A single issue program in an isolated area: mammography screening in Darwin, NT

Margot J. McLean

(Formerly) Northern Territory Breast Screen

John R. Condon

Northern Territory Health Services

Abstract

Objective: A process evaluation of the Northern Territory (NT) mammography program, NT Breast Screen (NTBS), during its initial 18 months of operation.

Methods: The study was undertaken in Darwin, NT, from December 1994 to May 1996. Clinical outcomes were obtained by reviewing computerised and manual program records to determine waiting times for results, recall rates and cancer detection rates. Client satisfaction was assessed by a questionnaire sent to all women with normal results over a 12-week period. General practitioner satisfaction was assessed by a questionnaire sent to all general practitioners in the region who had one or more clients who had attended the service.

Results: During this time, 2,882 screening mammograms were performed; 98 women were recalled for assessment (3.4%). Breast cancer was detected in 10 women (3.5 per 1000 women screened). The program was well accepted by clients and general practitioners. Performance criteria were not met for waiting times for results.

Conclusions: NTBS faced challenges because of its small and dispersed population, a lack of local radiologists with mammographic experience and the conflict with other pressing health issues, particularly in Aboriginal health. Despite these challenges, the program functioned effectively during its initial 18 months.

Implications: Mammography screening programs in isolated areas can function effectively. The constraints encountered by NTBS are likely to apply to similar programs. Issues identified requiring further research are the psychological consequences of long waiting times for results, and the prioritisation of mammography for Aboriginal women.

(Aust N Z J Public Health 1999; 23: 357-61)

Northern Territory Breast Screen (NTBS) is part of the national mammography screening program, Breastscreen Australia. NTBS operates in an environment which differs from mammography programs in more populated areas of Australia: the Northern Territory (NT) is remote from the centres of specialised expertise in mammography screening, the number of women in the target population is relatively small and the high proportion of Aboriginal people in the NT population means that the priorities for health spending differ from that in other states and territories.

We found no published articles describing the outcomes from mammography services in the more isolated areas of Australia, yet the issues facing such programs are relevant to the national mammography program and to other nationally co-ordinated programs. This article describes the challenges to program delivery which were identified prior to NTBS commencing and the results from the first 18 months of screening in Darwin as measured by screening rates, waiting times for results, cancer detection rates and client and GP satisfaction. It is hoped that this article will provide a useful framework for the identification and discussion of issues surrounding implementation of nationally co-ordinated, single-issue programs in remote locations.

Prior to the implementation of NTBS there was local debate about whether a mammography screening program was appropriate for the NT. In the NT, patterns of morbidity and mortality, and thus arguably the priority areas for health spending, are quite distinct from the more urbanised states.[1] The NT has the highest proportion of Aboriginal people of all states and territories in Australia, and for Aboriginal women the risk of breast cancer ranks low in a long list of pressing health and social problems.

The documented rate of breast cancer is lower in the NT than the rest of Australia. The age-adjusted incidence rate for non-Aboriginal women is 56.9 per 100,000 population, and the rate in Aboriginal women is one-third of this at 18.9 per 100,000 population. The Australian rate is 64.4 per 100,000 population.[2] The reasons for lower incidence rate in Aboriginal women are not clear but are likely to be related to the protective effect of early childbearing and high breast-feeding rates. The slightly lower rates for non-Aboriginal women is thought to be due to the effect of temporary NT residents returning to their home states for investigation and diagnosis of breast cancer.

