2004 marked the 10th anniversary of BreastScreenNT.

In 10 years BreastScreenNT has:
- **Taken** over 171,086 films
- **Screened** over 37,500 women
- **Diagnosed** over 160 women with breast cancer
  (invasive and in situ disease)
BreastScreenNT has managed to overcome many challenges related to running this type of population-based service, given the small population size and remoteness of the Northern Territory compared with the rest of Australia. BreastScreenNT has provided a screening service to Darwin, Alice Springs and the regional centres of Nhulunbuy, Katherine and Tennant Creek. The program has also provided a best practice model for assessment clinics, where the client’s care needs are assessed by a multidisciplinary team.

This report tells the story of the 10-year service history of BreastScreenNT – the early days, achievements and challenges along the way and where the program is now. It includes facts and figures about the NT population, women’s participation in screening and program outcomes. It tells women’s personal stories about being screened and recalled for assessment, about being diagnosed with breast cancer and about working in the program or in association with it over those 10 years.

Lesley Kemmis, Director Community Health
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The photographs in this report have been reproduced with permission. DHCS would like to advise readers that this document might contain pictures of Aboriginal and Torres Strait Island people that may offend.
Abbreviations & Definitions

ABS  Australian Bureau of Statistics
AHW  Aboriginal Health Worker
AIHW  Australian Institute of Health and Welfare
ATSI  Aboriginal and Torres Strait Islander
BCN  Breast Care Nurse
BSE  Breast Self Examination
BSNT  BreastScreenNT
CALD  Culturally and Linguistically Diverse
DHCS  Department of Health and Community Services
DCIS  Ductal Carcinoma In situ
ERP  Estimated Resident Population
GLBTI  Gay, Lesbian, Bisexual, Transgender, Intersex
GP  General Practitioner
A decade of achievement 1994-2004

NAS  National Accreditation Standards
NT   Northern Territory
NTCR Northern Territory Cancer Registry
PHC  Primary Health Care
RAN  Remote Area Nurse
WCPP Women’s Cancer Prevention Program
WHE  Women’s Health Educator
WWCS Well Women’s Cancer Screening
Ductal carcinoma in situ is a disease that involves cellular changes in the ducts of the breast. Although the changes are like those seen in breast cancer, DCIS has not spread beyond the ducts.

This report uses the phrase ‘breast cancer (invasive and in situ)’ to indicate the inclusion of DCIS. However, DCIS is not routinely included in breast cancer statistics published by the NT (or interstate) Cancer Registry, or the Australian Institute of Health and Welfare, as seen in this report.
What is BreastScreenNT?

BreastScreenNT provides a free breast screening service to asymptomatic women at five sites throughout the NT, and screens more than 4000 women each year. Service is provided from first mammogram to the point of breast cancer diagnosis and referral for treatment.

Each state and territory in Australia has established the breast-screening program to suit its demographics, geography and resources. BreastScreenNT was set up alongside the NT Cervical Screening Program, under the umbrella name of Women’s Cancer Prevention Program (WCPP), now called Well Women’s Cancer Screening (WWCS). WWCS sits under Community Health in the Department of Health and Community Services (DHCS).

The Australian and Northern Territory Governments jointly fund BreastScreenNT.

BreastScreenNT’s identity

Both the national and NT programs have had name changes over time. The national program, originally called the National Program for the Early Detection of Breast Cancer, was changed to BreastScreen Australia in 1996.

The NT program, originally called NT Breast Screen, changed to BreastScreenNT in 1999, in line with national and other state changes.

The NT BreastScreen and NT cervical screening programs originally came under the umbrella of the WCPP, which changed to WWCS in 2001.
BreastScreenNT's identity

The job was out for open tender. I submitted four thumbnail sketches and was fortunate to have one selected. It was just pure and simple, mainstream style and to do with promoting BreastScreen [NT] at that time … so that’s what the logo is about.

I believe art is a vital part of improving Aboriginal health. It cuts across all languages and it removes the stigma attached to sensitive topics like breast screening. I’m glad my design got up. It’s important to me – I’m Territory born, this is my homeland and I want to give something back.

Joanne Nasir, Aboriginal Artist, Darwin

BreastScreenNT's identity

The BreastScreenNT logo was designed in 1994 by Darwin Aboriginal Artist, Joanne Nasir.
Breast cancer is the leading cause of cancer-related death in Australian women and the second leading cause in NT women (after lung cancer). Incidence increases with age - more so after the age of 50. While the cause and means for prevention remain unknown, screening for early detection is the best available strategy for reducing morbidity and mortality. Evidence suggests that screening is most effective for women aged 50 to 69 and, that for this age group, two-yearly screening can reduce mortality by 30 per cent (Zhao, Condon and Garling 2004, Brawley 2004, AIHW 2003b).

Current lifetime risks for women in Australia and the NT

Lifetime risk refers to a woman’s likelihood of being diagnosed with, or dying from, breast cancer before the age of 75. This is the same as the proportion of women who will be diagnosed with, or die from, breast cancer by the time they reach the age of 75.

Australian women have a:
- one in 11 chance of being diagnosed with breast cancer
- one in 50 chance of dying from breast cancer.

NT non-Indigenous women have a:
- one in 13 chance of being diagnosed with breast cancer
- one in 51 chance of dying from breast cancer.

NT Indigenous women have a:
- one in 22 chance of being diagnosed with breast cancer
- one in 55 chance of dying from breast cancer.

(Zhao, Condon & Garling 2004).

There are marked differences in incidence and mortality rates between NT non-Indigenous and NT Indigenous women. Where separated data are available they will be shown with data for the total Australian population for comparison.
Increasing incidence rates

For Australian women aged 50 to 69, the age-standardised incidence rate has risen from 196.9 new cancers per 100,000 women in 1987 to 305.4 new cancers per 100,000 women in 2001 (AIHW 2005a). Increasing breast cancer rates can be attributed to a ‘true’ increasing risk of the disease (more women are actually developing breast cancer), as well as an increased chance of being diagnosed due to screening (without screening, asymptomatic cases would not be diagnosed) (Brawley 2004).

Note: These statistics do not include Ductal Carcinoma In situ (DCIS).

Declining mortality rates

The age-standardised death rate for Australian women aged 50 to 69 has fallen from 68 per 100,000 women in 1993 to 57 per 100,000 women in 2002 (AIHW 2005a). Declining breast cancer mortality rates can be attributed to early detection, making simpler and more effective treatment options available, as well as continual improvements made to treatments (AIHW 2003a).

NT incidence and mortality

NT data do not show such neat trends in incidence and mortality. With small population numbers, rates are vulnerable to huge variation, which limits the interpretation of data (Condon et al 2005a, 2005b).

Importantly, NT Indigenous women’s breast cancer incidence increased by more than 200 per cent between 1991 and 2001. An increase in breast cancer deaths in the same period suggests a true increase in incidence (Condon et al 2005a, 2005b).

The mortality rate for non-Indigenous women is significantly lower than their incidence rate, showing a high survival rate. For Indigenous women however, the mortality rate is much closer to the incidence rate, indicating that most Indigenous women do not survive breast cancer (Condon et al 2004a, Zhao, Condon & Garling 2004, Condon et al 2005a, 2005b).

[See Appendix 1 for NT breast cancer incidence and mortality trends]
Goal of BreastScreenNT

To achieve significant reductions in mortality and morbidity from breast cancer by actively recruiting and screening women aged 50 to 69 years for early detection of the disease (BreastScreen Australia 2002).

Aims of BreastScreenNT

Consistent with BreastScreen Australia, BreastScreenNT aims to:

- Ensure the program is implemented in such a way that significant reductions can be achieved in morbidity and mortality attributable to breast cancer
- Maximise the early detection of breast cancer in the target population
- Ensure screening for breast cancer (in Australia) is provided in dedicated and accredited screening and assessment services as part of the BreastScreen Australia Program
- Ensure equitable access for women aged 50 to 69 years to the program
- Ensure services are acceptable and appropriate to the needs of the eligible population
- Achieve high standards of program management, service delivery, monitoring and evaluation and accountability.

