



Australian Health Ministers' Conference

**National Service
Improvement
Framework for
Cancer**

CANCER

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Contents

PREAMBLE: NATIONAL SERVICE IMPROVEMENT FRAMEWORKS

Introduction	1
Why National Service Improvement Frameworks?	1
What are National Service Improvement Frameworks?	2
Guiding Principles	3
Action Points	3

CHAPTER 1: NATIONAL SERVICE IMPROVEMENT FRAMEWORK FOR CANCER

Overview of National Service Improvement Framework for Cancer	6
Approach to the National Service Improvement Framework for Cancer	6
The National Service Improvement Framework for Cancer	7
The Framework and its scope	7
The analysis	8
Key Considerations	10
Critical Intervention Points for Cancer Control	10
Reduce risk	10
Find cancer early	10
Management and support during active treatment	11
Management and support after and between periods of active treatment	11
Care at end of life, if cancer is not curable	11
National Priority Actions for Change	11

CHAPTER 2: REDUCE THE RISK OF CANCER

People's Needs	13
Optimal Services	13
Rationale for the components of Optimal Services and Critical Intervention Points	15
Information about risk reduction	15
Environments to reduce cancer risk	18
Environmental strategies to reduce rates of smoking	18
Environmental strategies to increase rates of skin protection	19
Environmental strategies to increase rates of physical activity	19
Environmental strategies to increase healthy diet	20
Encouraging risk reduction	20
Mass media campaigns	20
Health professionals advice	21
Smoking cessation programs	21
Reducing risk in special needs communities	21

CHAPTER 3: FIND CANCER EARLY

People's Needs	23
Optimal Services	23
Screening	23
Diagnosis	24
Rationale for the components of Optimal Services and Critical Intervention Points	26
High quality screening programs	26
Information about screening programs	27
Access to and participation in screening programs	28
Information about signs and symptoms	29
Access to high quality diagnostic services	30
Information and support in diagnosis	32
Access to diagnostic services for communities with specific needs	33
Provision of results	33
Referral to treatment	35

CHAPTER 4: TREATMENT AND SUPPORT DURING ACTIVE TREATMENT

People's Needs	37
Optimal Services	38
Rationale for the components of Optimal Services and Critical Intervention Points	40
Access to treatment	40
Seamless and continuous care	43
Evidence-based treatment	45
Clinical practice guidelines	45
Local protocols, audit and quality improvement	46
Clinical trials	47
Multidisciplinary care	47
Acceptable, accountable and appropriate care	49
Information about treatment	50
Written information	50
Patient held records and treatment plans	51
Communication with the treatment team	51
Appropriate support	51

CHAPTER 5: MANAGEMENT AND SUPPORT AFTER AND BETWEEN ACTIVE TREATMENT

People's Needs	55
Optimal Services	55
Rationale for Optimal Services and Critical Intervention Points	56
Issues in cancer survivorship and living with cancer	56
Transition from active treatment	57
Care planning for follow up of cancer survivors	57
Managing effects resulting from treatment	58

CHAPTER 6: CARE AND SUPPORT AT END OF LIFE

Individual and Family Needs	61
Optimal Services	62
Rationale for the components of Optimal Services and Critical Intervention Points	62
Needs of people with a life limiting illness	62
Organisation of services: palliative care, coordination and integration	63
Palliative care	64
Supportive network: family, friends and other caregivers	65
Services that meet physical, psychological, social and other needs	65
Providing care to groups with special needs	66
Information and choice for people with cancer	67
Bereavement	67

CHAPTER 7: CRITICAL INTERVENTION POINTS FOR CANCER CONTROL

Selection of Critical Intervention Points	69
The Critical Intervention Points	69
Reduce risk	69
Find cancer early	70
Management and support during active treatment	70
Management and support after and between periods of active treatment	70
Care at end of life, if cancer is not curable	70

CHAPTER 8: NATIONAL PRIORITY ACTIONS FOR CHANGE

Overview	71
Priority Actions	71
Next Steps	72

ACKNOWLEDGEMENTS 73

REFERENCE LIST 75

PREAMBLE:

National Service Improvement Frameworks

INTRODUCTION

In October 2002, the Australian Health Ministers' Advisory Council agreed to the development of National Service Improvement Frameworks for the national health priority chronic conditions of cancer, diabetes, asthma, cardiovascular disease and stroke, and arthritis and musculoskeletal conditions, under the auspices of the National Health Priority Action Council. The frameworks are joint initiatives of the Australian and State and Territory Governments.

The National Health Priority Action Council's purpose is to drive health service improvements to achieve better health outcomes for all Australians, including disadvantaged groups, for the national health priority chronic conditions.

The National Service Improvement Frameworks are an integral component of a broader National Chronic Disease Strategy, being developed by the National Health Priority Action Council under the health reform agenda.

The Frameworks draw upon the expertise of a range of stakeholder groups including leading clinicians, Australian and state and territory policy makers, consumers and members of non-government and other health organisations. The Cancer Framework was the first to be developed.

WHY NATIONAL SERVICE IMPROVEMENT FRAMEWORKS?

