

BF

Anti-Cancer Council Of Victoria
1 Rathdowne Street, Carlton South, 3053, Australia
Tel: 61 03 9279 1106 (Director's Office) Fax: 61 03 9279 1250

FACSIMILE COVER SHEET

Date: 28 May 1996
To (fax no) : 06 273 4146
Attention : Mr Terence Barnes
Acting General Senior Adviser
To Dr Michael Wooldridge
Minister for Health and Family Services
From : Dr Robert Burton
Director

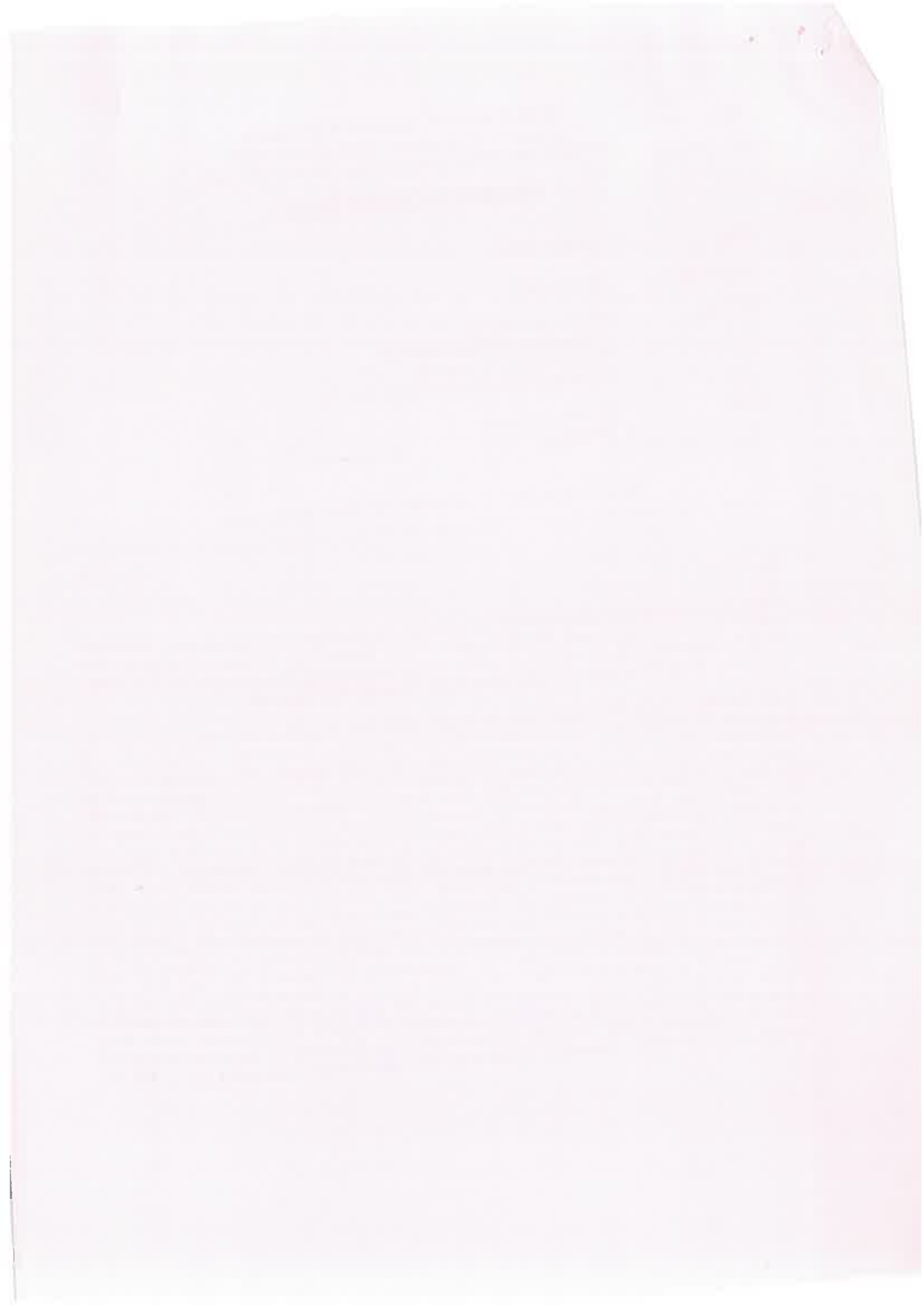
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Dear Terry

Ref 1-3539

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I am writing because there have been three calls in the last 8 weeks for national screening programs or modifications of national screening programs: Prof Forbes, Professor of Surgical Oncology, University of Newcastle calling for mammographic screening of women aged 40-49 years, Prof Kaye, Professor of Urology, University of Western Australia calling for PSA screening of older men and 26th May, at the beginning of Quit Week, Associate Prof McCaughan, Associate Professor of Thoracic Surgery at Royal Prince Alfred Hospital of Sydney University calling for 6 monthly chest X-ray screening of all smokers and ex-smokers. None of these calls can be justified on the basis of current evidence. This is however widespread informal mammographic screening of women aged 40-49 years and PSA testing for prostate cancer in older men. It is possible that as better evidence accumulates the case for screening the 40-49 years old women can be made in the future and a selective screening program for prostatic cancer might be justified. Of particular concern now is that the policy of the Executive of the Urological Society of Australia that PSA screening should not be done, has been overturned by the "young Turks" led by Prof Kaye. There is to be a plebiscite for urologists in Australia to determine what the policy will be. It is possible that the majority will favour PSA testing for prostatic cancer with a potential bill in the hundreds of millions! In respect of chest X-ray screening for lung cancer this is simply wrong. Evidence was in decades ago following up smokers detected through the TB screening programs. It has been very clearly shown that smokers and ex-



smokers who have small asymptomatic lung cancers detected by chest X-rays do not do any better than if they had presented later in the disease.

This brings me to the crux of this fax, and that is that things are hotting up in cancer control. Many things come across my desk which may be of relevance to the Minister I am very prepared to provide regular summaries and pass on items with or without comment that may be useful to you.

Kindest regards.

Yours sincerely

A handwritten signature in cursive script that reads "Robert".

Robert Burton
Director

FAKED
30/5/96

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Yours sincerely

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Robert Burton
Director

***** TRANSMISSION REPORT *****

S.I.D. :

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Anti-Cancer Council Of Victoria
1 Rathdowne Street, Carlton South, 3053, Australia
Tel: 61 03 9279 1106 (Director's Office) Fax: 61 03 9279 1230

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Attention: Mr Terence Barnes
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To Dr Michael Wooldridge
Minister for Health and Family Services
From: Dr Robert Burton
Director

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Ref 1-8599

Dear Terry

I hope you received my letter reporting our progress on developing a proposal for a National Cancer Control Council and the description of the Breast Care treatment program for women diagnosed with breast cancer, which would complement BreastScreen in Victoria, and which is currently under consideration by the Victorian Government.

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Director: Dr Robert Burton MD, PhD, BS, BA, BMedSci, FRACP, FRACS, FAFPHM
Direct telephone: 61 (03) 9279 1106 Facsimile: 61 (03) 9279 1250

BF - include attachments

16 May 1996

CONFIDENTIAL DOCUMENT ATTACHED

Mr Terence Barnes
A/g Senior Adviser
Office of the Minister for Health and Family Services
MG 48
Parliament House
Canberra ACT 2600

Ref 1-3492

Dear Terry

I am sending you the new Australian Cancer Society (ACS) mission statement and strategic objectives, as requested by the Minister. We are meeting again in June to carry the process forward.

I have also included a letter to Tony Adams summarising our meeting of 9th May 1996 which he called at the Minister's request to further the National Cancer Control Council concept. Subsequent to that meeting we (the ACS executive working party) are initiating its documentation and have planned a full day workshop with representation from the Royal Australian College of General Practitioners in Sydney on 28th May 1996. The current plan is to finalise a document for the Minister at the 14th June 1996 meeting here with Tony and colleagues from the Department.

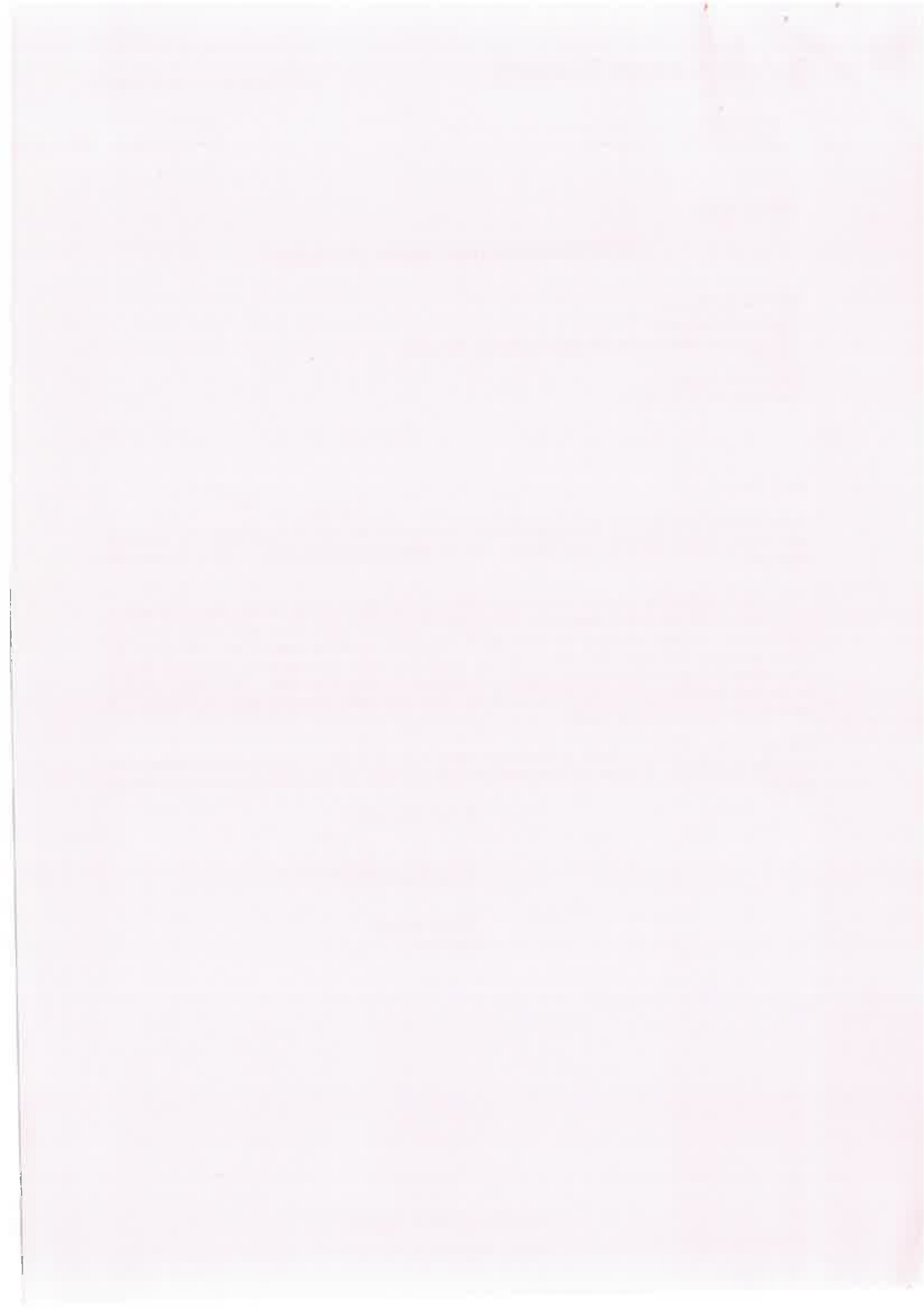
Finally I am including a copy of the breast cancer report to the Victorian Government that Michael requested. It must be kept confidential although its contents are known to many people.

Yours sincerely

Robert Burton
Director

Encl.

Leading the fight





Director: Dr Robert Burton MD, PhD, BS, BA, BMedSci, FRACP, FRACS, FAHPM
Direct telephone: 61 (03) 9279 1106 Facsimile: 61 (03) 9279 1250

13 May 1996

Dr Tony Adams
Chief Medical Adviser
Commonwealth Department of Health & Territory Services
7th Floor, Alexander Building
Furzer Street
Woden ACT 2606
Fax: 06 285 1994

Dear Tony

I very much enjoyed our meeting last Thursday. I am writing to supply the further information you requested and to summarise the outcome of our meeting, based on my recollections, to make sure I have not missed any important points and that the emphasis is correct.

The membership of the National Cancer Advisory Committee (NCAC) is as follows:

Chairman: Prof R Burton, ACCV, Victoria

ACS/COSA nominees:

Dr Michael Byrne (WA)	Medical Oncologist
Prof Tony Burgess (Vic)	Scientist
Prof John McCaffrey (Qld)	Surgeon
Prof Lester Peters (Vic)	Radiation Oncologist
Ms Anne Piasczyk AM (Tas)	Oncology Nurse
Dr Melanie Wakefield (SA)	Public Health

Nominees of ACS Council:

Prof Bruce Armstrong (NSW)	Epidemiologist
Prof Jim Bishop (NSW)	Medical Oncologist
Prof Gordon Clunie (Vic)	Surgeon
Prof John Kearsley (NSW)	Radiation Oncologist
Prof John Lowe (Qld)	Behavioural Scientist
Prof Peter Ravenscroft (NSW)	Palliative Care
Ms Gabrielle Prest (NSW)	Oncology Nurse

Ex Officio

Prof Dick Fox (Vic) President ACS	Medical Oncologist
Prof Bob Thomas (Vic) President COSA	Surgeon

The NCAC is the Medical and Scientific Committee of both the Australian Cancer Society (ACS) and the Clinical Oncological Society of Australia (COSA), and is also the Executive Committee of the Australian Cancer Network (ACN). It is, therefore, the peak Committee of Organisations involved in cancer control in Australia. It is important to also note that the Council of the ACN is a Council of representatives of all stakeholders, both Government and non-Government Organisations (NGO) involved in cancer control in Australia and that that Council appoints half of the fourteen members of the NCAC using skills as a basis. The other seven members are appointed by the

Leading the fight

Chairman of the NCAC, who is a joint appointment of the ACS and COSA, from nominations by the State Cancer Councils and COSA to the ACS.

I am mailing to Margaret Dean the papers that you should have had for the ACS Strategic Planning in Sydney on May 3 and 4. Included are papers explaining the relationship between the ACS, COSA, ACN and the NCAC with terms of reference etc. I am also mailing the Medical Journal of Australia reports you requested of the first two Victorian Breast Cancer Treatment Surveys, run by the Breast Study Committee of the Victorian Cooperative Oncology Group (VCOG) of the Anti-Cancer Council of Victoria. You will recall that the third Breast Cancer Treatment Survey is underway, but this time it is National.

Following is my summary of our meeting:

Outcome Summary:

That I, as Chairman of the NCAC, was to convene a working party of the President of the ACS, the Chairman of COSA, the Chairman of the NCAC and the Executive Director of the ACN, to commence preparation of a proposal to establish a non-Government National Cancer Control Council (Organisation, Centre), in collaboration with yourself and Officers of your Department and that we would meet at the Anti-Council of Victoria on June 14 to finalise the proposal for submission to your Minister. The proposal would seek funding of the order of \$100,000,000 over five years to establish the National Cancer Control Council (NCCC), which would have as one of its goals implementing cancer control measures in the area of screening and early detection of cancer which should save at least \$100,000,000 per annum of the amount that the Federal Government is currently spending in this area.

The NCCC could consist of a highly skilled secretariat in one of the major capital cities and, based upon the National Breast Cancer Centre model, devote a large proportion of its resources to the funding of cancer control activities in the non-Government and Government Cancer Control Organisations in all of the States. There would be a Governing Council or a Board of Governors, which could consist in a large part of the current NCAC, together with yourself and senior officers of your Department and consumer representative(s) as a minimum. The National Breast Cancer Centre, National Breast and Cervical Screening Programs and the National Tobacco Control Organisations would report to the NCCC, which would in turn report through its Council or Board of Governors to the Minister of Health via the Secretary of your Department.

The following could be the goals of the NCCC:

1. To rationalise and focus current expenditures in cancer control in the light of best evidence based practice.
2. To prepare a National Cancer Control Plan.
3. To develop policy and set priorities for National Cancer Control based on the plan.
4. To facilitate implementation of the plan through contracts with State Bodies.
5. To monitor implementation and outcomes of the National Cancer Control Plan.
6. To revise the National Control Plan accordingly.
7. To develop the capabilities of other organisations to "pick up and run with the National Cancer Control Plan".