Although the incidence rate of breast cancer for non-Aboriginal women is three times that of Aboriginal women, both had a similar death rate at 15.2 and 17.0 deaths/100,000 respectively between 1987 and 1993.[2]

Cancer was the leading cause of death for non-Aboriginal women in the NT from 1989 to 1991, with the most common cancer being breast cancer.[1] For Aboriginal women, despite the high case fatality rate of breast cancer, cancer is the third leading cause of death behind circulatory and respiratory causes, and breast cancer deaths are less common than lung and cervical cancer deaths.[1]

Correspondence to:
Dr Margot McLean, Regional Public Health, Private Bag 31907, Hutt Hospital, Lower Hutt, New Zealand. Fax: +64 4 570 4405; e-mail: Margot.Mclean@hvhl.co.nz

Submitted: October 1998
Revision requested: February 1999
Accepted: April 1999

Additionally, the demographic and geographic features of the NT mean that it is more difficult to implement a successful mammography screening program in this region. The population is extremely dispersed and younger than elsewhere in Australia with a relatively small number of women in the target age group: in 1996 there were an estimated 8,767 women aged 50-69 in the entire NT.[3] Thirty-two per cent of the population live in remote areas, much of which is accessible only by unsealed road or air.[3]

In 1992, a feasibility study examined the logistical and prioritisation issues in implementing mammography screening in the NT, and concluded that money would be more effectively spent in developing a holistic women's health program for Aboriginal women, including clinical breast examination and education.[4] However, at that time mammography screening programs were operating in all other states and territories in Australia, raising concerns of equity of access for women in the NT.

The final structure of NTBS, negotiated with Breastscreen Australia, attempted to achieve a compromise between the concerns of equity of access to services for all women in the NT and the question of relevance to Aboriginal women living in remote communities. Of the money allocated for screening, 10.8% was diverted to a Well Women's Program to increase generic health checks for Aboriginal women. This figure was equal to the proportion of Aboriginal women over 40 living in remote areas. The target for screening numbers was decreased accordingly. The effectiveness of this program was the subject of a preliminary evaluation in 1996 and is not reviewed in this article.[5]

The mammography screening component of NTBS operated in accordance with the policies determined by Breastscreen Australia. Features of the program include:

- Funding through cost-shared arrangements between the Commonwealth and NT Governments.
- Free mammographic screening available to all women aged 40 to 75 years.
- Health promotion strategies directed at the target group of 50-69-year-old women.
- Two yearly mammograms (annual for a high risk minority).
- Screening by mammograms in two views, read by two appropriately qualified readers.
- Abnormalities to be followed up at assessment clinics staffed by a multidisciplinary team including radiographers, radiologist, surgeon, pathologist and counsellor.
- The program should meet clearly defined performance objectives as outlined in the National Accreditation Requirements.[6]

NTBS opened as a fixed site in Darwin in 1994. The target population was women aged 50-69 years in the 'Top End' of the NT: the Darwin urban and rural areas, and East Arnhem.

During this time there were no mobile services. The policy for increasing access for women in remote communities was the encouragement of 'opportunistic screening' when women were in Darwin for other reasons.

In 1996, NTBS opened an additional screening and assessment service in Alice Springs with a relocatable machine able to be set up for screening in the smaller NT towns of Katherine, Tennant Creek and Nhulunbuy (East Arnhem).

This article presents the recruitment rates, clinical outcomes and acceptability of the program at the Darwin site, from 28 November 1994 to 31 May 1996.

Methods

Screening numbers

Screening numbers, broken down by age and ethnicity, were obtained from the program's computer database (Natscreen). These figures were compared with the targets for screening over this time, derived from 1991 ABS data on the NT population.

Breastscreen Australia aims to screen 70% of the female population aged 50 to 69 years after a program has been operating for five years. Targets for the first four years are lower, building steadily up to the 'steady state' target. All women over 40 are eligible for free screening mammography but the program aims to screen no more than 40% of the female population aged 40-49 years and no more than 15% of the female population aged 70-79 years.

Only the target number for the 50-69 year age group represents a true target which can be used to measure the performance of the service. The numbers for the other age groups represent ceilings above which there will be no further reimbursement from the Commonwealth for screening.

Waiting time for results and frequency of assessment clinics

The waiting time for results, and the proportion of women screened who were recalled for further investigation (recall rates) were reviewed from the program database and compared with performance indicators.

