THE PARLIAMENT OF THE COMMONWEALTH OF AUSTRALIA

BREAST CANCER SCREENING AND TREATMENT IN AUSTRALIA

REPORT OF THE SENATE STANDING COMMITTEE ON COMMUNITY AFFAIRS

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Secretary

Dr Pauline Moore
The Senate
Parliament House
Canberra

Telephone	(06) 277 3515
Fax	(06) 277 5829

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LIST OF ABBREVIATIONS AND ACRONYMS

AAS	Australian Association of Surgeons
AIH	Australian Institute of Health
AIHW	Australian Institute of Health and Welfare
AHMAC	Australian Health Ministers' Advisory Council
AHMC	Australian Health Ministers' Conference
AIR	Australian Institute of Radiography
AMA	Australian Medical Association
ARL	Australian Radiation Laboratory
BreastScreen	Victorian Breast Screening Co-ordination Unit Inc.
DHS&H	Department of Human Services and Health
GP	General practitioner
HIC	Health Insurance Commission
Intercollegiate Committee	Royal Australasian College of Surgeons Royal Australasian College of Radiologists Royal College of Pathologists of Australasia Royal Australian College of General Practitioners
MBS	Medicare Benefits Schedule
MDS	Minimum Data Set
MWDRC	Medical Workforce Data Review Committee
NCU	National Co-ordination Unit
NHMRC	National Health and Medical Research Council
NPEDBC	National Program for the Early Detection of Breast Cancer
RACR	Royal Australasian College of Radiologists
RACS	Royal Australasian College of Surgeons

RCPA	Royal College of Pathologists of Australasia
RHW	Royal Hospital for Women, Paddington
SABXRS	South Australian Breast X-Ray Service
SAS	Screening and Assessment Service
SCU	State Co-ordination Unit
SECU	Screening Evaluation Co-ordination Unit

RECOMMENDATIONS

Chapter 1

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.

Para 1.35

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

Para 1.45

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.

Para 1.65

Chapter 2

4. That the supply of radiographers be regularly monitored by Commonwealth and State and Territory Governments.

Para 2.32

5. That the supply of radiologists be regularly monitored by Commonwealth and State and Territory Governments.

Para 2.37

6. That breast cancer support and counselling services be encouraged and expanded.

Para 2.50

Chapter 3

7. That strategies be implemented to improve access to the Program in rural and remote areas and that these strategies involve, where appropriate, the provision of financial assistance to encourage women to participate in the Program.

Para 3.27

8. That strategies, sensitive to Aboriginal and Torres Strait Islander cultural values, be implemented to increase the access of these women to the Program, and that these strategies involve:

   - close liaison with Aboriginal and Torres Strait Islander community-based health organisations, especially the Aboriginal Health Services; and

   - the dissemination of culturally appropriate information about the Program throughout the Aboriginal and Torres Strait Islander community.

Para 3.42

9. That strategies, sensitive to the cultural backgrounds and values of women of non-English speaking backgrounds be implemented to increase the access of women from these groups to the Program.

Para 3.49

Chapter 4

10. That the focus of the Program remain women aged 50-69 years, but that mammographic screening continue to be available to women aged 40-49 years and 70 years and over.

Para 4.22

11. That recognising that the Program is for well women, that symptomatic women inquiring or phoning for appointments be advised why the Program is not appropriate for them; and be provided with specific advice and information regarding the availability of other medical services.

Para 4.35

12. That should symptomatic women present for mammographic screening they be screened under the Program; and be provided with advice and information regarding the availability of further medical services.

Para 4.35

Chapter 5

13. That information about the screening Program be more widely disseminated to the medical profession, and in particular to GPs; and that the further education of GPs in relation to all aspects of the Program be given priority.

Para 5.29

14. That the role of GPs in their recruitment and support roles be recognised and encouraged under the Program.

Para 5.29

15. That Fellows of the Australian Society of Breast Physicians may be employed as second film readers under the Program, on condition that indemnity is provided by the employing authority.

Para 5.45

Chapter 6

16. That the Program avoid any duplication in the provision of screening services, but that it utilise both the private and public sectors in the provision of screening services subject to all services meeting the guidelines for accreditation established by the National Program.

Para 6.34

17. That the funding of screening mammography under the Program continue to be independent of Medicare fee-for-service schedules.

Para 6.52

Chapter 7

18. That open biopsy not be included as part of the screening Program.

Para 7.10

19. That action to implement the above recommendation await any recommendations that the House of Representatives Standing Committee on Community Affairs, which is currently inquiring into the management and treatment of breast cancer in Australia, may propose in this area.

Para 7.10

20. That more information be provided to women diagnosed with breast cancer on the various treatment options available to them; and that women be encouraged to participate in decisions regarding appropriate courses of treatment.

Para 7.28

21. That the supply of radiotherapy services be regularly monitored by the National Breast Cancer Centre.

Para 7.54

22. That the geographical distribution of radiotherapy facilities be improved so that women living in areas outside the major metropolitan centres can obtain equitable access to these services.

Para 7.54

23. That the Commonwealth Government, in co-operation with the State/Territory Governments, improve the level of travel and accommodation assistance available to women living in areas outside the major metropolitan centres requiring radiotherapy treatment.

Para 7.54

24. That hospital-based cancer registries be established as a matter of priority.

Para 7.65

25. That statistics collected by State and Territory cancer registries be collected

on a more uniform and consistent basis and that data on cancers generally be provided to the Commonwealth Government on a timely and regular basis to ensure that current national statistics on the incidence of cancers are readily available.

Para 7.69

26. That recognising the fundamental importance of research into the diagnosis and treatment of breast cancer, that the Commonwealth Government provide a specific allocation for research into breast cancer in future Commonwealth Budgets.

Para 7.82

27. That the Commonwealth Government provide additional funding for the conduct of clinical trials into breast cancer to assess existing management protocols and to develop new treatment schedules.

Para 7.87

FOREWORD

The issue was referred to the Committee on 27 May 1993, and was to be reported on by 1 March 1994. The Committee sought extensions to this reporting date and reported on 9 June 1994.

The terms of reference of the inquiry are to examine:

Breast cancer screening and treatment in Australia with particular reference to:

(a) the current state of the National Program for the Early Detection of Breast Cancer;

(b) cost efficiency of the screening program;

(c) Commonwealth/State funding;

(d) organisation of screening and treatment services;

(e) the availability of screening; and

(f) Medicare rebate;

with the aim of determining the optimum service for Australia.

The reference was advertised in the national press on 5-6 June 1993. The closing date for submissions was originally 17 August 1993; however, given the high level of interest expressed, this deadline was extended. One hundred and thirty-five submissions and a large amount of supporting evidence were received. A list of submissions is at Appendix 1.

The Committee held eight public hearings, a list of which appears at Appendix 2; a list of witnesses who gave evidence at these public hearings is at Appendix 3.

The Committee expresses its appreciation to those who made written submissions to the inquiry and who co-operated with the Committee by giving public evidence.

The Committee also notes that the House of Representatives Standing Committee on Community Affairs is currently conducting an inquiry into the management and treatment of breast cancer in Australia and is expected to report later this year.

PREFACE

Cancer of the breast is the most common cause of death from cancer among Australian women.[1] Neither the cause of breast cancer nor the means of preventing the disease are known. At present, the only way to reduce the number of deaths from the disease is to detect it before the patient presents with symptoms. In the case of breast cancer, the early detection of the disease through mammographic screening is the most effective method of reducing mortality from the disease. Other screening methods such as clinical examination (that is, a physical examination by trained medical or nursing personnel) or breast self-examination (that is, the regular examination of the breast by the woman herself) have not been shown to be effective in reducing breast cancer mortality, however, these methods may have some value when used in combination with mammography.[2]

Overseas studies have shown mammography to be an effective screening technique for the early detection of breast cancer in women over 50 years of age, in that significant reductions in breast cancer mortality have been achieved.[3] The Australian program, the National Program for the Early Detection of Breast Cancer (NPEDBC), which was announced in 1990, is modelled on these successful overseas programs.

The Program, to be effective in reducing mortality, needs to achieve a high participation rate in the age groups most at risk. The Report of the Screening Evaluation Co-ordination Unit (SECU), which has formed the basis for the development of the Program in Australia, estimated that if 70 per cent of women aged 40 to 69 years participated in the Program, a 16 per cent reduction in mortality among all Australian women (including those not offered screening and those who do not participate) could be achieved.[4]

Based on overseas studies, individual women participating regularly in high quality mammographic screening, can anticipate approximately 60 per cent reduction in the risk of death from breast cancer while they are participating in the Program.[5] Other factors contributing to a reduction in mortality include regular (that is, every 2 years) attendance for screening mammography, provision of high quality screening and assessment services by a multidisciplinary specialist team and effective

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[1] Submission No.114, p.2.1 (DHS&H).

[2] Australian Health Ministers' Advisory Council, *Breast Cancer Screening in Australia: Future Directions*, Australian Institute of Health, Canberra, 1990 (hereafter referred to as the SECU Report), pp.17-18,22; Sir Patrick Forrest, *Breast Cancer Screening: Report to the Health Ministers of England, Wales, Scotland and Northern Ireland*, HMSO, London, 1986, pp.21-25.

[3] See Chapter 4.

[4] SECU Report, *op. cit.*, p.26.

[5] *ibid.*, p.16.

treatment for women in whom breast cancer is detected.

The screening 'pathway' involves a number of different processes. These involve:

- the initial mammographic screen to detect an abnormality which may or may not be cancer;
- the assessment of the abnormality to determine whether a surgical biopsy is required;
- biopsy and histological examination of the removed tissue; and
- treatment of the screen-detected cancers.

Mammographic screening is an X-ray technique which has been specially developed for taking images of the breast. Mammography can detect tumours that cannot be detected by a clinical examination. Radiographers, using specially designed equipment, take one or more X-rays of each breast. The women is positioned so that the entire breast tissue is included on the film (mammogram). The films, which must be of high quality, are usually read in batches after the screening session by radiologists (in most cases).[6]

Reading of mammograms will separate women into three groups – those with negative findings, which indicate that no evidence of cancer has been found; those with positive findings requiring treatment; and those with inadequate films for making a decision. The first group will be recalled for another routine screening in two years' time; the second group will need assessment; and the third group will need to be recalled to the screening unit for further mammograms to clarify the situation.

As noted above, a woman found to have an abnormality will be recalled for assessment to determine whether malignancy is present. Treatment of screen-detected cancers is the last stage in the process. In view of the complex nature of the treatment methods, treatment is increasingly being undertaken by a team of medical specialists with a special interest in breast cancer, supported by suitably trained nurses and other health professionals.[7]

Screening mammography, even when conducted in highly specialised units, is not 100 per cent effective in that some cancers may be missed and there will be some false positives, that is, some women will be recalled for further investigation and will subsequently be found not to have cancer.[8] Cancers may also develop in the time period between mammographic screenings. Regular screenings every two years do

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6. Forrest Report, *op. cit.*, p.17.

7. *ibid.*, pp.17-19.

8. NPEDBC, *Program Information Statement*, 1992, p.5.

not prevent a malignancy from developing. Nevertheless, screening mammography remains the most satisfactory method presently available for the early detection of breast cancer, and, in a well organised program, will save women's lives and reduce the extent of surgery for the treatment of cancer.

An important distinction needs to be drawn between the use of mammography for screening, and its use for diagnostic purposes. Screening mammography is performed in an organised and systematic manner on asymptomatic women (that is, 'well' women – women without any symptoms of breast cancer) for the purpose of detecting unsuspected cancers at an early stage so that early treatment can affect outcome. It has been shown to be highly effective in decreasing mortality of breast cancer in women who regularly attend for screening mammography. Diagnostic mammography is for women who have clinical breast symptoms which require investigation. Women with symptoms or a family history of breast cancer may be referred for diagnostic investigation by their doctor – the screening Program is not designed for these women.[9]

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[9] *ibid.*, p.4.

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

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[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.

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[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 women 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 parallelled 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]

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[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 Health[31] 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;

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[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]

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[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

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[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.

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[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.

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[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

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[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

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[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

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[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]

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[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;

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[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

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[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.

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[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]

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[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]

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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.

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[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.*

CHAPTER 2

OPERATION OF THE PROGRAM

2.1 The Program's effectiveness depends, in large measure on the nature of the physical and human resources devoted to it. This chapter examines aspects of the operation of the Program including the physical aspects of the Program – dedicated centres/mobile units; mammographic equipment; and aspects of staffing, including supply and demand factors relating to the number and distribution of radiographers, radiologists and breast physicians. This chapter also discusses the adequacy of counselling and support services.

Dedicated Screening and Assessment Services

2.2 A network of dedicated Screening and Assessment Services has been established in all States and the Australian Capital Territory. The Screening and Assessment Services consist of screening units, which may either be fixed or mobile units, and assessment centres. Both screening and assessment may be provided at the one fixed location. The units are located in health centres, shopping centres, specific purpose buildings and private radiology premises. The Services maintain a computerised data base of client records.[85] This information is used for the recall of women at appropriate intervals and for the monitoring of the Services' performance.[86]

2.3 In the more highly populated States there are between 8 and 11 Screening and Assessment Services, whereas in South Australia, Western Australia and the Australian Capital Territory there is only one Service. Services are delivered in a mix of public and/or private sector institutions.[87] All services, however, are required to be accredited and to meet the same standards and to provide the same data returns to the relevant State Co-ordination Units.[88]

1. Screening

2.4 The Committee visited screening and assessment centres in Adelaide and Brisbane in November 1993 to observe first-hand the screening process. The Committee was impressed by the standard of the facilities available and the

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[85] See Chapter 1.

[86] Submission No.114, p.5.5 (DHS&H).

[87] Services are located in both the public and private sectors in New South Wales, Victoria, Queensland, Western Australia and Tasmania and are located in the public sector in South Australia and the Australian Capital Territory. See Chapter 6 for further details.

[88] Submission No.114, p.5.3 (DHS&H).

dedication and commitment of the staff. In informal discussions with the personnel at the centres it was able to gain a fuller appreciation of the nature of the screening services available. Individual members of the Committee have also taken the opportunity to visit screening and assessment centres in several States recently.

2.5 As noted in Chapter 1, the screening program specifically targets asymptomatic women aged 50-69 years (although women aged 40 years and over are eligible for screening). Under the Program women are invited to attend for screening every two years. This may be by personal invitation or more generalised recruitment methods. Many women attend on the advice of their GP, although a formal referral is not required. A woman's GP is notified of the results of the screening mammograph (subject to her consent). This is to assist the GP to make an informed response to any questions or concerns a woman may have, especially when further assessment is required. Screening units are required to provide women with easily understood information about the screening process. Written consent is obtained for the procedures and for the collection of information for recall, monitoring and evaluation. All women are screened by two-view mammography (that is, a mammogram taken from two different angles) by specially trained radiographers. The films are read, usually, at the assessment centre, by two or more readers. (This issue is discussed further in Chapter 5.) Both readers are trained in screening mammography and are expected to meet the same performance standards. In over 90 per cent of women screened no evidence of cancer is detected. Between 5-10 per cent of women are recalled for assessment.

2. Assessment

2.6 The assessment service is usually located in or near hospital facilities. However, where practicable, the services may be located in areas in close geographical proximity to their clients. Assessment is undertaken by a multidisciplinary team consisting of at least a radiologist, surgeon and pathologist (with special skills in the detection of small cancers), and often a breast physician. A written report of the results of the assessment is notified to a woman's nominated GP. Trained counsellors are also available to provide counselling and support for women. The multidisciplinary team has primary responsibility for quality control and management of screening and assessment procedures.

2.7 The multidisciplinary approach is considered critical to ensure high quality and to minimise the number of invasive procedures for women. In most cases the multidisciplinary team will either make a definitive diagnosis or be able to reassure the women during the assessment visit that no cancers have been detected. In a small number of cases an open (surgical) biopsy (that is, the surgical removal of a sample of breast tissue) will be necessary to reach a definitive diagnosis. (A discussion of the issues relating to open biopsy is given in Chapter 7.)

2.8 In those States which do not include open biopsy as part of the Program, the woman will be referred to the public sector breast clinic if appropriate, or to her general practitioner for referral for histological investigation. If cancer is diagnosed, the women will be referred to her general practitioner, or (in consultation with her nominated general practitioner), to a surgeon specialising in breast cancer.[89]

3. Appropriate Use of Mobile Vans

2.9 Some concerns were expressed during the inquiry in relation to the placement of mobile units in urban settings. Particular concerns were expressed about the use of mobile vans in the Brisbane metropolitan area. Several witnesses stated that it was an inappropriate use of this facility.[90]

2.10 One witness noted that women in most metropolitan areas can access fixed screening units without much difficulty. The witness also noted that it was a better use of resources to concentrate the mobile units in rural areas where access to screening services is more difficult for women.[91] Another witness also raised the issue of the lack of privacy, and the possible lack of dignity - from a woman's point of view - that goes with using mobile units in metropolitan areas.[92]

2.11 The Committee believes that mobile units play an important role in facilitating access to screening for women in rural areas (see Chapter 3), but it may be inappropriate to use mobile units in certain metropolitan areas where there are already fixed screening units available. However, in some metropolitan areas, especially where there is a lack of public transport, the availability of mobile units can play an important role in ensuring access to screening services. The Queensland Department of Health noted that many older women, and especially those in socio-economically disadvantaged situations, such as widows and pensioners, would not travel considerable distances by public transport to be screened without access to mobile units.[93] One witness also noted that when mobile units were used in urban settings the service was able to achieve 'extremely high levels of participation'.[94]

Mammographic Equipment

2.12 It is important that high quality mammographic equipment be available for screening purposes and that this equipment be maintained in good working condition. Poor quality films from poorly maintained equipment result in poor image quality and an increased likelihood of inaccurate assessment, multiple films being required and a high recall rate.

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5. *ibid.*, pp.5.4-5.5 (DHS&H). See also Chapter 5.

90. *Transcript of Evidence*, p.826 (Professor McCaffrey); p.858 (Wesley Breast Clinic, Brisbane).

91. *Transcript of Evidence*, p.826 (Professor McCaffrey).

92. *Transcript of Evidence*, p.858 (Wesley Breast Clinic, Brisbane).

93. *Transcript of Evidence*, p.982 (Queensland Department of Health).

94. *ibid.*

2.13 Evidence presented to the inquiry suggested that the standard of equipment was generally good.[95] The Committee was told that radiology equipment is checked regularly by radiographers with the chief radiographer having an overseer role.[96]

1. Distribution of Equipment

2.14 The Australian Radiation Laboratory (ARL) undertook a survey of mammography units in Australia; the survey identified 267 mammography units. The response to the survey was incomplete, with the ARL estimating that the response represented about 90 per cent of the total number of units. The distribution by State and Territory of the units identified in the survey was: New South Wales (89); Victoria (80); Queensland (48); South Australia (19); Western Australia (13); Tasmania (8); Australian Capital Territory (6); Northern Territory (4).[97]

2.15 A more recent study published by the ARL of the geographical distribution of mammography equipment throughout Australia shows that there is a concentration of X-ray units around the major capital cities and coastal areas, with few units located in rural areas.[98] A breakdown of the number of units on a State-by-State basis is given in Table 1. The table shows that there is a fairly even number of X-ray units on a per capita basis with the exception of Western Australia, which has about half the number of machines per capita of the other States.[99] The urban/rural imbalance in the number of mammographic units was illustrated by information provided to the Committee by the Victorian Department of Health and Community Services. The Department noted that of the 122 mammography units registered in that State, 92 units were located in the metropolitan area whilst only 30 units were located in rural areas.[100]

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[95] *Transcript of Evidence*, p.250 (Dr Frayne).

[96] *Transcript of Evidence*, p.1236 (AIR).

[97] The total number of units was 267. The ARL survey did not provide information on the number of units available for screening purposes solely - the units may be used for diagnostic or other uses. For details of the ARL survey see AIH, *Screening Mammography Technology*, AIH, Canberra, 1990, p.11.

[98] ARL, *Radiation Doses from Mammography in Australia*, May 1991, pp.18-19.

[99] *ibid.*, pp.18-19, 41.

[100] Additional information from the Victorian Department of Health & Community Services, dated 8 April 1994, p.3.

TABLE 1
GEOGRAPHIC DISTRIBUTION OF MAMMOGRAPHIC UNITS, 1989-1990

State	Population '000s	Number of Mammography Units	No. of Units per 100,000
NSW	5,612	85	1.52
VIC	4,208	77	1.83
QLD	2,676	49	1.84
WA	1,500	13	0.86
SA	1,394	18	1.29
TAS	447	7	1.46
ACT	266	5	1.87
NT	156	4	2.56
AUST	16,259	258	1.59

Source: ARL, *Radiation Doses from Mammography in Australia*, May 1991, Table 3, p.41.

2. Role of the Commonwealth and the States

2.16 DHS&H advised the Committee that the States and Territories are responsible for the distribution and quality of mammography equipment. The various State and Territory radiological licensing boards exercise control on quality and safety through requirements concerning standards, safe installation and use by qualified personnel.[101] In Victoria, the Radiation Safety Section of the Department of Health and Community Services keeps a register of all radiography equipment in the State. The register includes details of the manufacturer, model, type and location of the unit.[102]

2.17 As to the Commonwealth's role, the Department noted that it is limited to special purpose funding to each State and Territory for the screening Program. The Department noted that as part of the evaluation of the Program it hopes to conduct an audit of all equipment used in the Screening and Assessment Services during the next two years.[103]

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[101] Additional information provided by DHS&H, dated 18 February 1994, p.3.

[102] Additional information provided by the Victorian Department of Health and Community Services, dated 8 April 1994, p.3.

[103] Additional information provided by DHS&H, dated 18 February 1994, p.4.

Staffing

2.18 An adequate supply of qualified staff is essential to the effective operation of the screening Program. Issues relating to the numbers and distribution of radiographers, radiologists and breast physicians are discussed in the following section.

1. Radiographers

Numbers

2.19 The Committee received a range of diverse, and often conflicting, evidence on the availability of radiographers in Australia. For example, some evidence suggested that there was a shortage of radiographers on a State-wide basis in New South Wales[104] and Victoria.[105] A shortage of radiographers was also noted in rural areas of Western Australia,[106] New South Wales[107] and Queensland.[108] Problems in recruiting sufficient numbers of radiographers were also noted in the Northern Territory[109] and the Australian Capital Territory. However, a witness representing the Australian Institute of Radiography, suggested that the numbers of radiographers are sufficient to meet demand, although there are some difficulties in staffing country areas.[110]

2.20 The Committee sought the advice of DHS&H, the Minister for Employment, Education and Training and the Minister for Immigration and Ethnic Affairs concerning the availability of radiographers. A representative of DHS&H noted the situation regarding radiographers was 'unclear':

> There is no adequate central collection of data which would give us a very clear picture. I think the experience of the program has been that there have been localised difficulties ... In overall terms, it is not easy to get a very clear picture.[111]

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[104] *Transcript of Evidence*, p.436 (New South Wales Health Department).

[105] *Transcript of Evidence*, p.1134 (BreastScreen).

[106] *Transcript of Evidence*, p.169 (Health Department of Western Australia).

[107] *Transcript of Evidence*, p.361 (North West Health Service, Tamworth).

[108] *Transcript of Evidence*, p.812 (Professor McCaffrey).

[109] *Transcript of Evidence*, p.1802 (Northern Territory Department of Health and Community Services).

[110] *Transcript of Evidence*, pp.1234,1240 (AIR).

[111] *Transcript of Evidence*, p.1449 (DHS&H).

2.21 The Minister for Employment, Education and Training advised the Committee that, regarding therapeutic radiographers, there is in general shortage both in metropolitan and regional areas in Queensland and South Australia only. However, there are regional supply difficulties in this occupation elsewhere, including north-west Tasmania (common across most health professions) and country areas of Western Australia.[112]

2.22 Given the perceived shortage of radiographers (at least in certain areas), demand can be met through either training locally or by overseas recruitment.

Training

2.23 The training of more local radiographers is one possible solution to the shortage of radiographers. Currently training for radiographers involves a standard three-year degree course. There is a training institution in each State in Australia.[113]

2.24 A witness told the Committee that there was no difficulty in recruiting students to undertake the degree course. The Institute noted, however, that 'burnout' and high staff turnover amongst radiographers are common.[114] In advice from the Minister for Employment, Education and Training it was also noted that there is a 'high wastage' rate for radiographers. This was attributed to the work stress, and in part to the structure of the courses in the past which did not prepare students adequately for the emotional demands of the job.[115]

2.25 The Institute of Radiography argued that a structured, consistent, training program Australia-wide, in dedicated centres in each State, should be introduced.[116] At present two States, Queensland and South Australia, run accredited training programs.[117] A one-year post-graduate course in breast imaging will commence at the Charles Sturt University (Wagga Wagga campus) in July 1994. The Committee understands that this is the first course of its kind in Australia. Training issues are dealt with more generally in Chapter 5.

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112. Letter from the Minister for Employment, Education and Training to the Committee, dated 8 March 1994, p.1.

113. *Transcript of Evidence*, pp.1239-40 (AIR).

114. *Transcript of Evidence*, p.1228 (AIR).

115. Letter from the Minister for Employment, Education and Training to the Committee, dated 8 March 1994, p.1.

116. *Transcript of Evidence*, p.1228 (AIR).

117. *ibid.*, p.1237.

Overseas Recruitment

2.26 In addition to training more local radiographers, it is also possible to recruit radiographers from overseas when there is a shortage.

2.27 The Minister for Employment, Education and Training advised the Committee that the skills of overseas qualified radiographers resident overseas applying for work permits are assessed by migration officers against guidelines contained in the Department's Procedures Advice Manual. Applications that are not able to be assessed by migration officers are referred to the AIR in accordance with a formal agreement between that professional body and the Commonwealth. Overseas qualified radiographers already resident in Australia are all assessed by the AIR.[118]

2.28 AIR has established procedures for assessing overseas qualified radiographers which include detailed consideration of their educational qualifications and post-graduate clinical experience. In addition, for applicants resident in Australia, or able to visit, a clinical skills appraisal is included as a part of the assessment process. Resident applicants may also be required to undertake an accredited bridging course. One witness told the Committee that based on her personal experience, many overseas-trained radiographers applying to work in Australia are not as well trained as radiographers in Australia.[119] The Minister for Immigration and Ethnic Affairs advised the Committee that there are no conditions placed on visas with regard to where visa holders may live and work, although certain temporary resident visas require their holders to seek permission to change employment or employer. In the case of radiography and other medical occupations, State government registration requirements may in fact apply conditions with regard to where the person from overseas is able to practise.[120]

2.29 The Minister for Employment, Education and Training advised the Committee that in the twelve months from 1 January 1993 a total of 110 overseas qualified radiographers have applied to AIR for skills assessment and 56 have been assessed as acceptable.[121]

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[118] Letter from the Minister for Employment, Education and Training to the Committee, dated 8 March 1994, p.2.

[119] *Transcript of Evidence*, p.1234 (AIR).

[120] Letter from the Minsiter for Immigration and Ethnic Affairs to the Committee, dated 28 March 1994, p.2.

[121] Letter from the Minister for Employment, Education and Training to the Committee, dated 8 March 1994, p.2.

Rural Access

2.30 As noted above, evidence suggests that there is a shortage of radiographers in rural areas. The extent of the problem is difficult to determine as little data are available. It also appears that there are difficulties in attracting and retaining overseas radiographers to work in rural areas. The Minsiter for Immigration and Ethnic Affairs, however, advised the Committee that no data are available with respect to the numbers of overseas radiographers working in rural or remote areas.[122]

2.31 DHS&H advised the Committee that generally the attraction and retention of health personnel to rural and remote areas poses a problem. In this regard the Department noted that the Commonwealth has responded with the introduction of the Rural Health Support, Education and Training Program which aims to improve the health of rural and remote communities by improving the recruitment and retention of the health workforce through increased education, training and support opportunities.[123]

2.32 The Committee notes that inadequate data are available to assess, with any degree of accuracy, the current availability of radiographers in Australia. It appears, however, that there is a shortage of radiographers in several States and almost certainly in many rural and remote areas across the country. Given the importance of an adequate supply of appropriately qualified radiographers for the success of the Program, the Committee considers that close attention needs to be given to monitoring the supply of, and demand for, radiographers on a State-wide and national basis.

Recommendation

The Committee RECOMMENDS:

4. That the supply of radiographers be regularly monitored by Commonwealth and State and Territory Governments.

2. Radiologists

2.33 Evidence presented to the Committee from several sources suggests that there is not an overall shortage of radiologists in Australia, but rather an uneven distribution in their numbers throughout the country.[124]

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[122] Letter from the Minister for Immigration and Ethnic Affairs to the Committee, dated 28 March 1994, p.2.

[123] Additional information from DHS&H to the Committee, dated 18 February 1994, p.5. See also Chapter 3.

[124] *Transcript of Evidence*, p.1433 (DHS&H); p.1579 (RACR).

2.34 The Royal Australasian College of Radiologists (RACR) noted there are some 1,400 actively practising radiologists in Australia.[125] One witness representing the College said that the radiologist workforce is adequate although it experienced the 'same maldistribution that all medical practitioners suffer'.[126]

2.35 The problems this maldistribution is causing the Program is illustrated in the case of Queensland. One witness noted that because radiologists are concentrated in certain areas of the State it has been difficult procuring sufficient radiology support in services outside the South-East corner of the State. According to the Medical Board Register of Queensland, of the 176 radiologists in the State, 149 (85 per cent) are located in the South-East corner, where under 50 per cent of the women eligible for the Program reside. The remaining 34 (15 per cent) are located through the rest of Queensland, and of those, most are located in provincial cities on the coast.[127] This suggests a noticeable shortage in the availability of radiologists to provide services especially in rural areas.

2.36 The difficulty in attracting radiologists to work in the Program has a number of causes. One cause is the lack of radiologists in certain areas, especially rural areas, as the situation in Queensland illustrates. The Queensland Department of Health noted that other key factors in terms of participation in the Program in Queensland are the interest and capacity of radiologists to be involved because of the heavy workload of other radiology services in both the public and private sectors.[128] Quality control considerations also need to be considered with radiologists working overtime for the screening program, that is, outside their normal 9 to 5 jobs.

2.37 The supply of an adequate number of suitably qualified radiologists is essential to the success of the Program. The Committee believes that the supply of, and demand for, radiologists needs to be closely monitored and assessed.

Recommendation

The Committee RECOMMENDS:

5. That the supply of radiologists be regularly monitored by Commonwealth and State and Territory Governments.

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[125] *Transcript of Evidence*, p.1579 (RACR).

[126] *ibid.*

[127] Additional information from the Queensland Department of Health to the Committee, dated 25 February 1994, p.4.

[128] *ibid.*

3. *Breast Physicians*

2.38 Given the shortage of appropriately qualified radiologists in certain areas and the likelihood that some of those employed by the Program are working excessively long hours, it has been argued by several witnesses that breast physicians could be usefully employed as readers of films. Breast physicians, as defined by the Australian Society of Breast Physicians, are qualified medical practitioners who have worked for three years full-time in a dedicated breast clinic which is recognised by the Society.[129] (For a further discussion of the role of breast physicians see Chapter 5.)

2.39 A submission noted that in the Queensland situation, 'given the current shortage of radiologists in regions outside the South East corner and the growing populations, it is unlikely that film reading requirements for the program can be fully met by private and/or public sector radiologists in the regions'. In these situations it may be necessary to employ breast physicians.[130]

2.40 However, other witnesses argued that breast physicians should not be employed as film readers as they lack adequate training and the experience of qualified radiologists.[131] One witness noted that there are 'sufficiently experienced radiologists in Queensland who have a commitment to mammography and mammographic analysis whose skills have not been utilised'.[132] The Committee believes that in areas where there is a shortage of radiologists, alternative means of ensuring the reading of films need to be sought, either through the use of experienced non-radiologist second readers or through the use of new technologies, such as teleradiology, whereby an X-ray is taken and the image is transmitted via a phone connection to a hospital or other facility in a major centre.

Counselling and Support Services

2.41 The provision of effective counselling and support services is an important element in addressing the emotional and other needs of women attending a screening Program and during any subsequent treatment that she may receive. It is important that all women who attend for screening and assessment have access to counselling to reduce the level of anxiety and to assist those who are diagnosed with breast cancer to better cope with their diagnosis.

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[129] Letter from the Australian Society of Breast Physicians to the Committee, dated 13 May 1994, p.1.

[130] Additional information from the Queensland Department of Health to the Committee, dated 25 February 1994, p.5.

[131] *Transcript of Evidence*, p.1485 (RACR, Queensland Branch).

[132] *Transcript of Evidence*, p.1496 (RACR, Queensland Branch).

1. Counselling

2.42 The National Accreditation Guidelines provide that professional counselling be an integral component of a dedicated breast screening and assessment service. Counselling should be accessible to all women who attend a screening centre and all counselling should be provided by trained counsellors. The Guidelines stress that emotional support at all stages of the screening process should be provided, but especially during assessment or if there is a diagnosis of breast cancer. Women with a diagnosis of breast cancer should be given comprehensive and easily understood information on treatment options and encouraged to be actively involved in decisions about these options.[133]

2.43 The issue of the adequacy of the counselling available at the time of screening was raised during the inquiry. It was pointed out that the counselling support available was generally adequate. One witness noted that 'the protocols that have been developed nationally and at State level are really very sensitive to that issue'.[134]

2.44 During the inquiry some witnesses identified a deficiency in the provision of counselling and psychosocial support after a woman has been diagnosed with breast cancer. (Treatment issues are covered more generally in Chapter 7.) A Senior Staff Specialist at the Royal Hospital for Women, Paddington, speaking from personal experience, noted that the psychosocial support offered at present is often fragmented and superficial. He added:

> I think that there needs to be a lot of work done on continuing in-depth support of women with breast cancer and their families.[135]

2.45 Another witness noted that what is needed is a dedicated psychologist to work with women diagnosed with breast cancer and with their families and this contact should begin when the cancer is diagnosed.[136]

2.46 The importance of providing adequate psychosocial support was noted by many witnesses and in several submissions, many of which drew on their personal experiences of confronting a diagnosis of breast cancer.[137] One submission noted that a woman confronted with breast cancer is understandably shocked and distressed. She is faced with many mental adjustments at a time when she is also confronted with a number of decisions regarding treatment or surgery. At various

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[133] Accreditation Guidelines, *op. cit.*, pp.21-22.

[134] *Transcript of Evidence*, p.480 (RHW).

[135] *ibid.*, p.481.

[136] *ibid.*, p.480.

