for women from Aboriginal or Torres Strait Islander origin and non-Aboriginal women (B. Richings, Australian Bureau of Statistics, personal communication, November 1995). It should be noted that the ABS included a small number of Aboriginal and Torres Strait Islander women in their survey and then extrapolated these data to the whole population in the data they provided for Table 2. The ABS adjusted the actual responses from survey participants to reflect the likely responses standardised by age and sex from the whole Aboriginal and Torres Strait Islander population.

The survey suggests that 52% of Aboriginal and Torres Strait Islander women and 63% of non-Aboriginal women report regularly examining their own breasts.

**Table 3**  
**Self-reported participation in early detection: a comparison of Aboriginal and Torres Strait Islander and non-Aboriginal women**

|                                | <b>Aboriginal and Torres Strait Islander women</b> | <b>Non-Aboriginal women</b> |
|--------------------------------|--|-----------------------------|
| Regularly examined own breasts | 52%  | 63%                         |
| Ever had breasts examined      | 57%  | 72%                         |

*Source: B. Richings, Australian Bureau of Statistics, personal communication; November 1995.*

## Clinical breast examination

Information about clinical breast examination is kept by Aboriginal Medical Services. However, extraction of these data would require an audit of individual medical records. Self-reported rates of clinical breast examination are also available from the ABS survey described above. As shown in Table 3, based on the ABS survey, 57% of Aboriginal and Torres Strait Islander women and 72% of non-Aboriginal women report ever having had a clinical breast examination.

## Mammographic screening

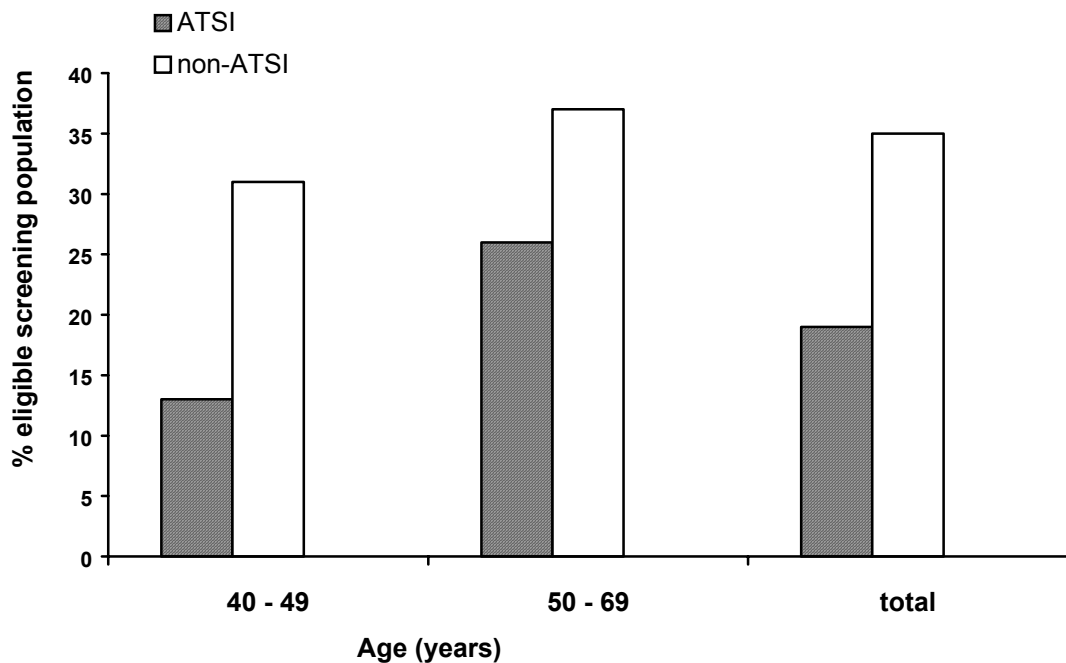
BreastScreen Australia reports the number of Aboriginal and Torres Strait Islander and non-Aboriginal women who have received a mammogram as part of the program (BreastScreen Australia, personal communication). There is no information available about the accuracy with which Aboriginal and Torres Strait Islander background is recorded when women attend for screening.

Self-report data are also available from the ABS survey described above; however, they have not been included as they refer to a period prior to the widespread establishment of the national mammographic screening program.

Figure 5 shows the proportion of Aboriginal and Torres Strait Islander women who received a mammogram as part of BreastScreen Australia between July 1993 and June 1995. It also shows participation rates for non-Aboriginal women. It is evident that mammographic screening rates among Aboriginal and Torres Strait Islander women are lower than those among non-Aboriginal women. For example, between July 1993 and June 1995 in the 50-69 age group, only 26% of the eligible Aboriginal and Torres Strait Islander population were screened, compared with 37% of the eligible non-Aboriginal population.

Of the total numbers of women aged 40-69 screened during the same period, only 19% of eligible Aboriginal and Torres Strait Islander women were screened compared with 35% of eligible non-Aboriginal women.

**Figure 6**  
**The proportion of eligible Aboriginal and Torres Strait Islander women and eligible non-Aboriginal and Torres Strait Islander women participating in BreastScreen Australia, the national mammographic screening program**



Source: BreastScreen Australia, personal communication.

## Conclusions

There are few data about early detection of breast cancer among Aboriginal and Torres Strait Islander women. Information about breast self-examination and clinical breast examination is based on self-report data from the ABS survey and it is not clear either how accurate the self-report responses are or how representative the sample was of all Aboriginal and Torres Strait Islander women. Nonetheless, these data suggest lower rates of breast self-examination and clinical breast examination than that in non-Aboriginal populations. It may be worth considering an audit of Aboriginal Medical Service records to establish rates of clinical breast examination and a more culturally appropriate technique to establish self-reported rates of breast self-examination.

Information from BreastScreen Australia suggest that Aboriginal and Torres Strait Islander women are less likely to receive a screening mammogram than non-Aboriginal women, with only 26% of the eligible Aboriginal and Torres Strait Islander population aged 50-69 years participating in screening in a two year period.