The concept is that there is an important national job to do in cancer control and that a five year contract for a National Cancer Control Council with a four year review would be an appropriate strategy to achieve this. At the four year review the decision could be made to continue the NCCC in its current or in a revised form, or to incorporate it into the NH&MRC, or to thank it for a job well done and support the State Government and NGO Cancer Control Bodies in carrying on the task with a small national monitoring and oversight committee reporting to the Federal Minister of Health.

In setting up the National Cancer Control Council, it would be helpful if the process did not produce competition between any individual state NGO involved in cancer control and the National Cancer Bodies listed above: the ACS, COSA, ACN and NCAC. The concept of a Centre without walls and a small highly skilled secretariat with travelling experts and experts working in the State NGO and Government Cancer Control Organisations but funded by the NCCC could facilitate this. The recruitment of these highly motivated and highly skilled individuals demands that the secretariat should be sited in a major Australian capital city in association with a Cancer Council which can provide appropriate material and intellectual infrastructure support.

I will be briefing my working party and their state and national bodies and we will immediately commence work on the documentation.

I wish you an enjoyable and productive overseas visit to the International Agency for Research on Cancer and the World Health Organisation and look forward to working together with you on this exciting venture when you return.

Warmest regards,

Yours sincerely



Robert Burton
Director

**Breast Cancer Services
in Victoria**

Recommendations

of the

Breast Disease Working Group

Terms of Reference

1. To recommend the future range and location of breast cancer services in Victoria, having regard to:
 - the recommendations of the Metropolitan Hospitals Planning Board;
 - the strategic directions for Women's Health in Victoria;
 - previous reports in this area;
 - genetic research developments and their expected impact on service delivery;
 - counselling services for women with a history of familial breast cancer;
 - methods of service delivery and locations which provide for future service demand and optimal accessibility;
 - consensus in the literature regarding optimal patient throughput for quality service provision;
 - coordination of the continuum of care;
 - informed patient consent on treatment options;
 - rural access;
 - palliative care;
 - linkages between clinical services and education and research.
2. To liaise with other Women's Health Hospital Facility Planning Groups to ensure compatibility of proposals.
3. To liaise with the Victorian Women's Health Planning Advisory Group to ensure consistency with broader strategic directions.
4. To advise the PCC of the capital implications of recommendations.
5. To advise the PCC on implementation issues.

Breast Disease Working Group

- Professor John Funder (Chair), Director, Baker Institute of Medical Research**
Miss Belinda Brown, Surgeon, Mornington Peninsula Hospital
Professor Robert Burton, Director, Anti-Cancer Council of Victoria
Dr Mitchell Chipman, Medical Oncologist, Austin Repatriation Medical Centre
Mr John Collins, Surgeon, Royal Melbourne Hospital & Royal Women's Hospital
Mr Mark Eastman, Surgeon, Shepparton
Dr Prue Francis, Medical Oncologist, Peter MacCallum Cancer Institute
Mr Stewart Hart, Breast Surgeon, Director of Breast Screening, Monash Medical Centre
Mr Michael Henderson, Surgeon, St Vincent's Hospital
Professor David Kissane, Director of Palliative Medicine, Caritas Christi Hospice
Ms Sue Lockwood, Breast Cancer Action Group
Dr Heather Mitchell, Epidemiologist, Victorian Cytology Service
Dr Denise O'Hara, Public Health Division, Health & Community Services
Professor Alan Rodger, Director of Radiation Oncology, Alfred Hospital
Mr Ian Russell, Surgeon, Royal Melbourne Hospital
Professor Joe Sambrook, Director of Research, Peter MacCallum Cancer Institute
Ms Lyn Swinburne, Breast Cancer Action Group
Dr Linda West, Radiologist, BreastScreen, Geelong
Ms Del Stitz, Primary Care, Health & Community Services
Ms Shirley Pinnell, Primary Care, Health & Community Services
Dr Angela Kirsner, Scientific Writer & Editor

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Introduction and Summary of Recommendations

In considering this report to Ministerial Planning Consultative Committee, the Breast Disease Working Group placed special weight on certain aspects of the management of breast cancer:

1. That breast cancer is a complex disease demanding multidisciplinary management. Early breast cancer may be indistinguishable clinically from a variety of benign breast diseases, which are the major (at least 90%) cause of breast symptoms in women who fear they have breast cancer.
2. That women want and need a breast service that is sensitive to their needs and, in this sense, is client-driven. This includes a breast cancer treatment service - "BreastCare" - that is as visible and recognisable as BreastScreen and offers comparable standards of psychological support, education, technical expertise and multidisciplinary management.
3. That the transition from diagnosis of breast cancer to treatment should be seamless, and that all aspects of BreastCare should be subject to and meet high standards of continuous quality assessment.

KEY RECOMMENDATIONS

1. BREASTSCREEN

To achieve the maximum possible benefit from mammographic screening, the Victorian BreastScreen service should be maintained as a Statewide (rather than a metropolitan hospital network) service.

2. BREASTCARE

A limited number of specialist breast disease (BreastCare) centres should be established within the metropolitan hospital networks and in rural Victoria, as appropriate. Each one should offer the full range of investigative services and clinical oncological services (surgery, medical oncology, radiation oncology) and the full range of psychological and support services, preferably but not necessarily within the same physical space, but recognisably linked in function.

The objective of the BreastCare Centres is to minimise the impact of breast disease on Victorian women. The strategies used to achieve this objective will include:

- providing access to methods for the early diagnosis of breast diseases;
- providing high quality multidisciplinary treatment including access to a range of support services;
- providing high quality information to women about breast disease control and management;
- ensuring public accountability of the service;
- involving women in the management of centres.

The centres should cater for women at all stages of breast disease: genetic counselling, investigation and diagnosis, initial treatment, longer term follow-up and support, and palliative care.

The centres should be of two types:

- i) **Principal BreastCare Centres:** There should be two of these, both sited in the Melbourne metropolitan area. Each should have established links to a number of the BreastCare Centres. As well as having the functions of a BreastCare Centre, they should have a major role in teaching, research, and quality assurance. This will entail:
 - establishing breast cancer clinical genetic services;
 - involvement in all levels of health care education (nursing, medical, undergraduate, post-graduate, allied health professional, continuing education, etc.);
 - involvement in basic and clinical research, maintaining close links with other research institutions, and stimulating and coordinating clinical research activities throughout their associated BreastCare Centres;
 - acting as tertiary referral centres, and the major intellectual and material resource centres for their associated BreastCare Centres;
 - coordinating quality assurance for their associated BreastCare Centres.
- ii) **BreastCare Centres:** There should be up to seven of these, two of which should be outside the Melbourne metropolitan area and Geelong. Each will be allied with one of the two Principal BreastCare Centres, with flow of information and collaboration particularly in the areas of research, quality assurance, and continuing professional education. All BreastCare Centres will have a strong commitment to participate in clinical research.

All BreastCare Centres should be represented on the Breast Study Committee of the Victorian Cooperative Oncology Group of the Anti-Cancer Council of Victoria.

3. FOSTERING LINKS AND SUB-SPECIALISATION

Specialists treating breast cancer (surgeons, medical oncologists, radiation oncologists) should be encouraged to:

- make that a significant part of their activity, to maximise their skills in the area;
- establish links with a BreastCare Centre, to foster the development of expertise and sub-specialisation in breast disease. BreastCare Centres should actively encourage this by forging links with medical personnel and groups working in their geographical area, and by offering ongoing professional education activities (nursing, medical, undergraduate, post-graduate, allied health professional, etc.).

Other facilities involved in the management of patients with breast disease, both public and private, should be encouraged to establish formal links with one of the BreastCare Centres in the hospital network (either principal or other centres), to ensure that women have access to the full range of breast cancer services.

4. AUDIT AND QUALITY ASSURANCE

The State Government should establish a BreastCare Quality Assurance Committee that includes representatives from consumer groups, State Government, health care experts, and the Anti-Cancer Council of Victoria, to be responsible for the overall scientific audit and evaluation of the BreastCare Centres (including Principal Centres). Resources and expertise offered by the National Breast ~~Care~~ *Cancer* Centre should be taken into consideration.

The State Government should resource the Principal BreastCare Centres to:

- conduct evaluation programs in their own centre and their associated BreastCare Centres;
- develop systems for quality assurance and common data collection.

5. RESEARCH

A long-term commitment by the State of Victoria is needed to funding investigations into the basic biology of breast cancer, randomised clinical trials, and broader clinical research that is closely allied to the management of women with breast disease.

6. IMPLEMENTATION

If these recommendations are accepted by the Ministerial Planning Consultative Committee, a BreastCare Committee should be set up immediately to plan, facilitate and oversee implementation. The Committee should include consumers, representatives of the State Government and the Anti-Cancer Council of Victoria, and appropriate health professionals. In the immediate implementation period it should liaise with the Acute Health Division of the Department of Human Services to identify areas in which existing services need redevelopment, areas where new services will need to be developed, and the resources required to meet the recommendations.

AREAS REQUIRING SPECIFIC ATTENTION

7. Radiotherapy

There should be equity of access to radiotherapy for city and rural patients, facilitated through transport subsidies and appropriate accommodation.

8. Multidisciplinary Management

The NHMRC *Clinical Practice Guidelines: The Management of Early Breast Cancer* should be used both to guide the management of women with early breast cancer and to establish treatment protocols for women being managed outside clinical trials. Similar NHMRC guidelines for patients with more advanced disease are currently in preparation.

9. Information for Women and Families

BreastCare Centres should place a high priority on providing information for women with breast cancer and their families. This will entail:

- an emphasis on developing the communication skills of health professionals;
- the ready availability within BreastCare Centres of information products (written, tapes, education courses etc), within the broader context of women's health care. Information should be consistent Statewide and draw upon established expertise such as the Anti-Cancer Council of Victoria and the National Breast Cancer Centre;
- publicity about the existence of BreastCare;
- attention to the needs of women from different cultures and non-English speaking background.

10. Integrated Psychosocial Care

Psychological care and access to the range of social supports should be fully integrated with surgical, medical and radiation oncology services through BreastCare Centres. Appropriate funding is needed.

11. Breast Cancer Support Nurses

All women with breast cancer should have access to a breast cancer support nurse both before and after surgery, and BreastCare Centres should be funded to support this.

12. Breast Cancer Clinical Genetic Services

Two breast cancer clinical genetic services should be established, one at each of the two Principal BreastCare Centres, to provide women with risk information and advice, psychological support counselling, and in appropriate cases, DNA testing.

13. Lymphoedema Clinics

Each BreastCare Centre should have a lymphoedema clinic staffed by trained physiotherapists or occupational therapists, offering specialist advice to all women who seek it.

14. Women with Advanced Breast Cancer

BreastCare Centres must recognise the special needs of, and deal effectively with, women with advanced breast cancer and their families.

15. Accommodation and Travel Support

The State Government should support appropriate accommodation and travel support for women and their companions attending radiotherapy and other outpatient appointments.

16. Waiting Times

All women diagnosed with possible breast cancer should be offered biopsy as soon as possible, i.e. within 14 days.

After histological confirmation of diagnosis, a definite date for operation should be established, in consultation with the individual woman, on the basis of her needs and expressed wishes. Breast cancer should thus clearly remain a Category 1 procedure in the public hospital system.

Every effort should be made to avoid undue pressure on the woman through either undue delay or undue haste in proceeding to surgery.

17. Access to Treatments

All women (both in public hospitals and private patients) should have equal access to proven treatments.

18. Breast Prostheses

A breast prosthesis of high quality should be readily available to every woman following mastectomy and, where indicated, on a regular basis thereafter. Obtaining a prosthesis must be simple, through a system that is easily accessed and adequately funded.

1. A Comprehensive Breast Disease Service for Victoria

Underpinning a comprehensive breast disease service must be a basic philosophical agreement that the service is established to meet the needs of the women. There must be:

- an emphasis on quality of care;
- respect for the individual woman;
- recognition that the woman is part of a family and a community, and recognition of her lifestyle;
- choices offered to women, with decisions about treatment resting ultimately with her;
- recognition of the need to cater for women of differing cultural backgrounds, and non-English speaking women.

Equity of access to services is also basic. This involves attention to geographical, cultural and language barriers that affect access.

The service needs to cater for women in three quite different groups, comprising:

- benign breast disease;
- early breast cancer - diagnosis, treatment and ongoing care;
- advanced breast cancer.

Women need to be offered:

- a high quality screening program for healthy women;
- clinical genetic services for those with a family history of breast cancer;
- prompt investigation, diagnosis and treatment of women with breast symptoms;
- treatment of early breast cancer, of a uniformly high quality, in accordance with the NHMRC *Clinical Practice Guidelines: The Management of Early Breast Cancer*;
- an opportunity to participate in appropriate clinical trials;
- support services available at all stages of the disease, both to women with breast cancer and to their families, including:
 - information and education
 - psychological support and counselling
 - financial support
 - accommodation and transport for women receiving treatment at distant centres
 - access to support groups
 - access to community services;
- comprehensive palliative care services of a high quality available to all women who need them, and including:
 - 24-hour access to on-call palliative care nursing specialists
 - consultative services available to all acute hospital breast cancer patients and units
 - sufficient designated inpatient palliative care beds
 - bereavement counselling.

For breast cancer, this will involve both individual patients and patient populations. Approaches focussing on individual patients include:

- the opportunity for all women with breast cancer to be actively involved in making informed choices regarding treatment and management options. This will involve ready availability of appropriate and intelligible information for women;
- the use of established protocols and best practice guidelines, and specifically the NHMRC *Clinical Practice Guidelines: The Management of Early Breast Cancer*. For more advanced breast cancers, NHMRC guidelines are in preparation;
- a multidisciplinary approach to management;
- ready access to second opinions for all women at all stages of management.

Activities focussing on patient populations include:

- research, both clinical and basic, to improve the understanding and treatment of breast cancer;
- facilities for uniform and comprehensive data collection, analysis and interpretation;
- ongoing education of all health professionals involved.

2. BreastScreen

Recommendation: BREASTSCREEN

To achieve the maximum possible benefit from mammographic screening, the Victorian BreastScreen service should be maintained as a Statewide (rather than a metropolitan hospital network) service.

Victoria's BreastScreen program is of exceptionally high quality and compares favourably with screening programs anywhere else in the world. Cancer detection rates are comparable with the best international rates, and expertise continues to grow. In terms of population screened, Victorian BreastScreen centres are closer than any other State in meeting targets set. In 1995, Victoria screened 96% of its target. Mammographic screening is one of the two proven approaches that will improve survival in breast cancer (the other being adjuvant treatment with chemotherapy and/or endocrine therapy).

Data documenting the extent of the benefit of mammographic screening, however, are not yet available. A drop in death rates from breast cancer will depend on ensuring the best treatment for those cancers diagnosed, a continued improvement in coverage of the eligible population, and a very high level of expertise and quality assurance within BreastScreen, with continuing improvement in the ability of the diagnostic team to identify earlier and smaller tumours. This in turn depends on throughput, professional education and training, and Statewide linkages, to achieve the maximum possible benefit from mammographic screening.

The hospital networks, as they are currently set up, would not support this structure. The Working Group thus would not support devolution of the program to a hospital network level. BreastScreen should not be split up or rearranged in any way to fit hospital network or any other boundaries.

While its separate funding and accreditation mechanisms set BreastScreen apart from other areas involved in the management of breast disease, it is important that BreastScreen be considered as an integral component in the spectrum of breast care in Victoria. BreastScreen needs to be well integrated with treatment services, to ensure that the transition from diagnosis to treatment is seamless (Australian Cancer Network policy).

BreastScreen has a number of specific strengths that should be maintained, and that might serve as a model for other areas of service delivery:

- The program is grounded on sound scientific evidence; it is an excellent example of evidence-based practice.
- Accurate assessments were made initially of what was to be done and what it would cost, and the program has been funded accordingly.
- Quality assurance is rigorous, applied to every element of the program, and incorporates a strict and comprehensive pattern of auditing. This will increasingly improve the expertise of the group involved, and ensures that BreastScreen will continue to improve over time.
- Counselling and other psychological support services have been an integral part since the start of the program.
- Multidisciplinary management is fundamental: surgical, radiological, and pathology specialists work together and meet on a regular basis, ensuring exchange of knowledge and leading to a much better understanding of the disease process.
- In recruiting women, BreastScreen plays a significant role in educating the community and providing information on breast disease. They do it well and have effectively targeted women of non-English speaking background.
- BreastScreen maintains a high public profile. Coverage of the target population depends on this, the service was funded accordingly, and it has gone about promotion in a professional manner. Women know how to access BreastScreen, and its high public profile facilitates self-management and decision making for women. (In comparison, breast diagnostic clinics, even those in public and private hospitals, are virtually unknown to women and there is no easy way to find them.)
- BreastScreen is women-orientated. Reference groups of clients and community representatives not employed within the program are actively involved in all levels of its management.

