

Chapter 3

Opportunities for cancer control in Australia

3.1 A framework for change

Cancer control encompasses a broad range of activity and effort. National effort through the NHPA process, and the National Health Goals and Targets process before it, have concentrated on cancer types and have determined particular indicators for those cancer types to measure progress in the control of cancer.

While a focus on cancer types is centrally important in determining progress, it provides only a portion of the whole picture. Other factors are important in building a holistic picture of cancer control in the nation. These 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. As discussed in Chapter 2, screening and early detection practices are possible or useful in some cases, such as for cancers of the breast or cervix, but not as useful for prostate cancer and largely unavailable for lung cancer, although research into better early detection techniques is continuing. 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. In addition, the framework would allow each endeavour to have a rightful place so that individual or State/Territory activities that contribute to national cancer control could be identified within it. The framework would provide a blueprint for collaborative action under the NHPA process, which also draws on non-government expertise.

A process to develop cancer control priorities in Australia was undertaken by the NCCI as part of its contribution to this report. This process involved a wide range of stakeholders, to focus on issues as they apply across cancer types as well as within cancers with a practical focus on actions. Through the wide consultation process undertaken, the NCCI was able to develop a broad overview of opportunities to improve cancer control.

This chapter addresses these opportunities within the suggested framework of cancer control, dealing first with the particular cancer types, and any specific stages along the continuum of care that can be identified as requiring attention. Secondly, the opportunities for improvements in the areas that are relevant across the spectrum of cancer control are examined. Section 3.6 identifies opportunities for utilising the Australian research effort in the most effective manner. Finally, Section 3.7 looks at scope within the health system to promote evidence-based best practice.

3.2 Specific issues for priority cancers

Lung cancer

Prevention

The intersectoral collaboration on smoking policy is a major reason for the success of preventive efforts to reduce lung cancer. There is a wide range of preventive strategies already in place at Commonwealth, State and Territory, local health authority and community level. Over the past 10 years, there have been legislative changes about packaging and advertising at a national level, State-based promotion of smoke-free workplaces, and many anti-smoking activities by government, non-government and community organisations.

There have been calls from community groups and health bodies suggesting additional changes to further restrict tobacco sales and consumption:

- promoting the widespread uptake of smoke-free policies which ban smoking in all workplaces and enclosed public places;
- a change in the method of calculating excise duty to cents per cigarette, which should reduce smoking prevalence by preserving the effect of price increases (Scollo 1996);
- development of a new regulatory framework dedicated to covering the range of nicotine products formulated to deliver nicotine for therapeutic reasons or recreational use (Borland 1997);
- introduction of generic packaging, to reduce the influence of brand consciousness in the media and among consumers;
- cessation of all forms of advertising and promotion, with an extension of present tobacco control legislation to prohibit point-of-sale advertising, including the display of packets to the general public; and
- more effective measures to persuade adolescents not to take up smoking, such as legislative changes to reduce promotion and increase price, as well as compulsory education in primary and high schools and population-wide smoke-free policies.

Skin cancer

Primary prevention

Epidemiological evidence demonstrates that overexposure to sunlight in the first two decades of life is an important risk factor for the development of skin cancer. If an impact is to be made on future incidence rates of skin cancer in Australia, the nature and amount of sun exposure in children and adolescents needs to be reduced.

While systematic efforts have contributed to an increased awareness of the dangers of sun exposure and decreased levels of sun exposure (Hill et al 1993), many people still have not adopted sun protection behaviours. Environments without sufficient shade place great demands on individuals to be sun safe. The fashionable appeal of non-sun-safe items can inhibit use of SunSmart alternatives, such as the use of baseball caps by adolescents (Centre for Behavioural Research in Cancer, unpublished). These remain major obstacles to improved protection and might be foci for concerted activity in the future.

Future efforts may concentrate more on structural change within the community to decrease available time in the sun, increase protective shade structures and other physical means of protection and encourage those at risk to use the highest SPF sun screen. Behavioural research is obviously a critical part of the development, delivery and measurement of new programs.

Screening and early detection

In 1995, almost 4 per cent of Australians had a skin lesion excised with the Medicare costs for this general practice procedure alone (pathology and consultation costs excluded) at almost \$50 million (Burton 1996). Melanoma incidence and mortality trends indicate that this amount is more than what may be required to control the disease (Burton 1996). Besides a reduction in the ratio of benign to malignant lesions removed by general practitioners has the potential to generate considerable cost savings for the health system.

A number of studies have found that simple interventions by general practitioners can improve their accuracy in detecting malignant pigmented lesions, thereby reducing the ratio of benign to malignant pigmented lesions excised (Del Mar & Green 1995). It is however important that this strategy does not result in a significant increase in missed malignant lesions, nor result in delay in diagnosis of melanomas while they are thin (<1mm in thickness).

Cancer of the cervix

Screening

Potential future directions and issues for cervical screening in Australia include the following.

Need to adequately test populations at risk — It thought that most cases of cervical cancer could be prevented if all women at risk were to be screened every two years. This risk group comprises women who are sexually active and who have an intact cervix. Where there is sufficient evidence of the effectiveness and acceptability of a specific recruitment strategy, it should be implemented. Where evidence is insufficient, responsive research to generate timely and sound evidence is required (Ward 1997).

Incorporation of automated and semi-automated devices into routine laboratory practice — Semi-automated slide preparation techniques and computer-assisted rescreening have been designed to assist cytotechnologists in evaluating Pap smear slides, which would minimise the number of sampling procedures and false negative laboratory results. While the former involves producing more representative samples which are easier to interpret, either conventionally or with the aid of a computer, the latter uses computer technology to assist rescreening of the conventional Pap smear.