(BreastScreen Australia 2002)
BreastScreenNT’s key messages

**Have regular screening mammograms:**

- Screening mammograms do not prevent breast cancer, but are currently the best method of detecting cancer at an early stage when treatment is most effective.
- Screening mammograms can detect cancers that are too small to be felt by women or their doctor.
- The risk of breast cancer increases with age. Breast cancer is more common in women over the age of 50.
- Screening mammograms are most effective for women aged 50 to 69.
- Research has shown that two yearly screening for women aged between 50 and 69 can reduce deaths from breast cancer by up to 30 per cent.
- Screening mammograms are clearer in older women due to breast tissue changes. The density of breast tissue in younger women makes a mammogram very difficult to interpret.
- As there is no evidence of benefit from screening women younger than 40, BreastScreenNT does not provide screening for these women.
- For most women who develop breast cancer, there is no significant family history of the disease.

(BreastScreen Australia 2002).

I’ve used the BreastScreen [NT] service every two years from the moment it was offered. It’s actually empowering – it’s a positive step towards keeping healthy. Most people my age have lost friends and family members to cancers that might have been treatable had they been detected earlier.

Every time I go I reward myself with something small like a book I’ve been wanting to buy, a film I’ve been wanting to see, or a long relaxed swim without counting laps.

Beryl Mulder,
Program participant, Darwin
Be breast aware:

- It is important for all women to be breast aware – aware of the normal look and feel of their breasts and of the need to see their doctor if they notice any change/s. This message refers to all women of all ages, even those having screening mammograms.
- If a woman has a symptom such as a lump or lumpiness, a change in the shape of the breast, dimpling of the skin, discharge from a nipple or pain, it is important that it is investigated. It is recommended that the woman goes to her doctor and is referred for tests, including a diagnostic mammogram. A diagnostic mammogram differs from a screening mammogram, in that it focuses on the area of concern.

(BreastScreen Australia 2005)

Six months after being screened for the first time and being OK, I felt a lump in my left breast. I was diagnosed with breast cancer four years ago at the age of 51. My experience is a lesson in the need for vigilance – for women to know their breasts, to be aware. Two-yearly screening doesn’t necessarily mean everything’s OK. My lump wasn’t there six months earlier – we went back and checked the BreastScreenNT films. The cancer was high grade. It grew quickly.

Pat Hancock, Breast cancer survivor and past program participant, Darwin.
Accessing BreastScreenNT:

- BreastScreenNT is free of charge
- A doctor’s referral is not necessary
- BreastScreenNT will provide information and take appointments on 13 20 50
- BreastScreenNT is a women’s service, staffed by women.

"I think BreastScreenNT can take the credit for a high level of knowledge out there, for women taking care of themselves"

Del Hird, past Manager BreastScreenNT, Alice Springs.

I had a diagnostic mammogram in 2004 because I had some pain. I was fortunate enough to visit one of the communities near Palmerston just beforehand. I was speaking to some of the old girls about it. One said: “Oh you’ll love it – if you don’t have pointy boobs now, you will when you come out. Your titties, they will be flattened!”

It was good. I’m glad I did it. I think if you don’t work with something straight away, you always wonder about it.

Joanne Nasir, Darwin.
I think it’s really important to say: “this is a service that is provided to all women, regardless of socio-economic background”. There are so many differences in opportunities for treatments, for health outcomes. Health is life. Everybody should have that – that’s everybody’s right.

Joanne Nasir, Darwin.

By being free it helps women get it done, because you know, there are lots of things to pay for. Women put their own needs at the back of the line in the family. To not have to think: “I better put some money away for that” is good.

Dottie Daby, Program participant, Darwin.
Demographics and remoteness

The demographic and geographical features of the NT make it expensive and difficult to implement the BreastScreenNT program successfully and equitably. The number of women in the target population is relatively small and these women are dispersed over 1.3 million square kilometres. Large geographical distances, remoteness and the small population create a lack of economies of scale.

The NT population is culturally diverse, with a very large Indigenous population compared with the rest of Australia, a significant proportion of people born outside Australia, and a very large proportion speaking a language other than English at home (ABS 2001a, 2001b).

Around 59 per cent of NT women aged 50 to 69 are residents of Darwin, the NT’s major urban centre, and the location of BreastScreenNT’s main screening and assessment site. Another 6 per cent live within the surrounding Darwin rural district (DHCS 2005).

Some rural and remote areas in the NT become difficult to access by road during the wet season from November to March. The BreastScreenNT relocatable mammography machine cannot travel on unsealed roads, so it is confined to major roads.

Many of these factors provide challenges for BreastScreenNT for recruitment, access and participation. Running the service in the NT requires creativity, adaptability and versatility.

Table 1 > Comparing percentages of people in the NT and Australia (ABS 2001a, 2001b).

<table>
<thead>
<tr>
<th></th>
<th>NT</th>
<th>Australia</th>
</tr>
</thead>
<tbody>
<tr>
<td>Indigenous origin</td>
<td>25.1%</td>
<td>2.2%</td>
</tr>
<tr>
<td>Born outside Australia</td>
<td>14.5%</td>
<td>21.9%</td>
</tr>
<tr>
<td>Speak language other than English at home</td>
<td>31.1%</td>
<td>20%</td>
</tr>
</tbody>
</table>
You’ve got to be very, very versatile to work in a service that’s so isolated.

Nina Odgers, past Radiographer and Central Australian Coordinator BreastScreenNT, Alice Springs.

Workforce issues

The recruitment and retention of health service staff is of concern in the NT. Compounded by national and international skill shortages, especially in areas such as radiography and radiology, getting skilled personnel is difficult.

Periodic block screening and assessment clinics require staff to be employed as locums in Alice Springs, Tennant Creek, Katherine and Nhulunbuy. Their availability often determines the dates of service, and can reduce the program’s flexibility for accommodating local needs.
Most often they are recruited from interstate, with their travelling and accommodation costs covered by BreastScreenNT.

All screening mammograms are to be read independently by two readers, one of who must be a radiologist. Due to an absence of local radiologists qualified for this, BreastScreenNT films are sent interstate. Weather, manual handling and confidentiality require the films to be packed and freighted in a protective way.

I was fortunate to be able to employ some of the same people again and again. I employed the same Aboriginal Liaison Officer for two weeks each year to assist with the recruitment and promotion when we screened at Congress Alukura. Her role was unique so it was good to have the continuity. She would ring all the remote communities that hadn’t made appointments to remind them, she would visit all the town camps – go down to the river bed to make sure the town women knew. And when the women arrived she would have tea and sandwiches there for them.

Nina Odgers, past Radiographer and Central Australian Coordinator BreastScreenNT, Alice Springs.

One of the tricky things about BreastScreen [NT] is that films have to be read by two people and we don’t have these people in the NT. So we’re always going to have to pay a lot of money for that part of the service – sending films interstate.

Jenni Judd, past Manager BreastScreenNT, Darwin (above).
Data limitations in the NT

The following features of the NT need to be considered when analysing data:

- The NT has a small resident population of less than 198,000, and less than 70 new cases of invasive breast cancer diagnosed each year. The number of women diagnosed with breast cancer each year can vary considerably from year to year in such a small population (Zhao, Condon and Garling 2004).

- Differences in NT and Australian cancer incidence and mortality rates are likely to be due to random variation rather than true differences (Zhao, Condon and Garling 2004).

- The NT has a different age structure to the total Australian population, with a median age of 30 years, compared with a national median age of 35 years (ABS 2001a, 2001b). This is important, as breast cancer risk increases with age (AIHW 2005a).

- Interstate migration is the most volatile component of population change for the NT. The migrant working population makes up approximately one-third of the non-Indigenous population. Migrant workers are likely to be well (able to move interstate, away from support of family and friends). If unwell, they may return to the support of family and friends. This may affect cancer mortality rates and, to a lesser extent, incidence rates for the non-Indigenous population, but is unlikely to affect rates for the Indigenous population (Condon, Warman and Arnold 2001).

- Not all Indigenous people diagnosed with cancer are identified as being Indigenous in notifications to the NT Cancer Registry. It is estimated that NT Indigenous cancer incidence rates underestimate the true incidence of cancer in the Indigenous population by 18 per cent. Cancer mortality rates are not affected by under-identification of Indigenous people to the same extent (Zhao, Condon and Garling 2004).

