

CHAPTER 1

DEVELOPMENT OF THE NATIONAL PROGRAM

Introduction

1.1 Breast cancer is the most common cause of death from cancer in Australian women. In 1992, 2,438 women died from the disease.¹⁰ The lifetime risk of a woman developing breast cancer is 1 in 15 in Australia (based on data for 1988).¹¹ Trends suggest that the lifetime risk may be approaching 1 in 12, and this lifetime risk may indeed be increasing. In 1990 (the latest date for which data are available), 6,998 women were diagnosed with breast cancer in Australia.¹²

1.2 In New South Wales alone in 1990 there were 2,472 new cases of breast cancer diagnosed, representing a 1 in 14 lifetime risk. Between 1973-77 and 1988-89 the incidence of breast cancer in New South Wales rose by 21 per cent.¹³ In Queensland in 1990, 1172 new cases of breast cancer were diagnosed and on average 300 women die from breast cancer each year.¹⁴ In South Australia, 234 women died from breast cancer in 1991, where the lifetime risk of a woman developing breast cancer is estimated to be 1 in 14.¹⁵

1.3 The incidence of breast cancer rises with age. At age 40-44 years the annual incidence is 96.7 in 100,000 in Australia. This rises to 159.3 per 100,000 at 55-59 years and to 213.2 by 65-69 years. The most significant risk factor for breast cancer is age. If a woman has a family history of the disease, for example a mother or sister who developed breast cancer pre-menopausally, her own risk is increased.¹⁶

1.4 Despite technical advances in the treatment of breast cancer, survival rates have remained largely unchanged in the last 50 years. This is likely to be because

10. Additional information from the Department of Human Services and Health (DHS&H), dated 22 April 1994, p.1.

11. Letter from the Australian Institute of Health and Welfare (AIHW), dated 2 May 1994, p.1.

12. The figure for 1990 is the latest year for which data are available. National breast cancer incidence figures rely on State data and 1990 is the last year that comparable data across all States is available.

13. *Transcript of Evidence*, p.374 (New South Wales Department of Health).

14. *Transcript of Evidence*, p.909 (Queensland Department of Health).

15. *Transcript of Evidence*, p.11 (SABXRS).

7. Submission No. 114, p.2.1 (DHS&H).

in the absence of screening many of the cancers would have been detected at a late stage of the disease.¹⁷

1.5 Breast cancer is also one of the most common cancers affecting women in overseas countries. In the United States, the incidence of breast cancer increased by 33 per cent over the last decade. In 1990, 1 in 10 women could expect to develop breast cancer over their lifetime. In 1991, the figure was estimated to be 1 in 9. Up to 175,000 women in the United States are diagnosed with the disease annually.¹⁸ In the United Kingdom, the breast cancer mortality rate is 52 deaths per 100,000 women. Breast cancer is the main cause of death for women between the ages of 35 and 54. In the United Kingdom, women have a 1 in 12 chance of developing the disease over their lifetime.¹⁹

1.6 As little is known about the causes of breast cancer it is difficult to take primary prevention measures. The best public health initiative at present is to screen to detect the cancer at its earliest stages and, with appropriate treatment, bring about a reduction in mortality. However, certain hereditary, biological and behavioural factors have been found to increase the risk of developing breast cancer. A family history of breast cancer is one clear risk factor. Of the 180,000 cases of breast cancer diagnosed in the United States in 1992, almost 10 per cent had a genetic basis. At least half of these inherited cases involve flaws in a single gene known as BRCA1.²⁰ Research at the Institute for Cancer Research at Sutton, England, has indicated that the risk of developing either breast cancer or ovarian cancer for women with the BRCA1 gene is 59 per cent by the age of 50 years and 82 per cent by the age of 70 years.²¹ Recent research has also isolated another gene which may lead to the development of breast cancer. The Garvan Institute of Medical Research has isolated the p16 gene which may contribute to up to 50 percent of breast cancers.²²

1.7 Biological factors may also increase the risk of developing breast cancer. Research has indicated that a woman's age of first menstruation (menarche), the age of menopause, and the age of first childbirth may be critical risk factors. Early menarche and late menopause independently increase the likelihood of developing breast cancer, while an early first child (in the teens or early twenties) reduces it.

17. *ibid.*

18. United States Senate, Committee on Labor and Human Resources, *Why are We Losing the War on Breast Cancer?*, United States Government Printing Office, Washington, June 1991.