These devices have been introduced in Australia over the past two years. AHTAC is undertaking a review of the effectiveness and cost-effectiveness of these devices and examining their likely usefulness in the national screening program.

Use of HPV typing to identify high-risk groups of women — HPV typing is now available in Australia, and could theoretically be used to identify two possible high-risk groups: women with low-grade abnormalities who require further investigation; and older women infected with high-risk HPV genotypes. Relevant research for both of these approaches is needed before they can become widely adopted.

Restriction of government funding to those laboratories that meet defined performance standards — Laboratory inspections from 1 January 1999 will assess the laboratory's performance against a set of nominated performance standards. This should increase the confidence of both women and health workers in the quality of Pap smears.

Better adherence to the two-year screening interval — Currently, there is no restriction on Pap smear screening. Although women and general practitioners are encouraged to adhere to two-yearly screening, women can seek testing at any time. Major cost reductions could be achieved if women and medical practitioners were encouraged to adhere to the two-year policy.

Despite the high age-standardised incidence rates for Indigenous women and immigrant women from specific countries, the screening rates for these groups are low. Research into effective and culturally appropriate recruitment strategies is currently being undertaken.

Breast cancer

Within Australia, many opportunities for reducing mortality and morbidity from breast cancer are missed. Also, service delivery is more complex, less effective and costlier than is optimal. Improving breast cancer control will require a more coordinated approach to offering all aspects of screening, diagnosis and management in a cost effective manner.

Some of the major issues which need to be addressed in improving breast cancer control include the following:

Mammographic screening

Although Australia has a fully expanded, high quality mammographic screening program, a number of issues need to be addressed:

- Strategies to review the national accreditation requirements and to facilitate the implementation of strategies to ensure that all aspects of the screening and assessment process that meet these requirements are put in place.
- At least 70 per cent of women in the target age range (50–69 years) should participate in the program to justify the expenditure on the program. Currently, participation is about 54 per cent (BreastScreen Australia, unpublished data). Re-attendance rates seem to be higher, with rescreening rates of between 68 per cent and 83 per cent (BreastScreen Australia, unpublished data). Based on current recruitment and rescreening rates it has been estimated that by the Year 2000 the participation rate may have increased to 64 per cent (Kricker, in press), but this is still short of the target. It appears there is a high level of community awareness of BreastScreen Australia and the role of mammographic screening (Barratt et al 1997). However more evidence-based and cost-effective approaches will be required to increase participation in the program. This may require the further development and implementation of targeted strategies to increase participation by Indigenous women and women from non-English speaking backgrounds.
- Indicators of the quality, participation and impact of the program must be developed so that governments and the community can be assured of an excellent program aimed at reducing mortality from the disease. Currently, key national data on participation and quality are collected, but there is little collation of this data. The comparability of State/Territory data is also problematic.
- The costs of the program should be reviewed to ensure that they come into line with appropriate benchmarks overseas. Cost structures within Australia should be investigated through the existing data sets, to determine where the Australian program is costing more, and to what degree this is amenable to change. However for reasons of quality and geography, among others, it is not always possible to match the costs of overseas programs.

Diagnosis

The establishment of a system that reduces unnecessary investigations and provides accurate and timely diagnosis of breast cancer is necessary. Currently, most women with breast symptoms present first to their general practitioner who may investigate the symptoms and/or refer to a surgeon. The National Breast Cancer Centre (NBCC) has developed and disseminated guidelines to general practitioners to assist this process.

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Spreading the message — There is a considerable lack of understanding among women about the importance of prompt investigation of breast symptoms. Fifty per cent of women in the National Breast Health Survey, who were found to have a breast symptom in the past two years, had not visited their doctor within one month of observing the symptom. One out of four women had not had the symptom examined at all (Barratt et al 1997). There is a need for community information programs and further research to explore the reasons why some women do not present until the cancer is fairly advanced.

Training health professionals — Practitioners need to receive adequate training in clinical breast examination at medical schools. There is a need for agreed evidence-based guidelines about both breast self-examination and clinical breast examination. Improved training opportunities for undergraduate medical students, general practitioners and other health professionals are needed. These will require innovative approaches to medical education to overcome the current lack of opportunity to perform breast examination on either asymptomatic or symptomatic women.

Existing guidelines — The NBCC guidelines (Irwig 1997) to assist general practitioners in investigating breast symptoms and ACN recommendations about the reporting of breast pathology (Australasian Cancer Network Working Party 1997) should be implemented and evaluated. The need for guidelines and/or quality assurance programs in breast cytology and in imaging techniques should be explored in conjunction with the relevant professional colleges.

Women at increased risk

The women who have ductal carcinoma *in situ*, lobular carcinoma *in situ*, atypical hyperplasia, a previous personal history of breast cancer or a significant family history of breast cancer are all at increased risk of developing breast cancer. It may be possible to make a major impact on the disease at the population level by increasing the identification of these women and providing appropriate surveillance and management should breast cancer develop.

Management

Reductions in mortality and morbidity from breast cancer can also be achieved by ensuring that all women receive management that accords with the best evidence about effectiveness. Effective management includes both the clinical treatment and supportive aspects of care.

High quality cost-effective management will require the following:

- Strategies to ensure that research findings flow rapidly into clinical practice. Experience to date suggests that this is best achieved through a process of systematic review such as that provided by the Cochrane Collaboration and through the development and implementation of evidence-based guidelines.
- The development of more coordinated models of care. For example, the cost-effectiveness of breast centres that provide a seamless transition from diagnosis or screening into treatment should be explored. Similarly, approaches to multi-disciplinary care should be trialed. This work will need to begin by developing a shared definition of multidisciplinary care and strategies that address the particular needs of the rural sector such as teleconferencing, regional clinics, and training. Multidisciplinary care requires agreed local protocols and audit, and the opportunity for multidisciplinary case conferencing about management. Specific strategies for providing supportive care must also be included.