[137] See Submission No.127 (Mrs McKimm); Submission No.22 (Dubbo Breast Cancer Support Group).

stages, she will have feelings of denial, rage, guilt and hopelessness. It is during this period that counselling and other support is vital.[138]

2. *Breast Cancer Support Services*

2.47 Breast cancer support services operate in all State and Territories under the auspices of local cancer societies. The services provide practical and emotional support to women with a diagnosis of breast cancer, and support for the families and carers of breast cancer sufferers. The services provide information about breast cancer, including current treatment options and prosthesis information and education to community groups and organisations.[139] Some groups, such as the Cancer Support Association of Western Australia, also provide information and advice on health therapies complementary to traditional treatment, such as meditation, nutrition, exercise and positive thinking.[140]

2.48 A representative from the Australian Capital Territory Breast Cancer Support Services, told the Committee how the Service operates in the Australian Capital Territory. The Service has a breast cancer support group that meets regularly and provides an opportunity for women to talk with other women in a similar situation about their experiences of breast cancer. At these sessions information is provided to the women on such topics as relaxation, diet, nutrition and treatment. The other support service is provided by trained women volunteers who themselves have been treated for breast cancer. The aim of this service is to provide hope and encouragement and an example of successfully coping with the disease.[141]

2.49 The important role the support groups play was underlined by the Cancer Support Association of Western Australia which cited a United States study that showed that women who attended support services had a significantly better quality of life and survived on average twice as long as other women who did not attend such groups.[142]

2.50 The Committee believes that it is important that adequate counselling and support services be available to women, their families and carers from the initial point of contact with the screening centre through to treatment and beyond. The Committee considers that counselling and support is especially required for women diagnosed with breast cancer and receiving treatment for the disease. For those women, emotional, social and psychological support is essential in coping with this life-threatening disease.

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[138] *Transcript of Evidence*, pp.456-57 (RHW).

[139] *Transcript of Evidence*, pp.1692,1697-8 (Australian Capital Territory Breast Cancer Support Services).

[140] Submission No.130, pp.2-3 (Cancer Support Association of Western Australia).

[141] *Transcript of Evidence*, p.1693 (Australian Capital Territory Breast Cancer Support Services).

[142] Submission No.130, p.3 (Cancer Support Association of Western Australia).

Recommendation

The Committee RECOMMENDS:

6. That breast cancer support and counselling services be encouraged and expanded.

CHAPTER 3

ACCESS TO SERVICES

3.1 A principal aim of the National Program is to ensure that all women in the eligible age group, regardless of their geographical location, ethnic background, Aboriginality or socio-economic status, have equal access to the Program. This chapter looks at the problems of implementing the Program in rural and remote areas. The chapter also looks at the problems associated with screening Aboriginal and Torres Strait Islander women, and women from non-English speaking backgrounds; and the extent to which these groups participate in the Program.

Rural and Remote Areas

3.2 Implementing the Program in rural and remote areas poses many problems, especially arising out of the difficulties created by distance, the lack of transport and the lack of medical facilities in these areas. One witness told the Committee that 'no-one should underestimate the difficulty in establishing a rural-based assessment and screening service ... '.[143]

3.3 In certain remote areas of the country, such as north-west Western Australia, Queensland and the Northern Territory (outside the main population centres) and the west coast of Tasmania, the problems of service delivery are often compounded by the problems of remoteness and isolation.

3.4 As noted above, the problems of service delivery in remote areas relate in part to the great distances involved. A witness, drawing on his experience in Western Australia, noted:

> The difficulties related to remoteness are enormous. It involves not just the actual distance and floods and 45 degree heat; it involves who you can hire to do the jobs, [and] transport for people from unbelievably remote areas into wherever the centre may be.[144]

3.5 The need for women to travel great distances for screening and assessment services may also result in personal (including financial), and social dislocation and family problems.

3.6 The lack of access in rural and remote areas was highlighted during the inquiry. One witness highlighted some of these concerns.

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[143] *Transcript of Evidence*, p.353 (North West Health Service, Tamworth).

[144] *Transcript of Evidence*, p.275 (Health Department of Western Australia).

> The way the screening is delivered is the first one. You are likely to need mobile facilities because you will have small populations which cannot justify a full-time fixed screening unit. Secondly, recruitment strategies are a little different and they are easier, in this sense. We have done our own studies and published randomised trials, looking at GP recruitment strategies ... compliance is in excess of 90 per cent if the GP is involved. So we have developed strategies which ultimately involve GPs in the process.[145]

3.7 One submission argued that there were considerable delays in implementing the Program in rural areas.[146] However, it needs to be noted that the Program aims to be progressively implemented over five years and often the provision of services is more difficult in rural and remote areas compared with urban settings. For example, the commissioning of mobile units to service rural and remote areas takes up to 12 months.[147] In addition, some States, especially Queensland, have adopted the strategy of introducing screening services initially in more populated areas, before rural services have been established.[148] A representative of DHS&H did, however, concede that more could be done to extend the program in rural areas, particularly in relation to the establishment of more screening and assessment centres in the larger provincial towns.[149]

Models of Service Delivery

3.8 There are basically two models of service delivery in rural and remote areas – one is to bring the service to the client, the other is to bring the client to the service. The first approach has involved the use of mobile units in rural areas.

1. Service to Client

3.9 One submission noted that mobile services represent an effective way to provide services in remote areas, such as north-west Western Australia, and parts of the Northern Territory and Queensland because the population density in these areas is too low to justify the cost of fixed units or any fixed radiological services.[150] Mobile units have been established in New South Wales (7 mobile units), Western Australia (3 units), Queensland (3 units) and South Australia and Tasmania (1 unit each).[151]

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[145] *Transcript of Evidence*, pp.735-6 (Professor Forbes).

[146] *Transcript of Evidence*, p.754 (RACS, Divisional Group of Rural Surgeons).

[147] DHS&H, Progress Report, *op. cit.*, p.5.

[148] *Transcript of Evidence*, p.923 (Queensland Department of Health).

[149] *Transcript of Evidence*, p.1432 (DHS&H).

[150] *Transcript of Evidence*, p.1340 (RACS, Section of Breast Surgery).

[151] *Transcript of Evidence*, pp.1402-4 (DHS&H).

3.10 Western Australia has had considerably more experience of screening in rural and remote areas than any other program in Australia and now offers screening to all women outside the Perth metropolitan area. Approximately one quarter of the target population in Western Australia lives outside the Perth metropolitan area. To bring women to Perth from these remote areas could cost up to $1000 so it was decided to develop a screening system based on mobile units. Mobile units now operate on two-yearly cycles in the south-west, northern and south-eastern regions of the State. The system involves the use of vans, with trailers attached, each moved by a prime mover with the added facility of on-board processing of films. The availability of on-board processing has made it easier to monitor the original and the additional film views; and it also allows the radiographer to take additional views at the patient's first attendance if the need arises.[152]

3.11 Queensland faces similar problems to Western Australia in providing an effective screening program, especially in relation to the decentralised population and remoteness of the State. In relation to the remote north of the State, it is proposed to provide a screening service for the Cape York Peninsula & Torres Strait Islands by providing a relocatable mobile unit and an assessment team to travel to the isolated Aboriginal and Islander communities in that region.[153]

3.12 The largely decentralised population outside the south-east corner of Queensland also poses problems of access to assessment centres. In most instances, assessment services will be provided in conjunction with a fixed screening unit, but in the more remote areas, assessment services will be provided at larger centres that fly in an assessment team to the remote location.[154]

3.13 The Committee received evidence of problems in relation to the use of mobile units. In South Australia, it was noted that there is a problem with the high staff turnover for radiographers in the mobile unit in that State.[155] This also has led to concerns about the quality of the films due to the necessity to retrain radiographers to staff the mobile unit.[156]

2. Client to Service

3.14 In some remote areas it is neither feasible nor practicable to bring the screening service to the client via a mobile service. For example, in the far west of Queensland, it was noted that efforts will be made to provide transport for

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[152] Submission No.41, p.2 (Dr Gibson); Supplementary submission No.41, pp.13-15 (Dr Gibson).

[153] *Transcript of Evidence*, pp.985-6 (Queensland Department of Health).

[154] *ibid.*, p.925.

[155] *Transcript of Evidence*, pp.64,88 (SABXRS).

[156] *Transcript of Evidence*, p.88 (SABXRS).

Aboriginal women, in particular, from outlying communities when mobile units are in the larger country towns to conduct screening services.[157]

3.15 One witness noted, in the Queensland context, that costs could be reduced by two-thirds by bringing patients to a major centre for screening, rather than providing a mobile service.[158] The high cost of providing a mobile screening service was raised during the inquiry. The Northern Territory decided against the introduction of a mobile screening service because of its high cost – up to $400,000 to set up the van (excluding running costs).[159]

3. Assistance for Travel Costs

3.16 Financial assistance for travel and accommodation expenses is currently provided by the States and the Northern Territory to assist people in rural areas to receive medical treatment.[160] The Committee was told that the eligibility criteria under these schemes varies considerably.[161] However, under the schemes women are generally eligible for assistance if recalled for assessment or treatment.

3.17 Patients are required to have been referred by a specialist for treatment. Assistance is payable for transport expenses, for example, the cost of travel by public transport from the point of referral to the treatment centre, travel by private motor vehicle (with a reimbursement for the distance travelled) and in some cases, by air travel, if the patients' medical condition requires it.

3.18 Under the Queensland and Western Australian schemes, patients are eligible for assistance if they reside more than 50 kilometres outside the metropolitan area. In South Australia and New South Wales patients are eligible if they are required to travel more than 200 kilometres from their place of residence for treatment, while in Victoria, eligibility is restricted to persons residing 100 kilometres from a treatment centre.

3.19 In Tasmania, if treatment is not available locally, patients are eligible for assistance to travel to Hobart or Launceston. Where specialist treatment is not available in Tasmania, patients may be eligible for assistance to receive treatment

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[157] *Transcript of Evidence*, p.925 (Queensland Department of Health).

[158] *Transcript of Evidence*, p.812 (Professor McCaffrey).

[159] *Transcript of Evidence*, p.1799 (Northern Territory Department of Health and Community Services).

[160] The Commonwealth scheme, the Isolated Patients Travel and Accommodation Assistance Scheme (IPTAAS) was abolished in 1987. The Commonwealth now provides funding directly to the States and Territories for their own travel assistance schemes. In NSW the scheme is called the Isolated Patients Travelling and Accommodation Assistance Scheme (IPTAAS). In the other States it is often called the Patients Assistance Travel Scheme (PATS) or an equivalent title.

[161] *Transcript of Evidence*, p.513-4 (North Coast Breast Screening Program, Lismore).

on the mainland. In the Northern Territory, if treatment is not available in the local town, the scheme pays for the travel costs of women required to receive treatment in Darwin or Alice Springs. The scheme also pays for women to go interstate for radiotherapy treatment.[162]

3.20 The schemes also provide assistance for accommodation expenses if the specialist regards it as necessary for the patient to stay overnight for follow-up treatment. The rates for accommodation vary between States but are generally in the range of $30-35 per night. Provision also exists in many States for an escort or attendant to accompany the patient where this is necessary for medical reasons.

3.21 Some deficiencies with the operation of the schemes were noted during the inquiry. One witness argued that the rate of subsidy payable under the scheme in New South Wales was inadequate, especially for women living in country areas of New South Wales and requiring any extended period of treatment in Sydney.[163] It was also noted that the low rate of benefit payable for accommodation costs would make it especially difficult for women from lower socio-economic groups to afford treatment. It was also noted that problems exist for women that are excluded from eligibility under the schemes because they reside in country areas but just outside the distance limits imposed by the various schemes. One witness noted that in the case of New South Wales, patients requiring treatment yet living within a 200 kilometre radius of the treatment centre are excluded from benefits under the scheme and may not be able to afford the travel and accommodation costs required.[164]

3.22 Several witnesses raised the possibility of introducing a special travel allowance to encourage women in rural areas to present for assessment and treatment. One witness suggested that attention should be given to funding transport for women, for example, by using local service groups or local health services to organise transport for these women to attend a screening and assessment centre.[165] The Northern Territory Department of Health & Community Services indicated that in the Territory, access for women residing outside the main population centres could be improved by introducing a scheme that paid for the transport and accommodation costs for women to come to major centres for screening.[166] The Committee referred to the problem of ensuring that assessment would also be available within a reasonable time after screening. However, it was pointed out that in Darwin it is planned to schedule appointments so that screening

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162. *Transcript of Evidence*, p.1800 (Northern Territory Department of Health and Community Services).

163. *Transcript of Evidence*, p.1575 (RACR).

164. *Transcript of Evidence*, p.513 (North Coast Breast Screening Program, Lismore).

165. *Transcript of Evidence*, p.333 (Health Services Association of New South Wales).

166. *Transcript of Evidence*, p.1803 (NT Department of Health & Community Services).

and assessment occurred on the same day or screening on day one and assessment on the following day.[167]

3.23 Some witnesses did not support the introduction of travel allowances. One witness argued that such a scheme would be very costly to operate.[168] DHS&H indicated that the current approaches, especially the mobile services, are proving effective without the need for special transport allowances.[169]

Other Problems of Service Delivery

3.24 Other problems relating to the implementation of the Program in rural areas were raised during the inquiry. One submission noted a lack of liaison and co-ordination with many regional facilities and personnel competent to provide screening and assessment services; and a lack of use made of existing private sector facilities in some rural areas.[170]

3.25 Another witness noted that rural health services are often deficient in many areas of medical expertise.[171] Another submission, supporting this view, noted the limited number of medical consultants available in surgery, radiology and pathology in rural areas.[172] Other submissions highlighted the difficulties often experienced in attracting radiographers to work in rural areas.[173] One submission noted that it was particularly difficult to attract radiographers to work in mobile units as this often involved extended periods of time away from home.[174] There are also problems attracting radiological staff. The Committee was told that in rural areas, radiologists in private practice often have difficulty in providing reading services to screening centres.[175] (These issues are discussed further in Chapter 2).

3.26 Another witness argued that more formal links should be established between various country screening centres and central treatment centres.[176] This could be

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[167] *ibid.*, p.1804.

[168] *Transcript of Evidence*, p.762 (RACS, Divisional Group of Rural Surgeons).

[169] *Transcript of Evidence*, p.1432 (DHS&H).

[170] *Transcript of Evidence*, p.754 (RACS, Divisional Group of Rural Surgeons).

[171] *Transcript of Evidence*, p.339 (Health Services Association of New South Wales).

[172] *Transcript of Evidence*, p.497 (North Coast Breast Screening Program, Lismore).

[173] *ibid.*, p.488; *Transcript of Evidence*, p.348 (North West Health Service, Tamworth).

[174] *Transcript of Evidence*, p.488 (North Coast Breast Screening Program, Lismore).

[175] *ibid.*, p.489.

[176] *Transcript of Evidence*, p.775 (Dr Renwick).

facilitated by linking, for example, five country centres with a central treatment centre with data being exchanged between the centres.

3.27 The Committee believes that access to the Program for women in rural and remote areas needs to be improved. As noted, access to services in these areas often requires special and innovative strategies to ensure that adequate access is provided.

Recommendation

The Committee RECOMMENDS:

7. That strategies be implemented to improve access to the Program in rural and remote areas and that these strategies involve, where appropriate, the provision of financial assistance to encourage women to participate in the Program.

Aboriginal and Torres Strait Islander Women

1. Problems of Access

3.28 Aboriginal and Torres Strait Islander women often encounter problems in gaining access to the screening Program. Some of these problems are associated with living in rural and/or remote areas. These problems, such as distance and isolation, were noted in the previous section. During the inquiry, however, the Committee received considerable evidence to suggest that a major impediment to the successful implementation of the screening program among Aboriginal and Torres Strait Islander women lies in the cultural differences between them and the non-Aboriginal population and the very different health priorities of these women. The Committee believes that the Program needs to take account of these factors in delivering a screening service that is relevant and culturally appropriate for Aboriginal and Torres Strait Islander women. The Committee believes that it is important that the Program not be 'imposed' on Aboriginal and Torres Strait Islander women but that a suitably modified form of screening program be introduced in consultation with this group.

3.29 The Committee received evidence that, at least in the Northern Territory, a modified type of screening program will be introduced. The Northern Territory Department of Health and Community Services told the Committee that, during consultations with Aboriginal women, it was made clear to the Department that the conventional 'model' of a screening program was not appropriate to these women. The Department noted that:

> They also told us that they really were not keen on these organ based programs and they wanted a holistic screening program looking at the whole of the woman, rather than ... focusing on the cervix today and the breast tomorrow. Experience in other States has shown ... that

> even where it is promoted very strongly to Aboriginal women, they are still not particularly interested in breast screening.[177]

3.30 In response to these concerns the Department noted that in the Northern Territory the Program will fund a holistic women's health promotion and screening program that incorporates breast examination and screening for cervical cancer.[178]

3.31 Other factors limiting Aboriginal and Torres Strait Islander acceptance of the Program were noted during the inquiry. One witness noted, for example, that Aboriginals are reluctant to present themselves for the type of breast examination required at the usual breast screening clinics. The witness stated that 'they [Aboriginals] tend not to report symptoms of breast lumps for a whole host of reasons. Therefore, they tend to present with rather late disease which patently is only open to palliative treatment.'[179] Another witness also noted that for Aboriginal and Torres Strait Islanders 'accepting a screening protocol ... that is quite formalised, with a lot of questions asked when you arrive and having to go through a routine are not very acceptable to the population as a group'.[180]

3.32 It was also noted during the inquiry that the health needs of Aboriginal women are different from non-Aboriginal women and there was a general lack of interest among Aboriginal women in the screening Program. The Northern Territory Department of Health and Community Services stated that:

> The health priorities of Aboriginal people are different from non-Aboriginal[s]. ... Aboriginal women have much higher death rates from much more common sorts of diseases that non-Aboriginal women never die of these days – or rarely die of these days. For example, respiratory diseases, circulatory diseases, diabetes, infection and all those types of things are really common causes of death amongst Aboriginal women. So they actually identified themselves that there are a whole lot of other things that they would like to address before breast cancer. So that was their priority.[181]

3.33 Another witness agreed that similar attitudes exist among urban Aboriginals. The witness noted that breast cancer is probably 'very low on their health needs

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[177] *Transcript of Evidence*, pp.1808-7 (Northern Territory Department of Health and Community Services).

[178] *ibid.*, p.1782.

[179] *Transcript of Evidence*, p.780 (Dr Renwick).

[180] *Transcript of Evidence*, p.793 (Dr Rickard).

[181] *Transcript of Evidence*, p.1806 (Northern Territory Department of Health and Community Services).

list. They have social and economic problems that are of much more major significance to them'.[182]

3.34 Data indicate that cancers in general are a much more common cause of death among non-Aboriginal women than among Aboriginal women. Statistics show that in the Northern Territory cancers are the third most common cause of death for non-Aboriginal women, while they represent the fifth most common cause of death for Aboriginal and Torres Strait Islander women. Cancer mortality rates are also very different for non-Aboriginal and Aboriginal women. While breast cancer is the most common cause of death from cancer for non-Aboriginal women, cervical and lung cancer are much more common causes of death than breast cancer for Aboriginal women.[183]

3.35 One witness suggested that the incidence of breast cancer among Aboriginal women may be lower than for the general population. Data indicate that the incidence of breast cancer among Aboriginal women in the Northern Territory is 11 per 100,000, compared with an incidence of 36 per 100,000 for non-Aboriginal women.[184] One witness suggested that this may be related to their lower socio-economic status and diet. Research in the United States has found that breast cancer is more commonly found among women in the higher socio-economic groups.[185]

3.36 The lower life expectancy of Aboriginal women may also be a factor in the lower incidence rate of breast cancer among Aboriginal women. The life expectancy of Aboriginal and Torres Strait Islander women is 64 years, some 15 years less than for women generally. In addition, only about half of Aboriginal females can expect to live to 65 years, compared with almost nine out of ten of the female population generally.[186] One witness noted that, given their lower life expectancy, further consideration may need to be given to the appropriate age at which Aboriginal and Torres Strait Islander women should be screened.[187]

2. *Numbers Screened*

3.37 The proportion of Aboriginal women screened under the Program varies between States. In Western Australia, 1.72 per cent of Aboriginal women in the 40-

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[182] *Transcript of Evidence*, p.793 (Dr Rickard).

[183] Northern Territory Department of Health and Community Services, *Feasibility Study – Northern Territory Participation in the NPEDBC*, September 1991, p.14.

[184] *ibid.*, p.13.

[185] *Transcript of Evidence*, p.780 (Dr Renwick).

[186] Australian Institute of Health & Welfare, *Australia's Health, 1992*, AGPS, Canberra, 1992, p.211.

[187] *Transcript of Evidence*, p.355 (North West Health Service, Tamworth).

69 years age group have been screened (compared with their representation of 1.35 per cent of the target population).[188] In South Australia, 0.4 per cent of Aboriginal women in the age group 40-64 years have been screened (compared with their representation of 0.6 per cent of the target population).[189] In the Northern Territory, where screening will begin in June 1994, there are 1,100 Aboriginal women in the target age group of 50-69 years.[190]

3. *Recruitment Strategies*

3.38 Several different successful recruitment strategies for Aboriginal and Torres Strait Islander women were discussed during the inquiry. Most emphasised that close liaison with Aboriginal and Torres Strait Islander community organisations and other groups was essential in encouraging Aboriginal and Torres Strait Islander women to participate in the program. The Committee believes that the Program should liaise closely with the Aboriginal Health Services (AHSs) in particular. Some 92 AHSs now operate throughout the country and provide a range of services such as primary health care and health education and promotion. The Committee believes that the AHSs would be a useful means by which the screening program could be promoted throughout the Aboriginal and Torres Strait Islander community.

3.39 Several States indicated during the inquiry the importance of close liaison with local Aboriginal health workers, community nurses and community health groups in their recruitment strategies for Aboriginal women.[191] In South Australia a full-time promotions and education officer has been employed to develop strategies to improve access for Aboriginal and other minority groups.[192]

3.40 A witness representing the North Coast Breast Screening Program told the Committee that the Service spends a great deal of time speaking with local Aboriginals and Aboriginal health workers in the area. The Service also provides transport for Aboriginal women from outlying areas attending the mobile service.[193]

3.41 In the Northern Territory, rural women, including Aboriginals, will be specially targeted when the program is introduced. The Northern Territory Screening Service has recently employed several remote area women's health nurses

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[188] *Transcript of Evidence*, p.162 (Health Department of Western Australia).

[189] *Transcript of Evidence*, pp.21,79 (SABXRS).

[190] Advice from the Northern Territory Department of Health and Community Services, 9 May 1994.

[191] *Transcript of Evidence*, p.79 (SABXRS); p.180 (Health Department of Western Australia).

[192] *Transcript of Evidence*, p.80 (SABXRS).

[193] *Transcript of Evidence*, p.515 (North Coast Breast Screening Program, Lismore).

and they will have the role of informing Aboriginal women of the availability of the service and encouraging their attendance.[194] The Committee, however, believes that to avoid a possible duplication of resources, the NT Department of Health and Community Services should seek to use the AHSs in the Northern Territory to disseminate information about the Program.

3.42 The Committee believes that more should be done to improve the access of Aboriginal and Torres Strait Islander women to the Program especially through the involvement of Aboriginal and Torres Strait Islander community-based organisations, especially the AHSs. The Committee notes that in several States, strategies are in place to improve access for Aboriginals and Torres Strait Islanders – strategies that often involve close liaison with Aboriginal groups and communities and display a sensitivity to Aboriginal and Torres Strait Islander cultural values. The Committee also considers that more information should be disseminated to Aboriginal and Torres Strait Islander communities about the Program and that more should be done to educate Aboriginal and Torres Strait Islander women about the benefits of the Program.

Recommendation

The Committee RECOMMENDS:

8. That strategies, sensitive to Aboriginal and Torres Strait Islander cultural values, be implemented to increase the access of these women to the Program, and that these strategies involve:
    - close liaison with Aboriginal and Torres Strait Islander community-based health organisations, especially the Aboriginal Health Services; and
    - the dissemination of culturally appropriate information about the Program throughout the Aboriginal and Torres Strait Islander community.

Women from Non-English Speaking Backgrounds

3.43 Many witnesses suggested that more should be done to target women from non-English speaking backgrounds. A representative of DHS&H noted that the dissemination of information to women of non-English speaking backgrounds needs to be supplemented by culturally appropriate strategies.

> Certainly it is a very great problem to reach women of non-English speaking backgrounds, and the solution is much more than providing information in multiple languages, because it is not only a matter of language, it is a matter of culture as well. Most of these efforts have taken place at the state level, and a number of the programs have gone out of their way to try innovative approaches to get women from non-

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[194] *Transcript of Evidence*, p.1805 (NT Department of Health & Community Services).

> English speaking backgrounds. Efforts have been made to go into, say local factories, and some of the programs have women on their staff who accompany a woman of non-English speaking background through the program, a woman who speaks the same language and from the same culture. So there are varying approaches, and I think that, as the program develops and as we try to increase the amount of recruitment, there needs to be a great deal of discussion.[195]

3.44 Access to the program by women from non-English speaking backgrounds varies between the States and Territories. In Victoria, 22 per cent of women screened are of non-English speaking backgrounds, equal to their proportion in the population;[196] in the ACT the proportion screened is 13.7 per cent (compared with their representation of 18 to 20 per cent of the target population)[197]; and in Tasmania the numbers screened are equal to or slightly below their representation in the population.[198]

Targeting Ethnic Groups

3.45 Some witnesses suggested that more information needs to be provided to ethnic groups about the screening program. A member of the South Australian Multicultural & Ethnic Affairs Commission noted that:

> I would like to see more information given – be it written information, audio information such as audio-tapes or personal consultation with the communities. If that were done, those women would be enlightened about the danger of breast cancer.[199]

3.46 Translation of material into various ethnic languages is important in disseminating information about the screening program. Several States have developed strategies in relation to the use of translation services. In South Australia, brochures about the Program have been translated into 15 languages and distributed via the screening service and through the Ethnic Communities Council and other ethnic organisations.[200] In Victoria, information and promotional material has been translated into 10 of the most common community languages. The consent forms used for all women who are recalled for further investigation are also currently being translated into these 10 languages.[201]

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[195] *Transcript of Evidence*, p.1441 (DHS&H).

[196] *Transcript of Evidence*, p.1129 (BreastScreen).

[197] *Transcript of Evidence*, p.1750 (Australian Capital Territory Department of Health).

[198] *Transcript of Evidence*, p.1775 (Tasmanian Breast Screening Service).

[199] *Transcript of Evidence*, p.81 (South Australian Multicultural and Ethnic Affairs Commission).

[200] *Transcript of Evidence*, p.21 (SABXRS).

[201] Additional information from BreastScreen to the Committee, dated 29 March 1994, p.1.

3.47 The Committee was told that certain ethnic groups, especially the more recently arrived groups need to be specifically targeted to encourage their participation in the Program. One witness noted that Vietnamese women are difficult to attract to a screening program. It was noted that 'it is more foreign to their background culture, and it is more difficult to communicate with them'[202]. Turkish and Arab women were also identified as difficult groups to recruit for screening.[203] The Committee was informed that well-established ethnic groups, such as Italians and Greeks were much less reluctant to attend for screening.

3.48 The Committee received evidence that it is important in some ethnic communities to target the male members of the household, so as to ensure that the women in these ethnic groups attend for screening.[204] The Women's Health Service for the West, Footscray, suggested that this is a particularly useful strategy in working with Arabic women. It was noted that in working with Arab women 'it would be difficult to access the women' without the cooperation of the Lebanese Welfare Council, which is composed of men.[205]

3.49 Several witnesses noted that close liaison with ethnic organisations, the ethnic media and migrant health services is also important in encouraging non-English speaking women to present for screening. The Women's Health Service for the West noted that the Service has developed strategies whereby staff work with key people in the ethnic communities and local women within these communities who are able to pass on the information about breast screening by word of mouth. It was noted that this strategy is particularly effective because women in the particular communities identify more closely with someone from their own community, especially someone who is not seen to be a 'health professional'.[206]

Recommendation

The Committee RECOMMENDS:

9. That strategies, sensitive to the cultural backgrounds and values of women of non-English speaking backgrounds be implemented to increase the access of women from these groups to the Program.

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[202] *Transcript of Evidence*, p.793 (Dr Rickard).

[203] *Transcript of Evidence*, pp.779 (Dr Rickard); p.1254 (Women's Health Service for the West).

[204] *Transcript of Evidence*, pp.779 (Dr Rickard); p.1136 (BreastScreen).

[205] *Transcript of Evidence*, p.1254 (Women's Health Service for the West).

[206] *ibid.*

CHAPTER 4

THE CLIENT GROUP

4.1 The Program identifies the main 'client' group for screening as asymptomatic women aged 50-69 years. However, issues were raised during the inquiry as to whether other age groups, especially women aged 40-49 years, should be actively recruited under the Program and how symptomatic women should be treated under the Program. This chapter discusses the issues of the appropriate age ranges for screening under the National Program and the appropriateness of screening symptomatic women under the Program.

Screening Age

4.2 The National Program provides that screening be made available to women aged 40 years and over but that recruitment strategies target women aged 50-69 years. Thus while the Program does not promote screening in the 40-49 age group, women in this age group are not excluded if they request screening. They are, however, not personally invited and the State and Territory publicity material about the Program targets women aged 50-69 years.

4.3 The Accreditation Guidelines require that women be advised of the risks and benefits of mammography screening. The Guidelines provide that 'each woman attending for screening should sign a consent form that clearly outlines the screening process including the possibility of recall for follow-up assessment. The women should also be informed in writing that screening does not prevent breast cancer, nor does it detect all breast cancers'.[207] DHS&H noted that all States and the Australian Capital Territory advise women that mammography screening is only of proven benefit to women aged 50 years and over.[208]

4.4 The selection of the age range to be screened under the Program was based on the SECU Report which analysed the latest overseas scientific studies. The report concluded that there was an international consensus that mammographic screening was effective in reducing breast cancer mortality for women aged 50-69 years, but the benefit for women aged 40-49 was much less clear for a number of reasons which are discussed below.[209]

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[207] Accreditation Guidelines, *op. cit.*, p.19.

[208] Submission No.114, pp.5.10 (DHS&H).

[209] SECU Report, *op. cit.*, p.70

1. Screening Women Aged 40-49 Years

4.5 A considerable body of evidence to the Committee suggested that women aged 40-49 years should not be screened under the Program.[210] For example, a representative of the Intercollegiate Committee suggested that there was no strong scientific evidence that mass screening of 40-50 year old women is an effective public health measure in terms of a reduction in mortality.[211] A representative of the Australian Association of Surgeons (AAS) told the Committee that:

> The Association feels that the inclusion of this group at the present state of knowledge is contrary to the scientific evidence that a benefit is gained. We feel that it also increases the cost of the program by increasing the number of cases which are difficult to interpret in that younger age group for reasons of more dense breasts and, consequently, increases the intervention rate for women who then derive no benefit.[212]

4.6 The National Health and Medical Research Council (NHMRC) has also noted that the biological differences in the breast tissue of younger women make it more difficult to detect cancer in the breasts of women under the age of 50 years.[213]

4.7 The Council has also concluded that on the basis of scientific data there is insufficient evidence to suggest the screening of women under 50 years will lead to a reduction in mortality from breast cancer in this group.

4.8 The Committee also received some evidence of the problems involved in screening this group. One witness argued that:

> On the negative side, we know that screening that age group results in a higher recall rate. It results in a higher benign to malignant biopsy ratio and it results in a lower cancer detection rate. These are all rather negative features of screening that particular age group.[214]

4.9 Another witness also told the Committee that screening this group may give

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[210] *Transcript of Evidence*, pp.1570-72 (RACR); p.1369 (AAS); p.1388 (AMA); p.1271 (Intercollegiate Committee).

[211] *Transcript of Evidence*, p.1272 (Intercollegiate Committee).

[212] *Transcript of Evidence*, p.1369 (AAS).

[213] NHMRC, *Mammography Guidelines for Women Under 50 years of Age*, October 1992, p.1.

[214] *Transcript of Evidence*, p.1348 (RACS, Section of Breast Surgery). See also *Transcript of Evidence*, p.1389 (AMA).

a false sense of security to these women.[215] As noted at Paragraphs 4.5-4.8, it is essential that these women be made aware of why the screening program is not appropriate for this particular age group.

4.10 Despite these arguments, the Committee believes that screening should still be available to women aged 40-49 years, although they should not be actively targeted. Several witnesses commented that the evidence in relation to screening this age group is still inconclusive. One witness noted that:

> The data are incomplete, no matter what anyone says, so it is impossible to make a reasoned decision based on sound data at the present time. There are good reasons ... for not changing the present policy.[216]

4.11 Another witness suggested that it is important to monitor overseas studies that are looking into this question before a decision one way or the other is made in Australia.[217] The witness noted that recent Swedish data indicate that mammography screening may not be as effective for women aged 40-49 as previously thought. He also pointed to current trials underway in the United Kingdom which are specifically designed to address this issue.[218]

4.12 A recent conference on breast cancer screening in premenopausal women held in Geneva in September 1993 concluded that the efficacy of screening women aged 40-49 years must be studied further with randomised controlled trials, although the available data can support a range of age guidelines, including screening from the age of 40 or from the age of 50 years. It was also announced that an international breast screening study of younger women aged 40-42 years would be conducted. The study will involve one million women in the United States and 500,000 in Europe and will be conducted over a ten-year period to assess the efficacy of mammography screening for younger women.[219]

4.13 The Committee is concerned that if women aged 40-49 are excluded from the Program they will continue to receive de facto screening under the Medicare arrangements which would add to national health costs, and this screening may not meet the same quality standards as set by the National Program.[220]

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[215] *Transcript of Evidence*, p.1735 (Pathology Reference Group).

[216] *Transcript of Evidence*, p.727 (Professor Forbes).

[217] *Transcript of Evidence*, p.698 (Dr Fett).

[218] *ibid.*

[219] 'Multinational Breast Cancer Screening Conference Hosted by UICC in Geneva', *UICC News*, vol.4, No.4, December 1993, pp.1-2.

[220] *Transcript of Evidence*, p.698 (Dr Fett); p.1425 (DHS&H).

4.14 The Committee received evidence that younger women are a particularly health conscious group and have an expectation that the screening Program will be available for them.[221] The Committee believes that information about the limited efficacy of mammography screening for this age group and the alternative options available to these women needs to be much more widely disseminated to these women.

4.15 Several witnesses commented that women in this age group do not understand the reasons why they are not being targeted.[222] Witnesses suggested that there needs to be an education campaign, perhaps through GPs and women's health centres, to explain to women why the Program is neither appropriate nor beneficial for them.[223] The Committee understands that, in this regard, the AMA has recently launched a program to disseminate information about the screening Program to GPs.

4.16 A representative of the Tasmanian Breast Screening Service explained that a large part of the State's education campaign was directed at this group explaining the lack of usefulness of screening mammography for this age group.[224]

4.17 Evidence received by the Committee indicated that women in this age group have the alternative of paying for a mammogram either at a public or private medical facility.[225] The RACR noted that women in this age group should not be in the Program, but if they wished to have a screening performed it should be self-funded.[226] However, this option may preclude many women, especially those from socio-economically disadvantaged groups, from obtaining a mammographic screening.