Taken together, these data suggest that Aboriginal and Torres Strait Islander women have lower rates of participation in early detection programs. In Section 2 it was suggested that Aboriginal and Torres Strait Islander women diagnosed with breast cancer may be more likely to die from the disease; the lower rates of participation in early detection programs may contribute to poorer survival since a lower proportion of cases may be diagnosed as early disease.

---

## 4 Knowledge, attitudes, and perceived needs in relation to breast cancer

### Data sources

In order to identify the published and unpublished literature, both qualitative and quantitative, about Aboriginal and Torres Strait Islander women's knowledge, attitudes, and perceived needs in relation to breast cancer, the following searches were conducted:

#### Published reports

- A Medline, PsycLIT and Healthplan search for articles published between 1985 - March 1995 (inclusive).
- A number of journals were manually searched including the Aboriginal and Islander Health Worker Journal, Aboriginal and Islander Health Worker, Aboriginal and Torres Strait Islander Health Information Bulletin, Medical Journal of Australia, Australian Family Physician, Australian Journal of Public Health, Australian and New Zealand Journal of Medicine, Australian Institute of Health and Welfare Annual Reports and the Menzies School of Health Annual Reports.
- The NH&MRC Aboriginal and Torres Strait Islander Health Research Report *Classification of current research and research from the past decade that has been conducted into Aboriginal and Torres Strait Islander health*<sup>38</sup> was accessed and searched for primary sources.

#### Unpublished reports

The following organisations were contacted and asked if they knew of any research looking at Aboriginal and Torres Strait Islander women and breast cancer:

- Aboriginal and Torres Strait Islander Commission;
- Australian Bureau of Statistics;
- Menzies School of Health Research;
- Australian Institute of Health and Welfare;

- Commonwealth and State Health Departments (New South Wales, Northern Territory, Queensland, South Australia, Western Australia);
- Australian Institute of Family Studies (database search);
- Australian Institute of Health and Welfare (database search);
- NSW Aboriginal Health Resource Cooperative;
- Anton Breinl Centre, James Cook University;
- HEAPS: Health Education and Promotion System (database search);
- Aboriginal and Torres Strait Islander Medical Services (New South Wales, Northern Territory, South Australia, Western Australia, Tasmania, Queensland, Victoria); and
- Funding bodies such as the National Health and Medical Research Council, Research and Development Grants Advisory Committee, state and territory cancer organisations.

## Identified research

No published research dealing directly with Aboriginal and Torres Strait Islander women and breast cancer was identified. Nine unpublished small studies or reports were identified as listed below. These studies and reports are described in detail in Appendix 3.

- 1 Awabakal Aboriginal and Torres Strait Islander Medical Service Study (NSW).
- 2 Women's Health Promotion Group Study (Durri Aboriginal Corporation Medical Service, NSW).
- 3 Djigay Koorie Health Survey (from Durri Aboriginal Corporation Medical Service, NSW).
- 4 Prevention and Early Detection of Cancer in Aboriginal and Torres Strait Islander Women Report (Royal Women's Hospital, Brisbane).
- 5 Feasibility study for Northern Territory participation in the National Program for the Early Detection of Breast Cancer.
- 6 National Program for the Early Detection of Breast Cancer consultants' report - Implementation issues associated with the delivery of the National Program for the Early Detection of Breast Cancer (BreastScreen Australia) across the remote north of Australia.

- 7 Congress Alukura response to the BreastScreen Australia consultants' report.
- 8 Project Cancer Awareness Strategies to Indigenous Health Workers and Individuals (C.A.S.T.I.H.W.A.I).
- 9 NHMRC National Breast Cancer Centre's Consultative Report.

Summary information describing the type of studies and reports is detailed in Appendix 3.

## **Findings**

These reports have largely been based on informal interviews and outcomes of small workshops, and therefore may not represent the views of Aboriginal and Torres Strait Islander women in general. However, several specific issues relating to breast cancer have been consistently identified in these reports.

### **Incidence and risk factors**

Several of the reports suggested that many women do not have a good understanding of the risk of breast cancer in Aboriginal and Torres Strait Islander communities or the mortality from the disease. For example, several reports indicated that some Aboriginal and Torres Strait Islander women view breast cancer as a white man's disease.<sup>39</sup> Another report indicated that the perception that breast cancer is always fatal and incurable seems to be a widely held view among some Aboriginal and Torres Strait Islander women.<sup>40</sup> Two other reports suggested that most Aboriginal and Torres Strait Islander women knew other women who had been diagnosed with breast cancer and that many of these women had died from their disease.<sup>39,40</sup>

There also appears to be a belief among some Aboriginal and Torres Strait Islander women that the role of environmental factors (such as pesticides), which may be of particular importance for Aboriginal and Torres Strait Islander women, in the genesis of breast cancer has not been properly investigated.<sup>39</sup>

### **Early detection**

There was some indication in the reports that there may be a misunderstanding about the purpose of early detection among Aboriginal and Torres Strait Islander women.<sup>39,40</sup> For example, one report suggested that some women believed that presentation to a health service for screening was unnecessary when there is little or no evidence of illness.<sup>39</sup>

The majority of reports located were aimed at exploring the perceptions of Aboriginal and Torres Strait Islander women about mammographic screening. These reports identified several barriers to participation in mammographic screening amongst Aboriginal and Torres Strait Islander women including perceptions that health services provided by men are not culturally acceptable to some Aboriginal and Torres Strait Islander women,<sup>39,41</sup> and even when it was understood that the screening mammogram would be performed by a female radiographer, there were concerns about the investigation of screen-detected abnormalities by male doctors. It was suggested that many Aboriginal women are likely to have 'felt stigmatised or disadvantaged' in some other way during health encounters in the past.<sup>40</sup> Such negative experiences may act as strong deterrents to Aboriginal women in accessing health services, particularly in the absence of any symptoms.<sup>40</sup> Additionally, in the absence of an accurate understanding about the purpose of breast screening among Aboriginal and Torres Strait Islander women, and in the presence of other epidemic health problems in their communities such as diabetes, mammographic screening may not be seen as a priority.