The original planning document for NTBS said assessment clinics would be held weekly.[7] By the time NTBS opened, it was clear that a lack of local mammographic radiology expertise meant that it would be necessary to recruit interstate radiologists to read films and to travel to Darwin for assessment clinics. The frequency of assessment clinics was decreased to fortnightly as the numbers of women requiring assessment did not justify weekly clinics. After four assessment clinics had been conducted on a fortnightly basis, the frequency was changed to monthly.

Screening mammograms were sent, weekly, to be read by radiologists interstate. All results were 'batched' with the results sent out to women during the week before the next assessment clinic. Women with abnormal mammograms were contacted at this time by telephone by the NTBS doctor or counsellor.

Clinical outcomes

Clinical outcomes were summarised by reviewing the medical records of all women requiring further investigation at an assessment clinic.

Client satisfaction

Client satisfaction with the program was determined by the responses to a questionnaire mailed to all women screened over a 12 week period (n=231) who had a normal result following screening. A questionnaire and reply-paid envelope were sent with the results of the mammogram.

General practitioner/DMO satisfaction

Satisfaction of primary care doctors was assessed by the responses to a mailed questionnaire sent to all general practitioners and District Medical Officers (DMOs) in the Darwin and East Arnhem region who had one or more patients attending NTBS (n=97). A current list of general practitioners and DMOs in the NT was examined to determine the number working in the region who had never been nominated by women attending NTBS. Nine doctors were in this category and no attempt was made to survey them. It was possible that these doctors did not know about the service or were dissatisfied, but also possible that they had specialised practices such as paediatrics or sports medicine. They were not included in the analysis.

The results of both the client and GP satisfaction questionnaires were analysed using Epi Info Version 6.[8]

Results

Program results are compared with Breastscreen Australia's performance indicators.[6]

Screening numbers

Some 2,882 screening mammograms were performed during this time; 2,860 women had a single screening episode (Round 1, or prevalent screen) and 22 also had a subsequent screening episode (Round 2, or incident screen).

In the 40-49 year age group, 60% of the women for whom funding was available were screened. In the 70+ group, 110% of the women for whom funding was available were screened. In the true target group of 50-69 year olds, 96% of the target number was reached (Figure 1).

Five per cent (148) of the women screened said they were of Aboriginal or Torres Strait Islander background. The total proportion of women in the Darwin/East Arnhem women aged over 40 who are Aboriginal is 12%. Excluding East Arnhem, 10% of women over 40 in the region are Aboriginal. Thus Aboriginal women are presenting for mammograms at half the rate of non-Aboriginal women in the Darwin area.

Waiting time for results and frequency of assessment clinics

Seventeen clinics were held during the first 18 months of screening. Since March 1995, assessment clinics were conducted every four to five weeks.

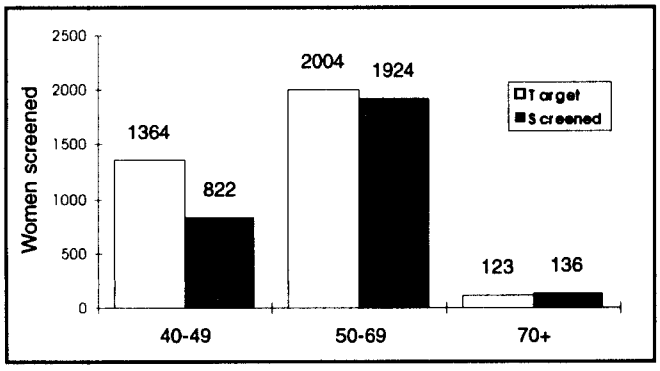

Figure 1: Number of women screened compared to target numbers, by age group, December 1994 to May 1996.

The monthly clinics mean that women in the NT waited a relatively long time for their screening results. On average, 25% of women screened during a four-week period received their results within 10 working days. Breastscreen Australia's performance requirements are that 95% of women should be notified of the results of screening within 10 days of screening.

Recall rates

Ninety-eight (3.4%) women were recalled for assessment of an abnormal screening mammogram. Breastscreen Australia's performance requirements are that assessment recalls should be less than 10% of women screened in a first round of screening.