- Emerging strategies for managing breast cancer are likely to be based on a better understanding of the development of the disease. The ways in which gene mutations lead to the development of breast cancer may help to identify early intervention strategies.

Many of these issues could be addressed by establishing a more integrated approach to the screening, diagnosis and management of the disease. This will require national coordination and collaboration between the key players which will include the Commonwealth, State and Territory health departments, BreastScreen Australia, the National Breast Cancer Centre, the professional colleges, treatment centres and consumer groups.

Colorectal cancer

Screening

As discussed in Chapter 2 (Section 2.5), there is evidence that screening using FOBT can help reduce mortality from colorectal cancer, but there is limited information on the feasibility or acceptability of this type of screening in Australia. Likely issues for a future screening program include ensuring that the participation rates for initial and follow-up screening are high and that screening is acceptable to the target group, to others in the community and to the health care providers involved.

An AHTAC review has considered the benefits, risks and costs of a national screening program for colorectal cancer (AHTAC 1997), and recommends commencing pilot programs using FOBT for the average risk population aged 50 years or more.

Treatment

There are several areas of controversy in relation to colorectal cancer treatment. The major impetus for the development and implementation of evidence-based management guidelines is to achieve a uniform acceptance of evidence about the newer developments in colorectal cancer treatment.

Prostate cancer

Screening

There is continuing uncertainty over the benefits of population screening for prostate cancer. The current recommendations of AHTAC (1996) are:

- men without symptoms should not be screened for prostate cancer using PSA tests as there is insufficient evidence for the benefit of the test;
- PSA should continue to be used in the monitoring of men known to have prostate cancer and in patients selected for active treatment of benign prostatic hyperplasia; and
- that all men requesting or being offered a PSA test must be fully informed of the limitations of the test and the possible further diagnostic and treatment choices which they could face.

It has been argued that limited PSA testing would lead to fewer potentially harmful consequences for men (including those from follow-up investigations, surgery and radiotherapy) with long-term benefits and substantial cost savings to the community. It would appear reasonable to discourage the inappropriate use of

PSA testing to screen well men for prostate cancer, unless evidence of benefit emerges which warrants development of a national screening program.

Staging and treatment

Recent increases in the detection of prostate cancer have highlighted uncertainty in both methods of treating early stage disease and treatment of metastatic disease, particularly in terms of quality of life and cost-effectiveness. A diversity of treatment practices reflect this uncertainty.

Ongoing audit is necessary as few Australian studies have reported outcomes of any form of treatment and there is often insufficient staging data to allow any comparison with international studies. Our ability to clarify the role of various treatments in prostate cancer is severely restricted by the lack of reliable evidence-based information. While the numbers required for screening studies in Australia would be high, outcome studies are certainly within the scope of the Australian experience.

3.3 Evidence-based practice in cancer control

In addition to cancer type specific issues described in the previous section, there are several issues that are common to all cancer types. For example early detection and accurate diagnosis are crucial to the effective treatment of most cancers. There are many similarities in the management of different cancers and other issues of general concern. The increasing complexity of cancer treatments, together with the necessity for treatment to be based on evidence of best practice, has led to widespread advocacy for clinical practice guidelines and to a belief that existing processes for multidisciplinary consultation should be extended. Other priority areas are palliative care, psychosocial care and the need to increase consumer involvement in all stages of cancer control.

Role of general practitioners in prevention and early detection

Most general practice prevention is described as opportunistic, despite the fact that 82 per cent of people visit their general practitioners at least annually (ABS 1992). In some practices, patients are contacted for specific preventive and screening procedures, but this is not common, because of the limited use of nurses in general practice and because individuals are not linked to particular general practitioners.

Opportunistic preventive activities can increase screening rates but it is difficult for Australian general practitioners to provide optimal preventive care (Ward et al 1991; Dickinson et al 1988; Dickinson et al 1989; Heywood et al 1994). But there are a number of barriers to cancer prevention in general practice. The beliefs of general practitioners and patients, paucity of resources, and the structure of primary medical care services form a complex set of factors which interact and limit the provision of preventive services in this setting.

Strategies that can overcome these barriers include:

- mass media campaigns;
- distribution of pamphlets in general practice waiting rooms;
- the adoption of practical, patient-centred general practitioner guidelines;

- audit of medical records with feedback;
- visits from practice facilitators to help set up a preventive care system;
- the use of inexpensive, reliable, fast and easy to use information systems about patients' individual risks and cost-effective management alternatives; and
- general practitioner input into planning and developing appropriate roles for general practitioners as part of all public health cancer programs.

Claims about remuneration issues for general practitioners which impede preventive care have been raised in the health sector over many years. Commonwealth funding through the General Practice Strategy has been designed to help overcome these problems, and the current review of the strategy may identify other opportunities in this area.

Clinical best practice

Evidence-based best-practice guidelines attempt to define and encourage best practice so that the most efficient and effective approaches to cancer prevention and treatment can be used and consistency in practice enhanced. As reviewing and interpreting available evidence to make decisions about what constitutes best practice is a considerable and complex task, it has been argued that a systematic and rigorous process with multidisciplinary input should be followed.

Progress has been made towards such a systematic approach in Australia. In 1995, the NHMRC published *Guidelines for the Development and Implementation of Clinical Practice Guidelines* (NHMRC 1995). This provides broad guidance on priority setting, review of evidence, development of guidelines, and dissemination, implementation, monitoring and evaluation of completed guidelines. Within the field of cancer control, a number of evidence-based guidelines have been developed, including *Guidelines for the Detection and Management of Early Breast Cancer* (NHMRC 1996). Guidelines for advanced breast cancer, ductal carcinoma *in situ*, colorectal cancer, and cutaneous melanoma are also being developed.