The mammographic screening services were also seen as inaccessible to Aboriginal and Torres Strait Islander women.<sup>39</sup> The physical location of a screening service may make access difficult for some women in terms of arranging transport and childcare.<sup>40</sup> For example, it was suggested that to participate in mammographic screening, particularly in rural and remote areas, women needed to own a telephone and car and to travel considerable distances often without public transport to both mobile and fixed services.<sup>40</sup> Kirk et al argue that even when the service itself is free, costs associated with attending may pose significant barriers.<sup>40</sup> Many Aboriginal women also felt that the mammographic screening program is structured to support Western values of time and work efficiency which fails to acknowledge traditional Aboriginal values such as family and community responsibilities. For example, an appointment made for a mammogram may in some communities defer to a women's social responsibilities.

There may also be some confusion about the operation of the national mammographic screening program. For example, it was reported that a television campaign about the national mammographic screening program had generally been misinterpreted (even by the Aboriginal and Torres Strait Islander health workers) to mean that women did not need an appointment for screening (Awabakal Aboriginal Medical Service - see Appendix 3, no. 1). Discussions with Aboriginal and Torres Strait Islander health workers revealed that there was also some concern amongst health workers about the policy of not screening women with breast symptoms; again, this may illustrate

a lack of understanding of the purpose of screening and the differences between screening and diagnostic approaches. There was also concern about the policy of not offering screening to women aged less than 40 years, particularly as it might apply to Aboriginal and Torres Strait Islander women.<sup>39</sup> Some Aboriginal and Torres Strait Islander women felt that because they have a life expectancy estimated to be fifteen to twenty years less than non-Aboriginal women mammographic screening should be commenced at an earlier age. This policy was interpreted as an equity issue rather than one of the efficacy of the technique.

The reports provided little information about Aboriginal and Torres Strait Islander women's attitudes and beliefs about breast self-examination. However two small studies (Awabakal Aboriginal Medical Service and Durri Aboriginal Corporation Medical Service - see Appendix 3, nos. 1 and 2) reported that fewer than half of the Aboriginal and Torres Strait Islander women participating in the studies reported regularly performing breast self-examination. It was reported that some Aboriginal and Torres Strait Islander women, in the absence of culturally appropriate information, may feel shame and embarrassment about performing breast self-examination (Project C.A.S.T.I.H.W.A.I. - see Appendix 3, no. 7). In addition, most resources which seek to promote breast self-examination encourage a women to perform an examination lying down on a bed. This advice fails to consider the many Aboriginal and Torres Strait Islander women who live in crowded living conditions sharing a small sleeping area with several family members. It was suggested that resources that considered varied living conditions and offered other options such as performing breast self-examination in a shower may encourage greater participation in this activity (F. Turner, Congress Alukura, personal communication, May 1996).

None of the reports included information about clinical breast examination; however, it might be inferred from the comments about mammographic screening that this would be more appropriate if undertaken by a female health professional.

### **Treatment and support**

Treatment for breast cancer is primarily provided by male doctors. Aboriginal and Torres Strait Islander women would prefer care from female health professionals, as breast cancer is considered women's business. Women from rural and remote areas must leave their communities and travel to urban areas for treatment for breast cancer.<sup>39</sup> Informal discussions with both Aboriginal and Torres Strait Islander and non-Aboriginal health workers suggest that some Aboriginal and Torres Strait Islander women elect not to undergo treatment for breast cancer or do not complete all aspects of treatment.

The extent to which this occurs and the reasons for it are unclear; the health workers felt that Aboriginal and Torres Strait Islander women who did not complete treatment did not always understand what was involved, felt that the treatment was unacceptable to their cultural beliefs and did not want to leave their communities for urban areas for extended periods of time. One report identified another view also likely to deter them from having treatment held by many of the women interviewed which was that 'mothers aren't allowed to be sick'. It was felt that women were less likely to seek treatment for themselves than for those of other family members. It was more common for them to just wait until their illness passed.<sup>40</sup>

Women's perceptions about hospital were identified in one report as important because one of the barriers to seeking treatment for symptoms may include a fear of having to go to hospital.<sup>40</sup> Most of the women contributing to the report had been hospital patients on at least one occasion and universally described it as a 'bad experience'.<sup>40</sup>

Several women commented during the workshops held by the NHMRC National Breast Cancer Centre on the isolation experienced by many Aboriginal and Torres Strait Islander women diagnosed with breast cancer. They felt that, because breast cancer was relatively uncommon among Aborigines, a woman diagnosed with the disease may be the only person in her community who had had breast cancer. This sense of isolation was reported to be compounded by a lack of understanding among some Aboriginal and Torres Strait Islander communities about breast cancer; some women felt that there was little understanding that the woman may die from breast cancer even if she survived the initial treatment phase. The feeling of isolation was also increased by the lack of understanding of Aboriginal and Torres Strait Islander culture by non-Aboriginal health professionals treating the woman.

The women commented on the lack of support services for Aboriginal and Torres Strait Islander women; it was noted that there were very few Aboriginal and Torres Strait Islander volunteers with the Breast Cancer Support Services throughout Australia. The special needs for supportive care for women who live in remote communities and travel to the major cities was discussed; for example, one woman with breast cancer who lived in a small remote community, 100 kms from Broome, described feelings of loneliness and confusion on arriving in Perth for debilitating radiotherapy and chemotherapy for the first time, and where she knew no-one.