19. C. Faulder, 'The Nation with the Highest Death Rate Debates Prevention', *Ms.*, May/June 1993.

20. G. Cowley, 'Family Matters', *Newsweek*, 6 December 1993, p.46.

21. P. Brown, 'Breast Cancer: A Lethal Inheritance', *New Scientist*, 18 September 1993, pp.34-5.

22. 'Research Uncovers Breast Cancer Gene', *Sydney Morning Herald*, May 9, 1994

A woman who gives birth before the age of 20 has significantly less risk of developing breast cancer than a woman who gives birth after the age of 30 years.²³ A woman who remains childless has a greater risk of developing breast cancer than a woman who has had children.

1.8 Other risk factors may include exposure to certain dietary patterns, especially high-fat diets and low fibre diets.²⁴ One witness noted that studies in the United States have shown an increase in the incidence of breast cancer for Japanese women who move to the United States to live. This is thought to relate to their changing dietary patterns, that is, a move away from the traditional low-fat Japanese diet to the more usual high-fat American diet.²⁵ A recent study has also shown that foods rich in dietary fibre may provide protection against the development of breast cancer. The study of 902 Australian women showed that those with the highest intake of fibre-rich food were half as likely to have breast cancer than those who consumed less fibre-rich food.²⁶

1.9 Studies in the United States have also suggested that a high-fat diet during adolescence, when the breast tissue is growing rapidly, may be an important factor causing breast cancer. The National Cancer Institute in the United States is currently undertaking a study into this question.²⁷ Data in the United States has also shown that high alcohol consumption may be associated with breast cancer.²⁸

1.10 Exposure to toxic chemicals, especially pesticide residues may also be a causal factor. One study has argued that the high incidence of breast cancer in the United States for women currently aged 50 years and over may, in part, be due to their exposure to DDT between the years 1945 to 1972. It has also been pointed out that the declining rates of breast cancer in Israel have paralleled a decline in environmental contamination with DDT and other chemicals.²⁹ Studies in the United States have also shown that women working in petroleum and chemical industries have a higher rate of breast cancer than the general population.³⁰

23. 'Search for a Killer', *Science*, 29 January 1993, p.620.

15. *ibid.*

25. *Transcript of Evidence*, p.780 (Dr Renwick).

26. P.Baghurst and T. Rohan, 'High-Fibre Diets and Reduced Risk of Breast Cancer' *International Journal of Cancer*, vol. 56, 1994, pp. 173-76.

27. 'Search for a Killer', *Science*, 29 June 1993, p.620.

28. *ibid.*

29. M. Wolff et al., 'Blood Levels of Organochlorine Residues and Risk of Breast Cancer', *Journal of the National Cancer Institute*, Vol.85, No.8, April 21, 1993, p.651.

30. L. Clorfene-Casten, 'The Environmental Link to Breast Cancer', *Ms*, May/June 1993, pp.52-56.

Background to the National Program

1.11 In 1987, under the auspices of the Australian Health Ministers' Advisory Council (AHMAC), the National Evaluation of Breast Cancer Screening Pilot Projects was established as a joint initiative of Commonwealth, State and Territory health authorities.

1.12 The Commonwealth Government made available \$3.6 million over the period 1987-88 to 1989-90 to evaluate the feasibility and cost-effectiveness of a national screening mammography program.

1.13 A Breast Cancer Screening Evaluation Steering Committee was appointed to provide a report to AHMAC and a Screening Evaluation Co-ordination Unit (SECU) was established at the Australian Institute of Health³¹ to oversee the evaluation and assist in providing a report to AHMAC by 1990.

1.14 The Report, *Breast Cancer Screening in Australia: Future Directions*, was submitted to AHMAC in May 1990. The report (the SECU Report) reviewed the scientific and economic evidence of relevant overseas trials and of the Australian pilots. It concluded that properly conducted mammography screening programs were effective in reducing breast cancer deaths. The report suggested that, with a fully operational screening program and a 70 per cent participation rate amongst eligible women, the reduction in mortality from breast cancer amongst all Australian women would be around 17 per cent.³²

1.15 The report recommended that a national mammography screening program be introduced and that this program should provide:

- mammographic screening as an integrated, systematic and co-ordinated program;
- national and State-Territory level co-ordination mechanisms;
- appropriate treatment services;
- provision of adequate resources, including specialised training for radiographers, radiologists, surgeons and pathologists;
- an appropriate balance of incentive for service providers to maximise quality of service;
- quantitative performance criteria;
- ongoing monitoring and evaluation of the screening program;

31. Now the Australian Institute of Health and Welfare.

32. SECU Report, *op cit.*, p.26.

- standardised accreditation procedures; and
- ongoing research and program review.³³

1.16 On the basis of these findings the Commonwealth Government announced its support for the National Program for the Early Detection of Breast Cancer (NPEDBC) in March 1990. At the same time the Commonwealth Government announced funding of \$64 million for the first three years of the Program.