Currently, the major issues facing guideline development and implementation are:

- establishing priorities for the development of guidelines;
- establishing evidence-based strategies for dissemination and implementation of guidelines; and
- evaluating the cost-effectiveness of the guideline approach to promotion of evidence-based best practice in the health system.

Multidisciplinary care

Multidisciplinary care is commonly understood to mean care based on formal consultation between medical specialists — generally surgeons, radiotherapists, medical oncologists and pathologists. But the term is increasingly being used to describe care based on broader consultation that may involve specialists in diagnostic imaging, pharmacy, nursing, social and psychosocial work, and palliative and other support services.

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The phase of a particular illness and the goals of any intervention define the skills required of a particular team, rather than the medical or other qualifications of the individual professionals involved in such teams.

The distinction between phases of an illness are seldom clear cut. Overlap and continuity of special skills are needed. With several health professionals involved in multidisciplinary care at any one time, it is essential that one individual is identifiable as the overall manager and decision maker, working closely with the patient and the patient's general practitioner.

The extent of advocacy for multidisciplinary care reflects a widespread belief that benefit for the patient will ensue in many cancers when there is a process that ensures individual patients are treated by specialists from several disciplines. Evidence to support this approach is however inconsistent (Selby et al 1996). Nevertheless, multidisciplinary teams are increasingly being established in relation to both adult and childhood malignancy and are seen as 'state of the art'. Further investigation is needed to identify the cancers and stages of illness in which patients are likely to benefit from multidisciplinary care.

Palliation

Palliative care services provide physical, emotional, psychological and spiritual support for patients and their families facing a life-threatening illness. In Australia, approximately 80–90 per cent of people who use palliative care services have a diagnosis of cancer (Kasap & Associates 1996). The Australian Association of Hospice and Palliative Care (AAHPC) estimates that of 19,000 individuals who died receiving palliative care services in 1995/96, 17,100 would have died of cancer (AAHPC unpublished data).

In Australia, palliative care has emerged as a specialised field in the health care system, with significant growth in the number and type of palliative care services available. Currently, however, there is considerable variation in the range and quality of these services. Palliative care services are not able to meet current demand and not all Australians requiring palliative care have been able to access a consistent range of high quality and appropriate services.

The Palliative Care Program Review Steering Committee comprising representatives from the Commonwealth and State and Territory Governments, the Consumers' Health Forum, the Australian Catholic Healthcare Association and the AAHPC is currently developing a draft national policy framework for palliative care until 2003. The Committee is examining ways to improve access to high quality palliative care; continuity of care for all terminally ill people; enhanced options for treatment at home, hospital or hospice; and making palliative care an integral part of the health care system.

Psychosocial care

It appears that cancer patients are largely satisfied with the quality of technical care they receive, but less satisfied with other aspects of their care, including communication and supportive services (Wiggers et al 1990; Girgis & Foot 1995). There is a lack of information about whether interventions in these fields can make a difference for patients.

Consumer groups argue that many of their concerns relate to the manner in which reductions in morbidity and mortality in the cancer control field are apparently achieved. Undue emphasis placed on the disease may result in social, emotional and practical needs not being considered. Research tends to support this argument, revealing high levels of physical and psychosocial problems experienced by cancer patients (Newell et al, in press; Perkins et al, in press). The provision of information about tests, treatment and prognosis is also an issue.

There is a growing awareness that patients should be treated as active participants in their health care. While the NHMRC recommends that cancer patients should be encouraged to participate in decision making about their treatment (NHMRC 1995), there is contradictory evidence about the level of involvement patients actually desire (Degner & Sloan 1992; Johnson et al 1996). Additional research, suggesting that patients do better when involved in the decision-making process at their desired level, highlights the need for doctors and patients to communicate effectively in this area (Miller & Mangano 1983).

Research shows that patients' needs for information about their disease, its treatment and their prognosis are not being currently met (Rainbird et al, in press). Patients have indicated that they do not know enough about the possibility of the cancer spreading, dealing with fear of potential pain and suffering, coping with anxieties relating to having treatment, and keeping up with work commitments. Doctors tend to underestimate the amount of information their patients desire and they overestimate the amount of time spent providing that information (Waitzkin 1984). Given the central role that information has in allowing individuals to be active participants in decision making, and in satisfying medicolegal requirements, such findings are of concern and indicate the need for effective action.

Promising data on the survival benefits of psychosocial interventions with cancer patients (Spiegel et al 1981; Spiegel et al 1989; Fawzy et al 1990a; Fawzy et al 1990b) are currently being investigated in randomised trials in Australia (Kissane et al 1996). Critical components for quality improvement in clinical care include feedback of patient-generated data on routine clinical performance and improved training of clinicians. A review of over 200 studies of training programs that target communication and interaction skills confirmed the positive impact of training (Kern et al 1989).

Supportive care

Concerns have been raised by consumers about the apparent lack of recognition of the need for supportive care in cancer control. The NHMRC guidelines about the clinical management of early breast cancer emphasise the need for cancer specialists to provide appropriate and adequate counselling and support. This includes being offered adequate counselling, access to support groups and desired practical assistance. Such psychosocial support has been found to have beneficial effects on the patient's quality of life, emotional adjustment, social functioning, knowledge levels, coping skills and even their disease and treatment related symptoms (NHMRC 1995; Burke & Kissane 1996; Meyer & Mark 1995; Devine & Westlake 1995).