2. Screening Women Aged 70 Years and Over

4.18 Women 70 years and over are outside the Program's target age group (i.e. women aged 50-69 years). Some witnesses argued that the Program discriminated against this group by not including them directly in the Program.[227] Evidence from some witnesses indicated that women aged 70 and over should be screened.[228]

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[221] *Transcript of Evidence*, pp.356 (North West Health Service, Tamworth); p.101 (Dr Roder).

[222] *Transcript of Evidence*, p.1774 (Tasmanian Breast Screening Service); p.1257 (Women's Health Service for the West).

[223] *Transcript of Evidence*, p.1735 (Pathology Reference Group).

[224] *Transcript of Evidence*, p.1774 (Tasmania Breast Screening Service).

[225] *Transcript of Evidence*, p.1517 (RACR, Queensland Branch).

[226] *Transcript of Evidence*, p.1573 (RACR).

[227] *Transcript of Evidence*, pp.1156-7 (Royal College of Nursing).

[228] *Transcript of Evidence*, p.1214 (Professor McKenzie); p.1232 (AIR).

4.19 One witness argued that it reflected an attitude of ageism not to encourage women 70 years and over to be screened. He also noted that breast cancer was just as tragic in human terms for an older women as for a younger woman.[229]

4.20 Other witnesses, however, indicated that there was no evidence of a reduction in mortality from breast cancer by screening women aged 70 years and over.[230] One witness noted:

> As women age, the cost benefit or the cost-effectiveness becomes more adverse, because people have less life expectancy involved.[231]

4.21 The Committee notes that while it may not be effective in terms of lives saved to screen women aged 70 years and over, in terms of quality of life it does offer a benefit. The Committee believes that the personal reassurance gained for older women due to regular access to mammographic screening is also an important consideration. The Committee also believes that there may be a perception amongst this age group that they are being unfairly discriminated against by being seen to be denied access to screening once they reach the age of 70.

Conclusion

4.22 On the basis of the evidence received the Committee believes that while the age range for recruitment under the Program should continue to concentrate on women aged 50-69 years, women outside this age range should also have access to screening, although they should not be actively targeted.

Recommendation

The Committee RECOMMENDS:

10. That the focus of the Program remain women aged 50-69 years, but that mammographic screening continue to be available to women aged 40-49 years and 70 years and over.

Screening Symptomatic Women

4.23 The screening program is designed to detect breast cancer in asymptomatic women. The National Program does not encourage women with symptoms to attend for screening. A symptom may, for example, include a lump or nipple discharge. Educational and promotional material provided by the States and Territories advise women who have symptoms to consult their general practitioner. However, if a woman with symptoms presents to a screening unit she will be screened.

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229. *Transcript of Evidence*, p.1214 (Professor McKenzie).

230. *Transcript of Evidence*, p.870 (Wesley Breast Clinic, Brisbane).

231. *Transcript of Evidence*, p.699 (Dr Fett).

4.24 The National Accreditation Guidelines require Services to have a protocol for handling symptomatic women. These protocols differ somewhat between States as to detail. However, in all cases, once the woman is screened, and regardless of the outcome of her mammogram, she will either be referred to her general practitioner for follow-up investigation/ongoing management or be recalled for assessment in accordance with the Service policy.[232]

4.25 The Committee received considerable evidence suggesting that symptomatic women be excluded from the Program.[233] It was put to the Committee that as the screening program is, by definition, designed to detect breast cancer in women who are asymptomatic, it is not appropriate for symptomatic women to be included. In addition, as the data collected from the Program is designed to demonstrate a benefit for screening asymptomatic women the inclusion of symptomatic women makes the interpretation of this data difficult.[234]

4.26 One submission noted that including symptomatic women in the Program would substantially increase costs. If such women were to be managed under the Program they would require assessment. It was estimated that a one per cent incidence of women with symptoms would generate an increase in up to 20 per cent in the number of assessments performed under the Program. As assessment is a costly part of the Program, this would generate a marked increase in Program costs.[235]

Alternatives for Symptomatic Women

4.27 The Committee recognises that excluding symptomatic women from the Program poses many problems. Some symptomatic women see the screening service as offering the advantage of a high quality service and may prefer to be examined by what they perceive to be as 'sympathetic' and suitably trained medical staff especially if they have been to a GP and are not happy with the advice that they have received from that source.

4.28 Others may be confused by the nature of the health-care system and, notwithstanding the purpose of the screening program, still consider the Program as offering a service that should be available to them, especially when they see other women utilising the service. The Committee received considerable evidence during the inquiry that there was a lack of understanding in the community generally

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[232] Submission No.114, p.5.11, (DHS&H).

[233] *Transcript of Evidence*, p.1272 (Intercollegiate Committee); p.1583 (RACR); p.828 (Professor McCaffrey); p.861 (Wesley Breast Clinic, Brisbane).

[234] *Transcript of Evidence*, p.1369 (AAS).

[235] *Transcript of Evidence*, p.1532 (RACR).

regarding the difference between screening and diagnostic mammography.[236] Still other women may live in areas where alternative screening services are not readily available or easily accessible and therefore see the Program's services as providing a useful health resource.

4.29 Women who deny that they have symptoms at the time of making an appointment for screening also present special problems. One witness noted that in Victoria, up to two per cent of women arriving at centres for screening actually have symptoms. This is despite the fact that there is a telephone protocol at the appointments stage which makes clear that if a woman indicates that she has any kind of symptom then it is suggested that she sees her GP.[237] Another witness noted that symptomatic women who insist on being screened should be screened as there is a 'duty of care to that patient ... This is a patient now, it is not a screenee who has arrived on your doorstep'.[238]

4.30 Several witnesses recognised the difficulty in situations where self-referred symptomatic women present for screening. For example, the Intercollegiate Committee noted that these women should not be turned away but should have a mammogram and be directed for proper medical assessment and management in consultation with their GP.[239] The Committee agrees with this approach and also believes that counselling and advice should also be made freely available by the screening services to these women.

4.31 The Committee also believes that information on the alternatives open to women need to be widely disseminated and publicised in the general community and to GPs in particular.

4.32 Women with symptoms who present for screening need to be advised that Medicare benefits are available for diagnostic mammography. If subsequently found to have no disease they are eligible for screening under the Program. A witness told the Committee that, based on her experience, when it is explained to them, symptomatic women generally accept the advice that the screening Program is not appropriate for them.[240]

4.33 The Committee notes that women in rural areas who present at a screening centre with symptoms present a difficult problem for the Program. One submission noted that because access to mammographic services is so restricted in many rural areas, women who present, for example, at a mobile clinic need to be accepted under

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[236] *Transcript of Evidence*, p.1030 (AMA, Queensland Branch); p.803 (Wesley Breast Clinic, Brisbane).

[237] *Transcript of Evidence*, p.1129 (BreastScreen).

[238] *Transcript of Evidence*, p.1584 (RACR).

[239] *Transcript of Evidence*, p.1265 (Intercollegiate Committee).

[240] *Transcript of Evidence*, p.862 (Wesley Breast Clinic, Brisbane).

the Program.[241] The Committee believes that, in these circumstances, they should be screened but that every effort should be made to direct these women to appropriate medical services outside the Program.

4.34 The Committee believes there needs to be an educational campaign directed at both the general public and medical profession so that women with breast symptoms are directed along established diagnostic pathways and that the screening program is not used for the de facto diagnosing of symptomatic women.

4.35 The Committee considers that the National Program must have a clearly defined and uniform policy with regard to symptomatic women – its objective must be to offer mammographic screening to asymptomatic women on a regular basis to allow for the detection of breast cancer which is amenable to treatment. The Committee also believes that the Program should offer advice and counselling to symptomatic women and information on follow-up medical services that are available. The Committee also considers that the Program needs to provide mammographic screening to symptomatic women who wish to be screened.

Recommendations

The Committee RECOMMENDS:

11. That recognising that the Program is for well women, that symptomatic women inquiring or phoning for appointments be advised why the Program is not appropriate for them; and be provided with specific advice and information regarding the availability of other medical services.

12. That should symptomatic women present for mammographic screening they be screened under the Program; and be provided with advice and information regarding the availability of further medical services.

Women with Identifiable Risk Factors

4.36 The Program is designed for well women and therefore makes no provision for screening women more frequently if they are considered to be at high risk of developing cancer, have a strong family history of cancer, have had a pre-cancerous condition or if they have had treatment for cancer in the breast in the past.[242]

4.37 Concern was expressed during the inquiry as to the best way of treating women with identifiable risk factors and especially whether they should be treated within the Program or outside it.

4.38 Much of the evidence presented to the Committee suggested that these women require ongoing medical care involving regular clinical examination and

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[241] *Transcript of Evidence*, p.1320 (RACS, Section of Breast Surgery).

[242] *Transcript of Evidence*, p.1265 (Intercollegiate Committee).

mammography and that this is best managed outside the National Program by existing medical services.[243]

4.39 The Committee believes that it needs to be emphasised that the Program is based on a significantly different ethos of health care than the dominant 'illness' model of health care – in that the Program specifically targets well women and the vast majority of women who participate in the Program will still consider themselves to be 'well' after having been through the Program.[244]

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[243] See *Transcript of Evidence*, p.1265 (Intercollegiate Committee); p.1320 (RACS, Section of Breast Surgery); p.1736 (Pathology Reference Group).

[244] See recommendation at Paragraph 4.35.

CHAPTER 5

OPERATIONAL EFFECTIVENESS OF THE PROGRAM

This chapter will examine the operational effectiveness of the Program in terms of the quality of staff and staff training; and the quality of service provision with special emphasis on the role of GPs in the Program and the use of non-radiologist readers.

Training

5.1 Staff employed in screening and assessment centres need to be suitably qualified professionals with a high level of competence in their respective fields of expertise. The Accreditation Guidelines state that medical personnel must have the accreditation status or appropriate qualifications as defined by their respective Colleges; radiographers are required to be fully trained in screening mammography through training courses accredited by AIR. Personnel involved in a counselling role need to be specifically trained in breast cancer screening, in particular dealing with anxiety, and discussing with women the outcomes of screening. They should also refer patients to expert counselling where this is appropriate. Support staff (that is, receptionists and other administrative staff) need to have participated in specific in-service training courses on breast cancer screening, that include skills training in dealing with women under stress.[245]

5.2 Training is primarily a State/Territory responsibility and $1.54 million has been allocated by the Commonwealth for this purpose over the period 1991-92 to 1993-94.[246] Much of the training is conducted within the services, with specialist radiographer training courses developed in Queensland, Victoria and South Australia. Victoria and New South Wales have conducted multi-disciplinary training courses which have been attended by personnel from interstate. These were followed by single speciality courses, which have also been conducted in Western Australia.

5.3 In an effort to promote consistent national training standards the Commonwealth has sponsored the development of a national training package which will be available to all States/Territories. The training package involves the development of single-disciplinary and multi-disciplinary training programs. The purpose of multi-disciplinary training is to provide training in the theoretical aspects of population screening and to provide a forum for an understanding of the significance of a team approach and the various elements of the screening process. The single-disciplinary courses will focus on more specific theory and practice. These courses will be available to all groups within the Screening and Assessment Services team including radiologists, radiographers, pathologists, surgeons, program

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[245] Accreditation Guidelines, *op. cit.*, pp.18-19.

[246] DHS&H, Progress Report, *op. cit.*, p.8.

managers and clerical staff.[247] All States and the ACT have accepted unmatched Commonwealth funds to develop and implement State training strategies consistent with the national approach. This will involve continuing education as well as multi-disciplinary and single-disciplinary theoretical programs using the national training packages.

1. Radiographers

5.4 At present there is a standard three-year degree course for the training of radiographers; there is one training institute for radiographers in each State.[248]

5.5 The Committee received some evidence that the training needs of radiographers in the Program need to be more adequately addressed. A representative of the Australian Institute of Radiography, for instance, argued that 'burnout' and high staff turnover among radiographers is a continuing problem in the Program. The Institute proposed that a structured, consistent training program Australia-wide in dedicated centres in each State needed to be introduced. The Institute also argued that continuous training programs as part of post-graduate studies are needed.[249] As noted in Paragraph 2.25, the Charles Sturt University (Wagga Wagga Campus) will begin a post-graduate course in breast imaging in July 1994.

5.6 The Committee was told that the current state of mammographic radiography training is *ad hoc*. One witness noted that:

> There is plenty of theory component offered, either in a multi-disciplinary aspect, or in each State with specialist visitors coming from overseas. But the actual, practical hands-on training for radiographers is very ad hoc, still. It is mostly done in each State in the pressurised screening clinic environment.[250]

5.7 The Institute explained that radiographers need to be trained in a non-pressurised dedicated environment ideally involving at least a three week induction training period to enable them to fulfil their role in a screening clinic environment.[251]

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[247] Submission No.114, pp.6.16-6.17 (DHS&H).

[248] *Transcript of Evidence*, pp.1239-40 (AIR).

[249] *Transcript of Evidence*, p.1228 (AIR).

[250] *ibid.*, p.1229.

[251] *ibid.*, p.1228.

2. *Radiologists*

5.8 Radiologists complete a five year specialist training program in radiology, upon completion of their medical degree course and two-year residency training. The RACR noted that many Australian radiologists have visited overseas screening centres to increase their knowledge of mammography screening and several overseas experts have visited Australia in the last several years and their courses have been attended by many radiologists. The College currently has an extensive training curriculum in mammography in its registrar course, and many training registrars are exposed to screening mammography during their training.[252]

5.9 The Committee, however, received evidence that radiologists are not necessarily adequately qualified to perform screening mammography work. One submission stated that the skills involved in reading mammographic films, particularly screening films, are very dependent on experience. For most radiologists this is only a very small part of their total practice and so the extent of their experience and competence may be 'significantly limited'.[253] A witness representing the RACR acknowledged that 'we feel that special training is required even for a radiologist in screening mammography. We train our trainees in mammography now but the technique of screening mammography requires some further training'.[254] The RACR envisaged that a short training course, perhaps over two days, would be beneficial. The course would, in particular, provide an introduction to the processes and philosophy involved in a mass screening program.

3. *Breast Physicians*

5.10 As noted in Chapter 2, the Australian Society of Breast Physicians defines a breast physician as a qualified medical practitioner who has worked for three years full-time in a dedicated breast clinic which is recognised by the Society as a training centre. The Member or Fellow of the Society is required to have documented evidence of the attainment of the required degree of experience and expertise in certain nominated skills and to have satisfied the requirements of the Examining Council of the Society.[255] There are nine fully trained foundation members of the Association and some 65 additional member practitioners in training.

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[252] *Transcript of Evidence*, p.1528 (RACR). The registrar course refers to the five-year training course for radiologists. A training registrar refers to a training position at a public hospital in specialist radiology.

[253] Submission No. 90, p.2 (Dr Warren).

[254] *Transcript of Evidence*, p.1571 (RACR).

[255] A Member of the Society is required to have demonstrated competency in 3 of the 5 following skills: clinical expertise, imaging, counselling, interventional procedures and management. A Fellow of the Society is required to possess competency in at least 4 of the 5 above skills.

5.11 The Australian Society of Breast Physicians offers a three year full-time training course at the Sydney Square Breast Clinic and the Wesley Breast Clinic in Brisbane. The training involves clinical expertise in breast examination; counselling skills to deal with the everyday concerns and anxieties of clients; expertise in the reading of screening mammograms and breast ultrasound images; and expertise in the sampling of screen-detected abnormalities by fine needle aspiration and core biopsy under ultrasonic and mammographic control.[256]

5.12 Breast physicians are eligible for membership of the Society of Breast Physicians. There are three categories of membership - Associate Member (member in training), Member (where mammographic skills are not essential) and Fellow (where mammographic skills are essential). The nine foundation members of the Society all qualify as Fellows and all have the necessary mammographic skills. There are five prospective members coming up for examination in June 1994. They have acquired the necessary mammographic skills to be classified as Fellows should they satisfy the Examining Council of the Society.[257]

5.13 To be eligible for membership of the Society, Members and Fellows must have experience with a minimum of 2000 physical breast examinations, a minimum of 2000 mammograms per year over a two year period and experience in the interpretation of 500 breast ultrasound examinations over a two year period. They must also have undertaken a minimum of 200 fine needle aspirations of breast tissue and have competence in counselling skills and experience in a management role within the health care system. Associate Members, as members in training, may have fewer than the number of clinical examinations and interventional procedures specified for Members or Fellows of the Society.[258]

5.14 Some evidence to the Committee suggested that breast physicians were not sufficiently trained to fulfil their role as film readers. The RACR argued that the five year specialised training program in radiology uniquely equips radiologists for this task. The College also suggested that for trained radiologists already qualified in mammography, any additional training required in screening mammography, will necessarily be easier for them compared with a non-radiologist, lacking background knowledge in the area of radiology.[259]

5.15 Other evidence to the Committee, however, argued that breast physicians are sufficiently qualified to undertake film reading. In a submission from a radiologist, it was noted that 'in all situations where I currently work, the second reader is a highly trained and competent breast physician'. It was also noted that the skills

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[256] *Transcript of Evidence*, pp.527-28 (Australian Society of Breast Physicians).

[257] Letter from the Australian Society of Breast Physicians to the Committee, dated 13 May 1994, p.1.

[258] Australian Society of Breast Physicians, *Memorandum of Membership Criteria*, December 1993, pp.3-6.

[259] *Transcript of Evidence*, p.1529 (RACR).

involved in reading films are very dependent on experience - breast physicians who devote their time entirely to this practice may be more suitable than a radiologist, for whom film reading is only a small part of their work.[260] This issue is discussed further at Paragraphs 5.30-5.44.

Role of General Practitioners

5.16 GPs have an important role in the overall effectiveness of the Program, especially in terms of providing women with information about the screening program, encouraging them to attend the Program, providing support and counselling (where this is appropriate) to women recalled to an assessment centre for further investigations and discussing management options with women found to have breast cancer. Family doctors also play an important role in the follow-up of patients being treated for breast cancer.

5.17 The Program recognises the important part GPs can play in the Program, especially in relation to encouraging women to attend for screening. A representative of DHS&H emphasised that the Program 'appreciates that general practitioners are an integral and very important part of the Program'.[261] Another representative of the Department noted that:

> In the program women are asked at several stages to nominate their GP, if they wish. ... When services begin, as a matter of practice, they get in touch and make contact with the local GPs to ensure that there is a relationship commenced. ...The College... is an important part of the national advisory committee. All of that means that we accept that GPs are a vital part of the process and we encourage the services to include them in the ways I have described.[262]

5.18 While a doctor's referral is not a prerequisite for attendance at a screening clinic, the National Accreditation Guidelines require that a woman's nominated GP be kept informed of the results of screening unless a woman directs otherwise. Where a woman does not have a GP, and a cancer is detected, she will be encouraged to nominate a GP or an alternative provider before proceeding to treatment.

5.19 The importance of GP involvement to the overall success of the Program, especially in the recruitment phase of the Program, was highlighted by several witnesses. One witness, noted:

> I think it is important that general practitioners are aware of the issues and the principles of screening and that they are very involved

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260. Submission No. 90, p.3 (Dr Warren).

261. *Transcript of Evidence*, p.1429 (DHS&H).

262. *ibid.*

> in recruitment of women to screening programs. There is data that show quite conclusively that the GP's influence on women who attend general practitioners is very important in their attending a screening program, so I would like the general practitioners to be better informed about screening and its differentiation from diagnostic mammography. I would like them to be involved very strongly in recruitment and I would like them to feel as if they were part of the program.[263]

5.20 Some witnesses, suggested that referral by GPs to the screening program should be introduced as a means of increasing GP involvement with patients from their initial contact with the Program.[264]

5.21 This proposal may, however, be less than effective as it was pointed out to the Committee that some women do not have GPs. From evidence presented to the Committee it is not clear what proportion of women do not have a GP. One witness suggested it was up to 20 per cent,[265] although other evidence suggested the number was low. The Committee, however, does not support the concept of exclusive GP referral as it believes it may act as a disincentive for many women to attend the screening program and would add to general medical costs.

5.22 Several witnesses also emphasised the role GPs play in the counselling and management of women with cancer. One submission noted that GPs 'have a pivotal role in providing continuity of care for women who have been found to have cancer'.[266] Many women may wish to discuss the results of their mammogram with their GP and, in particular, may wish to seek further advice should an abnormality be detected. The GP is often an important source of information, support and counselling for women and their families in these situations. GPs also play an important role in the referral of women to surgeons and other health professionals.[267]

5.23 The Committee, however, received some evidence to suggest that the level of knowledge of GPs about the Program was deficient and that it was an area that needed to be addressed so that GPs could play a more effective role under the Program. The Committee also received some anecdotal evidence to suggest that some GPs do not fully support the Program nor understand fully the benefits that can flow from such a Program.

5.24 Several witnesses argued that more should be done in the area of general GP

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[263] *Transcript of Evidence*, p.856 (Wesley Breast Clinic, Brisbane).

[264] *Transcript of Evidence*, p.893 (Queensland Medical Women's Society).

[265] *ibid.*, p.892.

[266] *Transcript of Evidence*, p.382 (New South Wales Health Department).

[267] *ibid.*

education.[268] One witness noted that 'I think GPs are undergoing a very steep learning curve about screening programs. I think many of them started ... with a very low base'.[269]

5.25 Several witnesses commented that the difference between screening mammography and diagnostic mammography was poorly understood by many GPs. One witness, drawing on her personal experience, noted that:

> On our referral form we have diagnostic clinic and in brackets 'symptomatic women'; screening program, 'asymptomatic women' in brackets – and every day of the week we get a number of inappropriate referrals [from GPs].[270]

5.26 Another witness stated that 'enormous numbers of the medical and nursing profession do not understand the scientific principles of screening ... Clearly, there is a problem if they do not understand in trying to actually get that message through them to the community'.[271]

5.27 Other witnesses noted that many GPs are not adequately trained to provide counselling and support for breast cancer patients. A representative of DHS&H told the Committee that 'not all GPs' have adequate training or experience in the vital area of counselling and support.[272]

5.28 The need for further education of GPs was again illustrated in evidence from a witness representing the Health Department of Western Australia. He noted:

> Our concern is that we have a fair bit of evidence of quite inappropriate ongoing referral from GPs who seem not to understand what the issues are in terms of further management of breast cancer; women having quite inappropriate operations by all judgments, that have been fed back to us after that time.[273]

5.29 The Committee believes that more should be done in the area of GP education. Program administrators should ensure that information about the Program is widely disseminated to GPs and that efforts are made to actively involve GPs, especially in the recruitment aspects of the Program. The Committee also

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[268] *Transcript of Evidence*, p.763 (Divisional Group of Rural Surgeons); p.856 (Wesley Breast Clinic, Brisbane).

[269] *Transcript of Evidence*, p.1733 (Pathology Reference Group).

[270] *Transcript of Evidence*, p.863 (Wesley Breast Clinic, Brisbane).

[271] *Transcript of Evidence*, p.430 (New South Wales Health Department).

[272] *Transcript of Evidence*, p.1428 (DHS&H).

[273] *Transcript of Evidence*, p.273 (Health Department of Western Australia).

believes that GPs need to be provided with sufficient information to assist them in their clinical decision-making and in further advising their patients. The Committee also believes that the Royal Australian College of General Practitioners and the AMA have a role in educating GPs and should be actively involved in disseminating information to GPs about the Program and ensuring that the nature and principles of the Program are clearly understood by all GPs. The Committee understands that the AMA has recently launched a program to disseminate information about the Program to GPs.

Recommendations

The Committee RECOMMENDS:

13. That information about the screening Program be more widely disseminated to the medical profession, and in particular to GPs; and that the further education of GPs in relation to all aspects of the Program be given priority.

14. That the role of GPs in their recruitment and support roles be recognised and encouraged under the Program.

Use of Non-Radiologist Readers

5.30 The desirability and practicability of using non-radiologists as film readers was raised during the inquiry. The Accreditation Guidelines require that all films be read twice and that at least one of the readers must be a radiologist. Both readers must be specially trained in screening mammography and both must meet the same performance standards.[274] This policy is in line with the recommendations in the SECU Report.[275] Whilst in all States except Queensland the film reading is done by radiologists alone, the option exists for States to employ non-radiologists as one of the two readers; these second readers are medical practitioners with special training.

5.31 RACR opposes the use of non-radiologist readers in the Program. The College argued that there are sufficient numbers of radiologists to staff the Program throughout the country. The College also argued that the Program should use the considerable body of expertise currently present in the radiological community. They noted that the diagnostic radiologist is the best qualified person to assess which technique can most effectively provide a definitive diagnosis and through radiological training and experience in these techniques is the best person to conduct the interventional procedures chosen.[276]

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[274] Accreditation Guidelines, *op. cit.*, p.9.

[275] SECU Report, *op. cit.*, pp.74-75.

[276] *Transcript of Evidence*, pp.1528-29 (RACR).

5.32 However, other evidence received by the Committee suggested that there is no reason why non-radiologists cannot be trained to read mammograms as effectively as radiologists, especially if they are medical practitioners. Indeed, as noted previously, not all radiologists have special training in screening mammography. In addition, many radiologists are employed by the Program to read films after their normal working hours and this may be less than an ideal situation from a quality control point of view.

5.33 The SECU report noted that non-radiologist film readers have worked successfully in trials in the United Kingdom and the Netherlands. Non-radiologists have also been successfully trained to interpret mammograms in hospital radiology departments in the United States.[277]

5.34 The RACR, however, noted that there are important medico-legal considerations involved in employing non-radiologist readers. The College added:

> One must realise that the inherent and inescapable false negative rate of screening mammography is likely to result in medico-legal actions against the Programme and against the readers of screening films. A radiologist reading screening films where the second reader is a non-radiologist would be concerned that any action would more likely be directed to him as either the only medical practitioner or the only specialist radiologist reading the films rather than equally to both readers. The Programme should also be concerned that the use of a non-radiologist reader may indicate to a plaintiff that the screening exercise is not being undertaken with appropriate care assuming that the plaintiff could demonstrate that two readers were appropriate.[278]

5.35 The Committee notes the above concerns expressed by the RACR in relation to possible legal action against the Program in situations where non-radiologists are employed as second readers. The Committee notes, however, that suitably trained non-radiologist readers have been accepted in the United States, a country where litigation in the medical area is often a major concern.[279] The Committee believes that the issue of indemnity needs to be clarified and appropriate protection afforded to the Program. The Committee understands that the legal situation rests largely with the States and Territories as the personnel employed under the Program are employees of the various State and Territory screening centres.

5.36 The Committee received evidence from several witnesses that the skills of non-radiologist readers should be used in the Program. The Australian Society of Breast Physicians argued that there are a number of advantages in using breast physicians as readers. They stated that the use of trained non-radiologist film

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[277] SECU Report, *op. cit.*, p.74.

[278] *Transcript of Evidence*, p.1529 (RACR).

[279] SECU Report, *op. cit.*, p.74.

readers augments the pool of skilled specialist readers available to screening services and provides flexibility of service provision.[280] The Committee notes, however, that the training program for breast physicians has only recently been introduced and the categorisation of 'breast physician' does not exist in overseas countries nor do any breast physicians work as second readers outside the capital cities in Australia.

5.37 In Queensland, where breast physicians are used as readers, the Department of Health indicated that their employment had proved 'highly desirable'. The Department noted that the inclusion of mammographic reading as part of the clinical skills of some medical officers enables them to cover all aspects of the screening program from point of entry at initial screen through to recommendation for open biopsy or reassurance that all is well. The Department also noted that given the current shortage of radiologists in regions outside the South-East corner of the State it is unlikely that film reading requirements for the Program can be fully met by radiologists in these regions or outside these areas.[281]

5.38 Another submission commenting on the work of breast physicians at the Wesley Breast Clinic noted their commitment and 'special ability in reading mammograms'. The submission also noted that it would be a 'travesty of justice if Cherrell [Hirst] and her highly skilled staff and other breast physicians throughout the nation were excluded from the Program and more importantly the women of this nation were denied access to their special talents'.[282]

5.39 The Committee raised a number of issues with the Society of Breast Physicians, including the training available to breast physicians and the level of proficiency in reading films.

5.40 As noted in Paragraph 5.11, there is a training program in place for breast physicians.[283] Breast physicians must also be specially trained in screening mammography and meet the same performance standards as radiologist readers.[284] As the DHS&H stated, from the point of view of Program outcomes, the important fact is that both readers are 'expert in screening mammography'. The Committee also believes that if breast physicians can demonstrate a competence equal to that of radiologists in film reading they should have the opportunity to participate as second film readers under the Program, especially in areas where there is a shortage of radiologists.

5.41 Regarding the reading of films, the Society noted that a study funded by the

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[280] *Transcript of Evidence*, p.529 (Australian Society of Breast Physicians).

[281] Letter from the Queensland Department of Health to the Committee, dated 25 February 1994, p.5.

[282] *Transcript of Evidence*, p.490 (North Coast Breast Screening Program, Lismore).

[283] See also *Transcript of Evidence*, p.531 (Australian Society of Breast Physicians).

[284] See Accreditation Guidelines, *op. cit.*, p.9.

Commonwealth showed that non-radiologist readers, with training, are able to read mammograms as proficiently as radiologists.[285] The study conducted at the Wesley Breast Clinic used two groups of readers – four radiologists and five non-radiologists. They read 2041 screening films under comparable 'blind conditions' and the results were compared. The study concluded that trained non-radiologist readers are able to achieve results comparable to those of radiologists in the interpretation of screening films within the context of a mammographic screening program.[286]

5.42 The Committee believes that it would be desirable to undertake further studies in Australia that compared radiologists and non-radiologists in their respective proficiency in film reading. Such studies would provide useful empirical evidence as to the relative abilities of both sets of film readers.

5.43 The Society also noted that non-radiologist film readers have been used in a number of screening services for some years. One witness noted that breast physicians are working quite successfully with radiologists in these centres.[287] Another submission from a radiologist stated that:

> In the State of Queensland ..... there are a large number, relatively speaking, of very highly experienced non-radiological mammographic film readers. These doctors have, by virtue of long years of experience dedicated entirely to breast disease, acquired enormous experience at both mammographic interpretation and clinical assessment of breast disease. I regard them as absolutely essential participants in the successful implementation of a National breast screening program.[288]

The Committee's View

5.44 The Committee believes that trained breast physicians may be included as film readers in the Program, especially where there is a shortage of radiologists. The Committee is disappointed at the attitude of the RACR which has advised its members not to participate in the Program where screens are being read by non-radiologists. DHS&H told the Committee that this directive from the College has resulted in some difficulty for radiologists who otherwise might wish to work within the Program.[289]

5.45 The Committee considers that permitting breast physicians as film readers will allow for greater flexibility in the implementation of the Program. The policy

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[285] *Transcript of Evidence*, p.533 (Australian Society of Breast Physicians).

[286] Wesley Breast Clinic, *Mammographic Interpretation Study*, October 1991, pp. 2,12.

[287] *Transcript of Evidence*, p.532 (Australian Society of Breast Physicians).

[288] Supplementary Submission No.90, p.3 (Dr Warren).

[289] Submission No.114, p.5.11 (DHS&H).

will allow those areas where there is a shortage of radiologists to employ breast physicians as the second reader.

Recommendation

The Committee RECOMMENDS:

15. That Fellows of the Australian Society of Breast Physicians may be employed as second film readers under the Program, on condition that indemnity is provided by the employing authority.

CHAPTER 6

COST-EFFECTIVENESS OF THE PROGRAM

6.1 One measure of the success of the Program will be the extent to which it delivers services in a cost-effective manner. This Chapter discusses the current funding arrangements for the Program and issues related to the cost-effectiveness of the Program, especially the extent to which it represents 'value for money'; and whether it is being delivered in the most efficient way. In relation to the delivery of services, the chapter discusses the current mix of public and private sector service delivery and the issue of the effectiveness of the current funding arrangements for the Program versus the introduction of a Medicare rebate system.

Current Funding Arrangements

6.2 Commonwealth funding for the Program for 1994-95 will be $41.8 million. The Commonwealth has also committed $236.6 million over the next five years from 1994-95 to 1998-99, to the Program. Commonwealth expenditure under the Program since its introduction is shown below:

Year	Expenditure ($million)
1990-91	1.0
1991-92	15.5
1992-93	14.9
1993-94 (est)	25.6
Other 1992/1993 savings (screening shortfalls)	1.2
Departmental Running Costs	2.6
Offset to Medicare (biopsies not performed under the Program)	1.5
Rollover to 1994/95	2.5
TOTAL	64.8

Source: Letter from DHS&H to the Committee, dated 25 May 1994, p.1.

6.3 The table shows that Commonwealth funds totalling $64.8 million were allocated since the establishment of the Program. Of this total, $57 million was for Program costs, and $2.6 million for Departmental running costs. A further $5.2 million reflected savings in 1992-3, offsets to Medicare and rollover funds to 1994-95.

6.4 Payments to the States consist of funding for three activities:

- screening and assessment (matched and unmatched funds);
- data management (unmatched funds); and
- training (unmatched funds).

6.5 All States and the ACT have signed a participation agreement with the Commonwealth for the first phase of the Program which provides funding for the establishment or expansion of the Program. They have also entered into a cost-sharing agreement with the Commonwealth which provides funding on a 50/50 cost-shared basis (to 30 June 1994). Under this agreement, Commonwealth funding for each State/Territory is based on the projected number of women screened.[290]

Cost-effectiveness

6.6 In determining the cost-effectiveness of the Program there are two basic questions that need to be addressed – whether the screening program contributes more per dollar spent to the improvement of health than other competing uses for health resources and whether the program is being delivered in the most efficient way to achieve the desired outcomes.

1. The Screening Program - is it Value for Money?

6.7 A number of studies have addressed the issue of whether the Program represents 'value for money'. The studies have looked at the balance of benefits and risks and converted them into a quantitative value, for example, the economic cost of a life year gained or the cost of a life saved. The SECU report found that if an economic cost per life year gained of approximately $6,600-$11,000 (at 1988-89 prices) is considered acceptable value for money then mammography screening, (as subsequently implemented by the National Program), can be recommended on economic grounds.[291]

6.8 A study was subsequently undertaken by Carter et al., applying more sophisticated computer analysis to the original cost data in the SECU study.[292] The study found that the screening policy under the National Program, that is,

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[290] Submission No. 114, p.8.7 (DHS&H).

[291] SECU Report, *op. cit.*, p.29. The SECU data was based on information from Australian pilot projects. Assumptions in the study included a 2-year screening interval and a 70% participation rate by women aged 40-69. The concept 'cost per life year gained' is the cost of lengthening the life by one year for each patient who could otherwise have died from breast cancer. For example, for some women early detection may result in say, 30 more years of life than if undetected, for others, detection may be too late to increase the life of the patient at all. All these 'extra' years of life are added together and the result divided by the total cost of the Program.