3. BreastCare

Recommendation: BREASTCARE CENTRES

A limited number of specialist breast disease (BreastCare) centres should be established within the metropolitan hospital networks and in rural Victoria, as appropriate. Each one should offer the full range of investigative services and clinical oncological services (surgery, medical oncology, radiation oncology) and the full range of psychological and support services, preferably but not necessarily within the same physical space, but recognisably linked in function.

The objective of the BreastCare Centres is to minimise the impact of breast disease on Victorian women. The strategies used to achieve this objective will include:

- providing access to methods for the early diagnosis of breast diseases;
- providing high quality multidisciplinary treatment including access to a range of support services;
- providing high quality information to women about breast disease control and management;
- ensuring public accountability of the service;
- involving women in the management of centres.

The centres should be of two types:

- i) Principal BreastCare Centres:** There should be two of these, both sited in the Melbourne metropolitan area. Each should have established links to a number of the BreastCare Centres. As well as having the functions of a BreastCare Centre, they should have a major role in teaching, research, and quality assurance. This will entail:
 - establishing breast cancer clinical genetic services;
 - involvement in all levels of health care education (nursing, medical, undergraduate, post-graduate, allied health professional, continuing education, etc.);
 - involvement in basic and clinical research, maintaining close links with other research institutions, and stimulating and coordinating clinical research activities throughout their associated BreastCare Centres;
 - acting as tertiary referral centres, and the major intellectual and material resource centres for their associated BreastCare Centres;
 - coordinating quality assurance for their associated BreastCare Centres.
- ii) BreastCare Centres:** There should be up to seven of these, two of which should be outside the Melbourne metropolitan area and Geelong. Each will be allied with one of the two Principal BreastCare Centres, with flow of information and collaboration particularly in the areas of research, quality assurance, and continuing professional education. All BreastCare Centres will have a strong commitment to participate in clinical research.

All BreastCare Centres should be represented on the Breast Study Committee of the Victorian Cooperative Oncology Group of the Anti-Cancer Council of Victoria.

BreastCare Centres will enable women to receive care and support of a consistently high quality, through providing a structure that brings together those involved in breast disease, maximises opportunities for communication between treating clinicians and researchers, and helps doctors to offer the best possible care. The centres will incorporate:

- an emphasis on quality of care;
- respect for the individual woman;
- recognition that the woman is part of a family and a community, and recognition of her lifestyle;
- choices offered to women, with decisions about treatment resting ultimately with her;
- a total quality management approach to quality assurance, as is the case with BreastScreen.

The model proposed has the potential to bring to treatment of breast disease in Victoria the same high standards of patient care, quality control, multidisciplinary management, counselling and social support services, and education of health care professionals and the public, that BreastScreen brings to diagnosis.

This model does not involve a Statewide organisation as for BreastScreen, and the Working Group would not support the creation of such an organisation. The model will fit into the hospital network

system and include current providers of treatment for breast disease. It would be appropriate for each hospital network to consider creating one BreastCare Centre.

It is important to note that such centres cannot be "created" from nothing, but must develop around existing activity. They can be fostered through appropriate resourcing.

In framing these recommendations, the Working Group has taken into account:

- the need for women and referring general practitioners to be able to identify high profile centres of expertise that offer high quality care in breast disease;
- the central importance of a multidisciplinary approach. This means that multidisciplinary expertise must be available at all crucial decision points in the management of all women with breast disease, and breast cancer in particular;
- the need for both public and private patients to be able to access the full range of services. It is envisaged that the BreastCare Centres will be open to both groups;
- the importance of both clinical and basic research, to improve management and understanding of breast disease.

The following points should be emphasised:

- the importance, for women, of information (both on breast disease and on women's health issues generally), good communication, and informed choice;
- the importance of catering for women from different cultures and non-English speaking backgrounds;
- the need for effective administration to ensure that patients are seen in way that is timely, appropriate, and customer-focussed;
- the need for regular review meetings among all the clinicians involved in this multidisciplinary exercise;
- the importance of clinical genetics;
- audit as a formal part of the set-up;
- facilitation of research either by clinicians and/or in association with more basic research;
- the importance of involving women in clinical trials, with respect for patient choice;
- the value of consumer involvement at a range of levels, including organisation and planning, evaluation of programs and services, and research directions.

3.1 Number of BreastCare Centres

The number of BreastCare Centres will be limited by:

- The population: Centres need to have sufficient throughput to maintain standards of service and expertise. Each centre should treat at least 100, but preferably 200 or more new breast cancer patients per year. Given that at most, only about one referral in 10 will be breast cancer, this means up to 2,000 or more new patients with breast disease per year for each centre.
- The number of specialist and experienced staff available: For example, radiation therapists and radiation physicists are scarce, and difficulties can be anticipated in attracting enough suitably qualified staff to rural areas and retaining them to ensure maintenance of a high quality service. This could be addressed in the future through teleconferencing, computer networks, and access to electronic libraries via CD-ROM and the Internet.

The throughput of at least 100, preferably 200 or more is based on:

- the recommendation of the UK House of Commons (Session 1994-95) Health Committee Third Report: Breast Cancer Services, which recommends that specialist breast units should see at least 100 newly diagnosed cases of breast cancer per year; and
- the demographic differences between the UK, which has a large number of medium-sized population centres, and Victoria, with its small number of larger population centres.

3.2 Staffing

All BreastCare Centres will require the following specialist staffing components:

- breast cancer support nurses
- chemotherapy nurse specialists
- cytologists
- data managers
- histopathologists
- medical oncologists
- radiation oncologists
- radiologists
- social workers
- surgeons.

Medical staff will specialise in breast disease, though not necessarily exclusively so; they will see a significant number of these patients each year.

The following professionals should also be available to and affiliated with the BreastCare Centre:

- endocrinologists
- gynaecologists
- occupational therapists
- palliative care teams
- pharmacists
- physiotherapists
- plastic surgeons
- psychiatrists
- psychologists.

Radiation therapy requires adequate numbers of:

- radiation physicists and technical support staff
- radiation therapists
- nurses.

In addition, the Principal BreastCare Centres will offer a breast cancer clinical genetic service, which should include:

- clinical geneticists
- genetic counsellors
- breast cancer specialists.

Each BreastCare Centre should also employ

- an information officer who will be responsible for developing the information services and publicity of the centre.
- data managers, for both trials and audit
- administrative and business management support
- clerical/secretarial staff.

3.3 Facilities

Facilities should include:

- clinics that provide appropriate space and privacy for the range of recommended activities;
- dedicated (rather than randomly allocated) in-patient beds to ensure that specialist nursing care is available to all;
- investigative services of a high quality. It is imperative that clinical mammography and diagnostic facilities reach the standards achieved by BreastScreen;
- access to radiotherapy, preferably but not necessarily on site.

3.4 Configuration of BreastCare Centres

Many women prefer to have all services available on or near the one site. It may not be feasible, however, for all BreastCare Centres to be discrete geographic entities. For example, a group of private clinics or practitioners might be allied to a public hospital where patients can have part of treatment on one site or part on another, with the ready availability of adequate social and psychological support. Radiotherapy and some diagnosis and surgery may be done outside the centre. It is envisaged that both public and private patients will have access to the full range of BreastCare services within a centre.

The overriding consideration is the availability of multidisciplinary information at all points of crucial decision making so that best decisions can be made for each individual patient.

3.5 Siting

The two Principal BreastCare Centres should be associated with medical schools or university groupings. Hospital networks need to consider their input in terms of funding to such centres.

The Working Group envisages that the remaining BreastCare Centres will be distributed in both urban and rural areas to provide equity of access throughout the State (see Section 3.6). Considerable expertise in and commitment to breast disease exists in a number of country areas. This should be utilised and built upon.

3.6 Radiotherapy

Recommendation: There should be equity of access to radiotherapy for city and rural patients, facilitated through transport subsidies and appropriate accommodation.

Many women with breast cancer will require radiotherapy at some time during their illness.

All BreastCare Centres need to have ready access to radiotherapy facilities and radiation oncologists, either at the centre or through established links with another radiotherapy facility. It may not be feasible to offer radiotherapy at all sites; however this should not preclude the establishment of additional radiotherapy facilities in country areas where the population can support such a centre.

The limiting factor may be the availability of appropriate professional expertise (e.g. radiation therapists and radiation physicists). It is possible, though not ideal, to have a stand-alone machine, provided modern technology is used. A stand-alone team, however, is not feasible: quality assurance depends on teams in smaller centres being part of a larger team, with regular and rigorous training and on-going professional education. There is evidence, from US Patterns of Care studies, of poorer outcomes in smaller, poorly equipped centres.

A stand-alone machine must, of course, stop for a week a year and usually half a day a fortnight for technical preventive maintenance. In addition, unexpected breakdowns are not covered by back-up machines. Close association with a multi-machine radiotherapy centre is therefore essential.

Geelong currently supports two machines, serving a population of 300 000. The Loddon-Campaspe-Goulburn-Ovens-Murray-Shepparton area, with a population of about 500 000, could support two machines. Gippsland, with around 250 000, could support a single machine. There is also a significant gap in radiotherapy services in the western suburbs of Melbourne. All of these areas of need should be reviewed.

Section 3.17 discusses the problems of transport and accommodation for women needing radiotherapy, particularly those from the country.

3.7 Multidisciplinary Management

Recommendation: The NHMRC *Clinical Practice Guidelines: The Management of Early Breast Cancer* should be used both to guide the management of women with early breast cancer and to establish treatment protocols for women being managed outside clinical trials. Similar NHMRC guidelines for patients with more advanced disease are currently in preparation.

It is widely accepted that management of breast cancer should be multidisciplinary. This means the involvement of medical and radiation oncologists, surgeon, histopathologist, radiologist, breast cancer support nurse, and further psychological back-up. It is, however, multidisciplinary knowledge and input (rather than the simultaneous physical presence of all specialists) that is essential at points of decision-making.

Breast cancer is now recognised as a complex disease, with each woman requiring a personalised, integrated treatment program where the timing, quantity and quality of each of the possible therapies must be optimised. For most women during the first year of treatment, as described in the NHMRC Guidelines, this means surgery with or without chemotherapy and/or endocrine therapy and/or radiotherapy. Protocols for management of the various forms of early (potentially curable) breast cancer are under constant review. For example, The scope for adjuvant chemotherapy is currently being broadened to include many women with lymph node negative primary breast cancer.

BreastCare Centres will provide a focus for the collaboration of specialists and subspecialists in the area, and for the interchange of knowledge. Implementing truly multidisciplinary management of all women with breast cancer will require a culture change among some breast cancer specialists.

Traditionally the surgeon has been the leader of the team, and this situation is likely to remain in most cases, at least in the early stages of treatment. It is crucial, however, that the team include medical oncology and radiation oncology specialists. The team will change over time according to treatment, stage of disease, and individual needs. Continuity of care must be a central consideration at all times: constant changes in the staff seen are very disruptive and counter-productive both for the woman, and from the professional point of view. Continuity of care can best be guaranteed by identifying a principal caregiver who has overall responsibility for the management of a woman at each stage of her treatment.

3.8 Adjuvant Systemic Treatment

Adjuvant treatment with chemotherapy and/or endocrine therapy is one of the two proven approaches that will improve survival in breast cancer (the other is early detection through mammographic screening). It is thus crucial that adjuvant therapy be optimised: both, that all women who should be receiving it are offered it, and that all women who might benefit are offered a consultation with a medical oncologist, who is qualified to assess the optimal adjuvant therapy for an individual woman.

Recent figures suggest that a proportion of women who could benefit may not be receiving optimal adjuvant therapy, and that, in total, only about one third of patients with breast cancer are referred for a medical oncology consultation. The remaining women either miss out on adjuvant therapy altogether, or are prescribed it by their surgeon, general practitioner or radiation oncologist.

The low consultation rate with medical oncology is an area of concern. The situation is particularly important for pre-menopausal women, who have the most to gain from adjuvant therapy. Raising this rate could result in an improvement in both well-being and survival for women.

It is the initial consultation and recommendation regarding management that are important. Chemotherapy and/or endocrine therapy may often then be given under guidance from, rather than necessarily by, the medical oncologist.

3.9 Adjuvant Radiotherapy

Clinical trial evidence shows that adjuvant post-operative radiotherapy for women with breast cancer reduces the incidence of local recurrence in all circumstances, both after mastectomy and after breast conserving surgery, and in the latter, for both invasive and non-invasive disease. However the risk of recurrence is variable, and may be so low as to obviate the need for immediate adjuvant radiotherapy. The radiation oncologist is the professional who is best able to inform the patient of not only all the possible advantages of treatment, but also the logistics of treatment delivery and possibly the acute and late toxicities.

Recent figures from Victoria suggest that fewer than 50% of women undergoing breast conserving surgery receive adjuvant radiotherapy. This would be contrary to the NHMRC *Clinical Practice Guidelines: The Management of Early Breast Cancer*. There is also a relatively low consultation rate by surgeons performing breast surgery with radiation oncology colleagues. This is also an area of concern and reflects an inadequate use of multidisciplinary care. Raising the rate of referral and delivery of radiotherapy would reduce the local recurrence rate in breast cancer patients.

3.10 Advice, Information and Education for Women

Recommendation: BreastCare Centres should place a high priority on providing information for women with breast cancer and their families. This will entail:

- an emphasis on developing the communication skills of health professionals;
- the ready availability within BreastCare Centres of information products (written, tapes, education courses etc), within the broader context of women's health care. Information should be consistent Statewide and draw upon established expertise such as the Anti-Cancer Council of Victoria and the National Breast Cancer Centre;
- publicity about the existence of BreastCare;
- attention to the needs of women from different cultures and non-English speaking background.

Women's ability to make informed choices relating to the management of their breast disease depends to a large extent on their having ready access to reliable and appropriate information from sources that they respect and trust. BreastCare Centres have an important role in this.

Information for both women and their families is needed at all stages of the disease: investigation and diagnosis, acute treatment, coping with side effects, recurrence, and palliative care. Women need to know about the full range of services available, and they need consistent advice on how to seek help and how to access second opinions.

BreastCare should also offer women information packages on all aspects of women's health care and in particular, well-women information. Information needs to be oriented towards the whole woman rather than individual organs or procedures.

The woman needs:

- appropriate information, possibly recorded or in written form for later access;
- explanations in simple, non-medical language;

- answers to her questions;
- adequate time for consultations;
- easy access to her management team;
- recognition that she may need to hear information a number of times, particularly in the early stages of the disease, and that she has the right and often the need to seek information from a range of different sources;
- access to a range of information products - printed, tapes, education course etc. - including Anti-Cancer Council of Victoria (ACCV) and National Breast Cancer Centre (NBCC) publications, and medical journals and publications;
- access to adequate interpreting services and literature in her language.

Sources of information will include the general practitioner, specialists, breast cancer support nurse, social worker, other health professionals, ACCV, NBCC, community health centres, support or advocacy groups, pharmacists, as well as friends, the media, books etc. ACCV's Can-HELP line offers a comprehensive information service.

Women with breast cancer would gain considerable value from an information centre specifically for breast cancer, located within or attached to their BreastCare Centre. This is particularly important in relation to information on clinical trials.

The ACCV Living With Cancer Education Program, providing patients and families with information and help to develop and use a range of coping skills, is run by health professionals at a number of hospitals and community organisations. It may be especially beneficial to women with advanced breast cancer, and should be supported by BreastCare Centres.

3.11 Counselling and Support Services

Integrated Psychosocial Care

Recommendation: Psychological care and access to the range of social supports should be fully integrated with surgical, medical and radiation oncology services through BreastCare Centres. Appropriate funding is needed.

Clear evidence now exists that there are moderate levels of psychological morbidity among women diagnosed with breast cancer. This includes increased levels of anxiety and depression, and interference with social and sexual functioning. Improved methods of reducing this are needed in Victoria.

Individual counselling and support should be available from medical practitioners as part of the routine clinical care received by women from breast cancer specialists and general practitioners. Courses in communication skills for clinicians can enhance the quality of this form of support: these are discussed under "Professional Education" (Section 4.1). Support should also be routinely available from breast cancer support nurses (see below).

Many women also experience more complex psychological problems and need more specialised care. Specialised counselling is provided by social workers, psychologists or psychiatrists, who will ideally have a particular interest in patients with a malignant disease. Funding restrictions currently make access to a psychologist or psychiatrist very difficult. BreastCare Centres should be funded to support this service. A major policy change in this regard is required for appropriate comprehensive care of women with breast cancer.