1.17 The Australian Health Ministers' Conference (AHMC) and AHMAC endorsed the Evaluation Report (SECU report) in June 1990 as the basis for implementation of a national program and for consultation with the States and Territories.

The National Program

1.18 The National Program is an integrated, systematic and co-ordinated program that offers screening mammography for asymptomatic women aged 40 years and over, with women aged 50-69 being actively recruited. The Program operates through a network of accredited and dedicated screening and assessment centres in all States and the Australian Capital Territory. The Program in the Northern Territory will begin in June 1994. A list of screening and assessment services is given at Appendix 4. The aims and objectives of the Program are at Appendix 5. The main policy features of the Program are listed at Appendix 6.

1.19 The Program is a joint Commonwealth/State and Territory funded initiative, and was originally funded for the first three years of its operation to June 1994. In the 1994-95 Budget, Commonwealth funding of \$236.6 million was provided for the Program over the next five years.³⁴ The total Commonwealth/State and Territory government commitment to the Program is over \$100 million to June 1994. Under the cost-sharing arrangements with the States and Territories an additional \$205 million will be provided by the States and Territories to the Program over the next five years.³⁵

1.20 The Program is being progressively implemented in all States and Territories over a five-year period and is planned to be fully operational in 1996, when it is anticipated that 860,000 women per year will be screened. Screening is available in all capital cities and large areas in all States are now covered by mobile units and/or regional-based fixed units, although services are not yet established in all provincial cities and country areas.³⁶

33. *ibid.*, p.7.

34. See also Chapter 6.

35. Summary: Budget 94-95 -- Human Services and Health.

36. Submission No. 114, p.7.1 (DHS&H).

1.21 A substantial increase in the number of Screening and Assessment Services occurred in the six months to June 1993 with an almost doubling in their number from 10 to 19 over that period.³⁷ There are currently 22 Screening and Assessment Services, operating 58 screening units (45 fixed and 13 mobiles) in all States and the Australian Capital Territory (as at January 1994).³⁸

1.22 The Program is operated through the relevant State Health Departments except in New South Wales and Victoria. In New South Wales, the Program is being implemented by the New South Wales Cancer Council and in Victoria by the Victorian Breast Screening Co-ordination Unit Inc. (known as BreastScreen), an incorporated body responsible to the Victorian Department of Health and Community Services. In Victoria, service providers, in either the public or private sector, are contracted by BreastScreen through a tender process.³⁹

1.23 The Program aims to screen 1.7 million women nationally every two years by 1996-97 when the Program achieves 'steady state', that is, when the Program expects to have all Screening and Assessment Services in place, and each Service is able to offer sufficient places to screen at its maximum planned capacity.⁴⁰ The numbers of women recruited to date as a proportion of steady state numbers is shown for each State/Territory in Appendix 7, Table 1.

1.24 As Table 1 shows, the total number of women screened is 377,375.⁴¹ This represents 22 per cent of the potential target group. The table also shows the number of women screened as a proportion of 'steady rate' numbers for each State/Territory. As indicated, the proportion varies considerably between States, with South Australia achieving the highest proportion of women screened (at 51 per cent). In Queensland, Western Australia and the Australian Capital Territory almost a third of the target group has been screened, while the proportion screened in New South Wales, Victoria and Tasmania is considerably less. The data indicate that all the States and Territories need to substantially increase the numbers of women screened to achieve their overall screening targets.

1.25 To screen 1.7 million women nationally every two years, screening capacity must accommodate 860,000 screening episodes annually. In November 1993, the Program screened 29,346 women, which amounts to an annual screening rate of 352,152. This is an increase over November 1992 (12,419 women = 149,028 per

37. *ibid.*, p.6.4.

38. DHS&H, *NPEDBC - Preliminary Progress Report*, January 1994, p.3.

39. Submission No. 114, p.5.6 (DHS&H); *Transcript of Evidence*, pp.1593-4 (Victorian Department of Health and Community Services).

40. DHS&H, *Progress Report, op cit.*, p.4.

41. The figures relate to the period 1/7/91-30/11/93.

year) and November 1991 (7,852 women = 94,224 per year).⁴² Figure 1 illustrates the monthly screening numbers since July 1991.

1.26 By June 1994, the Services anticipate that they will be screening 53,260 women per month, which represents 639,120 annual screening episodes or 74 per cent of the planned capacity at steady state.⁴³ Progress towards the 1994 target for each Service, and overall progress of each State towards the total number of screens to be taken during the three year period July 1991 to June 1994, are shown in Figure 2.