These issues are further compounded by BreastScreenNT's data collection not adequately separating and reporting clearly on Indigenous status, or cultural and linguistic diversity.
BreastScreenNT’s development

Setting up

The NT was the last state or territory to implement the BreastScreen Australia program. Both the Australian and Northern Territory governments had previously determined, by cost-benefit analysis, that the program would be neither sustainable nor the highest priority for health gains in the NT (O’Connor and Carter 1993, McLean 1996). However, NT women successfully lobbied government, claiming that they should not be denied access to a program that was available elsewhere in Australia (McLean 1996). Program planning went ahead, although there was opposition for some time.

People begrudged BreastScreen [NT] getting the money it did – mainly people working remotely, people who scratched for every cent they could get – for enormous health issues! They could see the injustice.

The way I dealt with that was – I said: “Well I can do this job and do it well, and make sure women have access to a good service.” Or I could walk away and say: “That’s not fair.” I stayed.

Cynthia Croft, past Manager BreastScreenNT, Darwin.
Setting up BreastScreenNT under WCPP, alongside the NT Cervical Screening Program, has provided the effective use of resources and enabled a more holistic approach to women’s health.

The NT WCPP Advisory Committee, comprising key stakeholders including professionals and consumer groups, advised and supported BreastScreenNT’s development and implementation.

It is hard. It’s probably still not cost effective, but it’s hard to refuse women the service in our society. Many doctors were against it in the beginning. I thought twice about the job actually, because it was so looked down upon. They said “You’re wasting our money.”

Dr Lorraine Lydiard, Medical Officer BreastScreenNT, Darwin.

The Darwin screening and assessment service opened on 28 November 1994 at Sturt House in Linton Street, Casuarina. The program was initially Darwin-based and targeted urban women. An evaluation 18 months after its opening found a high level of satisfaction from women and their general practitioners (GPs) (McLean 1996).
Adapting BreastScreen Australia to suit the NT

The BreastScreenNT program was modified to suit the NT – to make it more culturally appropriate and cost effective.

Darwin, being the largest catchment area in the NT, was provided with a fixed screening site which was evaluated prior to extending the service to other regions (McLean 1996).

After consideration of demographic issues, remoteness and a lower breast cancer risk in Indigenous women, BreastScreenNT, with Australian Government agreement, diverted 10 per cent of program funding to the development of the Remote Areas Well Women’s Program. While focusing primarily on cervical screening (a higher priority for Indigenous women), this program also provided (and still does provide) breast health education and clinical breast examination for bush women.

While BreastScreenNT does not travel to very remote areas, a relocatable screening machine visits four of the largest regional towns in the NT and promotes breast screening to remote women living in these regions. Some communities have determined breast screening as a priority for their women’s health, and organise transporting women into regional towns. The funding for this is usually raised through local efforts. BreastScreenNT welcomes group bookings from remote communities.

I started working at the time of the first assessment clinic. I just came along and two doctors from Queensland came too. They were running the breast clinic in Mount Gravatt [in Brisbane] at that stage. They helped set things up and showed me what to do.

Dr Lorraine Lydiard, Medical Officer BreastScreenNT, Darwin.
What we did manage to do back in the early days was negotiate with the Australian Government about the needs of remote women, particularly Aboriginal women. It wasn’t a priority to provide breast screening in the bush, so we used about 10 per cent of the money to develop the Remote Areas Well Women’s Screening Program – because we worked out that about 10 per cent of the women in our target group lived in remote areas. It was a good outcome. We employed regional Women’s Health Educators. They worked in a Primary Health Care (PHC) framework, promoting well women’s checks. They focused more on cervical screening – as that was more of a priority and can be done easily out bush – but they also promoted going into town for breast screening.

The program is holistic. Aboriginal women told us that they didn’t want to be seen as a ‘cervix today and a breast tomorrow’. The program focused on community development and capacity building – training Remote Area Nurses (RANs) and raising the profile of women’s health issues.

We used it as an opportunity to talk with women about being responsible about their own health – that they didn’t just get sucked into a system. We used breast screening as an example – making sure they had the right information, that it was their decision to enter the program and go right through – that they had control. Hopefully then they could transfer that across to other health issues.

Cynthia Croft, past Manager BreastScreenNT, Darwin.
Growing the program

In 1995, BreastScreenNT extended to Central Australia. The service was set up in Alice Springs with a relocatable X-ray machine, and a view to taking the machine to regional areas. The part-time Alice Springs screening and assessment service opened on 25 January 1996 at Euriipa House, where it remains today. Screening first happened at Congress Alukura, an Indigenous women’s health service just outside Alice Springs in September 1996.

Screening services began in Tennant Creek in April 1996, Katherine in May 1996 and Nhulunbuy in May 1997.

The Darwin service moved from Sturt House to Casi House at 25 Vanderlin Drive Casuarina in October 1996, and then to the Casuarina Health Services Centre at 9 Scaturchio Street in April 2003.

The BreastScreenNT operations model has changed over time. Since June 2003 it has been coordinated on an NT-wide basis, conducting a full-time screening service in Darwin with periodic screening blocks in Alice Springs, Tennant Creek, Katherine and Nhulunbuy.

Women love the BreastScreen [NT] service. For a small specialist service it is an excellent example of what can be done in a challenging environment. The staff are really committed and friendly.

Jenni Judd, past Manager BreastScreenNT, Darwin.
Target population

Women aged 50 to 69 years

The clearest risk for breast cancer is increasing age. BreastScreenNT selects women based on age alone, with women aged 50 to 69 actively targeted for two yearly screening. In line with other states and territories, BreastScreenNT aims to screen 70 per cent of women in this age group every two years. Evidence suggests that this will reduce mortality rates by 30 per cent (BreastScreen Australia 2002).

The number of NT women aged 50 to 69 is growing. When BreastScreenNT began operating in 1994 there were 7721 women in the target group – of which 5405 made up the 70 per cent screening target. Ten years on, this number had almost doubled to a 70 per cent screening target of 9909 women (DHCS 2005).

BreastScreenNT faces the challenge of recruiting and re-screening more women every year so that current participation rates are maintained, program growth is able to match target population growth and participation rates head towards 70 per cent of women aged 50 to 69.

Confusion about the 50 to 69 year target group and reduced access for younger and older women has, at times, caused emotional responses from community members and politicisation of the service. BreastScreenNT faces the challenge of providing clear, evidence-based messages to the target group as well as other women for whom screening is less beneficial. BreastScreenNT does not deny that younger and older women can develop breast cancer – the challenge lies in communicating that screening is not as effective for them (Brawley 2004, BreastScreen Australia 2002).

Other target groups

Women aged 40 to 49 years

There is no strong evidence to support breast screening as an effective tool for all women aged 40 to 49. Women in this age group are not actively encouraged to attend screening. If they request screening they are advised of the risks, benefits and limitations of screening, so that they can make an informed decision (BreastScreenNT 2000, NBCC 2004).
Women aged 70 years and over

As breast cancer risk increases with age, women aged 70 and over do face a higher risk than those aged 50 to 69 (see Table 2, page 20). However, the older women do not benefit to the same extent from early detection. For this reason, these women are not actively targeted, but like women in the 40 to 49 year group they are eligible to attend screening if they choose (NBCC 2004, BreastScreenNT 2000).

Women under 40 years

Women under 40 do not benefit from population screening mammograms. Their risk for breast cancer is relatively low and their breast tissue density prevents clear detection of abnormalities. Consistent with BreastScreen Australia policy, women younger than 40 are not eligible to attend BreastScreenNT (NBCC 2004, BreastScreenNT 2000).

Table 2 > Age-specific breast cancer incidence rates per 100,000 women, Australian total, NT total, NT Indigenous and NT non-Indigenous, 1991-2003 (NT Cancer Registry 2005)

<table>
<thead>
<tr>
<th></th>
<th>Australia</th>
<th>NT non-Indigenous</th>
<th>NT Indigenous</th>
<th>NT</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-39 years</td>
<td>12.4</td>
<td>12.1</td>
<td>4.4</td>
<td>8.2</td>
</tr>
<tr>
<td>40-49 years</td>
<td>147.7</td>
<td>142.2</td>
<td>65.4</td>
<td>103.8</td>
</tr>
<tr>
<td>50-69 years</td>
<td>276.1</td>
<td>250.7</td>
<td>102.5</td>
<td>176.6</td>
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<tr>
<td>70+</td>
<td>311.6</td>
<td>247.7</td>
<td>191.3</td>
<td>219.5</td>
</tr>
</tbody>
</table>

Note: These statistics do not include DCIS. Australian data is for 1991-2001 only. NT data is incomplete for year 2003.
Women with breast symptoms

Misunderstanding and community debate have also surrounded access for women with breast symptoms. BreastScreenNT provides screening mammograms for women without symptoms and recommends that women with symptoms have a diagnostic mammogram, accessed through their general practitioner. In addition to the diagnostic service requiring a different approach, BreastScreenNT may take up to six weeks to deliver women’s results – not ideal for those with symptoms (BreastScreen Australia 2002, BreastScreenNT 2000).