Development of a consumer network

The NCCI priority setting process has reinforced the need to establish a national consumer forum. Such a forum would aim to foster a national network of consumers and facilitate their active participation in cancer control. Consumers would be concerned with prevention, treatment and palliation of cancer and they would develop, implement and monitor the application of a national policy on the inclusion of consumer representatives in organisations involved in cancer control.

A consumer charter could be developed that embodies principles including consumer involvement in decision making; the right to an informed choice; care which takes account of physical, social, emotional and practical concerns; and equity of access to information and resources. This charter could be incorporated into accreditation and quality assurance programs of appropriate services and would be promoted through cancer networks, professional colleges, hospitals, research bodies and incorporated into funding guidelines for services. Such a charter could ensure comprehensive consumer participation in all aspects of cancer control.

3.4 Special populations

The underlying principles of health care delivery in Australia include the provision of quality health care to all Australians. However, special populations such as Indigenous peoples, people from non-English speaking backgrounds, socio-economically disadvantaged groups and people living in rural and remote areas all require special consideration.

Indigenous peoples

Cancer is the fourth most frequent cause of death for Indigenous males and the second most frequent cause for Indigenous females, accounting respectively for 10 per cent and 13 per cent of deaths in 1992–94 (Anderson et al 1996). Overall, mortality from neoplasms is higher among Indigenous males than females.

Indigenous mortality by type of cancer reveals a slightly different pattern than that obtained in the non-Indigenous population (Bhatia & Anderson 1995). Indigenous women have a high relative risk of cancer of the cervix; in 1992–94, it was estimated to be 8.3 times higher than that for non-Indigenous women (Anderson et al 1996). In comparison, the relative risk for prostate cancer among Indigenous males was found to be one-fifth of that noted for non-Indigenous males. Although the overall numbers are small, the relative risks for deaths from liver cancer and lung cancer are high among Indigenous Australians.

The death rate for cancer in the Indigenous population fluctuated widely between 1985 and 1994, especially for Indigenous males, so no consistent trend was observed. Mortality from specific cancer sites all decreased between 1989–91 and 1992–94, but only breast cancer mortality decreased significantly.

The greater preventable cancer mortality among Indigenous people may be attributable to a lack of access to effective and culturally appropriate prevention

and treatment programs, particularly those that focus on smoking, alcohol consumption and screening for cancer of the cervix. However, limited information has become available on the extent to which Indigenous Australians receive appropriate preventive care. Existing data suggest that up to 40 per cent of Indigenous peoples who smoke do not receive 'quit smoking' advice from a health care provider (Perkins 1995). Strategies for improving the delivery of such care by existing health care providers need to be developed.

Socio-economically disadvantaged people

Overall cancer mortality rates are up to 93 per cent higher among socio-economically disadvantaged groups in Australia than those in higher socio-economic groups (Mathers 1994). The principal contributor to this differential is a 152 per cent greater mortality due to lung cancer. Higher mortality rates among disadvantaged groups also apply for cancers of the mouth, pharynx, oesophagus, stomach, rectum, liver, larynx and cervix (Smith et al 1996).

The prevalence of smoking is significantly greater among socio-economically disadvantaged individuals, with males 43 per cent more likely to smoke and females 54 per cent more likely to smoke (Mathers 1994). Such differentials appear to be widening as a result of a more marked reduction in smoking rates among those who are socio-economically advantaged (MacFarlane & Jamrozik 1993). Women who are socio-economically disadvantaged are 18 per cent less likely than those in higher socio-economic groups to report having cervical cancer screening at the recommended interval (Mathers 1994).

Diet, smoking, occupational exposures and utilisation of health care services all play a part in creating these differentials. However, existing cancer risk reduction programs focus on reducing cancer risks in the community as a whole, rather than special groups, thereby failing to focus on specific social and economic factors that predispose disadvantaged individuals to such risks. Additional research is required to establish programs that have a greater capacity to reduce the prevalence of such risks among socio-economically disadvantaged people.

People from non-English speaking backgrounds

For some cancers, incidence rates are higher among migrants than among the Australian-born population. Migrants from northern Europe have greater incidence rates of lung, bladder and stomach cancers, whereas those from Fiji and Vietnam have a greater incidence of cancer of the cervix (MacCredie et al 1993). The differentials in incidence and mortality parallel differentials in risk behaviours and use of preventive services (Mathers 1994).

For many migrants to Australia, many factors may foster exposure to cancer risks and influence the pattern of health service utilisation. In order to address these issues, cancer control initiatives directed at developing culturally appropriate models of preventive health care delivery are required.

Rural and remote populations

In contrast to the patterns noted for injury mortality and morbidity, no large differentials in cancer mortality exist between Australians who live in rural and remote areas and those living in metropolitan areas, with the possible exceptions of breast cancer and melanoma. In 1991–95, death rates for all neoplasms were similar across all seven of the Rural, Remote and Metropolitan Area (RRMA) categories (see Appendix 2) (Titulaer et al 1997). Mathers (1994) found lower breast cancer mortality in non-metropolitan areas. Titulaer et al (1997) reported slightly lower rates of melanoma deaths in the remote zone.

Some differences have been reported between RRMA categories with respect to self-reported actions taken to reduce cancer risks. Respondents to the 1995 National Health Surveys from remote areas reported the use of sun protection more often than those living in other areas (Titulaer et al 1997). Mathers (1994) reported that females residing in non-metropolitan areas were more likely to smoke, and males in these areas were more likely to consume alcohol at 'at-risk' levels. In terms of health care utilisation, Australians in non-metropolitan locations were less likely to consult a doctor, but more likely to visit hospitals as outpatients. Women in non-metropolitan areas were less likely to have regular mammographic screening, but more likely to have regular cervical screening.

