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

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 multi-disciplinary 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