Cancer detection rates

Ten cancers were detected from 2,860 first round screens, a rate of 3.5 per 1,000. Breastscreen Australia's performance requirements are that the cancer detection rate in the first round of screening should be more than five per 1,000 women screened.

The rate of cancer diagnosis at NTBS is 71% of the minimum number as set out in the performance objectives. Due to small numbers, however, the 95% confidence interval is wide (0.32-1.61). Although the cancer detection rate is lower than the rate specified by the performance objectives, the difference is not statistically significant.

Women attending NTBS were asked whether they had had a previous mammogram. During the first 12 months of screening, 50% of women screening reported having had a previous mammogram elsewhere.

Client satisfaction

One hundred and thirty-seven questionnaires were returned from 231 sent out (59%). 71% of the women were in the target age group of 50-69, 28% were aged 40-49, and two were over 70. 17% were from a non-English speaking home.

The reception staff were described as helpful or very helpful by 99% of women. Eighty-seven per cent had read the information leaflet describing the program and, of those who did, 98% found the information clear or very clear. The radiographer's explanation prior to the mammogram was described as clear or very clear by 98%. The mammogram itself caused discomfort to 19%, some discomfort to 57%, mild pain to 19% and severe pain to 5%. Ninety-eight per cent of women would recommend a screening mammogram to others.

Results took 1-2 weeks to arrive for 27% of women, three weeks for 29%, four weeks for 30%, five weeks for 8% and six weeks for 2%. Several other women (4%) were unable to recall how long the results took or were away when the results arrived. Sixty-four per cent reported that they were 'not at all anxious' while waiting for results, 32% reported being slightly anxious, 3% were anxious and one woman (0.7%) was extremely anxious (Table 1).

The five women who reported anxiety or extreme anxiety while waiting for results all had longer than the mean waiting time: each reported waiting four weeks. Women who waited four or more weeks had a significantly higher anxiety level (Fisher 2-tailed p value: 0.01).

Table 1: Anxiety level while waiting for results by time taken for results.

	Not at all anxious/ slightly anxious	Anxious/ extremely anxious	Total
Results took 1-3 weeks	74	0	74
Results took 4-6 weeks	47	5	52
Total	121	5	126

General practitioner/DMO satisfaction

Ninety-seven questionnaires were sent out and three were returned as current address unknown. There were 61 replies, a response rate of 65%.

Most doctors (61%) had a mainly urban practice, 26% had a mainly rural practice and 13% had a balance between. Twenty-three per cent had predominantly Aboriginal patients and 3% had predominantly non-English speaking background patients. Seventy-five per cent were in private practice, and the others worked for the government or for non-government organisations.

Eighty-nine per cent of the doctors routinely recommended screening mammography to women aged 50-69. Of the seven doctors who did not, six had predominantly Aboriginal patients (Table 2). This was a significant finding (Fisher 2-tailed *p* value: =0.0003). The reasons given for not recommending screening mammography were that this was not a priority for Aboriginal women (three comments), that it was difficult or impossible for their patients to access the service (three comments) and one comment from a doctor with non-Aboriginal patients who was unconvinced of the benefits of mammography.

Overall, 31 doctors (54%) were very satisfied with NTBS, 18 (31%) were satisfied, six (10%) were neutral and three (5%) were very dissatisfied.

Limitations

The findings of both the general practitioner and client questionnaires must be interpreted with caution as the low response rates may be a source of bias.

Discussion

This report illustrates some of the challenges of implementing a single issue vertical program in a remote area: a small target population, distance from specialists with the necessary technical expertise, and conflicting health priorities.

Table 2: GPs' practice in recommending mammograms according to Aboriginality of clients.

Do you recommend screening mammography to women aged 50-69?	Yes	No	Total
Clients predominantly Aboriginal	8	6	14
Clients predominantly non-Aboriginal	46	1	47
Total	54	7	61

The number of women screened in the 50-69 age group was satisfactory: 96% of the target number for this time period. In the 40-49 year age group, only 60% of the number of women for whom funding was available were screened. This is in line with the national policy of allowing but not actively promoting mammography screening in women aged 40-49. However, low participation rates from women aged 40-49 may have a significant impact on the total throughput of NTBS in the future. Once a service has been operating for three years, it is expected to have a minimum throughput of 3,000 women per year to conform with accreditation requirements. The two screening and assessment services in Alice Springs and Darwin have a target population of only 8,767 women aged 50-69 in the whole of the Northern Territory.