The National Service Improvement Frameworks are important tools to bring about more person centred, equitable, timely, effective and affordable care for all Australians, and a more cohesive approach to health care delivery.

They recognise that the provision of high quality health services is complex, as it is a shared responsibility of Australian and State and Territory Governments, the public and private sectors and non-government organisations. Service delivery partnerships, multidisciplinary teams, and seamless, coordinated and psychosocial care are strongly encouraged as part of optimal care.

The frameworks also recognise that the health of individuals and populations is influenced by many factors (e.g. biomedical, lifestyle and behaviour, knowledge, attitudes and beliefs, genetic and environmental factors) that may act alone or in conjunction with others. They acknowledge that the existence of co-morbidities in individuals and populations can lead to complex care needs.

In driving improvements in health services for people with National Health Priority Area chronic conditions, the aims of the frameworks are to:

- prevent and limit the progression of these chronic conditions
- slow the onset of the complications that can cause severe disabilities

- reduce preventable hospital admissions
- reduce variations in care that are provided
 - by different clinicians and health services
 - to people from metropolitan, regional, rural and remote areas, and
 - to disadvantaged groups.

WHAT ARE NATIONAL SERVICE IMPROVEMENT FRAMEWORKS?

The National Service Improvement Frameworks are high level guides for health services to inform:

- consumers
- clinicians
- planners and designers
- policy makers, funders and providers
- professionals and managers.

They are designed to support and complement state and territory clinical frameworks and local plans as well as the range of national initiatives already established or in train. These broader public health strategies are aimed at reducing the burden of chronic non-communicable diseases such as the national tobacco, alcohol, nutrition and physical activity strategies.

Many chronic diseases have common risk factors (e.g. nutrition, obesity and physical activity). Attention to lifestyle behaviours may prevent or delay their onset as well as reduce progression and complications.

The frameworks are not intended to replace clinical practice guidelines and pathways, or processes of accreditation, clinical audit or benchmarking approaches. Rather, they are provided to encourage the adoption of processes so as to translate evidence into practice. They don't attempt to prescribe what services will look like at the jurisdictional or local level. The frameworks therefore state what needs to happen to achieve optimal care in cancer. They are not, however, implementation plans or guides as to how to achieve change. Separate implementation plans will be developed in consultation with State and Territory Governments and other key stakeholders.

Many of the building blocks already exist to facilitate the delivery of optimal services. States and territories have their distinctive arrangements and programs to deliver care to their communities, including a range of local service plans, service frameworks and strategies. These, together with Australian Government programs, joint national initiatives, and activities of non-government organisations, are consistent with, supported and complemented by the frameworks. Examples include diagnostic and screening services (e.g. breast cancer screening services), and treatment and rehabilitation services provided by states and territories.

GUIDING PRINCIPLES

The following guiding principles are being applied in mapping out the health service needs of the Australian community through the National Service Improvement Frameworks:

- placing people, families and communities affected by chronic diseases at the centre of care
- spanning the continuum of care and life course for the condition—embracing where required prevention, screening, diagnosis, management, rehabilitation, living with the condition, and palliation
- spanning different clinical and community settings
- supporting the application of evidence-based practice
- focusing on disadvantaged and special population groups having appropriate health services.

People, carers and families affected by chronic disease are acknowledged as part of the broader experience of these conditions. Disadvantaged groups include people with mental disorders, people who are socioeconomically disadvantaged, people in regional, rural and remote communities, people from culturally and linguistically diverse communities, and particularly Aboriginal and Torres Strait Islander people. Additionally, it is acknowledged that special population groups such as people who are frail aged, people who are younger or with disabilities, may have special needs.

ACTION POINTS

The National Service Improvement Frameworks identify Critical Intervention Points—those opportunities representing aspects of prevention and care where Australia might most usefully invest.

Critical Intervention Points have been selected through identifying the:

- needs of the well community for information about a chronic disease
- needs of people with a chronic disease
- optimal system or service response
- gaps between the optimal system or service and what currently happens
- gaps representing the best opportunity for gains in health outcomes and improvement at the system level.

Broad strategies for the adoption of the frameworks and improvements to care focusing on the Critical Intervention Points are also outlined, covering national, regional, rural, remote and local levels. Specific performance measures will be used to assess whether service improvements are taking place.

CHAPTER 1. National Service Improvement Framework for Cancer

Cancer is a chronic and complex set of diseases with different tumour sites. For some cancers, there is considerable knowledge about their causes and optimal treatment. This varies for other cancers. The outcomes for people with cancer also vary markedly, as does the experience of each individual, often referred to as the ‘cancer journey’.

The Australian health system is complex. Initiatives related to cancer control are many and diverse. The Australian Government has a leadership role in policy making and particularly in national issues like public health, research and national information management. State and Territory governments are primarily responsible for the delivery and management of public health services and for maintaining direct relationships with most health care providers, including the regulation of health professionals. The Cancer Councils, the National Cancer Control Initiative, the National Breast Cancer Centre and the Clinical Oncological Society of Australia play an important role in research, education, programs for prevention and detection, and management. Also important are consumer groups, community organisations, general practitioners, allied health professionals, professional bodies, educational institutions and the private sector.