1.27 Participation by women of various age groups is presented in Table 2. Column 4 shows the percentage of all screens which were performed on women in each age group. Column 5 shows the expected proportions in each age group, based on the numbers in that State in each age group and the proportion of places allocated to each age group in the planned capacity. The table shows that for Australia as a whole 35 per cent of women screened have been aged 40-49 years, 59 per cent have been aged 50-69 years and 6 per cent have been aged 70-79 years.

Implementation Process

1.28 A number of issues relating to the implementation of the Program were raised during the inquiry; these related to recruitment under the Program; accreditation and data collection processes; and the possible 'bureaucratisation' of the Program.

Recruitment

1.29 It is considered that the most successful single recruitment strategy for encouraging women to present for screening is to receive a personal letter of invitation. To facilitate this process it is important that access to State or Commonwealth Electoral Rolls is obtained. Other recruitment strategies may include referral by GPs, print and media advertising and promotion through professional, community and other channels.

1. Access to the Electoral Roll

1.30 All States have now obtained access to their State Electoral Rolls, except Victoria,⁴⁴ where access has recently been granted to the Commonwealth Electoral Roll. The Committee understands that the Victorian Electoral Commissioner had denied BreastScreen access to the Victorian roll on privacy grounds.

42. DHS&H, Progress Report, *op cit.*, p.4.

43. *Transcript of Evidence*, p.1399 (DHS&H).

44. *Transcript of Evidence*, p.1438 (DHS&H).

1.31 A representative of the Victorian Department of Health & Community Services, noted that the difficulties in accessing the State Electoral Roll had meant that the recruitment of women in the target age group in Victoria was 'not proceeding at a rate which would underpin an efficient and effective screening program'.⁴⁵

1.32 Under the *Commonwealth Electoral Act 1918* the Australian Electoral Commission cannot disclose the dates of birth or ages of electors, although it may provide the names and addresses of electors by decade age range, for example 50-59 years, 60-69 years. Similarly, the Commission may provide the names and addresses of electors who are over a certain age.⁴⁶ Breastscreen has now obtained a list of relevant names from the Electoral Roll, although the information is not available by gender or date of birth.

1.33 During the inquiry the question of whether individuals had raised any privacy concerns relating to the use of the electoral rolls was raised. In Western Australia, the Committee was told that the Screening Service had received some complaints from women indicating that the letter inviting them to present for a screening was an intrusion of their privacy. However, in other cases, women had indicated to the Service that they considered this method of recruitment was entirely appropriate.⁴⁷

1.34 Generally, most States indicated that the privacy issue was not perceived to be a serious problem. In South Australia, the Committee was told that the use of the Electoral Roll was well accepted by women and that no negative response had been received by the screening service regarding its use.⁴⁸ The Service also indicated that many positive responses had been received by women indicating that they were grateful for the Service's invitation in prompting them to make a screening appointment. The South Australian screening service indicated that about 50 per cent of women invited to city clinics and over 60 per cent invited to the mobile service using the Electoral Roll information attend for screening on the basis of the initial letter.⁴⁹

1.35 As noted above, all States have now obtained access to their State Electoral Rolls, except Victoria. While Victoria has obtained access to the Commonwealth Electoral Roll, the information is deficient in that it is not provided by gender or date of birth. The Committee believes that it would reduce administrative costs and assist in the recruitment of women to the Program in Victoria if access to the Victorian Electoral Roll was provided to the screening Service in that State.

45. *Transcript of Evidence*, p.1684 (Victorian Department of Health and Community Services).

46. Letter from the Australian Electoral Commission to the Committee, dated 8 February 1994, pp.1-2.

47. *Transcript of Evidence*, p.181 (Health Department of Western Australia).

48. *Transcript of Evidence*, p.20 (SABXRS).

49. *ibid.*

Recommendation

The Committee RECOMMENDS:

1. That representations be made to the Victorian Electoral Commissioner to obtain access to the Victorian Electoral Roll for the purposes of the screening Program in Victoria.