[292] R. Carter et al., 'Cost-Effectiveness of Mammographic Screening in Australia', *Australian Journal of Public Health*, vol. 17, No.1, 1993, p.42.

screening women aged 40-69 years every two years, has an average cost-effectiveness of $20,300 per life gained which is comparable to many other uses of health care resources. The study concluded that screening all women aged 50-69 years every 2 to 3 years is 'reasonable value for money'.[293] The study noted that 'a properly conducted breast cancer screening program could be cost-effective by current standards, and certainly more cost-effective than quite a number of health programs currently being funded in Australia'.[294]

6.9 One submission also provided estimates of the cost-effectiveness of the Program. The RACS, Section of Breast Surgery estimated that, based on the cost of the Program in NSW, the cost per life saved is $167,000.[295] The College noted that if the benefits of mammographic screening provide less than a 30 per cent reduction in mortality and if participation is significantly less than 70 per cent, the cost per life saved will increase substantially.

6.10 Using the same reduction in mortality but with a participation rate of 50 per cent, the College estimated that the cost per life saved would increase to $235,000. The College argued that 'it is difficult to justify' continued funding for the Program based on this cost-benefit analysis.[296] These data indicate, that if the Program fails to achieve a 70 per cent participation rate and/or the reduction in mortality is less than anticipated, for much the same costs overall (that is, with facilities and staff in places) then the average cost of the Program will increase substantially.

6.11 Evidence received by the Committee indicated that little quantitative data are available on the overall cost-effectiveness of the Program. DHS&H stated in its submission that it is expected that valid estimates of average and marginal costs for each program component will only be possible after some years when it can be expected that 'economies of scale' will be realised and the Program is at 'steady state' operation (that is, fully operational and screening at maximum planned capacity).[297]

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[293] *ibid.*

[294] *ibid.*, p.49.

[295] *Transcript of Evidence*, p.1328 (RACS, Section of Breast Surgery). This estimate was based on a 30 per cent reduction in mortality and a 70 per cent participation rate amongst eligible women in NSW. Note: the figure quoted, i.e. $167,000, is the cost per life saved and not the cost per life year saved as cited in the SECU study.

[296] *ibid.*, p.1329.

[297] Submission No.114, p.9.7 (DHS&H). DHS&H stated that at the current stage of implementation, the start-up and other fixed costs would distort cost analysis. In the longer term, capital costs are annualised (that is, averaged out over a period of time), and this bears little relationship to the patterns of actual expenditure currently being experienced within the National Program.

6.12 The Department also noted that it is not anticipated that a detailed economic analysis will be possible except as part of the longer term evaluation of the Program. A specific analysis will, however, be made of remote area costs from available expenditure data, and an attempt will be made to compare the cost-effectiveness of the various models of service delivery which have been adopted within the Program. The evaluation, in the long term, may also attempt to assess the relative efficiency of delivering a population-based screening program through the coordinated, controlled model recommended by the SECU Report or through some other model.[298]

6.13 DHS&H provided some information to the Committee on the rural and remote area costs associated with the Program. The Department noted that a detailed study of remote area costs is currently being undertaken. The Department stated that preliminary results indicate that the additional cost of service delivery in rural and remote areas is estimated to be $20 per woman screened.

6.14 The factors contributing to the additional costs in rural and remote area service provision were identified by the Department as:

- the specific costs of operating mobile services in rural/remote areas (living away allowances and travel expenses, film courier expenses, van towage expenses, costs of transporting an assessment team to the mobile);
- rural/remote area capacity utilisation constraints stemming from climate, terrain, down-time;
- mobile service design factors (providing an expert breast assessment service to remote areas; film processing on board); and
- ' learning curve ' issues associated with running a mobile in rural/remote areas, particularly with respect to planning and implementing an effective service.[299]

6.15 The States generally indicated that the Program would be cost-effective, at least in the longer term. Several States, including Victoria and Queensland, noted that the initial costs associated with establishing the screening Program have been relatively high.[300] BreastScreen noted that these high start-up costs were due to the investment in infrastructure development (for example, purchase of radiology equipment, and data system hardware), and other capital costs associated with establishing new Services. The States indicated, however, that cost reductions will occur when the Program is fully implemented over subsequent years as economies of scale will be achieved through much higher throughput of women screened (i.e.

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[298] Submission No.114, p.9.7 (DHS&H).

[299] Additional information from DHS&H to the Committee, dated 18 February 1994, pp.1-2.

[300] *Transcript of Evidence*, p.951 (Queensland Department of Health); p.1118 (BreastScreen).

increasing numbers of women using the Services).

6.16 BreastScreen noted that 'in Victoria, steady state capacity will result in screening over 220,000 women per annum. Achievement of this high participation rate will result in the maximum use of capped funds which will see the unit cost of providing BreastScreen services fall accordingly'.[301]

6.17 The ultimate test of the effectiveness of the Program will be the extent to which it has led to a reduction in breast cancer mortality. DHS&H noted that a recent analysis of the combined results of five randomised controlled trials in selected overseas countries have demonstrated a statistically significant reduction in mortality of about 30 per cent in the women aged 50-69 invited for screening.[302]

6.18 One witness noted, however, that it will prove difficult to demonstrate that the Program has been effective in Australia in terms of a reduction in mortality. The witness noted that the benefits of mammographic screening have to be measured by the difference in mortality between a screened population and a control group (that is, an unscreened population group). This cannot be done in Australia because it is not a population-based program in that there is no control population against which to compare the results in the group that has been screened. In Australia, there is the additional problem of extensive de facto screening in the existing health care system. Due to these factors, the witness noted that it will be difficult to obtain a clear answer to the question of whether mammographic screening has been beneficial or not.[303]

6.19 Overseas studies have shown benefits of up to 60 per cent in terms of reductions in mortality from screening programs. These studies have been carefully conducted population-based controlled trials. Populations were identified in several geographic areas and invited to attend for screening and the mortality in these populations was compared with the mortality from breast cancer over the same period of time in populations which had not been invited for screening. In the populations which had not been invited for screening, the incidence of de facto screening or other mammographic examination was also low.[304]

6.20 The Committee notes also that the morality of population-based controlled trials would need to be considered, in that the 'control' population would be denied access to the probable benefits of a screening program.

Future Funding

6.21 Evidence to the Committee indicated that continuity of funding is needed for

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[301] *Transcript of Evidence*, p.1118 (BreastScreen).

[302] Submission No.114, p.9.2 (DHS&H).

[303] *Transcript of Evidence*, p.1343 (RACS, Section of Breast Surgery).

[304] *ibid.*, pp.1343-4.

the Program's future development. For example, the Western Australian Health Department indicated that the joint funding agreement should be extended to at least June 1996 to allow for the full implementation of the Program in that State.[305] Prior to the announcement in the 1994-95 Budget, funding for the Program was guaranteed only until June 1994.

6.22 The Committee believes that on-going funding should be guaranteed so that the Program can be effectively implemented throughout Australia. In this regard, the Committee welcomes the announcement in the 1994-95 Budget of the Commonwealth's commitment of $236.6 million over the next five years to the on-going implementation and expansion of the Program.

Conclusions

6.23 The Committee recognises that any detailed and systematic attempt to assess the cost-effectiveness of the Program must necessarily be conducted over the longer-term, especially when the Program becomes fully operational. The Committee, however, considers that a detailed cost-benefit analysis of the Program should form part of any on-going evaluation of the Program as it is an important means by which the benefits of the Program, in a quantifiable way, can be demonstrated. The collection of uniform data by the States and Territories is also an important prerequisite in determining the Program's cost-effectiveness.

6.24 The Committee, however, notes that the cost-effectiveness of the Program in a purely economic sense is only one measure of the overall effectiveness of the Program. Even measures of economic cost-effectiveness involve subjective judgements and often the measures themselves may be open to question. Any attempt to assess the overall effectiveness of the Program must take into account factors other than purely economic ones, including the effect of the Program on mortality rates, community values and other non-quantifiable, quality-of-life issues.

Delivery of Services

6.25 The cost-effectiveness of the Program also needs to address the issue of whether services are being delivered in the most efficient manner. In the following sections issues relating to the mix of public/private services and the provision of a Medicare rebate are addressed.

Mix of Public and Private Services

6.26 Screening and assessment services may be located in either the private or public sectors. The SECU Report argued that these services could be established within either sector at the discretion of the States and Territories. The Report noted that the keys to obtaining optimal performance from a screening program are training, quality assurance and monitoring, accreditation and the funding mechanisms, not whether the service is located in the public or private sector. The

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[305] *Transcript of Evidence*, p.160 (Health Department of Western Australia).

report noted:

> Since no particular benefits arise from a screening program being located wholly in the public or private sectors, there is no reason to recommend that a screening program be located wholly either in the public or private sectors. The expertise and facilities which would be required by a screening program currently reside in both the public and private sectors and it is likely that a screening program would involve both sectors. Such an approach also has the advantage that it maximises the use of currently deployed resources.[306]

6.27 In line with the recommendations of the SECU Report, the Program has left the determination of the public/private mix of services to the individual States/Territories. Currently, screening and assessment services are located in both the public and private sectors in NSW, Victoria, Queensland, Western Australia and Tasmania, while they are wholly located in the public sector in South Australia and the Australian Capital Territory.[307] All States, however, utilise private sector practitioners in the provision of services.

6.28 The Accreditation Guidelines provide that screening and assessment services, located in either the public or private sectors, must meet the same accreditation guidelines in order for the Service to qualify for funding under the Program.[308]

6.29 The Committee received evidence during the inquiry of the cost advantages of permitting mammography services to be provided by existing private radiological practices. One submission argued that many of the facilities, including expensive mammography equipment, used by the Program are simply a duplication of private facilities that already exist throughout Australia.[309] It was argued that, to an extent, existing mammographic facilities are under-utilised at present. It was also argued that in urban areas especially, high quality private mammographic services already exist and many of these facilities are more conveniently located than the fixed centres established under the Program.[310] However, the submission did not address the problem of access to mammographic services in rural areas and the Committee believes that without the establishment of public services in these areas under the auspices of the National Program, screening services, would in all likelihood, be denied to women in these areas.

6.30 In Queensland, in particular, it was argued that there has been little attempt

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[306] SECU Report, *op. cit.*, p.87.

[307] Submission No. 114, p.6.3 (DHS&H).

[308] Accreditation Guidelines, *op. cit.*, p.3.

[309] *Transcript of Evidence*, pp.1331-2 (RACS, Section of Breast Surgery).

[310] *Transcript of Evidence*, p.1316 (RACS, Section of Breast Surgery).

to integrate and coordinate the services of existing private radiology practices with the Program in that State.[311] It was argued that the failure to involve these private sector facilities has significantly delayed the implementation of the Program in Queensland.[312] The Queensland Department of Health commenting on these assertions argued that they have undertaken negotiations with at least two private sector facilities with a view to involving them in the Program in Queensland.[313] The Committee was advised that a private radiology service in Cairns has been contracted to the Program as the fixed screening and assessment facility for the Peninsula and Torres Strait Regional Health Authority and commenced screening operations in March 1994. Plans are also well advanced for the Wesley Breast Clinic in Brisbane to provide screening as part of the Program.[314] The Committee was advised that the Wesley Hospital Board has approved the Hospital's participation in the Program.[315]

6.31 It was stated during the inquiry that several States, including New South Wales and Victoria, already successfully use a mix of facilities in the public and private sectors. The NSW Health Department[316] and the Tasmanian Breast Screening Service[317] both stated that a positive feature of the Program in their respective States has been the involvement of the private sector in both screening and assessment. In Tasmania, utilisation of the private sector for the provision of screening and assessment services has enabled the Service to increase the accessibility of the Service to women, while keeping establishment costs to a minimum.[318]

6.32 One witness emphasised that it was more important to ensure standards of quality essential to achieving the aims of the Program, irrespective of whether the service was provided in the public or private sector.[319]

> The performance standards relating to equipment, data collection and the expertise of the service providers have already been defined by the

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[311] *Transcript of Evidence*, p.1483 (RACR, Queensland Branch).

[312] *Transcript of Evidence*, p.1481 (RACR, Queensland Branch). See also *Transcript of Evidence*, p.1015 (Dr Noble).

[313] *Transcript of Evidence*, p.980 (Queensland Department of Health).

[314] Additional information from the Queensland Department of Health to the Committee, dated 25 February 1994, p.3.

[315] Advice to the Committee from the Queensland Department of Health, dated 16 May 1994.

[316] *Transcript of Evidence*, p.380 (New South Wales Health Department).

[317] *Transcript of Evidence*, p.1767 (Tasmanian Breast Screening Service).

[318] *ibid.*, p.1761.

[319] *Transcript of Evidence*, p.1048 (St Andrew's Breast Clinic, Brisbane).

> National Program. It would seem to be a reasonable proposal that any dedicated service, whether in the public or the private sector, should be able to be assessed by the multi-disciplinary panel already established for that purpose in each State.[320]

6.33 Evidence presented to the Committee suggested that the quality control of radiological services in private practice is equal to that of public screening and assessment units.[321] However, other evidence suggested that it may be difficult to ensure that the high standards of quality control demanded by the Program could be replicated in the private sector. One submission noted that private sector diagnostic and management quality is 'variable' whereas the Program offers an integrated, highly specialised and high quality diagnostic service.[322] Another submission noted that monitoring the quality of service and maintaining the necessary records poses great difficulties in private practice. The submission noted that many private practitioners are 'disinclined to operate according to, and to provide records for, programs imposed upon them'.[323] It was, however, noted that it is important to use the high standard of expertise that is currently available in the private sector.[324]

6.34 The Committee considers that screening and assessment services need not be wholly located in either the public or private sectors. The Committee believes, however, that all such services, whether they be in the private or public sectors, should meet the same stringent requirements for accreditation by the Program set down in the Accreditation Guidelines. The Program's aim should be to provide high-quality and accessible services throughout the country and where services are able to be provided by the private sector, such services should be part of the National Program. The Committee believes, however, that such services should not operate in competition with accredited services.

Recommendation

The Committee RECOMMENDS:

16. That the Program avoid any duplication in the provision of screening services, but that it utilise both the private and public sectors in the provision of screening services subject to all services meeting the guidelines for accreditation established by the National Program.

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[320] *ibid.*, p.1049.

[321] *Transcript of Evidence*, p.1341 (RACS, Section of Breast Surgery).

[322] *Transcript of Evidence*, p.785 (Dr Rickard). See also Submission No. 90, pp.3-4 (Dr Warren).

[323] Submission No. 25, p.4 (Anti-Cancer Council of Victoria).

[324] *Transcript of Evidence*, p.427 (New South Wales Health Department).

Medicare Rebate

6.35 Under the Program, funding of mammography screening and assessment is independent of the Medicare rebate system.[325] The SECU Report argued that funding screening mammography through the Medicare system would be a less effective means of ensuring a comprehensive, high quality and cost-effective national approach to the early detection of breast cancer. The Report noted, that while an administratively simple option, requiring only a minor change to the Medicare Benefits Schedule (MBS), it 'fails to effectively target the appropriate categories of women and has the potential to maximise costs'.[326]

6.36 Evidence presented to the Committee[327] suggested that the current arrangements are the most cost-effective means of providing a screening program. One witness noted that the effect of the Program being funded through the MBS fee-for-service would have serious cost and other implications:

> One can have a Medicare rebate for an individual process such as taking and reading film. One could conceive of a rebate for the entire process ... But one can see problems there, and one of the key issues in rebates would seem to me ... the incentives that operate in those fees. If one was to have a global fee for taking a woman, once she had fronted up for screening, all the way through the entire process, it is possible that that could lead to under-investigation ... just as a rebate for every individual step along the way has the potential to lead to over-investigation ... one has to look at the incentive effects of rebates and see what implications they have for the health of the people that are going through, for the likelihood that they are going to be investigated when they may or may not need it, and also for the cost to the public purse broadly.[328]

6.37 One submission provided data on the additional cost of introducing a fee-for-service approach to funding. The submission estimated that the additional cost of funding the Program via MBS would be $20 million per annum higher than using the current system. (It was estimated that the cost of the current arrangements is $68.6 million per annum, whereas funding under MBS would be $89 million per annum). There would also be additional financial costs imposed on women from the fee for service approach through the Medicare gap payment. Under

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[325] Medicare benefits are payable for diagnostic mammography for women who present to their doctor with symptoms or indications of malignancy in the breast, or with a family history of breast cancer. For rebate purposes, diagnostic mammography is required to be rendered by a specialist in diagnostic radiology and the patient is referred with a specific request for the procedure. See Submission No. 114, p.8.3 (DHS&H).

[326] SECU Report, *op. cit.*, p.78.

[327] *Transcript of Evidence*, p.693 (Dr Fett); p.168 (Health Department of Western Australia).

[328] *Transcript of Evidence*, pp.692-3 (Dr Fett).

this approach there is also likely to be a GP referral for the original visit, and then at least one, and possibly more for any further specialist investigations, significantly increasing the cost of the program.[329] The submission concluded that:

> Funding the program under fee for service is quite unlikely to improve outcomes for women, but is likely to substantially increase the cost of the program. We are concerned, therefore, that a move away from the program funding approach will compromise both efficiency and effectiveness of this significant national initiative.[330]

6.38 However, the cost-effectiveness of present arrangements was questioned by some witnesses. One witness argued:

> There have been doubts raised about the cost-effectiveness of both systems in various aspects of health care. ... If the Medicare system is effective for other diseases in a cost-effective sense, it could be cost-effective for this [program].[331]

6.39 The Committee notes, however that while the cervical cancer screening program, which is funded under Medicare, has been an effective screening tool for cervical cancer, it has not been cost-effective. A report analysing the Program found that there has been 'insufficient coverage of the target population resulting in significant under-screening of some subgroups of the population' and while cervical cancer screening has been a growth area in the health system 'much of the current effort is poorly directed and cost-inefficient'.[332]

6.40 It was also claimed that if the Medicare rebate system were available for screening mammography it would make the Program more accessible to increased numbers of women than is currently the case.[333]

6.41 Other witnesses, however, mentioned other advantages of retaining the present system. One witness, arguing that a Medicare rebate should not be available for screening mammography, noted that 'I do not think there is any other way to have quality control ... adequately done'.[334]

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[329] Submission No. 134, pp.2-6 (Monitoring and Evaluation Reference Group).

[330] *ibid.*, p.1.

[331] *Transcript of Evidence*, p.1304 (RACS, New South Wales State Committee).

[332] AIH, *Cervical Cancer Screening in Australia: Options for Change*, AGPS, Canberra, 1991, pp.3-4.

[333] *Transcript of Evidence*, p.1304 (RACS, New South Wales State Committee).

[334] *Transcript of Evidence*, p.538 (Australian Society of Breast Physicians).

6.42 It was noted that extending the Medicare rebate for screening would make quality control difficult, especially as it involves many more private providers of services. One witness raised the following scenario:

> How do you know that the accredited radiologist is reading films that day? His partner might be reading films that day, and so on. It is too difficult to police, and I think the quality control would be just about impossible. The only way to get volume through and for people to have experience is in a centre where there is very good quality control.[335]

6.43 One submission noted that funding through the MBS would lead to fragmentation of the screening/follow-up process between various providers and a tendency for unnecessary procedures; central elements of monitoring, evaluation, accreditation and limitation of numbers of services would be extremely difficult to manage; there would be no method for controlling charges to women with serious implications for access for women and for recruitment rates; and there would be difficulties associated with establishing and monitoring call and recall systems. The funding approach also has the potential for maximisation of procedures. This has cost implications and increases the number of invasive investigations to which women may be subject. The MBS fee-for-service approach also introduces a charge for women, which may discourage participation in the Program.[336]

6.44 Some witnesses considered that data collection would be compromised if Medicare rebates were introduced. One witness argued:

> If there are Medicare rebates introduced for the individual elements of the program, that greatly weakens the opportunity to collect those data. It also has the potential to significantly reduce the continuity of clinician involvement at every stage ... The spectre that the Medicare rebate raises is that there is a rebate for taking and reading a film and a rebate for assessment and a rebate for a biopsy and a rebate for treatment, and all of those different bits then become independent. They could be done by different people; the individual clinicians do not have a feel for the implications of their decisions at various points, and it becomes much more difficult to put the data together. It is not the best way to save women's lives for the money invested.[337]

6.45 Some witnesses,[338] however, suggested that it would be feasible to introduce a Medicare rebate system at accredited screening and assessment centres with appropriate quality control mechanisms in place. One witness noted that 'the

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[335] *ibid.*

[336] Submission No. 134, pp.3-4 (Monitoring and Evaluation Reference Group).

[337] *Transcript of Evidence*, p.691 (Dr Fett).

[338] *Transcript of Evidence*, p.1296 (RACS, New South Wales State Committee); p.794 (Dr Rickard).

bottom line is quality and ... how you pay for it is not really the big issue; it is how you are going to ensure that you can get quality as the outcome'.[339]

6.46 Concern is expressed during the inquiry by several witnesses that the Medicare system was being used for de facto or opportunistic screening by many women.[340] One witness expressed concerns about this practice in the following terms:

> There are a great number of women in Australia who are having mammograms, and although the Medicare benefit is designed for people with a specific range of problems there are a number of people without those problems who are having mammograms, and that is opportunistic screening. It is appropriate that screening be done with quality control ... There may not be very serious concerns about quality in most of the private and public practices that are involved in mammographic work, but there may be some and that is why quality control is appropriate. Opportunistic screening, without recording of details, allows us to have no idea of what the end result of the screening process might be.[341]

6.47 A representative of the Health Insurance Commission (HIC) advised the Committee that in relation to the extent of de facto mammography screening under Medicare the Commission had 'no hard data at all about the extent to which screening may be occurring under the Medicare program'.[342] However, data provided to the Committee by the Commission showed that the number of Medicare rebated mammography services showed some decrease in Queensland, South Australia and the Australian Capital Territory since 1990-91, although it increased in the other States.[343]

6.48 A representative of the Commission acknowledged that one factor involved could be that de facto screening decreased in those States and the ACT over the period as the screening program was being progressively implemented.[344]

6.49 The Committee believes that it is important that de facto screening not continue under Medicare. This would compromise the achievement of a high quality screening service as de facto screening is being provided without organised quality

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[339] *Transcript of Evidence*, p.794 (Dr Rickard).

[340] *Transcript of Evidence*, p.540 (Australian Society of Breast Physicians); p.1016 (Dr Noble).

[341] *Transcript of Evidence*, p.1298 (RACS, New South Wales State Committee).

[342] *Transcript of Evidence*, p.1422 (HIC).

[343] *ibid.*, pp.1410F,1415. There was, however, an increase in services in Queensland from 1991-92 to 1992-93.

[344] *ibid.*, p.1442.

control or specific targeting of the women most at risk. The Committee recognises that it is difficult for GPs not to provide mammography services where a woman requests a mammogram. The Committee believes, however, that more should be done to inform women about the difference between diagnostic and screening mammography.

6.50 The Committee also considers that GPs should be encouraged to provide those services only where it is necessary for adequate medical care of the patient concerned. The HIC advised the Committee that 'occasionally practitioners may apply a liberal interpretation to the item description [for mammography], particularly the 'symptoms or indications of malignancy found on examination of the patient' by a medical practitioner'.[345]

Conclusion

6.51 The Committee considers that on the basis of the evidence presented to it, funding for screening mammography needs to be provided independently of the MBS fee-for-service system.

6.52 The Committee believes that the present system provides a more cost-effective system than the alternative funding approach under Medicare. The current system also ensures a rigorous approach to quality control and data collection that would be difficult if screening and assessment services were provided on an ad hoc basis through individual providers. The Committee believes that a move away from the current funding approach would compromise both the efficiency and effectiveness of the Program.

Recommendation

The Committee RECOMMENDS:

17. That the funding of screening mammography under the Program continue to be independent of Medicare fee-for-service schedules.

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[345] *ibid.*, p.1410G.

CHAPTER 7

PROGRAM BOUNDARIES AND TREATMENT

7.1 This chapter discusses the issue of where the 'end-point' of the Program should be and, in particular, whether open surgical biopsy should be included as part of the screening program or not. The chapter also addresses, more generally, certain issues relating to the treatment of breast cancer, including the availability of treatment services and current treatment options. As noted in the Foreword, the House of Representatives Standing Committee on Community Affairs is currently conducting an inquiry into the management and treatment of breast cancer in Australia and will discuss the issue of treatment in more detail in its forthcoming report. In the concluding section of this chapter, issues relating to the funding of breast cancer research are discussed.

The Inclusion of Open Biopsy

7.2 There was considerable debate during the inquiry in relation to where the appropriate end point of the Program should be. This revolves around the question of whether open biopsy should be seen as an element in the screening process or whether it is essentially a component of the treatment regime.

7.3 Currently, the Commonwealth's policy is to include open biopsy as part of the Program. A representative of DHS&H explained the rationale for this in the following terms:

> That is consistent with our opinion that the intention of the Program is to provide a service which gives either a definitive diagnosis or a recommendation for a routine rescreen – in other words, that concludes with a definite end point.[346]

7.4 Some States such as Queensland, Western Australia, Tasmania and South Australia, have not included open biopsy in their programs. Where open biopsy is not included Commonwealth funding to the States in question is reduced (as this procedure will be paid for through Medicare arrangements).[347]

7.5 The SECU Report proposed that open biopsy be included in the Program. The Report argued that screening and assessment, including open biopsy, should be provided as integrated services to maximise the skills of medical practitioners involved in screening by providing them with feedback on the accuracy of their

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[346] *Transcript of Evidence*, p.1421 (DHS&H).

[347] *ibid.*, p.1427.

decision to intervene at each point on the screening pathway.[348]

7.6 Most professional groups were opposed to the inclusion of open biopsy in the Program. These groups argued that if a woman requires an open surgical biopsy, it is more appropriate that it be performed by a surgeon who is going to assume responsibility for the on-going surgical management of that woman.[349] One submission noted that the inclusion of open biopsy in the Program seems to be based on the false premise that there is a lack of expertise amongst surgeons to perform the procedure. The submission noted that while this may have been the case in the past it is no longer so.[350]

7.7 Another submission noted that if open biopsy remains as part of the Program, it will divert resources from the screening program proper. In addition, it was argued that maintaining open biopsy within the Program will prove a time-consuming and complex administrative burden as individual arrangements for payment will need to be made with a number of hospitals and surgeons, pathologists and radiologists for the surgery and the assessment of the tissue removed at open biopsy.[351] It was also put to the Committee that as treatment is not part of the Program it was inappropriate to include open biopsy, as this procedure is part of the 'treatment' regime.[352]

7.8 The Royal College of Pathologists of Australia (RCPA), taking a different view to the other major professional groups, argued that women should be given the option of undergoing open biopsy either within the Program or through their own doctor, outside the Program.[353] A witness representing the College noted, however, that open biopsy 'probably ... is better in the Program from our point of view, and probably from the patients' point of view'.[354] The College argued that open biopsy is an essential step in the overall management of the woman who attends a screening centre and therefore the woman should have access to such diagnostic procedures in the Program if she wishes.

7.9 Several witnesses noted that including open biopsy in the Program facilitates effective data collection and consistency in the reporting of that data.[355] One

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[348] SECU Report, *op. cit.*, p.46.

[349] *Transcript of Evidence*, p.1268 (Intercollegiate Committee); p.1294 (RACS, New South Wales State Committee).

[350] *Transcript of Evidence*, p.1321 (RACS, Section of Breast Surgery).

[351] *Transcript of Evidence*, p.1294 (RACS, New South Wales State Committee).

[352] *ibid.*, p.1293.

[353] *Transcript of Evidence*, p.1704 (RCPA).

[354] *ibid.*, p.1707.

[355] *Transcript of Evidence*, p.1728 (Pathology Reference Group); pp.1706-7 (RCPA).

witness noted that 'one of the advantages of having a central program like this where data is collected about women who have lesions is that you should be able to use that information and research into the pattern of [the] spread of breast cancer, the aetiology of breast cancer and the development of lesions from atypical to cancerous lesions'.[356] The College of Pathologists noted that if biopsy and other management is brought outside the Program it is essential that measures be introduced to ensure that information relating to biopsies for all patients, both within and outside the Program, is available to the Program for data management purposes.[357]

7.10 The Committee considers that open biopsy should be part of the treatment protocol and not be part of the screening Program. The Committee believes, however, that any decision regarding this matter should await any recommendations that the House of Representatives Standing Committee on Community Affairs inquiry into breast cancer treatment may make regarding this issue.

Recommendations

The Committee RECOMMENDS:

18. That open biopsy not be included as part of the screening Program.

19. That action to implement the above recommendation await any recommendations that the House of Representatives Standing Committee on Community Affairs, which is currently inquiring into the management and treatment of breast cancer in Australia, may propose in this area.

Treatment

7.11 Treatment is not part of the National Program; women diagnosed with breast cancer are given the choice of referral either to their own GP or to a specialist in breast cancer treatment. The outcomes of the screening program in terms of reduced morbidity and mortality will finally be dependent on access to a high quality screening Program.

Types of Treatment Available

7.12 The initial treatment of primary breast cancer invariably involves surgical intervention. However, there are now numerous options and combinations of treatment which involve surgery, radiotherapy, chemotherapy and hormonal therapy. The treatment of breast cancer is best considered from two aspects. The first is the treatment of the cancer in the breast and the second is the treatment of possible spread of the disease, either to the draining lymph nodes or elsewhere in the body.

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356. *Transcript of Evidence,* p. 1728 (Pathology Reference Group).

357. *Transcript of Evidence,* p.1705 (RCPA).

7.13 The selection of appropriate treatment for an individual woman with primary breast cancer is determined by the size and type of the tumour, the presence or absence of lymph node metastases, the age of the woman and the woman's preference when the various treatment options have been explained to her. The main treatments are described below.[358]

1. Surgery

7.14 Surgical excision is appropriate when the tumour is localised. In most cases, the suspicious area is removed and examined by a pathologist. If the tumour contains no malignant cells, no further treatment is needed. If the tumour contains malignant cells, the surgeon will either remove the breast or have the residual breast tissue irradiated. However, depending on the type and stage of the tumour, cancer will recur in a certain percentage of cases either adjacent to its original location or at some distant site. The tendency of cancer to metastasise (spread) before the parent tumour is diagnosed and removed constitutes a major problem in the management of the disease.[359]

2. Radiotherapy

7.15 The purpose of radiotherapy is to damage the genetic structure (DNA) of tumour cells to make them incapable of further growth and division. In radiotherapy, a beam of X-rays, gamma rays (from cobalt or radium) or electrons is aimed directly at the tumour from an X-ray machine, which is located at a specific distance from the body. Radiotherapy is often given in conjunction with another form of cancer treatment such as surgery or chemotherapy.[360]

3. Chemotherapy

7.16 Chemotherapy refers to the use of drugs or medications to treat the disease. The purpose of chemotherapy is to treat more advanced or metastatic cancer. It is also used as a cancer preventive by being used as an extra safeguard after surgical removal of a tumour (adjuvant chemotherapy) for cases with a high risk of recurrence. Chemotherapy is generally reserved for systemic or invasive cancers, cancers that are spread by the lymph or blood systems to many parts of the body, whereas surgery or radiotherapy is used to treat more localised cancers. Originally used only in cases in which surgery and radiotherapy were no longer effective, chemotherapy is increasingly given after surgical treatment or in conjunction with radiotherapy as an additional safeguard or preventive measure. Adjuvant chemotherapy is a program of additional chemotherapy administered to patients who have a high risk of recurrence of their cancer. It is given after basic treatment by surgery or radiotherapy with the aim of eliminating any undetectable microscopic

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[358] C. Furnival & J. Kearsley, 'Treatment of Primary Breast Cancer – Lessons from a Screening Program?', *Medical Journal of Australia*, vol.160, 16 May 1994, p.599.

[359] E.Rosenbaum, *Living with Cancer*, Mosby Press, New York, 1982, pp.60-61.

[360] *ibid.*, pp.61-3.

cells that may have travelled to other parts of the body.[361]

4. *Hormonal Therapy*

7.17 Many cancers, including breast cancer, are responsive to hormonal therapy, an attempt to reduce a tumour by administration of hormones, orally or by injection, or by the removal of organs that produce hormones. These hormones are given to reduce the body's production of, or to block the action of, specific hormones that promote the growth of cancer cells. Tumours of the breast, for example, have been controlled or significantly reduced by hormonal therapy.[362]

Treatment Options

7.18 Concern was expressed during the inquiry at the bias in Australia toward the use of radical (for example, mastectomy) rather than conservative surgery (for example lumpectomy and radiotherapy). A witness representing the RACR noted that the proportion of patients who had conservative surgery was relatively low compared with other countries.[363] The NSW Department of Health noted in its submission that data from cancer registries indicated a slow acceptance of conservative surgery as a means of treating breast cancer in Australia, with only 5 per cent and 22 per cent of patients undergoing breast conserving operations in 1978 and 1986 respectively. The submission indicated that survival rates for women undergoing conservative surgery are as good as for women undergoing radical surgery.[364] The end result for women undergoing these more conservative treatments is obviously beneficial in terms of psychological outcomes and in maintaining a woman's body integrity and body image.

7.19 Another witness noted that partial mastectomy and lumpectomy are relatively new treatments that are not necessarily being promoted as much as they could. It was also noted that both of these treatments offer as good a chance of survival as more radical treatments.[365]

7.20 A recent study found that there is now more of an acceptance of conservative surgery for primary breast cancer, although the mastectomy rate was still relatively high. The study, based on the surgical management of women with screen-detected breast cancer from the Central Sydney Breast Screening Programme, found that almost 60 per cent of breast cancers detected were treated by some form of mastectomy. This showed a decline since the 1980s, when more than 70 per cent of Australian women with primary breast cancer were being treated by mastectomy.

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[361] *ibid.*, pp.63-6.

[362] *ibid.*, p.66.

[363] *Transcript of Evidence*, p.1576 (RACR).

[364] *Transcript of Evidence*, p.385 (New South Wales Health Department).

[365] *Transcript of Evidence*, p.471 (RHW).

However, the Australian figures are still high by international standards. For example, a recent review of treatment in South-East England showed that, in the screening age group, fewer than 25 per cent of primary breast cancers are now treated by mastectomy because of earlier detection of breast cancer by mammography and an appreciation of the relative merits of lumpectomy and removal of lymph nodes.[366]

7.21 It was stated during the inquiry that the breast screening program has resulted in an increase in the diagnosis of small invasive cancers of the breast and also an increase in a newly detected disease – non-invasive or DCIS (ductal carcinoma in-situ). The current standard best treatment practice for both is conservative surgery followed by radiation therapy. The RACR argued that due to the increase in the number of patients with early invasive and non-invasive cancers and with increasing knowledge of treatment options, women will be more likely to request conservative surgery and radiotherapy rather than total mastectomy.[367]

7.22 Several witnesses noted that it was essential to ensure that adequate radiation oncology services are available for these women. As noted in Paragraph 7.51, there is a maldistribution of such facilities throughout Australia at present. As noted in several submissions, the lack of adequate accessible facilities may mean that women with an early breast cancer discovered by the screening program may, of necessity, be subject to an inferior treatment option, that is, either total mastectomy or local excision without radiation therapy (with the subsequent likelihood of further treatment by mastectomy).[368]

7.23 The Committee received evidence that the problem of access to radiation oncology services may be particularly difficult for women in rural areas. Often women in rural areas opt for radical surgery, such as mastectomy, rather than conservative surgery, which necessitates a 4 to 6 week course of radiotherapy in a major centre, usually a capital city. One witness noted the 'very horrendous dislocation of family life' that this situation often entails.[369]

7.24 Another submission noted that many women in rural areas may not be able to afford such a long stay in a capital city.[370] It was noted that in New South Wales, for example, the travel assistance scheme fails to adequately compensate women for the financial cost of transport and accommodation for those receiving treatment in the major cities.[371] The RACR suggested that this financial disincentive is one of the

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[366] Furnival & Kearsley, *op. cit.*, p.600.