Counselling may be delivered individually, or via both groups and family methods. All approaches need to be available: one method of approach - be it group or individual - is not suitable to all, and the woman's right to decide needs to be respected. Professionally led groups are better coordinated through Principal BreastCare Centres to avoid unnecessary delays in commencement, but should still function in all BreastCare Centres.

Individual counselling, group therapy, and bereavement counselling should also be available to family members, particularly partners and children (especially daughters) of women with breast cancer.

Social workers, as well as their counselling role, have a crucial practical role in coordinating community services (e.g. home help) and/or financial assistance for women and families on discharge or post-treatment, and coordinating volunteer outreach schemes.

Breast Cancer Support Nurses

Recommendation: All women with breast cancer should have access to a breast cancer support nurse both before and after surgery, and BreastCare Centres should be funded to support this.

It is imperative that the multidisciplinary team include a breast cancer support nurse, who should be available to all women with breast cancer. The support nurse must be acknowledged as part of the team, with particular expertise and accessibility. Breast cancer support nurses play a critical role in patient counselling, particularly around the time of initial treatment and early rehabilitation, but also as an ongoing and available resource to women.

BreastCare Centres need secure funding for breast cancer support nurses.

3.12 Breast Cancer Clinical Genetic Service

Recommendation: Two breast cancer clinical genetic services should be established, one at each of the two Principal BreastCare Centres, to provide women with risk information and advice, psychological support counselling, and in appropriate cases, DNA testing.

Genes responsible for an inherited predisposition to breast cancer have recently been identified, and genetic testing is possible for some high-risk women.

About 15% of women with breast cancer - that is, about 300 Victorian women newly diagnosed each year - have a family history of the disease. While not all these cancers will be due to inherited susceptibility genes, women in such families need ready access to genetic counselling, assessment of risk, and DNA testing where appropriate. This service needs to be integrated with services that can provide follow-up screening and assessment over years, and treatment where necessary.

Currently there is no coordinated Statewide service to deal with familial breast cancer, essentially because optimal management for these women has yet to be determined. Annual mammographic screening is recommended starting 10 years before the age at which the woman's mother was diagnosed with breast cancer. Many of these high-risk women fall outside the BreastScreen target age-group. Women over the age of 40 will be screened if they present to BreastScreen, and will be followed up for repeat screening if they have a family history of breast disease. Younger women are directed to Medicare (screening is rebatable for high-risk women).

To meet the needs of these women, the two Principal BreastCare Centres should each establish a clinical genetic service, comprising

- a medical geneticist
- a genetic counsellor
- breast cancer specialists as required.

This could be supplied as a regular genetic clinic, along the lines of the colorectal cancer genetic service provided by the Victorian Clinical Genetic Service. Funding will also be needed to support a breast cancer genetic registry.

There will need to be access to genetic testing after pre-test counselling for those women likely to have a mutated inherited susceptibility gene.

3.13 Lymphoedema Clinics

Recommendation: Each BreastCare Centre should have a lymphoedema clinic staffed by trained physiotherapists or occupational therapists, offering specialist advice to all women who seek it.

The lymphoedema clinic should provide women with relevant information, including arm care and prevention strategies.

3.14 Other Specialists

Linkages are needed with specialists in other areas who have expertise related to breast cancer, with appropriate referrals for women. This is particularly appropriate for later stages of the disease. For instance, a gynaecologist with an interest in the area may be able to help with side effects.

3.15 Women with Advanced Disease

Recommendation: BreastCare Centres must recognise the special needs of, and deal effectively with, women with advanced breast cancer and their families.

Services for women with advanced disease need to include:

- access to the full range of cancer treatment services (medical oncology, surgical oncology, radiation oncology);
- ready access to clinical trials of treatment of advanced breast cancer;
- access to, and ready use of, palliative care consultant teams and community care programs;
- medical, psychological, social and spiritual care;
- 24-hour access to consultancy for relief of symptoms and pain management;
- recognition of the physical limitations and difficulties of women with metastatic disease (e.g. provision for wheelchairs);
- an emphasis on quality of life issues;
- bereavement counselling.

Palliative care for women with breast cancer should be coordinated with existing and projected palliative care services. The Working Group does not support the creation of a separate breast cancer palliative care service. It should be noted that existing palliative care services are under-funded and unevenly and inequitably distributed across the State.

3.16 Specific Issues for Rural Areas

Resources will be necessary to ensure that both women and professional staff (especially those practising outside but associated with BreastCare Centres) have adequate access to the facilities of the BreastCare Centres.

Responsibility for referral should remain with the local surgeon, who is best placed to decide on the most appropriate referral for a particular patient. Referrals should not be "tied". They may, for instance, be influenced by availability of transport and accommodation, or by where relatives live.

Travel and accommodation during treatment is a major problem for many rural women. This is discussed in the next section.

3.17 Travel and Accommodation for Women

Recommendation: The State Government should support appropriate accommodation and travel support for women and their companions attending radiotherapy and other outpatient appointments.

Problems of travel and accommodation can severely limit access to radiotherapy for rural women. The difficulty and expense entailed is currently a substantial disincentive to conservative breast surgery for these women. Even with some decentralisation, most country women will continue to need to travel for radiotherapy. Radiotherapy is also a major modality for treatment of women with advanced breast disease.

There is a pressing need for inexpensive accommodation for rural women receiving radiotherapy, and for travel support. This would also be of benefit to rural women attending other outpatient appointments. Accommodation needs to be pleasant, and cost no more than \$10-20 per night. It should cater for those women who may need to bring their young children. Access to a breast cancer support nurse would be of considerable benefit.

Travel can also be a major problem for urban women, particularly those in outer suburban areas, depending on where the source of expertise is located in relation to their home. Some women are not well enough to drive themselves shortly after surgery and while undergoing radiotherapy, and many older women lack transportation or family support. Red Cross no longer transports people for radiotherapy, for financial reasons. Ambulances are funded through hospital budgets and are normally only provided if there is clinical need. Taxis can be prohibitively expensive for the number of visits and distances often involved. Hospital budgets have not been increased to cover these costs.

These issues should be addressed on a Statewide basis; they should not be compromised by competition between individual radiotherapy centres. It will be a matter of urgency for the BreastCare Committee (see Recommendation 6, Implementation) to consider how travel and accommodation might be funded.

3.18 Waiting Times

Recommendations:

All women diagnosed with possible breast cancer should be offered biopsy as soon as possible, i.e. within 14 days.

After histological confirmation of diagnosis, a definite date for operation should be established, in consultation with the individual woman, on the basis of her needs and expressed wishes. Breast cancer should thus clearly remain a Category 1 procedure in the public hospital system.

Every effort should be made to avoid undue pressure on the woman through either undue delay or undue haste in proceeding to surgery.

Women within the public system assessed as needing surgery or other inpatient treatment for breast cancer are not always able to be given an admission date. This is in contrast with the usual procedure for those receiving private treatment. It is also inconsistent with promoting the importance of early detection through BreastScreen.

BreastScreen specifies that women should have biopsy within 14 days of its being recommended.

3.19 Access to Treatments

Recommendation: All women (both in public hospitals and private patients) should have equal access to proven treatments.

Public patients can be disadvantaged over private regarding access to more expensive drugs because budget constraints in public hospitals lead often to cuts in pharmacy budgets.

If a drug is approved for treatment of breast disease in Australia, it should be readily available to all women who need it.

3.20 Breast Prostheses

Recommendation: A breast prosthesis of high quality should be readily available to every woman following mastectomy and, where indicated, on a regular basis thereafter. Obtaining a prosthesis must be simple, through a system that is easily accessed and adequately funded.

Breast prostheses cost about \$500 upwards. They are of vital concern for women following mastectomy. In terms of health budgets, the amount involved is small. For individual women, it can be a significant problem.

Access to high quality prostheses through the health system is difficult. The woman requires a letter from the surgeon stating that she needs a prosthesis. Public patients must apply along with other PAPD patients, competing with people who need a wide range of other, often expensive prostheses. Some, but not all, hospitals provide breast prostheses, but these are usually the cheapest, and of lowest quality. Such a prosthesis may be sufficient for the first year or so, but not in the long term.

Women of non-English speaking background may have specific requirements, and their needs should be identified and met.

4. Fostering Expertise Among Practitioners

Recommendations: FOSTERING LINKS AND SUB-SPECIALISATION

Specialists treating breast cancer (surgeons, medical oncologists, radiation oncologists) should be encouraged to:

- make that a significant part of their activity, to maximise their skills in the area;
- establish links with a BreastCare Centre, to foster the development of expertise and sub-specialisation in breast disease. BreastCare Centres should actively encourage this by forging links with medical personnel and groups working in their geographical area, and by offering ongoing professional education activities (nursing, medical, undergraduate, post-graduate, allied health professional, etc.).

Other facilities involved in the management of patients with breast disease, both public and private, should be encouraged to establish formal links with one of the BreastCare Centres in the hospital network (either principal or other centres), to ensure that women have access to the full range of breast cancer services.

Communication between specialists presents a particular challenge for those who do not work in a breast centre. This may include surgeons in private practice without a link to a breast centre, those who are geographically distanced, and those who see smaller numbers of women with breast cancer.

These links are thus particularly important for the large numbers of women receiving treatment as private patients. Over half those currently having surgery for breast cancer are private patients, and they are treated across a range of private hospitals. Private patients seen outside the context of a multidisciplinary breast clinic often do not have access to the range of clinical trials, ancillary and support services available at such clinics.

Cooperation already exists between many individual clinicians and treating hospitals, but this tends to be informal and variable across the State. Quality assurance under such circumstances is extremely difficult. Existing cooperation needs to be fostered, extended and formalised, to provide better management and access to the full range of resources for women seeking private treatment. All women with breast cancer should receive multidisciplinary management.

Linkages with a BreastCare Centre will provide a focus for ongoing professional education and upgrading of skills, access to clinical research and new treatments, and a means of systematising quality assurance, as described in the NHMRC *Clinical Practice Guidelines: The Management of Early Breast Cancer*.

There is a particular need to involve surgeons, who are the first point of contact for most symptomatic women, and who have a considerable influence on their management. Sub-specialisation will help to ensure that women are offered the best possible care. There is already a move in this direction: for instance, the number of surgeons treating breast cancer has declined over recent years, with a smaller number of surgeons seeing the majority of women with breast cancer.

4.1 Professional Education

Professional education on breast cancer is carried out at a number of levels by organisations including the professional colleges and the ACCV, which plays a major role in this area. BreastCare Centres should play a major role in the continuing development of existing professional education programs.

Continuing education for general practitioners is currently available through the Royal Australian College of General Practitioners, the ACCV, and now the National Breast Cancer Centre. Clear advice and direction are important regarding referral of patients. Student teaching is another area of importance.

The Royal Australasian College of Surgeons is very active, through its Breast Section, in educating surgeons about breast cancer.

All health care professionals and trainees require:

- an improved understanding of the management of advanced breast cancer;
- information about the rationale for, design and implementation of, and results from clinical trials in the management of breast cancer.

The establishment of BreastCare Centres will provide scope for all health care professionals and students to see best practice in action, with "hands-on" training in real situations. These centres should be responsible for dissemination of the NHMRC *Clinical Practice Guidelines: The Management of Early Breast Cancer*, and facilitate their implementation.

Communication, for example, is probably the area about which women express most dissatisfaction. While the NHMRC Clinical Practice Guidelines devote a large section to communication, women still regularly report very poor communication with some specialists; for instance, receiving their diagnosis in an inappropriate manner and place. Substantial change is needed in this area, in the short and the long term. BreastCare should make courses in communication skills available to all health care professionals involved in the management of breast cancer, and dedicated funding is needed to achieve this.

5. Quality Assurance

Recommendation: AUDIT AND QUALITY ASSURANCE

The State Government should establish a BreastCare Quality Assurance Committee that includes representatives from consumer groups, State Government, health care experts, and the Anti-Cancer Council of Victoria, to be responsible for the overall scientific audit and evaluation of the BreastCare Centres (including Principal Centres). Resources and expertise offered by the National Breast Care Centre should be taken into consideration.

The State government should resource the Principal BreastCare Centres to:

- conduct evaluation programs in their own centre and their associated BreastCare Centres;
- develop systems for quality assurance and common data collection.

BreastScreen provides an excellent model for quality assurance activities. It has gained women's support and respect in part through its rigorous quality assurance.

In like manner, BreastCare needs to be publicly accountable and subject to rigorous overall quality assurance programs and auditing procedures. These should include evaluation of patient satisfaction (with attention to the complexity of such measures).

Quality assurance and a total quality management approach should be implemented and funding for such an approach be guaranteed. Funding needs to cover data managers and a data management system.

The BreastCare Quality Assurance Committee recommended by the Working Group will be responsible to the Department of Health and Community Services for quality assurance in BreastCare.

The Principal Centres should carry out routine review of their associated centres, including collection, aggregation and review of data, and periodic site visits. Site visits should be conducted by an expert team including health professionals, consumers, and government representatives. (The Working Group has avoided the term "peer review" as it has connotations of a single profession overseeing its own standards, without outside input.)

The Principal Centres should report regularly to the BreastCare Quality Assurance Committee, which will review and aggregate data at a Statewide level and publish it at appropriate intervals. Such data handling will require the use of a common information/data form throughout the State. Funding should be available for this.

5.1 Surgery: Patterns of Practice and Quality Assurance

It is important that consumers and referring general practitioners have access to information that enables them to identify surgeons who have the appropriate specialised knowledge, skills, experience, training, or particular skills to manage breast disease. These surgeons should have established collaborations with medical and radiation oncologists.

The general practitioner is the informed patient advocate and holds clear responsibility for appropriate advice and referral. This should be carried out on the basis of clear guidelines and an awareness of the complexity of breast disease.

Surgeons need to take a leadership role in this area. Information provided to general practitioners about surgeons might include: whether they practise breast conservation, whether there is an established collaborative relationship with a radiation oncologist and a medical oncologist, and whether they have an affiliation with BreastCare. Such an affiliation would increase linkages, communication between professionals, and facilities for ongoing education. It would place the focus not only on numbers of patients seen, but also on the context in which they are treated, with back up in terms of education, and ready access to other specialist services and to counselling and social work services.

6. Research

Recommendation: RESEARCH

A long-term commitment by the State of Victoria is needed to funding investigations into the basic biology of breast cancer, randomised clinical trials, and broader clinical research that is closely allied to the management of women with breast disease.

While some improvements in patient outcomes and population mortality can be achieved through better and wider application of current knowledge and best practice, further substantial change will only come through research.

The essential problem is that very little is known of the basic biology of breast cancer. Currently, however, basic research into breast cancer has little support at the Federal level, with no coherent policy and no long-term view. Money is given in very small amounts that are inadequate to sustain the effort to solve large-scale problems.

Research is needed in all areas of breast cancer. However particular needs are to:

- understand the function of genes that contribute to breast cancer;
- identify genetic and physiological risk factors;
- find molecular markers to chart the progression of tumours, with particular emphasis on factors involved in spread and metastasis.

Success will require unique collaboration between basic scientists, epidemiologists and clinicians. The remit of the studies undertaken should extend through basic molecular biology and biochemistry of breast cancer and genetics to molecular pathology.

There is a need for a long-term commitment to research in the area, with funding guaranteed for 10 to 15 years. The community needs to be aware that this is the most promising avenue to substantial improvements in outcomes for women with this disease.

6.1 Clinical Research

About 5-10% of women recently diagnosed with breast cancer in Victoria become involved in clinical trials, which aim to improve outcomes. (The figure in the US is about 2%.) Victoria has the highest rate of accrual to clinical trials in the country. About 50% of patients on clinical trials in Victoria are private patients.

Enrolling patients in clinical trials is time-consuming for both clinician and patient. Proper data management support can alleviate this. Data managers are required at each of the Principal BreastCare Centres, and to be available within private practices, to encourage patient accrual to clinical trials. Currently ACCV is supporting data managers; these, however, need to be funded as an integral part of the breast services.

Appendix: The Current Victorian Scene

Incidence and Prevalence

Breast cancer is the most common cancer and the leading cause of cancer death in women. Overall, it is the second most common cancer (after bowel cancer).

ACCV data for 1992 show that there were:

- 2070 new cases of breast cancer, an age standardised rate of 69.9 per 100 000 women per year;
- 677 deaths from breast cancer, an age standardised rate of 21 per 100 000 women per year.

The incidence of breast cancer has risen very slightly over the past 10 years, from an age standardised rate of about 60 to nearly 70 per 100 000 women per year. This is probably due to the effects of screening and earlier detection. Mortality has been stable for decades.

Incidence rises steeply with age. For example, in 1992 there were:

- 56.9 breast cancer per 100 000 women aged 35-39 years;
- 169.6 breast cancers per 100 000 women aged 45-49 years;
- 221 breast cancers per 100 000 women aged 55-59 years;
- 271.6 breast cancers per 100 000 women aged 65-69 years;
- 312.8 breast cancers per 100 000 women aged 75-79 years.