## **Service delivery**

Most of the reports provided recommendations about changes to service delivery which might improve breast cancer control among Aboriginal and Torres Strait Islander women. There was a view that the lack of information about the incidence of, and mortality from, breast cancer among Aboriginal and Torres Strait Islander women was a major difficulty in planning service delivery. However, almost all of the reports indicated that Aboriginal and Torres Strait Islander women believe that existing health services need significant change to ensure that they are appropriate in improving all aspects of breast cancer control.<sup>39,40</sup>

Recommendations about specific aspects of care were made as follows:

### **Community control**

The importance of local community ownership of programs and resource development was stressed in a number of reports (Congress Alukura response to the NPEDBC [now BreastScreen Australia] consultants' report - see Appendix 3, no. 6).<sup>39,40</sup> Programs should take account of the fact that Aboriginal and Torres Strait Islander communities are heterogenous with many different languages and cultural groups, and that therefore local control is necessary to ensure that the program is appropriate and acceptable.<sup>39,40</sup> Kirk et al emphasised this point noting that the relative importance of barriers to care will be more important to some Aboriginal and Torres Strait Islander women than others, dependent upon their respective sociodemographic, geographic, and cultural environment.<sup>40</sup>

It was recognised that there was some discordance between the concept of local community control and the objectives of an organisation like the NBCC which is seeking to develop nationally generalisable programs and resources. During the NBCC consultations, it was suggested that the Centre may assist by affirming the principle of local ownership and working with organisations at the national, state or regional level to encourage the development of local programs within this model.

### **Holistic care**

Two reports emphasised that care should be holistic rather than focusing only on breast cancer.<sup>39,40</sup> In part, this was seen as a cultural issue; it was argued that Aboriginal and Torres Strait Islander people think of their bodies and health more holistically and are less inclined to consider parts of the body separately than non-Aboriginal Australians. An holistic approach to health care is also likely to be

cost-effective for women living in remote areas where access to health information and care may be limited. For example, women attending a pilot mammographic screening programme at Alukura in Alice Springs reflected that they wanted mammography delivered in an holistic way, so that they could access other routine health checks such as pap smears, blood pressure and blood sugars at the same visit. Focusing on one organ of the body is described as an alien concept to most Aboriginal and Torres Strait Islander women (L. Geia, Congress Alukura, personal communication, November 1996). A visit to health services for a breast check should also therefore include checks for other health issues.

### **Confidentiality**

Several reports stressed that confidentiality of information provided to and by health services was a key issue for Aboriginal and Torres Strait Islander women.<sup>39</sup> Consultations emphasised that woman's health business is not discussed with just anybody, even within their own cultural groups (K. Abbott, NT Remote Health, personal communication, May 1996). Some Aboriginal and Torres Strait Islander women are not always clear about how and if their confidentiality is protected from other health professionals, researchers and members of their own community. It was suggested that services must not only ensure confidentiality, but also make it clear to women how this is being achieved.<sup>40</sup> For example, separate services for Aboriginal and Torres Strait Islander women was one way of increasing their trust that confidentiality was assured.

### **Information provision**

Information about risk of breast cancer and the role of early detection is provided by a number of agencies, which include BreastScreen Australia, the state and territory cancer organisations, and local health agencies. One of the potentially most useful sources of information was seen as being the Aboriginal Medical Services and Aboriginal and Torres Strait Islander health workers. However, an NBCC report which reviewed the provision of the levels of training in the area of breast cancer provided to Aboriginal and Torres Strait Islander health workers throughout Australia indicated that few institutions provide extensive training in regard to breast health including providing information about breast cancer, in performing clinical breast examinations or in teaching breast self-examination.<sup>41</sup> Most training programs cover risk factors and early detection to varying degrees rather than areas such as treatment options, support and the availability of resources for health workers and consumers. The report emphasised, however, that whilst many of the training programs do not currently offer extensive training in breast health they expressed an interest in doing so.

Consultations also emphasised that in rural and remote areas information about breast cancer would be most acceptable if it was provided by the grandmothers as part of women's business, particularly in communities living a more traditional lifestyle (L. Geia, Congress Alukura, personal communication, May 1996).

The NBCC identified six resources about breast cancer developed for Aboriginal and Torres Strait Islander women as shown in Appendix 4. However, the reports emphasised that, among women living in rural and remote areas of Australia, it is likely that locally produced resources will be most effective in providing information. In part, this is because of language; in Central Australia alone there are over sixty language groups and many more dialects, and some women will not be able to read English language resources. It is likely that there will also be cultural differences which need to be taken into account in developing resources; for example, the use of particular visual images and colour and their significance may vary between areas.

Some of the consultations stressed that printed information resources about breast cancer should focus on visual images rather than text; there was a strong suggestion that audiovisual resources are likely to be of more use, and that media campaigns should use existing Aboriginal and Torres Strait Islander networks such as Imparje, Tanami, and the Broadcasting for Remote Aboriginal Communities Scheme.

Given the view that there was a lack of information about the occurrence of breast cancer among Aboriginal and Torres Strait Islander women, it was suggested that a first step for the NBCC might be to develop a public information campaign about the occurrence of breast cancer in Aboriginal and Torres Strait Islander women and the role of early detection.

### **Mammographic screening**

There remained considerable concern about the national mammographic screening program and its appropriateness for Aboriginal and Torres Strait Islander women. A number of specific recommendations to make the program more appropriate were made, including: the involvement of Aboriginal and Torres Strait Islander health workers; the incorporation of no appointment times or flexible appointments;<sup>40</sup> the development of better recruitment resources and strategies emphasising the availability of the service to Aboriginal and Torres Strait Islander women and the confidentiality of the program; and the incorporation of an holistic approach as previously described in this report.

However, two inter-related issues were seen as fundamental; first, it was clear that Aboriginal and Torres Strait Islander women did not feel informed about or involved in the development of the national mammographic screening program, and this isolation meant that it was less likely that effective local programs would be developed to encourage women to attend for screening.

