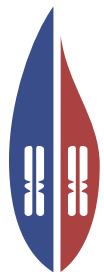


OPTIMISING CANCER CARE IN AUSTRALIA

A consultative report prepared by the
Clinical Oncological Society of Australia,
The Cancer Council Australia and the
National Cancer Control Initiative



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National Cancer Control Initiative
1 Rathdowne Street
Carlton Vic 3053
Australia
Tel: +61 (0)3 9635 5108
Fax: +61 (0)3 9635 5320
Email: enquiries@ncci.org.au
Internet: www.ncci.org.au

Published February 2003
ISBN 1 876992 01 8

© National Cancer Control Initiative 2003

Suggested citation: Clinical Oncological Society of Australia, The Cancer Council Australia and the National Cancer Control Initiative 2002: Optimising Cancer Care in Australia. National Cancer Control Initiative, Melbourne, 1–122

This document is available at www.ncci.org.au

PROLOGUE: OPTIMISING CANCER CARE IN AUSTRALIA

There is much to be proud of in relation to provision of cancer services in Australia. However, from the point of view of cancer patients and their loved ones, all is not well. Stories abound of frustrations caused by the inability to access appropriate and timely care, fragmented management and lack of ongoing support along the cancer journey.

These frustrations are not limited to those with limited influence or resources. Indeed, one of the most poignant examples is the case of Hephzibah Tintner, partner of Sydney Lord Mayor, Frank Sartor, whose story was published in the *Sydney Morning Herald*, 23 August 2001. Launching the NSW Cancer Council's annual fundraising Daffodil Day in 2001, Mr Sartor recounted his experiences as Ms Tintner's carer and articulated his belief that something is fundamentally wrong with the way cancer patients are managed. His passionate criticisms were not directed at the individual doctors who cared for Ms Tintner, but rather to the lack of a coordinated approach to her care. The article goes on to describe some of the systematic problems in the cancer care delivery in Australia.

The key issue highlighted is the failure of the 'health system' to provide integrated cancer care. Implementing changes that are known to improve the way treatment is delivered and to empower those who are living with cancer to take control of their lives would greatly improve the quality of life for both cancer patients and their carers. The purpose of this report is to provide a distilled report of the views of a broad cross-section of Australian consumers and cancer care providers as to how this can best be achieved.

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ABBREVIATIONS AND NOTES

ABS	Australian Bureau of Statistics
AHMAC	Australian Health Ministers' Advisory Council
AIHW	Australian Institute of Health and Welfare
AMWAC	Australian Medical Workforce Advisory Committee
ANCAHRD	Australian National Council on AIDS, Hepatitis C and Related Diseases
BCAGNSW	Breast Cancer Action Group New South Wales Inc.
CCORE	Collaboration of Cancer Outcomes Research and Evaluation
COSA	Clinical Oncological Society of Australia
CSC	Cancer Services Collaborative (UK)
CSCC	Canadian Strategy for Cancer Control
CSG	Cancer Strategies Group
GP	General practitioner
IMDC	Integrated multidisciplinary care
IMDT	Integrated multidisciplinary team
IOM	Institute of Medicine
IPTAAS	Isolated Patients' Travel and Accommodation Assistance Scheme
MBS	Medicare Benefits Schedule
MDT	Multidisciplinary team
MOG	Medical Oncology Group of Australia
NBCC	National Breast Cancer Centre
NCCI	National Cancer Control Initiative
NHMRC	National Health and Medical Research Council
NROSPSC	National Radiation Oncology Strategic Plan Steering Committee
PATS	Patient Access/Accommodation and Travel Scheme
PBS	Pharmaceutical Benefits Scheme
PCA	Palliative Care Australia
RACP	Royal Australasian College of Physicians
RACS	Royal Australasian College of Surgeons
RANZCR	Royal Australian and New Zealand College of Radiologists
TCCA	The Cancer Council Australia
TCCNSW	The Cancer Council New South Wales
TCCV	The Cancer Council Victoria
TGA	Therapeutic Goods Administration
YLL	Years of life lost

Accuracy of URLs

In parts of this report, addresses (URLs) for relevant Internet material are provided. The URLs were correct when checked before publication (11–16 October 2002).

ABS data

ABS data used with permission from the Australian Bureau of Statistics (www.abs.gov.au).

PREFACE

This report was prepared under the auspices of the Clinical Oncological Society of Australia (COSA), The Cancer Council Australia (TCCA) and the National Cancer Control Initiative (NCCI). The consultations (see Sections 1 and 2) were undertaken and a draft report prepared by Mr Brian Wall of Oceania Health Consulting. The study was overseen by a Steering Group consisting of the Chair of the Medical and Scientific Committee of TCCA and COSA, the Chair of the Patient Support Committee of TCCA, and the Director and Deputy Director of the NCCI. An Advisory Committee consisting of a wider group of stakeholders also provided invaluable input to the document. The members were:

- Professor Lester Peters*, Chair, Medical and Scientific Committee, TCCA/COSA
- Associate Professor Kerry Kirke*, Chair, Patient Support Committee, TCCA
- Professor Mark Elwood*, Director, NCCI
- Dr Paul Ireland*, Deputy Director, NCCI
- Ms Sally Crossing, Consumer representative, Cancer Voices NSW
- Dr Stephen Ackland, Medical Oncologist
- Professor Robert Thomas, Surgical Oncologist
- Dr Liz Kenny, Radiation Oncologist
- Professor David Currow, Palliative Care Physician
- Dr Rosemary Knight, Department of Health and Ageing.

*Also members of the Steering Committee

Acknowledgment is given to all those who gave time to be interviewed and took trouble to provide material for the report and comment on it. Special thanks are given to those who attended the one-day workshop in Sydney to provide further input at that stage. The people consulted and who attended the workshop are listed in Appendix 1.

Two levels of recommendations are made in this report:

- **Recommendations:** which are intended for immediate consideration, adoption and action by the Commonwealth Minister for Health and Ageing, sometimes in consultation with the State and Territory Government Ministers or others, or by referral to the Australian Health Ministers' Advisory Council (AHMAC). These aim to have an immediate strategic impact on the planning and/or delivery of cancer services.
- **Action items:** actions that could be undertaken at the Minister's direction but are not fundamental to the transformation of cancer services (they are narrower in scope); actions that require working through with other stakeholders before the objective can be achieved; or actions that are consequential to a major recommendation. These are intended to be further considered by the body charged with taking the report forward.

'Cancer' in this report refers to all cancers *excluding* non-melanocytic skin cancer, unless the contrary intention is apparent. 'Cancer care' refers to management of the total needs of a person with cancer, from the time of onset of symptoms of an underlying cancer or from the point of diagnosis of an asymptomatic cancer. 'Cancer control' refers to all actions that aim to reduce the burden of cancer on individuals and the community: research, prevention, early detection/screening, treatment, education and support for cancer sufferers and their families and monitoring cancer outcomes.

EXECUTIVE SUMMARY

There is a strong conviction held by consumers and cancer care providers that Australian cancer services can be, and must be, improved substantially. Survival, quality of life and the 'cancer journey' would greatly improve if everyone received optimum treatment. Outlined in this report are some of the key reforms required. They are achievable and affordable but require a new approach.

The report is based on the views of the consumers, practitioners and representatives of organisations who were consulted, published evidence and international reforms. It aims to provide the Minister for Health and Ageing, and her State and Territory Government colleagues, with the outline of an agenda and a process for reform of cancer care. The scope of the report was to outline key recommendations for improvement in cancer care in Australia. This report complements the *Priorities for Action in Cancer Control 2001–2003* (CSG 2001) and the *National Cancer Prevention Policy* (TCCA 2001) reports, which have identified priorities for new developments in cancer control and recommendations on how Australia can enhance its achievements in cancer prevention.

Methods

The approach used was to consult with a wide range of stakeholders – providers, consumers and others with an interest in cancer care – and identify key themes that occurred repeatedly during the consultations. These themes were developed into a workable number of key issues. This was done first through a stakeholder workshop and input by a steering committee and a consultative committee, and finally by a wider process involving organisations with a stakeholding in cancer care, as well as by reference to literature relevant to those issues.

This methodology does not necessarily give rise to conclusions that can be taken up without further work-up: they are based on key stakeholders' identification of issues as problematic. A detailed scientific analysis of each problem is a further step for whoever is charged with progressing the issues identified. This report seeks to generate ideas about how to address the issues of cancer care, that is, thinking broadly about possible approaches. There is a substantial consensus that the issues outlined are priority issues.

Why is cancer reform important?

Cancer directly affects nearly a third of the Australian community (one in three men and one in four women) before they are seventy-five years. Those affected experience social, psychological, economic and physical health impacts. The number of new cases is increasing each year and it is the commonest cause of death.

Australian cancer survival is relatively good – close to the best in the world on an age-adjusted basis. However, **we could do much better** by routinely applying what the evidence shows is best practice, that is, by treating people appropriately all the time using currently available knowledge.

Survival does not equate with quality of life. Cancer reform is also necessary because the treatment can be complex, involving many disciplines and therapies, and there are many opportunities for someone to become 'lost' in the system, causing unnecessary morbidity and personal distress. The experience of treatment and the quality of life for the person living with cancer would greatly improve if the deficiencies and inequities were addressed. This is another reason for urgent reform.

What is cancer care costing?

Cancer affects one-third of Australians and is the major cause of death in adults. Treatment accounts for 6% of health expenditure. The gaps in cancer care identified in this report will support the case that we are under-investing in cancer. Even drug costs, about which much is heard, are quite modest. The cost of anti-cancer drugs is only 15% of the most expensive drug group (lipid-lowering agents) and 2.7% of the total expenditure on the Pharmaceutical Benefit Scheme. Indirect costs, that is, costs other than the health care costs, are unmeasured and often ignored. For a devastating disease like cancer, these are generally much greater than the cost of treatment.

Stakeholder views

Consultation with stakeholders covered a wide range of views. Of particular note are the views of consumers. People who have had cancer diagnosed and treated often find the process bewildering, and not one that they believe delivers consistent, high-quality care. Other consultations suggested their belief is well founded. Services are often not organised around the patient. They need to be more multidisciplinary, evidence-based, timely and consider people's wider needs, such as travel. Travel for radiotherapy and other forms of treatment is a major difficulty for many. Subsidies are inadequate, leaving many people financially disadvantaged or unable to access therapy. There is also a lack of access to a range of supportive services, including psychosocial and palliative care.

The findings of the consultations fell into three broad areas of activity:

- **Models of cancer care:** multidisciplinary or not, and what to do about the relationship of volume to outcome.
- **Improving the quality of cancer care:** ensuring patients receive evidence-based, comprehensive care.
- **Resource issues in cancer care:** including workforce and their skills (for example, communication skills), physical infrastructure (for example, radiotherapy), drugs, and access issues.

Models of cancer care

Traditional versus integrated multidisciplinary care (IMDC)

The traditional model of care is one where the general practitioner (GP) refers a patient to a specialist (usually a surgeon) who conducts the primary intervention, usually removal of a tumour. Patients may then see other cancer specialists sequentially for opinions before (but more often after) the primary intervention. This is the model for which Medicare and the private health insurance system cater most comprehensively. This traditional model is criticised for its dependence upon the primary specialist reaching a view that further referral is necessary. They see too great a risk of suboptimal therapy unless there is a formalised way of accessing IMDC.

Multidisciplinary care (MDC) relates to the team, communication, the full therapeutic range, standards of care and involvement of the patient (Appendix 9). The term integrated multidisciplinary care (IMDC) is used here to emphasise that integration of the services provided, with the patient as the point of focus, is essential; care can involve several disciplines, but if it is not integrated, it is not optimal.

IMDC is based on the fact that many people living with cancer require input from more than one discipline to optimise treatment and care. A team agrees on the diagnosis and staging of the disease and on the best treatment option for the patient – taking the patient's preferences into account – before irrevocable steps are taken.

It is preferable to obtain a clinical consensus about treatment than to risk poorly coordinated, often poorer, care. Of the common cancers, the most advanced models of IMDC in Australia are in breast cancer (although other, less common, tumours also have well-developed IMDC). In the US and, more recently, the UK, it is the recommended approach for most or all cancers. Some level of IMDC is required by the US Cancer Center's accreditation system and by the UK Cancer Plan. While IMDC has its strengths and weaknesses, for many people living with cancer, there is no alternative to ensuring that all perspectives are considered before definitive treatment (including palliative and supportive care) is undertaken. Optimal cancer care is multidisciplinary for the majority of patients and a formal process is required to ensure that it is available as needed. It is, of course, recognised that single modality treatment is appropriate for many cancers but ensuring that these cases are correctly identified requires accounting for all cancer diagnoses in an integrated multidisciplinary setting.

The challenge of providing optimal care for all Australians requires approaches, which take account of the unique geography and demography of the Australian population. The geographic and cultural challenges are greater than those in the UK or US and require specific approaches which need to be evaluated and improved.

Complexity of an intervention, volume of procedures and outcome

There is increasing evidence that outcome of cancer care, particularly for difficult primary surgery, is linked to volume of interventions (for example, operations) undertaken. The US Institute of Medicine (1999) has found this to be true for institutions. In Australia there is, for example, evidence showing volume–outcome benefits for individual colorectal surgeons when undertaking difficult rectal surgery, though this difference is not apparent for less difficult surgery (Clinical Governance Unit 2002).

Models of cancer care need to consider how to achieve the best possible outcome through concentration of services where the evidence demands it, while maintaining access locally where this can be done without unacceptable impact on quality. It is important to be able to measure the impact of complexity, volume and outcome, so that we are clear about what needs to be done centrally and what can be done just as well locally, and under what arrangements, for example, with links to a specialist cancer centre.

Improving the quality of cancer care

Several major initiatives underway in Australia are seeking to assess mechanisms to improve quality in cancer care.

- An important generic one is the work of the Australian Council on Safety and Quality in Health Care, which addresses safety first.
- The Cancer Council New South Wales (TCCNSW) has recently commissioned a \$1.5 million cancer quality improvement program.
- BreastCare Victoria is an important quality improvement initiative in that state.
- Nationally, the National Breast Cancer Centre (NBCC) is undertaking a project entitled Doorways to Quality Care. It is a Breast Cancer Service that is the 'doorway' to quality care, that is, to an organised, integrated, high-quality service on screening, diagnosis, multidisciplinary treatment and supportive care.
- The Royal Australasian College of Surgeons (RACS) has an audit program that allows rapid feedback to a breast surgeon on their practice compared to that of peers', and it provides aggregate data on the management of breast cancer nationally in a very timely manner.
- The clinical management surveys that are conducted nationally and at the state level are also an extremely valuable way of addressing quality of care, and are unique to Australia.

While this list is not comprehensive, what is striking about these initiatives is that there are relatively few of them, especially for cancers other than breast cancer.

Empowering the cancer service user (consumer) is also important to improving quality. The GP's ability to help and advise is strengthened when consumers have access to information – for example, about surgeons' subspecialties and consumers' own treatment – plus training in advocacy.

One important quality mechanism in the US is the Commission on Cancer's voluntary accreditation system, which accredits the great majority of the institutions that treat cancer regularly. A similar mechanism could make a substantial difference in Australia and would be attractive to those institutions that wish to claim to be an 'Accredited Cancer Centre'. It would need the support of the professions and institutions. Compliance requirements would be phased in slowly, and would always be voluntary.

Other drivers for quality could include the Medicare Benefits Schedule (MBS). The schedule may need to change to promote quality care. Differential rebates for subspecialists is one possibility, but the current move in the MBS is in the other direction. That may not change until the medical profession changes its collective view. Other issues are the lack of suitable MBS items for the various specialists that attend multidisciplinary team meetings in the private sector. Consideration needs to be given to reviewing the MBS items with a view to promoting higher quality cancer care.

Improving quality through information and research

There are many gaps in our knowledge of the cancer care process – how advanced the disease is at diagnosis, how people are treated, their quality of life, etc. Researching these issues is applied research. Funding for this type of research is relatively limited, but it is needed to inform cancer planners and managers about what is going on and ensure services are meeting the need and are cost-effective. Health services research, clinical trial research and psychosocial research are three key areas that are critical to the provision of high-quality cancer care.

Resource issues in cancer care

Workforce issues

The first thing to note about the cancer care workforce is that there are shortages in almost every category. These shortages are sometimes severe. There are shortages of nurses – especially those who have specialised in cancer – radiation therapists, pharmacists and all the specialist clinicians. The shortages show themselves most acutely in areas outside capital cities. There must be a major effort to address the cancer care workforce requirements if the current shortages are not to become completely unmanageable.

GPs also need development, as cancer is increasingly treated in a community setting. They have a pivotal role as providers of information and support. At present this role is not always fulfilled, in part due to structural barriers in the system of general practice. As well as skills development, there needs to be greater opportunity for GPs to practise in ways that offer consumers and GPs a better treatment environment, for example, more time and greater information.

Communication is widely recognised as problematic and formal communications training is recommended for all those routinely involved in cancer care. The training should also cover cultural issues, to improve communication with, and care of, Australian Aboriginals and those with a culturally and linguistically diverse background.

Access issues

A number of key access issues affect the quality of cancer care. Access to radiotherapy is the subject of a separate review and will not be discussed further, except to say that it is often quite poor and is in need of urgent attention.

Access to drugs is a key problem for clinicians and consumers. Both very new and older drugs are problematic, for active medical treatment and palliative care. Many of the desired changes to access would actually save the Pharmaceutical Benefits Scheme money, but there are also a large number of new agents in the pipeline and some of these will be expensive. A better process for addressing the competing priorities is required. So far, there has been no move to 'change the rules' to improve access significantly. A process is required whereby the issues are gone through item by item, with all parties trying to solve what is becoming a significant obstacle to quality cancer care. There are, however, difficult public policy issues to be addressed and some of the problems may be insoluble.

Travelling to a treatment centre is a serious barrier to access. The current travel schemes do not seem to work well. Substantial cost is incurred in accessing treatment and some people just cannot afford it, especially for long periods of radiotherapy. Some populations are experiencing a disproportionate impact – Aboriginal peoples, people living just within distance limits, etc. A national review of the problem is required, to see if the aims of the original scheme are being met.

Social and psychosocial factors are also in need of reform. Greater access to home care, better access to psychosocial support, and support for carers and families can all be provided at relatively low cost, and would decrease the impact of cancer.

Palliative care access is another difficulty. Referral to a palliative care service is often too late or in crisis, and one-third of the potential population are never referred. There is a need to demystify palliative and supportive care and ensure that this is not seen as only being in the terminal phase of care.

National cancer centres

There is a need to extend the role of the existing two national cancer centres – the NBCC and the NCCI – or create new ones, to address more adequately the whole spectrum of cancer care. At present there is not the capacity to do so. The NBCC has made a difference to breast cancer, but the other seven out of eight main cancer cases are largely unaffected by this improvement. There needs to be greater capacity to undertake and promote the cancer reform agenda, which NBCC has done so successfully for breast cancer, across the whole spectrum of cancer. If several new centres are established, they should operate as a single collaboration, providing a seamless network of expertise.

Improving the delivery of cancer services nationally – a Task Force on Cancer

The many priorities identified in this report need a mechanism to implement them. It is proposed that a Task Force on Cancer be established to take the recommendations of this report, and potentially other cancer care issues, and develop and implement a national cancer reform agenda. Reform could take a decade, but initially the Task Force might be set up with a life of three years, with a review before any renewal.

The Cancer Strategies Group (CSG) is limited by its terms of reference and leverage capacity and the restricted funding of the National Health Priority Program. It is therefore difficult for the CSG to give effect to the magnitude of change to cancer care delivery that is required.

Another mechanism with higher-level linkages is needed, like the Australian National Council on AIDS, Hepatitis C and Related Diseases (ANCAHRD), which has been very successful in the control of blood-borne viral illness. Like ANCAHRD, the Task Force on Cancer should be a Ministerial committee.

Getting the necessary change happening

Changing health systems is particularly difficult. Successful change requires structural interventions as well as culture change. Stakeholders have to be involved and 'brought along' in the change process. Thus the arrangements for coordinating national change in cancer are particularly important. Neither the Commonwealth, States and Territories, nor the cancer care professionals, can do this alone – all must work together. The system of governance is critical and the body responsible to bring about the change must be linked to a very high level in government.

The change process must be adequately supported, and be able to influence existing programs and resource new directions. The alternative to a rigorous program of strategic change is continuing non-strategic change, inefficiency and suboptimal care.

RECOMMENDATIONS

Recommendations of this report are offered to the Commonwealth Minister for Health and Ageing, and to the Ministers with responsibility for health in each of the states and territories, for adoption and implementation.

The treatment experience and the quality and length of life of most people with cancer can be greatly improved if these recommendations are implemented. The three main themes predominating in these recommendations are quality, access and resourcing.

INTEGRATED MULTIDISCIPLINARY CARE

1 That investigation of the incentives required to foster, maintain and evaluate integrated multidisciplinary cancer care in both the public and private sectors be undertaken, with a view to widening availability of multidisciplinary cancer care in all settings.

IMPROVING THE CANCER JOURNEY

2 That a national process of quality-driven organisational reform be implemented to improve ongoing supportive care throughout the cancer journey. This would include palliative and supportive care, and improved consumer access to information.

VOLUNTARY ACCREDITATION

3 That a system of voluntary accreditation for Australian cancer care services be developed, broadly modelled on that of the US Commission on Cancer. This must involve and be 'owned' by the specialist colleges and the organisations with a specific interest in cancer. The Commonwealth should consider funding the development and testing of the initial accreditation criteria.

ACCESS TO CLINICAL TRIALS

4 That the capacity to undertake clinical trials be increased, along the lines recommended in the recent review of capacity for cooperative clinical trials in cancer, including the need for a public register of trials.

WORKFORCE

5 That the recommendations of the National Strategic Plan for Radiation Oncology (Australia) and The Specialist Haematological and Medical Oncology Workforce in Australia be implemented urgently.

6 That the Australian Health Workforce Advisory Committee be requested to consider the entire non-medical cancer care workforce, but particularly cancer nurses, radiation physicists and radiation therapists, as an urgent priority.

PSYCHO-ONCOLOGY

7 That the need for additional psychologists or other appropriately trained health professionals who have specialist skills in psycho-oncology, identified as a cost-effective intervention in Priorities for Action in Cancer Control 2001–2003, be brought to the attention of the Australian Health Ministers' Advisory Council for urgent consideration.

RADIATION ONCOLOGY

8 *That the recommendations of the National Strategic Plan for Radiation Oncology (Australia) be implemented urgently.*

ACCESS TO PHARMACEUTICALS

9 *That the Minister for Health and Ageing establishes a joint working party – including the Medical Oncology Group, the relevant national palliative care organisations, consumers, the pharmaceutical and the health insurance industries and the Department of Health and Ageing – to review and where possible develop solutions to the key problems of access to new and old pharmaceuticals.*

ACCESS TO SUPPORT FOR TRAVEL

10 *That there be a national review of matters that affect access to cancer care, including an investigation into problems with travel, as an urgent matter. Particular attention should be paid to populations that may be experiencing disproportionate difficulties with access and the magnitude of that impact on cancer outcomes. This would include Australian Aboriginals and people living in isolated areas or just inside travel subsidy distance limits.*

EQUITY OF ACCESS

11 *That the needs of special populations, especially Aboriginal peoples, be the focus of special efforts to bridge the current gaps in access to and utilisation of culturally sensitive cancer services.*

Recommended strategy for implementation

A NATIONAL TASK FORCE ON CANCER

12 *That a national Task Force on Cancer be established to oversee and drive the reform process, with the aim of ensuring cancer care services throughout Australia are evidence-based and consumer-focused, and that sufficient funding be allocated to support the Task Force to implement necessary change across the entire spectrum of cancer care delivery.*

OTHER ACTION ITEMS

These are actions that need to be addressed but are less urgent or are of a lesser magnitude than the matters addressed by the recommendations.

I That health services research be commissioned to define the essential elements of integrated multidisciplinary cancer care for at least the common cancers, and the costs and benefits of providing it in public and private settings in metropolitan and regional Australia.

II That the evidence on procedural complexity, volume and its impact on outcome be fully considered in the funding, planning and organising of cancer services in Australia.

III That the relationship between practitioner, institution and outcome be monitored through greater use of clinical cancer registries.

IV That the specialist colleges and other relevant associations be strongly encouraged, through incentives if necessary, to provide information about their members' subspecialisation and facilitate systems that allow general practitioners and consumers to readily establish a specialist's interest and experience in a particular cancer area.

V That consideration be given to ways to enhance the Medicare Benefits Schedule so that it better supports an evidence-based, integrated multidisciplinary approach to cancer care.

VI That dedicated funding be identified for applied research in cancer, including studies of quality of life, so that quality and efficiency in the Australian cancer care system can be improved.

VII That the minimum data set developed by the National Cancer Control Initiative be collected across Australia.

VIII That the development of site-specific surgical oncology as a subspecialty be encouraged.

IX That resources be made available to support the training of cancer specialists in regional areas.

X That incentives to undertake relevant postgraduate training in cancer nursing be developed.

XI That the model of the breast care nurses be tested more widely and across all cancers, with ongoing funding support based on the cost-effectiveness of the intervention for each of the major cancers.

XII That the Australian Medical Council be enlisted to assist in incorporating The Cancer Council Australia's Ideal Oncology Curriculum and the Australian and New Zealand Society of Palliative Medicine Ideal Curriculum into undergraduate medical education as appropriate, through the accreditation process for undergraduate medical training.

XIII That a training module in cancer care be developed and run by general practitioners, with assistance from cancer care specialists in a range of disciplines as required.

XIV That any accreditation scheme includes access to psycho-oncological support services as one of the accreditation criteria.

XV That the feasibility of other health professionals providing psychological support, and the role of low-cost interventions such as peer support, be further assessed.

XVI That ongoing communication training be promoted for all people who work in a cancer care setting, including general practitioners.

XVII That regular communications training be required as part of any credentialling or accreditation process associated with cancer care.

XVIII That the costs, benefits and cost-effectiveness of home care be identified, and the incentives adjusted so that home care becomes a more viable and attractive option for cancer service users and providers.

XIX That the Commonwealth and State and Territory Governments work with national palliative care organisations, relevant colleges and others to address the issue of late or crisis referral of people for palliative care.

SECTION 1: INTRODUCTION



THERE IS A strong conviction held by cancer service users (consumers) and cancer care providers that cancer services in Australia can be substantially improved. If everyone received optimum treatment, better survival and quality of life could be achieved. The goal of this report is to outline achievable steps that can greatly improve survival, quality of life and the 'cancer journey'.

Substantial improvement can be achieved without spending vastly greater sums of money. Optimum treatment does not necessarily mean greatly increased activity and expense, but more appropriate, higher quality and more timely therapy. In fact, unless a process of structured reform that facilitates agreed best practice is undertaken, costs may increase even more rapidly through inappropriate and sometimes unnecessary interventions. There are, of course, some resource gaps that need to be addressed.

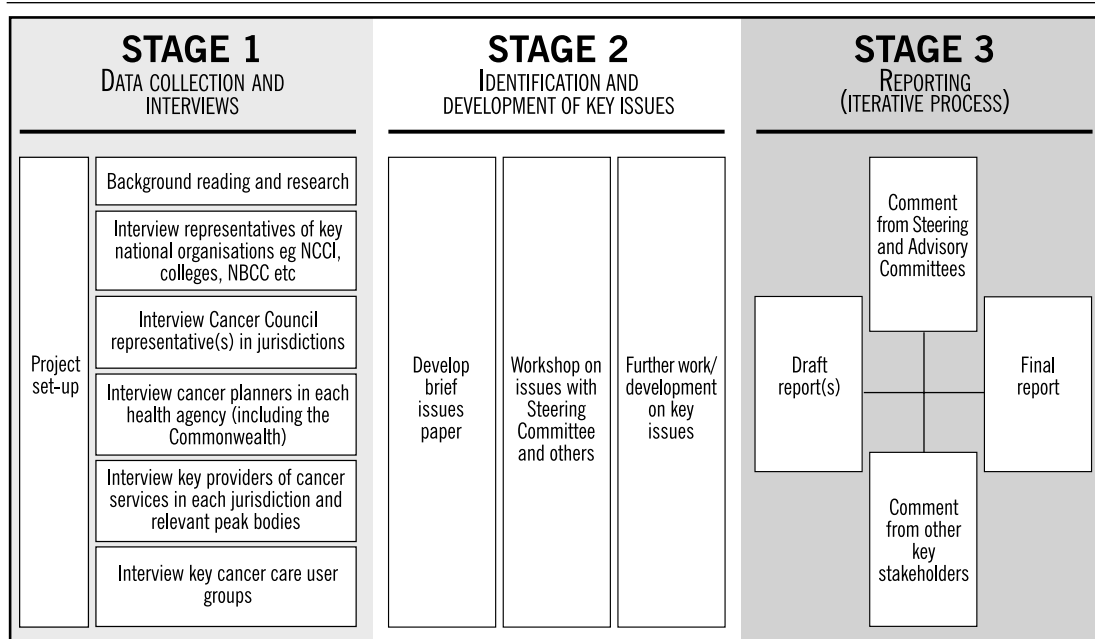
The report aims to provide the Commonwealth Minister for Health and Ageing and her State and Territory Government colleagues with the outline of an agenda and a process for reform of cancer care.

It will also provide State and Territory Ministers for Health with a basis for concomitant action to be taken at a state and territory level, as appropriate.

Outline of the methods

The approach used was to consult with a wide range of stakeholders – providers, consumers and others with an interest in cancer care – and to identify key themes that occurred repeatedly during the consultations. These themes were developed into a workable number of key issues through a stakeholder workshop, input by a steering committee and a consultative committee, and finally by a wider process involving organisations with a stakeholding in cancer care and reference to the literature relevant to those issues. An outline of the process is given in Figure 1.

Figure 1 An outline of the methodology used to develop this report



Appendix 1 provides a list of those consulted and attendees at a workshop conducted to consider draft findings and develop recommendations, as well as the terms of reference.

This report outlines some of the key cancer care issues that are in need of reform in Australia, based on views of the consumers, practitioners and representatives of organisations who were consulted, and published evidence and international reforms. The methodology used does not necessarily give rise to conclusions that can be taken up without further work-up; they are based on what key stakeholders identify as problematic rather than a detailed scientific analysis of each problem, which may be a further step. For example, in many areas the data for such analyses are lacking and gathering data is then the first step. The report seeks to generate ideas about how to address the issues of cancer care, that is, thinking broadly about possible approaches. There is a substantial consensus that the issues outlined are priority issues.

The report identifies key strategic steps that could make a substantial difference to cancer care and that are achievable within a reasonable timeframe and at reasonable cost. These are given as recommendations, intended for early consideration, and action items, intended for consideration by an implementation team or others in due course.

Background

Cancer affects nearly one-third of the Australian community at some stage in their lives, and cancer service users report substantial social, psychological and economic effects, as well as the impact on physical health. The number of newly diagnosed cancer cases is increasing steadily, as is the number of people living with a diagnosis of cancer (cancer prevalence). It is imperative that the health system provides these people with diagnostic and treatment services and ongoing care that is patient-centred. This is not reported to be the case at the moment.

The problem of cancer

Cancer will affect one in three males and one in four females before they are seventy-five years. It is the commonest cause of premature death and disability (see Appendix 2). In addition, its social, psychological and economic impacts are a considerable burden on the individual and on the community. Some of these issues are discussed more fully below.

The only outcome we routinely measure for cancer is mortality and there is one recent national report that describes survival. Morbidity and other quality of life measures are not measured routinely, and the social and economic effects are rarely studied. We have some information on morbidity, for example, from clinical management surveys, of which we now have a reasonable number (see Appendix 3). These are probably the best measure of the standard of treatment but they tell us nothing about consumers' experiences and opinions.

Cancer survival

A recent Australian report established the pattern of cancer survival and compared our data with other countries (AIHW & AACR 2001). Cancer survival in Australia appears to be about as good as anywhere else in the world. The Australian time series data show a significant (but unspectacular) improvement over time. Women generally do better than men with a 6.6% difference in relative survival at five years (AIHW & AACR 2001). Graphs of the time series are given in Appendix 2.

We could do much better. By providing everyone with what is known to be best practice, survival (and quality of life) would improve markedly. This does not require new therapeutic breakthroughs or more screening programs (although they would provide further benefit). We just need to provide the known best treatments to patients with cancer from the time they present to their doctor with symptoms.

One group for whom we could do much better is older patients. In 1998, people aged seventy-five years and over made up just 5% of the population, yet they represented 29% of new cancers and 42% of cancer deaths. Relative survival is poorer in older patients, which may relate in part to the type of care that they receive (possible undertreatment). Adjuvant chemotherapy and radiotherapy are much less likely to be given to older patients, perhaps only partly because of co-morbidity or informed decisions to decline further treatment. If cancer care is to improve generally, then older Australians represent a key group with relatively poor outcomes. The US Institute of Medicine (IOM) (1999) reported that:

Some undertreatment is explained by provider attitudes toward treating the elderly, who are perceived as less willing or able to tolerate aggressive treatment. Some undertreatment may also be due to patient preferences and unwillingness to experience the side effects of certain treatments.

This is probably just as true in Australia.

Cancer survival is not the whole story

Although we know we can improve cancer survival, it does not reflect the problems that users of cancer services experience during the cancer journey, nor does it indicate the quality of life. It may be more important for a person with head and neck cancer, for example, to be able to swallow and speak than to maximise survival (although they are usually not mutually exclusive objectives).