Women with a strong family history of breast cancer

Women with a strong family history are eligible for screening every year at BreastScreenNT. A woman is said to have a strong family history if she meets one of the following criteria:

- a first-degree relative (mother, sister, daughter, father, brother, son) with breast cancer diagnosed before 50 years of age
- a first-degree relative with cancer in both breasts – diagnosed at any age
- two or more first-degree relatives with breast cancer – diagnosed at any age.

(BreastScreenNT 2000).

Women with a personal history of breast cancer

Women with a history of breast cancer can attend BreastScreenNT five years after diagnosis if they are no longer under the care of a specialist. These women are also eligible to be screened every year (BreastScreenNT 2000).
Participation rates indicate the proportion of the eligible populations attending for screening within a 24-month period. The primary focus is on targeted women aged 50 to 69, and other age groups are monitored.

To set targets and measure subsequent participation rates, BreastScreenNT has used various methodologies over the last 10 years.

The initial methodology was developed to accommodate the Public Health Outcome Funding Agreement between the Australian and NT Governments, which recognised that BreastScreenNT did not have the capacity to offer screening in remote areas. The target numbers were adjusted by removing 10.8 per cent of women (equal to the percentage of women living in remote areas, as defined by the Department of Health and Community Services). According to this methodology, BreastScreenNT’s participation rate for women aged 50 to 69 was at a high 91 per cent in the first 18 months of service (McLean 1996).

The second methodology was based on NT regional population data, excluding Darwin Rural and Alice Springs Rural areas, as defined by the Health Gains Unit of the DHCS. Again, the target number was adjusted.

Both of these methodologies resulted in an over-estimation of true participation rates and prevented true comparison with interstate rates.

From mid 2004, targets and participation rates have been determined according to the National Accreditation Standards (NAS) (BreastScreen Australia 2002) program data dictionary, using the Australian Bureau of Statistics (ABS) Estimated Resident Population (ERP), without adjustments. Targets and participation rates for the 10 years of service have been retrospectively corrected using this methodology. This has resulted in higher targets and significant reductions to participation rates.
### Table 3 > Number of women screened, all rounds, bi-calendar years 1994-2004

<table>
<thead>
<tr>
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<td>1406</td>
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<td>5783</td>
<td>6026</td>
<td>6121</td>
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<tr>
<td>70+</td>
<td>122</td>
<td>210</td>
<td>202</td>
<td>300</td>
<td>391</td>
<td>452</td>
<td>499</td>
<td>512</td>
<td>543</td>
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### Table 4 > Female ERP, (average ERP for bi-calendar years) 1994-2004

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<tbody>
<tr>
<td>40-49</td>
<td>5.58%</td>
<td>11.78%</td>
<td>15.73%</td>
<td>17.75%</td>
<td>16.87%</td>
<td>16.60%</td>
<td>16.80%</td>
<td>15.85%</td>
<td>14.77%</td>
<td>13.42%</td>
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<tr>
<td>50-69</td>
<td>20.19%</td>
<td>33.22%</td>
<td>42.10%</td>
<td>50.98%</td>
<td>49.30%</td>
<td>49.32%</td>
<td>47.76%</td>
<td>45.69%</td>
<td>45.42%</td>
<td>44.18%</td>
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<tr>
<td>70+</td>
<td>11.72%</td>
<td>19.23%</td>
<td>17.62%</td>
<td>25.24%</td>
<td>32.47%</td>
<td>36.59%</td>
<td>38.81%</td>
<td>38.15%</td>
<td>38.34%</td>
<td>33.34%</td>
</tr>
</tbody>
</table>

(BreastScreenNT 2005b).
**Participation**

Women’s participation in the BreastScreenNT program is measured over a 24-month period by calculating the number of individual women screened in each age group (shown in Table 3, page 23), as a proportion of the Australian Bureau of Statistics (ABS) Estimated Resident Population (ERP) for that age group (shown in Table 4, page 23). The bi-calendar year ERPs shown are averages of the paired years. Participation rates are expressed as percentages (shown in Table 5, page 23).

BreastScreenNT’s participation rates for women aged 50 to 69 reached 50.98 per cent within four years of operation. Since then however, there has been a slow decline to 44.7 per cent in 2001-2002 (AIHW 2005a).

Although the proportion per population of target group women screened over the reporting period has decreased, the actual number of women aged 50 to 69 years screened by BreastScreenNT has increased.

The national participation rate reached 57.1 per cent in 2001-2002 (AIHW 2005a).

**Re-screening**

Re-screen rates indicate the proportion of women who return for screening within 27 months of their previous screening mammogram. Re-screening is crucial for the program’s success in early detection (AIHW 2005a).

The profile of women screened at BreastScreenNT has changed over the course of 10 years. Since 2001, approximately 80 per cent of women attending BreastScreenNT have previously been screened (BreastScreenNT 2005b).

![Figure 1 > Women aged 50-69 screened by attendance, 1994-2004 (BreastScreen NT 2005b)](image-url)
Under-screened groups

Much evidence indicates lower screening participation rates in particular groups of women. Consistent with BreastScreenNT data, Indigenous women and culturally and linguistically diverse (CALD) women are less likely to participate in screening than other Australian women (AIHW 2005a).


BreastScreenNT undertakes targeted promotion to reach these groups.

What I want is for the woman to come back. She’s with me for five or 10 minutes – in that time I need to establish rapport, get the right position and take a good picture. Her comfort is paramount throughout, although the compression can be uncomfortable.

Vivienne MacDonald, Senior Radiographer BreastScreenNT, Darwin.
BreastScreenNT works to achieve participation in the program that is representative of the socio-economic, ethnic and cultural profiles of the population. Careful monitoring of participation data and relevant public health evidence is required to inform recruitment strategies. Under-screened groups are targeted with evidence-based approaches, minimising barriers and enabling participation. For 10 years, program promotion and recruitment of women has been a key focus and challenge for the program.

Darwin (urban and rural areas), with 65 per cent of NT women aged 50 to 69, is BreastScreenNT’s largest catchment area (DHCS 2005). Such numbers make promotion within Darwin a major priority.

BreastScreenNT promotion requires a combination of approaches within each of the regions screened, including communications, community action, collaborating with service providers and research and evaluation.

**Communications**

Communications, promotion and media plans are developed for each region in the NT to enable reaching maximum numbers of women in the target group. Regional target numbers are derived from the Australian Bureau of Statistics (ABS) Estimated Resident Population (ERP) and the BreastScreenNT register indicates the number of women in each area already in the program.

Mass communications in unpaid and paid media, such as newspapers, radio, television and displays, promote screening to women prior to each screening block in regional centres, and on an ongoing basis in Darwin.
BreastScreenNT also develops and distributes resource materials such as videos, books, brochures and research literature to women, community groups, health service organisations and health professionals.

From 1995 to 2002, Well Women’s Cancer Screening (WWCS) produced and distributed *Screening Matters*, a newsletter for health service providers about the goings on at WWCS and current evidence around screening.

Women registered in the BreastScreenNT program receive reminder letters by mail, informing them that their next screening mammogram is due.

Evidence indicates that sending personalised letters of invitation to women to commence screening when they turn 50 is a very effective recruitment strategy, with response rates of between 33 and 40 per cent (BreastScreen Australia 2002). For this strategy, BreastScreen NT had access to the electoral role from 1997 to 2001 and will submit an application in 2005 to the Australian Electoral Commission to regain access.

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It’s really wonderful to get the letter. I have quite a few senior moments these days, and if I don’t write things down I forget. I’ve now been going to BreastScreen [NT] for 10 years.