For men, age standardised breast cancer incidence rate was 0.5 per 100 000, and mortality was 0.2 per 100 000 per year.

BreastScreen Victoria

BreastScreen provides free mammography to asymptomatic women through an organised screening service incorporating recruitment and recall for screening every two years.

A network of 36 screening units serve Victoria. Each is affiliated with one of the 8 Screening and Assessment Centres:

- Bendigo Regional BreastScreen
- Central Highlands and Wimmera BreastScreen
- City and North Eastern BreastScreen
- Geelong BreastScreen
- Gippsland BreastScreen
- Monash BreastScreen
- Maroondah BreastScreen
- The Royal Melbourne Hospital Essendon BreastScreen and Principal Assessment Centre.

BreastScreen targets women aged 50-69. Women aged 40-49 are also screened if they request it, but recalled for biennial screening only if they have a strong family history of breast cancer.

In 1993, 29 030 women attended for breast screening; in 1994, this rose to 116 335, and provisional figures for 1995 show that 134 367 women were screened.

By the end of 1994, 55% of target population had been screened.

Of the 116 335 women screened in 1994, 771 were diagnosed with breast cancer. Detection rates in the Victorian service are world class.

Diagnostic Services for Symptomatic Women

The following hospitals run diagnostic breast clinics. Those which do not require a doctor's referral are indicated *. Those which are fully rebatable through Medicare are indicated #.

- Dandenong Valley Private Hospital
- Diamond Valley Community Hospital
- Epworth Breast Clinic*
- Essendon Breast Clinic*#
- Freemason's Breast Clinic*
- Maroondah Breast Service#
- Monash Breast Clinic
- Preston and Northcote Community Hospital#
- Royal Melbourne Breast Clinic#
- St Vincent's Breast Clinic*#.

Hospitals Treating Breast Cancer - Public patients

A total of 90 hospitals treated public patients for breast cancer (ICC9 code = 174) during 1993/4. Of these, 45 treated 10 breast cancers or less. Those hospitals with 20 or more separations for breast cancer are listed below:

Alfred Healthcare Group, Prahran	Southern Metropolitan	27
Alfred Healthcare Group, Caulfield General Memorial Centre (formerly Southern Memorial)	Southern Metropolitan	541
Dandenong Hospital	Southern Metropolitan	46
Monash Medical Centre	Southern Metropolitan	596
Mornington Peninsula Hospital	Southern Metropolitan	71
Sandringham Hospital	Southern Metropolitan	33
Royal Melbourne Hospital	Western Metropolitan	2140
Royal Women's Hospital	Western Metropolitan	71
Western General Hospital	Western Metropolitan	140
Austin Hospital	Northern Metropolitan	241
PANCH	Northern Metropolitan	84
St Vincent's Hospital	Northern Metropolitan	744
Box Hill Hospital	Eastern Metropolitan	573
Cancer Institute	Eastern Metropolitan	403
Maroondah Hospital	Eastern Metropolitan	174
St George's Hospital	Eastern Metropolitan	79
Geelong Hospital	Barwon - South Western	246
Hamilton Base Hospital	Barwon - South Western	40
Timboon Hospital	Barwon - South Western	21
Warrnambool Hospital	Barwon - South Western	46
Gippsland Base Hospital	Gippsland	105
Latrobe Regional Hospital	Gippsland	134
West Gippsland Hospital	Gippsland	34
Ararat Hospital	Grampians	26
Ballarat Base Hospital	Grampians	163
Wimmera Base Hospital	Grampians	25
Goulburn Valley Hospital	Hume	179
Kyabram Hospital	Hume	23
Wangaratta Base Hospital	Hume	76
Wodonga Hospital	Hume	28
Bendigo Base Hospital	Loddon Mallee	193
Echuca Hospital	Loddon Mallee	36
Mildura Base Hospital	Loddon Mallee	94
Swan Hill Hospital	Loddon Mallee	21

Hospitals Treating Breast Cancer - Private patients

A total of 79 hospitals treated private patients for breast cancer (ICC9 code = 174) during 1993/4. Of these, 38 treated 10 breast cancers or less. Those hospitals with 20 or more separations for breast cancer are listed below:

Saint Francis Xavier Cabrini Hospital	Malvern	920
Freemasons Hospital	East Melbourne	827
Warringal Private Hospital	Heidelberg	499
Ringwood Private Hospital	Ringwood	493
Masada Private Hospital	St Kilda	279
St John of God Private Hospital	Ballarat	201
Repatriation Hospital	Heidelberg	197
John Fawcner Hospital	Coburg	153
Beleura Private Hospital	Mornington	140
Linacre Private Hospital	Hampton	101
South Eastern Private Hospital	Noble Park	86
St John of God Hospital	Geelong	72
Epworth Hospital	Richmond	70
St Vincent's Private Hospital	Fitzroy	67
Dandenong Valley Private Hospital	Mulgrave	60
Knox Private Hospital	Wantirna	50
Mitcham & District Private Hospital	Mitcham	49
Waverley Private Hospital	Mount Waverley	49
Peninsula Private Hospital	Frankston	46

Mornington Bush Nursing Hospital Inc.	Mornington	42
Mt Alvernia Hospital Inc	Bendigo	41
Mercy Private Hospital	East Melbourne	41
Coonara Private Hospital	Prahran	38
Jessie McPherson Private Hospital	Clayton	34
Stanlake Private Hospital	Footscray	34
Diamond Valley Community Hospital	Greensborough	33
Vimy House Private Hospital	Kew	32
Reservoir Private Hospital	Reservoir	27
Berwick Hospital Inc.	Berwick	26
Bellbird Private Hospital	Blackburn	25
Northpark Private Hospital	Bundoora	25
Cotham Private Hospital	Kew	22
Shepparton Private Hospital	Shepparton	20

Radiotherapy Facilities

Public hospitals with radiotherapy facilities are:

- Peter MacCallum Cancer Institute
- Box Hill Hospital (under contractual arrangements with Peter MacCallum Cancer Institute)
- Moorabbin Campus, Monash Medical Centre (under contractual arrangements with Peter MacCallum Cancer Institute)
- Austin Repatriation Hospital, Repatriation Campus
- William Buckland Radiotherapy Centre, Alfred Hospital
- Geelong Hospital

Public separations with radiotherapy (ICD9 code = V580) for these facilities for 1993/4 are as follows:

Alfred	184
Monash Medical Centre	30
Geelong Hospital	129
Box Hill Hospital	22
Cancer Institute	1363

Private separations with radiotherapy for 1993/4 are:

Freemasons'	526
Repatriation	93
Epworth	42
Coonarra	32

Patterns of Care

In two identical surveys, in 1986 and 1990, all patients over a six month period with primary operable breast cancer were identified through the Victorian Cancer Registry, and the surgeon of each was asked to complete a questionnaire.^{1,2} The surveys showed the following:

- **Detection:** In 1986, 1% of patients were referred from screening clinics. In 1990, surgeons reported that 6% were referred from screening clinics and 14% were first detected by screening mammography.
- **Referral:** In 1990, 82% of patients were referred to surgeons by general practitioners.
- **Surgeons:** In 1990, 176 surgeons performed 764 operations, compared with 200 surgeons performing 635 operations in 1986. In 1990, surgeons treating over 20 patients annually operated on 36% of the patients surveyed, compared with 22% in 1986. The proportion of women treated by surgeons who operated on 10 or less declined from 56% to 41% between 1986 and 1990.
- **Breast conservation:** The proportion of women receiving breast-conserving surgery rose from 22% in 1986 to 42% in 1990. Surgeons operating on more than 20 breast cancers per annum were most likely to perform breast-conserving operations.
- **Breast reconstruction:** In 1990, among women having mastectomy, reconstruction was done at the time of primary treatment in 13%, subsequently in 2%, and was planned by another 5%.
- **Radiation oncology:** Of the 1990 patients, 33% were referred to a radiation oncologist and 24% actually received radiotherapy (similar to 1986).

- **Medical oncology:** In 1990, medical oncologists saw 33% of the patients, and 20% received chemotherapy, similar to 1986. Chemotherapy was given by a medical oncologist in 83% of cases.
- **Endocrine therapy:** Use of endocrine therapy increased from 20% in 1986 to 40% in 1990.
- **Clinical trials:** In 1990, 1 patient in 20 entered adjuvant therapy trials, a level that is regarded as high by international standards.
- **Metropolitan vs country patients:** In 1990, metropolitan patients were more likely than non-metropolitan patients to have their cancer detected by mammographic screening (18% versus 6%), and to be conservatively treated (46% versus 33%), but no more likely to receive radiotherapy, postoperative chemotherapy, or endocrine therapy. A higher proportion of metropolitan surgeons' patients (43%), however, were referred to a radiation oncologist compared with the patients of non-metropolitan surgeons (28%).

Public Versus Private Sector

The data available cover only inpatient treatment for breast cancer. This does not include the majority of radiotherapy and chemotherapy treatments.

1994/1995 H&CS data show that:

- Two thirds of all breast cancer inpatient treatment takes place in the public sector. However more than half of diagnostic procedures and close to half of the surgical procedures are done in the private sector.
- 74.8% of all separations for radiotherapy (for any diagnosis) and 68% of all separations (for any diagnosis) are carried out in the public sector. 9.1% of all radiotherapy separations and 15.1% of all chemotherapy separations are for breast cancer.
- 83% of all radiotherapy separations associated with breast cancer are in the public sector, and 64% separations for chemotherapy associated with breast cancer are in the public sector. These figures do not distinguish between adjuvant and palliative treatment.

References

1. Hill DJ, Giles GG, Russell IS, Collins JP, Mapperson KJ. Management of primary, operable breast cancer in Victoria. *Med J Aust* 1990;152:67-72.
2. Hill DJ, White VM, Giles GG, Collins JP, Kitchen PRB. Changes in the investigation and management of primary operable breast cancer in Victoria. *Med J Aust* 1994;161:110-122

COPY

29 April 1996

The Hon Dr Michael Wooldridge
Federal Minister for Health and Family Services
Parliament House
Canberra ACT 2600

Dear Michael

We realised we had sent you off with a rather stark, unheaded, unsigned summary of the points we discussed with you at our very pleasant and stimulating lunch last Friday. Hereunder is that summary :

Background - Cancer is a major and increasing problem in the Australian community and it is likely to be the major cause of death for all Australians early in the next century. However, there are processes and procedures which can reduce this problem. The Government and NGOs have a major role in pursuing these processes.

Proposal - There is a unique opportunity with the creation of a National Cancer Control Council (NCCC), which draws on the Australian Cancer Society, Clinical Oncological Society of Australia, and the Australian Cancer Network of learned colleges, societies and the National Health & Medical Research Council, for the integration of the various prevention, screening and treatment programs which currently exist around Australia, in order to cost save (potentially massive) and improve the health of the community.

We believe the immediate benefits from this move would be to get rid of the "ad hocary" and apply current knowledge in a systematic and coordinated fashion to save money and save lives. We comment on six cancers - (1) Lung, (2) Breast, (3) Prostate, (4) Colorectal, (5) Skin, (6) Cervix as examples.

- (1) **Lung** - national coordination of Quit campaign and national targeted advertising. (Savings - \$ billions - from falling incidence)
- (2) **Breast** - preservation of the National Breast Screening Program and the National Breast Cancer Centre and the creation of an excellent breast diagnosis and treatment program by the improved coordination of breast services (matching the Breast Screening Program). (Savings - \$ uncertain)
- (3) **Prostate** - maintain a holding operation to control the diagnosis and treatment of prostate cancer over the next five years. Promote and support controlled clinical trials, encouraging collaboration in international trials. (Savings - \$100 millions - from indiscriminate PSA testing and unnecessary surgical management)
- (4) **Colorectal Cancer** - support the Australian Health Technology Advisory Committee in the development of recommendations on colorectal cancer screening. Dependent on AHTAC's recommendations, be ready to introduce programs that will define the best screening as distinct to adhoc screening arrangements that already exist. (Savings - \$ millions)
- (5) **Skin** - develop better education and coordination of GPs in screening for skin cancer. Be prepared to act on the recommendations of the Australian Cancer Network

sub-committee's guidelines for screening for skin cancer. (Savings - \$ 40 million per year)

- (6) **Cervix** - the current national screening program for cancer of the cervix is not working optimally. It requires better education of GPs and coordination of the recall system. (Savings - \$40 million per year)

I have also written to you formally thanking you for meeting with us and offering our services in national cancer control.

Warmest regards

Yours sincerely

Robert Burton

Director, Anti-Cancer Council of Victoria

Chairman, National Cancer Advisory Committee
to the Australian Cancer Society, Clinical Oncological Society of Australia
and Australian Cancer Network

COPY

29 April 1996

Mr Terence Barnes
Acting Senior Adviser
Office of the Minister for Health and Family Services
MG 48
Parliament House
Canberra ACT 2600

Dear Terry

Thank you very much for your help in respect of our meeting with the Minister last Friday. I am enclosing a properly letterheaded summary of the points we discussed at the meeting.

I am also enclosing a letter to the Minister expressing our appreciation for the opportunity we had to discuss cancer control with him and to emphasise our willingness to help in national cancer control planning and implementation.

With kindest regards,

Yours sincerely

Robert Burton
Director

Director: Dr Robert Burton
MD, PhD, BS, BA, BMedSci,
FRACP, FRACS, FAFPHM

29 April 1996

The Hon Dr Michael Wooldridge
Federal Minister for Health and Family Services
Parliament House
Canberra ACT 2600

Dear Michael

We were very encouraged by your interest in a National Cancer Control Council, which would create a national cancer control plan and advise you on best evidence-based practices in the prevention, screening and treatment of cancer. This would be a natural extension of the role that the members of the National Cancer Advisory Committee of the Australian Cancer Network play in their various states. Further we are accustomed to acting as an expert intermediary body between government and both the health care profession and the Australian public in promoting best practice in cancer control and answering critical responses from either the profession or the public.

We were very interested in your suggestion that a system of fee for service based on best practice could be a way of immediately addressing non-evidence-based practices in cancer control which are consuming increasing amounts of resources with no evidence that cancer health outcomes will be improved and, indeed, the real possibility that unnecessary morbidity and even mortality will result. We believe that such a system could be rapidly introduced. It could, for example, immediately address the mal-use of resources in cervical cytology screening, the excessive colonoscopy rates in 40-50 year olds, and the epidemic of PSA testing for prostatic cancer.

We would be interested in further discussions on the possibility of capitation for a disease like breast cancer. We believe that the implementation of this would probably be more difficult than the fee for best practice system suggested in the paragraph above, which could achieve the same aims.

Finally, should you request it of us, the National Cancer Advisory Committee would be able to provide you with authoritative statements on holding positions for mammographic screening of women aged 40-49, and PSA screening for prostate cancer, within a two week time frame.

Thank you very much for meeting with us.

With kindest regards

Yours sincerely



Robert Burton

Director, Anti-Cancer Council of Victoria

Chairman, National Cancer Advisory Committee
to the Australian Cancer Society, Clinical Oncological Society of Australia
and Australian Cancer Network

Leading the fight

Director: Dr Robert Burton MD, PhD, BS, BA, BMedSci, FRACP, FRACS, FAHPHM
Direct telephone: 61 (03) 9279 1106 Facsimile: 61 (03) 9279 1250

24 April 1996

The Hon. Michael Wooldridge, MP
Minister for Health
Parliament House
Canberra ACT

Dear Michael,

The following is a narrative and copies of the data we showed you plus additional resource material for the Australian Cancer Society Strategic Planning Meeting to be held in Sydney - May 3 & 4 1996.

Attached are 17 figures and tables which aim to provide an overview of where we are today in cancer control in Australia. It is not meant to be comprehensive but to highlight a number of important issues. The data are as follows:

Figures 1 & 2 These figures show the cancer mortality for the period 1950-1994 for males and females in Australia. For males the 5 leading causes of cancer death show trends where the mortality rates from lung, bowel and stomach cancer are now declining. The mortality rate for melanoma has actually plateaued in the last four years and it is only mortality from prostate cancer which is on the increase. Not included on this figure are the mortality rates for multiple myeloma and lymphoma which are now showing an upward trend in adult males. In females the mortality rates for bowel, stomach, cervical cancer and melanoma are now decreasing whilst breast has plateaued and lung may be plateauing. The increase in mortality rates for multiple myeloma and lymphoma seen in males are not present in females.