There are, therefore, several dimensions to the measurement of the performance of cancer services. Two of these relate to health outcomes – survival, and the morbidity (one aspect of quality of life) experienced by the person with cancer. Another aspect of quality of life relates to the experience of the person with cancer as they receive curative or palliative treatment – what the treatment process is like.

There are deficiencies and inefficiencies in the cancer care system that adversely affect the quality of care and support available to cancer patients. The principles of access, equity and quality are not always met. While we generally succeed in providing a basic level of health care to all Australians, issues such as inequitable distribution of resources, inadequate coordination and models of care, and inappropriate targeting, can lead to inefficiency, reduced effectiveness and frustration and confusion for cancer sufferers and their carers.

Evidence or perceived inadequacies of orthodox care may lead people with cancer to pursue complementary and/or alternative therapies. The focus of this report, however, is on the provision of evidence-based cancer care. Recommendations do not address complementary/alternative therapy, although it is recognised that such therapies are widely used.

Given the number of significant health issues, why is cancer so important?

There are a number of reasons why cancer is a particularly high priority. It is arguably the most dreaded of the common diseases in Australia, but there are other 'objective' reasons:

- Cancer is already the commonest cause of premature death and disability.
- The number of newly diagnosed cancers is increasing, while other major causes of death and disability are decreasing. Thus, cancer is not only the commonest cause of early death and disability, but it is increasingly important when compared to the impacts from other diseases. This also has social and economic impacts and consequences that are important, though unmeasured, and therefore often ignored.

- We face increasing prevalence of cancer as people live longer, and as those with cancer do not die as quickly (with some notable exceptions where longer-term survival is poor, for example, lung cancer).

These are discussed more fully in Appendix 2.

The complexity of cancer

The other reason cancer is among the most important, if not the most important area for health services reform, is the complexity of the treatment.

Cancer is not a disease of a single organ system but is a group of about one hundred diseases that affect every type of tissue and organ – solid and non-solid. The treatments are multimodal and becoming more so, in an effort to get the greatest benefit while minimising adverse effects (especially longer term) through an appropriate mix of surgery, chemotherapy, radiotherapy and, in future, gene therapy. This necessarily involves people seeing multiple specialists if the full range of alternatives is to be considered. This complexity leads to problems in the ‘cancer journey’ for some, as they negotiate the maze of diagnostic, treatment and support services that are offered – or, in some cases, not offered where they ought to be – and try to assimilate messages from each clinician. These messages do not always seem to be saying the same thing.

What does cancer care cost?

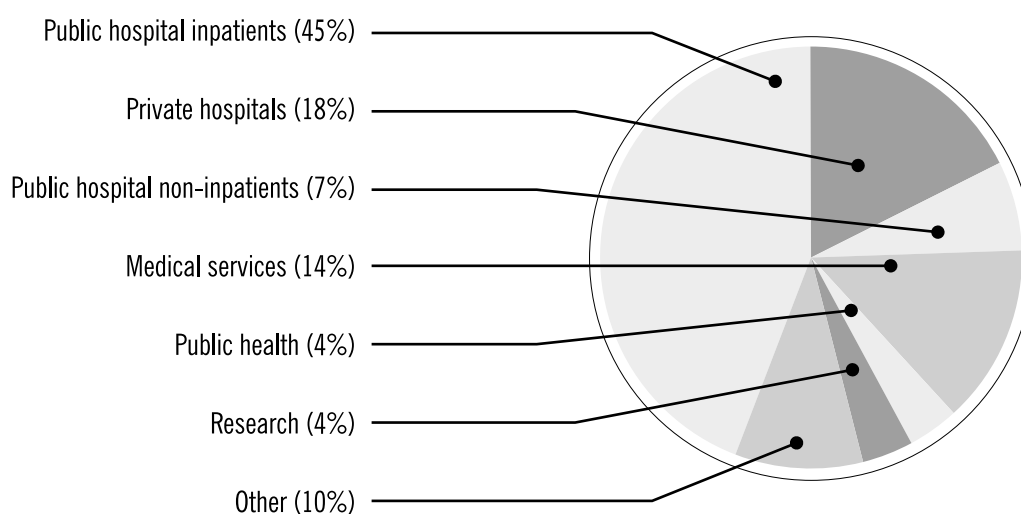
As a disease that affects up to one-third of Australians, and is the most common cause of premature death (under sixty-five years) and the second most common cause of death overall, one would expect the health costs to be substantial. Mathers et al. (1998) estimated the health care costs of cancer are nearly \$2 billion per year. While this is, in itself, a large sum, it is a small proportion (6%) of total health expenditure.

The cost estimates for cancer do not take account of indirect (non-health service) and social costs of cancer. There is a risk that costs that are not explicitly measured are ignored. Canada has recently estimated its direct and indirect costs as being C\$2.8 billion and C\$11.7 billion respectively in 1998 (CSCC 2002), which may be a rough guide to the relative size of each in the Australian context. If the four to one ratio held for Australia, that would mean indirect costs of \$8 billion in 1993–94 dollars.

Some data are being developed to look at costs and benefits more broadly, for example, by TCCNSW in relation to colorectal cancer (Penman A 2002, pers. comm., 21 January). Work done by TCCNSW on faecal occult blood test screening suggests economic value is generated within five years of such a program and there is a net economic benefit a decade after that. Clearly, if the economic impact of a cancer is high, the treatment costs may be an excellent investment on economic grounds alone.

This may change the picture of cancer as a relatively low-cost disease, which would offset treatment costs.

Most of the expenditure identified by Mathers et al. (1998) is related to inpatient treatment costs (see Figure 2). Since 1993–94 there has been a steady trend away from treating cancer in hospital (the most expensive setting). Thus the cost per case may be falling in real terms, although overall expenditure may be rising because the number of cases is rising. The data of Mathers et al. (1998) give no indication of trend and there are no other data at present. This is one of many important gaps in information. (The trend is also important for health service planning because, in general terms, the states and territories pay for inpatient care and the Commonwealth meets the cost of community-based care, so this trend effectively transfers costs from the states and territories to the Commonwealth.)

Figure 2 Total health system costs of cancer in Australia 1993–94 by sector

'Other' includes pharmaceuticals 3%, nursing homes 2%
Source: Mathers et al. 1998

In spite of cancer being responsible for 27% of deaths and costing \$2 billion, cancer is still only responsible for 6% of the total recurrent health expenditure (1993–94) (Mathers et al. 1998). The most costly cancer was non-melanocytic skin cancer, which is responsible for relatively few deaths. The most expensive cancers in 1993–94 and the number of new cases and deaths (1993 and 1998) are set out in Table 1.

Table 1 The most costly cancers (1993–94): new cases and deaths (1993 & 1998)

Cancer	Cost (\$m) 1993–94	New cases 1993	Deaths 1993	New cases 1998	Deaths 1998
1. Non-melanocytic skin cancer (NMSC)	232.3	243,691	379	Not reported	341
2. Colorectal	204.9	9,538	4,440	11,289	4,634
3. Breast*	183.9	8,448	2,641	10,665	2,526
4. Leukaemia	111.3	1,662	1,210	2,106	1,318
5. Lung	107.3	6,911	6,393	7,795	6,893
6. Lymphoma (incl. multiple myeloma)	105.7	3,698	2,288	4,629	2,164
7. Prostate	101.1	10,013	2,544	9,869	2,544
All cancer (excluding NMSC)	1,672.0	69,960	32,797	80,864	34,270

*Includes female breast cancers only
Sources: Mathers et al. 1998; AIHW 2001

The direct health cost of cancer, as noted above, is a relatively small proportion of total health costs. The most expensive eight disease categories, their total health costs and the number of deaths are given in Table 2. As can be seen, cancer is eighth in the list in terms of cost. It is second in terms of overall mortality if heart disease and stroke are combined (as circulatory diseases, as shown) but first if they are not (AIHW 2001).

Table 2 The highest-cost disease categories, and estimated expenditure (1993–94) and deaths (1993) for each category

Ranking	Total costs 1993–94 (\$m)	No. of deaths 1993
1. Circulatory*	3,719	53,240
2. Digestive	3,715	3,759
3. Musculoskeletal	3,002	681
4. Injury	2,601	7,021
5. Mental	2,586	2,344
6. Respiratory	2,521	9,245
7. Nervous system	2,334	2,794
8. Cancer	1,904	33,176

*Circulatory includes both heart disease and stroke, which combined exceed the number of cancer deaths but individually do not
Source: Mathers et al. 1998

Particular items such as drug therapy for cancer have a reputation as being highly costly. The most recent pharmaceutical benefits cost data, however, paint a different picture (see www.health.gov.au/pbs). Antineoplastic (cancer) drugs are twelfth on a list of drug group costs under the Pharmaceutical Benefits Scheme (PBS) as at September 2001, and are only 15% of the cost of the highest-cost group (lipid-lowering agents) and 2.7% of the total cost of the PBS. (These figures do not include all the costs in state hospitals, or the cost of cancer treatment with drugs other than antineoplastics.) While the unit cost of antineoplastic drugs is the highest of all, the number of prescriptions is relatively low.

The unit cost of anti-cancer drugs is increasing (20% in the most recent twelve months). Unless systems are put in place to ensure that new treatments are applied only when the best evidence supports their prescription, the cost of cancer treatment generally, and antineoplastic drugs in particular, has the capacity to rise out of proportion to any additional benefit.

Ensuring that any increase in expenditure on new drugs is justified can be achieved within a framework of high-quality care but not otherwise. At present, restrictions are on particular drugs. A more 'rational' approach (although unmanageable under the existing arrangements) would be to link availability with use in accordance with recognised national guidelines or protocols. This would drive best practice and ensure inappropriate use is minimised.

The experience of cancer service users

People who have gone through the experience of having cancer diagnosed and treated often find the process bewildering, and not one they believe necessarily delivers consistent, high-quality care. There is evidence that their belief is well founded, for example, in the case of lung cancer (Ball & Irving 2000). Some of the negative feeling about the experience is no doubt related to people coming to terms with their recent diagnosis. However, consumer groups and others, for example, those who handle Cancer Helpline calls, report the experience as being suboptimal too consistently to leave any doubt that it is so.

A recent qualitative survey of women's experiences of breast cancer services in NSW (BCAGNSW & TCCNSW 2001) reported perceived gaps in care. The gaps they found are outlined in the box below.

An earlier random computer-aided telephone interview survey of five hundred women by the NBCC found that most women with early breast cancer are satisfied with their care and the amount of information received. They reported, 'there were some noted exceptions, however, with a large proportion of respondents indicating they did not receive adequate information in areas such as prostheses and lymphoedema' (Davis et al. 1998).

Although the problems identified relate specifically to breast cancer, there is every reason to think the experience of patients in the organisation of care is no better (and is probably worse) in the case of other cancers. The current concerns of Cancer Voices NSW, a consumer group that is concerned with all of cancer, is given as Appendix 4.

The underlying causes may be reflective of health care generally, not just cancer care. However, cancer diagnosis for most people is so devastating, and the treatment pathway often so complex, that special efforts are required. If system-wide reform were a preferred option, cancer care would still be a good place to start.

Problems in breast cancer care reported by Breast Cancer Action Group NSW and The Cancer Council NSW

- Poor patient communication and information provision.
- Inappropriate, unsupportive or uncaring attitudes of health professionals.
- Problems with quality of the clinical care received, including misdiagnosis, poor management of radiotherapy burns, poor infection control, and poor management of other clinical symptoms such as depression and lymphoedema.
- Problems relating to the organisation and delivery of treatment, including: delays throughout the treatment pathway; lack of ongoing follow-up and after care particularly primary care; long clinic waiting times; travelling long distances for treatment, follow-up and support; inconvenient appointment times; seeing different doctors each time.
- Physical and psychological effects of diagnosis and treatment, such as pain, discomfort, swelling, wound infection, scarring, depression and anxiety.
- Limited attention paid to women's emotional and psychological needs.
- Lack of a coordinating or central focus to treatment, no single point of contact for information, advice or access to different components of care.

Source: BCAGNSW & TCCNSW 2001

What are the attributes of a model cancer care system?

It is important to consider the attributes of an improved system of cancer care. The US IOM's National Cancer Policy Board recently considered this in its report, *Ensuring Quality Cancer Care* (IOM 1999). It describes the attributes of an ideal cancer care system, and some aspects of a cancer care system that would support such an ideal state of care. The model system described by the National Cancer Policy Board is set out in the box below. This model seems just as applicable in Australia.

Although Australia is not the United States, these lists do resonate with our consumer consultations (see Section 2) and provide a starting point in identifying the direction in which the Australian cancer care system needs to head. In both countries there is some way to go. The IOM concluded that, 'for many Americans with cancer, there is a wide gulf between what could be construed as their ideals and the reality of their experience with cancer care'. That is, unfortunately, also true in Australia.

A model for an ideal cancer care system

Excellence in cancer care would be achieved if individuals had:

- access to comprehensive and coordinated services
- confidence in the experience and training of their providers
- a feeling that providers respected them, listened to them, and advocated on their behalf
- an ability to ask questions and voice opinions comfortably, to be full participants in all decisions regarding care
- a clear understanding of their diagnosis and access to information to aid this understanding
- awareness of all treatment options and of the risks and benefits associated with each
- confidence that recommended treatments are appropriate, offering the best chance of a good outcome consistent with personal preferences
- a prospective plan for treatment and palliation
- a health care professional responsible (and accountable) for organising this plan in partnership with each individual
- assurances that agreed-upon national standards of quality care are met at their site of care.

A system of ideal cancer care that promoted the above arrangements would:

- articulate goals consistent with this vision of quality cancer care
- implement policies to achieve these goals
- identify barriers to the practice and receipt of quality care and target interventions to overcome these barriers
- endeavour to coordinate the currently diverse systems of care
- ensure appropriate training for cancer care providers
- have mechanisms in place to facilitate the translation of research to clinical practice
- monitor and ensure the quality of care
- conduct research necessary to further the understanding of effective cancer care.

Source: IOM 1999

The recommendations of the IOM report are given in Appendix 5 for information and ease of reference, as are the recommendations from the recent report of the Canadian Cancer Control Strategy Treatment Working Group (CSCC 2002).

Summary

This section has briefly described the size of the problem of cancer in Australia. Cancer is the major cause of premature death (see Appendix 2 for detailed data on the morbidity and mortality of cancer). The burden of cancer is not improving significantly, as it is for the other major causes of death and disability. Furthermore, the complexity of the treatments, and the confusion that this produces in patients, is strongly suggestive that cancer needs to be 'first among equals' in efforts to reform these health services into a more patient-centred model.

The gaps in the system as identified in this report will support the case we are under-investing. This has resulted in problems of accessing and negotiating a way through required services, difficulty in accessing some therapeutic interventions (new drugs and radiotherapy in particular) and in suboptimal supportive care and other causes of negative patient experiences.

Reorganisation of service delivery could address many of these issues without great increases in cost to the health system. If the system is not reformed it is possible, even likely, that cost will increase even faster. The choice is between strategic expenditure to produce an efficient, effective system of cancer care, or a laissez-faire approach that will continue to result in inappropriate and sometimes unnecessary interventions. Strategic reform will require organisational and cultural change, and this will need to be driven by robust processes and structures, with incentives for adoption of improved approaches to cancer care.

SECTION 2: ISSUES CONSISTENTLY IDENTIFIED DURING CONSULTATIONS



CANCER CARE providers, consumer representatives, cancer councils, cooperative oncology group members, State, Territory and Commonwealth Government officials, and others, were asked to identify the key barriers to optimal cancer care. Most interviews were held during January 2002. The timing affected who was available, but a suitable range of people was interviewed. An effort was made to see all the members of the Medical and Scientific Committee of The Cancer Council Australia (TCCA) and Clinical Oncological Society of Australia (COSA), and others as suggested by the Steering Committee and by cancer councils in the states and territories. As aspects arose that required consultation with particular individuals, they were also contacted. Every effort has been made to see a range of people with a balance of interests. The list of persons consulted (in addition to those on the Steering Committee) is given in Appendix 1.

The interviews covered a wide range of issues, and there was sometimes a wide range of views on a particular issue. This section summarises issues raised consistently or which are particularly salient. The main or contending views on each issue are outlined.

Consumers' perspective

As indicated in Section 1, for many consumers, the cancer care system does not provide what they feel is necessary and reasonable. Consumers want to see cancer services organised around the patient. The referral system should not be a 'lottery' as to the type and adequacy of the initial treatment one receives. Consumers want to be able to choose how they are involved in the development of their treatment plan, and they want treatment in a multidisciplinary setting. They want treatment that is evidence-based, timely (no unnecessary long waits) and organised around their wider needs, for example, the need to travel. They expect evidence-based information to be routinely provided to them and to be told where to get more. They want reasonable access to a range of supportive care services (including psychosocial and palliative care). They expect that care is of the same standard in both the public and private sectors and that these sectors are as integrated as possible. They want the providers to be skilled, sensitive communicators who are aware of their wider needs.

Availability of a 'care coordinator' – such as breast care nurses and other specialist nurses, available in some institutions – is seen to be important in supporting people through treatment. Sometimes, the clinical trial coordinator plays this role for those lucky enough to get into a clinical trial, and greater access to trials is seen as important (not for that reason). Care coordinators also need to be available in regional areas, not just in the major cities.

A patient-held record (paper-based or electronic) is seen by some consumers to be important in empowering them and assisting in their continuity of care. The Department of Health and Ageing is currently undertaking major projects assessing the feasibility and viability of electronic medical records, access to which would be controlled by the patient (see www.healthconnect.gov.au).

In 2001, the Patient Support Committee of TCCA ran a consultative project involving nearly one thousand people around the nation. It culminated in a national workshop to identify, clearly and authoritatively, the key consumer concerns in cancer. The proceedings of this workshop will be published in 2002.

Integrated multidisciplinary care

There is much discussion on the need for, and the strengths and weaknesses of 'integrated multidisciplinary care' (IMDC). In this context it refers to integrated care by two or more clinical disciplines. It is less commonly, but perhaps more accurately, referred to as interdisciplinary care. IMDC is used in this report to emphasise that it is not simply treatment by several clinicians sequentially.

Consumers strongly support a system of IMDC. Many of the contacts made to consumer groups related to the lack of IMDC. They want an end to the 'cancer care lottery' that they believe currently affects many consumers. They also see IMDC as a way of ensuring greater continuity of care, both during initial treatment and after the intense period of initial treatment.

Clinicians working mainly in the public sector argue that treating cancer is intrinsically a multidisciplinary endeavour, and an approach that involves discussion by a multidisciplinary team is the only way to ensure optimum care for people whose cases are not straightforward.

Opinions vary on what IMDC is, who needs to be involved and who needs it. IMDC may refer to both initial treatment and to ongoing care. The role of the integrated multidisciplinary team includes confirming the diagnosis and planning the primary intervention(s). Supportive care, rehabilitation and palliative care may be needed either from the time of diagnosis or at a later stage. Some providers and consumers firmly believe that all or nearly all new cases of cancer should have the diagnosis and staging confirmed, and a treatment plan agreed, at a multidisciplinary team meeting. Others (providers more than consumers) feel a lesser model is appropriate, one that requires 'agreements' between clinicians that treatment is in accordance with institutional protocols (agreed by the team), with serious cases referred to the team meeting for discussion. The patient may or may not be present at these discussions – some feel they should be, others see no need.

Clinicians practising wholly or substantially in the private sector, however, often express a different view. They feel that the present system of patients seeing specialists serially works well. They argue it is cost-effective and is presently funded under the MBS, which integrated multidisciplinary team meetings are not. They can refer to their colleagues in other specialties quite readily: very quickly if the need arises. They feel that the team meeting approach is inefficient and probably unfeasible in the private sector.

This dichotomy of views was the clearest difference in perspective encountered during the consultations. It is based on relatively small numbers of provider interviews, particularly in the private sector. Many clinicians worked in both, and there was tacit acknowledgment from some that while they worked in an IMDC setting in the public sector, it would be hard to replicate in the private sector with the current funding arrangements and differences in infrastructure, notwithstanding its merits.

There is sensitivity that care in the private sector is judged by public sector practitioners as inferior because of a lack of multidisciplinary teams. However, there are problems in both sectors, particularly at smaller centres in either sector that treat serious cancers (see the next section regarding the relationship between volume and outcome).

Even in the public sector, problems are reported in maintaining participation in a team meeting. For example, if surgeons could not get access to sufficient theatre time in the public sector, they would lose the incentive to attend. Some specialists, for example, histopathologists, could have substantial demands made of them if there were multiple meetings to attend.

Clearly, some of these issues hinge on what IMDC is. It can range from a team that considers every patient who comes to an institution, through to a range of lesser models, even including teleconferencing to regional areas, etc. This is further discussed in Section 3.

The relationship between volume of procedures and outcome

The relationship between outcome and the frequency with which a particular type of surgery is undertaken by a particular surgeon, or at a particular institution, was raised as a general issue, in particular for cancers that were especially technically demanding. Included in this latter category are ovarian cancer and rectal cancer. This is further discussed in Section 3.

Role of general practitioners

The role of general practitioners (GPs) is seen differently by different groups and individuals within groups. There are clear problems for GPs managing patients with cancer: many are not of their own making; some may be.

The initial referral is widely agreed to be critical for the GP. However, GPs are poorly placed to do it well, as the information they have available to them does not make accurate referral easy – it is difficult to establish who specialises in what.

After the initial referral, there may be a long gap during which GPs hear nothing. If the patient returns at the end of this time, they are poorly placed to manage them effectively. GPs often have no current information about the patient's treatment; the patient may be being treated with drugs they have not heard of, and they cannot access them in any case. The patient may have supportive care and psychosocial needs that the structure of general practice leaves little time for. Unless the GP is very motivated/determined, management is quite difficult. Upskilling in all the fields required seems scarcely warranted to the average GP, when he or she sees only a few new cases of cancer a year, and so much of the person's care is undertaken by others. Finally, there is the problem of varying consumer expectations of GPs and their role in patient management – some want the GP to be their 'care coordinator', others do not.

Support of GPs by others, for example, a palliative care team, can improve this state of affairs.

Problems of access from rural, remote or isolated locations

The organisation of services in non-metropolitan centres was frequently raised during consultations and referral was often made to the Cancer in the Bush workshop held in Canberra in 2001 (Margo & Goldstein 2001) and the follow-up at COSA's annual scientific meeting in 2002. Approaches such as tele-medicine and formal outreach services from major centres were discussed. The problems raised most often related to distance – especially travel and accommodation.

Patient access and travel schemes

Cancer councils, consumers and clinicians in most jurisdictions reported that Patient Access and Travel Schemes (PATS) are a severe problem. There is variation between and within jurisdictions, in the rules that apply and the way they are applied. In some cases it is alleged that the funding is provided to regional health services without 'ring fencing' and it is not clear that it is being spent on the intended purpose.

The distance limit (100 km in most jurisdictions but 50 km in one and 200 km in another) is considered to be too great in some circumstances. The fact that funding is sometimes by reimbursement is problematic for those without means. Making the case for special circumstances, for example, an escort, is often time consuming for clinicians, especially when they regarded the case as clear-cut. People who live just inside the limit are also disadvantaged. The needs of a sick person living just within 100 km of a treatment centre are likely to be as great as those of a person living in a rural area. If they have little money or support, their situation is especially hard.

The general view is that there is a need for a national inquiry into the operation of PATS across Australia as it is not operating as originally intended.

Travel issues for Australian Aboriginals living outside cities

Aboriginal people living in rural and remote areas, or even in Darwin, are reported as being particularly disadvantaged in accessing cancer services, especially radiotherapy.

Treatment often requires long periods at or frequent visits to places that are unfamiliar, alienating, often lacking in cultural awareness and sometimes seen as overtly discriminatory. The Aboriginal liaison officer at the treatment institution, if there is one, is typically over-stretched.

There are sometimes problems getting transport assistance for an escort. The fact that PATS is sometimes reimbursed also creates difficulties. There are also problems of loss of family support, homesickness and/or boredom for both the patient and their escort if they have travelled to a distant city for longer-term treatment.

Other issues for Australian Aboriginals dealing with a diagnosis of cancer that lead to access failures

The gender of the clinician may be a barrier to having symptoms investigated. Other factors, such as a high tolerance of discomfort and pain, as well as denial or failure to grasp what symptoms may mean, may also lead to late presentation. The diagnosis of cancer is regarded as meaning death, as it is (for many Aboriginal people) rapidly fatal. The person is usually living in a community that must regularly deal with premature death. In addition, there are cultural and cross-cultural issues – such as fear, disfigurement, failure to be given or to fully understand the treatment options – which play a substantial part in treatment ‘choices’. The long time away from a workplace may also lead to the loss of a job with consequent financial and other impacts. One person consulted said the people often ‘just implode’ under the pressure that is generated by the diagnosis.

The maze that confuses so many cancer patients is completely un-negotiable for many Aboriginal people, given the financial, organisational, geographic and communication barriers. Many simply withdraw from active treatment after their initial experience of it.

Access to radiation oncology

There is a well-known crisis in accessing radiation oncology services. The feedback received emphasised this; in some places, there are waiting times of over two months for access to public facilities.

The Royal Australian and New Zealand College of Radiologists (RANZCR) routinely surveys waiting times. In May 2001, less than half (44%) of the patients surveyed started treatment within optimum waiting times, 30% were within ‘acceptable’ times and 26% were outside the acceptable range. (The ranges are those of the UK Royal College of Radiologists, which the RANZCR has accepted as reasonable.) As there is a separate Radiation Oncology Inquiry being undertaken this issue has not been explored in any depth, but the situation corroborates that described in the *National Strategic Plan for Radiation Oncology*

(Australia) (NROSPSC 2001). Clearly, access from the Northern Territory is particularly problematic, but many centres across jurisdictions are said to have long waiting lists. Australian Council on Healthcare Standards data show that the proportion waiting more than three weeks for radiotherapy has doubled between 1999 and 2001 to 20% of people (ACHS 2002).

There is some frustration that the single machine unit trials in Victoria are taking so long to mount and will take too long to report. (It may be worth noting that similar frustration was expressed in relation to the colorectal cancer screening trials, which were also taking a very long time to commission and, once running, to be reported.) Some feel that a process giving earlier indicative results is not being adequately considered. However, it is also argued that outcomes may not be as good from a single machine unit, and they thus require thorough evaluation.

Communication

Many people, particularly consumers but also providers, raised the need for improved communication skills in cancer care providers, from the specialists through the whole care team, including GPs.

Research has indicated that some clinicians do not pick up relevant cues from patients. There is good evidence that formal communication training makes a difference to clinicians' beliefs and behaviour in recognising and responding to psychosocial aspects of cancer treatment (Jenkins & Fallowfield 2002). Other factors such as the setting are felt to be highly influential in preventing (or achieving) effective communication. Formal, ongoing communications training is proposed as the most reliable way to ensure that matters improve.

Consultations also indicate that communications training needs to extend to training in communicating with people from culturally and linguistically diverse backgrounds. Cultural awareness is also vital for effective communication with Aboriginal people.

Psycho-oncology

Psycho-oncology and other supportive care services are regularly identified as difficult to access. There is concern that they are considered optional add-ons to other cancer services. Many people consulted were at pains to emphasise that this is not the case. *Priorities for Action in Cancer Control 2001–2003* (CSG 2001) identified the provision of psychologists in cancer centres and clinics as a cost-effective, much-needed intervention.

Consumers believe that clinicians are not sufficiently aware of the psychosocial aspects of care. The perception is supported by UK evidence (Fallowfield et al. 2001), which is likely to more-or-less reflect Australian practice.

Advice was received that most people with early stage cancer get better from a psychological point of view over time and return to their usual level of functioning (although they may need short-term support). Others do not do well and continue to have significant psychological morbidity. This second group is said to need in-depth psychological interventions delivered by a skilled clinical psychologist, as suggested by the CSG. Generic psychosocial support guidelines, covering stress and distress, are being developed by the NBCC and NCCI.

Supportive and palliative care

Access to supportive care in some major cancer treatment centres is generally excellent, but in others it may be left almost entirely to the non-government sector. Also, at the time of discharge from hospital, many people are not aware of resources they may need in future, such as the Cancer Helpline or lymphoedema support services. They are either not told about these services, or do not 'absorb' the information.

Consultations identified the need for greater awareness of, and access to, expert sexual counselling and rehabilitation services, as well as the need for professional training in this area to be available within Australia.

Several initiatives to provide supportive and psychological support exist in the network of cancer councils. It is clear that many potential users miss out because of lack of integration within mainstream health services and lack of awareness. Interventions – such as linking with another person with the same diagnosis, who is at least two years after initial diagnosis and who has been trained – are proving popular and successful. Obviously, quality assurance is an issue.

There is a fairly consistent view that referral to palliative care is generally not early enough. This is felt to be due to some patients' and doctors' view of palliative care as essentially synonymous with terminal care. Referral patterns then reflect this view. Some also think the reluctance of the treating oncologist to refer people to palliative care services may be because they believe such a referral represents failure – so they leave it as late as possible.

While palliative care practitioners differ on how early they should be involved (some saying from diagnosis, others saying that is too early) all say they should be involved much earlier.

This less-than-complete view of what palliative care could offer is also felt to affect other aspects of palliative care service delivery. There are similar workforce issues in palliative and supportive care to the issues faced by the other clinical disciplines in cancer control.

Metropolitan areas are generally well served. Non-metropolitan access to centres of expertise in palliative care and hospice services is clearly problematic in some places. Palliative care fails to reach one-third of the target population in cancer, although this level of access is at least equal to anywhere else in the world (Nightingale E 2002, pers. comm., 15 February). Access is further discussed in Appendix 6.

One potential problem identified is the lack of access to state palliative care services in the home if your 'home' is an aged care facility for which the Commonwealth has responsibility. Access to some drugs is a key issue and is discussed under that heading.

Workforce

There was a consistent message about workforce shortages in all areas of cancer care. Either there are professionals but no positions (for example, psychologists) or, much more commonly, positions, but no professionals to fill them, particularly outside the capital cities. This is true of medical oncologists, some surgeons, radiation oncologists, radiation therapists (the most acute shortage), nurses with experience and/or qualifications in the treatment of cancer and pharmacists. There is a real risk of burn-out of the staff presently in the field. Most people view the situation as likely to get worse as the population ages and the prevalence of cancer continues to rise. Some areas are not regarded as attractive; for example, within nursing, intensive care and paediatrics are more attractive than cancer nursing, and the palliative care area seems less attractive than cancer generally.

There is concern that the shortage in regional centres will not ease until specialist colleges and others are more supportive of training in non-capital city centres. Training rules and lack of infrastructure and personal support are cited as reasons that few trainees ever do any of their training outside the major centres.

The workforce issues are discussed in greater detail in Section 3. An outline of cancer services in Australia – in particular workforce gaps – is given in Appendix 6.

Availability of antineoplastics and other drugs

The problem of accessing drugs was frequently raised. The problem may be divided into three Commonwealth issues and one state issue, although they overlap to some extent:

- Lack of access to new drugs (not yet registered for that indication in Australia and/or not on the PBS).
- Difficulty accessing older drugs or drugs currently marketed for another indication. This may be because they are not on the Australian Register of Therapeutic Goods or the PBS, either at all or not for that indication, and are therefore not accessible and/or affordable.
- Lack of access to drugs for palliative care. In general, these are in one or other of the above categories but are used in the palliative care setting.
- Individual institutions' or states' drug committees failing to include new drugs in formularies, even though they are sometimes available on the PBS. This is seen to be 'second-guessing' the Therapeutic Goods Administration (TGA) processes but without its resources and expertise in drug evaluation.

Access to drugs is more fully discussed in Section 3 and Appendix 7.

Guidelines

Clinical guidelines are available or about to become available to cover most of the common cancers, thanks to substantial (often voluntary) efforts by cancer organisations and individuals. A list of guidelines is provided in Appendix 8. The guidelines have been developed with the input of a number of groups (in particular, the Australian Cancer Network, NBCC, NCCI and the National Health and Medical Research Council (NHMRC), mostly at very low cost and with a large component of voluntary effort. Participants emphasised more structured process is required for the future.

With the exception of breast cancer guidelines, guideline development has sometimes been associated with barely adequate dissemination and implementation, and a lack of evaluation. This has mainly happened because of lack of funding to do better. Effective implementation requires clinical leaders and a coordinated program of outreach, for which there is not adequate funding at present. In addition, there is no formal process or funding for the maintenance of most of the guidelines that we have.

There is concern that guidelines may propose strategies for and levels of cancer care that are not achievable in the current organisational and financial climate, particularly in the private sector. This includes some aspects concerning access to therapeutic drugs. However, clinical guidelines are valuable in combating a tendency to nihilism, which sometimes is seen in managing patients with a poor prognosis. This only emphasises the need for organisational reform of the way that cancer care is delivered. This concern may also reflect the lack of an implementation strategy discussed above.

Clinical guidelines are said to have the capacity to greatly improve the efficiency and effectiveness of care, potentially saving funders millions of dollars. Yet their implementation, evaluation and ongoing revision are substantially unfunded. What has been achieved has been done through the substantial altruistic efforts of a few.

Some suggested that guidelines need to be 'living documents' but there was acknowledgment that there are not the resources for this. They do need reasonably frequent review.