2. *Publicising the Program*

1.36 Another means of facilitating recruitment is to use the print and electronic media to publicise the Program. Several witnesses suggested that greater efforts should be made in the publicity area by disseminating information more widely about the Program so that women are encouraged to participate in the Program.⁵⁰

1.37 A representative of the Royal College of Nursing, told the Committee that, in addition to advertising and the distribution of pamphlets to women, information should be available in supermarkets, shopping centres, community health centres, and infant welfare centres. She added:

We would like the publicity or information centres to be identified where women's lives take them, so that the information is available at that point. We believe that a lot of people do not get the information, and that that situation could be much better dealt with and improved.⁵¹

1.38 Another witness suggested that advertising in women's magazines would be a useful way of providing information about the Program to a wide cross-section of women in the community.⁵²

1.39 Several witnesses noted that GPs also have an important role in providing information about the Program to women. (The role of GPs in the Program is discussed in more detail in Chapter 5.) One witness suggested that more information should be provided to GPs because they are able to encourage women to attend for mammography screening. It was noted that a woman's GP is 'the biggest single influencing factor in whether that woman actually attends for screening'.⁵³ One witness suggested that as about 80 per cent of women attend a GP more than once a year there exists an enormous potential for the GPs to be actively involved in

50. *Transcript of Evidence*, p.1346 (RACS, Section of Breast Surgery); p.1053 (St Andrew's Breast Clinic, Brisbane); p.1554 (Royal College of Nursing).

51. *Transcript of Evidence*, p.1153 (Royal College of Nursing). See also Submission No.132 (Mrs Simcic).

52. *Transcript of Evidence*, p.1346 (RACS, Section of Breast Surgery).

53. *Transcript of Evidence*, p.1053 (St Andrew's Breast Clinic, Brisbane).

recruiting these women for screening.⁴⁵ The Committee believes that the recent initiative by the Australian Medical Association (AMA) in launching a women's health policy, which includes information on breast cancer screening, is commendable.⁴⁶ The Committee understands that this material will be widely distributed throughout the medical profession.

1.40 As discussed in Chapter 3, the importance of providing information about the screening Program to Aboriginal and Torres Strait Islander women and women from non-English speaking backgrounds was highlighted during the inquiry. It was also noted that it is vital to access these particular groups through their local organisations, community health workers and local media outlets.

1.41 At the Commonwealth level, the Department of Human Services and Health (DHS&H) explained to the Committee that the publicity for the Program has, to date, been relatively low key. This was to prevent the situation of creating an expectation among women about the Program where services were not fully operational.⁴⁷ However, the Department noted that a number of information activities have been undertaken. These include the publication of a Program Information Statement which provides basic information on the Program; an information kit distributed to all GPs in Australia in 1992; and the development of a video for women of non-English speaking backgrounds which was screened on SBS-TV in 1993.⁴⁸

1.42 Like the Commonwealth approach, most States to date have not been actively promoting the Program. For example, in Queensland the Committee was told that the Service has not been promoting the screening Program in a high-profile manner but has tended to rely on local promotional strategies, such as the local media, visits to GPs, and talks to women's groups and organisations because the services are still being established.⁴⁹

1.43 Likewise in Victoria, the Committee was told that a large-scale mass media campaign has not been introduced because screening services are not available in all areas. In that State the Service has relied on local newspaper advertisements and 'word of mouth' as the means of recruitment.⁵⁰

1.44 A representative of DHS&H told the Committee that the Department now needed 'to have a more active publicity and communications strategy, and we are

45. *ibid.*

46. *Transcript of Evidence*, p.1391 (AMA).

47. Submission No. 114, p.6.21 (DHS&H).

48. Submission No. 114, pp.6.21-6.22 (DHS&H).

49. *Transcript of Evidence*, p.987 (Queensland Department of Health).

50. *Transcript of Evidence*, p.1106 (Anti-Cancer Council of Victoria).

looking at that'.⁵¹ The Department is currently giving consideration to developing a national communications strategy for the program designed to reach women, health professionals and the general public.⁵²

1.45 The Committee believes that a concerted and nationally co-ordinated information and education campaign should be implemented. This campaign should include information about the Program, emphasising the importance to women of the early detection of breast cancer, the benefits of regular screenings and the services offered by the Program. It should also emphasise that the Program is for 'well' women and that it especially targets asymptomatic women in the 50-69 years age range. The campaign should be directed not only at women but also at the medical profession and the community generally. The campaign also needs to be targeted at special needs groups, such as Aboriginal and Torres Strait Islander women and women from non-English speaking backgrounds.

Recommendation

The Committee RECOMMENDS:

2. That the Commonwealth Government, in co-operation with the States and Territories, undertake a national education campaign promoting the National Program for the Early Detection of Breast Cancer and that the educational campaign:
 - emphasise the importance for women of the early detection of breast cancer and the services currently available;
 - clarify the limitations of the screening program, emphasising that mammographic screening is an aid to the diagnosis of breast cancer but will not prevent the disease;
 - provide information to women and the community generally as to why the Program specifically targets women aged 50 - 69 years;
 - provide information to women, the medical profession and the community generally on the difference between diagnostic and screening mammography;
 - disseminate culturally relevant information about the Program to Aboriginal and Torres Strait Islander women; and ensure that this information is widely disseminated through Aboriginal and Torres Strait Islander organisations, especially through the network of Aboriginal Health Services; and

51. *Transcript of Evidence*, p.1440 (DHS&H).