[367] *Transcript of Evidence*, pp.1562-63 (RACR).

[368] *ibid*, p.1563.

[369] *Transcript of Evidence*, p.759 (RACS, Divisional Group of Rural Surgeons).

[370] *Transcript of Evidence*, p.1565 (RACR).

[371] For a discussion of financial assistance schemes for travel and accommodation costs in the States/Territories, see Paragraphs 3.16-3.22.

reasons for the low referral rate of cancer patients from country areas for radiotherapy treatment in the major centres.[372]

7.25 The RACR noted, for example, that in New South Wales in 1990-91, whereas 35.6 per cent of new cancer patients in metropolitan areas were treated by radiotherapy, the corresponding figure for non-metropolitan areas was only 19.2 per cent.[373] The Committee believes that the lack of access to radiotherapy and chemotherapy services for women in rural areas needs to be addressed and discusses this issue further at Paragraphs 7.39-7.54.

Access to Information

7.26 The Committee was also told that women are not always sufficiently informed about the types of treatment options available and the relative survival rates of these different types of treatment.[374] Another disincentive for the treatment by lumpectomy and irradiation is the fact that preservation of the breast necessitates annual mammography and continual concern about local recurrence. It is acknowledged that 10 per cent of patients treated by conservative measures will subsequently need mastectomy.

7.27 Several submissions stated that more needs to be done to encourage participation by women in treatment decisions. One submission cited studies that showed women benefit from active participation in, and discussion of, their treatment options. The submission suggested that more information in easily readable, written form and in non-medical 'jargon' needs to be provided to patients and their families so that an informed decision regarding treatment options can be made. One submission noted that women should be actively encouraged to seek a second opinion regarding treatment options, by both the referring doctor and the surgeon/oncologist giving the first specialist opinion.[375]

7.28 The Committee believes that women need to be better informed about the various treatments currently available and also need to be encouraged to participate in decision-making about the treatment options available to them.

Recommendation

The Committee RECOMMENDS:

20. That more information be provided to women diagnosed with breast cancer on the various treatment options available to them; and that women be encouraged to participate in decisions regarding appropriate courses of treatment.

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[372] *Transcript of Evidence*, p.1565 (RACR).

[373] *ibid.*, p.1568.

[374] *Transcript of Evidence*, p.471 (RHW).

[375] Submission No.56, pp.9-11 (Ms O'Keefe).

Appropriate Treatment Services

7.29 At present, treatment services for breast cancer patients are provided through the public hospital system or through private referral to individual surgeons. Many public hospitals, especially in the capital cities and provincial centres have specialised units within their surgical services and women attending such hospitals are treated through a breast unit ensuring that surgeons experienced in breast disease supervise their treatment and work in conjunction with radiation and medical oncologists.[376]

1. A Multidisciplinary Approach

7.30 Several witnesses argued that the treatment of breast cancer is best managed by multidisciplinary teams. Multidisciplinary treatment provides the opportunity for better sharing of knowledge and education for medical practitioners and also better back-up and support for patients. One witness, emphasising the importance of the multidisciplinary approach, argued that because the treatment of breast cancer is so complex and is becoming more complex and demanding and because of a lack of suitably qualified practitioners, it is important to identify first class multidisciplinary teams so that optimal care is available to all patients.[377] One witness noted that at present there are between 8 and 12 multidisciplinary teams operating in Australia offering 'world class' care for breast cancer patients.[378]

7.31 However, it was noted that multidisciplinary teams are rarely available outside teaching hospitals, which are concentrated in the major cities. The problem of providing access to women in regional and rural areas was raised during the inquiry. One witness suggested that formal links should be established between various screening centres in rural/regional areas and treatment centres in capital cities so that information on patients could be exchanged between the centres.[379] Information on patients could also be sent by fax or phone to breast cancer treatment units in the major cities using the latest telemedicine technology and treatment protocols could be advised to the treating surgeon in rural areas.[380]

2. Dedicated Breast Cancer Units

7.32 Several submissions argued that dedicated, state-of-the-art, breast cancer units need to be established.[381] One witness noted that many current treatment

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[376] *Transcript of Evidence*, p.847 (Wesley Breast Clinic, Brisbane).

[377] *Transcript of Evidence*, p.728 (Professor Forbes).

[378] *ibid.*, p.729.

[379] *Transcript of Evidence*, p.775 (Dr Renwick).

[380] *ibid.*, p.775.

[381] *Transcript of Evidence*, p.449 (RHW); p.770 (Dr Renwick).

facilities have not been upgraded to state-of-the-art facilities which are needed for the effective treatment of the disease.[382]

7.33 Another submission noted the urgent need to establish comprehensive multidisciplinary and holistic care for women with breast cancer in dedicated treatment centres.[383] The submission noted that while the Program is likely to lead to the earlier detection of breast cancer leading to earlier treatment intervention and improved survival for women, there has not been a parallel development in providing facilities for the optimal treatment of the disease.[384] The Committee notes, however, that these dedicated treatment centres only provide services during normal working hours. There is, in addition, no evidence to suggest that the treatment outcomes for patients from these centres is better than that provided by other treatment services.

7.34 Several submissions outlined the types of services that should be offered in these specialised breast cancer units. For example, one submission argued that dedicated breast cancer clinics should provide multidisciplinary access to surgical, radiation and medical oncologists, as well as reconstruction surgery, pain therapists and palliative care experts. Dedicated counselling and other allied health staff and support services also need to be provided. The centres should also provide a focus for the education and training of health professionals and should also work to establish protocols for the care of women with breast cancer. The comprehensive care of these patients should ensure that they receive both multidisciplinary medical care and follow-up appropriate psychological assessment, counselling and support.[385]

7.35 The Committee considers, however, that the establishment of centres of excellence specialising in the treatment of all cancers may be more effective than the establishment of centres specialising only in the treatment of breast cancer. Other evidence to the Committee also questioned the efficacy of establishing specialised units solely for breast cancer treatment. One witness suggested that most breast surgery can be effectively performed by most specialist general surgeons, with the more complex cases referred to specialists in the area, as already occurs.[386]

7.36 One witness noted that:

> If we convert breast cancer treatment to something that can only be done in a small number of teaching hospital centres, you will find that the standard of care of people who do not have breast cancer but have breast problems, will be reduced, because there will be fewer people

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382. *Transcript of Evidence*, p.772 (Dr Renwick).

383. *Transcript of Evidence*, p.462 (RHW).

384. *ibid.*, p.448.

385. *ibid.*, pp.463-5.

386. *Transcript of Evidence*, p.1302 (RACS, New South Wales State Committee).

> who will understand the surgical management of benign conditions as well as the malignant conditions of the breast.[387]

7.37 Another witness argued that current treatment services are by no means inadequate and that the treatment for screen-detected breast cancer falls within the ambit of traditional medical practice.[388] It has also been noted that because of the high cost of establishing these specialised centres more information is needed about the outcomes and benefits of this approach to treatment.[389]

7.38 The Committee believes that the optimal care of women with breast cancer depends on the establishment of comprehensive, multidisciplinary services. The Committee considers that the establishment of clinics specialising in the treatment of all cancers, including breast cancer, should be encouraged so that effective treatment options for women can be maximised. As noted in Paragraph 7.31, the Committee believes that linkages between screening centres in rural and regional areas and treatment centres in the major centres should be encouraged so that information transfer regarding effective treatments can be facilitated.

Radiotherapy Services

7.39 The Committee received some evidence during the inquiry that there is a shortage of radiotherapy services in Australia.

7.40 The Australian Institute of Radiography noted that the screening program, by providing for the earlier detection of breast malignancies, has resulted in an increased demand for radiotherapy services. This demand 'places pressure on already overloaded radiotherapy treatment services, especially when current long waiting lists are taken into account'.[390] One witness noted that the waiting lists for radiotherapy are substantial in most States, except Victoria.[391]

7.41 The RACR suggested that at least 10,000 newly diagnosed cancer patients do not receive radiotherapy each year due to a shortage of radiation oncology services.[392]

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[387] *ibid.*, p.1303.

[388] *Transcript of Evidence*, p.848 (Wesley Breast Clinic, Brisbane).

[389] National Health Goals and Targets Implementation Working Group on Cancers, *National Goals, Targets, and Strategies for Cancer Control*, February 1994, p.22.

[390] *Transcript of Evidence*, pp.1225-6 (AIR).

[391] *Transcript of Evidence*, p.1108 (Anti-Cancer Council of Victoria).

[392] *Transcript of Evidence*, p.1575 (RACR).

1. Radiation Oncologists

7.42 The need for radiation oncology services was examined in 1989 by a working group of AHMAC, which proposed the immediate provision of 21 new training posts to address the under-supply of radiation oncologists. The report recommended that there should be at least 130 radiation oncologists positions in Australia by 1995.

7.43 In addition, the Report of the Medical Workforce Data Review Committee (MWDRC) confirmed that there was a shortage of radiation oncologists, and an undersupply of funded training positions in this speciality.[393]

7.44 The MWDRC report concluded that there should be an increase of 14 in the number of training posts for this speciality, in order to increase the total number of training posts to 58. This would allow a minimum planning target of 7.5 radiation oncologists per million of the population to be achieved by 1997. The report recommended that the issue of productivity amongst radiation oncologists be addressed by reducing the average training period from seven to five years.[394]

7.45 DHS&H advised the Committee that there are 90 radiation oncologists in current positions and 44 training posts, of which 39 were filled as at 1 February 1994.[395]

7.46 The MWDRC report noted that the recommended number of 130 radiation oncologists by 1995 would not be achieved unless there was an increase in productivity of training posts, or an increase in the number of training posts, or both.[396]

7.47 MWDRC has also recommended that the academic infrastructure for this specialty be strengthened, by increased research and involvement in undergraduate medical research. There is at present no properly funded and supported Chair of Radiation Oncology in Australia. This is despite the fact that most radiation oncologist centres are situated in or near teaching hospitals at universities around Australia.

7.48 DHS&H noted that radiation oncologists are part of a wider group of oncologists, which includes medical oncologists and surgeons, and supply and demand issues for each of these three specialties will be necessarily interlinked. Training requirements for the oncology workforce may in future need to incorporate elements from each of these specialties, and the MWDRC has recommended that

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[393] Medical Workforce Data Review Committee, *Annual Report 1993*, AGPS, Canberra 1993, p.12.

[394] *ibid.*, pp.12,29-37.

[395] Additional information from DHS&H to the Committee, dated 18 February 1994, p.2.

[396] Medical Workforce Data Review Committee, *op. cit.*, pp.32-3.

AHMAC seek assistance from the Committee of Presidents of Medical Colleges in addressing this issue.

2. Radiation Oncology Facilities

7.49 DHS&H advised the Committee that there are 29 radiation oncology facilities currently in Australia (21 in the public sector and 8 in the private sector).[397]

7.50 The 1989 report of AHMAC[398] on radiation oncology services recommended that Australia requires one radiation oncology centre per million of population. DHS&H noted that on current population figures, Australia requires 35 units as against the number at present (29). The distribution by State/Territory of radiation oncology facilities is shown in Table 2.

TABLE 2 – DISTRIBUTION OF PUBLIC AND PRIVATE RADIATION ONCOLOGY FACILITIES IN AUSTRALIA

State	No. of Facilities	Location
NSW	11	Sydney (9), Newcastle (1), Wollongong (1)
VIC	7	Melbourne (7)
QLD	3	Brisbane (3)
SA	2	Adelaide (2)
WA	3	Perth (3)
TAS	2	Hobart (1), Launceston (1)
ACT	1	Woden (1)
TOTAL	29	

Source: Additional information from DHS&H to the Committee, dated 18 February 1994, Attachment 2.

7.51 The table shows that the facilities are largely located in the major capital cities, with few facilities outside these major population centres. As noted in Paragraphs 7.23-7.25, the concentration of radiotherapy facilities largely in the major capitals may discourage women from country areas from opting for radiotherapy treatment because of the dislocation to family life of a 4 to 6 week course of radiotherapy at these centres and the considerable financial burden that this may impose.

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[397] Additional information from DHS&H to the Committee, dated 18 February 1994, Attachment 2.

[398] Report cited in *ibid.*

7.52 However, DHS&H noted that, while it may be convenient for patients if radiotherapy centres were located outside the major urban centres, evidence suggests that for a radiotherapy facility to operate effectively and efficiently it is necessary to have suitably qualified staff, sufficient population in the catchment area and adequate specialist support for diagnosis and management of patients and these conditions are often difficult to meet in areas outside the major population centres.[399]

7.53 The Committee believes that it is essential that adequate radiotherapy services be available to all women with breast cancer and that the supply of, and demand for, such services should be regularly monitored. The Committee believes that this monitoring role should be undertaken by the National Breast Cancer Centre, which is to be established independently of the NHMRC.[400]

7.54 The Committee considers that radiotherapy facilities need to be provided in major provincial centres to allow women who live outside the metropolitan areas to obtain equitable access to these services. The Committee also believes that it may be necessary to review the level of assistance provided by the various State and Territory travel and accommodation assistance schemes so that a more adequate level of financial assistance to patients is provided.

Recommendations

The Committee RECOMMENDS:

21. That the supply of radiotherapy services be regularly monitored by the National Breast Cancer Centre.

22. That the geographical distribution of radiotherapy facilities be improved so that women living in areas outside the major metropolitan centres can obtain equitable access to these services.

23. That the Commonwealth Government, in co-operation with the State/Territory Governments, improve the level of travel and accommodation assistance available to women living in areas outside the major metropolitan centres requiring radiotherapy treatment.

Role of Specialist Surgeons

7.55 Currently patients with breast cancer may be treated by general surgeons or surgeons specialising in the area of breast disease. One submission noted that there is a need for surgeons to specialise in breast surgery as it is difficult for a surgeon

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[399] Additional information from DHS&H to the Committee, dated 18 February 1994, Attachment 2.

[400] See also Paragraph 7.72.

who occasionally treats breast cancer patients to be expected to maintain the same interest and knowledge necessary to manage women effectively with this disease.[401]

7.56 Another submission noted that in Victoria, of the 200 surgeons treating women with primary operable breast cancer, some 60 percent treat between one and four cases per year. The submission questioned whether the surgeons involved would be sufficiently skilled at breast surgery with 'so little practice'.[402]

7.57 Another submission noted that the system whereby women are referred to individual surgeons in private practice does carry with it potential problems, especially in relation to the expertise of the surgeon concerned.[403]

7.58 However, several submissions noted that the various training programs for the management of breast cancer at the post-fellowship level by the RACS (and seminars conducted by the College) has led to a marked improvement in the expertise of surgeons, especially in recent years. One submission noted that the College has also recognised the problem by further reviewing the credentials of surgeons seeking appointments at breast units.[404]

7.59 Another submission also noted that there has been more of an acceptance by GPs of the need for surgeons treating women with breast cancer to have demonstrated a special interest in breast disease and this should lead to better provision of treatment for women with screen-detected breast cancer than in the past.[405] The Committee believes that adequate information needs to be provided to GPs so that they are in a position to refer patients to surgeons best qualified in the area of breast disease. The Committee also considers that the screening program has an educative role to play in providing information to GPs in this area.[406]

7.60 Some evidence to the Committee suggested that surgeons treating breast cancer patients should specialise in breast surgery. One submission argued that surgeons wishing to treat breast cancer patients should be required to treat a minimum number of women per year; attend professional seminars, etc., to ensure that their knowledge of breast cancer was up-to-date; and demonstrate that they have close links, and regularly consult with, their colleagues in other disciplines (such as pathologists, radiotherapists and oncologists). It was suggested that implementation of these guidelines should be the responsibility of the College of

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[401] *Transcript of Evidence*, p.386 (New South Wales Health Department).

[402] Submission No.56, p.12 (Ms O'Keefe).

[403] *Transcript of Evidence*, p.848 (Wesley Breast Clinic, Brisbane).

[404] *Transcript of Evidence*, p.386 (New South Wales Health Department).

[405] *Transcript of Evidence*, p.848 (Wesley Breast Clinic, Brisbane).

[406] See also Chapter 5 for a discussion of the role of GPs.

Surgeons.

7.61 Other evidence to the Committee suggested that the establishment of dedicated breast cancer centres would provide a focus for the education and training of health professionals. It was also suggested that surgeons associated with these centres would have the opportunity to gain the necessary expertise in treating breast cancer patients, especially as they provide a comprehensive and multidisciplinary approach to breast cancer treatment.[407]

7.62 The Committee believes that there is a need to foster the development of specialist surgeons in the area of breast cancer treatment. The Committee considers that a multidisciplinary approach whereby surgeons work closely with their colleagues in radiation and medical oncology offers the opportunity for high quality care for women with breast cancer.

Cancer Registries

7.63 Evidence to the Committee suggested that hospital-based cancer registries need to be established.[408] The Committee was told that few, if any, hospitals in Australia have cancer registries which contain information on the number and status of patients with cancer treated at the institution. In the absence of hospital-based registries or data on outcomes in clinically relevant groupings from a central registry, a doctor's notes may be the only record of the precise treatment given to a cancer patient. The establishment of these registries is needed so that data relating to treatment outcomes can be assessed so that the efficiency of cancer care delivery can be measured.[409]

7.64 Several witnesses also suggested that these hospital-based registries should be linked to a central registry. One witness suggested that regional cancer registries linked to a central State registry should be established. An agreed set of minimum data would be provided to the State registry with the regional registry collecting 'complete data but localised and in more detail'.[410] Another witness suggested that hospital-based registries could be linked with cancer registries established for each area health service.[411]

7.65 The Committee believes that priority should be given to establishing hospital-based cancer registries to work in conjunction with State/Territory central cancer registries. These registries should collect information on clinical characteristics,

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[407] *Transcript of Evidence*, pp.464,469 (RHW).

[408] *Transcript of Evidence*, p.99 (Dr Roder); Submission No.54, p.3 (NSW State Cancer Council); Submission No.52, p.3 (Professor Tattersall).

[409] Submission No.52,p.3 (Professor Tattersall).

[410] *Transcript of Evidence*, p.741 (Professor Forbes).

[411] *Transcript of Evidence*, p.741 (Dr Boyages).

treatment, and outcomes so that a system of monitoring the outcomes of cancer treatment can be established. With the introduction of Casemix funding, data in relation to all forms of cancer will be collected in each hospital and this will provide the nucleus of a hospital-based cancer registry.

Recommendation

The Committee RECOMMENDS:

24. That hospital-based cancer registries be established as a matter of priority.

7.66 The Committee also received evidence that there is a need for improvements in the collection of national cancer statistics. National statistics on cancers are reliant on State and Territory cancer registries supplying the relevant data, and evidence suggests that many States and Territories are several years behind in their data processing of these statistics. It has been noted that some of the registries are not well resourced and this affects their capacity to process the large number of cancer notifications. Consequently, a national picture on the incidence of breast and other cancers is difficult to determine. Delays in processing data also affect policy development, health services management, and the charting of emerging incidence trends.[412]

7.67 It has also been noted that there are inconsistencies and gaps in the recording of cancer registry data, especially in relation to data pertaining to race and country of birth. There are also inconsistent practices for the collection of data relating to in situ tumours amongst State and Territory cancer registries.[413]

7.68 DHS&H advised the Committee that all States and Territories have now agreed to provide data on the incidence of breast cancer (and other cancers) to the Australian Institute of Health and Welfare (AIHW). However, the Department noted that despite approaches to the States and Territories over a number of years and representations made through the Australasian Association of Cancer Registries the latest data provided to the AIHW by each State and Territory is often several years out of date. Currently the AIHW has collected data on cancers for all States and Territories for the period 1982 - 1990, except in the case of the Northern Territory where data has not yet been provided to the AIHW for 1990. In the case of South Australia data has been provided to the AIHW for 1991 and 1992.[414]

7.69 The Committee believes that it is important that up-to-date national data on breast cancer and other cancers be available. To this end the Committee considers that improvements need to be made in the collection of such data by the States and

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[412] National Health Goals Working Group, *op. cit.*, p.27.

[413] *ibid.*, p.28.

[414] *ibid.*, p.29. Letter from DHS&H to the Committee, dated 22 April 1994.

Territories. The Committee also believes that the data collected by the States and Territories needs to be provided to the Commonwealth Government on a much more timely basis than has occurred in the past.

Recommendation

The Committee RECOMMENDS:

25. That statistics collected by State and Territory cancer registries be collected on a more uniform and consistent basis and that data on cancers generally be provided to the Commonwealth Government on a timely and regular basis to ensure that current national statistics on the incidence of cancers are readily available.

Treatment Protocols

7.70 With cancer being managed by many individual practitioners as well as by multidisciplinary teams there is a wide diversity in the treatment given for the same type of cancer at the same stage of progression. Equally there is little information available to patients about options to guide their thinking about different treatment options. At present, Australia lacks agreed guidelines for the treatment of any cancer, although the Committee understands that Guidelines for the Treatment of Breast Cancer are currently being prepared by NHMRC and that national guidelines for the clinical management of breast cancer will be developed by 1995.[415]

7.71 Several witnesses pointed to the need for the establishment of effective breast cancer treatment protocols.[416] One witness suggested that there should be a network of breast cancer treatment centres established throughout Australia which would formulate treatment protocols and review them on a regular basis.[417]

7.72 The Committee notes the New South Wales Government recently announced a proposal to establish a breast cancer institute. The institute aims to disseminate information on best practice and conduct research into breast cancer treatment options. The Committee also notes the recent Government initiative to establish a National Breast Cancer Centre (with funding of $16.4 million to be provided over four years). This Centre will analyse research, provide a clearing house on best practice, develop treatment and management protocols as well as provide accessible information to doctors and patients on breast cancer-related issues.[418] The Committee welcomes these initiatives as important initial steps in facilitating improvements in the available treatment for breast cancer patients.

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[415] National Health Goals Working Group, *op. cit.*, pp.23,50.

[416] *Transcript of Evidence*, p.771 (Dr Renwick).

[417] *ibid.*

[418] Portfolio Budget Measures Statements 1994-95, Human Sciences and Health Portfolio, p.35.

Research

7.73 Many contributors to the inquiry argued that there should be substantially more funding for research into breast cancer.[419] One witness told the Committee that funding into breast cancer research in Australia is 'hopelessly underfunded'.[420] Professor Forbes argued that an extra $50 million needed to be spent annually on breast cancer research.[421] Another witness described the current 'token' funding allocated to breast cancer research as an 'outrageous insult to the women of Australia'.[422]

7.74 In 1993-94, $1.4 million was allocated by the Commonwealth Government through the NHMRC for research into breast cancer, and an additional $300,000 was allocated to the NHMRC clinical trials centre. Of the $1.4 million, some $750,000 was allocated to the Garvan Institute of Medical Research. One witness suggested that a comparable amount was collectively spent on breast cancer research from State Cancer Councils and similar bodies.[423] Other research monies are also spent on different types of breast cancer research from time to time, but this is done in an *ad hoc* manner. Private industry also supports some research into breast cancer.[424]

7.75 The Committee notes that in 1994 some $14.9 million will be allocated by the NHMRC for cancer research generally in Australia. The Committee believes that this research effort into cancers generally will provide indirect benefits for the research currently undertaken into breast cancer in Australia and complement that research effort.

7.76 In the 1994-95 Budget, funding for health and medical research overall received a funding increase of $92.8 million to be provided over four years from 1944-95 to 1997-98. This funding increase will allow the NHMRC to allocate $119.6 million for medical research in 1995, compared with $110.5 million for 1994. While funding for breast cancer research was not given a specific allocation in the Budget, the Government announced that breast cancer will be identified as a 'special initiative' area for NHMRC project funding. This means that applications for research into breast cancer that meet the specific funding criteria will be given high

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[419] *Transcript of Evidence*, p.733 (Professor Forbes); p.795 (Dr Rickard).

[420] *Transcript of Evidence*, p.733 (Professor Forbes).

[421] *Sydney Morning Herald*, 25 March 1994.

[422] *Transcript of Evidence*, p.318 (Hancock Family Breast Cancer Foundation).

[423] *Transcript of Evidence*, p.733 (Professor Forbes); advice from the NHMRC to the Committee, 30 May 1994.

[424] *Transcript of Evidence*, p.733 (Professor Forbes).

priority.[425]

7.77 The Government also announced that it would provide assistance for the establishment of a non-Government Breast Cancer Fundraising Foundation. The Commonwealth will contribute $1 million for each of the next three years to assist in the Foundation's establishment. In addition, the Commonwealth will match any donations to the Foundation from the public, dollar for dollar, up to maximum of $1 million for three years. The Foundation will act as a central co-ordinating body to attract corporate and private donations for basic and applied research into breast cancer.[426]

1. Areas of Research

7.78 During the inquiry several areas were identified as requiring further research. For example, some witnesses argued that more research is needed in the area of breast cancer screening.[427] One witness noted that more research is required in this area to determine if the quality of mammography could be improved, if there are newer methods, similar to mammography that could be successfully introduced, if there are serum tests that could be introduced and if newer and more effective methods of detection could be devised.[428]

7.79 Another witness claimed that at present research into the area of screening is largely confined to behavioural science issues (for example, the impact of counselling on patients' well-being) and economic issues (for example, issues relating to the cost of screening and treatment).[429]

7.80 The importance of conducting research into screening was underlined by one witness who stated:

> With screening ... I have heard of uncertainties being expressed about many issues. I do not want to come back to this comparable Committee in five years time and hear exactly the same uncertainties considered. We do not wish to screen the same way in five, or certainly 10 years time as we are doing now.[430]

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[425] Summary: Budget 94-95 – Human Services & Health. NHMRC advises the Commonwealth Government on the funding of medical and health research in Australia.

[426] Portfolio Budget Statements, *op. cit.*, p.35.

[427] *Transcript of Evidence*, p.731 (Professor Forbes); p.558 (Dr Fett).

[428] *Transcript of Evidence*, p.1208 (Professor McKenzie).

[429] *Transcript of Evidence*, pp.557-8 (Dr Fett).

[430] *Transcript of Evidence*, pp.731-2 (Professor Forbes).

7.81 Evidence also suggested that research into treatment needed to be given high priority. One witness noted that research is needed in the health services area – for example, how best to establish breast cancer treatment centres and how to measure the impact that they have on breast cancer mortality; how to increase the level of specialisation in the treatment of breast cancer; how to enrol more women with breast cancer into breast cancer treatment trials; and how to maximise the application of what is known about how to treat breast cancer into the treatment by individual doctors.[431]

7.82 The Committee believes that the funding for research into the diagnosis and treatment of breast cancer has been inadequate in the past. The Committee commends the Commonwealth Government for its recent initiatives in the area of funding for breast cancer research announced in the 1994-95 Budget. The Committee also believes that funding for breast cancer research needs to be guaranteed over the longer-term to ensure some continuity of the research effort and to facilitate the development of a body of research expertise in this country. The Committee also considers that these research funds should only go to projects demonstrating the highest scientific merit.

Recommendation

The Committee RECOMMENDS:

26. That recognising the fundamental importance of research into the diagnosis and treatment of breast cancer, that the Commonwealth Government provide a specific allocation for research into breast cancer in future Commonwealth Budgets.

2. *Clinical Trials*

7.83 A number of witnesses argued that there should be more government funding for controlled clinical trials into breast cancer.[432] Controlled clinical trials provide a method of assessing the results of different types of treatment by allotting patients in a randomised way to one group that receives a particular treatment and to another group that acts as a 'control' group. The results of the trial are then compared. Clinical trials provide an important means of evaluating new therapeutic methods and provide the scientific basis for the development of options in situations where there is some uncertainty about effective methods of treatment.

7.84 However, only a small proportion of women with breast cancer enter into clinical trials. One witness estimated that it may be as low as five per cent in Australia.[433] Professor Forbes advised the Committee that a much higher

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[431] *Transcript of Evidence*, p.695 (Dr Fett).

[432] *Transcript of Evidence*, p.1576 (RACR); p.1107 (Professor Lovell).

[433] *Transcript of Evidence*, p.572 (Dr Fett).

proportion of women need to be enrolled in clinical trials. The more women that are enrolled in these trials the more quickly results regarding different treatments can be obtained. Professor Forbes also noted that in Denmark, for example, 90 per cent of eligible women with breast cancer are entered into clinical trials. In the Scandinavian countries it the 'norm' for women to be enrolled in clinical trials. He also noted that it is essential that all eligible women who wish to, should be enrolled in clinical trials in this country. [434]

7.85 In appropriate cases where a relevant trial protocol is available, the recruitment of women would assist the development of more effective treatment schedules. Clinical trials in Australia are currently strictly controlled by DHS&H, by the ethics committees of individual institutions, and by the Guidelines on Human Experimentation which have been established by the NHMRC. For people who are considering participation in a clinical trial, an assurance must be given that a framework has been established to ensure ethical conduct in relation to all aspects of the clinical trial.[435]

7.86 The RACR stated that clinical trials in Australia to date have only looked at chemo-hormonal therapy of breast cancer and no trials have addressed the role of either surgery or radiotherapy in breast cancer management. The trials conducted to date have been financed almost entirely by pharmaceutical companies. The RACR argued that this caused 'some doubts about the propriety of the trials [and] ... the relevance of those trials for the management of breast cancer'.[436] The RACR stated that in view of the impact of breast cancer on the lives of women and their families, and the diversity of approaches adopted by prominent individual oncologists and oncology institutes, there is a need for further exploration of the management of breast cancer by other than chemo-hormonal therapy.

7.87 The RACR stated that advances in this area can only be achieved with financial support from Government for clinical trials in the multidisciplinary management of breast cancer and this will necessarily involve investigating the roles of radiotherapy and surgery in management. The RACR concluded that the lack of funding for clinical trials is exposing women to breast cancer management protocols 'which many believe are inappropriate and need urgent revision'.[437]

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434. Advice from Professor Forbes, 27 May 1994.

435. National Health Goals Working Group, *op. cit.*, p.27.

436. *Transcript of Evidence*, p.1576 (RACR).

437. *ibid.*, p.1567.

Recommendation

The Committee RECOMMENDS:

27. That the Commonwealth Government provide additional funding for the conduct of clinical trials into breast cancer to assess existing management protocols and to develop new treatment schedules.

Senator Sue West
Chairperson

June 1994

LIST OF APPENDICES

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APPENDIX 1

ORGANISATIONS AND INDIVIDUALS WHO PRESENTED WRITTEN SUBMISSIONS TO THE INQUIRY

Submission No.	
1	Ms Merran Cooper
2	Ms Marie V. Heaney
3	Professor Ian F.C. McKenzie, The Austin Research Institute
4	Dr Peter Greenberg
5	Ms Barbara Newman
6	Dr Christopher Lawson-Smith
7	Ms Mavis Tassicker
8	The Health Services Association of New South Wales
9	Ms Janete Griffin
10	The Royal Australasian College of Radiologists
11	Ms Judith Cesari
12	East Melbourne Radiology
13	Dr Patrick C. Cregan
14	South Australian Health Commission
15	Catholic Women's League, Australia
16	Dr James Ryan
17	Mrs Diane Schmidt
18	Dr Virginia R. Billson
19	The Country Women's Association of Western Australia (Inc.)