Data issues

Several data issues were raised during consultations. These included:

- The need for national measures of quality of life as well as survival (such as an occasional quantitative survey after qualitative research, for example, of focus groups, to identify key factors).
- The need for staging data to be collected so that survival data are more meaningful.
- The need to implement the NCCI minimum data set (NCCI 2001) nationally, which will require the establishment of clinical cancer registries where these do not already exist. The development of such registries will allow a much clearer picture of cancer care to be drawn, including better assessment of staging, treatment and survival, and more comprehensive evaluation of critical issues in care, for example, waiting times for radiotherapy. (The CSG is understood to be currently examining the issue of take-up of the NCCI minimum data set.)
- The capacity to analyse what we already collect, including analysis of individual and institutional audits and performance. This is often based on the premise that 'what you do not measure you cannot reliably change'.

Participation in clinical trials

Providers and consumers expressed concern at the relatively low enrolment of people in clinical trials. Enrolment is around 2–3% for adults. This contrasts with essentially every child with cancer considered for a trial and over 50% entered, and all treated in accordance with a relevant protocol whether or not they enter a trial.

There is evidence that people do better if enrolled in trials (see <http://hiru.mcmaster.ca/ebm/trout> for a compendium of this evidence) and consumers want to see this benefit made known and to be more widely available. There is also some evidence that clinical outcomes are generally better in centres that conduct trials – the rigour they engender systematically improves quality (Miles, Bingham & Dilts 2002).

Consumers want to see establishment of a publicly available clinical trials register, so that they can find out which trials are available in Australia and how to access them. Consumers indicate that they have had trouble getting clinicians to advise them of the existence of trials, either because (in the consumer's assessment) the clinicians do not know themselves or because of a paternalistic view about whether the person needs to know.

A large number of industry-sponsored trials are conducted in Australia at any one time, but the more important cooperative group trials have a serious problem with lack of capacity (Oceania Health Consulting 2002). This undoubtedly affects access to trials in this country, as well as knowledge about them and willingness to be enrolled. Unless that barrier is addressed, the consensus view is that trial enrolment will not increase substantially. It is simply too hard without infrastructure.

The need for systematic reform in the cancer care system





The need for organisational and cultural reform of the cancer care system was expressed by consumers, public sector providers and the cancer councils, some of which are engaged in trying to bring about reform in their jurisdiction. Examples of what might be attempted include children's cancer services in Australia, the UK Cancer Services Collaborative reforms (www.doh.gov.UK/cancer/executivesum.htm), the quality management of cancer reforms being funded by TCCNSW (www.cancercouncil.com.au/cncrinfo/research/newresearchgrants/funded_index.htm) and the BreastCare initiative in Victoria (<http://breastcare.health.vic.gov.au/02/02.htm>). Many of those consulted indicated the need for 'cultural reform' of cancer services, to make them patient-centred, with a reasonable assurance of quality and cancer care practice that is based on best available evidence, and linked to supportive, rehabilitative and palliative care services.

The proposal to 'change the culture' of cancer care is often heard. Unfortunately, desirable cultural change is hard to achieve, particularly in health (Davies, Nutley & Mannion 2000). It typically requires a serious crisis to create sufficient momentum to make a widespread difference to core values. (An example of a 'crisis' producing action is the publication of the poor survival data for the UK versus the rest of Europe in the late 1990s, which gave rise to the more concerted cancer effort in the UK.) While consumers are becoming increasingly empowered and vocal about the need for change, the Australian cancer care scene could not be said to be in crisis, at least not yet.

A more reliable approach to achieving desirable change is to provide structural drivers (for example, the introduction of financial incentives, audit systems and accreditation) and let organisational culture follow rather than lead the reform of cancer services. Traditional values and culture – or 'the way we do things here' – cannot be ignored, but it is unlikely that attempts to change culture will succeed without significant structural change.

A structured approach to the issues raised

The issues discussed so far can be divided into four broad areas. Key priorities and activities that will make a difference to cancer care will be considered under these four broad areas:

-  models of cancer care
-  quality of cancer care
-  resource issues in cancer care
-  improving the delivery of cancer care.

The consumer issues span all of these areas, and the categories are not mutually exclusive, simply a useful framework for consideration.

SECTION 3: KEY AREAS FOR CHANGE, EVIDENCE OF THE NEED TO CHANGE AND MODELS OF CHANGE



THE MATTERS that stand out from the consultations and research as being key areas that need to be considered for change include:

▣ Models of cancer care:

- multidisciplinary or not?
- the volume–outcome relationship – is there a need to move to fewer centres seeing larger numbers of patients?

▣ Quality of cancer care: how to ensure patients receive care that is evidence-based, appropriate and comprehensive, and how would we know? We need to develop both quality systems and systems that measure how we are going.

▣ Resource issues in cancer care: this subdivides into several key areas covering the main (but not all) resource issues:

- workforce (shortages, roles, training, communication skills)
- physical infrastructure (particularly radiotherapy units)
- drugs
- access (particularly transport to treatment centres).

▣ Improving the delivery of cancer care. This is discussed in Section 4.

▣ Models of cancer care

There are essentially two models of cancer care operating in Australia. Both occur in both the public and the private sectors, although an integrated multidisciplinary model is much less common in the private sector.

The traditional model of referral and care

Probably the most common model is one when the GP refers a patient to a specialist (usually a surgeon) who makes the diagnosis and conducts the primary intervention, usually removal of part or all of a tumour. The initial specialist may refer the patient for opinions from other cancer specialists (medical oncologist, radiation oncologist or surgeon) before the primary intervention or after, if they think that further treatment is necessary. There will also be referrals to radiologists, pathologists, etc. as part of the diagnostic work-up.

This model is said by private practitioners to work well and it is the model around which Medicare and the private health insurance system is organised.

Its critics say the inherent defect of the traditional model is its dependence upon the primary specialist reaching a view that further referral is necessary, either before they intervene (with the associated risk of possible loss of income) or afterwards. There are too many opportunities to receive suboptimal therapy without the discipline of IMDC. Consumers are particularly concerned about this risk but so are many providers.

The integrated multidisciplinary model of care

This model is based on a team approach. The team agrees on the precise diagnosis and staging of the disease, the best treatment option for the patient (taking into account the patient's own preferences), and development of a treatment plan.

The rationale for IMDC is that most people with cancer require input from more than one (usually several) clinical disciplines to optimise treatment and care. This is most obviously true at the commencement of treatment, but is equally important through rehabilitative and palliative phases, with different expertise at different stages. It is preferable to obtain a clinical consensus about treatment at a particular stage, than for each discipline to act unilaterally, which results in poorly coordinated, and potentially poorer, care. This consensus can be through a multidisciplinary team meeting, or (some argue) through adherence to previously agreed protocols, when the diagnosis, treatment and outcome for the condition are relatively uniform from case to case. This means that the team does not necessarily consider every patient, but treatment of those who are not considered accords with the relevant institutional protocol developed and maintained by the team.

The most advanced IMDC models of cancer care are in areas such as children's cancer, gynaecological cancer and head and neck cancer. Children's cancer is unique in that essentially all children are treated in the children's hospitals and so get 'best practice' care, whereas persons with, say, ovarian cancer may or may not receive IMDC, depending upon where they are treated, and this affects outcome (see information on increasing procedural volume, later in this section). These provide models of care but they are largely restricted to the metropolitan tertiary public hospital setting. Other models of IMDC, applicable in the private sector and, more broadly, in the public sector, need to be developed.

With videoconferencing, multidisciplinary team meetings can take place over a distance. They are, for example, routinely conducted between Darwin and Adelaide. There is a significant overhead in organising any team meetings, but especially when they are conducted remotely, for example, in duplicating x-rays.

Of the common cancers, more is being done to address the need for IMDC in breast cancer than in cancers of the gastrointestinal tract, prostate, lung, etc. The NBCC has published an outline of its demonstration program on MDC (Luxford & Rainbird 2001) and the principles of multidisciplinary care (MDC) that are outlined in that publication are given in Appendix 9. These principles are the nearest thing to a formal definition of integrated (although they do not use the word) multidisciplinary care (MDC) that has been published in Australia. It is aimed only at breast cancer.

Available scientific evidence for the value of MDC for improving outcomes is complex. A review of evidence relating to MDC in cancer is provided in Appendix 10.

Overseas models of integrated multidisciplinary care

The UK National Health Service (NHS) Cancer Plan requires that a multidisciplinary team review the treatment of all people with cancer. Since publication of the Cancer Plan, a great deal of work has been done in improving access to care by the NHS, particularly by the Cancer Services Collaborative (CSC), including working towards all patients being considered by a multidisciplinary team. The activities of the CSC and some aspects of the multidisciplinary team (MDT) approach is given in Appendix 11. Further information may be found at www.modern.hmg.com/scripts/default.asp?site_id=26&id=5620. The reforms they are implementing are deceptively simple in their management approach; they are potentially quite far-reaching.

North America has long had models of integrated multidisciplinary care (IMDC). The US Commission on Cancer's accreditation program requires multidisciplinary teams (or Tumor Boards) to exist in hospitals that are Accredited Cancer Centers. Appendix 12 provides an outline of this program. The Commission on Cancer indicates that while only 25% of US health care facilities are accredited under its program, those centres diagnose and treat 80% of the annual incident cases (Commission on Cancer c. 1996).

There are, however, only limited data on the cost-effectiveness of IMDC. Fader et al. (1998), for example, investigated the costs for IMDC of inpatients with melanoma in the US and found it to be cost-effective. There are no Australian data on cost-effectiveness of MDC/MDT. This is a gap that urgently requires local health services research.

The status of integrated multidisciplinary care in Australia

In Australia there are varying views and practices around IMDC and the role of the multidisciplinary team. Most of the major cancer centres in the larger capitals have implemented models of IMDC. There are, however, considerable difficulties in running an integrated multidisciplinary team in the private sector with funding arrangements for private health care as they are. There are no appropriate MBS items for most specialists and little or no funding for the specialised ancillary support that is required, such as the various therapists, psychologists and counsellors.

The essential elements of a multidisciplinary team approach in the Australian context include participation by all the specialists identified in the national guidelines for management of that disease. The precise composition of the team on any day may depend upon the point in the disease course that is being considered – if palliation is the aim, then the composition will differ from that of a team considering staging, surgical procedure, radiation etc., with curative intent.

At a minimum, IMDC requires agreement to treatment protocols/pathways that are evidence-based. 'How we do things around here' would be written down, agreed to and complied with, and the patient considered by an appropriate team where significant non-compliance is being contemplated. In the end, the managing clinician will pursue the course they believe to be in the patient's best interest (with the patient participating or their wishes fully considered), notwithstanding the protocols. However, within a framework of IMDC, variations from protocols are subject to peer review, and not done lightly.

Reported difficulties in managing a team-based model include:

- The time that team meetings take and the number of attendees, not all of whom will have a particular role at any given moment.
- The time it takes to prepare presentations to the meetings (greatly facilitated for the specialist when there are resources such as registrars to draw on).
- The greater impact on some specialists who may have to be involved in several such meetings, for example, histopathologists, or who do not see most of the cases presented.
- The difficulty in running an interdisciplinary approach in the private sector due to lack of remuneration in a non-salaried or environment, funding for specialised ancillary care, etc.
- The resources required to convene, conduct and record outcomes of the meetings.

Some of the strengths and weaknesses of IMDC are summarised in the box on the next page.

Some strengths and weaknesses/barriers to integrated multidisciplinary care in the Australian context

Strengths	Weaknesses/barriers
<ul style="list-style-type: none"> • Treatment is less likely to reflect particular professional biases. • Input on treatment decisions is from a far broader base of expertise and is thus more likely to be up to date and evidence-based. • The MDT can be used to agree on institutional treatment protocols, which improve treatment overall in the facility and may make the meetings more efficient. • MDT meetings provide a form of clinical governance and provide assurance of quality. • Continuity of care may be maintained by minimising impact of 'pass-offs' from one clinician to the next (known to be a common cause of trouble). • Consumers want it. 	<ul style="list-style-type: none"> • MDT meetings may consume a lot of time when not all of those present are going to be involved in every case. • Each presentation requires preparation by the oncologist(s), radiologist, pathologist, etc., which takes more time. • The preparation and attendance is not remunerated unless the attendees are salaried or sessional. • If the meetings are not frequent enough they can lead to delays. • It is hard to get attendance of some specialists if their time at the institution is limited and few of the cases are theirs. • It can burden some participants disproportionately. • They are very difficult to mount in the private sector due to lack of funding mechanisms that support IMDC, including specialised ancillary services and team meetings.

The argument for IMDC, in the final analysis, seems to be that there is no alternative if one is to ensure treatment does not remain the decision of a single specialist who may, wittingly or unwittingly, rely on their own discipline rather than consider all alternatives. Cancer is inherently a multidisciplinary activity and a team approach assures the patient and the organisation that the necessary linkages are made. Teams are, in fact, a management tool rather than an end in themselves.

IMDC is not perfect, just better than the alternative, but that thesis is not accepted by all the professionals involved in treating cancer in Australia at present.

It is clear that the barriers to IMDC, and the lack of incentives for its practice, have held back the dissemination of IMDC. Incentives could include financial levers, accreditation and education of GPs and consumers about the benefits of IMDC. All of these will have to be used to achieve an appropriate level of IMDC.

Not every patient would require detailed consideration by an integrated multidisciplinary team – for example, the case of a simple excision of a melanoma. However, that excision is also part of a staging process and access to IMDC may be required and should be available, if the staging of the tumour suggests that adjuvant therapy may be needed.

The need for IMDC should be determined in accordance with an agreed protocol or other authoritative document. It should not be the decision of a single clinician.

RECOMMENDATION ON INTEGRATED MULTIDISCIPLINARY CARE

1 *That investigation of the incentives required to foster, maintain and evaluate integrated multidisciplinary cancer care in both the public and private sectors be undertaken, with a view to widening availability of multidisciplinary cancer care in all settings.*

ACTION ITEM

I That health services research be commissioned to define the essential elements of integrated multidisciplinary cancer care for at least the common cancers, and the costs and benefits of providing it in public and private settings in metropolitan and regional Australia.

Achieving better results for complex interventions by increasing procedural volume

The literature on the relationship between outcome and the volume of procedures undertaken in a particular institution or, usually, by a particular surgeon is mixed, partly because there are few well-designed studies. There is quite extensive tumour-specific literature that supports concentration of surgical interventions for technically challenging surgery, for example, for ovarian cancer (McGowan 1993), and there are recent data to suggest that the Australian experience in ovarian cancer is worse than could be achieved by best practice care (Tracey & Armstrong, forthcoming).

In the US, Hillner, Smith and Desch (2000) undertook a review of the literature on volume of surgery either by institution or by surgeon for cancer specifically, at the behest of the National Cancer Policy Board. The review was published as *Ensuring Quality Cancer Care* (IOM 1999). The review found that, notwithstanding several caveats, most reports support a volume–outcome relationship in initial cancer treatment. The summary states that, for all forms of cancer, ‘efforts to concentrate its initial care would be appropriate’. The paper concludes by saying:

This report provides strong background for the (National Cancer) Policy Board’s first recommendation: ‘Ensure that patients undergoing procedures that are technically difficult to perform and have been associated with higher mortality in lower volume settings receive care at facilities with extensive experience.’ This should be done concurrently with the development, measurement and monitoring of a core set of quality measures for cancer for which hospitals, provider groups, and managed care systems should be accountable.

Australian data from the recent national colorectal cancer care survey support a positive volume–outcome relationship at the individual practitioner level for the *most complex* surgery. For example, there was twice the risk of a permanent stoma if lower rectal cancer (technically difficult) was treated by a surgeon who undertook one to four colorectal operations in three months (stoma 61% of the time, in seventy-seven tumours in the lower-third of the rectum) than for those who undertook more than twenty colorectal procedures in that period (stoma 30% of the time, in twenty-three tumours in the lower-third of the rectum) (Clinical Governance Unit 2002).

The difference in quality of life for people who may have an avoidable permanent stoma is considerable. The number of cases treated by surgeons who operated on colorectal cancer occasionally was three times that of surgeons who undertook many colorectal procedures. If the findings of this single study were systematically addressed, a substantial improvement in the survival and quality of life would be achieved.

It should be noted, however, that lower rectal cancers represent the most technically difficult colorectal surgery and the differences in outcome are less marked or not demonstrable for less technically challenging surgery.

There could be, and may need to be, a significant shift of technically complex elective surgery away from small centres, however regrettable that may be for the local centre. Visiting surgeons and other specialists can address some of the issues of quality in regional centres, but for complex procedures there may not be the critical care and other support that is often required. If the price to pay for halving the risk of a permanent stoma is travelling to a major centre for surgery, it is likely that most people with a lower rectal cancer – if informed about the risk – would pay that price.

A tiered but linked approach may be the way to maintain and improve quality while retaining local availability of cancer care. Use of a superspecialty centre's visiting specialists, its protocols and its other external support systems (for example, teleconferencing) should enable essentially the same quality of care to be delivered at the regional centre for all but complex care.

Reviewing all the evidence on volume and outcome is beyond the scope of this report. However, a brief summary of volume–outcome relationships in cancer is attached (Appendix 13). Suffice it to say that, at least for complex surgical procedures, there is a *prima facie* case that volume and outcomes are linked. For non-surgical procedures, the picture is less clear but IMDC would drive subspecialisation in other areas as well.

A high-quality cancer system must be able to measure the relationship of volume and outcome over a range of procedures (not all surgical) and find the point at which level of complexity no longer matters.

On the other hand, a corresponding effort needs to be made to provide as much care as possible locally for those who do not live in cities. Building and maintaining the networks may be the trade-off for greater concentration of the complex surgical and other complex procedures. Where there is additional risk from local treatment, consumers must be given the information that allows them to make an informed choice about where they go. And getting there must be affordable.

ACTION ITEMS

II That the evidence on procedural complexity, volume and its impact on outcome be fully considered in the funding, planning and organising of cancer services in Australia.

III That the relationship between practitioner, institution and outcome be monitored through greater use of clinical cancer registries.

Quality of cancer care

Initiatives to improve quality of care are occurring across all health care systems. The IOM (1999) states, 'Good quality means providing patients with appropriate services in a technically competent manner, with good communication, shared decision making, and cultural sensitivity.' Poor quality can be associated with too little care, too much care or inappropriate care. Explicit review of quality is the best way to assess it, and three dimensions can be measured – structure, process and outcome. Structure refers to the characteristics of the health system, process refers to what is done and outcome refers to the resulting health of the patient. Chapter 4 of the IOM report (1999) (available at <http://books.nap.edu/html/cancercare/>) provides a detailed discussion of each of these aspects.

Overseas activities addressing quality

In 1999, the IOM published *To Err is Human*, which focused on the level of errors that occur in health care. The same year, the institute published *Ensuring Quality Cancer Care* (IOM 1999). The IOM is addressing some of the issues raised in that report, and has also turned its attention to the way US health services are delivered, that is, the structure of the US health care system.

Around the same time, the UK initiated clinical governance as a major reform that aimed to ensure high-quality care generally. It created a statutory duty on health institutions to seek quality improvement through clinical governance, defined as:

... a system through which the NHS organisations are accountable for continuously improving the quality of their services and safeguarding high standards of care by creating an environment in which excellence in clinical care will flourish. (Scully & Donaldson 1998)

Alongside this has been the work of the Cancer Services Collaborative (see Appendix 11). This is mainly focused on access but has a big component of quality improvement as well. This initiative provides a potentially highly useful model for Australia.

Australian initiatives in quality

In Australia, safety, the most critical aspect of quality, has been the subject of special focus through the Australian Council for Safety and Quality in Health Care. (Further information can be found at <http://www.safetyandquality.org/>.)

A number of specific, discrete efforts to address quality in cancer care are also being made. Some of the major ones include initiatives in NSW, Victoria and nationally.

The Cancer Council NSW has recently let a tender providing \$300,000 p.a. for five years, seeking to improve quality in cancer care. The objectives are:

(First) to apply quality management resources, skills and procedures to demonstrably and reliably improve the conformance of cancer care to specifications so that it:

- *more perfectly meets consumer expectations*
- *optimises health status improvement/health care outcomes resulting from care*
- *represents best value from the viewpoint of patient preference and health care resources.*

The second is to create, through a lead area, a centre of excellence within NSW that establishes quality management as a discipline incorporate in health care, markets its role and achievements, and provides consulting, training and development programs throughout the cancer care system in NSW. (TCCNSW 2001)

In Victoria, the BreastCare initiative is seeking to redevelop breast services in a number of ways to improve quality, access and coordination of the services in that state (see <http://breastcare.health.vic.gov.au>).

Nationally, the NBCC is undertaking a project entitled Doorways to Quality Care. It will focus on breast cancer but will use a methodology that would be applicable to other cancers. It will test the feasibility (including cost) of a 'Breast Cancer Service' model (Redman S 2002, pers. comm., 24 January). This service will be the 'doorway' to quality care, that is, to an organised, integrated, high-quality service on screening, diagnosis, treatment and supportive care. Treatment will be multidisciplinary, evidence-based and audited.

Another valuable Australasian quality initiative in cancer care is the RACS breast cancer surgical audit program. This provides timely feedback on a surgeon's performance relative to that of his or her peers'. The data set collected includes tumour variables, methods of diagnosis, surgical intervention, summary pathology and details of adjuvant therapy.

As well as providing a form of peer review that is highly acceptable to surgeons, it provides timely information about the management of breast cancer across Australia (and New Zealand). Aggregated data provide the opportunity to assess trends and influence them in a timely way, rather than discovering them years later.

Finally, the clinical management surveys conducted at the state and national levels (see Appendix 3) must be acknowledged as a unique and invaluable suite of evidence to improve the quality of care provided.

Empowering the cancer service user/consumer

Australia is fortunate in having several highly professional consumer organisations and individuals working to improve cancer care. These provide strong groups for providers to work with and to advocate for change. As has been alluded to elsewhere, cultural change is not easy to bring about, particularly if the culture is deep-rooted, and 'benign paternalism' (Coulter 1999) has been and remains a feature of cancer as well as other health care.

Breast cancer has been particularly effective at throwing off the shackles, and now has a strong group of articulate advocates behind it, which is no doubt the reason for some of its successes, for example, the availability of Herceptin. Other cancers have not been able to build such a strong advocacy, although some jurisdictions are building generic cancer consumer constituencies, and this will no doubt grow. In diseases such as lung cancer we know the treatment in Australia is quite poor (CSG 2001; Ball & Irving 2000) but there is no specific consumer advocacy, in part because average survival is so short. Reliance is then on the advocacy of enlightened providers and generic advocacy groups. In any case, involvement of the person who has cancer in treatment decisions about their care should not be a matter for advocacy but part of normal practice. Advocacy training is, however, an important element in improving quality.

Which other tools are needed to allow cancer service users an 'even chance' of participating effectively in their care? The first is a GP who involves them in the referral decision. If the right decision is to be made, the right information needs to be available to the GP and to the person that may have cancer, for example, regarding the interest of particular specialists in particular problems. This requires GP education about what information to seek and where to seek it, and essentially the same information needs to be provided to the person at the time that they need it. At present, it is hard to look up, say, a list of colorectal surgeons. If one goes to the RACS website one might be lucky enough to find the Surgical Specialties icon (it is buried) and then go from there to the Colorectal Surgical Society of Australia website. It is more likely that the person will find the canceranswers website (www.canceranswers.com.au), a commercial response to the gap in the market. Whether this is a good thing or not seems to depend upon your point of view – it could be said to be better than nothing. At least one advocacy group is looking to produce a directory of providers and their areas of expertise.

No information is likely to be available about the number of procedures of that type that the surgeon undertakes. As can be seen from data already presented, that may be critical. There needs to be a way to overcome the initial referral 'lottery'.

Having achieved an initial referral, there may then be the need for a team approach to finalising diagnosis, staging and the treatment plan. If this is best practice for some or most cancers, that information should also be readily available to people with a recent provisional diagnosis of cancer. At present this is often not the case.

Assuming the person negotiates all of these steps satisfactorily, they may eventually go back to their GP, who often has no recent information about their treatment. The person is not likely to be able to describe their treatment in the detail required, and so the GP is left unable to help much at that point. Better records, perhaps patient-held, could overcome this.

Clearly there are critical information gaps at every level. We have described just a few of them. A system of process re-engineering is required to address some of these within institutions, as well as a considerable effort to get information into the hands of consumers and their representatives, for example, GPs.

RECOMMENDATION ON IMPROVING THE CANCER JOURNEY

2 *That a national process of quality-driven organisational reform be implemented to improve ongoing supportive care throughout the cancer journey. This would include palliative and supportive care, and improved consumer access to information.*

ACTION ITEM

IV *That the specialist colleges and other relevant associations be strongly encouraged, through incentives if necessary, to provide information about their members' subspecialisation and facilitate systems that allow general practitioners and consumers to readily establish a specialist's interest and experience in a particular cancer area.*

What else needs to be done?

What is striking about the above examples is not how much is being done in relation to improving quality but how little and how fragmented it is. There is no national, comprehensive approach other than in breast cancer. The establishment of a virtual National/Australian Cancer Centre would be a positive step. But that will take a long time to impact at the individual service unit level.

Other approaches that could drive the implementation of an integrated multidisciplinary care approach at this level could include:

A national accreditation system for cancer centres

At present, the issue of credentialling is being driven by the Australian Council for Safety and Quality in Health Care. In some areas of surgery, there are arrangements for audit, for example, as part of a credentialling process.

At the organisational level, however, there are no requirements. Knowing a centre is an 'Accredited Cancer Centre' would give consumers confidence that fundamental, cancer-oriented quality mechanisms were in place. The US cancer centre accreditation requirements are summarised in Appendix 12. A similar set of guidelines could be developed by cancer practitioners for use in the public and private sectors in Australia. Accreditation would be voluntary, and could be fairly basic initially, with a phase-in period of five years or longer. It would take two years simply to develop accreditation criteria and it may require re-organisation of some funding mechanisms to achieve the right settings for success.

The benefits could include (assuming these are included in the accreditation criteria) evidence-based therapy using protocols where possible/appropriate, overseen by a multidisciplinary team. There could be a more formal approach to ensuring that patients, their carers and families know that options such as supportive care and palliative care are available.

Some areas have accreditation systems partly or fully developed and are awaiting the opportunity to implement them. The Faculty of Radiation Oncology, in particular, has an accreditation system that it would like to see in place. Some aspects of radiation oncology are accredited now, but by no means all.

The decision to pursue accreditation would be based on the willingness of the professions and institutions to support it in principle. If it is to succeed it will need this support, and they would have to take responsibility for its ongoing maintenance and management. It should be attractive to private and public institutions to say that they are Accredited Cancer Centres.

Government's role might be to fund development of the initial accreditation criteria. This will take a considerable time, up to two years given the level of agreement that would need to be reached about criteria and their phasing in. The process could cost in the order of \$1 million.

RECOMMENDATION ON VOLUNTARY ACCREDITATION

3 *That a system of voluntary accreditation for Australian cancer care services be developed, broadly modelled on that of the US Commission on Cancer. This must involve and be 'owned' by the specialist colleges and organisations with a specific interest in cancer. The Commonwealth should consider funding the development and testing of the initial accreditation criteria.*

Developing financial drivers towards evidence-based, better quality care through Medicare

It is fair to say that the current Medicare system does not provide a flexible means of delivering cancer care through a team of highly trained professionals, for example, it neither recognises the need for nor rewards subspecialisation, which IMDC care promotes. There is disagreement within the specialties whether it should, although many see this as an important way to achieve better cancer care. If it were to do so, there are a number of ways this could be addressed.

A differential rebate for subspecialisation where evidence shows outcomes are better

As outlined above, there is a growing body of evidence that subspecialists, particularly in surgery, provide better results for difficult procedures, for example, in ovarian and rectal cancer, and sometimes for less difficult ones, for example, breast cancer. At present the MBS rebates do not reflect this – for example, in the case of ovarian cancer, a gynaecologist gets the same rebate as a gynaecological oncologist. In fact, the MBS rebates are deliberately being made uniform, irrespective of who carries out the procedure. This is on the basis that only doctors who are suitably trained and qualified will provide the services. The Department of Health and Ageing maintains that the MBS does not have a 'regulatory' function in terms of doctors' skills and training (this is seen as a matter for the states and territories and for the relevant specialist colleges). The profession has also argued to the Department of Health and Ageing that work that is essentially the same in terms of intensity and complexity should be remunerated on an equal basis, regardless of who does it. This argument fails to take account of an increasing body of evidence that subspecialists, individually or within specialist units, achieve better results for some procedures, and may therefore warrant greater reward, and that there should be a disincentive for others, given the potential impact on the patient's life.

Another argument put forward for removing the differentials is that because Medicare is a national scheme, patients may suffer problems with access and equity if the items are too restrictive. At the moment, anyone can bill for any item in the procedural part of the MBS, regardless of specialty (apart from the few remaining items with a fee differential, which are being removed over time). The Department of Health and Ageing argues that only those doctors suitably trained and qualified would access the items (with a further barrier being that hospitals would be unlikely to let unqualified doctors operate in their theatres). In addition, doctors must satisfy the requirements of the state or territory law under which they operate.

The Department of Health and Ageing is concerned that restricting the type of specialists who can perform specific services would result in problems relating to accreditation, specialist training and workforce issues that could make the process overwhelmingly complex.

These arguments may fail to take account of the national movement towards credentialling as a means of differentiating levels of specialist, and the strong move towards subspecialisation, driven in part by IMDC. They also overestimate the willingness and/or ability of hospital administrators to involve themselves in the professional activities of the medical staff in many hospitals.

Clearly this will take considerable time to resolve. It requires resolution *within* the medical profession before the Department of Health and Ageing can successfully respond to the view that subspecialists

should be rewarded for their additional skills and demonstrated high-quality results. When the health system is in transition, the MBS will necessarily reflect yesterday's practice more than tomorrow's. It will, in time, reflect the needs of the community.

In this context it is notable that NSW Health has moved to promote gynaecological cancer treatment in the public sector at only four state centres, on the basis that 'women with these types of cancer need a specialist team' (Knowles 2001). Data showing survival differences in NSW is awaiting publication.

Remunerating involvement in multidisciplinary teams

There is a need for directly or indirectly remunerating attendance at multidisciplinary teams, given that they improve cancer outcomes. At present, there is little incentive for involvement in a multidisciplinary team in the private sector. If private medical, surgical and radiation oncologists review a patient together, they can all claim a relevant MBS item, but if they have a meeting without the patient they get nothing. The current MBS items (801–805) are not available other than to physicians and are not appropriate for a team that sees, say, six to eight patients in a one-hour meeting.

If a multidisciplinary approach to cancer treatment is necessary, then there needs to be some accommodation made for team meetings. It would be exceptional to have an item that applied to only one disease, but it is highly likely that there is a similar need in other disease areas, for example, the management of stroke. There seems little reason not to have an IMDC item that is payable whether or not the patient is present, provided the item's criteria are tightly specified. The payment might only be made when the team meeting is not in, or associated with, a public hospital, irrespective of whether the patient is public or private. The MBS items 801–805 could be expanded to include all (perhaps only accredited) specialists involved – including medical, surgical and radiation oncologists, pathologists and radiologists – but with shorter consultations, less than thirty minutes (currently the shortest). There may be a requirement that records of the meeting be kept that included certain minimum data, such as what is decided about whom (which is good practice in any case).

Another alternative to a special item for attending a meeting would be to have a higher level of rebate for related services, that is, when the practitioner certifies that the item is in preparation for, or subsequent to, a multidisciplinary meeting that they attend.

There may need to be random audit of the certification. A parallel for this is the GP item for removal of skin cancer that is histologically proven. This is much more highly remunerated than removal of a suspect lesion that is not proven to be skin cancer.

There may also be other more appropriate funding mechanisms for IMDC.

ACTION ITEM

V That consideration be given to ways to enhance the Medicare Benefits Schedule so that it better supports an evidence-based, integrated multidisciplinary approach to cancer care.

Improving the quality of cancer care through better information and research

One of the key issues in improving cancer care is knowing more about how cancer is managed in everyday practice. We know the number and type of cancers, we know the mortality and we know something about the period from diagnosis to death (survival), although we do not know the stage of the cancer at diagnosis on a population basis. We know very little about cancer care in the community except that it is sometimes quite poor, for example, for lung cancer (Ball & Irving 2000) and we have almost no quantitative data on quality of life and long-term outcomes. Some of the work that is needed to improve our understanding of cancer treatment is discussed below. The NCCI has developed a

national minimum data set that, if collected Australia-wide, would make available clinical information on cancer occurrence and treatment (NCCI 2001).

Improving quality through health services research

There needs to be a much better understanding of what happens to cancer patients during treatment, that is, how cancer care is provided, as a precursor to knowing how to do better. Australia is fortunate in having a suite of clinical management surveys for most of the common cancers. These are a unique resource – other countries have no equivalent. Applied health services research, like the surveys, is essential to improving the cancer care system, but surveys are not the only requirement. The stakes are too high for the patient – in terms of quality of care, quality of life and survival – and for the funders – in terms of economic efficiency – not to undertake more health services research into cancer.

An important project by the Collaboration for Cancer Outcomes Research and Evaluation (CCORE), coordinated by NCCI, is assessing the optimal utilisation of radiotherapy for different cancer sites (which would result if the evidence-based guidelines were followed, and comparing this to actual utilisation). This type of work has not been done previously in Australia. It clarifies where actual and optimal utilisation differ and leads to consideration of factors which may impede optimal care. In principal, this approach could be extended to chemotherapy and other modalities of treatment.

Health services research into cancer has been done best in breast cancer. We now know more than we did about quality, how to achieve it, and the extent to which it is achieved, through the work of the NBCC. We need to strive to reach the same position for the other major cancers over the next few years. There are two fundamental issues in relation to this item, first the quantity and quality of the data that are collected, and second the capacity to analyse it. Both need to be addressed.