Figures 3 & 4 - These figures show impact of smoking related lung cancer on total cancer mortality trends in Australia in males and females for most of this century. As you can see, without the smoking related epidemic of lung cancer, all cancer mortality in males would have remained on a plateau for most of the century and for females would have decreased by about 25% between 1910 and 1994. Happily the decrease in adult male prevalence of smoking from 70% in the 1950s to 25% in the 1990s has had the desired effect on lung cancer mortality, albeit with the 25 to 30 year lag one would expect in prevention programs which impact on carcinogenesis.

Figure 5 Shows the cancer mortality rates in Australia between 1950 and projected through to the year 2010 using current trends on prevention and screening maximised to yield substantial reductions in all cancer mortalities for both males and females. For males the introduction of a screening program for colorectal cancer and better organisation of melanoma early detection would have an additional impact on reducing all cancer mortality beyond that already apparent for the trending decline in cancer mortality from reduced adult male smoking. For females there will be reductions in all cancer mortality due to the impact of smoking prevention on lung cancer and screening programs for breast, cervical

Leading the fight

and colorectal cancer and better organisation of the early detection of melanoma. These projected mortality declines do not take into account the effects of adjuvant therapy in the treatment of breast cancer and colorectal cancer, the introduction of chemoprevention for colorectal cancer with non steroidal anti inflammatory drugs and the impact of the Slip Slop Slap and SunSmart campaigns on prevention of melanoma. Therefore, we believe that they are conservative trends for declining mortality in all cancers for males and females.

Figure 6 Shows projected colorectal cancer mortality with the effects of prevention and the impact of screening. The screening impact is much more profound in males than in females. The prevention we take to be altered dietary habits in males and females where the females seem to have altered their diets back in the 1950-60s. That has only begun to occur in males in the 1980s. We take it that this is decreased consumption of protein and calories and fat, and increased consumption of vegetables, cereals and fruit.

Tables 7 & 8 and Figure 9 Show the current situation of over utilisation of cervical cytology. My understanding is that the two year screening interval was a compromise between what was logical and scientific, i.e. 3 years (Table 7), and pressures from the medical profession, who may have been doing a little shroud waving in claiming that 1-year would be the optimal interval. The data we have for the Victorian Cytology Service on early Pap smear testing shown on Table 8 reveals that current trends in early re-screening of women who receive a negative Pap smear report in Victoria would produce over a million women tested unnecessarily early in the whole of Australia with a wastage of \$38.8-million in the next 2 years. This data does not suggest that the National Cervical Screening Program is working either optimally or in the best interests of the women being screened. Further, one could make the case that cervical screening should commence at the age of 25 years since cervical cancer is rare before that age (Figure 9) Additional significant savings would accrue to the health care system from such a policy.

Figs .10,11,12 and Tables 13,14 There is a lot of pressure to do something specifically for males (Figure 10). Some aspects of the current epidemic of PSA testing for prostatic cancer which is in part a response to this are shown. The data are from Victoria and Australia and the first two figures show that the incidence of prostatic cancer in Victoria doubled between 1989 and 1993 due to an epidemic of PSA testing (Figures 11, 12). The Medicare data for PSA testing for the whole of Australia in 1993 is shown in Table 11 which reveals that overall 6% of 50-59 year olds and nearly 12% of 60-69 year olds had a PSA test in that year if we assume that each test is 1 person (which it isn't). Mortality from prostatic cancer in Victoria has been essentially stable over the period 1982-1993 (Table 11) so we now have very large diverging trends in incidence and mortality from prostate cancer. There are 1,000,000 Australian men between the ages of 55 and 69 in Australia and if these one million men were screened by the PSA test then 150,000 would screen positive and 850,000 would screen negative based on the prevalence of positive PSA testing in populations of this age from European and North American data (Table 14). Of the 150,000 who screen PSA positive, 45,000 would have a positive biopsy and 105,000 would have a negative biopsy. If all of the 45,000 who had a positive biopsy came to radical prostatectomy then about

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about 22,000 (50%) would be rendered incontinent to some degree and about 40,000 (90%) would be rendered impotent without any convincing evidence available that they would have been given a survival advantage. About 450 (1%) would be killed by the operation! Of the 105,000 who had a negative biopsy 1000 would have complications of haemorrhage and septicaemia, and a large number would have been subjected to psychological stress. Further, of the 850,000 who tested negative 76,500 would develop prostatic cancer. My conclusion is that the PSA test is nowhere near good enough a screening test for prostatic cancer even if we had an effective proven treatment for screen detected prostatic cancer.

Figs. 15, 16 and Table 17 Show data on skin cancer treatment in Australia. Figure 15 shows the total melanoma incidence for both sexes in Australia in the 1980s together with the rate of persons having skin lesion excisions in the same decade and the excision costs, all taken from the Medicare data. My interpretation of this figure 15 is that by 1988 sufficient skin lesion excisions were being undertaken to discover all the melanoma that the current widespread popular practices of early detection could achieve. We know that two thirds of all fatal melanoma is now concentrated in the over-50 age group and yet data from Adele Green in Brisbane suggests that it is the well worried 20-40 year old age group where the excision rates are highest. In any event by 1990-91 it appears we could have been wasting almost \$20-million per year on excessive skin lesion excision in respect of further detection of melanoma. The following figure 16 shows the skin lesion destruction costs in Australia. As you can see, skin lesion destruction by diathermy and other means only really took over in 1986-87 after having been on a low plateau for the previous 3 years. Skin lesion destruction has increased from 5 per 1000 persons to 20 per 1000 or now 2% of the population over a period of only 5 years with costs to the health care budget which have quadrupled. Non melanoma skin cancer incidence has remained essentially stable over this period and so it is very difficult to see that this money has been well spent! The final Table 17 reveals that we spent almost twice as much in 1989-90 on skin cancer treatment than on any of the other common serious malignancies. It is hard to believe that there is not considerable savings achievable here with much better education of the public and primary health care professionals, and perhaps regulation of skin biopsy and skin lesion destruction.

Again, in summary, this is not meant to be a total picture on where we are in cancer control today. It is meant to provide material to provoke thought and discussion.

Yours sincerely

Robert Burton
Director

The first part of the document discusses the importance of maintaining accurate records of all transactions. It emphasizes that every entry should be supported by a valid receipt or invoice. This ensures transparency and allows for easy auditing of the accounts.

In addition, the document outlines the procedures for handling discrepancies. If there is a difference between the recorded amount and the actual amount received or paid, it is crucial to investigate the cause immediately. This could be due to a clerical error, a missing receipt, or a fraudulent transaction.

The final section of the document provides a summary of the key points discussed. It reiterates the need for diligence and accuracy in all financial reporting. It also offers advice on how to prevent common mistakes and maintain the integrity of the accounting system.

By following these guidelines, you can ensure that your financial records are reliable and accurate, which is essential for the success of your business.

Thank you for your attention.

Sincerely,
 [Signature]

FAXED
17/4/96
11:15 am

Anti-Cancer Council Of Victoria
1 Rathdowne Street, Carlton South, 3053, Australia
Tel: 61 03 9279 1106 (Director's Office) Fax: 61 03 9279 1250

FACSIMILE COVER SHEET

Date: 17 April 1996
To (fax no) : 9317 8525
Attention : Prof Robert Thomas
President
Clinical Oncological Society of Australia
From : Dr Robert Burton
Director

If you do not receive 3 sheets please telephone above number

Dear Bob

Here is the letter I sent to Michael Wooldridge today. Could you please meet me at 11 am in my office on Friday April 26th so we can talk for one hour before meeting with Michael for lunch at noon.

Yours sincerely



Per: Robert Burton
Director

*** TRANSMISSION REPORT ***

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Anti-Cancer Council Of Victoria
 1 Rathdowne Street, Carlton South, 3053, Australia
 Tel: 61 03 9279 1106 (Director's Office) Fax: 61 03 9279 1280

FACSIMILE COVER SHEET

Date: 17 April 1996

To (fax no): 9317 8525


Attention: Prof Robert Thomas
 President
 Clinical Oncological Society of Australia

From: Dr Robert Burton
 Director

If you do not receive 3 sheets please telephone above number

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Yours sincerely


Per: Robert Burton
 Director

Director: Dr Robert Burton MD, PhD, BS, BA, BMedSci, FRACP, FRACS, FAHPHM
Direct telephone: 61 (03) 9279 1106 Facsimile: 61 (03) 9279 1250

17 April 1996

The Hon Dr Michael Wooldridge
Minister of Health
C/- P O Box 31
Box Hill Vic 3128

Ref 1-3447

Dear Michael

I am writing to you as Chairman of the National Cancer Advisory Committee (NCAC) to summarise some information which should be helpful to you prior to our lunch meeting of the 26th April at the Anti-Cancer Council of Victoria. You will be lunching with Professors Richard Fox, Richard Lovell and Robert Thomas and Mrs Elaine Henry, Mr Lawrie Wright and myself. We represent the major non-government cancer control bodies in Australia. A brief description of the NCAC and its relationship to them is attached.

Dick Fox, Dick Lovell and I discussed cancer and health issues in general with you in mid 1995 at a meeting arranged by Nigel Gray at the Anti-Cancer Council of Victoria. We hope to build on that meeting and discuss three important priorities for cancer control in Australia for the period 1997-2000 with you. They are:

1. The need for a National Cancer Control Council which would prepare an Australian Cancer Control Plan, facilitate and monitor its implementation, evaluate its outcomes and then revise the plan accordingly. The implementation of cancer control measures is necessarily local, and so state and other local authorities would be responsible for much of the implementation of the plan. We will propose that the National Cancer Control Council be composed in large part of members of the NCAC, with the addition of senior members of your department and appropriate representatives of other stakeholders eg. consumers. A draft plan could be completed in 1996 for widespread circulation and comment, because there is much national consensus on the priorities for cancer control; four national reports have been prepared in the last three years. We will present data to show you what could be achieved in reducing mortality from cancer in the future, and where substantial savings are possible from rectifying current inappropriate and excessive cancer control activities (Summary attached).

Leading the fight

2. A health promotion/disease prevention approach to primary health care. To achieve what is possible in the field of cancer control we believe there is a pressing need to introduce a system into primary health care which rewards health promotion and disease prevention. Significant reductions in the incidence and/or mortality of colorectal, breast, lung, skin and cervical cancer can be achieved over the next 15 years via prevention and/or screening programs which depend heavily upon general practitioners.

3. Familial cancer and the revolution in cancer genetics. Up to 15% of colorectal, breast, prostate cancer and melanoma clusters in families (familial cancers). In colorectal and breast cancer dominantly inherited highly penetrant cancer susceptibility genes have been discovered and cloned. Mutations in these genes cause 2-3% of these cancers, and DNA testing can detect the mutations. Familial cancer is a national problem as families do not respect state boundaries, and a very small number of nationally sponsored DNA testing laboratories could cover the genetic testing needs for patients and their families. For colorectal cancer a total cancer genetics service is now possible, with genetic counselling followed by DNA testing leading to close surveillance and/or prophylactic colectomy for gene positive members of affected families, with reassurance and no surveillance for gene negative individuals. We have estimated that the savings on regular frequent sigmoidoscopy and colonoscopy for the gene negative family members could pay for most of a national service! I have attached a copy of the program of the first national cancer genetics conference held this month which shows that much is happening, and that national leadership to cover all stakeholders is urgently required. We will seek your support for the publication of national guidelines which will arise from that meeting.

I am very much looking forward to our meeting.

Warmest regards.

Yours sincerely



Robert Burton
Director

Att.

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THE NATIONAL CANCER ADVISORY COMMITTEE (NCAC)

Ref 1-3448

The National Cancer Advisory Committee (NCAC) was established in 1991 as the Medical and Scientific Advisory Committee of both the Australian Cancer Society (ACS - established 1961) and the Clinical Oncological Society of Australia (COSA - established 1973).

In 1992, as a consequence of a recommendation from the NCAC on the need for a National Cancer Institute like that of the USA or Canada, the Australian Cancer Network (ACN) was formed. The ACN is an "institute without walls". It has a council of representatives from all its stake holders, which are both cancer-specific and also more generic agencies which have an element of cancer control in their mandates: the cancer centres and hospitals, Commonwealth and State government agencies, cancer health care professionals, medical schools, the NH & MRC National Breast Cancer Centre, non government organisations concerned with cancer, Royal Colleges and other professional bodies, research institutions and groups and state cancer councils.

In 1996 the NCAC was reconstituted to serve as the Executive Committee of the ACN in addition to remaining the Medical and Scientific Advisory Committee of the ACS and COSA. It now consists of fourteen members, a chairperson appointed on a rotating basis by the ACS and COSA, six members chosen by the chairperson from nominees of the state cancer councils and COSA and approved jointly by ACS and COSA, and seven members nominated on the basis of their skills by the ACN council.

Summary

The NCAC is the peak national non-government national cancer control authority for scientific and medical advice in Australia. It represents the ACS, COSA and the ACN. The ACS, which is made up of representatives of all the State Cancer Councils, is principally concerned with policy formulation and implementation in areas of primary prevention and early detection of a cancer, as well as supportive care for cancer patients and their families. COSA, which is made up of oncology health care professionals, is largely concerned with the clinical management and care of cancer patients. The ACN is the national coalition of all stakeholders in cancer research and treatment in Australia. The draft terms of reference of the NCAC are attached.

Officer bearers of the NCAC/ACS/COSA/ACN and ACCV attending the meeting with Dr Michael Wooldridge at the Anti-Cancer Council of Victoria (ACCV) on 26/4/96

Professor Robert Burton, Chair of the National Cancer Advisory Committee (NCAC)
Professor Richard Fox, President of the Australian Cancer Society (ACS)
Mrs Elaine Henry, Executive Director of the NSW Cancer Council and a member of the Executive of the ACS
Emeritus Professor Richard Lovell, Chair of the ACCV Genetics Ethics Committee,
Professor Robert Thomas, President of the Clinical Oncological Society of Australia (COSA)
Mr Lawrie Wright, Executive Director of the ACS who is deputising for Emeritus Professor Tom Reeve, Executive Officer of the Australian Cancer Network (ACN)

Att.

TERMS OF REFERENCE

The National Cancer Advisory Committee shall:

1. Identify and respond to new issues in cancer medicine and encourage or initiate research, investigation or meetings to resolve them.
2. Respond on behalf of both Societies to requests from Federal Government or other national organizations on medical or scientific issues.
3. Monitor and review clinical practice in respect of cancer management and make recommendations in respect of treatment, resources and training.
4. Consider the scientific elements of cancer control and by periodic review and the issue of position papers, guide the professional and public education policies of the ACS and its member organizations.
5. Direct and utilise the resources of the ACN to undertake projects and provide position statements and recommendations for action by Network members and/or Government.
6. Lobby Government in support of the policies of its parent bodies.

AUSTRALIAN CANCER GENETICS CONSENSUS MEETING

THURSDAY - 11 APRIL, 1996

8.15 am	Registration
9.00 am	Arrival Tea & Coffee
10.00 am	Welcome - Dr Sally Redman - Director, NBCC Dr Eric Haan - Vice-President, HGSA Emeritus Prof Tom Reeve - Executive Officer, ACN
10.03 am	
10.06 am	Introduction- Prof Richard Smallwood - Chair, NHMRC
10.09 am	A/Prof Rick Kefford - Chair, ACN Cancer Genetics Working Party
10.15 am	Opening - Professor Richard Smallwood
10.25 am	Announcements re meeting
10.30 am	Breast Cancer
11.00 am	Panel Chair - Dr J Hopper - Dr B Barraclough, Dr I Hopper, Dr J Kirk, Prof M Friedlander, Mrs H Varney * A/Prof R Kefford
11.30 am	MORNING TEA
12.00 pm	Breast Cancer Panel Continued - Dr Judy Kirk, Prof Emeritus R Lovell
12.30 pm	Ethics - Dr Judy Kirk, Rev Dr D McCaughey, Dr M Kearney, Dr K Tucker, Prof Emer R Lovell, Dr M Gardner, Dr I Walpole, Ms Avis Macphie - Prof Emeritus R Lovell
12.45 pm	LUNCH
1.45 pm	Ethics Panel Chair - Dr I St John - Dr J St John, Dr K Tucker, Dr D Koorey, Dr M Kohonen-Corish, Mr D Wells - Prof Jeremy Jass
2.45 pm	Colon Cancer Panel Chair
3.15 pm	
3.45 pm	AFTERNOON TEA
4.15 pm	Laboratory Accreditation Panel Chair - Dr C Suthers - Dr G Suthers, Dr B McDonald, Dr S Forrest, Dr G Mann, Dr G Chenevix- Trench - Prof R Burton
5.15 pm	CLOSE
6.30 pm	DRINKS
7.00 pm	DINNER

AUSTRALIAN CANCER GENETICS CONSENSUS MEETING

FRIDAY - 12 APRIL, 1996

8.30 am	Arrival Tea & Coffee
9.00 am	Research Panel Chair - A/Prof R Kefford - A/Prof R Kefford, Dr G Mann, Dr T Burgess, Dr G Giles, Prof G Tregear * Dr G Chenevix-Trench
9.30 am	
10.00 am	Clinic Accreditation - Dr K Tucker
10.30 am	MORNING TEA
11.00 am	Clinic Accreditation Panel Chair - Dr K Tucker, Dr J Kirk, Dr M Gardner, Dr I Walpole, Dr E Haan, Dr M Gattas - Dr I Halliday
11.30 am	Education Panel Chair - Dr K Barlow - Dr K Barlow, Dr A McBride, Ms D Reading, Prof M Tattersall - Dr E Haan
12.00 pm	
12.45 pm	LUNCH - Session Coordinator: Prof M Friedlander
1.30 pm	Group Leaders - Presentation of Final Guideline Recommendations (30 mins each)
3.15 pm	AFTERNOON TEA - Group Leaders & Chairs Moderator: A/Prof R Kefford
3.45 pm	Meet the Press
4.30 pm	Departures for airport. Bus, hire car depending on numbers and cost.