20 Dr David A. Noble

21 Ms Clare Crafoord

22 Mrs June Griffith

23 Dr Sue Uren & Dr Adrian Sheen

24 Dr David Lipp

25 Anti-Cancer Council of Victoria

26 Ms Deborah Roots

27 Wellington Graduate Nurses Association

28 Northern Territory Anti Cancer Foundation Inc.

29 Ms Leonie M. Short

30 Dr Heather Mitchell

31 The Royal Australasian College of Radiologists
Queensland Branch

32 Mr D.J. Benjamin

33 Australian Cancer Society, National Breast Cancer Advisory Committee

34 Ms Gladys Rigney

35 Victorian Imaging Group

36 Medical Oncology Group of Australia

37 Pathology Reference Group

38 Women's Health Reference Group, Central West Region, Queensland

39 The Royal Australasian College of Radiologists,
Mammography Sub-committee, Victorian Branch

40 Dr Mary Rickard

41 Perth Imaging

42 North Coast Breast Screening Program Inc.

43 Bankstown Diagnostic Breast Centre

44 Dr Roger Livsey

45 Darling Downs and South West Queensland Breast Screening Service

46 Central Queensland Medical Imaging Pty Ltd

47 Hastings Road Breast Clinic

48 Ms Ann Poulos

49 Queensland X-Ray Services

50 Dr John P. Collins

51 Dr Michael McDonnell

52 Professor M.H.N. Tattersall

53 Ms Agnes Tait

54 The New South Wales State Cancer Council

55 The NSW State Planning & Co-ordination Unit (SPCU)
for Mammographic Screening

56 Ms Marcia O'Keefe

57 South Australian Branch of the Mammography Subcommittee of the
Royal Australasian College of Radiologists

58 Dr Elizabeth M. Kenny

59 St Andrew's War Memorial Hospital Brisbane Breast Clinic

60 Dr Paula Sivyer

61 Dr Roslyn M. Adamson

62 Dr E.J. Wylie

63 The Medical Executive Committee of the South Australian
Breast X-Ray Service

64 Intercollegiate Committee –
  Royal Australasian College of Surgeons
  Royal Australasian College of Radiologists
  Royal College of Pathologists of Australasia
  Royal Australian College of General Practitioners

65 Royal Australasian College of Surgeons, Section of Breast Surgery

66 Royal Australasian College of Surgeons, New South Wales State Committee

67 Australian Nursing Federation (WA Branch) and Industrial Union of Workers Perth

68 Faculty of Health Sciences, The University of New England, Northern Rivers

69 Dr Mark Ready

70 Women's Health Service for the West

71 Dr Julian R. Frayne

72 South Australian Breast X-Ray Service (SABXRS), South Australian State Advisory Committee

73 Mrs Judith Roberts

74 The Rachel Forster Hospital Breast Clinic

75 Dr Frances Holly-Archer

76 Ms Bronwyn Chapple

77 Brisbane South Region Breast Screening and Assessment Service

78 Dr Michael A. Henderson

79 The Council of the Shire of Cobar

80 Mr Murray Schirmer

81 Royal Australasian College of Surgeons, The Divisional Group of Rural Surgeons

82 The Anti-Cancer Foundation of the Universities of South Australia

83 Dr Stella Wiese

84	BreastScreen – Victorian Breast Screening Program
85	The Royal Australian College of General Practitioners, West Australian Faculty
86	Mr Anthony J. Maeder
87	Ms Julie Evans
88	Professor P. Grantley Gill
89	The Wesley Hospital Breast Clinic
90	Dr Graham Warren
91	NSW Health Department
92	Ms Karen Irvine
93	Australian Medical Association Limited
94	AMA Council of General Practice (Qld) & Queensland Medical Women's Society
95	Ms Joan M. Wright
96	Dr John Osborn
97	Royal College of Nursing, Australia
98	Health Department of Western Australia
99	Consumers' Health Forum of Australia Inc.
100	Breast Study Committee of the Victorian Cooperative Oncology Group (VCOG) of the Anti-Cancer Council of Victoria (ACCV)
101	New South Wales Breast Screening and Assessment Service Units – Central Sydney – Hunter – Western Sydney – North Coast – Northern Sydney
102	Liverpool Breast Centre
103	Australian Association of Surgeons

104 Professor J McCaffrey

105 North West Health Service

106 Tasmanian Breast Screening Service

107 Australian Institute of Radiography

108 Reference Group to provide a Monitoring and Evaluation Plan for the National Program for the Early Detection of Breast Cancer

109 Northern Territory Department of Health and Community Services

110 Western Australian Women's Cancer Advisory Board

111 Council of Remote Area Nurses of Australia Incorporated

112 Royal Hospital for Women, Paddington, New South Wales

113 ACT Health

114 Department of Health, Housing, Local Government and Community Services (now Department of Human Services and Health)

115 Multicultural Women's Health Centre, Fremantle, Western Australia

116 Eastern Sydney Area Health Service

117 Queensland Branch of Australian Medical Association

118 Dr Clem Nommensen

119 Monash Medical Centre

120 Ms T. Matthews

121 Australian Society of Breast Physicians

122 Radiological Council of Western Australia

123 Queensland Department of Health

124 Ms Amanda Tattam

125 Dr Michael J. Fett

126 Victorian Department of Health

127 Mrs Pauline McKimm

128 Dr D P Doessel

129 Women's Electoral Lobby

130 Cancer Support Association of Western Australia Inc.

131 The Royal College of Pathologists of Australasia

132 Ms Mary Simcic

133 Health Insurance Commission

134 Monitoring & Evaluation Reference Group

135 Australian Society for Medical Research

DATES OF PUBLIC HEARINGS

10 November 1993
Commonwealth Centre
ADELAIDE

12 November 1993
Sir Charles Gairdner Hospital
PERTH

29 November 1993
Rachel Forster Hospital
Redfern
SYDNEY

30 November 1993
Parliament House
BRISBANE

3 December 1993
Parliament House
MELBOURNE

4 February 1994
Parliament House
CANBERRA

28 February 1994
Parliament House
CANBERRA

14 March 1994
Parliament House
CANBERRA

APPENDIX 3

WITNESSES WHO APPEARED AT PUBLIC HEARINGS

Dr R M Adamson	Applecross WA
Dr L E Albertyn	Member, State Branch Royal Australasian College of Radiologists Sydney NSW
Mrs J K Anderson	Acting Executive Director Royal College of Nursing, Australia Melbourne Vic
Dr C C Bennett	General Manager Royal Hospital for Women Paddington NSW
Dr A M Bilous	Chairman Pathology Reference Group Pathology Department Westmead Hospital Westmead NSW
Mr M Bonnici	Finance Manager Victorian Breast Screening Coordination Unit Inc. Carlton South Vic
Dr J Boyages	Western Breast Screening Unit Parramatta NSW
Ms Kim Boyer	Chair State Advisory Committee Tasmanian Breast Screening Service State Coordination Unit Hobart Tas
Mr D S Briggs	General Manager North West Health Service Tamworth NSW
Ms J R Brogan	Director Women's Health Programs ACT Health ACT Government Canberra ACT

Dr K A Brownlie	Member Radiological Council of Western Australia Nedlands WA
Mrs B A Chapple	Chief Radiographer South Australian Breast X-Ray Service Wayville SA and Committee Member Australian Institute of Radiographers Collingwood Vic
Ms F Cheok	Head, Screening Support & Evaluation Unit South Australian Breast X-Ray Service Wayville SA
Dr M Cohn	President Australian Medical Association Queensland Branch Kelvin Grove Qld
Dr C Crane	South Australian Spokesperson Mammography Subcommittee Royal Australasian College of Radiologists Millers Point NSW
Ms C Croft	Northern Territory Coordinator Women's Cancer Prevention Program Darwin NT
Dr J Croll	President Australian Society of Breast Physicians Sydney Square Breast Clinic Sydney NSW
Dr L E Dougan	Member, Women's Advisory Council Women's Cancer prevention Unit Advisory Board Health Department of Western Australia Mt Hawthorn WA
Ms B M Edwards	Acting Manager Women's Cancer Prevention Unit Health Department of Western Australia Mt Hawthorn WA
Dr R G Edwards	Executive Director Anti-Cancer Foundation North Adelaide SA

Ms S E Farnan	Assistant Coordinator Women's Health Service for the West Footscray Vic
Dr M J Fett	Balmain NSW
Prof. J F Forbes	Director Hunter Breast Cancer Screening and Assessments Service Newcastle NSW
Dr J R Frayne	Cottesloe WA
Ms V Gardner	Manager Women's Cancers unit Tasmanian Breast Screening Service State Coordination Unit Hobart Tas
Dr P Garvey	Senior Staff Specialist Royal Hospital for Women Paddington NSW
Dr J Gill	Disease Control Branch Health Department of Western Australia East Perth WA
Dr S Goldstein	Director of Medical Services Royal Hospital for Women Paddington NSW
Dr J Grace	Member Royal College of Pathologists of Australasia Surry Hills NSW
Dr N J Gray	Director Anti-Cancer Council of Victoria Carlton South Vic
Mrs B E Grealy	Former National Secretary Catholic Women's League of Australia Adelaide SA
Mrs H M Hamilton	Projects Officer Royal College of Nursing, Australia Melbourne Vic

Dr S J Harbison	President Queensland Medical Women's Society Red Hill Qld
Dr B M Hartley	Secretary Radiological Council of Western Australia Nedlands WA
Dr F Hearnden	Medical Director St Andrews Breast Clinic Brisbane Qld
Mrs E Henry	Executive Director New South Wales State Cancer Council Woolloomooloo NSW
Dr C Hirst	Director The Wesley Breast Clinic Toowong Qld
Dr Z C Hodge	Immediate Past President and Committee Member Queensland Medical Women's Society Red Hill Qld
Mr P A Hopkins	Coordinator North and North West Breast Cancer Screening Service Tamworth NSW
Mrs S Kanas	Member South Australian Multicultural and Ethnic Affairs Commission and Executive Member South Australian Ethnic Communities Council Inc.
Mr R N Linacre	Program Surgeon Tasmanian Breat Screening Service State Coordination Unit Hobart Tas
Prof. R R H Lovell	Consultant Anti-Cancer Council of Victoria Carlton South Vic
Prof. J F McCaffrey	Chairman Medical Advisory Committee Queensland Cancer Fund Brisbane Qld

Prof. I F C McKenzie	Director Austin Research Institute Heidelberg Vic
Dr J McNulty	Chairman Radiological Council of Western Australia Nedlands WA
Dr P S Morey	Chief Health Officer New South Wales Department of Health North Sydney NSW
Ms J M Muller	Co-ordinator-Manager Women's Cancer Prevention Program and Deputy Director Women's Health Policy Unit Queensland Health Brisbane Qld
Dr D A Noble	Partner Queensland X-Ray Services Stones Corner Qld
Dr I M O'Loughlin	Director Brisbane South Breast Screening and Assessment Service Queensland Breast Screening Program Brisbane Qld
Dr S B Porges	Executive Member Divisional Group of Rural Surgery Royal Australasian College of Surgeons Melbourne Vic
Ms J M Rabach	Nurse Educator Royal College of Nursing, Australia Melbourne Vic
Ms C Rae	Senior Policy Officer Community Health Program Northern Territory Department of Health Darwin NT
Ms D J Reading	Director of Education Anti-Cancer Council of Victoria Carlton South Vic

Dr S B Renwick	Executive Director Royal prince Alfred Hospital Breast and Surgical Oncology Service and Surgeon in Charge Rachel Forster Hospital Breast Centre Sydney NSW
Dr M T Rickard	Strawberry Hills NSW
Mrs D A Robert	Past Mammography Panel Member Australian Institute of Radiography Collingwood Vic
Mrs J M Roberts	Chairperson Advisory Committee South Australian Breast X-Ray Service Wayville SA
Dr J I Robinson	Clinical Head of Screening/Assessment Services South Australian Breast X-Ray Service Wayville SA
Dr D M Roder	Director of Epidemiology Public and Environmental Health Division South Australian Health Commission Adelaide SA
Dr J Ruhno	Medical Director Australian Society of Breast Physicians Sydney Square Breast Clinic Sydney NSW
Mr I S Russell	Chairman Intercollegiate Committee on Breast Screening Royal Australasian College of Surgeons Melbourne Vic
Ms E Ryan	Manager State Planning and Coordination Unit for Mammographic Screening New South Wales State Cancer Council Woolloomooloo NSW
Mrs N Shepherd	Executive Director Hancock Family Breast Cancer Foundation West Perth WA

Ms D M A Smith	Community Health Nurse Women's Health Service for the West Footscray Vic
Ms K Sorensen	Coordinator Breast Cancer Support Service and Cancer Information Service ACT Cancer Society Breast Cancer Support Services Curtin ACT
Mr W J Spehr	Director South Australian Breast X-Ray Service Wayville SA
Ms O Stagoll	Director BreastScreen Carlton South Vic
Mrs Y F Strawbridge	Nurse/Counsellor Australian Nursing Federation West Perth WA
Ms M Strong	Director Clinical and Community Services Rural Health Directorate Lismore NSW
Mrs K M Tobin	Coordinator Breast Cancer Support Service Anti-Cancer Foundation North Adelaide SA
Mrs E A Trevan	Director North Coast Breast Screening Program Lismore NSW
Dr C R Watson	Chairman Women's Cancer Advisory Board C/- Health Department of Western Australia East Perth WA
Mrs J Webster	Executive Officer Health Services Association of New South Wales Leichhardt NSW
Dr S M Wiese	Senior Medical Officer Women's Cancer Prevention Unit Health Department of Western Australia Mount Hawthorn WA

APPENDIX 4

SCREENING AND ASSESSMENT SERVICES

Source: *Transcript of Evidence*, pp.1402-4 (DHS&H).

NATIONAL PROGRAM FOR THE EARLY DETECTION OF BREAST CANCER

SCREENING AND ASSESSMENT SERVICES
AS AT 31 JANUARY 1994

	FIXED	MOBILES
NSW	* Central/Eastern Sydney Screening and Assessment Service	
	Clinics - Rachel Forster Hospital (pilot) Royal Women's Hospital Paddington (Aug 93) Sydney Square (Jan 94) Ashfield (Jan 94)	2 (Mar 88 & June 90)
	* Western Sydney Screening and Assessment Service	
	Clinics - Parramatta Health Service (Feb 93)	2 (Sept 93 & Nov 93)
	* Northern Sydney Screening and Assessment Service	
	Clinics - Royal North Shore Hospital(May 93) Hornsby (July 93) Chatswood (July 93) Lindfield (Aug 93) Manly (Oct 93) Wahroonga (Oct 93) Dee Why (Oct 93) Mona Vale (Jan 94)	
	* Hunter Breast Cancer Screening Project	
	Clinics - Newcastle (pilot) Kotara (April 93) Charlestown (April 93)	2 (Apr 89 & Oct 91)
	* North Coast Breast Screening Program (Lismore) (May 93)	
	Clinics - Lismore	1 (Dec 93)
	* South West Region Screening and Assessment Service	
	Clinics - Wagga Wagga (Jan 94)	

	FIXED	MOBILES
VIC	* Essendon BreastScreen (pilot) Clinics - Essendon and District Hospital plus a relocatable service to screen at eight locations in Western Region	
	* Monash BreastScreen Monash Medical Centre (Feb 93) Clinics - Mentone Clayton East Bentleigh Mt Waverley Berwick Malvern Dandenong Elsternwick	
	* City and North Eastern BreastScreen (Sept 93) Clinic - Fitzroy East Melbourne	
	* Geelong Screening and Assessment Service (Aug 93) Clinic - Geelong	
	* Maroondah BreastScreen (Jan 94) Clinics - Ringwood East	
QLD	* Royal Women's Hospital Breast Screening Clinic (pilot) Clinic - Herston	1 (1990)
	* Brisbane South Breast Screening Service Clinic - Upper Mt Gravatt (Mar 93)	
	* South Coast Region Breast Screening Clinic - Southport (Aug 91)	
	* Sunshine Coast Breast Screening Service Clinic - Nambour (Feb 93)	

	FIXED	MOBILES
QLD (cont'd)	* Darling Downs Region Breast Screening Service	1
	Clinic - Toowoomba (June 92)	(June 92)
	* Central Queensland Breast Screening Service	
	Clinic - Rockhampton (Mar 92)	
	* Northern Queensland Breast Screening Clinic	
	Clinic - Townsville (Sept 91)	1 (May 92)
SA	* South Australian Breast X-ray Service (pilot)	
	Clinics -Wayville Seacombe Gardens Adelaide Central Woodville South Elizabeth Vale	1 (Apr 92)
WA	* Western Australian Breast Cancer Screening Program (pilot)	3
	Clinics -Cannington Mirrabooka Hillarys	
TAS	* Tasmanian Breast Screening Service - Augusta Road	
	Clinic - Lenah Valley (Feb 93)	
	* Tasmanian Breast Screening Service - Frederick St	
	Clinic - Launceston (May 93)	
	* Tasmanian Breast Screening Service - Collins Street	
	Clinic - Hobart (July 93)	1 (Jan 94)
ACT	* ACT Breast Screening	
	Clinic - Canberra (Feb 93)	

AIMS AND OBJECTIVES OF THE NATIONAL PROGRAM

Aims

The aims of the National Program were developed by the National Advisory Committee and form part of the agreement between the Commonwealth and all participating States and Territories. These aims are to:

- ensure that 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 that screening for breast cancer in Australia is provided in dedicated, accredited Screening and Assessment Services as part of the National Program for the Early Detection of Breast Cancer.
- ensure equitable access of eligible women to the Program.
- ensure that 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.

Objectives

- After five years, a 70 per cent participation rate in the National Program by women in the target group (50-69 years) and access to the Program for women aged 40-49 years and 70-79 years.
- All women in the Program re-screened at not more than two yearly intervals.
- To achieve agreed performance outcomes to minimise recall rates, retake films, invasive procedures, 'false negatives', and 'false positives', and maximise the number of cancers detected, in particular, the number of small cancers detected.
- Referral to appropriate treatment services and the collection of information about the outcome of treatment.
- Funding by the National program through State Co-ordination Units of only Screening and Assessment Services accredited according to agreed National

Accreditation Guidelines, and the monitoring and review of those guidelines by appropriate National and State Accreditation Committees.

- Recognition of the real costs to women clients of participation in the Program, and the minimisation of those costs, including the provision of services at minimal or no charge, and free to eligible women who would not attend if there were a charge.

- Information about mammographic screening and the implementation and outcomes of the National Program available in easily comprehensible and appropriate forms in a variety of forums and to women and health-care providers in particular.

- Patterns of participation in the Program which are representative of the socio-economic, ethnic and cultural profile of the target population.

- Services provided in accessible, non-threatening and comfortable environments by staff with appropriate expertise, experience and training.

- Appropriate service in that counselling, education and information is provided as an integral part of the Program, sensitive procedures for notification of recall are in place, and the time between initial screen and assessment is minimised.

- High levels of participation in the development and management of the Program by members of significant professional and client groups.

- The collection and analysis of data sufficient to monitor the implementation of the Program, to evaluate its effectiveness and efficiency, and to provide the basis for future policy and program development decisions.[438]

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[438] Submission No.114, pp.4.1-4.3 (DHS&H).

MAJOR POLICY FEATURES OF THE PROGRAM

- The National Program selects women on the basis of age alone. In line with the recommendation of the SECU report, the Program is made available for women 40 years and over, but recruitment strategies actively target those women aged 50-69 years.
- Screening is made available as widely as possible to all eligible women with the objective of rescreening them every two years.
- Screening Services are provided in an accessible, non-threatening and comfortable environment - information about the screening Program, emotional support and counselling is also provided.
- Screening and assessment is carried out at accredited centres.
- General practitioners are kept informed of the results of screening, unless a woman directs otherwise. A doctor's referral is not required for screening purposes.
- Screening employs film-screen mammography as the principal screening method for reducing breast cancer morbidity.
- All mammograms are taken by a radiographer appropriately trained in screening mammography and all mammographic films are read and reported independently be two or more readers, at least one of whom is a radiologist. Both readers must be specially trained in screening mammography and both must meet the same performance criteria.
- Women are actively involved in decisions about their management, particularly in relation to further assessment and treatment.
- The Program takes a woman from screening up to and including histological or cytological diagnosis of breast cancer. Women with histologically or cytologically confirmed breast cancer are given the option of referral to a treatment clinic specialising in the treatment of screen-detected cancer or returning to their GP for referral to a specialist breast surgeon.[439]

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[439] Accreditation Guidelines, *op. cit.*, pp.8-9.

APPENDIX 7

NPEDBC - STATISTICS ON NUMBERS OF WOMEN SCREENED

Sources: DHS&H, *NPEDBC Preliminary Progress Report*, January 1994, Tables 1-3; *Transcript of Evidence*, pp.1405-6 (DHS&H).

Table 1

Progress towards 'steady state' recruitment

State (1)	Number of women recruited before the program No. (2)	Number of women recruited since 1 July 1991 No. (3)	Total number of women recruited No. (2)+(3) (4)	Steady state recruitment number No. (5)	Number of women recruited as a proportion of steady state % (4)/(5) (6)
NSW	31,712	72,960	104,672	599,011	17%
VIC	20,422	24,417	44,839	440,373	10%
QLD	30,815	56,979	87,794	289,922	30%
WA	21,160	26,910	48,070	162,840	30%
SA	17,633	57,566	75,199	146,930	51%
TAS	0	9,982	9,982	44,199	23%
NT	0	0	0	12,365	0%
ACT	0	6,819	6,819	25,835	26%
AUST	**121,742**	**255,633**	**377,375**	**1,721,473**	**22%**

Period: 1/7/91 - 30/11/93 + previous years for pilots and pre-existing services

Participation by Age

State (1)	Age (2)	Number of screening episodes during the period (initial screens) No. (3)	Actual proportions according to age % (4)	Anticipated proportions according to age* % (5)
NSW	40-49 yrs	13,003	39%	29%
	50-69	18,492	55%	66%
	70-79	2,158	6%	5%
	TOTAL	33,653		
VIC	40-49 yrs	3,989	32%	30%
	50-69	7,801	63%	65%
	70-79	632	5%	5%
	TOTAL	12,422		
QLD	40-49 yrs	16,725	40%	30%
	50-69	21,548	52%	65%
	70-79	3,254	8%	5%
	TOTAL	41,527		
WA	40-49 yrs	6,779	32%	32%
	50-69	13,878	65%	64%
	70-79	841	4%	4%
	TOTAL	21,498		
SA	40-49 yrs	13,131	29%	29%
	50-69	29,944	67%	65%
	70-79	1,810	4%	6%
	TOTAL	44,885		
TAS	40-49 yrs	1,074	35%	31%
	50-69	1,931	63%	66%
	70-79	43	1%	3%
	TOTAL	3,048		
ACT	40-49 yrs	1,324	43%	37%
	50-69	1,630	53%	60%
	70-79	123	4%	3%
	TOTAL	3,077		
TOTAL/ AUST	**40-49 yrs**	**56,025**	**35%**	**30%**
	50-69	**95,224**	**59%**	**65%**
	70-79	**8,861**	**6%**	**5%**
	TOTAL	**160,110**		

* Based on the population distribution between those ages.

Note: apparent errors in percentages due to rounding

Table 3

National performance on key Indicators

Period (1)	Service (2)	Initial/Rescreen (3)	Age of women (4)	Women screened during the period No. (5)	Women who underwent assessment No. (6)	Women who underwent open biopsy for diagnosis No. (7)	Women with cancer No. (8)	Proportion of women assessed % (6)/(5)	Proportion of women who underwent open biopsy % (7)/(5)	Proportion of women with cancer per 10,000 (8)/(5)
1/7/91-30/6/93	AUST	INITIAL	<40 yrs	1,150	118	6	3	10%	1%	26
			40-49	56,025	3,527	348	147	6%	1%	26
			50-69	95,224	5,145	831	597	5%	1%	63
			70+	9,600	547	114	122	6%	1%	127
			TOTAL	**162,010**	**9,337**	**1,299**	**869**	**6%**	**1%**	**54**
1/7/91-30/6/93	AUST	RESCREENS	<40 yrs	449	32	4	1	7%	1%	22
			40-49	12,833	657	78	34	5%	1%	26
			50-69	64,287	2,494	387	233	4%	1%	36
			70+	8,444	321	64	54	4%	1%	64
			TOTAL	**86,014**	**3,504**	**533**	**322**	**4%**	**1%**	**37**

Note: Incomplete reporting for services in NSW and Victoria, and minor discrepancies between monthly and quarterly reports provided by NSW services and V1 - see Table 2

In column (5), TOTALS include women of unknown age, mainly in WA

Figure 1

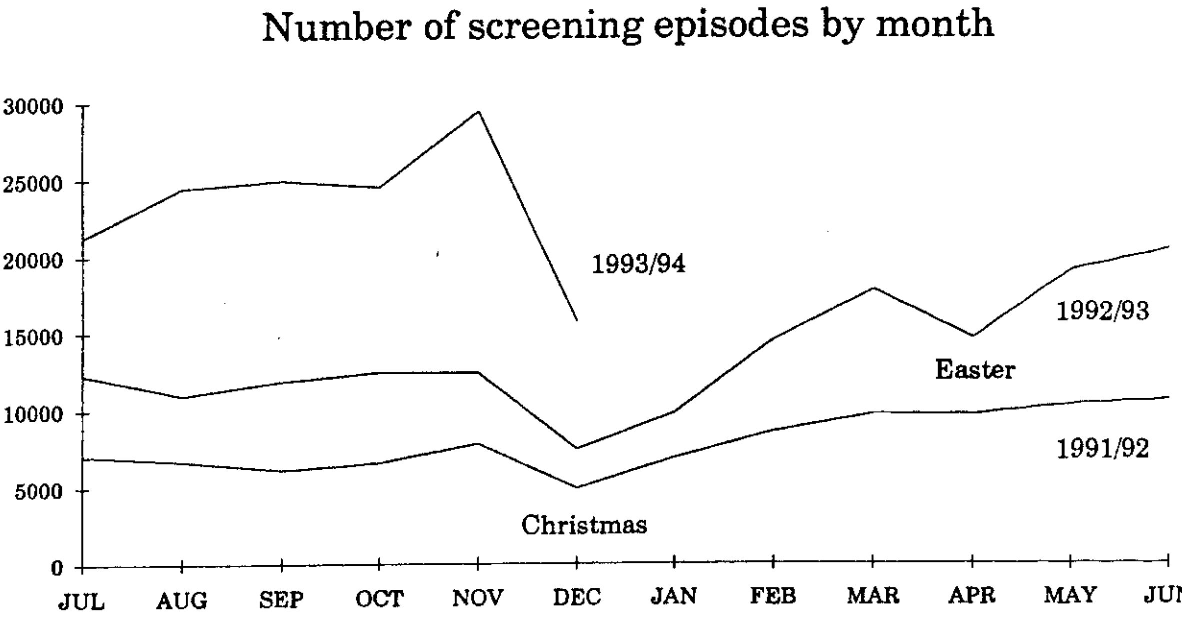
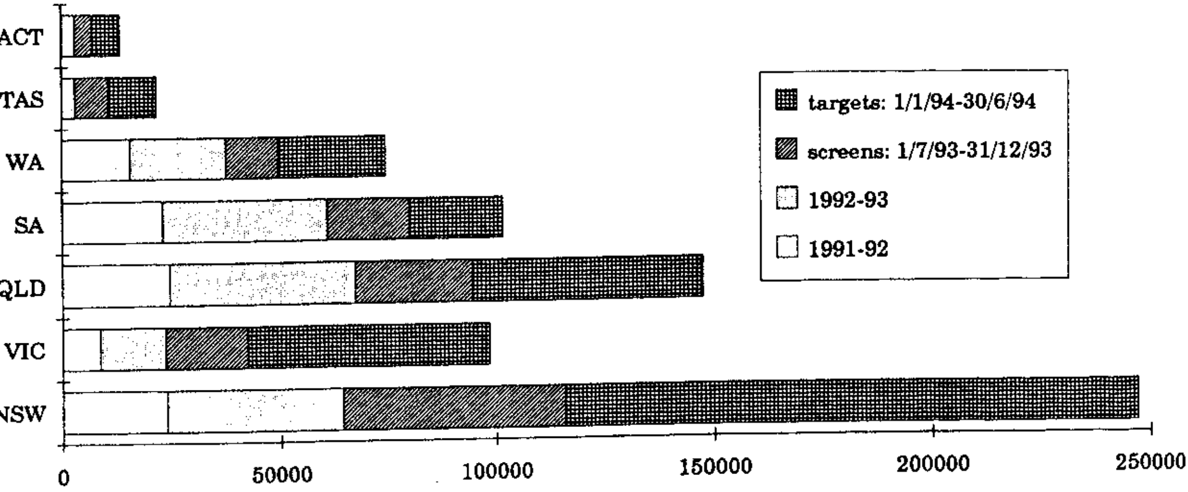

Number of screening episodes by month

Figure 2

NATIONAL PROGRAM FOR THE EARLY DETECTION OF BREAST CANCER

Screening episodes to 31 December 1993 and screening targets to 30 June 1994



	1991-92	1992-93	screens: 1/7/93-30/11/93	targets: 1/12/93-30/6/94
ACT	0	3,090	3,729	6,830
TAS	0	3,052	6,930	11,770
WA	15,525	22,057	10,146	26,554
SA	22,800	37,802	17,617	23,514
QLD	24,481	42,546	24,710	55,790
VIC	8,679	14,793	15,628	54,372
NSW	23,731	40,410	45,808	137,192
TOTAL	95,216	163,750	124,568	316,022

APPENDIX 8

NATIONAL ACCREDITATION GUIDELINES

NATIONAL PROGRAM *for the* EARLY DETECTION
of BREAST CANCER

NATIONAL ACCREDITATION GUIDELINES

Developed by a Working Party of the National Advisory Committee
for the Early Detection of Breast Cancer

NOVEMBER 1991

NATIONAL ACCREDITATION GUIDELINES

These Guidelines were developed by a working party of the National Advisory Committee for the Early Detection of Breast Cancer.

The National Advisory Committee is comprised of representatives of the following organisations and interests:

Aboriginal and Torres Strait Islander Commission
ACT Board of Health
Australian Cancer Society
Australian Institute of Radiography
Australian Medical Association Ltd.
Commonwealth Department of Health, Housing and Community Services
Consumers' representative
Department of Health, Tasmania
Health Department Victoria
Health Department of Western Australia
New South Wales Health Department
Northern Territory Department of Health and Community Services
Public Health representative
Queensland Department of Health
Royal Australasian College of Surgeons
South Australian Health Commission
The Royal Australian College of General Practitioners
The Royal College of Pathologists of Australasia
The Royal Australasian College of Radiologists

The hard work and expertise contributed by the individuals on the working party to the development of these Guidelines is greatly appreciated.

The Guidelines were ratified by the National Advisory Committee for the Early Detection of Breast Cancer on 22 November 1991.

The Guidelines were developed to set accreditation standards within existing policy, as was the brief of the working party. Policy is set by State and Commonwealth Ministers. In ratifying the Guidelines, the National Advisory Committee noted reservations by some groups about current policy:

- The reading of screening mammograms by non-radiologist readers (Royal Australasian College of Radiologists, Intercollegiate Committee on Mammographic Screening);

- The inclusion of women 40–49 years in the Program (Royal Australasian College of Radiologists, Australian Medical Association);
- The inclusion of breast physicians (Australian Medical Association);
- The inclusion of open surgical biopsy in the Program (Intercollegiate Committee).

For further information on the Guidelines, please contact the National Co-ordination Unit, National Program for the Early Detection of Breast Cancer, Department of Health, Housing and Community Services, on (06) 289 7323.

Additional copies of the Guidelines can be obtained from each State Co-ordination Unit.

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Section 1

OVERVIEW *of the* NATIONAL PROGRAM

1.1 INTRODUCTION

Breast cancer is the most common cancer threatening the lives of Australian women. Over 5000 Australian women develop breast cancer each year, and each woman has a one in 16 chance of developing breast cancer during her life.

Each year more than 2000 Australian women die from breast cancer. Despite technical advances in the treatment of breast cancer, survival rates have remained unchanged in the last 50 years.

There is now widespread agreement among public health authorities that well controlled mammographic screening can substantially reduce deaths from breast cancer among women aged 50–69. Mammography is the only effective means for detecting non-palpable cancers, which are at a stage when they are more likely to be amenable to effective treatment.

The evidence that breast cancer screening by mammography is efficacious comes from a number of studies, including four randomised controlled trials and three studies of case-control design.

In the United States, 29 tightly monitored demonstration projects have shown that screening mammography is practical and effective under normal 'field' conditions.[1,2]

Based on the results of the overseas trials, individual women participating regularly in mammographic screening of high quality can expect their risk of death from breast cancer to be reduced by more than half while they participate in such a program.

Currently, the evidence suggests that breast cancer deaths could be reduced by around one third among those offered screening, which includes those women who choose not to participate in screening.

The report of the Australian Health Ministers' Advisory Council (AHMAC) Screening Evaluation Steering Committee, *Breast Cancer Screening in Australia: future directions*[3] suggests that, with a fully operational screening program and a 70% participation rate amongst eligible women, the reduction in mortality from breast cancer amongst all Australian women would be around 17% (p. 26).

1.2 PROGRAM HISTORY *and* ORGANISATION

Between 1987 and 1990, 11 breast cancer screening projects in five Australian States participated as pilots in a three year evaluation which advised the Australian Health

Ministers' Advisory Council on the various policy aspects of developing national strategies for extensive screening programs.

Based on this evaluation the Commonwealth Government announced that it would contribute $64m in the first three years towards the development of a national breast cancer screening program. The National Program for the Early Detection of Breast Cancer (the National Program) is to be implemented over five years from the time of agreement by the States and Territories to participate.

Subsequently five States have signed participation agreements with the Commonwealth, and the others have conducted feasibility studies (as at October 1991).

The National Program will be funded through cost shared arrangements between the Commonwealth Government and the Governments of the States and Territories. In the start-up phase, the Commonwealth is providing $14m in unmatched funds to enable States and Territories to either establish a program or expand their services in line with the National Program policies and objectives.

Funding will be provided to State and Territory Governments through agreements between the Commonwealth and State and Territory Governments, and is expected to be administered through the State Co-ordination Units.

The National Program will be a clearly identifiable, integrated, systematic and co-ordinated program. A network of accredited and dedicated Screening and Assessment Services will be established within each participating State and Territory to provide screening to all women over 40 years of age. Women aged 50–69 will be actively recruited.

Each Screening and Assessment Service will operate as an integrated system consisting of an assessment centre/service, and associated screening unit(s). The Service will be responsible as a whole to the State Co-ordination Unit. Screening units may be fixed or mobile, and will not operate independently but in close association with a designated assessment centre/service.

The State Co-ordination Unit (SCU) in each State and Territory will have primary responsibility for implementation of the National Program within the State or Territory. This responsibility includes recommendations about the location, type and number of screening units and assessment centres/services, recruitment, training co-ordination, accreditation monitoring, financial management and data management.

The National Co-ordination Unit will provide a central co-ordination and management function for the National Program and the National Advisory Committee for the Early Detection of Breast Cancer. It will be responsible for national data collection, compilation and analysis, and National Program evaluation and monitoring.

1.3 ACCREDITATION *within the* NATIONAL PROGRAM

For a population based mammographic screening program to achieve its full potential, it must be of high quality and achieve high participation rates. Furthermore, women with screen detected abnormalities must receive appropriate follow-up assessment as well as have access to high standard treatment facilities where required.

The development of successful overseas programs has been based on a recognition that, for benefits to be maximised and any adverse effects minimised, screening mammography must be implemented with stronger control and guidance than is customary in health service development. The possible adverse effects of screening which must be minimised may include anxiety, radiation exposure, over diagnosis and under diagnosis and unnecessary intervention (including open biopsy).

The report of the AHMAC Breast Cancer Screening Evaluation Steering Committee[3] emphasised the need for a highly integrated, systematic and co-ordinated program, including standardised accreditation processes, specialised training, quantitative performance criteria, ongoing monitoring and evaluation, and national and state level co-ordination mechanisms[3].

The Accreditation process, and these National Guidelines, will together be a critical component in the achievement of sufficiently high standards throughout the national network of Screening and Assessment Services to enable the achievement of the desired outcomes.

It is the integrated Screening and Assessment Service which will be accredited under these Guidelines. The Service, or parts of it, may be located in the public or private sectors, but all elements will need to meet accreditation guidelines in order for the Service to qualify for funding under the National Program.

The Screening and Assessment Service must be a discretely identifiable Service, with a clear management and service delivery structure and processes dedicated to the purpose of mammographic screening.

The services under the National Program should not be provided concurrently with any other radiological or diagnostic services.

The continued funding of such Screening and Assessment Services will depend upon their compliance with these National Accreditation Guidelines which have been developed and approved by the National Advisory Committee for the National Program for the Early Detection of Breast Cancer. That Committee consists of professional, program management, government, consumer and public health representatives.

Their implementation will be overseen and regularly reviewed by a National Accreditation Committee. This Committee will include relevant professional and program management representation. It will have direct reference to an Intercollegiate Committee on Breast

Cancer Screening for advice on professional matters. It will also maintain a register of accreditation experts upon which States and Territories may draw to assist the process of accreditation.

Responsibility for ensuring the accreditation of Screening and Assessment Services lies within the State or Territory Co-ordination Unit. Each State will have in place an appropriate accreditation advisory group for this purpose (see Section 4).

These National Accreditation Guidelines apply to the accreditation of Screening and Assessment Services as described above. They do not apply to the accreditation of professional personnel. The latter process is seen to be the prerogative of the relevant Professional Colleges and Institutes. The Guidelines require that staff employed by the Services funded by the National Program be appropriately qualified, and that where recognised professional guidelines exist they should be the standards (see Section 2.2).

Screening and Assessment Services may be provisionally accredited for 12 months after which re-accreditation will be required each two years.