Second, it was apparent that there was a need to consider the role of mammographic screening in providing an early detection service to Aboriginal and Torres Strait Islander women, particularly those living in remote areas of Australia. Not only is service provision likely to be expensive and possibly not cost-effective but it may never fit well within an holistic, primary care health service such as that which is the basis of health care in rural and remote Australia (NPEDBC [now BreastScreen Australia] consultants' report - see Appendix 3, no. 5). There needs to be a careful consideration of the relative costs and benefits of encouraging attendance at mammographic screening versus developing excellent local skills in the performance of clinical breast examination.

### **Treatment and support**

It was suggested that treatment services may be perceived as more appropriate if they were provided by female health professionals. Recognising that there are few female surgeons, it was felt that a more integral involvement of female Aboriginal and Torres Strait Islander health workers in the team caring for Aboriginal and Torres Strait Islander women with breast cancer would improve the acceptability of care.

To improve support, the NBCC consultations suggested that Aboriginal and Torres Strait Islander volunteers be recruited to the Breast Cancer Support Service and that special programs be developed to provide support for women from rural and remote communities travelling to urban treatment centres.

### **Workforce issues**

The reports made several recommendations about the health workforce to improve service delivery. First, if female Aboriginal and Torres Strait Islander health workers are seen as centrally important in improving breast cancer control, there was a need to increase the numbers of workers and to ensure that they have adequate training in all aspects of breast cancer. Second, more effective care could be provided if non-Aboriginal health professionals had a better understanding of Aboriginal and Torres Strait Islander culture and values, especially as they related to women's business. It was suggested that this could be provided during training programs and some models for this already

exist (J. Smith, Royal Australian College of General Practitioners, personal communication, October 1996). Third, it was suggested that the establishment of Aboriginal and Torres Strait Islander liaison positions within screening programs, cancer care centres and palliative care units would greatly assist in increasing the acceptability of these services to Aboriginal and Torres Strait Islander women.

## **Conclusions**

Overall, there have been few attempts to explore the perceptions of Aboriginal and Torres Strait Islander women about breast cancer. There have been no methodologically rigorous qualitative or quantitative studies about Aboriginal and Torres Strait Islander women's knowledge, attitudes and beliefs about breast cancer. The little existing information is based on informal interviews and reports of workshop outcomes.

The data that are available highlight the need for new models of information provision and for service delivery to ensure that these are culturally appropriate and accessible to Aboriginal and Torres Strait Islander women. It appears that some Aboriginal and Torres Strait Islander women may not be aware of the risk of breast cancer, and may find early detection programs culturally inappropriate and difficult to access. If an Aboriginal and Torres Strait Islander woman is diagnosed with breast cancer, she is unlikely to be able to access appropriate information, treatment or support. Improving breast cancer control will require the development of different models that recognise the importance of local control and an holistic approach to improving breast cancer control. It may also require a reconsideration of how the early detection of breast cancer can best be achieved in Aboriginal and Torres Strait Islander women.

---

## 5 Conclusions and recommendations

It is evident that there is very little information about breast cancer among Aboriginal and Torres Strait Islander women. There were few data about any of the aspects of breast cancer described in this report, and that which does exist may be seriously biased. All of the conclusions are very tentative and must await further and better data.

However, bearing in mind these limitations, the small amount of existing data suggest that there is a need to improve breast cancer control among Aboriginal and Torres Strait women. There may be approximately sixty cases of breast cancer among Aboriginal and Torres Strait Islander women each year and it appears that these women have special needs in relation to information, treatment and support.

### Recommendations

#### 1 Improving incidence and mortality data

There is an urgent need to collect more complete and accurate information about breast cancer among Aboriginal and Torres Strait Islander women.

**It is recommended that:**

- the NHMRC National Breast Cancer Centre encourage state and territory cancer registries to systematically record Aboriginal and Torres Strait Islander background; and
- an evaluation of the accuracy of registration of Aboriginal and Torres Strait Islander background on breast cancer records be undertaken.

#### 2 Improving information about Aboriginal and Torres Strait Islander women with breast cancer

There is currently no information other than anecdotal reports of the special needs of Aboriginal and Torres Strait Islander women who are diagnosed with breast cancer.

**It is recommended that:**

- an exploration of the needs of Aboriginal and Torres Strait Islander women with breast cancer be undertaken using a cohort design.

### **3 Early detection**

Given the possibility that there is a higher case fatality rate among Aboriginal and Torres Strait Islander women and the lower rates of participation in early detection programs, a priority in improving breast cancer control must be to improve early detection of breast cancer. To be effective, any programs in this area must be culturally appropriate and conducted in full collaboration with relevant community groups. Such programs will need to be based on a community understanding that Aboriginal and Torres Strait Islander women do get breast cancer and that early detection is important in survival.

#### **It is recommended that:**

- a widespread community information program be implemented in consultation with Aboriginal women and Aboriginal Health Services to ensure that Aboriginal and Torres Strait Islander women understand their risk of breast cancer and the importance of early detection. The campaign should use audiovisual resources and consider involving the Aboriginal and Torres Strait Islander media;
- the campaign be supported by the development of locally produced resources about breast cancer and early detection fostered through state and regional agencies;
- special training programs be developed for Aboriginal and Torres Strait Islander health workers to develop skills in clinical breast examination and an understanding of its importance; and
- an examination of the costs and benefits of different strategies for increasing the early detection of breast cancer among Aboriginal and Torres Strait Islander women, particularly those living in rural and remote areas be undertaken. This may include the collection of information about the accessibility and acceptability of mammographic screening to urban, rural and remote Aboriginal and Torres Strait Islander women.

### **4 Management and support**

While available data are limited, it would appear that many Aboriginal and Torres Strait Islander women do not receive culturally appropriate management and support. Information from a cohort study of Aboriginal and Torres Strait Islander women with breast cancer as outlined in Recommendation 2 would assist in identifying specific needs.