Dottie Daby, Program participant, Darwin

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**Service Providers**

BreastScreenNT works to build and maintain relationships with various health and other service providers who influence women’s participation in screening. General practitioners, Aboriginal Health Workers and Women’s Health Educators, for example, play a vital role in promoting breast screening across the NT. Evidence indicates that direct recommendation from a GP results in a response rate of between 60 and 91 per cent (Cockburn et al 1993, Clover et al 1996).
I’m hoping BreastScreen will come again – that we can build it up and get more women coming. It’s holistic here; they can have a well women’s check and a pap screen too. Having it as a social thing is good.

The Alukura Council is running again – it fell apart a few years ago. So we have the older women involved again – better connections happening. The women said it would be OK to invite white women for screening here if BreastScreenNT came again – they said: “They’re women too.”

Ameeta Patel, Medical Officer Congress Alukura, Alice Springs. Left to Right; Barbara Purcell, Theodora Allan, Ameeta Patel, Jo Hammond.
Breast screening is a promotional priority for me. When the dates of screening blocks are sent to me I ensure that everyone gets them – all the clinics in town and out bush. I talk about breast care and breast screening every time I have contact with the nurses in the clinics, and every time I have contact with women.

Sandy McElligott, Women’s Health Educator, Alice Springs Rural.

We ensure that communities are well prepared for BreastScreenNT’s visit. We communicate with GPs, Community Health Nurses, clinics, there will be community notices posted around town, ads on radio and in newspapers. Flyers end up in hairdressers and grocery shops, but a lot of it happens because the communities take it on.

Lisa Patamisi, Senior Health Promotion Officer BreastScreenNT, Darwin.
Research and Evaluation

Through careful monitoring of demographic and screening participation data, as well as breast cancer, health promotion and public health evidence, BreastScreenNT develops evidence-based promotion strategies.

Client feedback mechanisms, provided and monitored by the promotion staff, allow valuable client input into the program.

Promotion staff work as a conduit between the national program and key stakeholders in the NT.

Lisa Patamisi, Senior Health Promotion Officer BreastScreenNT.

Having good data is a really good thing. You can actually use it to argue for more resources, you can use it to inform the community, and you can use it to see how the program’s working or not working. It provides a baseline – you get to find out how you’re going with recruitment.

Jenni Judd, past Manager BreastScreenNT, Darwin.

We have thousands of women participating in the program – there’s evidence of a rich history of promotion which all happened before my time.

I frequently come across health workers and key community women who have been on advisory committees or lobby groups. There’s a good sense of ownership of BreastScreenNT in the community – many women have something to say about the service.

Lisa Patamisi, Senior Health Promotion Officer BreastScreenNT, Darwin.
Community Action

BreastScreenNT works collaboratively with consumer groups that provide support and advocacy for breast cancer survivors. Well networked and respected in the community, such groups play a valuable role in assisting BreastScreenNT promote screening and breast awareness.

In Darwin, being a small community, it really pays for all the groups to work together. If we can get the message across louder and clearer it’s to everybody’s benefit out there.

Judy Smith, Breast cancer survivor and NT Breast Cancer Voice member (NTBCV), Darwin.

NT Breast Cancer Voice has been around for about six years. One of our biggest achievements is the ‘My Journey’ folder for women diagnosed – we started that in a small way and it’s gone national. We’ve also lobbied for continuation of the breast care nurse position in the NT and more information and support for lymphoedema. Whenever we see a need we take it on. But we’re also very careful – we do our homework and we don’t go off half-cocked. That’s basically the secret of our success.

Michelle Hanton, Breast cancer survivor and NTBCV member, Darwin.
Dragons Abreast NT was a germ of an idea I had and it’s grown to a membership of 20 or so breast cancer survivors and 20 or so supporters in the NT, and thousands across Australia. What keeps it going is that nothing else like it exists – the fact that we do something positive with women in a fun environment, even though some of the women are very ill and do die. We encourage participation in life. ‘Living life to the full’ is what we say. We promote breast cancer awareness and screening through the sheer numbers and the stories the women have to tell. Our message is always ‘early detection’.

Michelle Hanton, Breast cancer survivor and National Coordinator Dragons Abreast, Darwin.

We achieve a lot up here because we’re small. When we go to meetings down south I think they think we’re making things up, but we’re not – it’s just that Darwin being Darwin, we know people. In some ways we make far better inroads. We can get to see politicians much more easily here and that’s important.

Susan Tulley, Breast cancer survivor and NTBCV member, Darwin.

At the end of the day we’re here for women who need us. We know that if you get the diagnosis, all you want to do is meet somebody who has survived!

Michelle Hanton, Breast cancer survivor and NTBCV member, Darwin.
Bosom Buddies was born in 2001, not long after we were diagnosed at the end of 2000 – Liz and I were diagnosed on the same day at the assessment clinic in Alice Springs. We went on a bit of a crusade when we were diagnosed, encouraging everyone to be screened.

Leslie Reilly, Breast cancer survivor and Bosom Buddies member, Alice Springs.

Our membership varies – we have six or eight regular members, and others move in and out. We laugh a lot. Sometimes we’re a bit macabre but it’s great.

Liz Locke, Breast cancer survivor and Bosom Buddies member, Alice Springs.

We help BreastScreenNT advertise. We put ads in school newsletters and up in supermarkets. We’re often on the radio – we’re always doing something.

Leslie Reilly, Breast cancer survivor and Bosom Buddies member, Alice Springs.
**Under-screened groups and promotion**

Targeted promotion with under-screened groups also incorporates communications, working with service providers, community action, and research and evaluation.

**Indigenous women**

Various factors contribute to Indigenous women’s low levels of participation. Indigenous women face significant health disparity – and breast cancer is one illness in a long list of complex health and social issues.

Indigenous women are more likely to be diagnosed with lung cancer, and are more likely to die from lung or cervical cancer, than breast cancer (Zhao, Condon and Garling 2004). However, breast cancer incidence in NT Indigenous women has increased by more than 200 per cent between 1991 and 2001. Changing risk factors that may explain this increase include rising rates of obesity, increasing the risk for post-menopausal breast cancer, and declining fertility rates, which have fallen by 50 per cent since the 1960s (Condon et al 2005a, 2005b).

While Indigenous women’s breast cancer incidence is still significantly lower than that of non-Indigenous women in the NT, their mortality rates are almost as high, and so Indigenous women die from breast cancer almost as often as non-Indigenous women. Such a high mortality rate is likely to be due to reduced access to services (including screening services), late stage of cancer at diagnosis, the presence of other chronic or infectious diseases and reduced likelihood of receiving or completing treatment. A Queensland study found factors such as language and other communication difficulties, rigid appointment systems, distance and isolation and discrimination all impact on access to health services there (James Cook University 2002, Condon et al 2001, Condon et al 2005a, 2005b). BreastScreenNT has also found that general practitioners are less likely to recommend breast screening to Indigenous women than non-Indigenous women, and that Indigenous women are less likely than non-Indigenous women to examine their own breasts for changes (McLean 1996, Condon et al 2003).

In 2003-2004, Indigenous women made up 10.7 per cent of all women screened at BreastScreenNT (BreastScreenNT 2005b).  

**Note:** Four per cent of women in the BreastScreenNT database have ‘unknown’ Indigenous status (BreastScreenNT 2005b).
BreastScreenNT acknowledged the unique needs of Indigenous women early in the planning phase of the program. Because Indigenous women had a low breast cancer risk among numerous more pressing health issues and the program had limited capacity to reach remote areas, BreastScreenNT developed the innovative Remote Areas Well Women’s Screening Program.

In 1995, 10 per cent of the BreastScreenNT budget was diverted to employ regional Women’s Health Educators (WHEs) to work in a Primary Health Care framework with remote women. Core components of their work include culturally acceptable education using local women, flexibility, and a true willingness to acknowledge and incorporate Indigenous knowledge in all areas of service delivery (Duquemin 1996).

The WHEs facilitated the introduction of ‘well women’s check’ clinics, incorporating clinical breast examination, cervical screening and other chronic disease screening – a more holistic and culturally sensitive model (Campbell and Kurnoth 2000).

There are five WHEs, one based in each of the regional centres in the NT, continuing to provide training and support to Remote Area Nurses (RANs), Aboriginal Health Workers (AHWs) and Medical Officers to perform well women’s checks and women’s health education.