◆ ◆ ◆

All health services can be conceptualised to consist of three elements—structure, process and outcome, and these are integral to the processes of quality assurance and evaluation.

Structure encompasses the resources of the Screening and Assessment Service which may be primarily expressed as financial or human. It also includes less tangible features of the management and administration such as quality assurance programs, clear program objectives and policies, programs of training and continuing education, procedures for ensuring client satisfaction, and staff appraisal and performance mechanisms.

Process refers to the activities of the Screening and Assessment Service and includes recruitment strategies, screening and assessment processes, and monitoring and evaluation activities.

Outcome relates to the results of activities undertaken through the Program. The ultimate aim of this National Program is reduction in mortality from breast cancer.

A population of women over 50 years of age offered breast screening can expect an approximate 30% reduction in deaths from breast cancer. Because this mortality reduction follows a delay of about five years from the commencement of screening, it is important to adopt interim performance measures for this key program outcome.

The basis of the anticipated reduction in mortality is the earlier detection of cancers (particularly small cancers) followed by their successful treatment. Therefore, the proportion of cancers detected, and more so the proportion of invasive cancers less than 10mm, have been adopted as two suitable intermediate indicators of the ultimate outcome (see Section 3).

While a reduction in breast cancer mortality is the ultimate goal of the National Program, this goal should not be pursued to the total exclusion of other important process or outcome objectives such as participation by women in health decision making, and recognition of women's rights and needs as health care consumers.

If the National Program is not to fall into disrepute with women, then there must be recognition of individual women's needs in service delivery. This philosophy has served as a guiding principle in the development of these National Accreditation Guidelines.

The three elements—structure, process and outcome—which underlie the aims and objectives of the Program, also define the scope of these Accreditation Guidelines, and form the basis of the various standards established herein.

It is important that the National Program, and each of the Screening and Assessment Services which comprise it, recognise that it is crucial to determine standards for these three elements and then to measure achievement of those standards, so that progress towards the end results can be effectively monitored.

Considerable evaluative work has already been done on the effectiveness of mammographic screening and these results have been used extensively in the development of the policies and management structures of the National Program, and in the development of the various standards established in these Guidelines. This includes the pilot projects conducted in Australia in the late 1980s as well as data from the various overseas trials.

The Guidelines have also drawn heavily on standards established by the Professional Colleges and Institutes, the Australian Institute of Health, the National Health and Medical Research Council and overseas programs.

The quality of a health service is a function of five different types of outcome:

Effectiveness	the degree to which the service reaches the objectives.
Efficiency	the maximisation of benefits for the minimum cost in resources of reaching the objectives.
Equity	the degree to which resources are used for the benefit of the whole population.
Appropriateness	the balance of risks and benefits.
Client satisfaction	the degree of satisfaction experienced by the clients.

These five types of outcome are implicit in the aims and objectives of the National Program and in these National Accreditation Guidelines.

Also integral to the Guidelines is the notion that quality of structure, process and outcomes will be continually monitored, evaluated, reviewed and improved. It is National Program policy that multi-disciplinary teams will be established in each accredited

Screening and Assessment Service for this purpose, in conjunction with appropriate processes of review and change.

Whilst monitoring and evaluation is critically important in relation to the clinical activities, it is also vital that the Program be equally rigorous in its monitoring and evaluation of recruitment, resource management, data collection and training activities. The establishment and maintenance of high quality standards in all its component parts and all its objectives will be imperative if the National Program is to achieve an acceptable balance between cost and public health benefit.

Criteria for establishing quality and for measuring performance need to be selected for validity, reliability and feasibility and be reviewed on an ongoing basis.

These National Accreditation Guidelines set minimum standards for the accreditation of Screening and Assessment Services as part of the National Program for the Early Detection of Breast Cancer. They are intended to ensure the achievement of the Program aims and objectives, which follow.

1.4 *The* AIMS *and* OBJECTIVES *of the* NATIONAL PROGRAM

The aims and objectives of the National Program have been derived from the report of the Breast Cancer Screening Evaluation Steering Committee[3], particularly from its recommendations. They have been developed by the National Co-ordination Unit in consultation with the Program's National Advisory Committee and its Working Parties. They will be reviewed from time to time.

Aims of the National Program

- To ensure that the Program is implemented in such a way that significant reductions can be achieved in morbidity and mortality attributable to breast cancer.
- To maximise the early detection of breast cancer in the target population.
- To ensure that screening for breast cancer in Australia is provided in dedicated, accredited Screening and Assessment Services as part of the National Program for the Early Detection of Breast Cancer.
- To ensure equitable access of eligible women to the Program.
- To ensure that services are acceptable and appropriate to the needs of the eligible population.
- To achieve high standards of program management, service delivery, monitoring and evaluation, and accountability.

Objectives of the National Program

- After five years, a 70% participation rate in the National Program by women in the target group (50–69 years) and access to the Program for women aged 40–49 years and 70–79 years.
- All women in the Program rescreened at not more than two yearly intervals.
- To achieve agreed performance outcomes to minimise recall rates, retake films, invasive procedures, 'false negatives', and 'false positives', and maximise the number of cancers detected, in particular the number of small cancers detected.
- Referral to appropriate treatment services and the collection of information about the outcome of treatment.
- Funding by the National Program through State Co-ordination Units of only Screening and Assessment Services accredited according to agreed National Accreditation Guidelines, and the monitoring and review of those guidelines by appropriate National and State Accreditation Committees.
- Recognition of the real costs to the women clients of participation in the Program, and the minimisation of those costs, including the provision of services at minimal or no charge, and free to eligible women who would not attend if there were a charge.
- Information about mammographic screening and the implementation and outcomes of the National Program available in easily comprehensible and appropriate forms in a variety of forums and to women and health care providers in particular.
- Patterns of participation in the Program which are representative of the socio-economic, ethnic and cultural profile of the target population.
- Services provided in accessible, non-threatening and comfortable environments by staff with appropriate expertise, experience and training.
- Appropriate service in that counselling, education and information is provided as an integral part of the Program, sensitive procedures for notification of recall are in place, and the time between initial screen and assessment is minimised.
- High levels of participation in the development and management of the Program by members of significant professional and client groups.
- The collection and analysis of data sufficient to monitor the implementation of the Program, to evaluate its effectiveness and efficiency, and to provide the basis for future policy and program development decisions.

1.5 PROGRAM POLICIES

The report of the Breast Cancer Screening Evaluation Steering Committee[3] has also formed the basis for the development of the policies of the National Program for the Early Detection of Breast Cancer[4].

Screening and Assessment Services accredited under the National Program for the Early Detection of Breast Cancer will be expected to operate according to, and to make freely available, the policies and information statements of the National Program.

Major policy features of the National Program

- The National Program for Early Detection of Breast Cancer selects women on the basis of age alone. In line with the recommendations of the Evaluation Report[3], the Program will be made available and publicised for women aged 40 years and above, but recruitment strategies will be targeted at women aged 50–69 years[5].
- There is international consensus that mammographic screening is effective for women aged 50 years and above, while there is not yet consensus in relation to women aged 40–49 years. Under the Program women in this latter group will have access to organised, high quality screening.
- The age range for screening will be monitored and reviewed as new data becomes available.
- Screening will be made available as widely as possible to all eligible women with the intention of rescreening them every two years.

  The screening interval will be reviewed as new data become available.
- Screening will be made available at minimal or no cost to the woman, and free of charge to eligible women who would not attend if there was a charge.
- Comprehensive and easily understood information, emotional support and counselling will be provided as appropriate. Women will be advised on the effectiveness and risks of mammography and on the maintenance of a regime of breast care e.g. breast self examination to reinforce the message that a negative mammographic screen does not preclude the diagnosis of breast cancer prior to the next screen.
- Screening services will be provided in a manner which is acceptable to women in the target group and in accessible, non-threatening and comfortable environments.
- General Practitioners should be kept informed of the results of screening and any further work-up required, unless a woman directs otherwise. Although a doctor's referral is not a prerequisite for attendance, a letter from the woman's doctor is welcomed.
- Screening will employ film-screen mammography alone as the principal screening method for reducing breast cancer mortality.

- All women will be screened with two view mammography. At a subsequent rescreening one view may be used if previous mammograms have indicated that two views are not required.
- All mammograms will be taken by a radiographer appropriately trained in screening mammography.
- All mammographic films will be read and reported independently by two or more readers, at least one of whom shall be a radiologist. Both readers must be specially trained in screening mammography and both meet the same performance criteria. Reports will be combined into a single recommendation.
- The results of screening will be provided promptly and directly to the woman who is the subject of the screening in a way which is sensitive to her possible anxiety.
- Women will be actively involved in decisions about their management, particularly in relation to further assessment and treatment, and written information will be provided.
- Screening and assessment will be carried out at accredited centres/services.
- The Program will take a woman from screening up to and including histological or cytological diagnosis of breast cancer.
- Women with histologically or cytologically confirmed breast cancer will be given the option of referral to a treatment clinic specialising in the treatment of screen detected breast cancer or returning to their General Practitioner for referral to a specialist breast surgeon.

1.6 CONCLUSION

In summary, both the objectives of the National Program and these Accreditation Guidelines require a comprehensive and integrated approach to the screening process. Without this, the Program will fail to achieve its public health goal as well as its potential to benefit individual women.

Further, without a commitment to effective teamwork and a screening 'culture' by all staff involved in the screening and assessment pathway (including administrative and clinical personnel), the Program will inevitably fail to fulfil its promise.

The remaining sections of this document cover the following matters, in sufficient detail it is hoped, to permit an evaluation of the extent to which a Screening and Assessment Service is meeting, or is likely to meet Program objectives.

Section 2 contains guidelines for various Program components, including education and recruitment, screening and assessment, data collection and management, training for staff, and program administration/management.

This section is intended to provide an outline of what aspects of an individual program will be evaluated, on what broad criteria, and some guidance on how various aspects of the Screening and Assessment Service should be delivered to the target group.

Section 3 gives performance objectives and standards. This section provides brief statements of the key performance objectives for each major program component, as well as quantifiable/objective standards for their measurement.

The Accreditation Process is spelled out in Section 4, including levels of responsibility within and between States, procedures for withdrawal of accreditation and so on.

Implementation, including relevant timeframes and a budget for the accreditation process is found in Section 5 and finally, the appendices cover specific aspects of all the above in greater detail.

So as to ensure greater uniformity in interpretation of these guidelines, a series of definitions has been agreed (see Appendix 1). These will facilitate not only uniformity of interpretation but also greater uniformity of implementation of the National Program.

Section 2

ACCREDITATION GUIDELINES *for* COMPONENTS *of the* PROGRAM

2.1 RECRUITMENT

The National Program for the Early Detection of Breast Cancer is a population screening program for women which is dependent upon obtaining high participation rates for its success and effectiveness. The aim of the program is to screen 70% of women aged between 50–69 years at two year intervals and to make breast screening available for women aged 40–49 years and 70 years and over. It is essential that these women return for subsequent screening.

Non-individualised and individualised strategies should be developed, monitored and evaluated centrally to ensure their effectiveness and efficiency. Equitable participation in the program should be achieved with eligible women having access to screening services irrespective of their social, economic, cultural or geographical circumstances.

2.1.1 Community education

The National Program should have co-ordinated community education strategies that operate within the following guidelines:

- The aim of community education should be to raise the awareness of the community in general and eligible women in particular about the objectives and policies of the National Program for Early Detection of Breast Cancer.
- Educational/promotional strategies should be developed from an understanding of the information needs of the target population.
- These strategies should recognise that women are not a homogeneous group—socio-economic status, culture, language, educational status and marital status should be considered.
- Educational/promotional programs should be developed in consultation with women from the target population to ensure their appropriateness and potential to be effective.
- Strategies used to recruit women for breast screening should be efficient with costs per woman recruited monitored closely.
- Educational resources should be produced at the State Co-ordination Unit level, based on qualitative and quantitative research that recognises the complexity of the relationship between knowledge, attitudes, beliefs and behaviour, so that a uniform message can be conveyed to women.

- Educational resources should provide accurate, honest and sensitive information to women so that they can make an informed decision whether or not to participate in the program.
- Educational resources should also be provided in a culturally sensitive way and in languages other than English.
- The priorities for education are to:
    - inform women that the goal of the National Program is to reduce morbidity and mortality amongst eligible women;
    - explain the eligible age group for screening including information about why it is not offered to women outside the eligible age group;
    - acknowledge women's anxiety about breast cancer;
    - highlight the benefits of early detection of breast cancer, including better treatment options;
    - reduce women's fear of breast cancer and its treatment;
    - explain the limitations of mammography screening in detecting breast cancer;
    - inform women of their risk of developing breast cancer;
    - inform women that there might be some discomfort with mammography;
    - inform women that up to 10% may be called back for further assessment in the first round, but that recall does not imply cancer;
    - encourage women who notice changes between screens to seek prompt medical advice;
    - provide women with practical information about the services i.e. how to book, what to wear etc.;
    - produce written material in plain language and present it in a manner that is appropriate to the eligible women—easy to read and appealing.
- All educational/promotional activities should seek the active participation of women in their development, design and implementation and be undertaken in the wider context of women's health.

2.1.2 Professional education

As the major providers of primary health care to women in the target population, general practitioners must themselves be a key focus of professional education strategies. However, professional education strategies should include the roles that are, or might be, played by other health workers in the community, particularly those with a community health/ women's health interest.

Thus, the National Program should have co-ordinated professional education strategies that function within the following guidelines:

- The strategies are developed from an understanding of the information needs of various health professional groups, these needs being identified from qualitative and quantitative research.
- Education activities and resources should be developed in consultation and close co-operation with relevant health professionals and their organisations.
- Education activities and resources should be developed and co-ordinated at National or State level, so as to avoid duplication of effort and to ensure consistency with respect to information and screening recommendations/guidelines.
- Educational materials should provide an up-to-date, accurate and honest appraisal of the research literature on screening mammography, with particular reference to its role, its relevance to different age groups, and relationship to other screening modalities (e.g. breast self examination), so as to assist health professionals in educating and/or advising women on whether or not to participate in the Program.
- Educational resources should provide guidance to health professionals on where to find additional information on key issues if required.
- Strategies and education materials should clearly support the role of the woman's general practitioner in the key areas of client education, recruitment and counselling. Educational strategies should recognise that in the event that an abnormality is confirmed at assessment, many women will turn to their general practitioner for advice and support.

Priorities for professional education are to:

- explain the rationale for limiting the screening program to women in the eligible group, and specifically targeting women 50–69 years;
- highlight the benefits and disadvantages of screening mammography;
- explain the rationale for a controlled, staged implementation process in the National Program, and for a funding mechanism other than Medicare fee-for-service.

2.1.3 Participation rates

The breast screening services will need to be implemented within a geographically defined population of eligible women to enable participation rates to be calculated.

In conjunction with appropriately timed recruitment strategies the following should be features of the breast screening service that will ensure high levels of participation:

- friendly and efficient bookings system;
- minimum waiting time for appointments;
- confirmation of booking and provision of clear instruction about the location of the service, parking, public transport etc.;
- after hours services, i.e. evenings and/or Saturday mornings.

To ensure high rates of participation, adequate resources should be allocated for the recruitment of women, which should be centrally co-ordinated.

2.1.4 Rescreen compliance

High levels of compliance to attend for rescreen must be an important feature of effective breast screening and assessment services.

Women's attendance for rescreen should be enhanced through inclusion of the following features:

- ensuring that the initial visit is as pleasant as possible for the woman. This would include both friendly, considerate and sensitive care from the staff and pleasant surroundings;
- informing women that they will receive a letter inviting them to attend for rescreening in the recommended period. This should be included in the woman's notification of her results. A booklet that includes a section for the woman to record her mammography history may also be useful;
- reminder letters to each woman preferably with an appointment date.

2.1.5 Equitable participation

There should be an understanding of the features of the eligible population in the defined area for the breast Screening and Assessment Service so that the recruitment strategies can be appropriately developed and implemented in the first instance.

Participation should be sampled regularly to assess the levels of participation on the basis of age, socio-economic status, language spoken at home, Aboriginality and marital status. Relevant qualitative and quantitative research should be undertaken to identify barriers to participation among eligible women, in conjunction and consultation with relevant women's groups.

Steps should be taken to redress any under representation of any sector of eligible women.

2.2 SERVICES *and* FACILITIES *for* SCREENING *and* ASSESSMENT

2.2.1 Introduction

The service to the client and the facilities provided to screen women for breast cancer will to a large extent determine the level of participation of women in the program, and will minimise any negative effects of the program, in particular unnecessary anxiety to the woman and her family and unnecessary biopsy.

Screening services are the first stage in the screening pathway and as such must be of a high quality as outlined in Section 2.2.2.

Assessment is an integral component of the screening pathway and should provide dedicated multi-disciplinary and simultaneous assessment in the following modalities; imaging (includes mammographic and/or ultrasound), clinical, cytological (sampling and interpretation) and communication and counselling skills needed to inform women of the outcome. Either one of the two screen readers should be part of the assessment team.

2.2.2 Screening

The services provided under the National Program should not be provided concurrently with any other radiological or diagnostic services. Such facilities could be developed within the public or private sector.

Individual screening units, which may be fixed or mobile, shall not operate independently of a dedicated assessment centre/service (see Section 2.2.3).

Written policies and management protocols should exist for each screening unit and the staff working in it. These should clearly identify:

- staff responsibilities and lines of authority;
- client consent procedures;
- procedures for handling complaints;
- procedures for early recall (if applicable);
- procedures for routine recall;
- procedures for discharge from the Program (e.g. in event of death, client too young, etc.);
- roles of the various components within the recruitment/screening/assessment pathway, and staff accountabilities within and between these components;
- information for clients;
- counselling procedures where appropriate.

Screen taking

Screening units within a State should possess *as far as possible* common protocols and data forms for management of the screening process which are in turn compatible with Commonwealth funding criteria and screening policies. A specified person should be designated to maintain these protocols in an up-to-date format at all participating assessment centres/services and to distribute these to affiliated screening units.

All staff should receive training in the procedures to be followed, including regular updates.

In accordance with national funding criteria, all mammograms must be performed by appropriately trained and qualified radiographers.

Staff working in screening units and assessment centre/services should be trained to provide concise, accurate information to women attending the screening unit, and to relate to women at all times in a reassuring and confident manner.

At the prevalent screening round, the two standard views (cranio-caudal and medio-lateral-oblique) must be taken of each breast.

Written protocols should exist, and be adhered to, for the following situations:

- women presenting with breast prostheses;
- choice of film format to be used for women with very large breasts; and
- minimum number of views to be performed at second and subsequent screening rounds.

To minimise anxiety and radiation exposures to individual women, radiographers and other technical staff (dark room attendant) must be able to maintain adequate technical standards, thus keeping client returns for technical repeats to a minimum.

Radiographic and technical staff should be able to demonstrate knowledge of and adherence to appropriate quality control procedures. (see Section 2.2.10 for quality assurance standards).

Screening units should have a minimum throughput of 5000 women per annum. These films to be read by the minimum number of readers.

Reading

All screening films must be read independently by two readers at least one of whom must be a radiologist, with the reports being combined into a single recommendation. Both readers must be specially trained in screening mammography.

The standard report of the initial screen should clearly indicate an outcome in a non-narrative form, approved by the State Co-ordination Unit.

Screening units must have explicit protocols for the procedures to be followed in the event of discordant calls between the film readers. This may involve use of a third reader or in other centres discussion between the two readers to reach consensus.

Film readers must have appropriate training and demonstrated experience and expertise in reading screening mammograms. Individually, screening film readers should each read a minimum of 2000 screening mammograms per annum and be able to meet the overall program performance standards, detailed in Section 3.2 of this document: 2.1(b), 2.1(c), 6.2(a), 6.2(b), 6.3.

2.2.3 Assessment

Assessment centres/services shall be responsible for all work-up and diagnostic procedures provided as part of the Program up to and including cytological or histological diagnosis of breast cancer.

Assessment centres/services should have access to comprehensive facilities for evaluating women with an abnormal screening mammogram and for evaluating women who report breast symptoms at the screening visit.

The assessment centre/service should have the capability for complete mammographic work-up (including cone compression and magnification views), ultrasound examination, clinical evaluation, needle biopsy (including ultrasound-guided and sterotactically-guided needle biopsies), and aspiration cytology.

Specific counselling services should also be available for the women involved, both prior to and during the assessment process as required.

Privacy should be provided for women at the assessment centre/service for counselling purposes.

The assessment centre/service should have access to and close liaison with facilities for open biopsy that can perform radiographic localisation of impalpable lesions and specimen radiography, as well as special histopathological techniques for evaluation of these lesions. Assessment centres/services must also have close liaison with facilities providing all forms of management, treatment and counselling for women with diagnosed breast cancer.

Centres/services should show evidence of educational and liaison activities conducted with general practitioners to support them in their role as the primary care provider, and as a major contributor in the recruitment, education and counselling processes associated with the screening/assessment pathway.

Where appropriate, assessment centres/services should also liaise with other relevant health professionals in their regions.

Written management protocols and policies should exist for each assessment centre/service and for the staff working within it. These should clearly identify:

- staff responsibilities and lines of authority within the service;
- client information;
- client consent procedures;
- procedures for early review;
- procedures for routine recall;
- procedures for discharge from the Program;
- the roles of various components within the recruitment/screening/assessment pathway, and staff accountabilities within and between these components.

Follow-up protocols

Assessment centres/services should have documented procedures to ensure that appropriate follow-up is undertaken for women with screen-detected abnormalities. This is critical to the eventual success of the National Program.

Common protocols for the management of screen detected abnormalities should be developed as far as possible at the State Co-ordination Unit in consultation with Radiologists, Surgeons, Pathologists and Directors.

Staff should be aware of the reason for attendance at assessment centres/services to permit appropriate client management and throughput arrangements.

Diagnostic procedures

Assessment centres/services and affiliated diagnostic services should have written protocols for the management of recall clients, that include criteria for case selection for specific diagnostic procedures and procedures to be followed at each step of the diagnostic pathway.

Assessment and biopsy centres/services should have an appropriately constituted group to develop these clinical protocols and to keep them under regular review.

Centres/services performing open biopsy should have co-located facilities for specimen radiography, as well as access to nearby facilities for performing special histopathological techniques for impalpable breast lesions.

All assessment/biopsy centres/services should have developed close links with facilities that provide a full range of treatment and counselling for women with diagnosed breast cancer.

Recommendations concerning pathology standards shall be made in consultation with the National Pathology Accreditation Advisory Council, the National Association of Testing Authorities and the Royal College of Pathologists of Australasia.

Review processes and quality assurance

Each assessment unit must have established, formal mechanisms for review of clinic policies and individual client outcomes. These should include written procedures for regular audit of film quality, equipment functioning, and clinical outcome measures.

2.2.4 Staffing

The assessment centre/service and its affiliated screening units should have an integrated administrative/management structure which ensures a close liaison between professional staff in the screening units and affiliated assessment centres/services, preferably with some staff overlap.

Assessment centres require multi-disciplinary, professional input, provided by teams that must include a radiologist, breast surgeon, and cytologist/pathologist as required.

Radiographers involved in screening units should spend some part of each year in an assessment centre/service. At least one of the radiologists involved in reading original screening films should also be involved in the assessment centre. The radiologists, surgeons and pathologists involved in the assessment centre should also be involved in open biopsy procedures performed as part of the Program.

These associations are necessary to maintain high standards for the screening process, by facilitating mechanisms for review and quality control and the development of diagnostic and therapeutic expertise.

The diagnosis and management of women with a screen detected abnormality requires a multi-disciplinary team approach with ongoing consultation and review of procedures and outcomes.

Medical personnel should have accreditation status or appropriate qualifications as defined by their respective Colleges.

Medical personnel should participate in at least monthly meetings to monitor performance and review the experience of the Service.

Radiographers are to be fully trained in screening mammography through training courses that have been accredited by the Australian Institute of Radiography.

Those personnel acting in a counselling role are to be specifically trained in breast cancer screening, in particular dealing with anxiety, and discussing with women the outcomes of screening.

Clinical and support staff all should have participated in specific in-service training in breast cancer screening that included developing skills to deal sensitively with anxious women.

2.2.5 Provision of information

Women attending breast screening and assessment services should be provided with comprehensive and easily understood information about screening.

Each woman attending for screening should sign a consent form that clearly outlines the screening process including the possibility of recall for follow-up assessment. The woman should also be informed in writing that screening does not prevent breast cancer, nor does it detect all breast cancers.

Information provided by the woman and data collected by the Service should be held in the strictest confidence. Service procedures must ensure the confidentiality of individual client information. All women must be informed that data will be collected about each screening episode for the purpose of monitoring and evaluating the screening service.

Women should be advised of the benefit to them of information about their screening being included in their family practitioner's record.

2.2.6 Physical environment

Services should be provided in pleasant surroundings that are comfortable and non-threatening.

It is desirable that the setting of the service is separate from medical services, either in the community or a separate setting within a hospital environment.

Waiting areas provided for women once they have gowned in preparation for their examination should allow women to feel comfortable while maintaining their privacy.

Wheelchair access should be provided where possible at screening and assessment services. Whenever possible, clinics should be located at ground level to enable easy access for women in older age groups.

2.2.7 Education and counselling for Screening and Assessment Services

Within a Screening and Assessment Service, education and counselling are integrally linked. Counselling will often be given in the context of provision of further information to the woman, and it is important that counselling is not seen as an isolated element of the program—all information should be provided in a sensitive manner.

Educational guidelines

The education of women at a screening unit or assessment centre is an essential component of a successful screening program. A large number of women who attend for screening will be informed about screening mammography and about the Program, but this cannot be assumed.

Therefore, while the major emphasis of an educational program within a screening and assessment service is to inform women about the procedure they are about to undergo and encourage and motivate women to attend for regular mammography screening, there will still be a need to educate women about mammography and the benefits and limitations of screening. This is also an opportune time for women to voice any of their queries about screening or breast cancer.

A combination of individualised and non-individualised approaches can be used to educate women within screening and assessment services.

General information about the Program and about breast screening can be provided on a non-individualised basis using similar material to that used for community education e.g. booklets, pamphlets, posters as well as continuous play breast self-examination videos, breast models, etc.

These resources should be made available in the waiting room or given to women to take home, and should be available in languages other than English.

The purpose of this material should be to:

- educate women about the benefits and limitations of mammography screening and the benefits of early detection;
- encourage and motivate women to attend for mammography screening on a regular basis and advise them of the recommended screening interval;
- educate women about the importance of regular clinical examination and encourage them to seek advice if changes occur between regular visits;
- provide information that will enable women to overcome barriers associated with breast screening;
- encourage women to ask questions and to voice any concerns they may have about breast cancer and screening;
- inform women who document that they have breast symptoms (lump or nipple discharge) at the time of screening that they will be recalled for assessment.

Information should also be provided to women on an individual basis.

The woman should be provided with information about breast self examination.

Accurate information on risk should be available where appropriate to those women who have a strong family or personal history of breast cancer or benign breast disease.

The woman should be advised of how and when the results of screening will be received.

If a woman is recalled or further work-up is required, the woman should be advised exactly what is involved and the reason for it.

Counselling guidelines

An integral component of a dedicated breast screening and assessment service is the provision of professional counselling. It is important that all women who attend for screening or assessment have access to counselling to reduce the level of anxiety and to assist those who are diagnosed with breast cancer to better cope with their diagnosis.

All counselling should be provided by counsellors who have received some level of appropriate training and who are able to determine the level of counselling required by each woman.

Counselling should be accessible to all women and their supporters who attend screening units or assessment centres.

Emotional support should be provided at all stages of the screening pathway, but particularly during assessment or if there is a diagnosis of breast cancer.

Women with a diagnosis of breast cancer should be given comprehensive and easily understood information on treatment options and encouraged to be actively involved in decisions about these options.

Women should be encouraged to voice their feelings or concerns about breast cancer and their treatment options.

If language is a difficulty all care should be taken, where appropriate, to utilise the services of qualified interpreters.

2.2.8 *Notification procedures*

So as to minimise anxiety, women should be notified in writing and at the earliest opportunity of the outcome of their screens. The results of screening should be provided in a way which is sensitive to the woman's possible anxiety. All letters sent to women should be subject to review.

The woman who attends for assessment should be informed of the outcome by a member of the assessment team who has skills in communication and counselling.

The woman's general practitioner should be kept informed of the screening and/or assessment outcome, unless otherwise directed by the woman.

Women who are recommended for open biopsy following assessment, and who have not nominated a general practitioner, should be encouraged to do so before proceeding with referral.

2.2.9 *Involvement of women in decisions*

All women attending for breast screening and assessment should be actively involved in decisions about, and discussion of, all procedures undertaken.

Women recommended to have open biopsy/cancer treatment should be encouraged to discuss this fully before proceeding. This may involve more than one session and could include follow-up counselling undertaken by a trained breast cancer counsellor. The information provided must be both comprehensive and easily understood by the women to enable them to make an informed decision.

2.2.10 *Quality assurance standards*

The Screening and Assessment Service should have a documented quality assurance program, the supervision of which will be the responsibility of the designated radiologist. The position paper *A Quality Assurance Program for Mass Screening in Mammography*[4] and the publication *Screening Mammography Technology*[5] give useful information. Appendix 2 is an extract from these publications, and should be used as a guide in the administration of the Program.

1 Equipment and radiation protection

The equipment used should comply with the relevant Standards Association of Australia standards where appropriate and also comply with and be approved by the State Radiation Protection Authorities. The radiation protection in the fixed or mobile installations should be approved by the relevant State Radiation Protection Authority.

Appendix 3 should be consulted to give a guide for the purchase of *new* equipment.

2 Processing

Centres should be able to provide documentary evidence of their adherence to a quality assurance program. It is essential that optimal processing conditions are achieved and maintained, both to increase cancer detection rates and to minimise radiation dose.

Processing of mammography film must be carried out in film processors used only for single emulsion film and optimised in accordance with particular equipment and film-screen combinations. The processors should be cleaned and serviced regularly.

Wherever processing is undertaken, written protocols must exist for staff involved, which should include the detailed quality control steps to be followed and their frequency.

Protocols should also contain specific guidance on remedial procedures. Written records must be maintained by all screening units and assessment centres/services, documenting quality assurance checks, equipment failure or malfunctions and the remedial steps undertaken.

The discharge of chemical waste from fixed and mobile installations should meet appropriate standards designed to reduce environmental pollution.

Given the likelihood of ongoing technical advances in the field, overly prescriptive recommendations as regards processing are inappropriate.

All radiographers or technicians employed within the accredited Screening and Assessment Services should be provided with opportunities for ongoing education/training, to ensure their up-to-date knowledge and attention to quality assurance principles.

3 Mammogram evaluation

Mammograms should be of good quality, properly identified and with minimal artefact. They should be of appropriate density, resolution and contrast. Mammograms should show optimal positioning. In addition to the continuous assessment of film quality, mammograms should be formally evaluated on a 1 to 3 month basis by the designated radiologist and records kept of number and nature of defects detected.

It is desirable that each examination be clearly identified as to the machine used and the name of the radiographer. The results of the evaluation should be transmitted to the radiographic staff directly on an individual basis. Meetings should be held from time to time with the radiographers to discuss the results and rectify any problems. The frequency of the formal assessments and staff meetings will vary depending on the number of radiographic defects, the experience of the staff and the length of time the particular program has been in operation.

4 Radiation dose measurement

The radiation dose on each mammographic unit should be calculated annually and records kept of the date, technique and dose measurement. The recommendation of the Australian Radiation Laboratory in the publication *Radiation Doses from Mammography in Australia*[6] should be a guide. A summary of the recommendation is as follows:

1 The International Commission of Radiological Protection recommendations (IC87) that 'the usual reference terms for radiation dose in the glandular tissue (excluding skin) in a uniformly compressed breast of 50% adipose, 50% glandular tissue composition. The reference breast thickness should be specified' be used as a standard within Australia.

2 The maximum mean glandular dose (MGD) from x-ray mammography in the glandular tissue (excluding skin) in a uniformly compressed breast of 50% adipose, 50% glandular tissue composition of 5 cm thickness for a single image of the breast, should not exceed 2.0 mGy when a grid is used and not exceed 1.0 mGy when a grid is not used.

3 Calculation of the MGD should be made using the method recommended by the NCRP (NC86) or by direct depth dose integration.

4 Regular quality assurance monitoring of x-ray equipment and processing, as recommended by the Australian Institute of Health (AI90b) should be undertaken by each centre conducting mammography.

5 The MGB for each mammographic unit should be measured annually by an independent body.

5 Breast ultrasound

A modern high resolution machine should be used with a hand held probe operating in the 5–10 megahertz range. A stand-off should be available for best resolution near the skin line, preferably attached to the transducer face.

Ultrasound examinations should be conducted under the supervision of a radiologist experienced in ultrasound of the breasts and preferably experienced in the use of ultrasound in other areas. The ultrasound machine should be regularly serviced.

An ultrasound phantom designed to check the system efficiency in detecting small lesions in a tissue equivalent material and to check the ability to distinguish small cysts from solid lesions should be designed and used to check ultrasound machines in all assessment centres/services.

2.3 DATA COLLECTION

2.3.1 *Principles of data collection*

The rationale, aims and objectives for the collection of data to monitor and evaluate the National Program have been clearly established and documented. This information should be available to, and understood by all staff participating in the Program.

The amount of data should be the minimum required to adequately assess the performance of the Program in general and individual services.

Assessment centres must be provided with the resources to collect and monitor their basic activity and have access to their performance data in a timely fashion. This feedback is essential to maintain staff interest and morale, as well as to improve individual program results.

Data which are collected should be accurate and should be collected to comparable standards by each clinic.

Access to individual client data should be restricted to the minimum number of persons, on a 'need-to-know' basis.

All data must be maintained with due respect to its personal nature. Staff should know and adhere to written protocols for maintaining clients rights to privacy and confidentiality of medical information.

Each data record should have a unique identifying number allocated to each client.

2.3.2 *Quality assurance*

Documented procedures are to be maintained for data collection including the designated movement of records within the clinic. This is to ensure records are not mislaid or sighted by unauthorised personnel.

Quality control procedures should be documented and undertaken at all levels in the screening and assessment pathway. These procedures should include regular audits of data quality and routine editing of relevant client/summary evaluation data. All staff must be instructed in these procedures and be able to demonstrate their knowledge and understanding of the procedures.

Standard maintenance procedures for hardware and software should be documented and adhered to.

There should be an identified person who takes overall responsibility for data integrity, assisted by clinical and administrative line managers.

2.3.3 *Ethical and medico-legal considerations*

All paper clinical records are to be signed by the health professional who is directly responsible for a particular episode in the screening or assessment pathway. This includes those taking and reading the mammograms, as well as those involved in clinical assessment.

Data items collected for each screening or assessment episode must be recorded accurately and legibly. Abbreviations should be avoided.

All records of each screening episode are to be securely maintained, using an accepted method of medical record filing that ensures easy access to a woman's record.