**It is recommended that:**

- culturally appropriate resources be developed to provide Aboriginal and Torres Strait Islander women with information about management and support options;
- undergraduate and continuing education programs include material on the special needs of Aboriginal and Torres Strait Islander women and culturally appropriate management and support strategies;
- innovative support options be trialed, such as a help line for Aboriginal and Torres Strait Islander women or specially trained support staff in hospitals with higher numbers of Aboriginal and Torres Strait Islander women with breast cancer; and
- Aboriginal and Torres Strait Islander Breast Cancer Support Service volunteers be recruited and trained to assist Aboriginal and Torres Strait Islander women diagnosed with breast cancer.

---

## References

- 1 Cleland JB. *Disease amongst the Australian Aborigines*. Journal of Tropical Medicine and Hygiene; 1928;31:53-9, 65-70,125-30,141-5,157-60,173-7,196-8,202-6,216-20, 232-5,262-6,280-2,290-4,307-13,326-30.
- 2 Basedow H. *Diseases of the Australian Aborigines*. Journal of Tropical Medicine & Hygiene; 1932;35:177-85,193-8,209-13, 229-33,247-50,273-8.
- 3 Crotty JM, Webb RC. *Mortality in Northern Territory Aborigines*. Medical Journal of Australia; 1960;2(13):489-92.
- 4 Binns RT. *A study of diseases of Australian natives in the Northern Territory*. Medical Journal of Australia 1945;1(17):421-6.
- 5 Moodie PM. *Aboriginal and Torres Strait Islander health*. Australian National University Press, Canberra; 1973.
- 6 *National Aboriginal and Torres Strait Islander and Torres Strait Islander survey 1994*. Australian Bureau of Statistics, Canberra; 1995.(Catalogue No. 4190.0.)
- 7 *Australia's Aboriginal and Torres Strait Islander and Torres Strait Islander population: census of population & housing 6 August 1991*. Australian Bureau of Statistics Canberra; 1993. (Catalogue No. 2740.0.)
- 8 *The Health & Welfare of Australia's Aboriginal & Torres Strait Islander Peoples*. Australian Bureau of Statistics,1997 (Catalogue No. 4704.0)
- 9 Kelsey JL. *Breast cancer epidemiology: summary and future directions*. Epidemiologic Reviews; 1993;15:256-63.
- 10 Kelsey JL, Gammon MD, John EM. *Reproductive factors and breast cancer*. Epidemiologic Reviews; 1993;15:36-47.
- 11 Hulka BS, Stark AT. *Breast cancer-cause and prevention*. Lancet; 1995;346:883-7.
- 12 *Estimated resident population by sex and age: states and territories of Australia, preliminary June 1994*. Australian Bureau of Statistics, Canberra; 1995. (Catalogue No. 3201.0.)
- 13 *Enough to make you sick: how environment and income affect health*. National Health Strategy Unit, Melbourne; 1992.

- 14 Australian Institute of Health and Welfare. *Australia's health 1994*. Australian Government Publishing Service, Canberra; 1994.
- 15 Gracey M, Veroni M. *Comparative hospitalisation and morbidity rates of Aboriginal and Torres Strait Islander and non-Aboriginal Western Australians in their sixth and seventh decades*. Australia and New Zealand Journal of Medicine; 1995;25:27-31.
- 16 Hopper J. Some public health issues in the current state of genetic testing for breast cancer in Australia. Australia and New Zealand Journal of Public Health; 1996;20:467-72.
- 17 Bhatia K. *Aboriginal and Torres Strait Islander and Torres Strait Islander health-related statistics: highlights from the Australian Institute of Health and Welfare publications*. Aboriginal and Torres Strait Islander Health Information Bulletin 1994;19:1-5.
- 18 Westley-Wise V, Taylor L. *Health of Aboriginal and Torres Strait Islander mothers and babies in NSW*. New South Wales Public Health Bulletin No. 5; 1994.
- 19 Chan A, Scott J, McCaul K, Keane R. *Pregnancy outcome in South Australia 1993*. Pregnancy Outcome Unit, South Australian Health Commission, Adelaide; 1994.
- 20 Gray A. *Aboriginal and Torres Strait Islander fertility: trends and prospects*. Journal of the Australian Population Association; 1990;7(1):51-77.
- 21 Gee V. *Perinatal statistics in Western Australia: eleventh annual report of the Western Australian midwives' notification system 1993*. Health Department of Western Australia, Perth; 1994.
- 22 Moodie PM, Pedersen EB. *The health of Australian Aborigines: an annotated bibliography*. Australian Government Publishing Service, Canberra; 1971.
- 23 Thomson N, Merrifield P. *Aboriginal and Torres Strait Islander health, an annotated bibliography*. Australian Institute of Aboriginal and Torres Strait Islander Studies, Canberra; Australian Institute of Health; 1988.
- 24 Thomson N, English B. *Aboriginal and Torres Strait Islander health statistics and the Australian Institute of Health and Welfare*. Aboriginal and Torres Strait Islander Health Information Bulletin; 1993;18:26-36.
- 25 Divakaran-Brown C, Honari M. *Aboriginal and Torres Strait Islander health indicators in South Australia*. Aboriginal and