Improving quality through entry into clinical trials

Entry of cancer patients into randomised controlled trials is important but is not common. Only 2–3% of cancer patients enter trials. It is not just that trial patients do better – which they do, irrespective of whether they are in the treatment or the control group – the culture change that occurs in an institution undertaking clinical research is also very important. Clinicians are reported to become more open to scientific approaches, more likely to comply with protocols, and generally improve their evidence-based practice.

Australia has a proud record in clinical research in the area of cancer but it is at risk of losing its place as costs increase but funding does not. This issue has recently been the subject of a separate report (Oceania Health Consulting 2002).

Children's cancer is the best example of an integrated multidisciplinary model of care in Australia. The children's cancer community commenced practising as they do in order to undertake clinical research. There became no alternative to a team approach, protocol driven therapy, etc., once the number of children entering trials reached a certain point. In children's hospitals, essentially all children are considered for trial entry and over 50% enter trials – more in some centres. The results in terms of quality of care are outstanding. There is considerable evidence that the rigorous approach has made a substantial difference to survival. Apart from the steady increase of average survival over two decades, teenagers, adolescents and young adults who get a childhood cancer late may not do as well if they are treated in an adult health care system as they do when treated in a children's facility (Chessells et al. 1998; Bleyer 2002).

Finally, cancer trials enable clinicians to remain abreast of the myriad new treatments that are coming onto the market, all heavily promoted by their sponsors. The true place of the treatment, however, may differ from the marketing hype. If we are going to be able to assess this, and include, or not include, the new therapy in evidence-based protocols, we need to be involved in international research.

RECOMMENDATION ON ACCESS TO CLINICAL TRIALS

4 *That the capacity to undertake clinical trials be increased, along the lines recommended in the recent review of capacity for cooperative clinical trials in cancer, including the need for a public register of trials.*

Improving quality through psychosocial research

As more people get cancer, but the number of people dying from cancer stays constant or falls only slightly, the number of people with a recent diagnosis of cancer (prevalence) increases, and the psychosocial burden increases with it. We know from consumer reports alone that we do not do well in this area, that we are short of resources and that demand is increasing. We have to learn how to do better with what we have, as well as identifying the areas of greatest need, and the most effective strategies to meet the need.

Australia does world-class psychosocial research, although the financial stringencies are just as great in this field as in any of the other cancer research areas. There is, however, no alternative to applied psychosocial research when trying to improve management of psychosocial morbidity. This will allow the cost-effectiveness of the interventions in an Australian setting to be further improved.

ACTION ITEMS

VI *That dedicated funding be identified for applied research in cancer, including studies of quality of life, so that quality and efficiency in the Australian cancer care system can be improved.*

VII *That the minimum data set developed by the National Cancer Control Initiative be collected across Australia.*

Resource issues in cancer care

The current resources do not allow us to always practise in accordance with Australian evidence-based guidelines. Appendix 6 outlines workforce and physical infrastructure issues, in particular the gaps that exist. This section discusses what might be done to address those and some other resource gaps, including access to drugs and patients' access to services where subsidised transport is required.

Workforce – shortages, training, communication skills

The most notable thing about the cancer care workforce is that there are shortages in almost every category. These sometimes reflect a more general shortage, for example, pharmacists and nurses, but may also be because the area's image is not positive. This is, for example, sometimes the case for cancer nursing, but not for oncology pharmacy.

Specialist workforce

The 2001 report of the Australian Medical Workforce Advisory Committee (AMWAC), examining specialist haematology and medical oncology workforce, indicates that the supply is presently deficient (by at least forty practitioners) and is going to become more so, particularly in regional areas. Some feel the AMWAC report significantly underestimates the future need for medical oncologists. The *National Strategic Plan for Radiation Oncology (Australia)* (NROSPSC 2001) suggests there is a current deficit of around twenty radiation oncologists, more acute in some places than others. There are also severe deficits in the radiation physics workforce and especially the radiation therapy workforce. This is also

the subject of the Radiation Therapy Review and so will not be discussed further, but they are very important gaps in the capacity to improve cancer care.

In surgical oncology, there is a major thrust by the RACS to recognise the importance and very specific nature of cancer surgery and to create training programs in cancer surgery across Australia and New Zealand. It also allows the development of an expert group within the Australian surgical scene to be recognised as being cancer surgeons. This is, however, in its infancy and the subspecialty will not account for the majority of cancer surgery for a very long time unless the process is strongly supported and facilitated by other organisational change, for example, possibly to the reimbursement system.

Specialist training in settings outside capital cities

The workforce shortages show themselves most acutely in areas outside capital cities. Training of any of the cancer specialties, even just for one or two terms, has rarely been undertaken outside capitals or other major urban areas in the past.

Specialist colleges have typically required core training in major centres. At present there are few professional incentives (and some say there are disincentives) to undertake any training in rural or regional settings. Some colleges are moving to a regionally based, rather than institutionally based arrangement, as the practice of medicine changes. However, this may not be enough to get significant numbers of trainees in rural settings unless there is other (such as funding) support. As well as potential professional disincentives, there are infrastructure costs for the individual in moving to a regional area for six or twelve months, including the relocation cost (direct and indirect), rent and higher cost of living. The benefit is a wider range of settings in which practice has been conducted, but that benefit is mixed. The regional setting maybe more frustrating (for example, access to other professionals and information) but that may be part of the learning. There would be benefit to the sponsoring institution immediately, through the input (as well as the output) of the trainee, but more important is the increased likelihood that a trainee will consider a regional setting for their ongoing career if they have lived and practised in one.

The Commonwealth has addressed similar workforce shortages through the Regional Health Strategy, including substantial amounts for rural GP registrarships (www.health.gov.au/budget2000/rural.pdf). A similar scheme, or another way of addressing the problem, for example, in partnership with the specialist colleges, could be considered to promote the idea that some of the specialist oncologist training is preferably undertaken in a regional setting.

RECOMMENDATIONS ON WORKFORCE

5 *That the recommendations of the National Strategic Plan for Radiation Oncology (Australia) and The Specialist Haematological and Medical Oncology Workforce in Australia be implemented urgently.*

6 *That the Australian Health Workforce Advisory Committee be requested to consider the entire non-medical cancer care workforce, but particularly cancer nurses, radiation physicists and radiation therapists, as an urgent priority.*

ACTION ITEMS

VIII *That the development of site-specific surgical oncology as a subspecialty be encouraged.*

IX *That resources be made available to support the training of cancer specialists in regional areas.*

Cancer nurses

A number of issues need to be addressed in relation to the cancer nursing workforce.

Training of nurses in cancer specifically

There are a number of postgraduate nursing courses in cancer. There is a shortage of nurses who have such training and those who undertake it have no assurance that they will receive additional salary because of the additional skill – for example, they may already hold a senior nursing position. The costs are quite high – at Queensland University of Technology, for example, the fee for the equivalent of one year full time is around \$4,000. It is a lot of money, especially if nurses are in early adult life. It would be possible to fund, through bursaries, the greater uptake of the advanced nursing training. A bursary might be for up to a certain number of full-time-equivalent years or capped at a certain level, for example, a limit of two years or \$8,000.

The need for generic nurses with roles based on the Breast Care Nurse model

Specialist cancer nurses can reduce psychosocial morbidity associated with cancer and its treatments, enhance early recognition of support needs and provide continuity of care, particularly in breast cancer. In Australia, studies in the context of breast cancer provide evidence that specialist cancer nurses are cost-effective (CSG 2001), acceptable to other health professionals and highly valued by consumers.

The absolute number of nurses available

Nurses make a substantial contribution in managing the burden of cancer in this country. One of the major difficulties that organisations providing cancer care face is a shortage of nurses. Coordinated national strategies to recruit and retain enough cancer nurses to meet future workforce needs are urgently required. These strategies would address nursing workforce needs across the care continuum, including screening and early detection, treatment, rehabilitation and palliative care, as well as the needs of special populations.

ACTION ITEMS

X That incentives to undertake relevant postgraduate training in cancer nursing be developed.

XI That the model of the breast care nurses be tested more widely and across all cancers, with ongoing funding support based on the cost-effectiveness of the intervention for each of the major cancers.

Undergraduate training of doctors

The Cancer Council Australia has developed an *Ideal Oncology Curriculum for Medical Schools* (see www.promo.com.au/clients/TCCA/documents/Ideal%20Oncology%20Curriculum.pdf). It was developed by the Oncology Education Committee – a sub-committee of the Medical and Scientific Committee of TCCA – with membership comprising representatives of the twelve Australian and New Zealand universities that have medical faculties. The curriculum has been used in some universities for curriculum improvement but has not been adopted by the majority.

ACTION ITEM

XII That the Australian Medical Council be enlisted to assist in incorporating The Cancer Council Australia's *Ideal Oncology Curriculum* and the Australian and New Zealand Society of Palliative Medicine's *Ideal Curriculum* into undergraduate medical education as appropriate, through the accreditation process for undergraduate medical training.

Continuing education of general practitioners

GPs have a key role in the management of cancer. However, they do not often see a new case of cancer. Furthermore, it is hard for them to manage cancer patients in the tight timeframes of the general practice environment. Consultations suggest that there are areas of particular importance that a GPs' cancer awareness/education package could address. Issues include:

- communications – some formal training (not just for GPs but for all practitioners who have contact with cancer patients)
- primary and secondary prevention
- risk assessment and genetics
- the primary referral – for example, what to ask of the person to whom a referral might be made
- psychosocial and supportive care
- palliative care, its role and the GP's role within it
- pain management.

One suggestion is that a cancer module be routinely included in GP education, for example, via GP Divisions' Strategic Plans, which would ensure at least some activity in continuing education in cancer. Incentives could include Continuing Medical Education points, and possibly accreditation/credentialling or a diploma.

ACTION ITEM

***XIII** That a training module in cancer care be developed and run by general practitioners, with assistance from cancer care specialists in a range of disciplines as required.*

Supportive care options

The importance of supportive care is well recognised by many cancer care providers but many others fail to refer patients for support when it is required. This, in part, relates to poor communication, that is, that fails to elicit information that indicates supportive care is required (Fallowfield et al. 2001). It is also because of lack of access to suitable services to refer people to. Supportive care includes physical, emotional (including psychosocial) and spiritual support.

The shortage of professional positions to provide psychosocial support is well known. The CSG has proposed an increased number of psychologist positions as being needed and cost-effective. The difficulty in responding, at least in the public sector, may be that the cost falls on the state, but not the benefit (at least not in any harvestable way), so it is hard to progress in an environment of capped budgets. It is reportedly hard to access expert psycho-oncological support in the private sector. Lack of sexual health counselling and rehabilitative services has also been commented on as an area of unmet need. There is no alternative to highly expert assistance in this area.

There is, however, a need for greater investment in broadly based support services that are readily available and low cost, to complement and supplement professional resources that may be best applied to those with ongoing psychological difficulty. Greater use of community-based interventions, such as one-on-one peer support, self-help groups, or guided group therapy (more efficient than individual psychological interventions) may be required, provided there is evidence for their effectiveness. There are many cancer support groups, as well as the cancer councils, that provide, or are keen to provide, supportive interventions.

In addition, increased numbers of cancer care nurses would provide greater levels of support. Their role in providing psychosocial support to seriously troubled individuals may also require evaluation – for example, do they prevent people getting to this stage and what can they do for them if they do?

The generic psychosocial guidelines that are under development by the NBCC will also greatly assist in improving this aspect of supportive care.

It is not clear what is 'best practice' in relation to the alternatives to a full psychological service. Information about the affordable, effective alternatives to psychological counselling, and advice on how they should be managed, may be a useful step.

RECOMMENDATION ON PSYCHO-ONCOLOGY

7 That the need for additional psychologists or other appropriately trained health professionals who have specialist skills in psycho-oncology, identified as a cost-effective intervention in Priorities for Action in Cancer Control 2001–2003, be brought to the attention of the Australian Health Ministers' Advisory Council for urgent consideration.

ACTION ITEMS

XIV That any accreditation scheme includes access to psycho-oncological support services as one of the accreditation criteria.

XV That the feasibility of other health professionals providing psychological support, and the role of low-cost interventions such as peer support, be further assessed.

Communication training

Consumers and many providers see great need for formal training and occasional re-training in communication skills with patients. Some cancer centres routinely train staff in communication skills but they seem to be the exception. The need for intra-professional communication skills improvement was also noted.

There needs to be more awareness of communications as an issue, and promotion of communication skills programs and what they offer.

One possible way to bring about routine communications training is by including the requirement in the accreditation framework. It is difficult to see another universal measure that could be applied. The need is well known – but the motivation to undertake it seems to be lacking.

Many Aboriginal people have requirements for successful communication that differ from the general population's, due to cultural beliefs about health and wellbeing that are not perceived or understood by non-Aboriginal providers. Cultural awareness should also be part of all communications training. The potential for misunderstanding is greatest when Aboriginal people are seen only occasionally.

ACTION ITEMS

XVI That ongoing communication training be promoted for all people who work in a cancer care setting, including general practitioners.

XVII That regular communications training be required as part of any credentialling or accreditation process associated with cancer care.

Physical infrastructure, particularly radiation oncology units

Gaps in physical infrastructure that were identified in the consultations mainly related to radiotherapy. The *National Strategic Plan for Radiation Oncology (Australia)* details the deficiencies and the Radiation Oncology Inquiry was specifically set up to address them. Given the extensive documentation provided in the strategic plan and reiterated in the inquiry, it is not appropriate to address them further here, except to say that a lack of access to radiation oncology creates considerable real and present hardship for many patients. This is true not only for people who live a long way from radiotherapy units, but also for public patients in metropolitan areas, who may have long waits before commencing treatment.

Australian Aboriginals who do not live in cities are particularly disadvantaged in accessing radiotherapy. Their strong links to place, family and culture means that travelling for radiotherapy – for example, from the Kimberley region or the Northern Territory to Perth or Adelaide – is a substantial burden.

It is also very difficult for many others, for example, a person with a small business to run, if they have to travel away from home for radiotherapy. The loss of income may hit a family very hard at a time when coming to terms with the diagnosis makes life very hard as well.

There is concern that the trials of single machine radiotherapy units are taking a long time to mount and will take so long to report. A process evaluation along management lines, rather than a full scientific evaluation, would be able to report much more quickly. That would allow health planning in this area to continue without having to rule out the single machine unit option more-or-less indefinitely.

RECOMMENDATION ON RADIATION ONCOLOGY

8 *That the recommendations of the National Strategic Plan for Radiation Oncology (Australia) be implemented urgently.*

Access to pharmaceuticals

Pharmaceuticals (drugs) that are difficult to access are of three main types:

- new drugs that are not yet approved by either the TGA or the Pharmaceutical Benefits Advisory Committee for that indication
- older drugs that have not been approved for the use that they are being applied to or that are no longer on the Australian Register of Therapeutic Goods
- palliative care drugs, which are a special subset of the other two categories.

New drugs

A large number of new treatments are under development. One cancer expert interviewed stated that there are as many cancer drugs under development currently as have been developed over the past forty years. Up to two hundred new cancer drugs are expected to be released by 2005 (Ward & Hawkins 2002). There is, at present, a polarisation between the cancer care community and the regulators over access to the new anti-cancer drugs.

Most significant is the process of including new items on the PBS, without which a new drug remains inaccessible for most cancer patients. There is particularly concern about the Pharmaceutical Benefit Branch's approach of cost:benefit analysis, which cancer clinicians feel unduly penalises cancer as a chronic disease. The current example of this is imatinib (Gleevec), which is available for some phases of chronic myeloid leukaemia but not for the chronic phase, where it is of great (if not greatest) value (Druker et al. 2001). The problem with new cancer drugs is set to become greater as new agents reach the worldwide market.

There is also a perception that TGA's approval processes are slower than in comparable countries, and that effective new agents are thus not available to Australian cancer patients. This too may be affected as more applications for new agents are received, with the risk of bottlenecks at the registration stage.

Until the medical oncologists (in particular) and others, sit down with the Pharmaceutical Benefits Branch and TGA staff and try and work through the differences of view, they are likely to continue to talk past one another via the media and other inappropriate forums. The law seems to provide plenty of flexibility – the constraints are matters of policy and cost.

A more strategic perspective may need to be taken towards the issue, given the large number of new agents that are on the horizon. The economic analytical approach seems to have served Australia's interests very well. Nevertheless, it may be that a 'one size fits all' approach creates substantial inequity.

Although the unit cost of new cancer agents is high, the overall expenditure is not. Antineoplastics are only 2.7% of total PBS expenditure. There has to be some capacity for a more acceptable outcome than the present stand-off, in which people living with cancer are the ones who suffer.

Older drugs

There are numerous problems of access to some older drugs via the PBS. Some are on the PBS but in inappropriate quantities for the purpose. Getting authorities can improve the availability only slightly and takes considerable time. One example is morphine and other opiates, which are low cost and low risk in cancer patients. There are restrictions that are entirely inappropriate for people using moderately large doses, for example, via a syringe pump. There is no rational reason for these restrictions.

Other examples are related to the TGA processes, for example, dosage forms that are available overseas but not in Australia. These may be manufactured in Australia and exported to the UK, but are not accessible here, for example, leukovorin 300 mg vials. On the face of it, this seems absurd.

The public policy issues in this area, however, are complex and will not be solved overnight. They include:

- The State–Commonwealth relationship. Cost shifting between PBS and state hospitals, in particular, is a problem.
- The inadequacy of the PBS list for the range of drugs that people may be taking when they are discharged from hospital and the difficulties in expanding the list without resultant prescribing for trivial conditions.
- The need for the Minister and the delegates to act consistently under both the *Therapeutic Goods Act 1989* (Cwlth) and the *National Health Act 1953* (Cwlth), although *prima facie* both give the Minister quite wide discretion.
- The need to avoid treating one disease or one drug or one sponsor's products in a way that sets a precedent that cannot be lived with. One of the difficulties, for example, is that the TGA has to fully cost recover. The Australian market is small and the fee for registration of medicines is relatively high. Therefore companies do not bother to register the product if the sales volume is small. It may require a review of quite fundamental policies, for example, the TGA's 100% cost recovery policy, or an extension of the orphan drug arrangements, or some new mechanisms to address some of these issues.
- Possible reform of the PBS cost–benefit model for new drugs for chronic use in conditions that are ultimately fatal. The Pharmaceutical Benefits Branch either needs to convince clinicians that cancer drugs are not worse off than other classes of drugs and that the model works and is justified, or amend the methodology so that it addresses clinicians' concerns. This needs to be done, however, without destroying that system altogether.

Further examples of the problems in accessing drugs are given in Appendix 7.

In essence it seems necessary for the parties to sit down and together work through each problem product individually to see what can be done. The cost in some cases is small, in others it may be large. In some cases it may even save money, for example, if higher strengths of morphine injection could be made available for palliative care patients. At present there are some perverse incentives towards greater Medicare consultations and hospitalisation simply to access adequate supplies of medication.

RECOMMENDATION ON ACCESS TO PHARMACEUTICALS

9 *That the Minister for Health and Ageing establishes a joint working party – including the Medical Oncology Group, the relevant national palliative care organisations, consumers, the pharmaceutical and health insurance industries and the Department of Health and Ageing – to review and where possible develop solutions to the key problems of access to new and old pharmaceuticals.*

Access to services

Practical assistance

People with cancer may have many practical needs, including financial support and access to wigs, prostheses, lymphoedema garments and other practical aids. Attention should be paid to providing equitable and patient friendly access to such aids.

Travel

Problems with access to services because of travel difficulties were often raised. There is some polarity of view. Some think that what we have is wholly unsatisfactory, others that we are lucky to have what we have. While the latter view is true at one level, there seems no doubt we could do better and there seems to be an underlying case for greater resources being put into this area on the grounds of equity.

The problems with accessing treatment, particularly radiation oncology, have already been described. Arrangements for assistance with patient's travel vary amongst states; the current arrangements are summarised in Appendix 15. Some states and territories have recently reviewed PATS but the findings of the reviews are not in the public domain. The Radiation Oncology Inquiry will, by addressing access to radiotherapy, alter the environment and perhaps lessen the associated transport problems. The cost of travel needs to be seen as part of the cost of treatment and it is unique for patients to have to contribute so heavily to this cost.

While the Commonwealth was the original funder of the Isolated Patients' Travel and Accommodation Assistance Scheme, it handed both the funding and the responsibility to the states and territories a decade ago. It is not clear if real funding has increased since that time, but it is clear that demand outstrips supply.

The Cancer Council Victoria recently investigated the problems of transport as part of a needs assessment for a voluntary driver scheme. It is unpublished but in general terms it supports the view that access may be problematic, particularly from outer areas, just inside travel limits.

Cancer care itself has changed since the travel assistance schemes were introduced, but it is not clear that delivery of services outside institutions has always changed with the times. Funding mechanisms may still act as perverse incentive towards, for example, day care at a hospital, rather than home care or GP care, although this may be technically possible and even less costly. The fact that travel cost is from a different budget means that this cost may not be considered in decisions about location of care.

RECOMMENDATION ON ACCESS TO SUPPORT FOR TRAVEL

***10** That there be a national review of matters that affect access to cancer care, including an investigation into problems with travel, as an urgent matter. Particular attention should be paid to populations that may be experiencing disproportionate difficulties with access and the magnitude of that impact on cancer outcomes. This would include Australian Aboriginals and people living in isolated areas or just inside travel subsidy distance limits.*

Access to home care

There has been a significant shift away from hospital-based cancer care to ambulatory and home care, as evidenced by progressive reduction in average length of hospital stays. This is clearest in the US, but a similar trend appears to be occurring in Australia. Technological advances now permit many procedures that used to require multi-day hospital admissions to be done safely and effectively on an outpatient basis.

Consumers express a preference for outpatient and home care, provided quality is not sacrificed and appropriate support is available. It is undoubtedly more cost-effective to treat patients out of acute hospitals whenever possible.

However, in the public sector of Australia's health care system, there are perverse financial incentives favouring hospital admission or day-only care, so the shift towards care in the home has not been as great as it could be. If it is to become more common, funding will have to move with the locus of care – that is, away from institutional care and towards home care. Monitoring such shifts is another area that requires applied health services research.

Failure of the money to follow the patient out of the institutions and into the community results in one of two outcomes: the person cannot be managed at home due to lack of support and has to be re-admitted; or the patient gets 'stuck' in hospital because they cannot be placed anywhere that can provide the level of support required. Both of these are common now, which is probably reflective of the underfunding of cancer care outside hospitals.

At present, the home care sector appears to be, in general terms, the least well funded, despite being the preferred place for cancer service users to receive care, especially for palliative and supportive care, but also for services such as some chemotherapy.

Investment in home care, with adjustment of the incentives so it is more 'profitable' to treat and support people at home than to admit them, is required.

ACTION ITEM

***XVIII** That the costs, benefits and cost-effectiveness of home care be identified, and the incentives adjusted so that home care becomes a more viable and attractive option for cancer service users and providers.*

Access to palliative care and supportive care

While overall access to palliative care in Australia is adequate (but one-third of persons who die of cancer are unknown to palliative care services) there are some deficiencies in palliative care services.

One major problem is late referral, or referral only in crisis. This may be related to a view of palliative care as terminal care. Clearly, education about palliative care and a change of image for palliative care are required, though neither is easily achievable. Late referral is closely related to the failure to involve palliative care providers in care planning at an earlier stage.

Demystifying (or destigmatising) palliative care, by educating specialists, GPs and the community, is part of the solution. This includes outreach to special groups such as Australian Aboriginals and those from a non-English-speaking background, ensuring they know about palliative care and how to access it.

Access to palliative care expertise and facilities in non-metropolitan settings is also an issue. The expertise can be overcome to some extent by telehealth and other outreach initiatives, if there are funds for them. Access to facilities is an issue everywhere, but is particularly difficult in more isolated settings.

ACTION ITEM

***XIX** That the Commonwealth and State and Territory Governments work with national palliative care organisations, relevant colleges and others to address the issue of late or crisis referral of people for palliative care.*

Access by special populations

Many 'special' sub-populations can be identified for cancer. Their access to cancer services may be through various health providers and various disciplines. There are two with a demonstrated problem of access that is leading to premature death: Australian Aboriginals and older patients.

Aboriginal peoples

The problems that Aboriginal people have accessing cancer care services are briefly outlined in Section 2. A number of the steps already outlined will improve access, for example, consideration of travel schemes and improving communication and cultural awareness. There are, however, broader reasons that inhibit appropriate access. Addressing these needs to be the focus of a special effort to identify, and identify solutions to, problems that lie outside the scope of this report. Addressing the cancer care needs of Aboriginal peoples warrants its own initiative.

Older Australians

The signs of undertreatment of cancer in older patients are outlined in 'Cancer survival' in Section 1. For example, current research by CCORE shows that utilisation of radiotherapy for several types of cancer decreases for patients aged over 55–60 years. There may be a subtle form of 'ageism' occurring, meaning persons who could be effectively treated are not being offered choices that would improve their survival and probably also their quality of life.

IMDC would make this less likely, as a team would be less likely to perpetuate such a bias than an individual. Also, the rigour required by treatment protocols would help ensure people received the same treatment, irrespective of age, or the reason for the variation would be very explicit. 'Too old' is not likely to be given as the reason very often, unless it is the patient's informed view rather than the health care provider's paternalistic one.

RECOMMENDATION ON EQUITY OF ACCESS

***11** That the needs of special populations, especially Australian Aboriginals, be the focus of special efforts to bridge the current gaps in access to and utilisation of culturally sensitive cancer services.*



SECTION 4: IMPROVING THE DELIVERY OF CANCER CARE



THE IMPACT of cancer, unlike most other major causes of morbidity and mortality in Australia, is not decreasing. Both the absolute number of new cases each year, and the prevalence are increasing as people live longer. Furthermore, treatments as currently delivered are only slowly improving survival.

If the efficiency and effectiveness of cancer care is not improved, the cost of treatment will overwhelm both the private and public health systems and outcomes will remain suboptimal despite the spiralling cost. The cancer care process needs 're-engineering' to ensure care is evidence-based and in accordance with what is agreed as best practice. Integrated multidisciplinary care (IMDC), quality improvement and workforce development are some of the issues that have been identified as needing attention. The question is, how to bring about desired change on a national basis in a timely manner?

The present national centres in cancer – gaps in roles

At present there are two national centres funded by the Commonwealth that have responsibility for a part of the spectrum of cancer reform. There is, however, a great deal of that spectrum for which no one has responsibility matched by resources.

The NBCC was established in 1995 to improve breast cancer control and it has recently had its role widened to address ovarian cancer as well as breast cancer. Its terms of reference (Appendix 14) specify major roles in improving breast cancer control, with reference to the whole community.

The NCCI was established in 1997, and its scope extends to the prevention, detection, treatment and palliation of cancer of all types. Its primary role is defined as giving expert advice to the Commonwealth and other national groups (Appendix 14). As such, it has not become involved in issues of direct cancer care delivery; its work has involved the development of clinical guidelines and clinical management surveys, for example in colorectal cancer, and involvement in Commonwealth-supported cancer screening services.

The NBCC and NCCI work together on several issues. What is clearly missing is a national body or collaboration with the capacity to catalyse cancer service reforms across all the areas of cancer, or at least the major (priority) cancers. The NBCC is widely regarded as a successful model showing the benefits that accrue from a dedicated initiative in a particular cancer. The experience with the NBCC suggests that similar improvements could be made in other cancers, including those affecting men, by specific initiatives and funding.

There is now a rich volume of material in relation to breast cancer: three sets of best practice guidelines, health services research such as assessment of their impact, and evidence on IMDC. There is evidence that breast cancer outcomes have improved as a result of the dissemination and assessment of the guidelines.

There is a much less rich body of information in relation to all other cancers, although they account for seven out of eight new cases. For example, the Australian Cancer Network has done a highly efficient (and highly commendable) job of developing guidelines in a number of areas of cancer treatment, but there is a lack of information about their impact on quality and cost.

Recent (as yet unpublished) work on patterns of care in colorectal cancer suggests that a focus on service improvement (similar to that in breast cancer) is needed. Better outcomes could be achieved if there were an active implementation process for all clinical guidelines, as there is for breast cancer guidelines. Prostate, lung, and head and neck cancer are other areas in which there are substantial needs.

The data from the Australian clinical management surveys, of which there is a commendable range, could be used more effectively if we had greater investigative capacity. There is, however, much about cancer care that such studies cannot answer, for example, the personal experiences of the patient during the period of active treatment and thereafter. This (lack of) information is important, as it is difficult for health service planners to know what is working well and what is not, unless there is the capacity to monitor the cancer care system more closely.

One obvious way of creating a more robust system for continuous quality improvement in cancer care nationally is the creation of linked national centres of expertise covering all of cancer. This virtual National (or Australian) Cancer Centre/Collaborative, could be made up of two or three or several smaller centres, including NBCC and NCCI. Ways of achieving this include:

- developing a new or overarching centre with a role encompassing those of the NBCC and NCCI but widened to address reform across all of cancer care
- continuing the role of NBCC in breast and other women's cancer and increasing the role and capacity of NCCI in regard to other cancers
- creating new specific cancer centres in addition to the NBCC and NCCI.

Clearly one could have a 'centre' of expertise that is a national collaboration, made up of individual centres. That model is almost essential if a national 'centre' is going to have an impact across Australia. 'Centre' does not necessarily imply a single physical location. Deciding the structure is a means – the end is to have a robust national system of achieving best practice in cancer care for all cancers.

The profile of cancer in health policy forums

Cancer was, rightly, one of the original National Health Priority Areas. The CSG meets regularly and is quite active. However, that activity reaches AHMAC and the Australian Health Ministers' Conference only through the National Health Priorities Action Council. The perception of the cancer community is that the CSG is too far removed from the Ministers to be effective.

Another major difficulty with the present arrangements for cancer care is that the National Health Priority process has limited funding. Apart from a relatively small allocation to manage the Commonwealth policy and secretariat to committees, and the support to the two major centres of the NCCI and NBCC, there is little or no national funding for initiatives to define quality problems, introduce service reforms, etc.

On one hand this is a sensible arrangement – the National Health Priorities Areas account for the great bulk of the burden of disease (over 80%) and the great bulk of all Governments' health budgets. The idea is that within those budgets there should be room for reform without new funding. That is true to some extent, but 'pump-priming' funding is often required to identify the quality problems, investigate how to fix them, and demonstrate that it can be done. These projects do not require large amounts of money relative to the total spending in the area, and they should eventually repay the investment but, typically, not immediately. Thus there is a cash flow problem even if, in the end, improving the quality of cancer services potentially saves money (or even just reduces the rate of increase of cost of new services).

Furthermore, if a program's funding base is too low, that will never be addressed in a framework that requires ongoing cost-neutrality. There is a need for nationally identified and managed funding if we are going to achieve quality improvement of cancer services Australia-wide, as we must.

Cancer treatment is less and less inpatient-based. The rate of change to outpatient-based services is not clear, but there is wide agreement that since the study of Mathers et al. (1998) on the cost of cancer care (1993–94) the switch to outpatient-based care has been substantial and is continuing. One impact of this is that the Commonwealth is increasingly the principal funder of cancer services, through the MBS and PBS. This is not as a result of cost shifting, but the natural consequence of trends in cancer care. It is, therefore, in the interest of the Commonwealth especially, to ensure that care services are efficient and appropriate, that is, in accord with best practice. It cannot, however, do this unilaterally. Institutional care may be a declining proportion of care but it remains critical, for example, in relation to surgical management, and is still a large proportion of the cost.

An improved system of implementing national cancer care service reform is required, given the increasing prevalence of cancer, the need for system-wide reform of services, the far-reaching consequences of those reforms, and the difficulty in funding necessary reforms under the present arrangements. There needs to be a national cancer care improvement plan, and a higher-level CSG or similar group responsible for implementing it. This group needs to have representatives from all governments and report to a very high level if it is going to make the necessary difference. The options for a system of governance that can ‘make things happen’ are discussed later in this section.

Relationship to *Priorities for Action in Cancer Control 2001–2003*

This report has already discussed recommendations for integrated multidisciplinary care (IMDC), improving quality (by working on processes to ensure patient-centred cancer care and possibly through accreditation), addressing gaps in the workforce, and a process to reconsider access to pharmaceuticals.

These are in addition to the recommendations of the *Priorities for Action in Cancer Control 2001–2003* (CSG 2001). Its recommendations are focused on proven interventions for cancer control, not just cancer care. The priorities outlined in that document, developed after considerable research, are important. They are supported by high levels of evidence but exclude areas where evidence is softer or absent. There are many other process reforms that lack strong evidence. The CSG document was also framed to be cost-neutral and so avoids mention of many health service delivery reforms. Some of the key steps in improving cancer care are addressed by *Priorities for Action in Cancer Control 2001–2003*, for example, the need for clinical practice guidelines, psychologists and breast care nurses, but other areas of perceived need are not considered. It is not surprising that the process of focussing down on issues, based solely on cost-effectiveness, did not identify them. By contrast, the consultative process followed in the development of this report is broad but is accompanied by the possible need for further work to consider issues such as cost-effectiveness and levels of available evidence as well as the effects of social disadvantage.

Many of the cancer care procedures that happen day after day are neither demonstrably cost-effective, nor are they delivering optimum care, so requiring cost-neutral interventions may be a quite limiting constraint. Additional activity is therefore proposed to achieve patient-centred, high-quality care through process (management) reform of cancer services. Thus the difference between the *Priorities for Action in Cancer Control 2001–2003* and the reforms suggested in this document, relate to the focus of one on changing what is done, and the focus in this report on how things are done. These perspectives overlap, of course, but they are in essence examining cancer care in two different ways.