WHEs are also a key link between remote Indigenous women and BreastScreenNT. For those women able to access regional screening blocks, they provide a crucial role in promoting and facilitating the women’s attendance, and providing valuable feedback to BreastScreenNT (Campbell and Kurnoth 2000).

Some remote Indigenous communities make group bookings and travel to town together for screening. Some camp overnight and use the opportunity to go shopping or to attend to other business in town. Health workers, RANs and WHEs assist by organising transport and camp accommodation and by providing support on the day with language and communication and paper work.
Even though I work in health and was brought up in the urban environment, I still get nervous about getting my health checked. How must women outside feel? When they’re from a different cultural background where English is a second or third language, it would be so overwhelming.

Joanne Nasir, Darwin.

It’s so hard – it’s really hard to get women in from hundreds of kilometres away for breast screening. One year we had some women come in from Kalkaringi – eight hours one way. They had to turn around and go back the same day. It’s a big day for older women. I wondered if it was worth it, but when I went out to that community later those women were really proud. They felt they’d done something really positive for their health.

The next year two full buses came in from remote communities. There were always lots of stories, flat tyres and so on. There weren’t meant to be any kids coming, but when the bus pulled up a big stream of kids came out from under the seats!

One year a group of women from Lajamanu stopped to chase and catch a large goanna on the way. This made them all late for their appointments, but that’s what it’s like. They cooked the goanna for tea and camped the night, before returning home the next day.

Sharon Weymouth, past Women’s Health Educator, Katherine.
I was diagnosed with breast cancer two years ago in 2003. I went to Darwin for my operation and chemo, then to Adelaide for six weeks of radiotherapy. There are five of us with breast cancer on the Tiwi Islands – four on Bathurst, and one on Melville Island. We comfort each other, and we tell others to get women’s checks. Some of the women went to BreastScreen [NT] together last year.

Eunice Orsto, Breast cancer survivor and Aboriginal Health Worker, Bathurst Island.

It was good to go all together. I was so nervous at first but then it was over! It was good.

The machine felt cold but I will be happy to go when it is my turn again in two years.

It’s something we will certainly be talking to some of the younger women about – so there is a better understanding about the importance of having a mammogram.

Virginia Galarla, Program participant and Aboriginal Health Worker, Melville Island.

Left to Right; Anne Marie Puruntatameri, Marie Puruntatameri, Irene Brown, Sister Gertrude Mase, Virginia Galarla.
To facilitate greater access for Indigenous women, regional screening blocks have been held on various occasions at Indigenous health services including Wurli Wurlinjang Medical Service in Katherine, Congress Alukura in Alice Springs, Anyinginyi Congress in Tennant Creek, and Nhulunbuy screening has usually been held at Miwatj Health Service.

Aboriginal Project Officers at WWCS have worked with Indigenous women directly and been involved in training other Indigenous and non-Indigenous health professionals. Targeted Indigenous promotion has involved community consultation, community action and collaborating with Indigenous service providers, through to evaluation. Indigenous women’s reference groups set up in Darwin and Alice Springs have informed the broad development of the program, as well as promotion activities and resources. Activities have included Indigenous women’s health days / camps, displays and promotion via Indigenous media. Resources produced by Indigenous women, for Indigenous women, include two videos titled *Mammograms for Women – Dee Dee’s Story* and *Have a Well Women’s Check* and a visual flip chart *Keep Strong Women – Look after yourself healthy way Grandmothers have a breast X-ray*.

Links are maintained with Indigenous health networks for accessing up-to-date information and presenting issues identified by NT women (BreastScreenNT 2005a).

"In the past they used to be these mad weeks – the women would all come in and camp – it was a big social thing. And for us, the opportunities were great. We used to run education sessions…"

Barbara Purcell, Midwife Congress Alukura, Alice Springs.
We made a breast video, which was sent to all clinics in the NT, and has been used in other states. We also made one about well women’s checks. Women from Darwin, Alice Springs and the Tiwi Islands were involved. The women didn’t want a script – except for the medical terminology – they just talked.

Patricia Kurnoth, past Aboriginal Project Officer BreastScreenNT, Darwin.

Culturally and linguistically diverse women

Culturally and linguistically diverse (CALD) women in Australia are less likely to participate in screening and other health services than other Australian women because of language and cultural barriers (Kelaher et al 1997, AIHW 2003b).

Almost 14.5 per cent of the NT population was born overseas. Of these, 5.7 per cent were born in the English-speaking countries of the United Kingdom and New Zealand. The most common non-English speaking place of birth is the Philippines (ABS 2001b).

Of all people in the NT, 31.1 per cent speak a language other than English at home. Half of these people are Indigenous – speaking Australian Indigenous languages, and the next most common languages are Greek and Chinese languages (ABS 2001b).

In 2003-2004 CALD women made up 11 per cent of all women screened at BreastScreenNT (BreastScreen Maintenance Database 2005). Data prior to these years is unreliable.
CALD is defined by BreastScreenNT as ‘speaking a language other than English at home’.

A WWCS CALD Project Officer promotes screening to CALD women in the NT. Consultation with CALD women has generated the establishment of the Ethnic Women’s Reference Group, identified a series of barriers to screening and informed numerous promotion strategies.

Identified barriers to screening for CALD women include modesty and embarrassment, anxiety and fear, language, poor use of interpreters, low levels of knowledge about screening, insensitivity and discrimination from health professionals, family commitments, and women’s roles (Farshidi 1999).

Promotion strategies targeting CALD women included CALD women’s health days, special screening clinics for CALD women, the Bilingual Health Education Program, communicating via ethnic media and translated brochures in 12 languages. BreastScreenNT has also purchased and disseminated BreastScreen Victoria’s (2000) For Me and My Family videos in various languages.

Women’s health days, held annually from 1998 to 2003, involved expos of government and non-government services relevant to women’s health. Concurrent sessions were delivered in various languages with the use of interpreters. These days attracted between 150 and 300 women each year (Farshidi 1999).

Special screening clinics were held in 1997 and 1998 in Darwin, Palmerston and Alice Springs for groups of CALD women. The clinics provided cervical screening and education and demonstration of breast self-examination (BSE) at a time when it was widely promoted (Farshidi 1999).

The Bilingual Health Education Program ‘Women Talking to Women’ involved training and supporting more than 14 women from Darwin, Alice Springs, Tennant Creek and Nhulunbuy to deliver cancer and early detection education to women in their respective CALD

I could not have managed the program without the input from the Indigenous and CALD reference groups. Those women brought knowledge and skills I didn’t have.

Cynthia Croft, past Manager BreastScreenNT, Darwin.
We ran about four or five sessions about breast cancer and breast screening. I think between us we reached all of them – about 500 Indonesian women! The Muslim bilingual educator worked with the Muslim women and I worked with the others.

The program made us trust ourselves and feel confident to share information.

Thien Hawks, past Indonesian Bilingual Educator, Darwin.

When you have fear you go back to your own language.

Leony Bowey, past Filipino Bilingual Educator, Alice Springs.

communities, in first language. The training was provided in English and then delivered by the bilingual educators in community language. The program had representation from the Thai, Greek, Indonesian, Cambodian, Timorese, Filipino, Vietnamese and Indian communities (Farshidi 1999).
Sometimes women don’t want to come to a session about cancer. It’s a sensitive thing so it’s hard to get them there. I tell them in other ways. I’m a Greek Welfare Worker so I might tell them when I’m working with them on something else.

Juliani Bousios, Greek Bilingual Educator, Darwin

The Bilingual Educator’s program was incredibly cost effective and it really made a difference. CALD women’s participation rates are high.

Cynthia Croft, past Manager BreastScreenNT, Darwin.
Women with disabilities

An estimated 20 per cent of Australian people have a disability, and prevalence increases with age (ABS 2003).

There is much evidence to suggest that women with disabilities are under-screened. Reduced access is caused by economic, physical, social, psychological and cultural barriers. In two studies (Temby and Frohmader, cited in Frohmader 2004), 41 per cent of women with disabilities in Australia aged 70 to 75 with a core activity restriction were found to have never had a mammogram.