- Torres Strait Islander Health Organisation of South Australia, Norwood; 1990.
- 26 Bhatia K, Anderson P. *Indicators for monitoring Aboriginal and Torres Strait Islander health*. Aboriginal and Torres Strait Islander Health Information Bulletin; 1995;20:42-54.
  - 27 Plant AJ, Condon JR, Durling G. *Northern Territory health outcomes: morbidity & mortality 1979-1991*. Northern Territory Department of Health & Community Services, Darwin; 1995.
  - 28 *Epidemiology of cancer in South Australia*. South Australian Health Commission, Adelaide; 1997.
  - 29 de Espaignet E, Measey M, Condon J, Jelfs P, Dempsey K. *Cancer in the Northern Territory 1987-1993*. Territory Health Services, Darwin; 1996.
  - 30 Kricker A, Jelfs P. *Breast cancer in Australian women 1921-1994*. Australian Institute of Health and Welfare, Canberra; 1996.
  - 31 Australian Institute of Health and Welfare, Australasian Association of Cancer Registries. *Cancer in Australia 1986-88*. Australian Government Publishing Service, Canberra; 1994.
  - 32 Threlfall T, Whitfort M, Thompson J. *Cancer incidence and mortality in Western Australia, 1992-94*. Health Department of Western Australia, Perth; 1996.
  - 33 Anderson P, Bhatia K, Cunningham J *Occasional Paper: Mortality of Indigenous Australians 1994* Australian Bureau of Statistics & the Australian Institute of Health and Welfare 1996.
  - 34 Taylor RJ, Smith D, Hoyer A, Coates M, McCredie M. *Breast Cancer in NSW 1972-1991*. Cancer Epidemiology Research Unit, NSW Cancer Council, Sydney; 1994.
  - 35 Australian Cancer Society. *National Cancer Prevention Policy 1993*. Australian Cancer Society, Sydney; 1993.
  - 36 Kerlikowski K, Grady D, Rubin SM, Sandrock C, Ernster VI. *Efficacy of screening mammography. A meta-analysis*. Journal of the American Medical Association; 1993;273:149-54.
  - 37 *1989-90 National Health Survey Users' Guide*. Australian Bureau of Statistics, Canberra; 1991. (Catalogue No. 4363.0.)
  - 38 Donbavand J. *Aboriginal health research. The classification of current research and research from the past decade that has been conducted into Aboriginal health. Report to the NH&MRC August-December, 1991*.
  - 39 Report of special workshop for urban Aboriginal and Torres Strait Islander women, 21 July 1995 and Report of Aboriginal and Torres Strait Islander women's workshop, Alice Springs, 21 August, 1995. In: *Consultative report. Volume 2: reports from state/territory*

*workshops*. NHMRC National Breast Cancer Centre, Sydney; 1996.

- 40 Kirk M, Carr B, Angus S, Boyle F. *Prevention and early detection of cancer in Aboriginal and Torres Strait Islander and Torres Strait Islander women*. Royal Women's Hospital, Brisbane; 1995.
- 41 Clapham K. *Review to identify all institutions that currently provide training for Aboriginal and Torres Strait Islander health workers and curricula audit. Report to NHMRC National Breast Cancer Centre*. NHMRC National Breast Cancer Centre, Sydney; 1997.

---

## Appendix 1

### **Key Aboriginal and Torres Strait Islander organisations and individuals consulted in preparing this report**

#### **National**

National Aboriginal Community Controlled Health Organisation,  
Naomi Meyers, Chair

#### **New South Wales (NSW)**

NSW Aboriginal Health Resource Cooperative, Sandra Bailey  
Aboriginal and Torres Strait Islander Commission, Dulcie Flower  
NSW Aboriginal Medical Services:

- Awabakal (Newcastle)
- Biripi (Taree)
- Boree (Orange)
- Bourke
- Brewarrina
- Bulgar (Grafton)
- Central West (Cowra)
- Coomealla (Dareton)
- Daruk (Mt Druitt)
- Doonooch (Nowra)
- Durri (Kempsey)
- Griffith
- Illawarra (Berkley)
- Jali (Wardell)
- Katungal (Narooma)
- Moree Sobriety House
- Narrandera
- Redfern
- Riverina (Wagga)
- South Coast (Nowra)
- Tharawal (Campbelltown)
- Walgett
- Walhollow (Caroona)
- Wellington

Women's Health Service (South West Sydney)  
Grace Kong - Parramatta Community Health Centre, NSW

### **Victoria (VIC)**

Victorian Aboriginal Health Service, Debby Birch  
Department of Aboriginal Affairs

### **Northern Territory (NT)**

Aboriginal Medical/Health services;

Danila Dilba (Darwin)  
Wurliwuriling (Katherine)  
Miwatj (Gove)  
Alukura (Alice Springs)  
Anyinginya (Tennant Creek)

Congress Alice Springs, Stephanie Bell

Congress Alukura, Alice Springs, Helen Liddle, Francie Turner

NT Remote Health, Kathy Abbott

NT Remote Health Aboriginal Health Worker Training, Valmai McDonald

### **Queensland (QLD)**

Anton Breinl Centre at James Cook University, Ian Ronski

Department of Family and Aboriginal and Islander Affairs

Townsville Aboriginal and Islander Health Service, Dr Barrett

Wuchoppem Medical Service

### **Tasmania (TAS)**

Tasmanian Aboriginal Health Service

Tasmanian Aboriginal Medical Service

Department of Aboriginal Affairs, Shane Nicholls

### **South Australia (SA)**

Aboriginal Health Council of South Australia, Denise Troon

SA Aboriginal Medical Service/Nunkuwarrinyunt, Sharon Clark

---

## **Appendix 2**

### **Cancer registries contacted**

**Australian Capital Territory**  
Cancer Registry

**New South Wales**  
Central Cancer Registry

**Northern Territory**  
Cancer Registry

**Queensland**  
Queensland Cancer Registry

**South Australia**  
Cancer Registry

**Tasmania**  
Tasmanian Cancer Registry

**Victoria**  
Cancer Registry

**Western Australia**  
Cancer Registry

---

## Appendix 3

### Unpublished small studies or reports identified

#### 1 **Awabakal Aboriginal Medical Service Study (NSW)**

The written report of this study was not able to be released, but a personal communication described this project as looking at the knowledge and attitudes of Aboriginal and Torres Strait Islander women living in the upper Hunter towards the use of the mobile mammographic screening van. Interviews were conducted with 200 women and noted a number of difficulties with the screening service, which have been included in this document. Information relating to the knowledge and attitudes of Aboriginal and Torres Strait Islander women to the mammographic screening van were unavailable.

#### 2 **Women's Health Promotion Group Study (Durri Aboriginal Corporation Medical Service, NSW )**

No written report was available, and data were obtained through personal communication. The study explored prevention and early detection behaviours in relation to cervical and breast cancer among 38 women aged between 16 and 60 years. No information was available about participants' knowledge or attitudes about breast cancer.