Options for managing change in provision of cancer care

The recommendations relating to integrated multidisciplinary care (IMDC), such as ensuring quality, and the many other action items that are identified in this report, need a mechanism to bring them about. It is proposed that a Task Force on Cancer be established to implement the recommendations of this report – and potentially other cancer care issues (for example, possibly the outcomes of the Radiation Oncology Inquiry) – and to develop and implement a national cancer care reform agenda focused on service delivery improvements.

The process of reform is perhaps a decade-long one, but initially the Task Force might be set up with a life of three years, with a review before any renewal for a further period.

The level of appointment of a Task Force on Cancer

The Task Force could be constituted at a number of levels. In the UK there is a Prime Ministerial Cancer Committee. The US has had Presidential cancer committees and of course it has the *National Cancer Act*, which created and maintains the National Cancer Institute.

Given the current health system arrangements in Australia, it is proposed that the Minister for Health and Ageing appoint a Task Force on Cancer. This would provide the best alternative to ensure cancer receives the attention that it warrants on grounds of both quality of care and financial risk to Government.

There are many statutory and non-statutory committees that report to the Minister. The parallel that is most relevant is the Australian National Council on AIDS, Hepatitis C and Related Disease (ANCAHRD) which has been highly successful in advising successive Ministers and governments on the control of blood-borne viral illness in Australia. Other options include:

- a Prime Ministerial Task Force – for which there are precedents, such as the issues of drugs and suicide
- a Task Force that reports to the Australian Health Ministers' Conference
- a Task Force that reports to the Australian Health Ministers' Advisory Council
- the Cancer Strategies Group, presently charged with the task of managing the process.

A Prime Ministerial Task Force

While cancer is important enough in terms of deaths and years of life lost to warrant a Prime-Ministerial committee, it may then be too removed from the health system, given the level of integration with health care facilities that cancer requires. (This is unlike suicide and drug use, which are essentially societal issues that cross portfolios, even though health is a major component for both.)

A Task Force that reports to the Australian Health Ministers' Conference

This is not a model that is in common use; only AHMAC routinely reports in this way. It would be possible if the Minister(s) felt it to be appropriate.

A Task Force that reports to the Australian Health Ministers' Advisory Council

There are many examples of such committees, including the National Health Priorities Action Council. The strength of this model is that it links in the states and territory health bureaucracies – which have funding and managerial responsibility for the public health sector, so vital to cancer care – as well as

the Commonwealth Department – which has carriage of MBS and PBS, both of which are also vital. The weakness of reporting through AHMAC is that there is a danger that cancer becomes lost in competing priorities that are part of the AHMAC process. Due weight may not be given to cancer as the major cause of death.

The Cancer Strategies Group as the manager of reform

The Cancer Strategies Group is one possible lead group for the reform of cancer care. This has the advantage of using an existing group with broad membership and a high level of expertise. There are difficulties in this course of action. It is perceived to be too far removed from the Ministers for organisational reform. Given the potential for a crisis in cancer care as demand and cost of therapies increase and workforce and budgets do not, it is necessary for cancer services reform to be linked in at a much higher level. If CSG were 'promoted' to Ministerial level, it would require a different remit.

The Ministerial Task Force on Cancer – further considerations

As indicated, the cancer care community is of the view that the most appropriate model for the Task Force on Cancer is one analogous to that for blood-borne viral illnesses, that is, the highly successful ANCAHRD model. This level of appointment provides the ability to make a difference to the cancer care system, private and public. The Task Force could have a limited life – of, say, three years initially – with renewal as required, as is the case for ANCAHRD. The Task Force would be comprised of representatives of major stakeholders, have a membership sufficiently senior enough to represent their agency, and have high-level input to the Health Ministers.

In considering the ANCAHRD model, it is important to note the role of the Intergovernmental Committee on AIDS, Hepatitis C and Related Diseases in linking the various governments into the activities of ANCAHRD. Similar arrangements may need to be made for cancer, although it would be undesirable to have duplication of cancer committees. It is, however, essential to have all jurisdictions supporting and linked to the work of the Task Force.

The need for a clearer understanding of what is happening within the cancer care system has already been discussed, as has the need to improve quality through measuring what we do and the effectiveness of the interventions. The same principle applies to the work of the Task Force. It will be critical to set performance criteria and measure the Task Force's performance, in part by measuring the effectiveness and cost-effectiveness of the implementation it supports. Celebration of success is also, in itself, an important means of culture change.

RECOMMENDATION ON A NATIONAL TASK FORCE ON CANCER

12 *That a national Task Force on Cancer be established to oversee and drive the reform process with the aim of ensuring cancer care services throughout Australia are evidence-based and consumer-focused, and that sufficient funding be allocated for the Task Force to implement necessary change across the entire spectrum of cancer care delivery.*

SECTION 5: CONCLUSION



FIVE YEARS ago, the *National Health Priority Areas Report on Cancer Control* was published (DHFS & AIHW1997). In its Section 3 it proposes a framework for change. It states, in part:

Factors (that) are important in building a holistic picture of cancer control in the nation ... include the role and rights of consumers, the transfer of existing or new knowledge available through research into strategies against cancer, the kinds of data systems that are available and whether aspects of cancer services or treatment are the same for all population groups.

In addition, there are a number of stages along the continuum of cancer control that need to be considered. These are research, prevention, screening and early detection, treatment and palliation ... Many treatment strategies or breakthroughs are applicable to more than one kind of cancer, and multimodal and multidisciplinary approaches to treatment and care are proving beneficial to patients across the whole spectrum of disease.

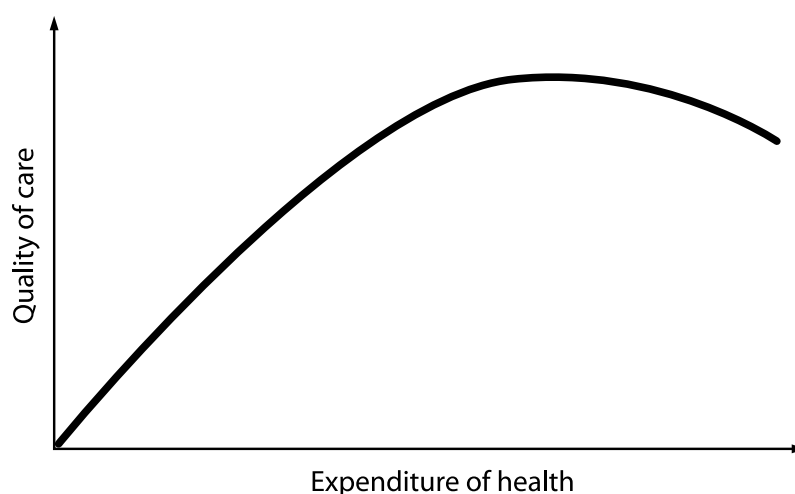
It would be useful to build a systematic framework for promoting a comprehensive, rational approach to cancer control at the national level. This framework should take into account the cancer types, the stages along the continuum of care, and other categories of health system activity that are relevant to cancer control. Taking this approach should make it easier to identify gaps or particular problem points in the system that, if addressed successfully, could lead to overall improvements.

Unfortunately, since that was written, relatively little reform of cancer care service at the local level has occurred, with the exception of breast cancer care. People are dying earlier and in more distress than they need to because we do not have a system that is based on what is known to be best (including cost-effective) practice.

There is an ongoing pattern of under-investment in cancer care, with the system driven by demand, not by strategy. Any attempt to intervene at a strategic level seems to be regarded as too risky or too expensive. In fact, the reverse is probably the case. Failure to intervene strategically will see an escalating demand for services and a failure to meet consumer expectations because of a lack of attention to issues of effectiveness and cost-effectiveness.

Many authorities have shown that increasing expenditure on health care shows diminishing returns (Figure 3). There is simply not enough health services research in cancer care to be able to say for sure where we are on the curve of quality care against cost.

Figure 3 A schema of health cost vs quality of care



Australia is almost certainly on the early part of the curve whereas the US (for example) may be over the peak. Where we are will determine whether improved care will increase cost. If we were over the peak we would expect to be able to decrease health expenditure by improving quality. Even if Australia is on the upward slope of the curve, improving care should still be cost-effective, that is, by saving more in non-health costs than the cost of the care itself. This is not hard when the indirect costs (many of which are also borne by government) are several times greater than the direct costs.

If, as this report has tried to show, we are failing to invest in cancer care in a strategic way, the work of the CSG in its present setting cannot redress the problem of under-investment and health services reform, given its remit and the cost-neutral environment of the National Health Priorities initiative. The under-investment in cancer care must be addressed by thoughtful, strategic change based on evidence.

The up-front costs of initiatives such as guideline development, implementation and evaluation will always require new money in the short run, with the rewards some years out. Similarly the restructure of health services (or any large system) always requires a significant up-front investment. Failing to fund such initiatives adequately is setting them up to fail.

Change is never easy and change in health systems seems particularly difficult (Davies, Nutley & Mannion 2000). Approaches to successful change have to rely on structural interventions as well as culture change. Neither will happen without the stakeholders being involved and 'brought along' in the change process. For that reason, the arrangements for coordinating national change in cancer care are particularly important. Neither the Commonwealth, State and Territory Governments, nor the cancer care professionals, can do this alone. All must work together. This makes the system of governance for any change critical. The governing/coordinating body must have strong links to all key parties and these links must be to a very high level in government.

The change process must be adequately resourced, including being able to effectively influence (although not necessarily directly manage) existing programs and other resources. The change process is a decade-long one (at least). The resources required over that time will be significant, but must be viewed against the total cost of cancer to the community and in relation to the savings that can occur by improving efficiency of large expenditures such as institutional care and the MBS and PBS, in the long run. The alternative to a rigorous program of strategic change is continuing non-strategic change, with concomitant inefficiency and suboptimal care, that is, there really is no alternative.

The recommendations of this report are offered to the Commonwealth Minister for Health and Ageing, and to the Ministers with responsibility for health in each of the states and territories, for adoption and implementation.

The treatment experience and survival of persons with cancer can be greatly improved if these recommendations are implemented.

APPENDICES



APPENDIX 1 People who were consulted or had other input into this report (including workshop attendees), background and terms of reference

Prepared by Brian Wall, Oceania Health Consulting (May 2002)

Note: these are in addition to members of the Steering Committee, that is, Lester Peters, Kerry Kirke, Mark Elwood and Paul Ireland.

Liz	Abell	The Cancer Council South Australia
Stephen	Ackland	Mater Hospital, NSW
Doreen	Akkerman	The Cancer Council Victoria
Vlad	Alexandric	Little Company of Mary National Office, ACT
Roger	Allison	Head Cancer Services, Royal Brisbane Hospital & member Cancer Strategies Group
Deb	Amery	The Cancer Council Northern Territory
David	Ashley	Royal Children's Hospital, Vic
Robert	Bain	Australian Medical Association, ACT
David	Ball	Peter MacCallum Cancer Institute, Vic Chair Lung Cancer Guidelines Working Party
Tonia	Barnes	Palliative Care Australia, ACT
Bruce	Barracough	Chair, Australian Council for Safety and Quality in Health Care, Vic
Joan	Bartlett	The Cancer Council ACT
Michael	Barton	Liverpool Hospital, NSW
Geoff	Beadle	Wesley Hospital, Qld
Richard	Bell	Barwon Health Service, Vic
Jim	Bishop	Sydney Cancer Centre, NSW
David	Boadle	Department of Health and Human Services, Tas
Jill	Boehm	Jean Colvin Private Hospital, NSW
Heather	Boulden	Territory Health Services, NT
Frances	Boyle	Royal North Shore Hospital, NSW
Graeme	Brien	Queensland Cancer Fund
Heather	Buchan	National Institute of Clinical Studies, Vic
Melissa	Burton	ACT Health Housing and Community Care
Robert	Burton	The Cancer Council Victoria
Michael	Byrne	Sir Charles Gairdner Hospital, WA
Geoff	Carse	Queensland Health
Jonathon	Carter	Sydney Cancer Centre, NSW

Con	Casey	Prostate Cancer Foundation of Australia, NSW
Dermot	Casey	Mental Health and Special Programs Branch, Dept Health and Ageing, ACT
Jenny	Cleary	Department of Health and Community Services
Gordon	Clunie	The Cancer Council Victoria
Alan	Coates	The Cancer Council Australia, NSW
Jill	Cockburn	University of Newcastle, NSW
Ian	Cole	The Australian Society of Oto-laryngology Head and Neck Surgery, NSW
Peta	Colebatch	The Cancer Council New South Wales
Noellene	Coutts	Palliative Care Services, Territory Health Services, NT
Sally	Crossing	Cancer Voices NSW and Breast Care Action Group NSW
Jane	Cruikshank	Cancer Voices NSW
Margaret	Culbong	National Aboriginal Community Controlled Health Organisations representative, Cancer Strategies Group
David	Currow	Department of Palliative & Supportive Services, Flinders University, SA
Robert	Cusack	Calvary Health Care, ACT
Clive	Deverall	Consumer Health Forum, WA
Margaret	Duckett	The Cancer Council New South Wales
Kerry	Dunbabin	Tasmanian Department of Health and Human Services
Rita	Evans	Mental Health and Special Programs Branch, Commonwealth, ACT
Patricia	Fagan	Office for Aboriginal and Torres Strait Islander Health, Department of Health and Ageing, ACT
Peta	Firns	Cancer Foundation of Western Australia
Susan	Fitzpatrick	The Cancer Council Victoria
Paul	Flemming	Royal Australian College of General Practitioners, Vic
Max	Gardner	Cancer Voices, NSW
David	Goldstein	Department of Medical Oncology, Prince of Wales Hospital, NSW
Stan	Goldstein	Australian Health Insurance Association, ACT
Julienne	Grace	Royal College of Pathologists of Australasia, Vic
Debra	Graves	Royal College of Pathologists of Australasia, NSW
Robert	Griffin	Calvary Health Care, ACT
Chris	Hamilton	Mater Hospital, NSW
Paul	Harnett	Westmead Hospital, NSW
Paula	Henriksen	Department of Health and Ageing, ACT
David	Hill	The Cancer Council Victoria
Elspeth	Humphries	Breast Cancer Network Australia, ACT
Denise	Hynes	OvCa Australia, Vic
Gael	Jennings	The Cancer Council Australia, NSW
Greg	Jones	Queensland Health
Alina	Katauskas	Department of Health and Ageing, ACT
Paul	Katris	WA Cooperative Oncology Group
Jennifer	Kavka	The Cancer Council ACT
Liz	Kenny	President, COSA
Ellen	Kerrins	The Cancer Council South Australia
David	Kissane	Centre for Palliative Care, The University of Melbourne, Vic
Rosemary	Knight	Department of Health and Ageing, ACT
Vanessa	Lambert	Consumer representative, SA
Jacqueline	Landells	Cancer Foundation of Western Australia

Brian	Lloyd	Department of Health, WA
Ray	Lowenthal	President, The Cancer Council Australia and Royal Hobart Hospital, Tas
Judith	Maher	Breast Cancer Network Australia, ACT
Carmel	Martin	Australian Medical Association, ACT
Kae	Martin	SA Dept Human Services
Brian	McCarthy	The Cancer Council Northern Territory
Finlay	McCrae	Royal Melbourne Hospital, Vic
Russell	McGowan	Cancer Advocacy Network, ACT
Karen	Menzies	Public Health Officer, NSW Health
Susan	Murray	National Breast Cancer Foundation, NSW
Ellen	Nightingale	President, Palliative Care Australia, ACT
Margaret	Norrington	Office for Aboriginal and Torres Strait Islander Health, Department of Health and Ageing, ACT
Len	Notaras	Royal Darwin Hospital, NT
Michael	O'Neill	Prostate Cancer Foundation of Australia, NSW
Ian	Olver	Royal Adelaide Hospital, SA
Anne	Pardon	The Cancer Council Northern Territory
Gil	Paulsen	Breast Cancer Network Australia, Vic
Marjorie	Pawsey	Australian Council on Healthcare Standards, NSW
Karen	Pedersen	National Cancer Control Initiative, Vic
Andrew	Penman	The Cancer Council New South Wales
Nathan	Pinsker	Royal Australian College Of General Practitioners, Vic
Susan	Poole	Deputy Director Pharmacy, Peter MacCallum Cancer Institute, Vic
Kathy	Rainbird	National Breast Cancer Centre, NSW
Maureen	Ramsden	The Cancer Council Tasmania
Peter	Ravenscroft	Palliative Care Unit, Mater Hospital, NSW
Rob	Rayner	Palliative Care Services, Territory Health Services, NT
Sally	Redman	National Breast Cancer Centre, NSW
Tom	Reeve	Australian Cancer Network, NSW
Michael	Rice	Director, Clinical Haematology/Oncology, Women's and Children's Hospital, SA
Lawson	Ride	The Cancer Council Tasmania
David	Roder	The Cancer Council South Australia
Alan	Rodger	Alfred Hospital, Vic
Michael	Roff	Australian Private Hospitals Association, ACT
Susan	Rooney	Cancer Foundation of Western Australia
Alison	Ross	Mental Health and Special Programs Branch, Department of Health and Ageing, ACT
Joel	Rousetty	Mental Health and Special Programs Branch, Department of Health and Ageing, ACT
Russell	Schneider	Australian Health Insurance Association, ACT
David	Scott	Royal Australasian College of Surgeons, Vic
Sid	Selva	Royal Darwin Hospital, NT
Harry	Sheiner	WA Cooperative Oncology Group
Alan	Singh	Commonwealth Department of Health and Ageing, ACT
Andrew	Sizeland	Royal Victorian Eye and Ear Hospital
Andrew	Skeels	Calvary Health Care, ACT
Terry	Slevin	Cancer Foundation of Western Australia

David	Smith	The Cancer Council New South Wales
Isabella	Smith	NSW Department of Health
Ray	Snyder	St Vincent's Hospital, Vic
Allan	Spigelman	Hunter Area Health Service, NSW
James	St John	National Cancer Control Initiative, Vic
Onella	Stagoll	BreastCare Victoria
Susanne	Steginga	Queensland Cancer Fund
Margaret	Stevens	Office of Cancer Planning, WA Dept of Health
Janelle	Stirling	Queensland Institute of Medical Research
Noelene	Swanson	Territory Health Services, NT
Lyn	Swinburne	Breast Cancer Network Australia, Vic
Martin	Tattersall	Department of Cancer Medicine, University of Sydney, NSW
Robert	Thomas	Surgical Oncologist, Peter MacCallum Cancer Institute, Vic
Norman	Thompson	Prostate Cancer Foundation of Australia, NSW
Jane	Turner	University of Queensland, Qld
Patricia	Valerie	Queensland Institute of Medical Research
Guy	VanHazel	Mount Hospital, WA
Rob	Walters	The Cancer Council Tasmania
Anna	Wellings Booth	Breast Cancer Network Australia, ACT
Lawrie	Wright	The Cancer Council Australia, NSW
Patsy	Yates	Oncology Nurses Group, COSA
John	Zalcborg	Peter MacCallum Cancer Institute, Vic

Background and terms of reference to Oceania Health Consulting, November 2001

Introduction

The Cancer Council Australia (TCCA) in collaboration with COSA and the NCCI, seeks to commission a report that outlines key priorities for improvement in cancer care in Australia for consideration by the Minister for Health and Ageing. It is to identify systematic problems, barriers and failings of the current system of cancer care in Australia, with particular emphasis on those that lie within the control or influence of the Minister for Health and Ageing. The report will focus on a small number (three to six) key priorities, and be based on consultations with key organisations and individuals in the field of cancer care. The project will be carried out by an independent consultant with knowledge and experience in the field of cancer. Oversight of the project will be provided by a Project Management Group consisting of the Chairs of the Medical and Scientific and Patient Support Committees of TCCA, and an NCCI staff member who will chair the group.

Goal

The goal of this project is to produce an outline of *Optimising Cancer Care in Australia* that addresses a small number of key issues (problems, barriers and failures) in cancer care in Australia. This will be provided to the Minister for Health and Ageing early in her tenure, to provide a basis for policy development in relation to the delivery of cancer care.

Background

There is a strong conviction held by members of the auspicing committees (representing a broad constituency of health care professionals and consumer representatives) that the current model(s) for health services delivery of cancer care in Australia could be substantially improved. Further, it is held

that such improvements in the cancer care pathway would lead to better access to quality care and ultimately ensure better outcomes for Australians with cancer.

The public health care policy of Australia is founded on the principles of access, equity and quality. Through the Commonwealth Medicare system and the state-run public hospitals it succeeds in many ways in providing a satisfactory basic level of health care to the Australian populace. There are, however, deficiencies and inefficiencies in the system, such as inequitable distribution of resources and inadequate coordination of care and inappropriate targeting, which adversely affect the quality of care and support available to cancer patients.

Scope and methodology

The project will have the terms of reference set out below. The report will address pertinent issues to provide a framework and recommendations for policy development. It is not within the scope of the project to develop policy. After the initial consultations and review of documentary material by the consultant, the Project Management Group and NCCI staff (and other invitees if appropriate) will meet with the consultant to identify the most significant (three to six) items identified as barriers to quality care. These will be chosen on the basis that correction of them would make a real difference and that the Commonwealth Government could mediate the corrective action. Recommendations to the minister will focus on these items.

Terms of reference

- 1 Based on consultations with key informants in each jurisdiction and review of available publications and other information:
 - identify the current arrangements for cancer detection, treatment, palliative care and psychosocial support services that exist in each state and territory, and outline any significant changes to the existing arrangements that are proposed
 - outline the reported gaps in the quantity and quality of services that are being experienced by cancer patients and their carers/families.
- 2 Discuss the initial findings with the Project Management Group and others as required and identify those issues the group believes are the key priorities for further consideration, that is, those that would 'make a difference' and that are potentially affordable.
- 3 Fully analyse the reported systematic problems, failures and barriers, and their causes for the identified priority items.
- 4 Draft a report on *Optimising Cancer Care in Australia* that outlines key changes to the delivery of cancer care.
- 5 Circulate draft document to those consulted and other stakeholders for comment.
- 6 Prepare final document in the light of the comments.

The consultant will review documentary material available relevant to the terms of reference and solicit input from representative groups. These include Commonwealth and state health agencies, state and territory cancer councils, private and public health care providers and their peak agencies, NCCI, NBCC, CSG, committees of learned colleges and professional societies and consumer organisations.

Management

The project will be funded by NCCI and managed by TCCA. The project is to be completed by 28 March 2002.

APPENDIX 2 Further information on why cancer care is a key health issue

Prepared by Brian Wall, Oceania Health Consulting (May 2002)

Most major causes of mortality are rapidly declining, cancer is not

Cardiovascular disease, injury and cancer account for 72% of the total mortality burden. In the cases of cardiovascular disease and injury (except self-inflicted injury), the mortality burden is falling significantly (Mathers, Vos & Stevenson 1999), whereas in the case of cancer, the decline is much slower. Table 3 provides data on changes in the mortality burden for the top five causes in each sex.

Table 3 *The five causes of the burden in mortality that showed the largest decreases in Australia, 1981–96*

		Change				Change	
Males		YLL/ 1000*	%	Females		YLL/ 1000	%
1	Ischaemic heart disease	-12.2	-41	1	Ischaemic heart disease	-6.0	-32
2	Road traffic accidents	-4.3	-54	2	Stroke	-3.3	-35
3	Stroke	-2.5	-36	3	Road traffic accidents	-1.4	-50
4	Lung cancer	-1.1	-15	4	SIDS	-0.4	-57
5	SIDS	-0.7	-63	5	Inflammatory heart disease	-0.3	-28

YLL/1000* = years of life lost per 1000 population (a measure of premature death)
Source: Mathers, Vos & Stevenson 1999 (portion of original reproduced here)

Even the single cancer success in the above table is offset by an additional one YLL/1000 for female lung cancer, a 62% increase in mortality. Stomach cancer has shown a substantial decline but others (for example, colon and breast) have offset any gains in YLL. With some exceptions (such as children's cancer) cancer remains an intractable source of premature death whereas, as the above data show, other major causes are declining.

Cancer is the commonest cause of years of life lost in adults 25–64 years

In people aged twenty-five to sixty-four years (what might be regarded as the prime of life and the most economically important years), 'all cancers' is the largest source of disease burden, accounting for 20% of the total (measured in Disability Adjusted Life Years or DALYs). Although cardiovascular disease (heart disease and cerebrovascular disease (stroke) combined) takes over from sixty-five years on (see Table 4) cancer remains a major cause of disability in those years as well. Cancer is bigger than either heart disease or stroke as a cause of death until over eighty-five years.

Cancer affects a substantial proportion of the population

Excluding non-melanocytic skin cancers, there were 80,864 new cancer cases and 34,270 deaths due to cancer in Australia in 1998 (AIHW 2001). At the incidence rates prevailing in 1998, one in three men and one in four women would be directly affected by cancer by the time they reach seventy-five years. An estimated 260,000 potential years of life would be lost to the community each year as a result of people dying of cancer before that age. Cancer currently accounts for 29% of male deaths and 25% of female deaths (AIHW 2001). The aged-standardised mortality rate from cancer is falling slowly, although in absolute terms mortality is increasing as the Australian population increases and gets older. Major causes of death in 2000 are set out in Table 5.

Table 4 Main causes of disease burden (DALYs) in adults aged 25–64 and 65+ years, Australia 1996

Disease	Aged 25–64 (%)	Aged 65+ (%)
Cancers	20	24
Cardiovascular disease	15	37
Mental disorders	17	–
Injuries	13	–
Nervous system disorders	6	15
Chronic respiratory disease	6	7
Musculoskeletal disorders	6	3
Diabetes mellitus	4	4
Other	13	12

Note: figures in 65+ category total 102 in source document
Source: Mathers, Vos & Stevenson 1999 (data presented in original as pie chart)

Table 5 Causes of death 2000

Age group	Causes of death	Males	Females	Persons	%
Under 1 year	All causes	725	565	1290	100
1–14 years	Malignant neoplasms	54	46	100	16
	Diseases of the nervous system	39	26	65	10
	Congenital malformations, deformations and chromosomal abnormalities	24	30	54	8
†	External causes of morbidity and mortality	191	94	285	44
	All other causes	69	68	137	21
	Total	377	264	641	99
15–24 years	Malignant neoplasms	64	54	118	7
	Mental and behavioural disorders due to psychoactive substance use	86	28	114	7
	Diseases of the nervous system	54	14	68	4
†	External causes of morbidity and mortality	874	284	1158	70
	All other causes	123	83	206	12
	Total	1201	463	1664	100

25–34 years	Malignant neoplasms	130	132	262	10
	Mental and behavioural disorders due to psychoactive substance use	159	42	201	8
‡	Diseases of the circulatory system	125	68	193	8
	Diseases of the digestive system	16	14	30	1
†	External causes of morbidity and mortality	1 217	304	1521	60
	All other causes	205	138	343	13
Total		1852	698	2550	100
35–44 years	Malignant neoplasms	405	533	938	25
	Mental and behavioural disorders due to psychoactive substance abuse	164	39	203	5
‡	Diseases of the circulatory system	439	173	612	16
	Diseases of the digestive system	79	40	119	3
†	External causes of morbidity and mortality	14	328	1342	36
	All other causes	1358	195	553	15
Total		2459	1308	3767	100
45–54 years	Malignant neoplasms	1413	1423	2836	43
‡	Diseases of the circulatory system	1079	385	1464	22
	Diseases of the respiratory system	121	103	224	3
†	Disease of the digestive system	222	106	328	5
	External causes of morbidity and mortality	676	207	883	13
	All other cases	525	320	845	13
Total		4036	2544	6580	99
55–64 years	Malignant neoplasms	3210	2281	5491	49
‡	Diseases of the circulatory system	2103	809	2912	26
	Diseases of the respiratory system	410	280	690	6
†	Diseases of the digestive system	312	127	439	4
	External causes of morbidity and mortality	391	178	569	5
	All other causes	711	493	1204	11
Total		7137	4168	11305	101
65–74 years	Malignant neoplasms	6213	3720	9933	41
	Endocrine, nutritional and metabolic diseases	581	408	989	4
‡	Diseases of the nervous system	299	260	559	2
	Diseases of the circulatory system	5139	2808	7947	33
	Diseases of the respiratory system	1330	828	2158	9
	Diseases of the digestive system	453	264	717	3
	All other causes	1027	790	1817	8
Total		15042	9078	24120	100

75–84 years	Malignant neoplasms	6335	4589	10924	27
	Endocrine, nutritional and metabolic diseases	667	664	1331	3
	Diseases of the nervous system	697	645	1342	3
‡	Diseases of the circulatory system	8734	8499	17233	43
	Diseases of the respiratory system	2338	1586	3924	10
	Diseases of the digestive system	575	670	1245	3
†	Diseases of the genitourinary system	538	533	1071	3
	External causes of morbidity and mortality	414	364	778	2
	All other causes	963	1170	2133	5
Total		21261	18720	39981	99
85 years and over	Malignant neoplasms	2326	2694	5020	14
	Endocrine, nutritional and metabolic diseases	368	635	1003	3
	Diseases of the nervous system	357	969	1326	4
‡	Diseases of the circulatory system	6087	13159	19246	53
	Diseases of the respiratory system	1608	2095	3703	10
	Diseases of the digestive system	396	854	1250	3
†	Diseases of the genitourinary system	430	729	1159	3
	External causes of morbidity and mortality	340	582	922	3
	All other causes	797	1947	2744	8
Total		12709	23664	36373	101
All ages	Malignant neoplasms	20153	15475	35628	28
	Endocrine, nutritional and metabolic diseases	2141	2016	4157	3
	Diseases of the nervous system	1839	2200	4039	3
‡	Diseases of the circulatory system	23756	25931	49687	39
	Diseases of the respiratory system	5923	4984	10907	9
	Diseases of the digestive system	2063	2078	4141	3
†	Diseases of the genitourinary system	1186	1506	2692	2
	External causes of morbidity and mortality	5517	2581	8098	6
	All other causes	4239	4703	8942	7
Total – all causes		66817	61474	128291	100

† Includes accidents and suicide

‡ Includes heart disease and stroke

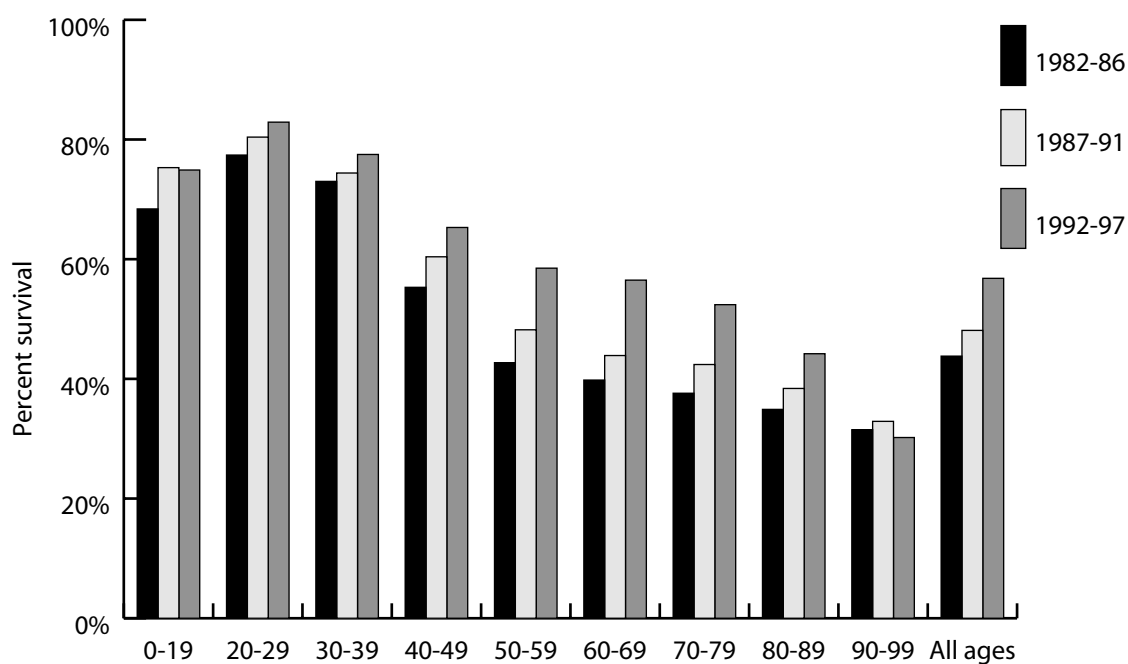
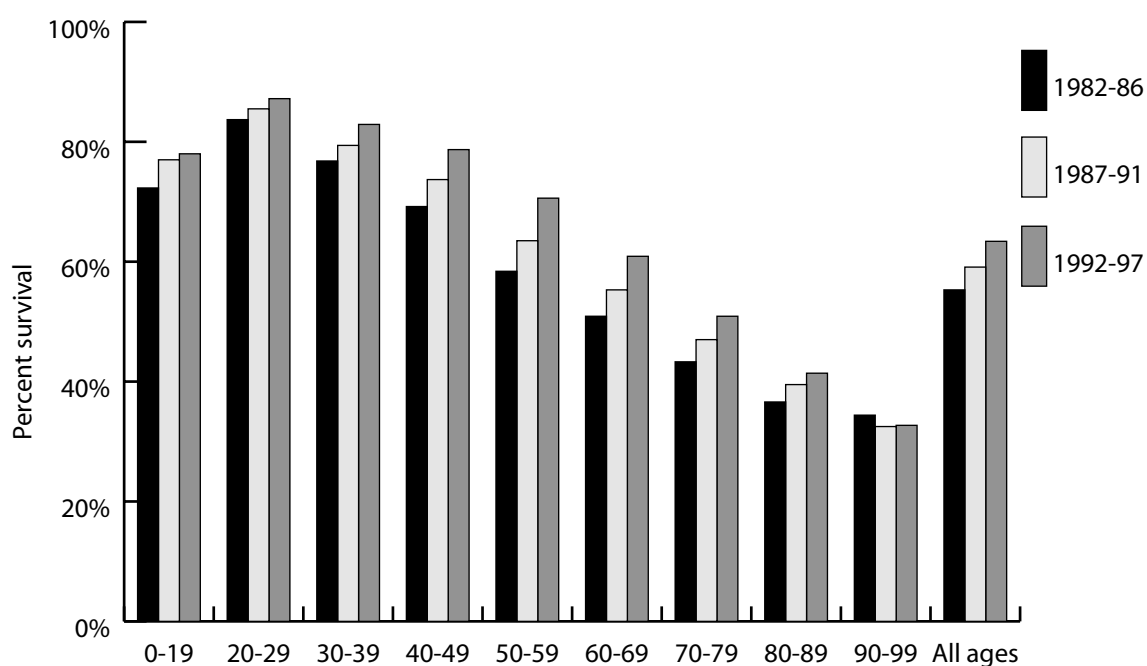
Source: ABS 2001

Survival is improving – but slowly

Figure 4 shows the percent survival at five years for all cancers in the Australian population (males and females separately). As can be seen, there is consistent improvement over the three time periods 1982–86, 1987–91 and 1992–97. Further information can be obtained in the recently published Australian survival report (AIHW & AACR 2001).