Available data do not provide a clear understanding of the need for, and access to, cancer control services in rural and remote areas. Particular issues that are of concern involve:

- accessibility of specialist cancer diagnostic and treatment services;
- accessibility of cancer-oriented support services; and
- strategies for providing cancer control programs in rural areas that are directed at reducing the risk of melanoma, lung cancer, breast cancer, cervical cancer and cancers associated with high levels of alcohol consumption.

3.5 Familial cancers

Most cancer occurs as a result of an interaction between genes and the environment. Advances in genetic technology have allowed a detailed understanding of the importance of genetic changes in the evolution of cancer. Some of these advances can be directly applied to cancer screening and prevention now, while further research is needed to refine current understanding and apply the advances to cancer diagnosis and treatment.

Family history is a risk factor for many common cancers, including breast, colorectal, prostate and melanoma. Approximately 20 per cent of cancer patients have a family history of cancer which may be due to genetic factors, common environmental factors or due to chance. An additional 5–10 per cent of all cancers are due to inheritance of genetic susceptibility that increases the lifetime risk of cancer. Individuals within these families who have inherited the specific mutation have a high (80–100 per cent) risk of developing cancer. In addition, gene carriers (heterozygotes) develop cancer some 10–20 years before the average age at which the cancer occurs in the general population. Thus, familial cancers may be associated with more potential years of life lost and cost to the community than other cancers. The ACN has

submitted comprehensive guidelines on the management of familial cancer in Australia to the NHMRC for endorsement. These guidelines cover all aspects of familial cancer considered in this section.

The identification of cancer predisposition genes involved in the inherited susceptibility to the common cancers has resulted in an improved understanding of cancer risk based on family history. Further, the ability to test for mutations in these genes offers the prospect of accurate identification of those individuals at a significantly increased risk of cancer. In those individuals, targeted cancer prevention and early detection measures should result in a reduction of morbidity and mortality from cancer. The genes involved in the inherited susceptibility to cancer have also been implicated in the more common, non-familial forms of these cancers. Knowledge of the normal function of these genes and their role in carcinogenesis will be applicable to all cancers.

Significant progress has been made in the identification of genes involved in the susceptibility to cancers. Some 10 per cent of all colorectal cancer (and up to 20 per cent of early onset colorectal cancer) may be due to mutations in genes involved in DNA repair. Similarly, 5 per cent of all breast cancer (and up to 15 per cent of early onset breast cancer) is due to mutations in genes such as BRCA1 and BRCA2. Melanoma and prostate cancer are other common forms of cancer in which inherited susceptibility plays an important role.

It is estimated that about 1,000 new cases of cancer a year in Australia are due to deleterious genes which are passed down from generation to generation within families. They result in some 300 deaths each year. The number is similar to the number of deaths from cancer of the cervix, for the prevention of which large resources are made available. By establishing an individual's genetic risk early, a significant proportion of the familial cancer deaths could be prevented now, and morbidity associated with other cancers significantly reduced (Järvinen et al 1995; Lynch & Lynch 1995; Lynch & Smyrk 1996).

Increasing awareness of family history as a risk factor has created a demand for access to specialised cancer genetic services. Through expert genetic counselling, individuals at high risk for the cancer are given accurate information about the probability of their developing the disease and the options available for prevention/early detection. In some cases, genetic testing may be used to clearly identify those individuals in a family who are at increased risk to develop the disease. Others in the family identified not to carry the mutation could avoid unnecessary and expensive cancer screening and may be relieved of their anxiety.

For example, individuals who inherit FAP genes are at greatly increased risk of developing colorectal cancer. A test for mutations in the gene involved in FAP is now available. Family members found to carry a mutation can be offered careful surveillance until the time when surgical removal of the bowel is indicated. Such predictive testing requires extensive genetic counselling with preparation for a positive or negative test result. Thus, although FAP accounts for less than 1 per cent of the 10,000 new cases of colorectal cancer diagnosed in Australia each year, the medical, social and financial impact of this cancer is high.

In Victoria, the Colorectal Cancer Genetics Program is underway, as a major pilot study for comprehensive and organised cancer genetics services.

3.6 Research and data collection

While there may be debate about the adequacy and distribution of funding and the content of policy, Australian Governments and the community have shown strong commitment to cancer research through policy, funding and support for institutional infrastructure. This covers the full spectrum of cancer control, from the basic biology of cancer genetics and molecular epidemiology, to clinical trials and psychosocial/behavioural research. However, Australian health systems are going through major changes and a continuing stable commitment to cancer research is needed.

Currently, approximately 12 per cent of government funding allocated through the NHMRC goes to cancer research.

Table 3.1 NHMRC funding for research in NHPAs: actual expenditure and percentage of total expenditure

Year	Total	Injury		Mental health		Cardiovascular		Cancer		Diabetes		Indigenous health	
	\$m	\$m	%	\$m	%	\$m	%	\$m	%	\$m	%	\$m	%
1994	121.24	2.10	1.7	15.19	12.5	23.34	19.3	15.50	12.8	2.97	2.4	N/A	
1995	131.15	2.00	1.5	17.89	13.6	24.86	19.0	13.74	10.5	3.06	2.3	N/A	
1996	145.20	2.37	1.5	20.69	14.3	26.73	18.4	16.13	11.1	3.07	2.1	2.51	1.7
1997	150.75	2.35	1.6	22.95	15.2	29.70	19.7	17.57	11.7	3.61	2.4	2.52	1.7

- Note:*
1. These figures are based on NHMRC and RADGAC funding and also include pro-rata expenditure estimates of relevant research done in NHMRC funded research institutes where appropriate.
 2. Indigenous health is a designated priority population within the National Health and Priority Areas process.
 3. Data not available for Indigenous health research funding in 1994 and 1995.

Source: NHMRC.