#### 3 **Djigay Koorie Health Survey (from Durri Aboriginal Corporation Medical Service, NSW )**

No written report was available and data were obtained through personal communication. A group of students from the local Institute of Technical and Further Education surveyed 115 people on a range of health issues including knowledge regarding breast cancer. Very limited information was available regarding the sampling and methodology for the study.

#### 4 **Feasibility study for Northern Territory participation in the NPEDBC**

The 1991 feasibility study for Northern Territory participation in the NPEDBC (now BreastScreen Australia) reported that in relation to the acceptability of a screening program for Aboriginal and Torres Strait Islander women living in remote areas, a diagnosis of breast cancer would mean leaving their community to travel to Darwin or Alice Springs for treatment

and then possibly interstate for radiation therapy. The study acknowledged that this pattern of diagnosis and care would have major psychological and social implications for Aboriginal and Torres Strait Islander and Torres Strait Islander women. The feasibility study reported that the concept of screening is not readily accepted by some Aboriginal and Torres Strait Islander people and noted that the period of compulsory chest X-rays for tuberculosis is remembered, on the whole, with resentment.

**5 NPEDBC consultants report - implementation issues associated with the delivery of the NPEDBC across the remote north of Australia**

The report, commissioned by the NPEDBC in the Northern Territory in 1993, provides a general overview of a number of implementation issues that were identified whilst conducting the feasibility study for the NPEDBC. The authors interviewed both Aboriginal and Torres Strait Islander and non-Aboriginal health professionals about the delivery of screening services to Aboriginal and Torres Strait Islander women in the Northern Territory.

**6 Congress Alukura response to the NPEDBC consultants' report**

A brief response from Congress Alukura, the Aboriginal and Torres Strait Islander community-controlled organisation responsible for the provision of some of the primary health care services to 4,000 Aboriginal and Torres Strait Islander women living in Central Australia to the above report. The response generally supports the issues detailed in the consultants' report, but suggests that consultation with Aboriginal and Torres Strait Islander organisations and Aboriginal and Torres Strait Islander communities was crucial to the successful implementation of the screening program in the Northern Territory and Central Australia.

**7 Project Cancer Awareness Strategies to Indigenous Health Workers and Individuals (C.A.S.T.I.H.W.A.I)**

In 1992, the Queensland Cancer Fund hosted a two day workshop to address the lower rates of attendance by Aboriginal and Torres Strait Islander women in the NPEDBC in North Queensland. The aim of the workshop was to identify the barriers faced by Aboriginal and Torres Strait Islander and Torres Strait Islander women in attending the NPEDBC. The workshop, which was attended by both Aboriginal and Torres Strait Islander and non-Aboriginal health professionals, highlighted that there was general lack of knowledge amongst health professionals about what Aboriginal and Torres Strait Islander and Torres Strait Islander women believe about breast

cancer, and identified several barriers to screening which have been incorporated in this report.

## **8 NHMRC National Breast Cancer Centre's consultations**

In July and August 1995, the NHMRC National Breast Cancer Centre held two consultative workshops for Aboriginal and Torres Strait Islander women about breast cancer.<sup>37</sup> The first workshop was held in Sydney and included 11 participants from Aboriginal and Torres Strait Islander communities along the east coast of Australia, South Australia and Perth.

Representatives from a wide range of groups were included: Aboriginal Medical Services, ATSIC Regional Council and the NSW Department of Health. The second workshop was held in Alice Springs and included 22 participants from Aboriginal and Torres Strait Islander communities in Central Australia, Western Australia, Queensland and the Torres Strait. The workshops used a semi-structured process to identify key issues in relation to breast cancer and to identify priorities for the NHMRC National Breast Cancer Centre.

## **9 Prevention and early detection of cancer in Aboriginal and Torres Strait Islander and Torres Strait Islander women report (Royal Women's Hospital Brisbane)**

In 1995 the Queensland Health Promotion Unit funded a pilot study amongst Aboriginal and Torres Strait Islander women, to investigate factors that may be associated with later diagnosis of breast and cervical cancer. These cancers are the two most common forms of cancer among women. The report of the study details the relevant literature and the fieldwork undertaken with a group of twenty-two Aboriginal and Torres Strait Islander women in Beaudesert, a semi-rural area of south-east Queensland.<sup>38</sup>

## **Appendix 4**

### **List of resources on breast cancer for Aboriginal and Torres Strait Islander**

**All women both young and old need to check for breast changes**

Available in English and Yolgha Matha.

Women's Cancer Prevention Program, Territory Health Services

**Arlwekere having a well woman's check - stay strong - stay healthy**

Available as a poster and brochure

Congress Alukura

**Have a Pap smear now**

Includes information about breast cancer and advice on breast care.

Women's Cancer Screening Service, Health Department of WA

**Healthy Aboriginal women in mind, body and spirit**

Available as a poster and brochure

BreastScreen Queensland

**The Pap smear**

30 minutes, Family Planning NT, 1993

Training video for Aboriginal health workers on Pap smears, which includes a 3 minute segment at the end on the breast examination.

**Women's health business: breast self-examination**

Flip chart with information on conducting breast examinations.

Family Planning NT

**Breast self-examination**

Women's Cancer Prevention Program, Territory Health Services

**Healthy Aboriginal women**

Brochure, A4 and A3 posters.

BreastScreen Tasmania

**Healthy Aboriginal women in mind, body and spirit**

Available as a brochure and a poster.

BreastScreen Queensland

**Hey, Tidda, breast cancer is serious business**

17 minutes, VHS

BreastScreen Queensland

**Important things for Aboriginal women to do for themselves**

A3 poster

Women's Cancer Prevention Program, Territory Health Services

**Wise grandmothers have a breast x-ray**

Flip chart and poster

Women's Cancer Prevention Program, Territory Health Services