Figure 4 A time series of relative survival for cancer in Australia: percent survival at five years by sex

Males**Females**

Source: AIHW & AACR 2001

APPENDIX 3 Australian Clinical Management Surveys in Cancer

Prepared by Karen Pedersen & Mark Elwood, National Cancer Control Initiative (December 2002)

The following is a list of Australian surveys of the clinical management of cancer. The list was compiled by the NCCI. It contains information on management surveys that we were able to identify that have been published, are ongoing or are planned. Our focus has been on identifying clinical management surveys in cancer that have a population base (either national or statewide); in particular, surveys based on population registry data were sought.

The NCCI would like to keep this list as comprehensive and as up to date as possible. Information on any additional Australian clinical management surveys in cancer or amendments to the information contained in this list are welcome. Further information and/or amendments can be sent to Dr Karen Pedersen at the NCCI via email at Karen.Pedersen@ncci.org.au

Published

Advanced cancer

(New South Wales)

- Breen S, Girgis A, O'Connell D, Armstrong B. *Feasibility Study of the Patterns and Outcomes of Care for Advanced Cancer in NSW*. Sydney: The Cancer Council NSW/University of Newcastle, 2001. www.health.gov.au/pq/cancer/pdf/patterns.pdf

Breast

(National)

- Craft PS, Primrose JG, Lindner JA, McManus PR. Surgical management of breast cancer in Australian women in 1993: analysis of Medicare statistics. *Medical Journal of Australia* 1997; 166(12):626–29. http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=9216581&dopt=Abstract
- Hill D, Jamrozik K, White V, Collins J, Boyages J, Shugg D, Pruden M, Giles G, Byrne M. *Surgical Management of Breast Cancer in Australia in 1995*. Sydney: NHMRC National Breast Cancer Centre, 1999. <http://www.nbcc.org.au/pages/info/resource/nbccpubs/surgmgmt/contents.htm>

(New South Wales)

- Adelson P, Lim K, Churches T, Nguyen R. Surgical treatment of breast cancer in New South Wales 1991, 1992. *Australian and New Zealand Journal of Surgery* 1997; 67(1):9–14. http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=9033369&dopt=Abstract
- The Western Areas Breast Group. *Breast Cancer Patterns of Care in the Greater Western Region of Sydney in 1992*, a NSW Health Outcomes Program project. Sydney: NSW Breast Cancer Institute, 1997.
- Kricker A, Haskill J, Armstrong BK. Breast conservation, mastectomy and axillary surgery in New South Wales women in 1992 and 1995. *British Journal of Cancer*, 2001; 85(5):668–73. http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=11531249&dopt=Abstract

(Victoria)

- Hill DJ, Giles GG, Russell IS, Collins JP, Mapperson KJ. Management of primary, operable breast cancer in Victoria. *Medical Journal of Australia* 1990; 152(2):67–72. http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=2296233&dopt=Abstract
- Hill DJ, White VM, Giles GG, Collins JP, Kitchen PR. Changes in the investigation and management of primary operable breast cancer in Victoria. *Medical Journal of Australia* 1994; 161(2):110–11, 114, 118. http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=8028535&dopt=Abstract
- Hill D, White V, Pruden M, Giles G, Collins J. *Surgical Management of Breast Cancer in Victoria in 1995*. Melbourne: BreastCare Victoria, Victorian Department of Human Services and Anti-Cancer Council of Victoria, 2000.
- Giles G, Russell I, Reed R, Marr G, Kavanagh A. In situ and small invasive breast cancer register in Victoria, 1988 to 1992: tumour characteristics and patient management. *Australian and New Zealand Journal of Surgery* 2001; 71(5):266–70. http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=11350377&dopt=Abstract

(Western Australia)

- Jamrozik K, Byrne MJ, Fitzgerald C, Parsons RW, Dewar JM, Harvey JM, Sterrett GF, Ingram DM, Sheiner HJ. Breast cancer in Western Australia in 1989. I. Presentation. *Australian and New Zealand Journal of Surgery* 1993; 63(8):617–23. http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=8338481&dopt=Abstract
- Byrne MJ, Jamrozik K, Parsons RW, Fitzgerald CJ, Dewar JM, Harvey JM, Sterrett GF, Ingram DM, Sheiner HJ, Cameron FG et al. Breast cancer in Western Australia in 1989. II. Diagnosis and primary management. *Australian and New Zealand Journal of Surgery* 1993; 63(8):624–9. http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=8338482&dopt=Abstract
- Sterrett G, Harvey J, Parsons RW, Byrne MJ, Jamrozik K, Fitzgerald CJ, Dewar JM, Ingram DM, Sheiner H, Cameron F, Cassidy B. Breast cancer in Western Australia in 1989. III. Accuracy of FNA cytology in diagnosis. *Australian and New Zealand Journal of Surgery* 1994; 64(11):745–9. http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=7945080&dopt=Abstract
- Harvey JM, Sterrett GF, Parsons RW, Fitzgerald CJ, Jamrozik K, Dewar JM, Byrne MJ, Ingram DM, Sheiner HJ. Breast cancer in WA in 1989. IV. Summary of histopathological assessment in 655 cases. *Pathology* 1995; 27(1):12–17. http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=7603745&dopt=Abstract
- Stevenson JM, Bochenek P, Jamrozik K, Parsons RW, Byrne MJ. Breast cancer in Western Australia in 1989. V. Outcome at five years after diagnosis. *Australian and New Zealand Journal of Surgery* 1997; 67(5):250–5. http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=9152153&dopt=Abstract
- Jamrozik K, Byrne MJ, Dewar JM, Harvey JM, Ingram DM, Parson RW, Watson N. The effect of mammographic screening in invasive breast cancer in Western Australia. *Medical Journal of Australia* 2000; 172(5):203–6. http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=10776390&dopt=Abstract

Colorectal

(National)

- Clinical Governance Unit 2002: *The National Colorectal Cancer Care Survey*. Australian clinical practice in 2000. The National Cancer Control Initiative, Melbourne, 1–124. http://www.ncci.org.au/pdf/Colorectal_care_survey.pdf

(Victoria)

- McLeish JA, Giles GG, Thursfield V. Investigation, follow-up and recurrence after resection of colorectal cancer. *Australian and New Zealand Journal of Surgery* 1992; 62(12):931–40. http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=1333762&dopt=Abstract
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(Western Australia)

- Semmens JB, Platell C, Threlfall TJ, Holman CD. A population-based study of the incidence, mortality and outcomes in patients following surgery for colorectal cancer in Western Australia. *Australian and New Zealand Journal of Surgery* 2000; 70(1):11–18. http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=10696936&dopt=Abstract

Lung

(Victoria)

- Richardson GE, Thursfield VJ, Giles GG. Reported management of lung cancer in Victoria in 1993: comparison with best practice. Anti-Cancer Council of Victoria Lung Cancer Study Group. *Medical Journal of Australia* 2000; 172(7):321–4. http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=10844918&dopt=Abstract

Prostate

(New South Wales)

- McCredie M, Bell J, Lee A, Rogers J. Differences in patterns of care of prostate cancer, New South Wales, 1991. *Australian and New Zealand Journal of Surgery* 1996; 66(11):727–30. http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=8918377&dopt=Abstract

(Victoria)

- Frydenberg M, Giles GG, Mameghani H, Thursfield VJ, Millar J, Wheelahan JB, Bolton DM, Syme RR. Prostate cancer in Victoria in 1993: patterns of reported management. *Medical Journal of Australia* 2000; 172(6):270–4. http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=10860092&dopt=Abstract

Radiotherapy

(National)

- Wigg DR, Morgan GW. Radiation oncology in Australia: workforce, workloads and equipment 1986–1999. *Australasian Radiology* 2001; 45(2):146–69. http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=11380358&dopt=Abstract

Testis

(Victoria)

- Toner GC, Neerhut GJ, Schwarz MA, Thursfield VJ, Sandeman TF, Giles GG, Snow RM. The management of testicular cancer in Victoria, 1988–1993. Urology Study Committee of the Victorian Co-operative Oncology Group. *Medical Journal of Australia* 2001; 174(7):328–31. http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=11346104&dopt=Abstract

Terminal care

(South Australia)

- Hunt R, Bonett A, Roder D. Trends in the terminal care of cancer patients: South Australia, 1981–1990. *Australian and New Zealand Journal of Medicine* 1993; 23(3):245–51. http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=7688953&dopt=Abstract

Submitted

Breast

(Victoria)

- Shugg D, White V, Kitchen P, Pruden M, Collins J, Hill D. The surgical management of DCIS in Australia in 1995. *Australian and New Zealand Journal of Surgery* (submitted).

Ovary

- The Cancer Council Victoria, Victorian Cancer Registry and the Victorian Cooperative Oncology Group (Victoria)

Ongoing/to be completed

Bladder

- Superficial and Invasive (The Cancer Council Victoria, Victorian Cancer Registry and the Victorian Cooperative Oncology Group) (Victoria)

Breast

- Trends in the Management of Key Cancers in Western Australia (Department of Public Health, University of Western Australia) (Western Australia)

Colorectal

- NSW Colorectal Cancer Study (NSW Cancer Registry) (New South Wales)
- South Western Sydney Area Health Service, Colorectal Group (New South Wales)
- Western Sydney Area Health Service (CCORE) (New South Wales)
- Trends in the Management of Key Cancers in Western Australia (Department of Public Health, University of Western Australia) (Western Australia)

Lung

- The Cancer Council NSW (New South Wales)
- Hunter Area Health Service (Department of Epidemiology and Medicine, John Hunter Hospital) (New South Wales)
- Northern Sydney Area Health Service (CCORE) (New South Wales)
- South Western Sydney Area Health Service (CCORE) (New South Wales)
- Trends in the Management of Key Cancers in Western Australia (Department of Public Health, UWA) (Western Australia)

Lymphoma

- NSW Cancer Registry (New South Wales)

Ovary

- The Cancer Council NSW (New South Wales)

Prostate

- NSW Cancer Registry (New South Wales)
- The Clinical Management of Prostate Cancer in Western Australia 1992 & 1997 (Department of Public Health, UWA) (Western Australia)

Skin

- Melanoma (The Cancer Council Victoria, Victorian Cancer Registry and the Victorian Cooperative Oncology Group) (Victoria)

Thyroid

- The Cancer Council NSW (New South Wales)

To commence (2002)

Breast

- Survey as part of the NBCC *Doorways to Quality Care* project: will identify referral patterns for radiotherapy. (National Breast Cancer Centre) (National)

Head & Neck

- Larynx, Oropharynx, Tongue (The Cancer Council Victoria, Victorian Cancer Registry and the Victorian Cooperative Oncology Group) (Victoria)

Brain

- Glioma (The Cancer Council Victoria, Victorian Cancer Registry and the Victorian Cooperative Oncology Group) (Victoria)

APPENDIX 4 Current consumer issues

Prepared by Cancer Voices NSW (March 2002)

The issues below were developed over the last twelve months by Cancer Voices NSW, a coalition of cancer groups which advocates on behalf of its members at state level. We seek their feedback on the priority of issues, and on any updates or additions, through our quarterly newsletter. We also seek to help in establishing cancer consumer groups for specific types of cancer where none presently exist, and to represent their needs accurately.

- Greater access to best practice cancer care, focused on patient needs, for all patients, wherever located.
- Better availability of information of the sort needed, when it is wanted and for all stages of cancer.
- Support groups to be recognised as having an important role in assisting many patients in dealing with treatment and psychosocial factors.
- Cancer consumers to participate at all levels of decision making in relation to their disease, in the areas of treatment, research, support and care.
- Need for comprehensive cancer care centres, preferably offering multidisciplinary services from diagnosis to palliation.
- Accreditation system in cancer care for Area Health Service to ensure standards are met.
- Greater access to multidisciplinary and psychosocial care.
- Greater access to radiotherapy services.
- Provision of treatment or cancer care plans, including discharge plans for all patients.
- Addressing anomalies and inequities in PBS, Medicare, private health insurance, other insurance and work-related problems.
- Greater access to, and understanding of the value of, clinical trials.
- Identifying and addressing the needs of special groups: children, young people, rural people, carers, families and ethnic communities.
- A more equitable share of total health expenditure to be allocated to treatment and research for cancer: cancer is the leading cause of death for Australians (27%).
- Call for productive debate about the challenge of access to new, high-cost, targeted therapies.

APPENDIX 5

Recommendations from the recent US and Canadian reports on cancer care

Summarised by Brian Wall, Oceania Health Consulting (May 2002) from Ensuring Quality Cancer Care (IOM 1999) and Canadian Strategy for Cancer Control (CSCC 2002)

1 US IOM Recommendations from Ensuring Quality Cancer Care

Recommendation 1: Ensure that patients undergoing procedures that are technically difficult to perform and have been associated with higher mortality in lower-volume settings receive care at facilities with extensive experience (that is, high-volume facilities). Examples of such procedures include removal of all or part of the esophagus, surgery for pancreatic cancer, removal of pelvic organs, and complex chemotherapy regimens.

Recommendation 2: Use systematically developed guidelines based on the best available evidence for prevention, diagnosis, treatment, and palliative care.

Recommendation 3: Measure and monitor the quality of care using a core set of quality measures. Cancer care quality should:

- span the continuum of cancer care and be developed through a coordinated public–private effort
- be used to hold providers, including health care systems, health plans and physicians, accountable for demonstrating that they provide and improve quality of care
- be applied to care provided through the Medicare and Medicaid programs as a requirement of participation in these programs, and
- be disseminated widely and communicated to purchasers, providers, consumer organizations, individuals with cancer, policy makers, and health services researchers, in a form that is relevant and useful for health care decision making.

Recommendation 4: Ensure the following elements of quality care for each individual with cancer:

- that recommendations about initial cancer management, which are critical in determining long-term outcome, are made by experienced professionals
- an agreed-upon care plan that outlines goals of care
- access to the full complement of resources necessary to implement the care plan
- access to high-quality clinical trials
- policies to ensure full disclosure of information about appropriate treatment options

- a mechanism to coordinate services
- psychosocial support services and compassionate care.

Recommendation 5: Ensure quality of care at the end of life, in particular, the management of cancer-related pain and timely referral to palliative and hospice care.

How can we improve what we know about the quality of cancer care?

The following recommendations relate to information needs:

Recommendation 6: Federal and private research sponsors such as the National Cancer Institute, the Agency for Health Care Policy and Research, and various health plans should invest in clinical trials to address questions about cancer care management.

Recommendation 7: A cancer data system is needed that can provide quality benchmarks for use by systems of care (such as hospitals, provider groups, and managed care systems).

Recommendation 8: Public and private sponsors of cancer care research should support national studies of recently diagnosed individuals with cancer, using information sources with sufficient detail to assess patterns of cancer care and factors associated with the receipt of good care. Research sponsors should also support training for cancer care providers interested in health services research.

What steps can be taken to overcome barriers of access to quality cancer care?

The following recommendations are concerned with access to quality care:

Recommendation 9: Services for the un- and under-insured need to be enhanced to ensure entry to, and equitable treatment within, the cancer care system.

Recommendation 10: Studies are needed to find out why specific segments of the population (for example, members of certain racial or ethnic groups and older patients) do not receive appropriate cancer care. These studies should measure provider and individual knowledge, attitudes and beliefs, as well as other potential barriers to access to care.

For further information see <http://books.nap.edu/books/0309064805/html/212.html>

2 Canadian Strategy for Cancer Control – Recommendations from the Treatment Working Group

Measures of disease-related outcomes and quality of life have established that patients with cancer are most optimally managed within systems of care that are inter-disciplinary, integrated across the continuum of care, meet defined standards of performance and quality, and relate processes of care to continuous monitoring of outcomes.

Recommendation – Priority 1

That a National Council be established to coordinate common, discipline-specific activities/projects across Canadian provinces. These activities would include:

- Surgical oncology
 - clinical practice guideline and intervention-specific guideline development
 - process and outcome measures for surgical oncology procedures and practice.

- Radiation oncology
 - needs-based population planning templates for radiation services
 - clinical practice guideline and intervention-specific guideline development
 - measures of capacity, process and utilization of radiation services
 - standards for equipment utility and obsolescence
 - new technology assessment and introduction
 - referral centres for high technology, limited application procedures.
- Systemic therapy
 - establishment of an electronic, web-based National Cancer Information Network
 - systemic therapy guidelines and policies development
 - web access to chemotherapy protocols, patient management tools, decision aids, and patient, professional and public education documents
 - linkage to clinical trials protocol inventory(ies)
 - establishment of confidential, electronic network for accredited health care providers to access provincial guidelines and new drug resource analyses which are under development and not yet approved for implementation
 - development of funding models for the resource impact of new drug programs.

Recommendation – Priority 2

That clinical trials research be expanded, with a target of a doubling of the current activity by 2002/03 through:

- The creation of a National Clinical Trials Bureau with the mandate to promote access to clinical trials inventories and information; to simplify and expedite trials development, approval and activation; to facilitate and promote the interface with legislative and regulatory agencies; and to reconcile and 'stream-line' central and local trials activation processes and procedures, including standardized operating procedures. The National Bureau would establish the research and development agenda integral to the design, conduct, interpretation, adoption and dissemination of clinical trials results.
- Establishment of a Joint Liaison Committee between industry (Rx and D) and a National Clinical Trials Bureau to address issues inherent in 'market place' and academic endeavours, and position Canada as an attractive country in which to perform high-quality, efficient and effective clinical trials research.
- The development of a human resources strategy to develop, recruit and enhance the career development of clinical research associates. This issue should involve the collaboration of industry and the academic/health services sector.

Recommendation – Priority 3

That care provided to patients with cancer should meet and comply continuously with defined standards of integrated care. These standards include:

- linkage to a provincial cancer registry
- commitment of health records resources to minimal data set abstraction and registration
- best practice according to provincial/national guidelines

- conduct of interdisciplinary patient management conferences/tumour boards
- compliance with defined standards for surveillance and outcome reporting
- participation in local/provincial networks overseeing standards for symptom control, palliative and end-of-life management.

Recommendation – Priority 4

That the principles and practices of ‘patient focused care’ be a standard for organizations involved in the care of patients. Inherent within this standard would be:

- The development of care networks between cancer centres and community care providers identifying roles and responsibilities in treatment and follow-up of cancer patients.
- The optimization of communication between care providers through utilization of electronic records.
- The development of navigation aids/navigators to guide patients through the cancer care system.
- Patient access to Internet sites for dissemination of information, for example, educational materials, guidelines, protocols, clinical trials, CAM, etc.
- Respect for patients’ right to pursue complementary and alternative health care, and where pursued in conjunction with conventional care, to ensure cooperative management between patient and practitioners around principles of safety, information and knowledge, accurate records and evaluation.

Recommendation – Priority 5

That the initiatives of the Human Resource Working Group relating to manpower recruitment and retention across cancer control disciplines be strongly endorsed. For the creation of working environments consistent with recommendations of the Treatment Working Group, special attention will need to be given to:

- Surgical oncology: practice plan arrangements necessary to establish surgical oncologists within interdisciplinary teams with defined roles, commitment and responsibilities related to cancer control.
- Radiation oncology: the establishment of Chairs in Clinical Radiation Research to reorient the focus of the discipline from that of ‘clinical service only’ to one of opportunity for significant clinical and translational research potential across biological, practice and process, technology and health systems applications. Such appointments would establish academic affiliations, and provide career path support, mentorship and role modeling consistent with an academic discipline.
- All clinical disciplines – support for the development of Chairs in Clinical Oncology and academic infrastructures and relationships to provide for the expertise and curriculum development necessary to address health manpower professional expansion in the context of increasing incidence and prevalence of cancer and the increasing role of clinical and translational research as a basis for determination of evidence-based care.

For further information see <http://209.217.127.72/csccl/pdf/finaltreatmentJan2002.PDF>

APPENDIX 6 An outline of cancer services in Australia (workforce and infrastructure)

Prepared by Brian Wall, Oceania Health Consulting (May 2002), with reference to AMWAC (2001)

As has been indicated in the main body of the report, a number of gaps in workforce and physical infrastructure in Australia affect our ability to provide appropriate cancer care.

There are reports that outline these gaps for medical oncology, radiation oncology and palliative care. The main findings of each of these reports, insofar as they are relevant to this report, are outlined below.

In the area of surgery, there are no similar reports, that is, that assess the gaps in cancer surgery. Shortages and gaps in some areas are well known, for example, thoracic surgeons, but it is difficult to get an overall picture that is based on objective data. It is true to say that specialist oncology surgeons are rare in any organ-specific area, and only found at the largest cancer centres. Assessment of the current situation and future needs in surgical oncology appears to be a need in itself.

Medical and haematological oncology – AMWAC report

The AMWAC report (2001) describes the then current specialist medical and haematological oncology workforce, assesses the adequacy of that workforce, and projects workforce supply and requirements to 2011. It concludes that the supply of specialist medical and haematological oncologists is deficient, particularly in rural regional centres. Some deficiencies are also evident in some metropolitan locations.

Workforce shortages are particularly evident in Queensland, Western Australia, Tasmania and the Northern Territory. The AMWAC Working Party considered that the shortfall of medical and haematological oncologists was not less than forty.

Number of practising medical and haematological oncologists

- In 2000, there were approximately 338 medical and haematological oncologists in active practice in Australia (180 medical oncologists and 158 haematological oncologists).
- Seventy percent of clinical haematologists spend some 60% of their clinical work time in oncology practice.
- Medical and haematological oncology is a relatively small specialty, representing approximately 2% of all medical specialists. Over the last five years, the medical oncology workforce is estimated to have grown by 2.7% per annum, and the clinical haematological workforce by

0.5% per annum. Between 1995 and 2000, the per annum increase in the Australian population was 1.1%, with an above-average increase in Queensland (2.1%).

Medical and haematological oncologists to population

- In 2001, there were 1.4 medical and haematological oncologists per 100,000 population. By subspecialty, there were 0.9 medical oncologists per 100,000 persons and 0.5 FTE haematological oncologists.
- Relatively well-supplied states/territories, as indicated by population share, were New South Wales, Victoria, South Australia and the Australian Capital Territory.
- The Northern Territory, Queensland and Western Australia were relatively poorly supplied.

Recommendations

The Working Party recommended, inter alia:

- 'The Royal Australasian College of Physicians (RACP) should progressively increase the number of first year advanced trainees in medical oncology over the period 2002 to 2007, from 13 per year to between 15 and 18.
- 'The RACP and the Royal College of Pathologists of Australasia (RCPA) should progressively increase the number of first year advanced trainees in the Joint Specialist Advisory Committee (JSAC) in Haematology training program from 14 to between 17 and 20. This assumes that 75% of trainees will choose to practise in oncology.' (AMWAC 2001)

The aim is to match workforce supply with an expected future growth in medical and haematological oncology requirements, over the projection period (2001 to 2011), of 2.6% per annum.

- The Working Party identified a shortage of specialist medical and haematological oncologists in some states/territories. Addressing this problem may require the establishment of additional funded specialist positions in areas of acknowledged shortage. The Working Party recommends that these issues be considered by state/territory-based medical and haematological oncology working groups.
- The Working Party encourages the RACP, Medical Oncology Group of Australia (MOG) and Haematological Society of Australia and New Zealand, together with Commonwealth, State and Territory Governments, to further develop strategies to encourage improvement in the provision of medical and haematological oncology services to rural areas.

These recommendations are regarded as being, if anything, conservative, and even if the increases occurred, may still not fully meet demand. The shortfall of forty medical oncologists could be sixty to eighty. The AMWAC targets, however, provide at least a good start.

Regional distribution

There is a substantial imbalance between the percentage of population that live in capital cities and the percentage of oncologists that practise there. The gap in regional access to medical oncology has been outlined by MOG (2001) with models of care for each level of regional service. Some states have significant gaps in metropolitan services, which impact on the ability to provide outreach services. There are issues of supply, funding, infrastructure etc., all of which impact negatively on access to appropriate medical oncology services regionally. This gap particularly affects those who cannot readily travel to capital cities, for example, people running small businesses or Aboriginal people with cancer.

Radiation oncology

The most recent assessment of the gaps in radiation oncology services is by the National Radiation Oncology Strategic Plan Steering Committee. Its National Strategic Plan for Radiation Oncology (Australia) identifies the major problems as:

- Only 38% of patients diagnosed with cancer receive radiation where there is a published benchmark of 50–55%. In 2000, this represented ten thousand patients who could have benefited from treatment, but did not get radiotherapy.
- The radiation oncologist, radiation therapist and radiation physicist workforces are inadequate to meet the benchmark level of service provision, and there are high vacancy rates and increasing attrition for the latter two.
- Existing training programs are inadequate to meet present needs.
- Training programs in radiation oncology physics need to be more formally established and recognised.
- The equipment base is inadequate, ageing and underutilised, and specific replacement policies in the public sector are uncommon.
- There are significant variations in the technology sophistication of the linear accelerators in use, with particularly the older machines not having features designed to enhance safety, quality and efficiency of use.

Significant interstate variation in the distribution of linear accelerators was noted in the strategic plan, with only one state (Tasmania) having the 6.5 machines per million people that is required to reach the 50% benchmark. The machines in each state were summarised in a table, reproduced below:

Table 6 *Distribution of linear accelerators by state*

	Australia	NSW*	Vic	Qld	SA	WA	Tas
Population (millions)	19.16	6.77	4.77	3.57	1.50	1.88	0.47
Linear accelerators	99	37	24	17	9	8	4
Linear accelerators/million	5.17	5.46	5.04	4.77	6.01	4.25	8.50

*Believed to include the ACT
Source: NROSPSC 2001

Many machines were either not fully operational or not operational at all, mainly because of staff shortages.

As a result of the report, an Inquiry into Radiation Oncology commenced, under the Chairmanship of Professor Peter Baume.

Palliative care

The best data on the availability of palliative care services are provided by the report of a national census of palliative care performed in 1998 by Palliative Care Australia (PCA 1998). There are no benchmarks for palliative services levels as there are, for example, for radiation oncology or for the number of medical oncologists, so whether the service is effective has to be inferred, for example, from the number of cancer patients known to the service versus the number who die from cancer. The data do, however, give some indication of the level of infrastructure in each jurisdiction.

The services and programs identified in each state and territory in that census are set out in Table 7.

Table 7 *Programs provided by palliative care services 1998*

State and number of services		Type and number of programs				
State/territory	Service	Community	Inpatient	Consultative	Outpatient	Day
NSW/ACT	67	55	28	38	16	12
NT	5	4	3	1	0	0
Qld	25	17	16	10	7	3
SA	20	18	12	11	3	1
Tas	8	6	2	3	1	0
WA	22	13	17	5	2	2
Vic	40	33	13	17	6	0
Total	187	146	91	85	35	18

Source: PCA 1998

Nearly 80% of services provide some community-based program (except in WA where the Silver Chain provides an almost exclusive metropolitan coverage). Nearly half provide some level of hospice program, although the size varies widely, from large, stand-alone hospices, to a single bed in a local hospital with no regular palliative care staffing.

Program location (metropolitan or country) is summarised in Table 8. Outpatient clinics and day centres were rare except in metropolitan Sydney and regional Queensland. It is clear that the models of care differ significantly from state to state. The split of palliative care beds between metropolitan and rural/remote location, and by type of facility, is given in Table 9.

Table 8 *Location of major programs in each state/territory*

State	Metropolitan				Country			
	Service no.	Community	Inpatient	Consultancy	Service no.	Community	Inpatient	Consultancy
NSW/ ACT	30	22	12	17	37	34	16	20
NT	2	1	2	1	3	3	1	0
Qld	8	5	5	3	17	12	11	7
SA	8	7	3	2	12	11	9	9
Tas	4	2	1	1	4	4	1	2
WA	9	2	6	4	13	11	11	1
Vic	17	10	6	5	23	23	7	12
Total	78	49	35	33	109	98	56	51

Source: PCA 1998

Table 9 *Palliative care beds by type, jurisdiction and location*

State	Location	Stand alone hospice	Dedicated in AH	Dedicated in non-AH or NH	Non-dedicated in AH	Non-ded. in non-AH or NH	Total
NSW/ACT	M	131	49	93	0	0	273
	RR	0	52	18	8	0	78
NT	M	0	1	2	0	0	3
	RR	0	0	0	0	0	0
Qld	M	0	16	28	0	12	56
	RR	17	37	0	6	0	60
SA	M	16	10	12	4	0	42
	RR	0	14	0	3	0	17
Tas	M	0	0	0	0	0	0
	RR	0	0	0	0	0	0
WA	M	46	22	0	0	0	68
	RR	8	16	0	3	1	27*
Vic	M	8	41	0	0	0	49
	RR	0	24	0	4	0	28
Totals	M	201	139	135	4	12	491
	RR	25	143	18	24	1	211

*This figure is as given in the original

AH = acute hospital, NH = nursing home, M = metropolitan, RR = rural/regional

Source: PCA 1998

The 1998 PCA report also has data on access of both inpatient and community-based services, by age, compared to the deaths from cancer (by far the most common reason for palliative care access). The data (Table 10) show disproportionate access by persons under fifty-five years, with reduced access by persons over seventy-five years. While there may be many factors responsible for the trend, one hopes that it is not because some people are regarded as 'too old' to warrant referral.

Table 10 *Age distribution of palliative care patients – comparison with Australian cancer deaths (%)*

Sample	Males			Females		
	<55 yrs	55–74	75+	<55 yrs	55–74	75+
ABS cancer death 1996	10.9*	49.8	39.3	15.3#	41.6	43.1
Inpatients 1998	16.6	49.0	34.5	19.7	44.1	36.3
Community 1998	14.4	52.9	32.7	22.5	45.4	32.2
Palliative care deaths 97–98	13.6	51.8	34.6	14.1	48.2	37.7

*Percentage of all males in the sample # Percentage of all females in the sample

Source: PCA 1998

In summary, the resources allocated to palliative care were quite rigorously described in the 1998 census by PCA. What is missing are some standards against which these levels of service can be assessed. These benchmarks do not exist, in part because the models of palliative care are quite varied from place to place. Whether a more uniform model will evolve over time is not yet clear. If one model is clearly superior to others, it will no doubt become dominant, but if the differences in efficiency and effectiveness are marginal, the system may remain quite diverse.

APPENDIX 7 Problems with access to pharmaceuticals for the treatment of cancer

Prepared by Brian Wall, Oceania Health Consulting (May 2002)

Two hurdles have to be crossed before the Commonwealth makes available a pharmaceutical for subsidised use. First, the drug must be registered for that use in Australia under the Therapeutic Goods Act. Second, the drug must be listed for that indication on the PBS.

Sometimes states and territories or individual public hospitals refuse to make a drug available within the hospital(s), whether or not it is approved for use in Australia. That is a local rather than national issue and will be disregarded in this discussion.

Registration of the drug for a particular use, or otherwise obtaining supply within Australia

The Therapeutic Goods Act has several mechanisms that allow use of a drug in Australia, the main one (for drugs with indications for serious diseases) being registration under Division 2 of Part 3.

There are mechanisms that allow importation for use without registration (under Division 1, specifically Sections 18, 19 and 19A) but medicines so imported are not considered to be eligible for subsidy under the PBS.

There are many reasons a drug does not get registered for a particular use. They include:

- the manufacturer/sponsor of the drug does not apply for that use, or even for any use
- the TGA, on behalf of the Secretary, does not find the evidence sufficient to warrant registration for that use
- the sponsor withdraws the drug from the Register because the drug is no longer commercially viable
- or for any one of a number of other reasons.