The cancer detection rate at NTBS was 0.35%, lower than services elsewhere in Australia which have published their findings. According to the performance objectives there should be at least five cancers per 1,000 women screened (0.5%) in the prevalent or first round of screening. Cancer detection rates in the initial screening rounds in three programs – South Australia, Central Sydney and Essendon (Victoria) – were 0.70%, 0.70% and 0.81% respectively.[9-11] Two major studies in Sweden and the Netherlands reported cancer detection rates of 0.50% and 0.68 %.[12,13]

The expected minimum number of cancers detected after 2860 women have been screened is 14. At NTBS, 10 cancers were detected after 2860 women had their first round of screening within the program. The rate of cancer diagnosis was 0.71 (95% CI 0.32-1.61) of the minimum number as set out in the performance objectives. Due to the small numbers, however, the 95% confidence interval is wide. The difference between these rates is not statistically significant.

The initial round of screening (prevalence round) within a mammography program is expected to yield higher rates of cancer than subsequent (incidence) rounds. The cancer detection rate is generally lower in subsequent rounds because the program will have already diagnosed a high proportion of the cancers that were prevalent within the unscreened population and is increasingly detecting cancers that have developed in the previous two years only. A high proportion (50%) of women attending the first round of screening within NTBS had had previous mammograms, so this screening round was not a true 'prevalence' round. This contrasts with other Australian screening programs which started several years previously, when screening mammography was not such a widely used procedure and the baseline rate of screening mammograms was lower.[9]

Aboriginal women were screened at half the rate of non-Aboriginal women in the Darwin region. General practitioners and DMOs with predominantly Aboriginal clients do not routinely recommend screening mammograms to women aged 50-69, unlike the majority of general practitioners whose clients are predominantly non-Aboriginal. Comments from doctors with Aboriginal clients identify breast cancer to be of low priority for Aboriginal women. Additionally, the lack of mobile services was a barrier to Aboriginal women in remote communities.

The perceived low priority for breast cancer screening in Aboriginal women is backed up by the fact that Aboriginal women have higher rates of lung and cervical cancer, cancers which are amenable to primary prevention strategies. Additionally, Aboriginal women face excess mortality from circulatory and respiratory diseases. However, this is a normative approach to the prioritisation of mammographic screening for Aboriginal women. Further research is needed to explore the views of Aboriginal women about breast cancer and screening.

Overall, the GP and client satisfaction questionnaires indicated a high level of satisfaction with the program, with 85% of doctors reporting to be satisfied or very satisfied with the program, and 98% of women reporting that they would recommend a screening mammogram to other women.

The client satisfaction questionnaire found that waiting time for results had a significant impact on women's anxiety levels. No women waiting 1-3 weeks for results reported more than slight anxiety while awaiting results, while five women waiting four or more weeks reported anxiety or extreme anxiety. A study of the satisfaction of attenders at the mammography program in Essendon found that the area of most dissatisfaction was the delay in getting results.[14] Longer than recommended waiting times are inevitable within NTBS because of the need to send films interstate for reading and because a lack of local mammographic radiologists mean that assessment clinics for follow-up of abnormalities are only held monthly. The psychological consequences of delays in receiving mammography results, of particular relevance to programs in isolated areas, requires further research.

Conclusions

In its first 18 months in Darwin, NTBS provided a mammography screening program which conformed to the majority of performance criteria set out by Breastscreen Australia. Performance criteria were not met for waiting times for results: this related to the small throughput and lack of specialised expertise locally.