Women with disabilities may be at increased risk of breast cancer due to having more breast tissue exposure to X-rays (particularly before the age of 20 years), higher rates of obesity related to differences in exercise and nutrition and no (or late) childbearing (Howe and Salthouse 2004, HealthInsit 2005).

BreastScreenNT does not collect disability data – targeted promotion is based on the above evidence. Such promotion has included collaborating with peak disability organisations acting on behalf of and for people with disabilities, and publicising the availability of wheelchair access and double appointment slots for women with disabilities. Letters to all clients include the following statement:

“If you have a disability, we may require extra time to complete your mammogram. When you make your appointment please let us know”.

Women making appointments for the first time are asked if they have any mobility restrictions. If extra information or support is required for informed consent, women are referred to a medical officer or breast care nurse (BreastScreenNT 2005a).

I was a member of the Consumer Advisory Group in the early days. It was exhilarating being a part of that groundbreaking work, and to have the needs of women with disabilities taken seriously from the beginning.

All I can urge women with disabilities to think about is that BreastScreenNT is advocating for women, for our health, and we need to take it on.

Mary Johnson, Darwin.
Lesbian and bisexual women

Approximately 2.2 per cent of women in Australia identify as lesbian or bisexual. A further 12.9 per cent of women report same-sex attraction or experience, but do not identify as lesbian or bisexual. (Smith et al 2003).

Health inequalities exist for lesbian and bisexual women, largely related to experiences of homophobic discrimination or heterosexism – the assumption that everyone is or should be heterosexual (McNair 2003, Leonard 2002). Such discrimination can lead to avoidance of healthcare and screening. Compared with heterosexual women, non-heterosexual women access screening less frequently, delay treatment and are less likely to have a regular GP (who might recommend screening) (Solarz cited in McNair 2003, Rankow and Tessaro cited in Leonard 2002).

Evidence suggests that lesbian and bisexual women are at increased risk of smoking, alcohol misuse and obesity – all associated with discrimination (Leonard 2002). They are also less likely than heterosexual women to bear children, and if they do, it is usually after the age of 30. These are all risk factors for breast cancer (Dibble and Roberts 1998, Cancer Council Victoria 2005).

While lesbian and bisexual women’s participation in the BreastScreenNT program is not measured, BreastScreenNT uses the above evidence to inform promotion strategies. BreastScreenNT started targeting lesbian and bisexual women in 2003 through lesbian / gay media, and plans to develop promotion further after consultation with lesbian and bisexual women (BreastScreenNT 2005a).

I’m 54 and I was recently screened at BreastScreen [NT] for the first time. I went with my colleague, during work time – she’d been before. It was good. I liked the confident and relaxed staff, and the serene, uncrowded atmosphere.

Lesbian woman (anonymous), Program participant, Darwin.
Rural and remote women

Most women living in rural and remote areas of the NT are Indigenous and, for reasons already discussed, have reduced access to BreastScreenNT and require unique promotion strategies.

Approximately 45 per cent of women aged 50 to 69 living in rural and remote areas (Australian Bureau of Statistics (ABS) regions of Darwin rural, East Arnhem, Katherine, Barkly and Alice Springs rural) are non-Indigenous. This equates to 1783 women (DHCS 2005).

While non-Indigenous women living in rural and remote areas do not face the multitude of access and health issues faced by Indigenous women, their access to BreastScreenNT is considered and maximised where possible.

Various strategies have targeted rural and remote women, including holding screening blocks in regional towns during ‘show’ weeks, when many women are likely to visit town, and widely advertising regional screening blocks in rural and remote areas.

It’s not just Aboriginal women in remote areas. It’s non-Aboriginal women too. People have often said that BreastScreen [NT] is an inequitable program, that it was designed to not service remote women. But that wasn’t it as such – it was more about trying to get remote women who live a long way from a regional centre in to get their screening done. That meant all women, not only Aboriginal women.

Jenni Judd, past Manager BreastScreenNT, Darwin.

I don’t think people really understand the issues faced around screening remote women. It’s really difficult. The regional and remote logistics are quite incredible.

Joy Kirk, past Executive Assistant BreastScreenNT, Darwin.
The BreastScreenNT service comprises three teams:

- Clinical services – breast screening and assessment services, up to and including cytological and histological diagnosis of breast cancer
- Promotion – promoting access and participation of women
- Data management – data collation, analysis and presentation.

Having the Darwin screening and assessment clinic co-located with program coordination staff allows opportunities for all staff to be involved in the whole sphere of activity. The promotion officers and database administrator see the women coming in for screening and assessment, and the data manager, medical officer and radiographers have input into promotion strategies. This results in better use of data and service cohesion.

Administration staff support all areas including locum clinical and reception staff operating regional screening blocks. Administration staff visit frequently to provide orientation and support onsite.

I prepare program data for BreastScreenNT staff and for published reports. I manage the database, support database administration staff and resolve system problems. I am not involved in service delivery. Aware of women's need for privacy, I stay away from reception area and clients. Women don’t expect to see men here.

Guillermo Enciso, Data Manager
BreastScreenNT, Darwin
My job’s a varied one – I like that. I support the planning and organisation of locum radiographers and radiologists. When we secure them I arrange their flights and accommodation. I prepare all accounts for payment, help with quality assurance – anything to be fixed, changed, whatever – it’s my job.

Lorraine Lee, Administration Support BreastScreenNT, Darwin

We had good people, a good team, we worked closely. I hope it has continued like that – with the data management and record keeping, clinical management and promotion and education sections working together. That is what makes a good public health program. If one area collapses the program doesn’t work. Even though I was a clinician I was very involved in the promotion and education as well and I used to find that very fulfilling.

Dr Sadhara Mahajani, past Medical Officer BreastScreenNT, Darwin.
Working in a satellite office means I really have to think on my feet – think outside the boundaries and be creative.

Beverley Neal-Clinton, locum Receptionist, Alice Springs.

I create the appointment slots, send out reminder letters, take calls for appointments, enter data, send films interstate, receive reports back and enter that data. I’m involved in the whole cycle – it’s great.

Sheila Long, Database Administrator BreastScreenNT, Darwin.
Screening sites

The relocatable X-ray machine and staff travel to particular regional centres, for particular lengths of time and with particular frequency based on ABS and BreastScreenNT participation data. The data indicates how many appointment slots are needed, how many days are needed in each place and how often. These arrangements have changed over the course of 10 years. The current schedule is as follows:

<table>
<thead>
<tr>
<th>Screening Site</th>
<th>Annual</th>
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<tbody>
<tr>
<td>Darwin</td>
<td>45 weeks</td>
</tr>
<tr>
<td>Katherine</td>
<td>3 week block</td>
</tr>
<tr>
<td>Tennant Creek</td>
<td>1 week block</td>
</tr>
<tr>
<td>Alice Springs</td>
<td>10 weeks (3 blocks)</td>
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</tbody>
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<thead>
<tr>
<th>Biennial</th>
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<tbody>
<tr>
<td>Nhulunbuy</td>
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When screening occurs in a regional centre the films are sent to Darwin or Alice Springs for processing. They have to be freighted daily because heat, humidity and time all affect film quality. After processing, the films are sent interstate for reading.

(BreastScreenNT 2005a)
Transporting the relocatable machine and setting up

The route and timing accommodate geographic features such as unsealed roads (requiring the machine to be taken by barge to Nhulunbuy), wet and dry seasons in the Top End, as well as regional ‘show’ weeks. The screening blocks also avoid school holiday times.

Timing also depends on availability of radiologists, surgeons, pathologists, radiographers and breast care nurses for assessment clinics that must follow soon after each screening block.

If only the machine could tell its stories – it goes up and down the track every year.

Nina Odgers, past Radiographer and Central Australian Coordinator BreastScreenNT, Alice Springs.
2001 was my introduction to BreastScreenNT. I’d just started as a Women’s Health Educator the week before. I wasn’t well prepared and the screening block coincided with school holidays. That wasn’t good because everyone in Nhulunbuy flies out.

The second time was in 2003 and it worked really well. We used the first week to focus on Indigenous women from both the town and remote communities, and the second week for non-Indigenous women. The groups required different levels and types of education and support – so for Indigenous women we played videos in language and so on.