52. *ibid*; See also Submission No.114, p.6.22 (DHS&H).

- disseminate information to women of non-English speaking backgrounds and women in rural and remote areas.

Accreditation

1.46 All services providing screening and assessment in the Program must be accredited in accordance with the National Accreditation Guidelines. These guidelines are reproduced at Appendix 8.

1.47 The National Accreditation Guidelines were developed by an expert working group of the National Advisory Committee, consisting of a radiologist, surgeon, pathologist, consumer's representative and Program representation including the Commonwealth. The Guidelines were endorsed by the National Advisory Committee for the Early Detection of Breast Cancer in November 1991.⁵³

1.48 The Guidelines cover all aspects of the Program, including education and recruitment, screening and assessment, data collection and management, training for staff and program administration and management.⁵⁴

1.49 The accreditation process includes completion of an accreditation assessment form which requires information on the screening and assessment service protocols; the quality assurance program for equipment, readers, data collection and management; and the qualifications of staff. The State Co-ordination Units (SCUs) then appoint two independent persons to conduct inspections of the assessment service. Once full accreditation is given to a screening service, the accreditation is reviewed at two-yearly intervals.⁵⁵

1.50 Evidence to the Committee suggested some problems with the accreditation process. The New South Wales Health Department suggested that there was a need for greater uniformity in terms of site visits to services seeking accreditation, and the rigour with which visits are carried out.⁵⁶ One witness argued that, at least in the initial stages of the Program not enough attention was paid to training the accreditors themselves.⁵⁷ It was noted that 'whilst one might be a very good clinician, or whatever it is one does in one's life related to breast screening, it does not mean you really understand what being an accreditor was, and I think that was a difficulty'.⁵⁸

53. Submission No.114, p.5.8 (DHS&H).

54. See NPEDBC, *National Accreditation Guidelines*, November 1991, pp.11-34.

55. *ibid.*, pp.40-1.

56. *Transcript of Evidence*, p.384 (NSW Health Department).

57. *Transcript of Evidence*, p.1136 (BreastScreen).

58. *ibid.*

1.51 One submission argued that the accreditation requirements are too detailed and intrusive, especially in relation to the volume of data and other material required for accreditation.⁵⁹ The submission noted that:

The requirements for accreditation are complex and frequently unattainable. The process has involved the establishment of a National Accreditation Committee, Individual State Accreditation Committees and Site Inspection Teams. The procedure includes the preparation of a substantial volume of data ranging from socio-economic considerations to details of the type of cancer detected. The insistence on an Accreditation process of this complexity is a unique imposition in the management of an individual disease in Australia.⁶⁰

1.52 One witness also suggested that the guidelines needed to be more flexible, especially in relation to the accreditation of centres in rural areas.⁶¹ It was noted in this regard that, in some circumstances, the accreditation guidelines preclude using existing facilities in rural areas which necessitates having to use expensive mobile services.

1.53 The Committee notes, however, that the accreditation guidelines set high standards for the Program as a whole and any suggestion that a lower standard of facilities in rural areas is somehow acceptable, is not appropriate and negates the purpose of the standards set by the accreditation guidelines.

Data Collection

1.54 Effective data collection and management is essential to the overall effectiveness of the Program. Consistency and compatibility of the data collected is necessary to monitor overall program performance. The SCUs have the role of ensuring that a database of individual women screened in the respective States is established and maintained.

1.55 A Minimum Data Set (MDS) has been established, the purpose of which is to collect the minimum items of data that will be collected on each woman, although some States have chosen to collect additional information, such as information on recruitment.

1.56 The States and the Australian Capital Territory provide information to the Commonwealth on the following data:

- monthly numbers of women screened, by initial and re-screen status;

59. *Transcript of Evidence*, p.1325 (RACS, Section of Breast Surgery).

60. *ibid.*

61. *Transcript of Evidence*, p.1136 (BreastScreen).

- quarterly data on numbers screened, by age group, and details of rates of recall, referral for open biopsy and cancers recorded;
- six monthly aggregate data on women of non-English speaking backgrounds or Aboriginal origin; re-screen intervals; notification times, procedures performed during assessment and number, type and size of cancers detected;
- service profile data on the catchment size, urban/rural profile of each screening service; and
- financial data on each Service.⁶²

1.57 The SECU report recommended the use of uniform computer software in order to have comparable data returns to facilitate uniform auditing and evaluation.⁶³ To meet this objective, a national system, NATSCREEN, has been introduced. This manages all data from the initial invitation and booking, through all subsequent procedures, to recall in two years time. It enables the greater part of the MDS to be collected at the screening and assessment centre level. The system is being used by all States and the Australian Capital Territory, except New South Wales and Western Australia.⁶⁴

1.58 During the inquiry, concerns were raised at the delays in implementing the data collection system, the value of the information collected and the degree of uniformity and comparability of the data collected.