Examples of problems with drugs, forms and strengths that are not registered in Australia

There is no power or requirement under any Act of Government to ensure that a drug of particular benefit is made available in the country, as is the case in New Zealand. Therefore, if a sponsor does not apply, the drug does not get approved. Of course, it is open to anyone who can get supplies of the drug to apply for marketing approval, but the process is lengthy and potentially expensive, even for a literature-based submission. The data package required is considerable, and the TGA has to fully cost-recover. Given the small size of the Australian market, this means that the fees to register a drug and maintain its registration are quite high for the size of the market.

Medicines manufactured in Australia for overseas use but not here

We have situations where, for example, the very high strength forms of leukovorin or fluorouracil are manufactured in Australia and exported for use in UK hospitals, but are not available to Australian hospitals because the sponsors do not bother to register them.

Lack of Australian registration for mainstream indications

An example of the problem of lack of registration for an indication accepted internationally is the use of cisplatin and etoposide for the treatment of germ cell (testicular) cancer. Australia has done the definitive clinical trial in the use of these drugs in this condition (Toner et al. 2001). The trial was stopped when an interim analysis found that overall survival was substantially better with one regimen than the other, although both used cisplatin and etoposide (and bleomycin), in differing doses, in accordance with the standard regimens in use at the time around the world. There were three and thirteen deaths in the two groups, due to deaths from cancer (one and nine), and not deaths from treatment (two and two). Regimen A of Toner et al. is now international best practice.

Etoposide is only registered for use in small cell carcinoma of the lung, acute monocytic and myelomonocytic leukaemia, Hodgkin's disease and non-Hodgkin's lymphoma.

Cisplatin is only registered for use in the *palliative* treatment of metastatic nonseminomatous germ cell carcinoma; advanced-stage, refractory ovarian carcinoma; advanced-stage, refractory bladder carcinoma; and refractory squamous cell carcinoma of the head and neck.

Thus any use of these agents for testicular cancer is an 'off-label' use and should be accompanied by informed consent, as if the treatment were experimental. A literature-based submission could be made to extend the indications for these old drugs, but even that is not an easy exercise (see *Literature-based Submissions: Points to Consider*, at <http://www.health.gov.au/tga/docs/html/litbsubs.htm>).

The sponsor-driven registration process provides no mechanism to correct anomalies such as the failure of the Australian registration system to allow use of these well-understood drugs for internationally accepted purposes. There needs to be a process whereby common sense is taken into account, not just sponsors' desires.

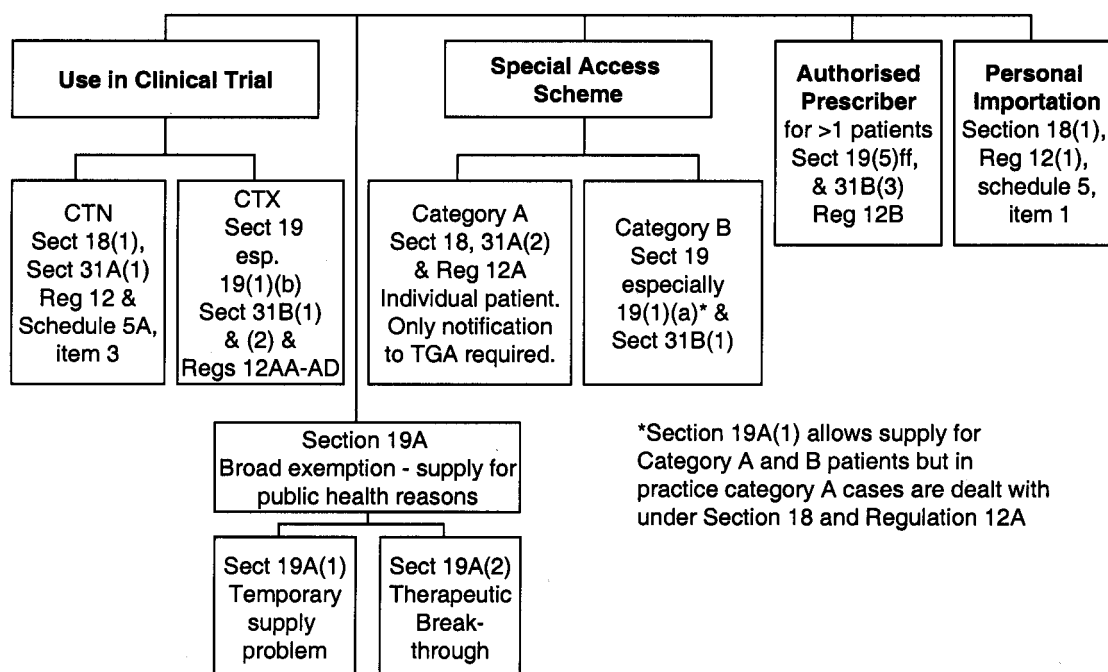
Access to unregistered drugs

If a drug is available overseas, or within Australia but not for that indication, there are a number of mechanisms for the doctor or the patient themselves to access the drug. These are summarised in Figure 5. Further detail is available at <http://www.health.gov.au/tga/docs/html/unapp.htm>.

While clinicians may regard some of these mechanisms as bureaucratic, they allow people with cancer to fairly readily obtain supplies of unapproved drugs. Many will fall into Category A (defined in the Regulations as 'persons who are seriously ill with a condition from which death is reasonably likely to occur within a matter of months, or from which premature death is reasonably likely to occur in the absence of early treatment'). This allows the clinicians to simply prescribe the drug with notification to the TGA after the event rather than obtaining prior approval. Another arrangement that is potentially of great use to regular prescribers is the Authorised Prescriber mechanism under Section 19(5).

What the clinicians want, however, is a faster and easier track to getting drugs on the market so that the PBS will, at least potentially, pay for them. This is a function of the speed of the TGA's evaluation process and the quality of the sponsor's submission. The TGA often has to go back to sponsors for additional information and this causes variable delay, depending how long it takes the sponsors to respond. Even when marketing approval is given, it may take a company some time to market the drug and to apply for PBS listing.

Figure 5 A summary of the arrangements for supply of pharmaceuticals that are not registered in Australia and their legislative basis



Adapted from TGA 2001

There does not seem to be any *specific* legislative blockage in the National Health Act to the PBS paying for drugs approved for use by mechanisms other than those in Division 2 of Part 3 of the Therapeutic Goods Act (the registration process); there may be legal and other impediments all the same.

In summary, individual access to drugs under the Therapeutic Goods Act is not the major problem, although it is an irritation, especially when the drugs are international best practice therapy for an indication that is not even registered in Australia.

Pharmaceutical Benefits Scheme

More important is the disinclination or inability of the Pharmaceutical Benefits Branch and ultimately the Minister to pay for drugs that are *not* registered under Division 2 of Part 3 of the Therapeutic Goods Act. This creates the biggest problem for patients. It could be solved by changing some of the legislation in that Division of the Therapeutic Goods Act, or by changing the policy or legislative provisions of the National Health Act relating to the PBS listing of drugs, that is, those that are not registered for a particular indication. Neither of these steps has been contemplated to date.

Problems with payment under the PBS

Problems with payment occur in a number of ways.

- A drug may be registered for an indication but the PBS will not subsidise the drug for that indication. A simple example is laxatives, which are available on the Repatriation PBS but not the PBS. This causes considerable expense for cancer patients (often pensioners) who are chronically constipated from taking opiate analgesics.

- Medications that are registered by the TGA for an indication, and are on the PBS but not for that precise indication. Clonazepam syrup (available to children but not to adults who cannot swallow) is an example.
- Medications that are on the PBS but in inappropriate quantities, causing unnecessary visits to the doctor and other hardships. An example is morphine for use in syringe pumps. If more appropriate strengths of morphine were on the PBS, not only would it save patients and their doctors a lot of trouble, it would also save the PBS money. The risk of addiction in cancer patients is essentially non-existent (and diversion for non-medical use is rare). Another example where the PBS strength is too low for common therapy is, again, leukovorin. Availability of, say, the 50 mg vials would save time, trouble for everyone and cost to the PBS.

These examples are sufficient to demonstrate the access problems with the present registration systems and the PBS. The drugs discussed above are low-cost, older drugs. The barriers that exist provide no public health or economic benefit whatsoever to either consumers or to Government.

Access to very new drugs under the Pharmaceutical Benefits Scheme

The cancer community feels that the present process of economic analysis before new cancer treatments are listed on the PBS penalises cancer drugs and thus patients. The cancer drugs have high unit cost but are typically only used in short bursts, and so the overall cost is not high. The newer drugs are often significantly less toxic than the existing therapies, and save money if they avoid hospital admission. Given that the PBS cost of cancer drugs is only 15% of the highest-cost drugs on the PBS (lipid-lowering agents), and 2.7% of the PBS overall, it is hard to see why access to newer anti-cancer drugs should be so difficult, when cancer kills more Australians than any other disease.

A great number of new anti-cancer drugs are being developed – up to two hundred new cancer drugs are expected to be released by 2005 (Ward & Hawkins 2002). Access is already proving problematic. The current example of this is imatinib (Glivec) which is available for some phases of chronic myeloid leukaemia but not for the chronic state, where it is of great (if not greatest) value (Druker et al. 2001). The other example is trastuzumab (Herceptin), which was made available by the Minister, contrary to the advice of the Pharmaceutical Benefits Advisory Committee.

These new drugs, of course, have the capacity to greatly increase the drug budget for hospitals and the PBS. The most effective way to ensure they are used cost-effectively is to only allow use in accord with best practice protocols. But as has already been shown, that does not even affect the registration process, let alone the PBS listing process.

At the very least, there needs to be a process of discussion so that cancer clinicians better understand the evaluation process. Conversely, perhaps the process could be adjusted to take account of the considerable benefits of anti-cancer drugs, which do not appear to be considered sufficiently at present.

Summary

This is a brief outline of examples of key problems that are being encountered with the present registration and PBS listing arrangements. There is a good *prima facie* case for a new system of access to anti-cancer drugs, unless great improvement is made to the present one. So far, Government officials have stuck to their traditional positions. If the pressure for change becomes great enough at the political level, change can occur. This was recently demonstrated in the recent review of the Therapeutic Goods Advertising Code. A similar review process is required for medicines registration and inclusion on the PBS. It needs to involve both the TGA and Pharmaceutical Benefits Branch, as well as all the relevant stakeholders external to the Department of Health and Ageing.

APPENDIX 8 Australian Clinical Practice Guidelines for Cancer

Prepared by National Cancer Control Initiative (March 2002)

The following is a list of Australian clinical practice guidelines for the management of cancer. The list was compiled by the NCCI. It contains information on clinical practice guidelines that we have been able to identify that have been published or are in preparation.

The NCCI would like to keep this list as comprehensive and as up to date as possible. Information on any additional clinical practice guidelines for cancer, or amendments to the current list, is welcome. Further information and/or amendments can be sent to Dr Karen Pedersen at the NCCI via email at Karen.Pedersen@ncci.org.au

Published

Breast cancer

- National Breast Cancer Centre, National Health and Medical Research Council. *Clinical Practice Guidelines for the Management of Advanced Breast Cancer*. Canberra: Commonwealth of Australia, 2001. <http://www.nhmrc.gov.au/publications/pdf/cp76.pdf>
- National Breast Cancer Centre, National Health and Medical Research Council. *Clinical Practice Guidelines for the Management of Early Breast Cancer – 2001*. Second edition. Canberra: Commonwealth of Australia, 2001. <http://www.health.gov.au/nhmrc/publications/pdf/cp74.pdf>
- National Breast Cancer Centre, National Health and Medical Research Council. *Psychosocial Clinical Practice Guidelines: Providing Information, Support and Counselling for Women with Breast Cancer*. Canberra: Commonwealth of Australia, 2000. <http://www.nhmrc.gov.au/publications/pdf/cp61.pdf>
- National Breast Cancer Centre. *Advice about Familial Aspects of Breast Cancer and Ovarian Cancer: A Guide for Health Professionals*. Sydney: iSource National Breast Cancer Centre, 2000. http://www.nbcc.org.au/pages/info/resource/nbccpubs/brovgl/brov_gl.pdf
- Australian Cancer Network. *The Pathology Reporting of Breast Cancer: A Guide for Pathologists, Surgeons and Radiologists. Recommendations of the Australian Cancer Network Working Party*. Sydney: The Stone Press, 1997. <http://www.nbcc.org.au/pages/info/resource/nbccpubs/pathrep/contents.htm>
- National Breast Cancer Centre, The Royal Australian College of General Practitioners. *The Management of Early Breast Cancer for GPs: Action Based on Evidence*. Sydney: National Breast Cancer Centre, 1997. http://www.nbcc.org.au/pages/info/resource/nbccpubs/mgmt_ebc.htm

- National Breast Cancer Centre, The Royal Australian College of General Practitioners. *The Investigation of a New Breast Symptom: A Guide for General Practitioners*. Sydney: National Breast Cancer Centre, 1997. <http://www.nbcc.org.au/pages/info/resource/nbccpubs/symptom/investig.pdf>
- National Breast Cancer Centre. *National Best Practice Guidelines for Familial Cancer Clinics*. Sydney: National Breast Cancer Centre, 1997.

Cancer genetics

- National Health and Medical Research Council. *Familial Aspects of Cancer: A Guide to Clinical Practice*. Canberra: Commonwealth of Australia, 2000. <http://www.health.gov.au/nhmrc/publications/pdf/cp67.pdf>

Colorectal cancer

- Australian Cancer Network. *Familial Aspects of Bowel Cancer: A Guide for Health Professionals*. Sydney: Australian Cancer Network, 2002.
- National Health and Medical Research Council. *Guidelines for the Prevention, Early Detection and Management of Colorectal Cancer (CRC)*. Canberra: Commonwealth of Australia, 1999. <http://www.health.gov.au/nhmrc/publications/pdf/cp62.pdf>
- National Health and Medical Research Council. *Guidelines for the Prevention, Early Detection and Management of Colorectal Cancer: A Guide for General Practitioners*. Canberra: Commonwealth of Australia, 1999. <http://www.health.gov.au/nhmrc/publications/pdf/cp64.pdf>
- National Health and Medical Research Council. *Guidelines for the Prevention, Early Detection and Management of Colorectal Cancer: A Guide for Patients, Their Families and Friends*. Canberra: Commonwealth of Australia, 1999. <http://www.health.gov.au/nhmrc/publications/pdf/cp63.pdf>

Pain management

- National Health and Medical Research Council. *Acute Pain Management: Information for General Practitioners*. Canberra: Commonwealth of Australia, 1999. <http://www.health.gov.au/nhmrc/publications/pdf/cp59.pdf>
- National Health and Medical Research Council. *Acute Pain Management: Information for Consumers*. Canberra: Commonwealth of Australia, 1999. <http://www.health.gov.au/nhmrc/publications/pdf/cp58.pdf>
- National Health and Medical Research Council. *Acute Pain Management: Scientific Evidence*. Canberra: Commonwealth of Australia, 1999. <http://www.health.gov.au/nhmrc/publications/pdf/cp57.pdf>
- *Therapeutic Guidelines: Analgesic*. Melbourne: Therapeutic Guidelines, 1997.

Palliative care

- *Therapeutic Guidelines: Palliative Care*. Melbourne: Therapeutic Guidelines, 2001.
- Mitchell G, Bowman J, McEniery J, Eastwood H. *The Blue Book of Palliative Care: Evidence Based Clinical Guidelines for Primary Practitioners*. Third Edition. Canberra: Commonwealth Department of Health and Aged Care, 1999.

Preventive interventions

- National Health and Medical Research Council. *Guidelines for Preventive Interventions in Primary Health Care: Cardiovascular Disease and Cancer*. Canberra: Commonwealth of Australia, 1997. <http://www.health.gov.au/nhmrc/publications/pdf/cp50.pdf>

Prostate cancer

- Australian Prostate Cancer Collaboration. *Localised Prostate Cancer: A Guide for Men and Their Families*. Melbourne: Australian Prostate Cancer Collaboration, 2001.
- National Health and Medical Research Council. *'Is it my prostate, doc?': A Guide for General Practitioners*. Canberra: Commonwealth of Australia, 1997. <http://www.health.gov.au/nhmrc/publications/pdf/cp43.pdf>

Providing information

- National Health and Medical Research Council. *General Guidelines for Medical Practitioners on Providing Information to Patients*. Canberra: Commonwealth of Australia, 1994. <http://www.health.gov.au/nhmrc/publications/fullhtml/cp60.htm>

Screening

- The Cancer Council New South Wales, The Royal Australian College of General Practitioners. *Screening for Cancer: A Guide for General Practitioners*. Sydney: The Cancer Council New South Wales, 2001.

Skin cancer

- National Health and Medical Research Council. *Clinical Practice Guidelines for the Management of Cutaneous Melanoma*. Canberra: Commonwealth of Australia, 2000. <http://www.health.gov.au/nhmrc/publications/pdf/cp68.pdf>
- *Therapeutic Guidelines: Dermatology*. Melbourne: Therapeutic Guidelines, 1999.

In preparation**Lung cancer**

- Guidelines for the management of lung cancer (Australian Cancer Network)

Lymphoma

- Guidelines for the diagnosis and management of lymphoma (Australian Cancer Network)

Ovarian cancer

- Guidelines for the management of epithelial ovarian cancer (Australian Cancer Network)

Prostate cancer

- Guidelines for the management of early prostate cancer (Australian Cancer Network)

Psychosocial

- Clinical practice guidelines for the psychosocial care of adults with cancer (National Breast Cancer Centre, National Cancer Control Initiative)

Skin cancer

- Guidelines for the management of non-melanoma skin cancer (Australian Cancer Network)

APPENDIX 9 Principles of integrated multidisciplinary care for the national demonstration program on multidisciplinary care for women with breast cancer

Prepared by Brian Wall, Oceania Health Consulting (May 2002), based on Luxford & Rainbird (2001)

A series of principles has been developed to guide the Multidisciplinary Care for Women with Breast Cancer – National Demonstration Program. The ways in which multidisciplinary care (MDC) is best implemented will vary; however, the principles of multidisciplinary care define the parameters within which this care should be delivered.

These principles of multidisciplinary care relate to the team, communication, the full therapeutic range, standards of care and involvement of the woman. The implementation of each principle aims to achieve a corresponding outcome.

Table 11 Principles of multidisciplinary care – National Multidisciplinary Care Demonstration Project

PRINCIPLE OF CARE	OUTCOME
Team	
The disciplines represented by the 'core' team should minimally include surgery, oncology (radiation and medical oncology), pathology, radiology and supportive care. The individual woman's general practitioner will be part of her team.	The 'breast cancer care team' is established and known.
In order to ensure that the woman has access to the full range of therapeutic options, the 'core team' may be expanded or contracted to include services (may be off site), such as genetics, psychiatry, physiotherapy and nuclear medicine.	Referral networks established for non-core team specialist services.
Communication	
A communications framework should be established which supports and ensures interactive participation from all relevant team members at regular and dedicated case conference meetings.	Communication mechanisms are established to facilitate case discussion by all team members.

Multidisciplinary input should be considered for all women with breast cancer, however, not all cases may ultimately necessitate team discussion.	A local protocol is established for deciding which cases may not require team discussion.
Full therapeutic range	
Geographical remoteness and/or small size of the institution delivering care should not be impediments to the delivery of integrated multidisciplinary care for women with breast cancer.	Systems are established for ensuring that all women have access to all relevant services.
The members of the team should support the multidisciplinary approach to care by establishing collaborative working links.	Systems are established to support collaborative working links between team members.
Standards of care	
All clinicians involved in the management of women with breast cancer should practice in accord with guideline recommendations.	Local clinician data is consistent with national benchmarks.
The treatment plan for a woman should consider individual patient circumstances and wishes.	The final treatment plan is acceptable to the woman, where possible.
Discussion and decisions about treatment options should only be considered when all relevant patient results and information are available.	Final reports are available to all core team members before treatment planning.
In areas where the number of new cancers is small, formal collaborative links with larger units/centres should give support and foster expertise in the smaller unit.	Systems are established for the exchange of knowledge and expertise between larger and smaller caseload centres.
Maintenance of standards of best practice should be supported by a number of activities that promote professional development.	Systems are established for the support of professional education activities.
Involvement of the woman	
Women with breast cancer should be encouraged to participate as a member of the multidisciplinary team in treatment planning.	Women are supported to have as much input into their treatment plan as they wish.
The woman diagnosed with breast cancer should be fully informed of her treatment options as well as the benefits, risks and possible complications of treatments offered. Appropriate literature should be offered to assist her in decision making. This information should be made available to the woman in a form that is appropriate to her educational level, language and culture.	All women are fully informed about all aspects of their treatment choices.
Supportive care is an integral part of integrated multidisciplinary care. Clinicians who treat women with breast cancer should inform them of how to access appropriate support services.	All clinicians involved in the management of women with breast cancer ensure that women have information about and access to support services.
The woman with breast cancer should be aware of the ongoing collaboration and communication between members of the multidisciplinary team about her treatment.	Women with breast cancer feel that their care is coordinated and not fragmented.

Source: Luxford K & Rainbird L. Multidisciplinary care for women with breast cancer: A national demonstration program. *NSW Public Health Bull.* 2001 12(10); 277–279. Available online from www.health.nsw.gov.au/public-health/phb/phb.html

APPENDIX 10

Multidisciplinary care in cancer

Prepared by Karen Pedersen, Senior Project Officer, National Cancer Control Initiative (June 2002)

Summary

This report was undertaken to examine evidence evaluating multidisciplinary care in cancer. Evidence relating to multidisciplinary care in cancer was identified from a search of published literature (Medline database), supplemented by the identification of additional papers from major articles. The literature search revealed that numerous articles provided information on the multidisciplinary care of cancer patients, however, only a limited number were identified that provided information on the evaluation of a multidisciplinary approach to cancer care. Available evidence indicates that multidisciplinary care has the potential to improve outcomes for patients with some cancers and increase patient satisfaction. It has been suggested that multidisciplinary care may also improve recruitment to clinical trials and reduce health care costs. Much of the identified evidence relating to the evaluation of a multidisciplinary approach in cancer care comes from retrospective, descriptive or comparative non-randomised studies. Issues that arose in considering the identified studies included potential difficulties in separating benefits of care delivered by a multidisciplinary team from those of multimodality treatment, lack of clarity as to what constitutes a multidisciplinary team in different settings and the uncertainty as to the applicability of findings to the Australian setting.

Multidisciplinary care in cancer

A major report into cancer services in England and Wales published in 1995 (the 'Calman-Hine report') recommended changes in professional practice to increase team-working among those providing cancer treatment and care (EAGC 1995). A more recent report on cancer care in England and Wales published in December 2001 has found that although multidisciplinary teams are increasingly common there is still considerable progress to be made in arrangements in many hospitals and for many cancers (CHI 2001). The report comments that:

- there is evidence that being cared for by a multidisciplinary team may improve outcomes
- although there is no research evidence on their cost-effectiveness, it has been suggested that multidisciplinary teams might result in savings by reducing the length of hospital stays or the need for readmission.

Literature search

To identify evidence evaluating multidisciplinary care in cancer a search was undertaken of the Medline database for articles relating to multidisciplinary care and cancer. The search strategy used is detailed below. This was supplemented by the identification of additional papers from major articles. The literature search identified over one thousand articles published in the last ten years that included multidisciplinary care and cancer as search terms. Review of the identified abstracts indicated that while numerous articles provided information on the multidisciplinary care of cancer patients, few provided information on the evaluation of a multidisciplinary approach to cancer care.

Search strategy and selection criteria

Information was obtained from the Medline database, supplemented by the identification of additional references from major articles. Search terms used were 'multidisciplinary care', 'multi-disciplinary care', 'integrated care', 'cancer', 'neoplasm(s)', 'survival', 'outcome', 'evaluation', 'readmission', 'hospital(s/z)ation', 'length of stay', 'quality of life' and combinations of these. The search strategy was limited to papers published in the period 1992 to 2002 and there were no restrictions placed on language or type of publication.

Evidence for multidisciplinary care in cancer

Outcomes

A number of studies have reported on variations in breast cancer care and outcome for women with the disease (Sainsbury et al. 1995; Gillis & Hole 1996; Richards, Sainsbury & Kerr 1997; Purushotham et al. 2001). Improved survival for women with breast cancer in the United Kingdom (UK) has been reported for patients whose surgeons had higher rates of usage of chemotherapy and hormone therapy (Sainsbury et al. 1995), as well as patients cared for by specialist surgeons (Gillis & Hole 1996) or surgeons with a high caseload (Sainsbury et al. 1995; Richards, Sainsbury & Kerr 1997). Gillis and Hole studied specialist care and survival in 3786 breast cancer patients operated on in the west of Scotland between 1980 and 1988 (Gillis & Hole 1996). They found that the five-year and ten-year survival rates for patients cared for by specialist surgeons were 9% and 8% higher, respectively, compared with women cared for by non-specialist surgeons. For patients treated by specialist surgeons there was a 16% reduction in the risk of death (relative hazard ratio=0.84), after adjustment for age, tumour size, socioeconomic status and nodal involvement. Indicators of specialist interest were the establishment of a dedicated breast clinic, a defined association with pathologists and oncologists, organising and facilitating clinical trials and maintaining a separate record of patients with breast cancer in their care.

Review of cancer registry data from 12,861 patients with breast cancer treated in Yorkshire between 1979 and 1988 found that patients of surgeons with higher rates of usage of chemotherapy and hormone therapy had prolonged survival (Sainsbury et al. 1995). The study authors determined that while there was considerable variation in survival of patients between surgeons, rate of use of chemotherapy and hormone therapy explained about 26% of this survival variation. It was estimated that had the practice of the surgeons with the better outcomes been used by all treating clinicians, five-year survival would have been increased by around 4–5%. Five-year survival for women with early breast cancer also appears to be greater in women who are treated by surgeons with a high caseload (defined as more than thirty to fifty new cases per year) (Richards, Sainsbury & Kerr 1997). It was suggested that this may relate to the increased likelihood that such patients are treated by a multidisciplinary team and receive adjuvant therapy.

There is evidence that some women with breast cancer may not be receiving the full treatment options. In one US study, the initial treatment recommendations received by women subsequently examined in a multidisciplinary breast cancer centre were compared with a second opinion provided by a multidisciplinary panel (Chang et al. 2001). For 43% of the women (32 of 75), the multidisciplinary panel would have recommended a different treatment, in accord with guideline recommendations, from that

recommended by the outside clinicians (this being most frequently breast-conserving treatment instead of mastectomy).

Management by a multidisciplinary team may improve survival for women with ovarian cancer (Junor, Hole & Gillis 1994). A retrospective study of all 533 cases of ovarian cancer registered in Scotland in 1987 addressed the value of multidisciplinary teams in the treatment of women with the disease. The study found that after adjustment for age, stage, pathology, degree of differentiation and presence of ascites, survival improved when patients were (1) first seen by a gynaecologist, (2) were operated on by a gynaecologist, (3) had residual disease of less than 2 cm post-operatively, (4) were prescribed platinum chemotherapy and (5) were referred to a joint clinic. The improved survival from management by a multidisciplinary team at a joint clinic was not solely due to the prescription of platinum chemotherapy (Junor, Hole & Gillis 1994). Altered diagnosis and management of women with gynaecologic malignancies following a pathology review was reported in one Canadian study. The retrospective review by a consultant pathologist altered diagnosis for 33% of specimens and management for 12% of patients (Chafe et al. 2000).

A significant improvement in three-year disease-free survival and local control has been reported for patients ($n=134$) with soft tissue sarcomas treated by a multidisciplinary group at a hospital in Finland (Wiklund et al. 1996). Outcomes for patients referred to the multidisciplinary group between 1987 and 1993 were compared with previously published results from the hospital in which the group was established and population-based Finish material. A retrospective audit of the management of thyroid cancer patients ($n=205$) in a large teaching hospital in the UK found that inadequate surgery and failure to administer radioiodine were less common in patients managed in a specialist clinic setting than in patients managed by clinicians outside the setting (Kumar et al. 2001). The specialist clinic involved joint management of patients by specialists (including surgeons, endocrinologists and oncologists) with an interest in the disease.

A survey of the opinions of non-radiologist clinicians regarding the active participation by abdominal radiologists in a multidisciplinary gastrointestinal cancer clinic in the US revealed that radiologist participation was highly regarded (Silverman et al. 1998). Specific benefits cited in the survey included improved interpretation, more efficient use of non-radiologist clinician time and improved rapport between radiologists and non-radiologists. Non-radiologist clinicians believed that patient care was improved.

Clinical trials

There is some evidence suggesting that management of patients by multidisciplinary teams may increase recruitment into clinical trials (Twelves et al. 1998; Saterén et al. 2002). In one study from Scotland, women with breast cancer seen by a specialist surgeon and those referred to an oncologist were significantly more likely to enter clinical trials. Women seen by surgeons with a high caseload or referred to an oncologist were approximately seven times and three times, respectively, more likely to enter a clinical trial (Twelves et al. 1998). The area of Scotland (Health Board) where the women were first treated also influenced study entry. In the US, investigation of patient accrual into National Cancer Institute-sponsored cancer treatment trials found that the number of oncologists and the presence of a hospital with an approved cancer program were both significantly associated with increased patient accrual into clinical trials (Saterén et al. 2002). Approval of cancer programs by the American College of Surgeons Commission on Cancer requires, among other things, hospitals to have a multidisciplinary cancer committee.

Patient satisfaction

Multidisciplinary care may increase patient satisfaction (Frost et al. 1999; Gabel, Hilton & Nathanson 1997). Positive benefits of a multidisciplinary team approach have been reported for women with newly diagnosed breast cancer in terms of their satisfaction with health and healthcare and physical and psychosocial adjustment (Frost et al. 1999). In this US study, women who received their medical oncology consultation as part of a multidisciplinary outpatient clinic ($n=66$) reported significantly higher levels of physical function and satisfaction with their health, physician and nursing care compared with women who received their medical oncology consultation in the hospital ($n=55$). In the outpatient

clinic setting, a concerted effort was placed on providing information and psychological support. In a separate study, instigation of a multidisciplinary breast cancer clinic within a hospital in the US was found to increase patient satisfaction by encouraging support group involvement (involvement of patient's families and friends) and by helping patients make treatment decisions (Gabel, Hilton & Nathanson 1997). A significant decrease in the time between diagnosis and initiation of treatment was also observed. The study compared all patients seen during the first year of the multidisciplinary clinic's operation ($n=177$), with all patients diagnosed with breast cancer at the hospital in the year prior to the clinic's inception ($n=162$).

High levels of patient satisfaction have been demonstrated for women attending a multidisciplinary one-stop diagnostic clinic for investigation of symptomatic breast lesions in the UK (Berry et al. 1998). High levels of patient satisfaction have also been reported for advanced cancer patients attending a half-day multidisciplinary symptom control clinic in a cancer centre in the US (Bruera et al. 2001). In these advanced cancer patients, significant improvements were reported in overall symptom distress, depression, anxiety and sensation of well being from the first ($n=166$) to the second ($n=110$) clinic visit, with further significant improvements recorded at two-week ($n=64$) and four-week ($n=38$) week telephone follow-up assessments.

Palliative care

Studies in the UK and Ireland involving the prospective collection of data on pain prevalence and severity have demonstrated that multidisciplinary palliative care teams are effective in alleviating pain in advanced cancer patients (Higginson & Hearn 1997). A systematic review has examined studies investigating the effects of home care intervention programs on the quality of life or readmission time to hospital for patients with incurable cancer (Smeenk et al. 1998a). The authors concluded that while the effectiveness of home care programs remains unclear, enabling team members to visit patients at home and holding regular multidisciplinary team meetings seem to be important elements for obtaining positive results. Limited evidence from the Netherlands has examined a program aiming to optimise cooperation, coordination and communication among the professional caregivers for patients with terminal cancer. The main objective of the program was to offer care to patients that was specifically tailored to meet their needs and offered by professional caregivers from primary and hospital teams. An intervention group ($n=79$) was compared with a control group ($n=37$) who received standard community care. Published results indicate that the intervention program improves quality of life for both the patients (Smeenk et al. 1998b) and their caregivers (Smeenk et al. 1998c) and results in less rehospitalisation during the terminal phase of illness (Smeenk et al. 1998b).

Health care costs

A cost-outcomes analysis of care for melanoma patients at a multidisciplinary melanoma clinic in the US has suggested that multidisciplinary care may reduce health care costs (Fader et al. 1998). The analysis evaluated whether coordinated multidisciplinary melanoma care that follows evidence-based, consensus-approved clinical practice guidelines in a large academic medical centre could provide a more efficient alternative to traditional community-based strategies with clinical outcomes that were at least equivalent. Costs incurred by a third-party payer for the diagnosis and initial management of patients with local disease were compared for a consecutive sample of 104 patients treated in the Michigan community with 104 blindly selected patients treated at the University of Michigan Multidisciplinary Melanoma Clinic, during an identical time period. Patients were matched for Breslow depth and melanoma body site. The study found that patients treated in the multidisciplinary clinic would save a third-party payer approximately US\$1600 per patient when compared with a similar group treated in the community. Surgical morbidity, length of hospitalisation and long-term survival of the multidisciplinary clinic patients were similar to those reported in the literature. The study authors indicated that differences in the usage pattern of health care resources explained the cost discrepancy (Fader et al. 1998).