Deb Penney, past Women’s Health Educator, Nhulunbuy

Oh the logistics – setting up was fun. Every year we had to find a venue. Like a spy I would always be looking for somewhere that was wide enough to fit the machine through the door and that had a little waiting area where we could set up tea facilities – we had to clean it up as it was usually somewhere that was disused, we had to find furniture...

Sharon Weymouth, past Women’s Health Educator, Katherine.
Screening and assessment pathway

**Screening**

Screening is the front end of a continuum of breast care – it is only one part. BreastScreenNT faces the challenge of communicating this to women; that the program is ongoing and for it to be effective, women not only need to undergo screening on a regular basis but also to go on to further assessment if required and when relevant, on to treatment.

BreastScreenNT has provided a lot of great information to women. It’s important to not just look at participation stats, but to consider that women need information to make informed choices to join or not to join the program. These women have received a BreastScreenNT service that we don’t measure.

Cynthia Croft, past Manager BreastScreenNT, Darwin.

Screening for the sake of it is a joke and a waste. Unless you have the capacity to follow-up you shouldn’t do it. That’s the good thing about BreastScreenNT – there’s a clear pathway.

Del Hird, past Manager BreastScreenNT, Alice Springs.

A couple of minutes of discomfort – for a couple of years of feeling good. I don’t think anyone can complain about that

Dottie Daby, Program participant, Darwin
Assessment

Each woman recalled for assessment of a screen-detected abnormality is notified by the breast care nurse (BCN). Assessment clinics are held in Darwin and Alice Springs. If the woman lives in a rural or remote area and does not have a telephone, the BCN will communicate and arrange assessment (including transport) through the local health clinic staff. The woman is asked to come for a whole day, is encouraged to bring a support person and is provided with further information if required.

On assessment day, each woman is first seen by the BCN to receive sufficient information and support to give informed consent. The radiographer who performs another mammogram then sees her. From this point she may be discharged if the films are clear, or she will go on to receive as many tests as are required to give a definitive result. Tests may include a physical examination by the medical officer, ultrasound and core biopsy. A multidisciplinary assessment team, consisting of a radiographer, medical officer, BCN, radiologist, pathologist and surgeon, works together.

They are usually stunned - they can’t think of what to ask, so I give them my phone number and they usually call back when they’ve got their head around it a bit more.

Gaye Gokel, Breast Care Nurse, Cancer Council NT/ BreastScreenNT
When I first went I got a scare and I had to go back. I was only 54 then – quite young. They rang me and asked me to go back as they’d found something. They said I could bring a friend with me. Well, that weekend I reviewed my life and looked at all my grandkids. I said to myself: “I want to be around for them”. I went back to BreastScreen [NT] and thankfully everything was OK.

Dottie Daby, Program participant, Darwin.

I was told I had some lumps and it scared the living daylights out of me. I couldn’t feel any lumps, but there were actually five – three in one breast and two in the other. So I had to go back. I was tempted not to but I realised that wouldn’t make them go away. I went back, faced it, and got the all clear! Not all lumps mean breast cancer. Oh it was a good day, the day the results came.

Dawn Chambers, Program participant, Howard Springs.
The Darwin assessment clinic is held monthly from the start of annual screening and the Alice Springs assessment clinic is held after each screening block (currently three times a year). Women screened in Katherine, Tennant Creek and Nhulunbuy who require assessment are referred to Darwin or Alice Springs. The Department of Health and Community Services Patients Assistance Travel Scheme (PATS) offers financial travel assistance to these women.

In 10 years, BreastScreenNT has screened 37,515 women. Of these, 1388 women (3.7 per cent) were recalled for assessment. For women aged 50 to 69, there was an average recall rate of 3.45 per cent (BreastScreenNT 2005b).

Diagnosis

When a woman is diagnosed by BreastScreenNT she is referred to both the BCN and surgeon for ongoing care outside the BreastScreenNT program, as their roles extend beyond the scope of BreastScreenNT.

Of 1388 women recalled for assessment in 10 years, 163 (11.7 per cent) women have been diagnosed with breast cancer (invasive and in situ disease) (BreastScreenNT 2005b).

Between 1994 and 2003, 560 women were diagnosed with breast cancer (invasive and in situ disease) in the NT (NT Cancer Registry 2005).

My diagnosis was made comfortable by the people I had contact with along the way. I was actually screened in Cairns in Queensland just before moving to Katherine. BreastScreen Queensland contacted BreastScreenNT and they found me. It was well managed, a really efficient interstate transfer – and I must say, my diagnosis was as pleasant and easy as it could’ve been.

Barbara Foggin, Breast cancer survivor and past program participant, Tennant Creek.
I’m usually invited to a woman’s first appointments with the surgeon. The surgeon goes over the procedure but women usually need to hear it again. I go over it with them and their families if they like – as many times as they need. I organise volunteers to visit women and supply them with special cushions to go under their arm. If they have a mastectomy, I organise a bra and prosthesis and fit them.

I try to be there when they receive their pathology results a week or so after surgery. It’s at these appointments that women find out whether they need radiotherapy or chemotherapy. If so, I prepare them for that – and then whatever comes next.

Gaye Gokel, Breast Care Nurse Cancer Council NT/BreastScreenNT, Darwin.
BreastScreenNT faces particular challenges in meeting and maintaining the BreastScreen Australia National Accreditation Standards (NAS) (BreastScreen Australia 2002) and gaining and maintaining accreditation. BreastScreenNT was fully accredited from 1999 to 2002 and provisional accreditation was granted for 2002 to 2003. Currently supported by BreastScreen WA, an accredited service, BreastScreenNT will apply for accreditation in mid-2005.

To receive accreditation, BreastScreenNT must comply with national standards of service provision and management, recruitment, technical quality, assessment, customer satisfaction and data management (BreastScreen Australia 2002).

BreastScreen Australia recognises that on occasion individual services may be unable to meet a small number of the required accreditation standards, due to geography, workforce, demographics or other considerations (BreastScreen Australia 2002) – all of which are relevant in the NT.

We got full accreditation in 1999 – that was a fairly large step for everybody.

Joy Kirk, past Executive Assistant at Well Women’s Cancer Screening, Darwin.
Acknowledgements

- Chris Tyzack, Manager, Well Women’s Cancer Screening
- Lisa Patamisi, Senior Health Promotion Officer, Well Women’s Cancer Screening
- Guillermo Enciso, Data Manager, Well Women’s Cancer Screening
- John Condon, Lindy Garling and Ramakrishna Chondur, DHCS Health Gains Planning, for providing NT Cancer Registry data
- All women interviewed who shared their personal stories – those of being screened, those recalled for assessment, and those diagnosed with breast cancer
- NT Breast Cancer Voice
- Dragons Abreast NT
- Bosom Buddies
- Women’s Health Educators
- Alukura Congress AMS
- Bilingual Educators
- Staff (current and past) who provided a great history and insight into the development, growth, challenges and achievements of the program. Past staff, despite not working at BSNT anymore, gave time and energy to the review and told of the rich history.
- Corporate Communications, DCHS
- Breast Care Nurses, NT Cancer Council, whose roles extend from assessment to support for women diagnosed, well beyond the role of BreastScreenNT.
### Appendix 1

**Age-standardised breast cancer incidence rates 1991-2003**

Per 100,000 women

Invasive cancers only (does not include DCIS)

All cases notified to Northern Territory Cancer Registry (NTCR)

Figures refer to NT residents, including NT residents diagnosed interstate and notified to NTCR by interstate cancer registries

#### NT non-Indigenous

<table>
<thead>
<tr>
<th>Year</th>
<th>Age-standardised rate</th>
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<td>1991 - 1994</td>
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<tr>
<td>1995 - 1997</td>
<td>94.2</td>
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<td>1998 - 2000</td>
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#### NT Indigenous

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<td>1998 - 2000</td>
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#### Australia

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<td>113.8</td>
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<tr>
<td>2001*</td>
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*Note*: The final period for Australian rates is for 2001 only
### Age-standardised breast cancer mortality rates 1991-2003

Per 100,000 women

All deaths of NT residents (in the NT or interstate) who died with breast cancer recorded as the underlying cause of death

#### NT non-Indigenous

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#### NT Indigenous

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#### Australia

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Note*: The final period for Australian rates is for 2001-2002 only

Small numbers in the NT are subject to huge variation, so trends do not appear as linear as total Australian rates.

(NTCR 2005).
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