1.59 Several witnesses noted that delays occurred in establishing the State-wide data systems, due especially to the modifications needed to suit the requirements of some States, especially Queensland and Victoria.⁶⁵ In Queensland and Victoria the data management system to collect the information required for the MDS only became operational earlier this year.

1.60 Some witnesses argued that there is a need for some rationalisation of the information collected in the MDS.⁶⁶ A witness suggested that 'too much' information was now collected.⁶⁷ One submission argued that a modified and simpler data set could provide the essential information necessary to monitor and

62. Submission No.114, pp.6.17-6.18 (DHS&H).

63. SECU Report, *op.cit.*, p.9.

64. Submission No.114, p.6.19 (DHS&H). NSW and WA have modified their existing computer systems to perform the same functions as NATSCREEN.

65. *Transcript of Evidence*, p.384 (NSW Health Department); p.1714 (RCPA).

66. *Transcript of Evidence*, p.1737 (Pathology Reference Group); p.255 (Dr Frayne); p.1502 (Dr Williams).

67. *Transcript of Evidence*, p.1737 (Pathology Reference Group).

record the results of the Program. It was noted that the MDS currently comprises 76 pages of definitions, codes and coding instructions, the administration of which requires a substantial number of personnel and which consumes a significant proportion of the cost of the Program.⁶⁸ A further discussion of the costs associated with the Program is given in Chapter 6.

1.61 A witness told the Committee that 15 sheets of information need to be filled out – 7 sheets of information are required to be filled out for every patient attending a screening centre and the other 8 sheets are for each woman recalled for assessment.⁶⁹

1.62 The Committee also received evidence that there was a lack of uniformity in data collection. The Chairman of the Intercollegiate Committee, noted that there 'is not a uniform software package or a uniform set of forms so you can get things and quickly compare them, and that is a pity. ... If I move from Victoria to another State, that State will be using a different set of forms altogether and they may ask slightly different questions and collect slightly different data, so the comparison is not as easy as it would be otherwise'.⁷⁰ The inclusion of symptomatic women in the Program will also create problems in interpreting the data collected (see Chapter 4).

1.63 The DHS&H noted that national agreement has now been reached on the data items to be collected by each Screening and Assessment Service (SAS) and that this should ensure consistency and comparability in the data collected by the States.

1.64 This should also facilitate a more effective system of monitoring and evaluation of the Program by State and Territory Co-ordination Units and also by the National Co-ordination Unit (NCU).

1.65 The Committee believes that the collection of such a comprehensive set of data provides a valuable research resource and a unique opportunity for the collection of national statistics as they relate to the screening program. The Committee considers that the data collected by the States and Territories should be provided to the National Breast Cancer Centre, which is to be established independently of the NHMRC, for analysis and further research.⁷¹ The Committee believes that this would complement the Centre's other functions, that include, *inter alia*, developing treatment protocols, providing a clearing house on best practice and providing information to the community generally on issues related to breast cancer.

68. *Transcript of Evidence*, p.1324 (RACS, Section of Breast Surgery).

69. *Transcript of Evidence*, p.1502 (Dr Williams).

70. *Transcript of Evidence*, p.1276 (Intercollegiate Committee).

71. See also Paragraph 7.72.

Recommendation

The Committee RECOMMENDS:

3. That the State and Territory Co-ordination Units provide data collected relating to the screening Program to the National Breast Cancer Centre for further analysis and research.

Administration of the Program

1.66 In relation to the administration of the Program, concerns were expressed during the inquiry about the administrative costs of the Program and the possible 'bureaucratisation' of the Program.

1. *Administrative Structure*

1.67 The administrative structure of the Program at the Commonwealth level consists of a National Co-ordination Unit, located within DHS&H. This Unit is responsible for the overall implementation of the Program by providing a central co-ordinating function and a monitoring and evaluation role.

1.68 At the State and Territory level there is a State or Territory Co-ordination Unit (SCU) which is responsible for the administration and implementation of the Program in accordance with a State Plan agreed between it and the Commonwealth. The State and Territory Units are responsible for the location of the Screening and Assessment Services, the mix of mobile and fixed screening units, the public/private mix of services, recruitment, accreditation, financial and data management and State/Territory monitoring and evaluation. As noted in Paragraph 1.22, SCUs are located within the State Health Departments except in New South Wales and Victoria.⁷²

1.69 The National Advisory Committee for the Early Detection of Breast Cancer was established in 1991. The Committee advises the Commonwealth and States and Territory Health Ministers on the implementation of the Program. Its membership includes State/Territory and Commonwealth representatives and professional and consumer representatives. The Committee has approved a number of working groups to facilitate its work in such areas as accreditation and education and information.