PROGRAM

AUSTRALIAN CANCER GENETICS CONSENSUS MEETING 11-12 APRIL, 1996

Ella Latham Theatre
Royal Children's Hospital
Flemington Road, Parkville VIC

Ph: (03) 9345 5045
Fax: (03) 9348 1391

SPONSORED BY:

Australian Cancer Network (ACN)
Human Genetics Society of Australasia (HGSA)
National Breast Cancer Centre (NBCC)



Future Projections for Cancer Mortality in Australia and Inappropriate Current Practices in Cancer Control

Ref 1-3456

- **If the epidemic of lung cancer caused by smoking had never occurred, cancer mortality rates in Australia would have remained at a constant level for men between 1910 and 1990, and would have fallen slowly and continuously during that period for women.**
- **Lung cancer mortality in men and melanoma mortality in women have now begun to fall, fruits of the QUIT, SLIP, SLOP, SLAP and SUNSMART campaigns which need increased support nationally.**
- **Population mortality from cancer can be expected to fall from now as a result of those trends in lung cancer and melanoma mortality, plus the effects of the introduction nationally of mammographic screening for breast cancer and cytology screening for cervical cancer, together with the establishment of preventive and screening programs for colo-rectal cancer in the near future. National facilitation and co-ordination of these programs will maximise outcomes.**
- **But there is evidence of inappropriate and excessive utilisation of medical services for skin cancer treatment, cervical cytology and testing for prostate cancer. With more rational use of resources substantial savings should be possible.**

FA-ED
16/4/96
9-55am
KL

Anti-Cancer Council Of Victoria
1 Rathdowne Street, Carlton South, 3053, Australia
Tel: 61 03 9279 1106 (Director's Office) Fax: 61 03 9279 1250

FACSIMILE COVER SHEET

Date: 16 April 1996
To (fax no) : 02 356 4558
Attention : Mr Lawrie Wright
Executive Director
Austalian Cancer Society
From : Dr Robert Burton
Director

If you do not receive 7 sheets please telephone above number

Dear Lawrie

Please find attached draft documents to be sent to Dr Michael Wooldridge. Could you please return with any comments **by Wednesday morning (17th April)**.

With thanks

Yours sincerely



Per: Robert Burton
Director

Anti-Cancer Council Of Victoria
1 Rathdowne Street, Carlton South, 3053, Australia
Tel: 61 03 9279 1106 (Director's Office) Fax: 61 03 9279 1250

FAXED
16/4/96
9-45
AM
KL

FACSIMILE COVER SHEET

Date: 16 April 1996
To (fax no) : 02 357 2676
Attention : Mrs Elaine Henry
Executive Director
New South Wales Cancer Council
From : Dr Robert Burton
Director

If you do not receive 7 sheets please telephone above number

Dear Elaine

Please find attached draft documents to be sent to Dr Michael Wooldridge. Could you please return with any comments **by Wednesday morning (17th April)**.

With thanks

Yours sincerely



Per: Robert Burton
Director

FAXED
11-20 AM
16/4/96
KE

Anti-Cancer Council Of Victoria
1 Rathdowne Street, Carlton South, 3053, Australia
Tel: 61 03 9279 1106 (Director's Office) Fax: 61 03 9279 1250

FACSIMILE COVER SHEET

Date: 16 April 1996
To (fax no) : 93428132
Attention : Prof Richard Fox
Director
Dept. of Clinical Haematology & Medical Oncology
From : Dr Robert Burton
Director

If you do not receive 7 sheets please telephone above number

Dear Dick

Please find attached draft documents to be sent to Dr Michael Wooldridge. Could you please return with any comments by **Wednesday morning (17th April)**.

With thanks

Yours sincerely

K. Layimer

Per: Robert Burton
Director

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*** TRANSMISSION REPORT ***

S.I.D. :

ANTI CANCER COUNCIL N° :

92791250

Date : 16/04/96 11:11

Date/Time	16-04 11:06
Dialled number	093428132
Subscriber	61 3 3428132
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Name	
Pages	7
Status	Correct

Anti-Cancer Council Of Victoria
1 Rathdowne Street, Carlton South, 3053, Australia
Tel: 61 03 9279 1106 (Director's Office) Fax: 61 03 9279 1250

FACSIMILE COVER SHEET

Date: 16 April 1996
To (fax no): 93428132
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Dept. of Clinical Haematology & Medical Oncology
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Director

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With thanks

Yours sincerely



Prof Robert Burton
Director

Anti-Cancer Council Of Victoria
1 Rathdowne Street, Carlton South, 3053, Australia
Tel: 61 03 9279 1106 (Director's Office) Fax: 61 03 9279 1250

✓
FAXED
10/4/96
4-30 PM
KL

FACSIMILE COVER SHEET

Date: 10 April 1996
To (fax no) : 9347 7508
Attention : Prof Richard Fox
Director
Dept of Clinical Haematology & Medical Oncology
From : Dr Robert Burton
Director

If you do not receive 6 sheets please telephone above number

Dear Dick

I wish to send this letter to Michael Wooldridge by April 17. I would appreciate your feedback and comments by April 16.

Thank you.

Yours sincerely



RCB

***** TRANSMISSION REPORT *****

S.I.D. :

ANTI CANCER COUNCIL N° :

92791258

Date : 10/04/96 16:26

Date/Time	10-04 16:20
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Pages	7
Status	Correct

Anti-Cancer Council Of Victoria
1 Rathdowne Street, Carlton South, 3053, Australia
Tel: 61 03 9279 1306 (Director's Office) Fax: 61 03 9279 1258

FACSIMILE COVER SHEET

Date: 10 April 1996
To (fax no): 9347 7508
Attention: Prof Richard Fox
Director
Dept of Clinical Haematology & Medical Oncology
From: Dr Robert Burton
Director

If you do not receive 6 sheets please telephone above number

Dear Dick

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Thank you.

Yours sincerely



RCB

FAKED
10/4/96
4:30pm
KL

Anti-Cancer Council Of Victoria
1 Rathdowne Street, Carlton South, 3053, Australia
Tel: 61 03 9279 1106 (Director's Office) Fax: 61 03 9279 1250

FACSIMILE COVER SHEET

Date: 10 April 1996
To (fax no) : 02 357 2676
Attention : Mrs Elaine Henry
Executive Director
New South Wales Cancer Council
From : Dr Robert Burton
Director

If you do not receive 6 sheets please telephone above number

Dear Elaine

I wish to send this letter to Michael Wooldridge by April 17. I would appreciate your feedback and comments by April 16.

Thank you.

Yours sincerely



RCB

*** TRANSMISSION REPORT ***

S.I.D. :

ANTI CANCER COUNCIL N° :

92791250

Date : 10/04/96 16:37

Date/Time	10-04 16:32
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Status	Correct

Anti-Cancer Council Of Victoria
1 Raffaldowne Street, Carlton South, 3053, Australia
Tel: 61 03 9279 1106 (Director's Office) Fax: 61 03 9279 1250

FACSIMILE COVER SHEET

Date: 10 April 1996
To (fax no) : 02 357 2676
Attention : Mrs Elaine Henry
Executive Director
New South Wales Cancer Council
From : Dr Robert Burton
Director

If you do not receive 6 sheets please telephone above number

Dear Elaine

I wish to send this letter to Michael Wooldridge by April 17. I would appreciate your feedback and comments by April 16.

Thank you.

Yours sincerely



RCB

DRAFT

9 April 1996

The Hon Dr Michael Wooldridge
Minister of Health
C/- P O Box 31
Box Hill Vic 3128

Ref 1-3447

Dear Michael

I am writing to you as Chairman of the National Cancer Advisory Committee (NCAC) to summarise some information which should be helpful to you prior to our lunch meeting of the 26th April at the Anti-Cancer Council of Victoria. We will be joined for lunch by Professor Richard Fox, President of the Australian Cancer Society (ACS), Professor Robert Thomas, President of the Clinical Oncological Society of Australia (COSA), Emeritus Professor Richard Lovell, Chair of the Anti-Cancer Council of Victoria Cancer Genetics Ethics Committee, Mrs Elaine Henry, Executive Officer of the NSW Cancer Council and a member of the Executive of the ACS, and Mr Lawrie Wright, Executive Director of the ACS who is deputising for Emeritus Professor Tom Reeve, Executive Officer of the Australian Cancer Network (ACN), I have attached a brief description of the relationships between the NCAC/ACN/ACS/COSA for your information.

Dick Fox, Dick Lovell and I discussed cancer and health issues in general with you in mid 1995 at a meeting arranged by Nigel Gray at the Anti-Cancer Council of Victoria. We hope to build on that meeting and discuss three important priorities for cancer control in Australia for the period 1997-2000 with you. They are:

1. The need for a National Cancer Control Committee (NCCC) who would prepare an Australian Cancer Control Plan, facilitate and monitor its implementation, evaluate its outcomes and then revise the plan accordingly. The implementation of cancer control

DRAFT

measures is necessarily local, and so state and other local authorities would be responsible for much of the implementation of the plan. We will propose that the NCCC be composed in large part of members of the NCAC, with the addition of senior members of your department and an appropriate representatives of other stakeholders eg. consumers. A plan could be completed in 1996, because there is much national consensus on the priorities for cancer control; four national reports have been prepared in the last three years. This committee should also make recommendations, where resources are currently not being utilised appropriately in cancer control in Australia. We will present you a summary data on skin cancer treatment, and informal screening for prostate cancer to illustrate this. Substantial savings could be made in such areas.

2. Familial cancer and the revolution in cancer genetics. Up to 15% of colorectal, breast, prostate cancer and melanoma clusters in families. In colorectal and breast cancer dominantly inherited highly penetrant cancer susceptibility genes have been discovered and cloned. For colorectal cancer these are the APC gene in familial adenomatous polyposis (FAP), and DNA mismatch repair genes in hereditary non polyposis colorectal cancer (HNPCC), which carry a risk of 50% to 100% colorectal cancer by age 50, and account for about 3% of all cases of this disease in Australia. In breast cancer there are the BRCA-1 and BRCA-2 genes which confer an 80% risk of breast and/or ovarian cancer to age 75, and account for about 2% of breast cancer. Familial cancer is a national problem as families do not respect state boundaries, and a very small number of nationally sponsored DNA testing laboratories could cover the genetic testing needs for patients and their families. For colorectal cancer a total colorectal cancer genetics service is now possible, with genetic counselling followed by DNA testing leading to close surveillance and/or prophylactic colectomy for gene positive members of affected families, with reassurance and no surveillance for gene negative individuals. We have estimated that the

savings on regular frequent colonoscopy for the gene negative HNPCC family members could pay for most of the national service!

3. A health promotion/disease prevention approach to primary health care. We believe there is a pressing need to replace the current fee for service model with a primary health care system which rewards health promotion and disease prevention. Significant reductions in the incidence and/or mortality of colorectal, breast, lung, skin and cervical cancer can be achieved over the next 15 years via prevention and/or screening programs which depend heavily upon general practitioners. We will present projections based on current and future achievable practices to illustrate these points. It is worth noting that if the smoking epidemic had never occurred mortality rates from cancer in Australian would have remained at a constant level between 1910 and 1990 for men, and would have fallen slowly and continuously during that period for women!

I am very much looking forward to our meeting.

Warmest regards.

Yours sincerely

Robert Burton
Director

At.

DRAFT

THE NATIONAL CANCER ADVISORY COMMITTEE (NCAC)

Ref 1-3448

The NCAC was established in 1991 as the Medical and Scientific Advisory Committee of both the Australian Cancer Society (ACS - established 1961) and the Clinical Oncological Society of Australia (COSA - established 1973).

The Australian Cancer Network (ACN)

The ACN was established in 1992 consequent upon NCAC working party recommendations on the need for a National Cancer Institute (NCI) of Australia like the NCI of the USA and Canada. The ACN is an "institute without walls". It has an ACN council of representatives from all its stake holders: the cancer centres and hospitals, Commonwealth and state government agencies, cancer health care professionals, medical schools, the NH & MRC National Breast Cancer Centre, non government organisations concerned with cancer, Royal Colleges and other professional bodies, research institutions and groups and state cancer councils.

In 1996 the NCAC was reconstituted to serve as the Executive Committee of the ACN in addition to remaining the Medical and Scientific Advisory Committee of the ACS and COSA. It now consists of fourteen members, a chairperson jointly appointed by ACS and COSA, six members chosen by the chairperson from nominees of the state cancer councils and COSA and approved jointly by ACS and COSA, and seven members nominated on the basis of their skills by the ACN council.

Summary

The NCAC is the peak non government national cancer control body for scientific and medical advice in Australia. It represents the ACS, which is mainly a policy making body concerned with coordinating state cancer council policies in primary prevention and early detection of cancer, COSA which is largely concerned with the treatment and support of cancer patients by health care professionals, and the ACN which is the national coalition of all stakeholders in cancer research and cancer management in Australia. The draft terms of reference of the NCAC are attached.

Att.

TERMS OF REFERENCE

The National Cancer Advisory Committee shall:

1. Identify and respond to new issues in cancer medicine and encourage or initiate research, investigation or meetings to resolve them.
2. Respond on behalf of both Societies to requests from Federal Government or other national organizations on medical or scientific issues.
3. Monitor and review clinical practice in respect of cancer management and make recommendations in respect of treatment, resources and training.
4. Consider the scientific elements of cancer control and by periodic review and the issue of position papers, guide the professional and public education policies of the ACS and its member organizations.
5. Direct and utilise the resources of the ACN to undertake projects and provide position statements and recommendations for action by Network members and/or Government.
6. Lobby Government in support of the policies of its parent bodies.

1935

FAXED ✓
10/4/96
4:30pm
KL

Anti-Cancer Council Of Victoria
1 Rathdowne Street, Carlton South, 3053, Australia
Tel: 61 03 9279 1106 (Director's Office) Fax: 61 03 9279 1250

FACSIMILE COVER SHEET

Date: 10 April 1996
To (fax no) : 003 911068
Attention : David Hill

From : Dr Robert Burton
Director

If you do not receive 6 sheets please telephone above number

Dear David

I wish to send this letter to Michael Wooldridge by April 17. I would appreciate your feedback and comments by April 16.

Thank you.

Yours sincerely



Robert Burton
Director

***** TRANSMISSION REPORT *****

S.I.D. : ANTI CANCER COUNCIL N° : 92791250

Date : 10/04/96 16:44

Date/Time	10-04 16:37
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Pages	7
Status	Correct

Anti-Cancer Council Of Victoria
1 Radcliffe Street, Carlton South, 3068, Australia
Tel: 61 03 9279 1106 (Director's Office) Fax: 61 03 9279 1250

FACSIMILE COVER SHEET

Date: 10 April 1996
To (fax no): 003 911068
Attention: David Hill

From: Dr Robert Burton
Director

If you do not receive 6 sheets please telephone above number

Dear David

I wish to send this letter to Michael Wooldridge by April 17. I would appreciate your feedback and comments by April 16.

Thank you.

Yours sincerely



Robert Burton
Director

Anti-Cancer Council Of Victoria
1 Rathdowne Street, Carlton South, 3053, Australia
Tel: 61 03 9279 1106 (Director's Office) Fax: 61 03 9279 1250

FAXED ✓
10/4/96
4:30
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KE

FACSIMILE COVER SHEET

Date: 10 April 1996
To (fax no) : 02 356 4558
Attention : Mr Lawrie Wright
Executive Director
Australian Cancer Society
From : Dr Robert Burton
Director

If you do not receive 6 sheets please telephone above number

Dear Lawrie

I wish to send this letter to Michael Wooldridge by April 17. I would appreciate your feedback and comments by April 16.