Screening and assessment units must obtain the woman's informed consent for all procedures. Her consent should also be obtained for the exchange of clinical data between clinicians involved in her management, and for the use of anonymous, aggregate data for program evaluation purposes.

Service protocols should provide guidance for staff in the event that the woman does not give her full consent at any stage of the screening/assessment pathway.

The consent form must contain a simple statement of the objectives of the screening program, as well as details of procedures to be performed. It should include an explanation, presented in lay terms, of the meaning of false positives and false negatives and their likelihood of occurrence. Every consent form should include:

- signed statement that the woman understands mammography does not pick up all cancers;
- agreement to/request for a mammogram (and fine needle aspiration and/or ultrasound if recalled);
- consent to provide information to the woman's doctor, or other doctors to whom she is referred;
- use of the information, providing identity is not disclosed, for monitoring and evaluation purposes;
- recording of identifying information on a confidential register primarily for the purposes of routine recall and follow-up.

It is intended to develop a form to be used as a model.

In those states where there are specific procedures or regulations governing privacy and confidentiality, screening and assessment units should provide written statements as to how these rights will be protected and all staff should demonstrate knowledge of the appropriate procedures.

2.4 TRAINING ACTIVITIES

Implementation of a National Program of Mammographic Screening is dependent on the availability of specially trained staff committed to providing a high quality efficient service. The need for specialised training of staff associated with the National Program has been recognised by the Intercollegiate Committee of the Royal Australasian College of Surgeons, the Royal College of Pathologists of Australasia, and the Royal Australasian College of Radiologists and these training guidelines draw on work already done by that Committee.

The creation of assessment centres with their associated screening units provides a focus for developing specialised training courses for all types of staff needed to expand the National Program. However, institutions providing basic training for radiographers should be urged to develop mammographic training facilities and provide training during the basic radiography course in mammographic positioning, equipment, radiographic techniques to minimise dosage, mammographic film processing and quality assurance. National co-ordination of course curricula is recommended via the Australian Institute of Radiography and the Royal Australasian College of Radiologists.

Facilitating the availability of appropriate and adequate training will be an integral part of the responsibility of the State Co-ordination Unit and such training will be part of a national network of recognised training centres. In some States the size of the program may not justify their own training course, however access to one should be assured.

It is likely that in States which develop a training program, an assessment centre/service (or possibly a consortium) will be charged with providing a specialised training course for all staff who join the screening program. The training course should cover not only professional aspects but also include an overview of the planning and development of assessment centres and their associated screening clinics.

Professional training should cover all aspects of screening and assessment of screen detected lesions. Although specific clinical/technical training should be provided for radiologists, radiographers, surgeons and pathologists who will be associated with the assessment centre/service and associated screening units, training should also be provided for management staff, data managers, counsellors and clerical staff. All trainees must be appropriately supervised.

It may be that some staff have received equivalent training elsewhere, however it is important also that they are familiar with local policies and practices.

Each State training program will be developed to suit the needs of that State, however it will be important that the expertise of staff from the training centre and the State Co-ordination Unit be utilised at the time new Screening and Assessment Services are being planned. After this initial stage all staff should have an appreciation of the policies and practice of the National Program.

Training courses will vary, but will include a period spent at an operational training centre. In general terms the course should include a planning and management component and professional group components. All staff of new Services should be trained, and wherever possible this should be in a multidisciplinary format.

Each State training centre will require:

- radiological expertise in screening maintained at a high level of screening activity which implies an annual rate of around 10,000 examinations;
- an extensive teaching file of mammograms;
- state of the art mammographic equipment, and facilities for localisation of impalpable lesions, and radiology of surgical biopsy specimens;
- a functional multi-disciplinary team;
- to appropriately liaise with any National Program which is developed.

The curriculum for an approved training program should include:

- the organisation of population screening programs including evaluation of process and outcome;
- technical aspects:
  - equipment
  - examination techniques
  - quality control routines
  - radiation dose monitoring;
- image interpretation in the screening context with particular attention to small carcinomas and exposure to a wide variety of normal and abnormal mammograms;
- the evaluation of screening detected abnormalities by radiological methods and in collaboration with clinical colleagues and the cyto and histo pathologist;
- the radiological localisation of non-palpable lesions;
- the radiology of surgical biopsy specimens;
- a working knowledge of modern surgical, radiotherapeutic and oncological procedures used in the management of breast cancer patients;
- an awareness of the possible psychological problems which may occur in dealing with women in a screening program.

2.4.1 Radiologists

Radiologists involved in breast screening programs who are responsible for screening mammography in a screening unit will have received an acceptable level of formal training and experience in mammography, and will have attended a course at a State or national level in screening mammography. A radiologist working at an accredited assessment centre/service will in addition have received an acceptable level of formal training in the radiological assessment of women with abnormal screening mammograms.

All radiologists associated with the Mammographic Screening Program should attend the State training course.

2.4.2 Radiographers

Screening units should employ only radiographers with experience in mammography. All radiographers in accredited screening units and assessment centres/services, should have attended a course at State or national level in screening mammography.

2.4.3 Breast physicians/clinicians

The role of breast physicians/clinicians in assessment centres/services varies. Where breast screening services employ medical practitioners who are not qualified radiologists, surgeons or pathologists, they should have had formal training in breast cancer screening (including examination and counselling) and should be responsible to the Director of the assessment centre/service or the Program Manager.

The training of breast physicians/clinicians should involve an extended period of work under supervision in an assessment centre. In addition attendance at a formal training course is obligatory as well as attendance at a course run by the State training unit.

2.4.4 Surgeons

Surgeons involved in breast screening programs should be members of the Section of Breast Surgery of the Royal Australasian College of Surgeons and have appropriate training and expertise in:

- the clinical assessment of women with screen detected abnormalities;
- needle-localised biopsy of impalpable lesions;
- surgical management of benign and malignant breast lesions detected in the screening programs.

The surgeon should attend regular assessment sessions where women with detected abnormalities can be seen jointly with the radiologist and where future management can be planned.

All women requiring needle localised biopsy will be seen by a surgeon in conjunction with the radiologist.

The surgeon should attend regular conferences with pathologists and radiologists where the activities of the Screening and Assessment Services will be reviewed.

The surgeon will be responsible for recording surgical and related clinical details.

The surgeon is responsible for ensuring that surgical quality assurance guidelines are met.

The surgeon should have access to suitable operating hospital facilities for the surgical management of women with detected abnormalities.

The surgeon should promote participation in clinical trials.

Surgeons participating in breast screening programs should initiate and guide training programs for surgeons and surgical trainees wishing to become proficient in the techniques required for the management of screen detected abnormalities and participate in multidisciplinary training activities.

2.4.5 Pathologists

Pathologists involved in breast screening programs should be Fellows of the Royal College of Pathologists of Australasia or hold an equivalent academic qualification in Pathology.

The pathologist must be skilled in interpreting breast cytological and histological specimens.

The designated pathologist or a deputy should be a member of the assessment team and should be responsible for the reporting of review of *all biopsies and fine needle aspirations of lesions detected by screening*. Training of registrars and other pathologists associated with the centre is also the pathologist's responsibility.

The pathologist is responsible for ensuring that optimum handling of mammographically detected lesions occurs.

This includes:

- receipt of mammogram with biopsy;
- specimen mammography for:
    - confirmation of excision and clearance of the lesion (includes the availability of a radiologist for consultation);
    - guidance in the selection of tissue sections;
- analysis of the pathology and cytological data in a manner suitable for quality control, reports and publication.

The pathologist should participate in regular multidisciplinary meetings with the radiologists and surgeons of the Screening and Assessment Service and review all fine needle aspiration and biopsy diagnoses of screen detected cases by that unit. This may involve retrieving biopsy tissues and aspirates from various pathology practices.

The pathologist should attend an internationally recognised mammography screening unit or a recognised training centre in Australia to participate in a course run by that centre or spend sufficient time to acquire the special skills needed. Attendance is to be within the first twelve months of the commencement of appointment to the screening program.

Designated breast screening pathologists and their deputies in each State should meet locally on a regular basis, perhaps once every two or three months initially and then six monthly to discuss and clarify reporting nomenclature, diagnostic criteria and any specific problems that are encountered.

Free inter-unit referrals for problematic cases is strongly recommended.

Breast screening pathologists should meet nationally at least once a year to co-ordinate and correlate diagnostic criteria and performance statistics of each of the units. These meetings would also be an excellent forum for furthering education in aspects of fine needle aspiration, borderline cases and research possibilities.

2.4.6 *Counsellors/educators*

Counsellors/educators are an integral part of the staff of a Screening and Assessment Service. Most of these staff will have particular experience and training in counselling women with breast symptoms or with abnormal screening mammograms. Counselling may be undertaken by a range of health professionals.

All counsellors associated with Screening and Assessment Services should have attended a counselling course and a State training course.

2.4.7 *Clinic/clerical Staff*

All clinic/clerical staff attached to an assessment centre or screening unit should attend a State or national training program. Ongoing inservice training should be available to all staff within the service.

2.5 PROGRAM MANAGEMENT

2.5.1 *Management structure*

The management structure of the Screening and Assessment Service must be clearly documented in writing. The documentation must:

- identify one person who has responsibility for the management of all facets of the Service (hereafter referred to as the Director);
- document the various functions of the Service (e.g. recruitment, screening, assessment); the responsibilities of specific individuals and or committees in relation to those functions; and the relationships between them;
- clearly delineate the relationships and responsibilities of medical and non-medical staff;
- document the means by which any appointments (to staff, committees etc.) are to be made;

- document the representation of relevant client and professional groups on advisory or management groups as appropriate.

In Screening and Assessment Services, a radiologist, surgeon and pathologist should be designated who will each be responsible for those aspects of screening and assessment related to their particular discipline.

2.5.2 Management responsibilities

The Director of the Screening and Assessment Service shall:

- ensure that the operations and management of the Service are in accordance with the aims, objectives, and policies of the National Program;
- ensure that the short and long term plans of the Service are in accordance with the appropriate State or Territory Plan, and that the functions undertaken by the Service are as agreed with the relevant State Co-ordination Unit, including adherence to screening and assessment protocols developed by the State Co-ordination Unit;
- ensure that the aims, objectives and policies of the National Program are made freely available to clients, staff and other relevant health professionals;
- regularly review service provision in relation to policies and plans, and to make adjustments as necessary;
- ensure that the Service is conducted in such a way that barriers to participation by any eligible woman are minimised, and that active measures are taken where appropriate to ensure equitable access;
- be responsible for the provision of high quality services and client care within the Service and the implementation of a quality assurance program, including the co-ordination of and co-operation in any inspection undertaken by the State Co-ordination Unit;
- ensure that a multi-disciplinary team operates within the Service: integrating the various elements of the screening and assessment processes; meeting regularly; reviewing the performance of the component parts in relation to the performance measures adopted by the National Program; and taking steps as necessary to improve performance;
- ensure that a written record is made of meetings of advisory or management committees which form part of the management structure;
- ensure the efficient management of the financial resources of the Service and that it operates within the budget agreed with the State Co-ordination Unit;
- ensure that the Service operates within financial guidelines established from time to time by the National Program and/or the State or Territory Co-ordination Unit;

- ensure that adequate cost and financial data are provided to the State Co-ordination Unit as required as part of regular review of the cost effectiveness of the Service;
- ensure that data are collected as required by the National Program for the Early Detection of Breast Cancer. It should be provided in a timely fashion, as required by agreement with the State/Territory Co-ordination Unit, and also be available to be utilised by the Service to monitor its own performance;
- ensure that required medical and other client information is maintained in a discrete and confidential manner;
- ensure that appropriate liaison occurs between the Service and external community and community health and hospital personnel;
- ensure that appropriate staffing policies and procedures are in place and adhered to;
- ensure that adequate staff provision is made, and that orientation and in-service training programs are available for staff members, to maintain staff knowledge and skills and to improve performance.

Section 3

PERFORMANCE OBJECTIVES *and* ACCEPTABLE STANDARDS

3.1 INTRODUCTION

The ultimate goal of breast screening by mammography is a substantial reduction in breast cancer deaths in the target population. It is impossible to measure any mortality reductions in the early, implementation phases of an organised, population-based screening program. Therefore, it is essential that key intermediate performance objectives, that may act as indicators of eventual mortality reductions, be clearly identified and monitored from the outset of the National Program.

The definition of these performance measures and their attainment should be the key focus of every State Co-ordination Unit and its affiliated assessment and screening centres.

3.2 PERFORMANCE OBJECTIVES

This section provides explicit statements of the performance objectives and minimum acceptable standards for specific components of the National Program for Early Detection of Breast Cancer. These statements encompass recruitment, screening, assessment, biopsy, treatment outcomes, wait times for key steps in the pathway, and overall program goals.

All values quoted for acceptable standards in the table overleaf are the minimum acceptable values for the National Program and its individual components. These standards will be reviewed in the light of program experience.

The Standards have been devised from overseas experience and the Australian pilot projects. Relevant sources are:

- Forrest Report[7]
- Pritchard Report[8]
- Breast cancer screening in Australia: future directions[3]
- British Association of Surgical Oncology (BASO)[9]
- NHS/BSP/Vessey 1991[10]

PERFORMANCE COMPONENT	PERFORMANCE (QUALITY) OBJECTIVE	ACCEPTABLE STANDARD
1. Recruitment	1. To maximise the number of women participating in screening	≥ 50% of eligible women (40–69 years)
	2. To maximise participation by women from Aboriginal and non English speaking backgrounds	Attendance in proportion to their representation in the population
	3. To minimise anxiety and increase acceptance of service by women	Interval from booking to appointment ≤ 4 weeks
2. Screening	1. To minimise anxiety and x-ray exposure among screened women by limiting the proportion of technical repeat films and the numbers of women recalled for mammographic assessment	a) Technical repeats < 3% of total films used b) Assessment recalls < 10% of women screened at prevalent round c) Recalls at < 5% at subsequent rounds
	2. To maximise client acceptance while at the same time minimising anxiety among screened women by providing prompt, written notification of results	a) Notification to occur within ≤ 14 days b) > 80% to be notified within 10 working days
	3. To maximise client acceptance of the screening service as evidenced by high participation rates among those invited for routine rescreen	a) > 75% participation at round 2 b) > 50% at 3rd and subsequent rounds
3. Assessment	1. To minimise waiting time and women's anxiety between initial screen and the first assessment visit	Interval < 2 weeks for > 90% of recalls

PROGRAM COMPONENT	PERFORMANCE (QUALITY) OBJECTIVES	ACCEPTABLE STANDARD
3. *Assessment (continued)*	2. To minimise the proportion of women referred for open biopsy	< 2% of women screened
	3. To minimise unnecessary invasive procedures (i.e. surgical biopsies for histology on benign cases)	Positive predictive value of biopsy > 25% (at prevalent screen) i.e. Benign: malignant biopsy ratio of • ≤ 3:1 for prevalent round • ≤ 2:1 in incident rounds
	4. To minimise the number of visits needed for further investigations	a) < 5% of women recalled for assessment for a screen abnormality are invited for early review b) Minimum period for review should be 6 months
4. *Biopsy*	1. To minimise the operative identification of lesions producing mammographic abnormalities	> 95% of impalpable lesions should be correctly identified at the first localisation biopsy
	2. To minimise the interval from a decision to operate for diagnostic purposes and the first offered admission date	90% should be admitted for an operative biopsy within two weeks of their first attendance at any assessment centre
5. *Treatment*	1. To ensure appropriate audit of follow-up	An annual follow-up form should be completed by the treating surgeon and returned to the assessment centre with the agreed data items

PROGRAM COMPONENT	PERFORMANCE (QUALITY) OBJECTIVES)	ACCEPTABLE STANDARD
6. *Overall Program performance*	1. To minimise the cost per women screened, based on a consideration of all aspects of the program for community education and recruitment up to and including histological diagnosis	a) ≤ $120/screen* at the prevalent screening round b) ≤ $80/screen* by year 5 of Program operation * 1990 prices
	2. To maximise the number of cancers detected	a) > 50% per 10,000 women screened in the prevalent screening round, including ductal carcinoma in situ (DCIS), but excluding lobular carcinoma in situ (LCIS) b) > 20 per 10,000 at subsequent rounds
	3. To maximise the number of minimal invasive cancers detected	> 15 per 10,000 screened women found to have invasive cancers < 10mm diameter on pathology
	4. To detect a representative proportion of DCIS at the prevalent screening round	10–20% of cancers detected
	5. To minimise the number of interval cancers	Proportion of women who develop breast cancer (including DCIS, but excluding LCIS) in 12 months following screening < 6 per 10,000

Section 4

ACCREDITATION PROCESS

4.1 LEVELS *of* RESPONSIBILITY

Levels of responsibility are illustrated in the Diagram at Figure 4.1 These are spelt out more fully below. The process will be that State Co-ordination Units will ensure that application is made for accreditation, and that appropriate documentation and inspection occurs. The State Co-ordination Unit will then make recommendations to the National Accreditation Committee which will formally approve the accreditation.

The National Co-ordination Unit in conjunction with the National Accreditation Committee and the National Advisory Committee, has responsibility for setting national guidelines and overseeing their implementation. State Accreditation Guidelines may be developed which will be approved by the National Accreditation Committee.

National Accreditation Committee

This Committee will consist of representatives of the relevant professional groups and of State and National Co-ordination Units.

It will be responsible for the development, publication and review of the National Accreditation Guidelines and for the formal accreditation of each Screening and Assessment Service within the National Program on recommendation from the State Co-ordination Units, acting in concert with the State accreditation group.

It will report to the National Advisory Committee and the National Co-ordination Unit on the implementation of the Guidelines and make recommendations following review. The National Accreditation Committee will also approve any State and Territory Accreditation Guidelines which may be developed to ensure that they are consistent with the National Guidelines.

The National Accreditation Committee will maintain a register of suitably qualified and experienced professionals to be drawn upon by State Co-ordination Units when forming their Accreditation Inspection Teams.

The National Accreditation Committee will establish a direct relationship with the Intercollegiate Committee on Mammographic Screening, and will refer matters to that committee as appropriate for professional comment or advice.

National Co-ordination Unit

This Unit has been established by the Commonwealth to manage and co-ordinate the implementation of the National Program. It has a specific function to provide secretariat support to the National Accreditation Committee and the National Advisory Committee in relation to accreditation issues.

State Co-ordination Unit

A State Co-ordination Unit (SCU) will be established in each State or Territory under the agreement signed between the Commonwealth and State and Territory governments. Each SCU will have similar functions which are defined by that agreement.

The SCU will have responsibility for ensuring that Screening and Assessment Services which are funded through the National Program in its State and Territory are accredited in line with these National Guidelines. The State Co-ordination Unit will also be responsible for the implementation of the National Guidelines within the State or Territory, and for the development of any State Accreditation Guidelines.

Each State Co-ordination Unit will establish an appropriate State Accreditation Group which will provide advice about accreditation within the State and Territory.

The State Co-ordination Unit will make recommendations to the National Accreditation Committee relating to the accreditation of each Screening and Assessment Service, and the National Committee will formally accredit the Service.

4.2 MECHANISMS *for* ACCREDITATION *and* REVIEW

The accreditation process will include the completion of an accreditation assessment form for the State Co-ordination Unit. The form will request information relating to:

- Screening and Assessment Service protocols;
- Quality Assurance Program for equipment, readers and takers, data collection and management, education and counselling services, booking/clerical staff;
- The qualifications of staff—only professionally qualified staff are to be used. Where College accreditation is applicable this should be the standard accepted.

As far as possible it is planned to develop nationally agreed forms and procedures for this process. This will be the responsibility of the National Co-ordination Unit in conjunction with the State Co-ordination Units.

The State Co-ordination Unit will appoint two independent persons, one a radiologist and preferably one from interstate, who will conduct inspections of Assessment and Screening Services, including equipment, following the provision of documentation as outlined above. The Service will be expected to achieve acceptable levels of performance based on data provided to the State Co-ordination Unit.

The National Accreditation Committee will establish criteria for the relative significance of various standards set in these National Guidelines, for use when an individual Screening and Assessment Service is being accredited.

After the above process has been undertaken, provisional accreditation for 12 months may be granted in the first instance to enable a particular Screening and Assessment Service time to implement the requirements of these Guidelines.

Within 12 months application must be made for full accreditation at which time the Service will be expected to comply with the Guidelines.

A fully accredited Screening and Assessment Service will be provided with appropriate certification by the National Accreditation Committee, and this certification, plus other related material will be displayed as appropriate in accredited Screening and Assessment Services.

Once full accreditation is granted to a Screening and Assessment Service, the accreditation will be reviewed at two yearly intervals.

The two yearly review will include a review of the performance outcomes of the Service as outlined in these National Guidelines, and will involve a reporting along similar, although less comprehensive, lines to that required in the first instance for accreditation.

The State Co-ordination Unit, either independently or at the request of the National Co-ordination Unit, may conduct additional reviews from time to time particularly if there is concern about maintenance of performance standards.

4.3 PROCEDURES *for* WITHDRAWAL *of* ACCREDITATION

Negotiation will take place between the State Co-ordination Unit and a Screening and Assessment Service which fails to meet the required standards, and opportunities will be provided for the Service to meet the standards within an agreed timeframe.

If the Service consistently fails to conform to the negotiated timetable for full compliance, the State Co-ordination Unit will notify the Service in writing of its intention to recommend that the National Accreditation Committee withdraw accreditation, and hence funding by a specified date. Sufficient notice should be provided, bearing in mind the impact on client services.

Such a recommendation should be considered by the National Accreditation Committee as expeditiously as possible.

A period of provisional accreditation, of not more than 12 months, may be an appropriate interim measure in an instance where the circumstances of an accredited Service have changed sufficiently to render it no longer accreditable at time of review.

4.4 REVIEW *of* ACCREDITATION GUIDELINES

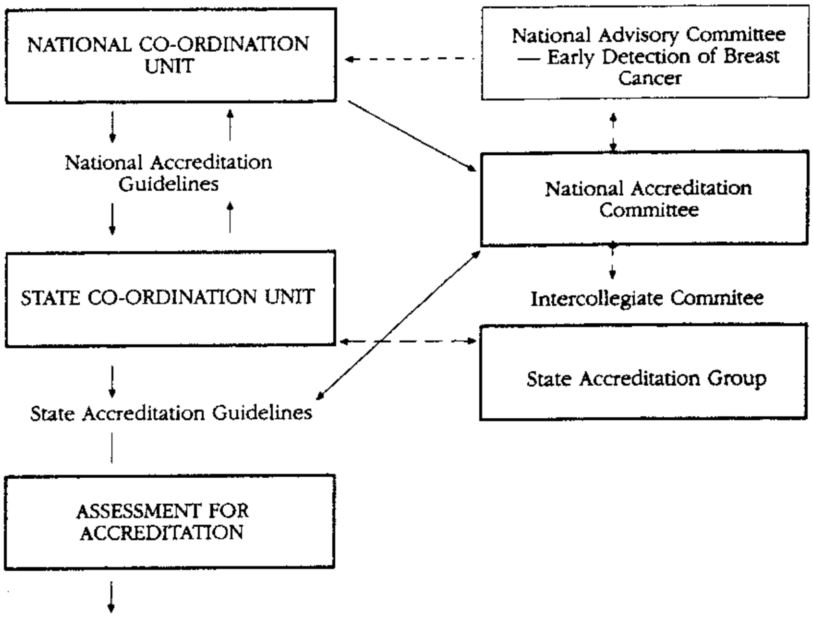
The National Accreditation Guidelines will be reviewed in the first instance in the third quarter of 1992, and thereafter each two years. They will be reviewed by the National Accreditation Committee which will make recommendations to the National Advisory Committee or the National Co-ordination Unit as appropriate.

At the same time State Co-ordination Units will be required to report on the implementation of any specific State Accreditation Guidelines.

State Co-ordination Units and/or their advisory groups on Accreditation will be able to make recommendations on the guidelines at any time to the National Accreditation Committee, and these will be considered, at least, in the next scheduled review.

Figure 4.1

ACCREDITATION *of* DEDICATED BREAST SCREENING *and* ASSESSMENT SERVICES



- Completion of Accreditation Assessment Form
  - — Provision of information to include
    - Screening and assessment service protocol
    - Quality assurance program outlined for
      - — equipment
      - — readers and takers
      - — data collection/management
      - — education/counselling services
      - — booking/clerical staff
- Achievement of acceptable levels of performance based on data provided to State Co-ordination Unit
- Independent inspection of services by two nominated persons
- Inspection and check of equipment by quality assurance program
- Provisional accreditation to new services for 12 months—then apply for full accreditation
- Thereafter two yearly review provided accreditation standards are maintained

- Breast screening and assessment services to ensure only professionally qualified staff are used—where College accreditation is applicable, this should be the accepted standard.

Section 5

IMPLEMENTATION

5.1 TIMEFRAME

An interim National Accreditation Committee was appointed following the November 1991 meeting of the National Advisory Committee which adopted the National Accreditation Guidelines.

The interim committee will oversee the early implementation of the Guidelines in those Screening and Assessment Services which are already provisionally accredited, or which will come into operation in the early stages of 1992.

The National Accreditation Committee will publish the Guidelines, and ensure that they are circulated as appropriate. It will also approve any State Accreditation Guidelines which are developed in addition to these Guidelines.

All Screening and Assessment Services currently operating will be required to submit to their State Co-ordination Unit for accreditation according to the National Guidelines by 30 June 1992. The National Accreditation Committee will devise a timetable, in consultation with the State Co-ordination Unit, for the orderly accreditation of existing services.

The Guidelines may also be used by planners of new Services within the National Program, as all Screening and Assessment Services funded by the National Program will be required to meet these standards.

Provision exists for provisional accreditation for up to 12 months. Thereafter re-accreditation will take place every two years.

The interim National Accreditation Committee will operate until 30 September 1992, or the nearest NAC meeting, when its functioning will be reviewed. Between 30 June and 30 September 1992 it will also review the National Guidelines and make appropriate recommendations to the National Advisory Committee.

5.2 BUDGET

The operating expenses of the National Accreditation Committee will be met from National Program Funds.

The Committee is expected to meet no more than three times each calendar year, and will meet in a location most suitable to the majority of members.

It is expected to operate within an annual budget determined by the National Advisory Committee.

Section 6

APPENDICES

APPENDIX 1—DEFINITIONS

Screening and Assessment Service	An integrated service consisting of an assessment centre and its associated screening units.
Assessment Centre	The centre within the Screening and Assessment Service where screen films may be read, and where women are recalled for diagnostic work-up following a screen-detected abnormality. It is anticipated that most assessment centres will have a number of associated screening units. Co-ordination of the Service, and functions such as training and performance review will take place from the assessment centre.
Dedicated	Services under the Program which are not provided concurrently with any other radiological or diagnostic service.
Screening Unit	This may be a fixed or mobile facility, the sole purpose of which is to provide the screening mammograms for presenting women. It may not function separately from an assessment centre/service.
False negative	Where women prove to have breast cancer but are mistakenly cleared by the screen.
False positive	Where women do not have breast cancer but have a screen that indicates they have breast cancer.

Definitions utilized in the minimum data set

Assessment	All follow-up investigative procedures arising from the woman's attendance for screening up to and including cytological or histological diagnosis.
Assessment unit identifier	Unique identification number for each assessment centre within the State and Territory.
Biopsy performed (in program)	'Program' is a centre or service accredited and funded as part of the national program.

Date of first attendance for assessment	First date of attendance for a given episode of assessment.
Date of commencement of primary treatment	First date of commencement of any of the primary treatment modalities used.
Date of open biopsy	Date of surgery for open biopsy.
Day procedure	Standard definition from the *Recommended minimum data set for institutional health care*[11].
Did the woman attend (for assessment)	Did the woman attend within three months of the screening mammogram.
Dominant lesion	If invasive, the largest size lesion; if invasive and of equal size then the one that has most Extensive Intra-duct Component (EIC); if the above does not help to discriminate, then lesion with most ductal carcinoma in-situ.
Episode	All attendances for screening and assessment relating to a particular round of screening. An episode is completed when i) a definitive diagnosis is made; or ii) the woman is returned to routine screening; or iii) the woman fails to attend for technical recall or assessment.
Family history	Mother or sister had breast cancer.
Grade	Use modified Bloom and Richardson system[12].
Initial screen	First screen in national program including pilot projects.
Interval cancer	Cancers detected after screening episode and with histologic confirmation not attributed to screening.
Length of Stay	Standard definition from *Recommended minimum data set for institutional health care*[11].
Localisation	Hook wire or carbon or dye to locate/identify impalpable lesion for surgical removal.
Lump	Palpable breast lump at time of presentation for screen irrespective of mode of detection.

Malignant	Includes ductal carcinoma in-situ (DCIS).
Mode of presentation (of interval cancer)	*Clinical* symptoms or signs were the first indication of the cancer. *Mammogram* mammogram findings were the first indication of the cancer.
Nodes sampled	Nodes surgically removed for histological examination.
Nodes examined	Nodes excised and examined histologically for presence of malignancy.
Nodes positive	Number of nodes examined which show malignancy.
Non-malignant	Includes normal and benign cases.
Non-screen detected cancers	Cancers detected with histological confirmation not attributed to screening.
Previous history of breast cancer	A previous diagnosis of breast cancer (to include ductal carcinoma in-situ).
Previous mammogram in the Program	Previous mammogram in the National Program (including pilot projects).
Previous mammogram outside the Program	A mammogram which a woman has had for any purpose (diagnostic or screening) excluding those already counted in Item 1.12 of the Program's minimum data set.
Primary treatment	All treatment modalities initiated within six months of diagnosis. This does not include treatment for recurrence or metastases.
Screening	Attendance by a woman for a mammogram to detect breast cancer.
Screening unit identifier	Unique identifying number for each screening unit, within the State/Territory.
Surgical unit identifier	Unique identification number for each surgical unit.
Technical repeat	Repeats initiated by radiographer or radiologist due to inadequate films.

Treating doctor identifier number	Unique identifier of principal treating surgeon.
Treatment declined	Woman chooses not to act on recommendation for treatment within three months of diagnosis.

APPENDIX 2—TECHNICAL ITEMS *to be* EVALUATED *in a* QUALITY ASSURANCE PROGRAM

ITEM	SPECIFICATION	FREQUENCY OF EVALUATION
Mammographic unit		
Focal spot	dual, 0.1 to 0.15mm and 0.3 to 0.4mm typically	acceptance, tube change annually
Leakage radiation	≤1 mGy/h at 1m from housing when maximum continuous rated technique factors used	acceptance, tube change
Half value layer	≤ 20uGy/h at 5cm from the cone on the chest wall margin	acceptance, tube change annually
Filter choice	0.03mm Mo	acceptance, tube change
kVp interlock	ensures Mo filter used at kVp≤35	acceptance, tube change annually
Light/X-ray field alignment	± 5mm of each other on all margins and not overlapping cassette holder on chest wall	acceptance, tube change annually
Compression device	should not be curved or mildly contoured	acceptance, annually
Output reproducibility	coefficient of variation ≤ 5%	acceptance, tube change annually
Output linearity	coefficient of linearity ≤ 0.1	acceptance, tube change annually
Timer accuracy	≤ 5%	acceptance, annually
Timer reproducibility	coefficient of variation ≤ 5%	acceptance, annually
kVp accuracy	≤ 2 kVp	acceptance, tube change annually
kVp reproducibility	≤ 1 kVp or coefficient of variation < 5%	acceptance, tube change annually

ITEM	SPECIFICATION	FREQUENCY OF EVALUATION
Automatic exposure control		
Reproducibility	coefficient of variation ≤ 5%	acceptance, tube change annually
Minimum response time	≤ 0.1 second	acceptance, annually
Backup timer	either operator set or < 2000mAs	acceptance, annually
Beam quality	OD = 1.4 ± 0.2	acceptance, annually
Routine quality control tests		
Assessment of image quality		
— step wedge radiograph		weekly
— imaging of breast phantom		weekly
Dose calculations		annually
Screens, films and cassettes		
— screen efficiency (≤ 10% variation)		every 3 to 6 months
— general screen conditions		every 3 to 6 months
Film processor		
— sensitometry		daily
— temperature and other operating conditions		daily
Viewing boxes		
— intra- and inter-box consistency of light output with time; image marking and ambient light control capability		weekly

Source: Australian Institute of Health. Screening mammography technology. Table 4: 14–15[5]. Health care Technology Series No 3> Canberra: AIH, 1990. (The AIH had, in turn, adapted their table from a position paper of the Australasian College of Physical Scientists and Engineers in Medicine.)

APPENDIX 3—SUGGESTED SPECIFICATIONS *for* MAMMOGRAPHY UNITS

This table is intended only as a guide for the purchase of new equipment. The suggested specifications should not be seen as mandatory requirements for equipment in any future screening program.

SPECIFICATIONS	SCREENING	ASSESSMENT
Target material	molydenum	molydenum
Norminal focal spot size	0.3 to 0.4	0.3 to 0.4 (regular) 0.1 to 0.15 (magnification)
Maximum ouput	≥ 100mA	≥ 100mA (regular focal spot)
Filtration	beryllium window molydenum filter aluminium filter with reversible interlock over 35 kVp	beryllium window molydenum filter aluminium filter with reversible interlock over 35 kVp
Automatic exposure control	essential	essential
Microprocessor control of automatic exposure	highly desirable	highly desirable
Magnification	not necessary	essential (1.5 to 2.2 times)
Motorised compression device with foot pedal (both directions) with quick release	essential	essential
Stiff support table (distorting less than 1mm under full compression)	essential	essential
Spot compression device	not necessary	essential
Stationary or moving grid	desirable	essential
Heat load capacity	important consideration (see text)	not critical

SPECIFICATIONS	SCREENING	ASSESSMENT
Film size	18 x 24cm essential, 24 x 30cm desirable	18 x 24cm essential, 24 x 30cm not critical
Dedicated single emulsion processor (cycle tailored to mammography film in use)	essential	essential

Source: Australian Institute of Health. Screening mammography technology. Health Care Technology Series No 3 Table 1.

Quality assurance test equipment

ITEM	DESCRIPTION AND REQUIREMENTS
Electrometer	must measure in integrate mode, should be a 3 1/2 digit device
Ion chamber	thin window chamber with a flat response down to 10 keV leakage chamber ideally capable of measuring down to 0.02 μGy
kVp meter	must be capable of measurement down to 24 kVp with Mo anode, and accuracy of 1 kVp
Timer	accurate down to 0.1 second
Star pattern	0.5 or 1 degree pattern
Filter	0.1mm, 0.3mm. Type 100 A1
Phantoms	i) perspex step wedge ii) breast phantom with inclusions mimicking clinical conditions
Sensitometer	sensitivity to blue and green. Should have 21 steps
Densitometer	should give readings in the range 0 to 3.0 optical density units and have its own light source

Source: Adapted from Australasian College of Physical Scientists and Engineers in Medicine. A quality assurance program for mass screening in mammography. 252-59: Table 5. Australasian Physical and Engineering Sciences in Medicine 1989; 12.

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