Types of research

In discussing research, it is helpful to distinguish between basic, strategic and applied research.

Basic research is directed towards advancing the frontiers of knowledge. For example, the basic curiosity driven research done in the 1950s on the structure of nuclear DNA, which won a Nobel Prize for James Watson and Francis Crick in 1962, laid the foundation for research into the genetic basis of disease.

Strategic research is also directed at advancing the frontiers of knowledge, but towards a particular health problem. The findings of such research will contribute knowledge and understanding of a health problem, with the potential for further development and evaluation leading to reducing the impact of the problem. Such research is usually investigator initiated. The importance of investigator-initiated strategic research is illustrated by the insights that are emerging from mechanistic studies that seem likely to lead to the next generation of progress in cancer prevention. Some examples are:

- inhibitors of specific cyclooxygenase pathways have recently given justification for studies of colorectal cancer prevention;

- identification of HPV as the major carcinogen responsible for cancer of the uterine cervix and of *Helicobacter pylori* as a cause of gastric cancer (derived from observations made in Australia) opens the door to studies of vaccines and preventive antimicrobial interventions;
- linkage of hepatitis B and C viruses with hepatocellular carcinoma opens another avenue for prevention;
- recent insights from strategic research into nicotine addiction are leading to pharmacologic strategies for the enhancement of behavioural approaches to tobacco control, with possible implications for reducing lung cancer; and
- Australian research on factors governing white blood cell activity is revolutionising the control of cancer by chemotherapy.

Applied research is undertaken with the specific aim of achieving some predetermined objective, such as the development and evaluation of a vaccine or new diagnostic tool. It may lead to specific development activities to produce a commercial product or new treatment protocol. For example, applied research includes development of a *Helicobacter* treatment regimen, gene therapy for genetically caused diseases, and other cancer treatments.

The importance of a diverse, but strong, basic and strategic research capacity should not be underestimated. It is critical to the development of solutions to the world's health problems as the directions from which a solution may come cannot easily be forecast. While it is important to identify the strategic areas in which research should be undertaken, it would be inappropriate to be too prescriptive and stifle novel approaches.

Transfer of research information

The development of evidence-based practice and policy advice for cancer control depends upon improvements in the linkages between research and decision-making processes in cancer prevention and care. This applies at individual, population and policy levels. Traditional mechanisms for disseminating research results often fail to engage practitioners and policy makers. For research to contribute most effectively to cancer control, mechanisms for promoting research transfer must be enhanced.

Some suggested priorities for cancer research

There are some important gaps in our knowledge of cancer prevention, early detection and treatment which need to be further researched.

- **Research on human behaviour** – Human behaviour and its resistance to change are acknowledged as the greatest barriers to the control of cancer. There have been gains in raising awareness of the dangers of behaviours such as smoking and unprotected sun exposure, but behaviour change is difficult to achieve. A better understanding of methods of behaviour modification is also needed for promoting the uptake of research-based knowledge into health care practice by health care professionals. Effective research transfer depends upon a readiness of health care professionals to change their practices and adopt new treatments.

Opportunities for cancer control in Australia

- **Research on methods of preventing cancers for which potentially preventable causes are known** – For some types of cancer, potentially preventable causes have been identified, but it is not known how to implement prevention. For example, large proportions of cases of cancer of the cervix and stomach are due to infections but no effective strategies exist to prevent them.
- **Research on effective methods of early detection and treatment** – Irrespective of the potential for primary prevention, effective early detection and treatment will contribute to the control of some cancers. These include, for example, cancers of the breast and cervix.
- **Research on genetics of cancer** – There is now a good understanding of the genetic basis of cancer. Advancements in genetic technology are creating new opportunities for understanding the causes of cancer, the detection and management of cancer risk, the early detection of cancer, and cancer treatment. Continuing support of both basic and strategic research in cancer genetics is a clear priority for the future of cancer control. Moreover, failure to invest wisely in Australian research on cancer genetics now is likely to lead to a future need to import expensive genetic technology.
- **Research on screening techniques** – Screening for cancer generally is a key area requiring focused research expertise. Large investments are already being made in cancer screening, either formally (eg for cancers of the breast and cervix) or informally (eg for cancers of the skin and prostate). It is doubtful whether all of these investments are yielding adequate returns. There are many unanswered questions about the performance of particular screening techniques, the efficacy and effectiveness of both prospective and established screening programs, and the efficiency and cost-effectiveness in practice of most of the established programs.

Participation in clinical trials

Evidence from randomised, controlled clinical trials is considered to be the standard for the evaluation of therapeutic effectiveness and provides the highest level of evidence on which to base individual patient recommendations (Sackett et al 1996). Major advances in the prevention, early detection and treatment of cancer have occurred through the use of randomised, controlled trials. Many clinical trials demonstrate only modest advances, but even these may translate into considerable community benefits.

Large numbers of patients are needed to accurately demonstrate such improvements. But no more than 3 per cent of patients with common cancers such as breast or colon cancer, and less than 1 per cent of cancer patients overall, receive treatment as part of a clinical trial (Fisher 1991). Participation among people from minority groups and non-English speaking backgrounds is even lower. Continuing low accrual rates significantly prolong the time taken to complete a trial, delaying potentially important results and threatening the viability of clinical trials.

Participation in clinical trials may offer benefits to individual patients. Patients invited to participate in a clinical trial should receive either the current best standard therapy or a therapy thought to be at least equally effective. There is some evidence that patients treated in clinical trials have better outcomes than patients receiving treatment outside trials (Davis et al 1985). This may be explained, in part, by the selection of patients with better-than-average prognoses for inclusion in clinical trials, but it may also reflect differences in the care received in a clinical trial. There is also evidence that doctors who participate in clinical trials incorporate the results of randomised trials more rapidly into routine clinical practice than doctors who do not (Ketley & Woods 1993).