Thank you.

Yours sincerely



RCB

***** TRANSMISSION REPORT *****

S.I.D. : ANTI CANCER COUNCIL N° :

92791258

Date : 18/04/96 16:31

Date/Time	18-04 16:26
Dialled number	0023564558
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Mode	FINE
Name	
Pages	7
Status	Correct

Anti-Cancer Council Of Victoria
1 Rathdowne Street, Carlton South, 3051, Australia
Tel: 61 03 9279 1106 (Director's Office) Fax: 61 03 9279 1250

FACSIMILE COVER SHEET

Date: 10 April 1996
To (fax no): 02 356 4558
Attention: Mr Lawrie Wright
Executive Director
Australian Cancer Society
From: Dr Robert Burton
Director

If you do not receive 6 sheets please telephone above number

Dear Lawrie

I wish to send this letter to Michael Woodridge by April 17. I would appreciate your feedback and comments by April 16.

Thank you.

Yours sincerely



RCB

FAXED
10/4/96
4:34pm
KL

Anti-Cancer Council Of Victoria
1 Rathdowne Street, Carlton South, 3053, Australia
Tel: 61 03 9279 1106 (Director's Office) Fax: 61 03 9279 1250

FACSIMILE COVER SHEET

Date: 10 April 1996
To (fax no) : 9317 8525
Attention : Prof Robert Thomas
President
Clinical Oncological Society of Australia
From : Dr Robert Burton
Director

If you do not receive 6 sheets please telephone above number

Dear Bob

I wish to send this letter to Michael Wooldridge by April 17. I would appreciate your feedback and comments by April 16.

Thank you.

Yours sincerely



RCB

***** TRANSMISSION REPORT *****

S.I.D. :

ANTI CANCER COUNCIL N° :

92791250

Date : 10/04/96 16:48

Date/Time	10-04 16:44
Dialled number	093178525
Subscriber	61 3 317 8525
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Pages	7
Status	Correct

Anti-Cancer Council Of Victoria
1 Rindowne Street, Carlton South, 3053, Australia
Tel: 61 03 9279 1106 (Director's Office) Fax 61 03 9279 1250

FACSIMILE COVER SHEET

Date: 10 April 1996
To (fax no): 9317 8525
Attention: Prof Robert Thomas
President
Clinical Oncological Society of Australia
From: Dr Robert Burton
Director

If you do not receive it, please telephone above number

Dear Bob

I wish to send this letter to Michael Wooldridge by April 17. I would appreciate your feedback and comments by April 16.

Thank you.

Yours sincerely



RCB

Director: Dr Robert Burton MD, PhD, BS, BA, RMedSci, FRACP, FRACS, FAFPHM
Direct telephone: 61 (03) 9279 1106 Facsimile: 61 (03) 9279 1250

BF

25 March 1996

Ms Alison Sewell
HASC Executive Secretary
NH & MRC Health Advancement Standing Committee
Mail Drop 82
Department of Human Services & Health
GPO Box 9848
Canberra ACT 2601

Ref 1-3433

Dear Ms Sewell

I am writing in reply to your invitation to make a submission on "HEALTH AUSTRALIA, Promoting Health in Australia Discussion Paper December 1995". This is an important document however I was disappointed by its length and reminded of Winston Churchill's comment on a report: "this, by its length defends itself from the risk of being read"! None the less I have read the document with care and it is a very comprehensive review of the current status of health promotion. I have the following comments to make in respect of the document in general and cancer specifically.

It is noted (page 245) that "health promotion activity in Australia has been most effective in the past when linked to a specific issue". When one considers the current priorities (as identified by program area at the national level) as set out on page 81, the national data sets that exist (page 85) and the indicative list of indicators for health promotion (pages 91-92) together with the national health targets (page 94), it is easy to understand why it has been so difficult nationally to set up programs with clear goals, which are implemented promptly, evaluated effectively and then revised in the light of that evaluation. Nationally, in cancer we have had four reports from the NH & MRC and other bodies concerned with cancer control, including health promotion issues, in the last three years, all of which have made recommendations, with little evidence of effective national implementation to date. (National Cancer Prevention Policy, 1993; Better Health Outcomes for Australians, 1994; Cancer Control in Australia, 1995; and now Health Australia, Promoting Health in Australia 1995.)

In general, all health promotion is local and so the implementation of national policies would generally be at a very local level. None the less it is important to have national oversight committees with real power to set goals, co-ordinate state and other endeavours, facilitate implementation, evaluate outcomes and review the goals in an ongoing fashion. For example, a National Cancer Control Committee would be a very good start in my field if it was wisely constituted calling on the expertise of the Australian Cancer Society through its Australian Cancer Network and included appropriate senior public servants from the Commonwealth Department of Human Services and Health and was given the powers needed to accomplish what I have outlined above.

This is not calling for any more money for cancer control. In fact I believe there are considerable savings to be made in the way that some cancers in Australia are now managed. For example almost 5% of all Australians have at least one skin lesion excised every year and treatment of skin cancer costs the Federal government more than any other cancer. Further, there is almost an epidemic of prostate specific antigen (PSA) testing going on with perhaps 20% of Australian men over the age of 50 having been tested when

Leading the fight

1. The first part of the document discusses the importance of maintaining accurate records of all transactions and activities. It emphasizes that this is crucial for ensuring transparency and accountability in the organization's operations.

2. The second part of the document outlines the various methods and tools used to collect and analyze data. It highlights the need for consistent and reliable data collection processes to support informed decision-making.

3. The third part of the document focuses on the role of technology in data management and analysis. It discusses how modern software solutions can streamline data collection, storage, and reporting, thereby improving efficiency and accuracy.

4. The fourth part of the document addresses the challenges associated with data management, such as data security, privacy, and integration. It provides strategies to mitigate these risks and ensure the integrity and confidentiality of the organization's data.

5. The fifth part of the document concludes by summarizing the key findings and recommendations. It stresses the importance of a proactive approach to data management and the need for continuous monitoring and improvement of data practices.

6. The sixth part of the document provides a detailed overview of the data collection process, including the identification of data sources, the design of data collection instruments, and the implementation of data collection procedures.

7. The seventh part of the document discusses the various methods used for data analysis, such as descriptive statistics, inferential statistics, and regression analysis. It explains how these methods are used to interpret the data and draw meaningful conclusions.

8. The eighth part of the document focuses on the presentation and communication of data. It discusses the importance of using clear and concise visualizations, such as charts and graphs, to effectively convey the results of the data analysis.

9. The ninth part of the document addresses the ethical considerations surrounding data management and analysis. It discusses the need for transparency, informed consent, and the protection of individual privacy and data security.

10. The tenth part of the document provides a final summary and concludes the report. It reiterates the key findings and emphasizes the importance of ongoing data management and analysis in supporting the organization's strategic goals and objectives.

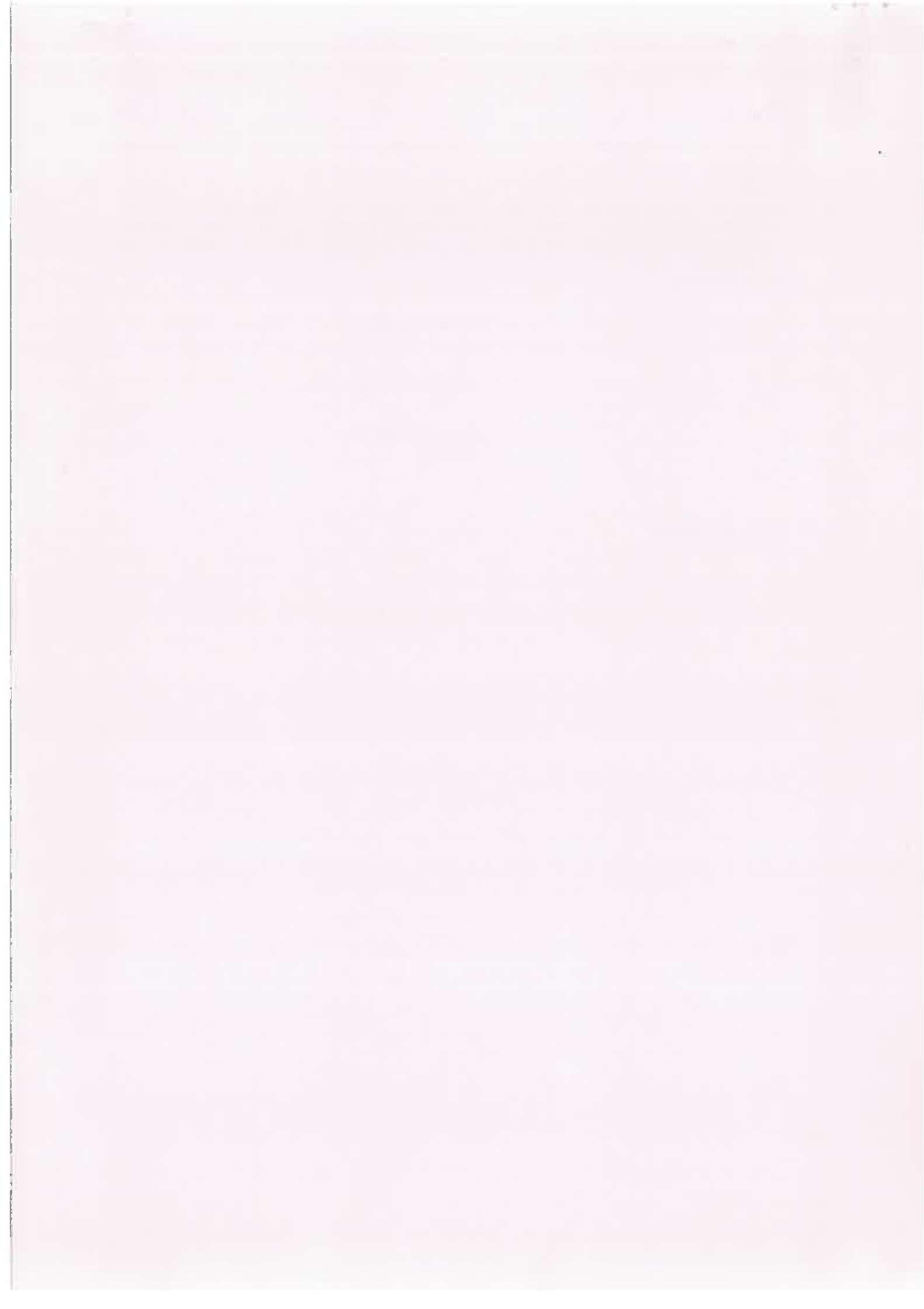
there is no proven effective treatment of PSA "screen" detected prostate cancer. An effective national cancer control committee should be able to rein in uncoordinated, excessive and non evidence based informal cancer screening endeavours. Savings from this would be used to support more effective health promotion endeavours in other areas of cancer control.

Yours sincerely

A handwritten signature in black ink, appearing to read "Robert Burton". The signature is fluid and cursive, with the first name "Robert" being more prominent than the last name "Burton".

Robert Burton
Director

cc *Dr Michael Wooldridge*
Minister for Health





Anti-Cancer Council of Victoria

Director: Dr Robert Burton
MD, PhD, BS, BA, BMedSci,
FRACP, FRACS, FAHPM

31 January 1996

The Hon Ralph Willis
Treasurer
Parliament House
Canberra

Fax: 06 273 3420

Dear Treasurer

I refer to your recent media statements on possible changes to taxation rates in the next Government. Federal tobacco excise rate increases have been linked to the CPI since 1983.

Tobacco taxation increases are universally recognised as being the single most important factor in reducing tobacco consumption in the short term. Measured by international standards, Australia still levies relatively low tobacco taxes compared with many industrialised nations. If total taxes are expressed as a percentage of final retail price, Australia, at 65%, ranks behind New Zealand (68%), the UK (77%) and eight other European countries (up to 85%).

The medical and scientific communities, strongly supported by many other community organisations and leaders, have consistently urged increases in tobacco excise *above* the rate of the CPI. I would ask you not to rule out tobacco tax increases above the CPI in the next Government because of the beneficial health effects which will flow.

Promises not to increase tobacco tax rates will have a detrimental effect on the health and well-being of the Australian people. Further, a decline in real terms of federal excise revenue could also occur.

I would be happy not to campaign on this issue at this time - and will propose the same to my counterparts in other concerned agencies - and would seek your private assurance that you will not rule out tobacco tax increases above the CPI rate.

I should be grateful to receive your response on my private fax line: 03 9279 1250. Thank you.

Yours sincerely

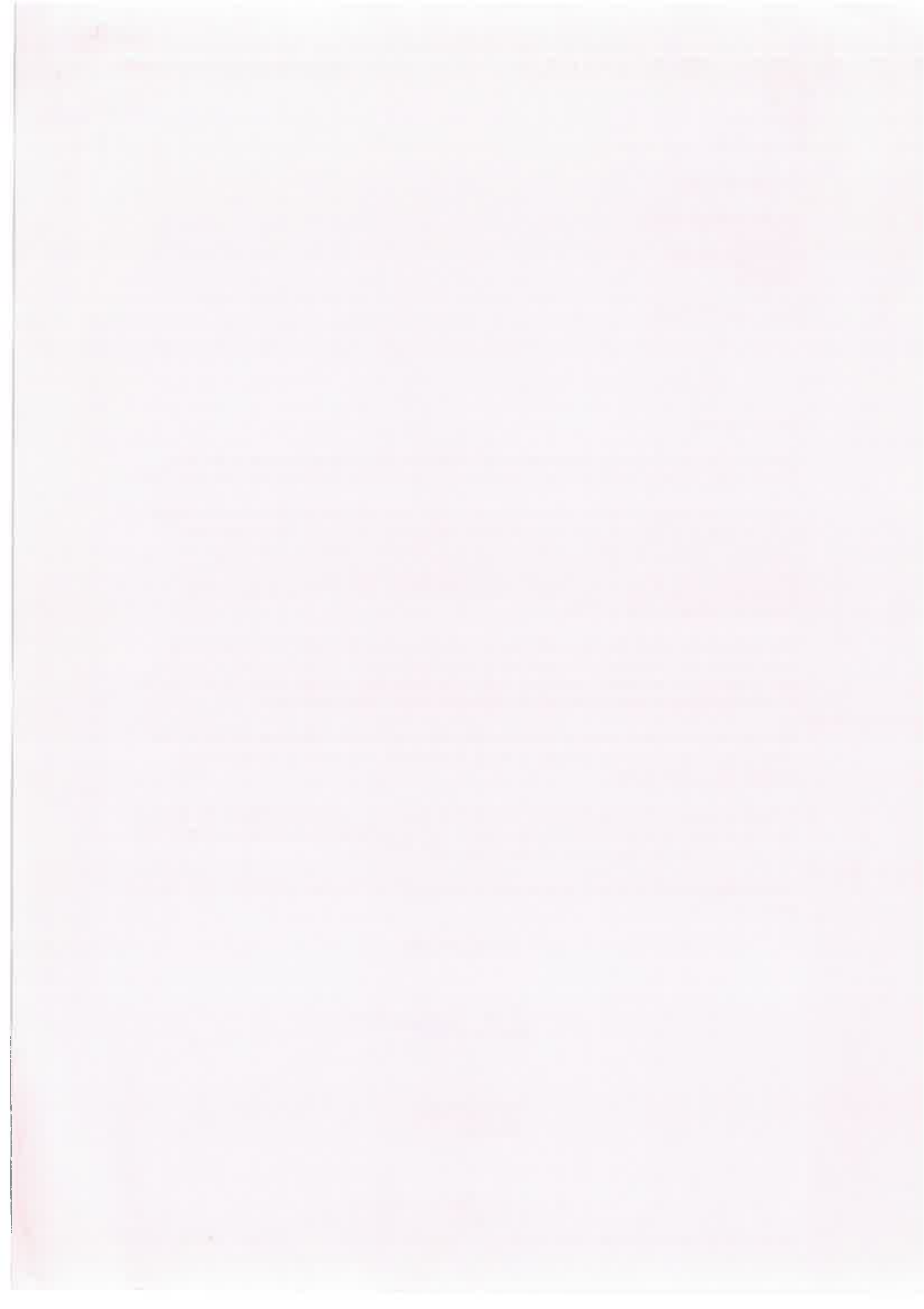
Robert Burton
Director

Leading the fight

(New file)

FED. Govt.

BROWN
HDCF



Fed Gov.
Newfile
BROWN
HDCF

31 January 1996

Mr Peter Costello
Deputy Leader of the Opposition
Parliament House
Canberra

Fax: 06 277 8500

Dear Mr Costello

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Yours sincerely



Robert Burton
Director

Leading the fight