Population-based mammographic screening is undoubtedly more efficient in large urban centres where economies of scale exist. However this evaluation shows that mammography can be effectively implemented in a small and remote population centre. Underlying the considerations of program effectiveness, however, are important questions of cost-effectiveness and resource allocation. Although cost-effectiveness evaluation is beyond the scope of this article, it is clear that there are increased costs associated with the implementation of such a program in a region of Australia which is remote from the necessary specialised expertise.

NTBS now has a mammographic screening and assessment screening service in Alice Springs, and a relocatable machine enables regular screening in Tennant Creek, Katherine and Nhulunbuy. The implementation of screening in these towns presents challenges which are similar in nature to those identified by this article, but magnified: the populations are even smaller, more remote and service delivery is more expensive. With increasing access there is likely to be decreasing cost-effectiveness within the program.

Recommendations

- Breastscreen Australia's accreditation requirements should recognise the conditions in which isolated services operate, while not allowing the quality of the isolated services to be compromised.
- NTBS should undergo review after five years: evaluation should focus on access to remote areas, cost-effectiveness and cancer detection rate.
- Further research is required to establish the length of time for receipt of screening results in other mammography programs in isolated areas, and the psychological consequences of long waits for results.
- Aboriginal women should be included in the process of identifying Aboriginal priorities for cancer prevention and screening.

Acknowledgments

We thank the staff at the Territory Health Services Women's Cancer Prevention Program, who provided assistance with data collection, and Cynthia Croft and Angela Merianos for their valuable comments on the manuscript.

References

1. Plant AJ, Condon JR, Durling G. *Northern Territory Health Outcomes, Morbidity And Mortality 1979-1991.* Darwin: Territory Health Services, 1996.
2. D'Espaignet ET, Measey ML, Condon J, et al. *Cancer In The Northern Territory: 1987-1993.* Darwin: Territory Health Services, 1996.
3. ABS. Demography, Northern Territory, 1996. Catalogue No. 3211.7. Australian Bureau of Statistics, Darwin, 1997.
4. NT Department of Health and Community Services. *Feasibility Study: Northern Territory Participation In The National Program For Early Detection Of Breast Cancer.* Darwin: NT Department of Health and Community Services, 1991.
5. Duquemin A. *Early Evaluation Of The Remote Areas Well Women's Screening Program.* Darwin: Women's Cancer Prevention Program, Territory Health Services, 1996.
6. National Program for the Early Detection of Breast Cancer. *National Accreditation Requirements: March 1994.* Canberra: Commonwealth Department Human Services and Health, 1994 December.
7. Northern Territory Department of Health and Community Services. *National Program For The Early Detection Of Breast Cancer: Territory Plan.* Darwin: Territory Health Services, 1994.
8. Dean AG, Dean JA, Colombier D, et al. *Epi Info* [a word processing, database and statistics program for epidemiology on microcomputers]. Version 6. Atlanta (GA): Centres for Disease Control and Prevention, 1994.
9. Robinson JI, Crane CEB, King JM, et al. The South Australian Breast X-Ray Service: results from a statewide mammographic screening program. *Br J Cancer* 1996; 73: 837-42.
10. Rickard MT, Lee W, Read JW, et al. Breast cancer diagnosis by screening mammography: Early results of the Central Sydney Area Health Service Breast X-Ray Program. *Med J Aust* 1991; 154: 126-31.
11. The Essendon Breast X-Ray Program Collaborative Group. A mammographic screening pilot program in Victoria 1988-1990. *Med J Aust* 1992; 157: 670-3.
12. Thurfjell EL, Lindgren JAA. Population-based mammography screening in Swedish clinical practice: Prevalence and incidence screening in Uppsala County. *Radiology* 1994; 193 (2): 351-7.
13. De Koning HJ, Fracheboud J, Boer R, et al. Nation-wide breast cancer screening in the Netherlands: Support for breast-cancer mortality reduction. *Int J Cancer* 1995; 60: 777-80.
14. Cockburn J, Hill H, De Luise T. Satisfaction of attenders during the establishment of an Australian mammography screening program. *Aust J Public Health* 1993; 17: 103-8.