Factors influencing patients' participation

Community understanding of randomised trials is generally poor, especially the need for randomisation. Younger people, women, those who have higher levels of education or are from higher socio-economic backgrounds and people expressing a desire to make their own decisions about treatment are all less likely to participate in clinical trials (Llewellyn Thomas et al 1995). Greater community awareness of the need for clinical trials and the manner and safeguards with which they are conducted is needed.

Factors influencing doctors' participation

Doctors may be uncomfortable inviting patients to participate in randomised trials. For example, Taylor et al (1984) have found that concerns regarding the doctor-patient relationship, difficulty in obtaining informed consent and a dislike of open discussions about uncertainty were the most commonly cited reasons for not entering patients into a randomised trial of partial versus total mastectomy.

A survey of Australian cancer specialists' attitudes to randomised trials in breast cancer have found that resource issues and concerns about the current trials (uninteresting research questions or inappropriate choice of standard therapy) are the cited reasons for not participating (Ellis 1997). There is a limited pool of central funding available for clinical research and hospitals provide little infrastructure for clinical research. Factors such as the availability of data management, availability of time, past experience with clinical trials and a feeling that the extra effort involved in trial participation is not justified are also cited as reasons for not participating.

Clinical trials should directly address key outcomes such as improvements in patients' quality of life or survival, rather than addressing indirect surrogate end-points such as tumour response. There are a number of important questions in cancer control about the relative merits of different treatment approaches. Many doctors express discomfort randomising patients on to trials with very different treatment options (eg radiotherapy versus surgery), or with large differences in the expected toxicity of treatment (eg high-dose versus standard-dose chemotherapy).

Data collection

Reliable data provided to clinicians, policy makers and consumers are required for the successful planning and evaluation of cancer control activities and for quality assurance and improvement. The capacity to collect standardised national data sets and incorporate them in a feedback loop to help guide clinical and public health practice is important for the systematic and informed progression of a national cancer control program in Australia.

Some gaps and issues for national cancer control data are outlined in Appendix 2.

3.7 Setting priorities and future directions

Cancer control in Australia encompasses a broad range of activity and effort. A consideration of specific cancer types, the stages along the continuum of care and other categories of health system activity that are relevant to cancer control have identified the complex nature of this activity, as well as gaps and problem points in the system. This discussion suggests a number of areas where there are opportunities to improve cancer control in Australia.

It is important for those involved in cancer control to recognise the role and rights of consumers in all its aspects. People who have cancer, together with their families and carers, must be involved as far as practicable in all phases of treatment, both curative and palliative, as well as having their social and psychosocial needs addressed.

Preventive and screening programs must be accessible as well as effective and should attempt to reach all population groups. This may involve further research, development and implementation of recruitment and targeting strategies specific to priority populations with higher rates of various cancer types.

All individual, environmental and social preventive strategies should be tested to determine their cost-effectiveness in achieving the desired outcomes. Current and any proposed screening programs should be developed in a way which ensures cost-effectiveness and sustainability, as well as acceptability by target groups and the whole community.

General practitioners have a central role to play in cancer control. Financial incentives to promote best practice among general practitioners have already been trialed through the General Practice Strategy. This strategy is currently under review and there is much interest in how the revised strategy might impact on the further promotion of best practice among general practitioners.

In the treatment of individual cancers, best practice is determined by the strength of evidence for the treatment modality or combination of modalities which leads to the best outcome for patients.

Setting priorities and future directions

Within Australia's complex health system, there are many opportunities for incentives to promote the adoption of evidence-based best practice. The Commonwealth Government has scope to provide financial incentives to promote best practice and discourage inappropriate practice, either through dedicated programs such as the General Practice Strategy, or through national health financing systems such as the Medicare Benefits Schedule and the Pharmaceutical Benefits Schedule. In addition, schemes to promote coordinated care may suggest ways to improve care and achieve better cost-effectiveness. The States and Territories also have a range of opportunities to provide financial incentives to promote best practice, especially through the public hospital system.

Professional organisations such as the Colleges can provide a range of strategies aimed at promoting best practice among peers. Many already do so by participating or driving the development of best-practice guidelines, and providing a range of other services, courses and education packages to promote best quality care among their members.

It is important to promote research which addresses important gaps in our knowledge of cancer prevention, early detection and treatment, and continue fostering a strong and diverse system of basic and applied research. The development of evidence-based practice and policy advice for cancer control depends upon improvements in the linkages between research and decision-making processes in cancer prevention and care.

Improving and maximising the use of data as an essential tool in decision making is also an important component of promoting evidence-based best practice in cancer control, across the whole spectrum of endeavour from prevention through treatment to palliation. Data should be collected in a timely fashion on a systematic basis and in accordance with nationally agreed data definitions. Data can be collected and used to assess the efficacy of preventive and screening programs, as well as for assessing clinical practice and outcomes.

The development of model centres of excellence in cancer care should be encouraged. These centres should involve all relevant providers and could be constructed by consolidating existing structures or by instituting new structures which ensure that people with cancer receive treatment, rehabilitation and palliation in the most effective way possible. Where it is not possible for all modalities of care to be geographically co-located, coordinated care could be sustained by ensuring that each provider of cancer care is affiliated to recognised centres of excellence in cancer care. These affiliations can also be encouraged between centres and/or practitioners in rural and remote areas and city-based centres.

In all cases, educational and training programs must be developed to ensure that the concept of an evidence basis for preventive, screening and therapeutic measures and the use of a systematic clinical database for the continuing evaluation of the evidence base is accepted as an integral part of the undergraduate and postgraduate medical curricula.