1.70 Each State and the Australian Capital Territory has an Advisory Committee with representatives from professional and community groups. In Victoria there is a Board of Management.⁷³

72. Submission No.114, pp.5.5-5.6 (DHS&H).

73. *ibid.*, p.5.6.

2. Administrative Costs

1.71 One submission noted that there is always a concern that with a program the size of the screening Program that the bureaucratic and administrative costs will be excessively high and that a disproportionate amount of the funds available for screening will be directed to administration rather than be available for the provision of screening services.⁷⁴

1.72 In particular, one submission argued that the administrative costs of the Program were up to 50 per cent of funding.⁷⁵ This figure is, however, not borne out by data provided by DHS&H nor by information provided by several States.

1.73 The Department advised the Committee that the National Co-ordination Unit has a total staff of seven, with an annual running cost of approximately \$400,000. Expenditure on national activities for accreditation, monitoring, evaluation, communication, and training totalled \$300,000 in 1991-92 and almost \$900,000 in 1993-94. The Department also stated that the proportion of total Program funds spent on administration will decrease over time.⁷⁶ Departmental running costs account for four per cent of total Program costs.⁷⁷

1.74 Some concerns were also expressed at what was seen to be the high administrative costs of the State operations. The Department, however, advised the Committee that the current Commonwealth/State Agreement sets a maximum expenditure on each State Co-ordination Unit at \$450,000 per annum, with a maximum of \$950,000 to be spent over the first three years of the Program. Of the original commitment for the first three years this represents a maximum of 10.5 per cent out of the funds available to the States and Territories. The funds are for the management of all State-wide functions including policy, planning and financing, service delivery co-ordination, accreditation, training, monitoring, evaluation, publicity and recruitment.⁷⁸ The Committee was told that in Queensland, funding for the State Co-ordination Unit represents 5 per cent of the total funds spent in the State on the Program.⁷⁹ In Victoria, co-ordination activities represent 4 per cent of the total State budget.⁸⁰

74. *Transcript of Evidence*, p.1266 (Intercollegiate Committee).

75. *Transcript of Evidence*, p.1542 (RACR).

76. Additional information from DHS&H to the Committee, dated 18 February 1994, p.1. See also *Transcript of Evidence*, pp.1443-4 (DHS&H).

77. DHS&H, Progress Report, *op. cit.*, p.16.

78. Additional information from DHS&H to the Committee, dated 18 February 1994.

79. *Transcript of Evidence*, p.998 (Queensland Department of Health).

80. *Transcript of Evidence*, p.1140 (BreastScreen).

3. 'Bureaucratisation' of the Program

1.75 Some concerns have been expressed during the inquiry in relation to what is seen as the excessive 'bureaucratisation' of the Program. One submission expressed some concern in this regard in the following terms:

One factor which has contributed to the costs of the National Screening Programme is the bureaucratisation of the service, with a proliferation of committees, guidelines, directives, and data collection services, all of which account for a substantial share of the overall costs of the programme.⁸¹

1.76 Another witness criticised the imposition of 'yet another health bureaucracy' in addition to the existing Commonwealth and State health bureaucracies.⁸²

1.77 However, a number of witnesses argued that a bureaucratic structure (and its associated administrative costs) is an essential element to the effective operation of the Program.

1.78 One witness noted that any public health measure, such as the breast screening Program, requires a certain administrative structure for data collection, quality control measures, and centralised recruitment – each of which entails a cost.⁸³ It was also noted that these considerations are not considered important by many in the medical profession whose orientation to medicine is one of individualised care and not the provision of public health medicine.⁸⁴

Conclusion

1.79 The Committee does not believe that there has been an excessive 'bureaucratisation' of the Program to date nor does it consider that a disproportionate amount of funding has been directed towards administration rather than to the provision of screening services. The Committee believes, however, that administrative costs need to be kept under review so that the main purpose of the Program, that is, to offer a screening service to all eligible women, remains the primary focus of its operations.

81. *Transcript of Evidence*, p.1324 (RACS, Section of Breast Surgery).

82. *Transcript of Evidence*, p.1456 (Dr Williams).

83. *Transcript of Evidence*, p.843 (Wesley Breast Clinic, Brisbane).

84. *ibid.*