Australia

In Australia, the NBCC is conducting a study to profile the provision of multidisciplinary care for women with breast cancer in a representative sample of hospitals from all states and territories (Luxford & Rainbird 2001). The NBCC is also coordinating a National Multidisciplinary Care Demonstration Project that is investigating the cost, acceptability, feasibility and impact on patterns of care of the multidisciplinary approach in three demonstration sites (Luxford & Rainbird 2001). The findings of the project will be used to make recommendations about the implementation of multidisciplinary care and are anticipated to help improve the coordination of treatment received by women with breast cancer in Australia. The project commenced in February 2000 and will be completed in December 2002. The evaluation of the three-year demonstration project includes a survey of women treated within the collaborations before and after commencement of nominated multidisciplinary strategies, a clinical audit, a cost analysis, surveys of clinicians and the logging of multidisciplinary activities.

APPENDIX 11 Details on the work of the UK Cancer Services Collaborative

Prepared by Brian Wall, Oceania Health Consulting (May 2002), based on the Service Improvement Guide (CSC c. 2001)

The CSC was set up as part of the modernisation program for the UK National Health Service (NHS). It is one of several initiatives – including clinical governance – that are parallel approaches to improving quality of and access to NHS health services.

The goal of the CSC is to improve the experience and outcome of care for people with suspected or diagnosed cancer by improving the way care is delivered. This is to be achieved by:

- providing certainty and choice for patients throughout their cancer journey
- enabling everyone who provides care to see themselves as part of the same system
- reducing unnecessary waits and delays
- providing a consistent, personalised service
- making sure that patients receive the best care, in the best place, from the best person or team.

In phase 1, the CSC comprised nine cancer networks. Each network received £500,000 to run up to five tumour-specific projects to improve services for patients with bowel, breast, lung, ovarian and prostate cancer over a period of eighteen months. The program began in October 1999 and ended in March 2001. The findings and a series of guides on rolling the approaches out across the UK NHS (phase 2) have recently been published (see <http://www.modern.nhs.uk/scripts/default.asp?siteid=26&id=5620>).

The basic techniques used to achieve its results are standard management approaches, although rarely applied in health in the way the CSC has done. Phase 2 is promoting the routine implementation of multidisciplinary teams. The key change principles are given in the box below.

The CSC has also produced a series of tumour-specific other guides, including working as a multidisciplinary team. The NHS Cancer Plan states that every cancer patient should receive management that has been considered by a multidisciplinary team (MDT). Phase 1 of the initiative identified a number of key challenges in the function of MDTs, including:

- agreeing appropriate membership for the MDT and ensuring that all team members attend the meetings
- ensuring that the care of every patient is discussed at MDT meetings
- developing effective systems for collecting and presenting the information that is needed for decision making at the meetings
- recording decisions
- setting up systems to check that the decisions are acted upon

- speeding up and simplifying the referral process between team members
- involving primary, secondary and tertiary care providers as part of a single team
- introducing systems to ensure palliative and supportive care is provided in line with patient needs.

The UK NHS's key change principles for improving cancer care	
<p>Strategy A: Connect up the patient journey</p> <p>A1: Understand the whole patient journey.</p> <p>A2: Design pathways of care for common patient needs.</p> <p>A3: Get the patient on the right pathway for care.</p> <p>A4: Create systems for tracking patients along the care pathway.</p> <p>A5: Simplify the process by which patients progress from one care provider to another.</p> <p>A6: Book appointments for care further along the journey as soon as the need is identified.</p> <p>A7: Improve communication between care providers across the patient journey.</p> <p>A8: Design follow-up systems to meet patient needs.</p> <p>Strategy B: Develop the team around the patient journey</p> <p>B1: Encourage primary, secondary and tertiary care providers to see themselves as part of a single team delivering cancer care.</p> <p>B2: Develop systems for team-based review, information sharing and decision-making for the care of every patient.</p> <p>B3: Deliver care according to evidence-based protocols agreed by the team.</p> <p>B4: Measure variation from agreed protocols and compare with outcomes information.</p> <p>B5: Redesign care roles to best meet patient needs along the patient journey.</p> <p>B6: Introduce systems to ensure palliative and supportive care is provided in line with patient needs.</p> <p>Source: Cancer Services Collaborative c. 2001</p>	<p>Strategy C: Make the patient and carer experience of care central to every stage of the journey</p> <p>C1: Remove all unnecessary delays for patients and carers.</p> <p>C2: Book care at times to suit patients and carers.</p> <p>C3: Understand what information patients and carers need at each stage of the journey.</p> <p>C4: Involve patients in decisions about their care at every stage of the journey.</p> <p>C5: Develop methods for obtaining regular patient and carer feedback about care.</p> <p>C6: Take action to respect the dignity, privacy and cultural needs of all patients and carers.</p> <p>Strategy D: Make sure there is the capacity to meet patient needs at every stage of the journey</p> <p>D1: Understand patient demand for services and use this to predict future need.</p> <p>D2: Group tasks by common patient need.</p> <p>D3: Identify bottlenecks in the patient journey and take action to alleviate them.</p> <p>D4: Effectively and appropriately reduce unnecessary demand.</p> <p>D5: Find ways to increase capacity.</p> <p>D6: Plan and coordinate staff annual leave.</p> <p>D7: Eliminate waiting lists.</p> <p>D8: Do this week's work this week!</p>

The CSC guide on MDTs indicates that some teams have begun to take multidisciplinary team working to a more advanced level. This includes making changes such as:

- agreeing on evidence-based protocols for care delivery and ensuring that care is delivered accordingly
- using the MDT meetings to discuss more complex cases that fall outside the protocols
- monitoring outcomes information and using this to refine and further develop protocols
- examining the existing care roles within the team and identifying how these can be redesigned to best meet patient needs.

Thus it can be seen that the reforms that the UK is undertaking in this area are, in essence, deceptively simple; they are not starting by tackling too much, too soon.

APPENDIX 12 Summary of the key provisions of the Cancer Program Standards of the US Commission on Cancer

Summarised by Brian Wall, Oceania Health Consulting (May 2002) from Standards of the Commission on Cancer (c. 1996)

These are standards prepared by the Commission on Cancer, a multidisciplinary body whose goal is to decrease the morbidity and mortality caused by cancer through prevention, monitoring and reporting of care, standard setting and education. Although the commission is auspiced by the American College of Surgeons, two-thirds of the commission's members are from other professional bodies.

It sets standards that 'promote and support the multidisciplinary approach to cancer'. Its requirements are based on four 'cornerstones':

- a multidisciplinary cancer committee
- multidisciplinary cancer conferences or tumor boards
- a program of patient care evaluation or quality outcome and improvement
- a cancer registry.

Institutions involved in the approvals program (accreditation) represent 25% of the health care facilities in the US but they are said to treat 80% of the annual incident cases. There are nine different types of approval according to the nature and size of the organisation.

The Commission's Committee on Approvals directs the Approvals Program. Ten areas are considered in relation to an approval. They are modified for paediatric programs because of the difference in treatment approach. In summary, the requirements are:

- 1 Institutional and programmatic resources:** These set out the management framework required in an institution seeking accreditation. It must have normal accreditation for an institution of its type, a cancer committee, cancer conferences, a quality management program and a cancer data management system.
- 2 Program management and administration:** This examines the role of the Cancer Committee. The Cancer Program Standard states: 'Leadership is the prime element in an effective cancer program ... (and) success depends on cancer committee leadership to plan, initiate, stimulate and assess all cancer related activities at that organisation'. The cancer committee's responsibilities include the following:
 - develop and evaluate the annual goals and objectives for the ... activities relating to cancer

- promote a coordinated multidisciplinary approach to patient management
- ensure that an active supportive care system is in place for patients, families and staff
- monitor quality management and improvement
- promote clinical research
- supervise the cancer registry
- perform quality control of the registry data
- encourage data usage and regular reporting.

3 Clinical management: The components of the clinical program vary depending upon the institutions but at a minimum they include availability of:

- modern pretreatment evaluation including accurate staging
- up-to-date multidisciplinary treatment
- ongoing quality assessment, including management guidelines.

The cancer care of each patient is the responsibility of the managing/treating physician, who retains responsibility for the patient's care and actively participates as a multidisciplinary team member. The managing physician is required to have initialled the notes on staging and have prepared a case summary and discharge plan for the patient.

Multidisciplinary case conferences cover a range of activities and there are minimum standards for the number of cases presented (at least 10% of the 'analytic case load'). The majority of presentations are required to be prospective, that is, timed so as to influence future treatment.

4 Inpatient and outpatient care: Oncology services are required to provide integrated multidisciplinary care. Physicians who specialise in all areas of diagnosis and treatment are required to be available. Nurses are required to be specialist oncology nurses. Rehabilitation services must be available (physical therapy, speech pathology, stomal therapy, etc.). Psychosocial and spiritual needs of the patient and their families must be addressed. Hospice services and grief counselling must be available. Comprehensive discharge planning, with referral to community services as necessary, must also be available.

This section also addresses the laboratory and treatment services that need to be available (depending upon the size and type of the facility) and the need for written policies on all aspects of care.

5 Supportive care and continuing care services: An appropriate range of rehabilitative, supportive and continuing care services must be available to patients. These may be available directly from the institution or by referral. Quality must be monitored.

There is required to be a multidisciplinary approach to planning and implementing supportive and continuing care services.

6 Research: Entry to clinical trials should be made available to patients. Those not involved in trials must provide patients with information about trials and how to access them.

Centres with 750 or more new cases of cancer per year must achieve 2% recruitment into clinical trials (for commendation the level is 6%).

7 Quality management and improvement: The quality of cancer patient care is required to be measured, evaluated and improved. A range of end-points are used to assess quality. The roles and responsibilities of the cancer committee in this regard are to be set out in the quality management plan. At least two aspects of quality must be reviewed each year.

8 Cancer data management: An institutionally based registry collects, analyses and reports demographic, cancer identification, treatment and long-term follow-up data on each eligible patient. These data then contribute to treatment planning, staging and continuity of care, as well as administrative and research roles. Data are submitted to national cancer registries.

9 Public education, prevention and detection: Prevention (including chemoprevention) and screening programs are available to the public as appropriate.

10 Professional education and staff support: Professional education is available to all members of the team, including the primary care physicians, allied health professionals, etc. Structured programs are publicised and evaluated, in addition to the cancer conferences. Staff are required to meet the requirements of national credentialling organisations and are supported to do so.

APPENDIX 13

Volume–outcome relationships and cancer

Prepared by Cleola Anderiesz, Senior Project Officer, National Cancer Control Initiative (June 2002)

Background

This report was undertaken to examine the evidence for a relationship between high caseload (volume) and better outcomes in the field of cancer. Literature was identified by a Medline database search and the search strategy is detailed below.

This report summarises the findings of major volume–outcome studies, major reviews and workshops, lists particular recommendations made to date and notes the chief concerns raised about the published literature. This report, however, does not cover policy or debate relating to regionalisation of cancer services.

Search strategy

Literature in Medline from 1966 to June 2001 was searched using the keywords ‘volume’, ‘outcome’ and ‘cancer’. No limitations on language or type of publication were imposed. The search strategy identified over seven hundred publications. In addition, other articles and reports were identified from the major articles.

Volume–outcome literature

The effect of the number of cases treated (volume) on outcomes has been studied for a wide range of cancers including cancer of the pancreas, oesophagus, stomach, liver, lung, kidney, colon, rectum, breast, prostate, ovary and testis. In particular, hospital volume, surgeon volume, centralisation and specialisation have been examined in the context of improved outcomes in cancer and several reviews have evaluated the evidence arising from these volume–outcome studies. Jarhult (1996) reviewed the published studies on the effects of large volumes or centralisation or specialisation on quality or mortality in cancer surgery. The relationship between specialisation and the processes and outcomes of cancer care was also examined in a review in by Grilli et al. (1998). A comprehensive review of Medline literature from 1988 to 1999 was undertaken by Hillner, Smith & Desch (2000) to search for evidence that hospital or surgeon volume or speciality affects the outcome of cancer. The article only reviewed studies that stratified or adjusted for clinical stage and each paper was assessed regarding whether it identified and controlled for casemix by adjusting for differences in demographics and/or co-morbidity. The review found that all but one paper used retrospective data collected in the 1980s and the majority of studies focused on short-term outcomes of cancers for which the primary mode of therapy was surgery that was performed with curative intent (Hillner, Smith & Desch 2000).

A recent workshop hosted by the IOM in the US brought together experts to: review the evidence of the relationship between volume of services and health-related outcomes for cancer and other conditions, discuss methodological issues related to the interpretation of the association between

volume and outcome, assess the applicability of volume as an indicator of quality of care, and identify research needed to better understand the volume–outcome relationship and its application to quality improvement (Hewitt 2000). As part of the workshop, a systematic review of literature published from 1966 to 1999 was conducted. Thirty-eight studies on cancer were identified. Eight studies of medical treatment of cancer were excluded because the studies did not examine volume as an independent variable. A further ten studies on surgical treatment were excluded; seven were not population-based, two did not evaluate volume as an independent variable and one was a review article and not primary research. In total, twenty population-based studies of surgical interventions for cancer were reviewed (Hewitt 2000). The white paper publication by Hewitt and Petitti for the National Cancer Policy Board (2001) summarises the findings from the workshop and presents board recommendations for implementing volume-based policies relevant to cancer care.

The major findings of the workshop together with the main points raised in the reviews are presented in this report.

Summary of findings

Studies investigating volume and outcomes have been undertaken for a variety of cancers with mixed results. Outcomes such as mortality, post-surgical complications, costs and duration of stay in hospital have been investigated in relation to hospital and surgeon caseload, and specialisation. The evidence supporting a positive relationship between high caseload (volume) and better outcomes is not consistent for most of the cancers studied to date.

Published studies predominantly used the hospital as the unit of analysis and measured in-hospital or thirty-day mortality, some investigated surgical complications (Hillner, Smith & Desch 2000; National Cancer Policy Board 2001). Few studies investigated long-term survival outcomes following surgery, cancers primarily treated with low-risk surgery or non-surgical cancers (Hillner, Smith & Desch 2000; Hillner 2001). Less than ten studies assessed cancers for which the principal treatment was chemotherapy (Hillner, Smith & Desch 2000), no studies examined recurrent or metastatic cancers (Hillner, Smith & Desch 2000; Hillner 2001) and no studies investigated outcomes such as quality of life or functional status.

Early reviews showed that more than 50% of all studies on surgery for solid cancers were unable to show a significant correlation between large volumes/centralisation and better outcomes (Jarhult 1996). However, it was noted that from a statistical point of view, many of these studies were of a low scientific standard, were retrospective and lacked corrections for casemix (Jarhult 1996). In contrast, a recent review has shown that when facilities – whether the facilities were cancer centres, university affiliated, designated as research centres or had residency training programs – were evaluated in relation to outcomes, a consistent trend of improved outcomes with specialisation was observed (Hillner, Smith & Desch 2000). Similarly, the review by Grilli et al. (1998) showed that lower mortality was associated with care provided by specialised centres and clinicians. However, the authors did not believe that the available evidence supported the suggestion that cancer patients were better off when treated in specialised centres due to major methodological flaws in the papers reviewed. Furthermore, the authors proposed that publication bias favouring the specialised centres might account for the trends observed (Grilli et al. 1998). At the IOM's workshop it was concluded that there was insufficient evidence to determine whether cancer care is better or worse off when offered by specialised compared to generalist facilities or providers, or in managed versus fee-for-service environments (National Cancer Policy Board 2001). It has been noted that the effect of institution specialisation on outcomes is difficult to study as specialisation is often closely tied to the size of the facility and the volume of the services and facility size is not controlled for in the analysis (Hillner, Smith & Desch 2000). In addition, the small number of institutions studied and adequate controlling for differences in patient populations are identified as limitations in these studies and consequently the evidence to support a relationship between institutional specialisation and outcomes has been deemed insufficient (Hillner, Smith & Desch 2000).

There has been little evaluation of the effect of specific surgeon volume and most of the analysis has focused on hospital volume (Hillner, Smith & Desch 2000). In the few studies that investigated hospital

and surgeon volume, only hospital volume was consistently related to better outcomes (National Cancer Policy Board 2001). Although improved outcomes with surgeon specialisation have been shown for surgery undertaken for some cancers, the definition of specialisation varies among the studies and it has been suggested that well-designed studies are needed to understand the importance of surgeon specialisation in outcomes for cancer (Hillner, Smith & Desch 2000).

In general, most of the studies reviewed to date evaluated hospital volumes and short-term outcomes and show a positive volume–outcome relationship in initial cancer treatment (Hillner, Smith & Desch 2000; National Cancer Policy Board 2001). An extensive and consistent body of literature supports a volume–outcome relationship for technically complex surgery (Hillner, Smith & Desch 2000). In particular, a strong volume–outcome relationship exists for low frequency, high-risk surgical procedures such as surgery for cancer of the pancreas and oesophagus. Based on the evidence of a strong and consistent association between technically difficult procedures and higher mortality in low-volume settings, the National Cancer Policy Board in 1999 recommended selective referral of patients with oesophageal and pancreatic cancer to high-volume facilities (National Cancer Policy Board 2001). However, the National Cancer Policy Board did not have evidence to support the broader application of this recommendation. In addition, the board recommended that when research confirmed a co-relationship the information should be disseminated to the public to support their health care decision making. Furthermore, the board specified that the limitations of the data and how to interpret them must be made clear to the intended audience (National Cancer Policy Board 2001).

Issues

It is important to note that concerns pertaining to the design and evaluation of the volume–outcome studies has been raised. The major issues raised about the published volume–outcome studies are listed below.

- Direct comparison of results is difficult due to methodological heterogeneity.
- The majority of the studies are retrospective.
- The publications rely on dated data.
- Many studies are out of date and the mortality associated with many procedures has fallen since these studies were conducted, hence, the relative importance of the volume of procedures performed may be declining.
- Minimum volume numbers vary for each study and it is often unclear where along the volume continuum a threshold exists for better outcomes.
- There is a potential for publication and self-interest bias, in that studies showing relationships are more likely to be published than those that find no relationship.
- There are limitations of using in-hospital mortality as an outcome measure as in-hospital mortality does not take into account premature discharge or post-discharge events.
- Mortality is a limited outcome to assess; ideally, complications, morbidity, re-admissions, functional status, quality of life, psychosocial impact and survival after discharge should be examined.
- The following variables are not always taken into consideration and adjusted for:
 - hospital size
 - total surgical volume
 - geographic location (if comparing facilities)
 - the number of surgical procedures of all kinds undertaken
 - casemix

- co-morbidity
- expertise of clinicians within that hospital
- post-surgical adjuvant therapy.
- Early studies lacked sufficient casemix adjustment.
- Surgeon volume was measured over limited duration.
- Early studies usually only explored linear or log-linear relationships between volume and hospital.
- Most published studies have used state-level databases or regional populations that are serviced by a small number of high-volume centres; it has been questioned whether these results can be generalised.
- It is not known how experience with other procedures that are closely related to the procedure under investigation affects outcomes.
- The interaction between the relative contributions of surgeon and hospital volume is unknown.
- Volume, when used as an indicator of quality, can be imprecise as not all high-volume providers will have better outcomes and not all low-volume providers will have worse outcomes.
- Small hospitals and surgeons with low-volume but with excellent outcomes are not always identified in the studies.

Conclusions

The relationship between volume and outcomes appears to be specific to the procedure or service undertaken and the outcome measured (Luft, Bunker & Enthoven 1979). Although a large number of studies have shown a positive relationship between volume and outcome, the evidence to support this relationship appears to be only consistent for technically complex surgery such as that undertaken for pancreatic, oesophageal and rectal cancers. The evidence for a volume–outcome relationship for surgery undertaken for other cancers is inconsistent. To date, the volume–outcome studies have focused on short-term outcomes and have primarily assessed mortality; whether outcomes such as quality of life or functional status are improved with higher volumes is as yet unknown (National Cancer Policy Board 2001).

The two main postulations used to explain the association between volume and outcome are; the ‘practise makes perfect’ hypothesis and the ‘selective referral hypothesis’. The ‘practise makes perfect’ hypothesis proposes that hospitals and surgeons have better outcomes because their experiences allows them to improve their systems and techniques (Daley 2002). The ‘selective referral’ hypothesis is that hospitals with better outcomes have larger volume because their excellence is well known and therefore, more patients come to be cared for in these high-volume hospitals (Daley 2002). Which of the two hypotheses is correct is unknown. Indeed, the mechanisms underlying the relationship between either hospital- or surgeon-volume and outcomes have not been fully characterised and it has been suggested that a wide-ranging research agenda is necessary to better understand this relationship and know how best to implement policies to improve care (National Cancer Policy Board 2001).

APPENDIX 14 Roles of the National Breast Cancer Centre and the National Cancer Control Initiative

Prepared by Brian Wall, Oceania Health Consulting (March 2002)

Note: Other groups, such as the NHMRC Clinical Trials Centre, also have an important – though much smaller – national role in improving cancer care.

National Breast Cancer Centre

The NBCC has been established to improve breast cancer control by:

- analysing research and making it readily available to women and health professionals
- developing, disseminating and encouraging the adoption of clinical guidelines to improve the diagnosis, treatment and support of women with breast cancer
- providing accurate and accessible information to well women, women with breast cancer, primary care providers and breast cancer specialists
- developing a national monitoring system to provide information about all aspects of breast cancer.

Philosophy and approach

The work of the NBCC is guided by the following values:

- Evidence-based: all aspects of the NBCC's work are based on the best available evidence.
- Informed by consumer perceptions: the NBCC ensures that the views of consumers inform all aspects of its work.
- Partnerships: the NBCC, wherever possible, works in partnership with the broad range of organisations concerned about breast cancer control.
- Multidisciplinary: the NBCC uses a multidisciplinary approach, bringing individuals with different expertise to work together.
- Outcomes-oriented: all aspects of the work of the NBCC are directed towards improving outcomes for women in information, diagnosis, treatment and support.
- Innovation and evaluation: the NBCC adopts an innovative approach in seeking to increase understanding of how best to improve care; it seeks to develop approaches that may be adapted for other cancers and other health issues.
- National: the NBCC has a national remit to improve breast cancer control across Australia.

Role

The NBCC has demonstrated the value of a national integrated approach to changing cancer care. This enables the best possible use to be made of research by ensuring that new evidence is used promptly and effectively to change health service delivery and care for women.

An integrated approach delivered by a national centre is able to avoid duplication of effort by providing a central base for the major and most costly tasks of review and guideline development. It ensures that the same accurate and timely information is provided to all stakeholder groups, including clinicians, consumers, policy makers and the media. It enables the identification of priorities in improving breast cancer control and the focusing of resources on these priorities.

National Cancer Control Initiative

Core purpose

The NCCI is a key expert reference body providing timely advice, identifying appropriate initiatives, and making specific recommendations to the Commonwealth Government and other key groups regarding the prevention, detection, treatment and palliation of cancer for all Australians.

Core values

The work of the NCCI is based on the values of:

- scientific validity
- independence
- integrity
- relevance
- responsibility.

The NCCI gives priority to solutions that achieve:

- effectiveness
- efficiency
- equity.

The NCCI:

- works with nationally identified priorities
- works with researchers, the cancer community, the community at large, public policy makers and others to develop consensus on new methods of cancer control
- takes a leadership role by consensus.

The five key strategies for 2002–4*Key strategy 1: Monitor and evaluate cancer control outcomes in Australia*

- Improve the information available on cancer, by developing improved methods to assess cancer occurrence, treatment and outcome.
- Report on the state of cancer control in Australia.

Key strategy 2: Identify emerging issues and new strategies for cancer control

- Assess current and new strategies for cancer control in Australia, highlighting priority issues.
- Identify new findings relevant to cancer control in Australia.
- Assess new developments in cancer prevention and screening.
- Assess cancer research in Australia in regard to cancer control.

Key strategy 3: Develop and assess strategies to translate research outcomes into improved public health and clinical practice

- Develop and assess new approaches in the prevention, early diagnosis and management of cancer, and in palliative and supportive care.

Key strategy 4: Identify gaps between current and best practice

- Seek to improve the involvement of Australian cancer patients in well-designed clinical trials.
- Support the involvement of consumers and assess ways in which their involvement can improve cancer control.

Key strategy 5: Develop and maintain the capacity to respond to issues in cancer control within the strategic priorities

- Review relevant issues, and provide independent, evidence-based reports to the Commonwealth and other groups.
- Respond to requests on priority issues as appropriate.
- Develop and maintain capacity to monitor international research and developments in cancer control.

APPENDIX 15 Isolated Patients' Travel & Accommodation Assistance Scheme

Prepared for the Cancer Strategies Group by the Secretariat at the Department of Health and Ageing (October 2002)

The Isolated Patients' Travel and Accommodation Assistance Scheme (IPTAAS) was established by the Commonwealth on 1 October 1978 to provide financial assistance to persons and their escorts, residing in isolated areas, who were referred for specialist medical and oral surgery treatment not available locally. The scheme was introduced to improve accessibility to health services for people who had to travel great distances to seek specialist treatment and to alleviate health costs to people in these areas.

The Commonwealth scheme was abolished in the 1986–87 Federal Budget and transferred to the states and territories. Additional ongoing funding was provided to the states and territories at that time to allow for the continuation of the scheme and for the elimination of the backlog of claims.

Under these arrangements, matters relating to reimbursement for patient travel and accommodation costs are the responsibility of each state and territory jurisdiction.

Table 13 provides a brief summary of the eligibility requirements, travel and accommodation assistance, and the patient contribution required as part of the IPTAAS for each state and territory.

Major issues

Patients who are required to travel large distances to receive specialist treatment are faced with a number of issues, including:

- financial costs associated with travel, accommodation and incidentals
- loss of income
- choice of care
- patient escorts and social networks.

Financial costs

Patients required to travel for medical treatment can incur significant financial costs as a result of travel, accommodation and incidentals (including meals, inner city transport and telephone calls).

Whilst some reimbursement may be received through the relevant state/territory IPTAAS, some patients are unable to access the scheme as they do not meet the eligibility requirements.

Cancer patients who may have to be away from home for extended periods of time, for example to undergo radiotherapy treatment, can incur varying levels of financial expenditure. This is dependent on variables that include:

- the distance the patient lives from the treatment centre
- the type and length of treatment required
- eligibility for reimbursement of expenses through IPTAAS (varies between states/territories)
- whether the patient has private health insurance.

The National Breast Cancer Centre published a report *Out-of-pocket Expenses incurred by Women for Diagnosis and Treatment of Breast Cancer in Australia* (1999) that provides a detailed breakdown of the costs associated with travel and accommodation for women with breast cancer. Table 12 provides the travel and accommodation costs for women travelling 450 km by car with a medically approved escort (for all services except radiotherapy) to receive breast cancer treatment or palliative care – NSW IPTAAS (Butler and Howarth 1999).

Table 12 *Travel and accommodation costs for women treated for breast cancer*

Treatment ¹	Total expense (\$)	Out-of-pocket expense (\$)
Pre-operative localisation and complete local excision/breast biopsy (3)	463.13	363.63
Partial mastectomy without axillary dissection (6)	763.13	573.63
Complete local excision or partial mastectomy with radical axillary dissection/simple mastectomy (7)	863.13	643.63
Modified radical mastectomy (11)	1,263.13	923.63
Breast reconstruction ²		
M'plasty (unilateral reduction) (3)	463.13	363.63
Tissue expander/permanent prosthesis (8)/(4)	1,526.26	1,147.26
Adjuvant radiotherapy – post-lumpectomy (37)	3,863.13	2,743.63
Adjuvant radiotherapy – post-mastectomy (30)	3,163.13	2,253.63
Palliative care – radiotherapy (56) ³	6,252.52	4,534.52
Palliative care – hospitalisation (14)	1,563.13	1,133.63

¹ Number of nights accommodation in parentheses

² Two examples only are included here. Insertion of a tissue expander, followed by removal of that expander and insertion of a permanent prosthesis, are two separate procedures and require two trips to be undertaken

³ Based on four courses of radiotherapy for bone metastases, with fourteen nights accommodation required for each course

For most patients, payment of travel and accommodation expenses is an up-front cost. This can have significant impact on low-income earners, singles, unemployed and those who have been forced to leave work to undergo treatment.

Loss of income

Patients required to travel large distances to receive treatment may be forced to leave work (either on a temporary or permanent basis). This can place a significant strain on an individual's ability to pay for related travel and accommodation expenses, and may also impact on the patient's choice of treatment. In addition, a patient's escort may also be required to leave work on a temporary or permanent basis. As a result, a two-income family may become a single-income or no-income household.

There is no consideration for loss of income within the current IPTAAS in each state and territory.

Choice of care

The costs associated with cancer treatment modalities may have an impact on the type of treatment a patient chooses, particularly those living in rural and remote areas as found by Craft et al. (1997):

Women living in rural or remote locations were more likely to undergo mastectomy. Breast conservation usually necessitates post-operative radiotherapy, and, as radiotherapy services are often not conveniently located for rural populations, this treatment can involve considerable social and financial costs to patients, which may influence the decision to undergo mastectomy.

For patients to receive reimbursement for travel and accommodation through IPTAAS, he or she must undergo treatment at the nearest treatment centre that provides the service required. This places restrictions on the patient's choice of treatment location and treating physician. Patients who wish to seek a second opinion (often requiring travel to another treatment centre) cannot receive IPTAAS funding if the centre is not the nearest place of treatment.

For patients undergoing palliative therapy, choice of treatment is also a significant consideration.

Patient escorts and social networks

Patients required to travel large distances to receive treatment are often forced to leave behind family members and their social networks. A patient escort can often assist in filling this gap, providing the patient with continued psychological support.

Financial assistance for a patient escort is only provided through IPTAAS if the patient is a child (age limit varies between states and territories) or an escort is required on medical grounds.

For patients undergoing lengthy treatment, the support that can be provided by a patient escort through the demands of surgery and subsequent follow-up treatment can be invaluable. This is significant for all patients, including Aboriginal people, who often have a strong and extensive family support network.

Options for improvement

People living in rural and remote communities are entitled to equitable access of public hospital services. To ensure that this is a reality, several recommendations have been developed for consideration.

- Following the devolution of IPTAAS to the states and territories, each jurisdiction has developed their own eligibility criteria and guidelines. This has resulted in patients who may be eligible for financial assistance in one state, considered ineligible in another. It is appropriate that consideration be given to the feasibility of advocating a cooperative approach to standardised eligibility criteria between the Commonwealth and states and territories.
- States and territories should undertake to increase patient awareness of IPTAAS and their eligibility for appropriate subsidies.
- States and territories should consider options for improving the financial assistance they provide for a patient's travel and accommodation.
- Patients should have the opportunity to access the treatment and treating physician of their choice, including the availability of accessing a second opinion on treatment options.

Table 13 *Summary of IPTAAS in Australia*

State/ territory	Eligibility requirements	Travel assistance	Accommodation assistance	Patient contributions
NSW	Patient must usually live more than 200 km from the nearest treating specialist	Assistance provided at economy surface rail or bus rates Fuel subsidy of 12.7c/km for private car	Commercial: \$33/night (single) or \$46/night (double) Private: \$30/week after 1 st week for pensioner patients with a Health Care Card	\$40 (\$20 for pensioner or Health Care Card holders) personal contribution deducted from the total benefits paid per claim
Vic	Patient must live more than 100 km from the nearest treating specialist	Assistance provided for the most direct means of public transport (economy rate) Fuel subsidy of 13c/km for private car	Commercial: Up to \$30/night for a maximum of 120 nights in a treatment year Private: Not eligible	Patients who are not concession card holders will have the first \$100 deducted from their payment each treatment year
Qld	Service must be more than 50 km from the patient's nearest public hospital	Assistance provided at the cost of the least expensive form of public transport from the town of local hospital to the transport terminal of the town the patient is travelling to Fuel subsidy of 10c/km for private car	Commercial: \$30/night for concession card holders; non-concession card holders must pay for the first four nights accommodation in a fiscal year Private: \$10/night for concession card holders; non-concession card holders to meet first four nights accommodation	Nil
SA	Patient must live more than 100 km from the nearest treating specialist	Assistance provided at economy rate for bus/ferry/train less a patient contribution of \$30 Fuel subsidy of 16c/km for private car	Commercial: Up to \$33/night, no reimbursement on first night for non-concession card holders Private: Not applicable	Patient contribution of \$30 deducted from total travel benefits: means tested exemption for genuine hardship
WA	Patient must live more than 100 km from the nearest treating specialist	Assistance provided at economy rate for the least expensive form of transport (bus/train/plane) Fuel subsidy of 13c/km for private car	Commercial: Up to \$35/night. Non-concession card holders are required to pay for the first three nights accommodation Private: \$10/night	Non-concession card holders pay the first \$50 for a maximum of 4 trips in a financial year
Tas	Patients must live more than 75 km from the nearest treating specialist	Assistance provided at economy bus travel from patient's residence Fuel subsidy of 10c/km for private car	Commercial: up to \$30/night Patients not on a pension are required to pay for the first two nights Private: not applicable Limit of \$2000 travel and accommodation costs/patient paid each year by Government	Card holders: \$15/trip; maximum contribution \$120/fiscal year Non card holders: \$75/trip; maximum contribution \$300/fiscal year

NT	Patient must live more than 200 km from the nearest treating specialist	Assistance provided at the cost of an economy return bus trip from the bus depot closest to the patient's residence Fuel subsidy of 15c/km for private car	Commercial: Up to \$30/night Private: \$10/night	Nil
ACT	Available to permanent residents of the ACT who are required to travel interstate for specialist medical treatment which is not available in the ACT	A maximum entitlement for travel by coach/train (Can/Syd/Can) is \$40/adult and \$20/child Greater reimbursement for travel to cities other than Sydney Travel by private car receives \$40/trip (Can/Syd/Can)	Commercial: up to \$30/night Private: \$10/night	Nil

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