To coordinate these differing roles and improve the efficiency of health care, the Australian and State and Territory governments work together on a range of major health initiatives, including cancer control, through the National Health Priority Area (NHPA) initiative.

Cancer became a NHPA in 1996. Eight priority cancers have been identified by all jurisdictions where significant health gains may be made through prevention, early detection and evidence-based management. These are breast cancer, cervical cancer, bowel cancer, lung cancer, melanoma, non-Hodgkins lymphoma, non-melanoma skin cancer, and prostate cancer.

Those cancers which represent the highest burden of disease are bowel cancer for its high incidence and lung cancer for its high mortality. The highest incidence of cancer in males is prostate cancer and breast cancer for females. Cancer continues to rise with a disproportionate rate of cancers in disadvantaged groups—e.g. high rates of lung cancer in low socioeconomic populations.¹

In 2002 approximately 459 000 people were newly diagnosed with cancer.¹ This includes 85 000 cases other than common skin cancers and about 374 000 non-melanoma skin cancers (a less threatening form of skin cancer). Excluding these skin cancers, cancer will affect one in three males and one in four females in Australia before the age of 75 years.¹ In 2001 there were an estimated 267 600 people in Australia with malignant cancer living in private households.²

Cancer is the most common cause of years of life lost for Australians aged 25–64 years—economically important years. Most cancer deaths in males are from lung cancer and breast cancer in females. Cancer currently accounts for about one-third of male deaths and one-quarter of female deaths.¹

Five-year survival rates for the most common cancers affecting men (prostate cancer) and women (breast cancer) are now more than 80%. In international comparisons, our cancer survival rates are second only to the US, with death rates in Australia falling on average by about 1.9% during the last decade alone. In 2002 more than 37 000 Australians died of cancer.²

While Australia is doing very well in relation to both survival and quality of life indicators, we could do much better by systematically implementing best practice treatments for people with cancer from the time of diagnosis.

Cancer requires highly specialised care. Care is delivered in a number of settings, by a number of health professionals, and through varying modes of treatment, e.g. surgery, chemotherapy, and radiotherapy. Increasingly, this care is being delivered in the community rather than only in acute care settings. Contributing to this growing trend has been increased survival with more periods of remission, new technologies and outpatient treatment options such as chemotherapy services.

The National Service Improvement Framework for cancer (referred to as the 'Framework') is the first to be developed and will serve as the prototype for the other health priority area chronic conditions. The frameworks are intended to be tools to drive improvement in health services for people with national health priority conditions to achieve better health outcomes for all Australians, including disadvantaged groups.

OVERVIEW OF NATIONAL SERVICE IMPROVEMENT FRAMEWORK FOR CANCER

This Framework is intended to outline what all Australians with or at risk of cancer should expect to receive through the Australian health care system, irrespective of where they live.

For people with cancer, the patient journey is complex and difficult. Indeed modern health care is probably the most complex activity ever undertaken by human beings.

Every person with cancer is unique. So each cancer journey is different. Yet drawing together evidence from studies and stories helps identify where critical improvements can be made at the national level, and provides ideas about what we know about successful health service arrangements.

This Framework describes what is currently known about high quality care for cancer. It also takes into account where in the body cancer is located as this is critical to optimal care.

As services are organised and resourced very differently in different parts of Australia, this Framework does not attempt to prescribe what services will look like at the jurisdictional or local level. It focuses instead on what should be expected to happen for all people with cancer, based on optimal pathways of care.

The adoption of the Framework will require a systematic implementation plan developed in consultation with states and territories, professional colleges, non-government organisations, consumer groups and other key stakeholders.

APPROACH TO THE NATIONAL SERVICE IMPROVEMENT FRAMEWORK FOR CANCER

A number of principles underlie the development of the Framework. The Framework:

- includes strategies for prevention through to care at the end of life—prevention is a critical component of cancer control since it can best reduce both future new cancers (cancer incidence) and, therefore, the number of people needing treatment for cancer, and also decrease the number of people who will die of cancer
- is based on the needs of people with cancer, carers, families and communities to reduce the burden of illness and distress associated with cancer—these needs are used to identify optimal cancer services; they are identified in the sequence of the cancer journey and are not in priority order

- considers the provision of best practice cancer care to all Australians—this requires the development of appropriate service delivery models for people living in regional, rural and remote areas, for people managed in the public and private sectors and for those aspects of treatment provided outside major centres with particular expertise
- recognises that some communities and individuals need special programs and services to ensure that they can access appropriate cancer care—these include, but are not limited to, people living in regional, rural and remote areas of Australia, people from culturally and linguistically diverse communities and lower socioeconomic backgrounds, and Aboriginal and Torres Strait Islander peoples
- draws on existing international and national plans—including the UK's National Cancer Plan³ and Australia's cancer plans and policies, including states and territories; it also draws on a number of recently developed documents including Optimising Cancer Care in Australia⁴, Priorities for Action in Cancer Control⁵, the report of the Radiation Oncology Inquiry⁶, the report from the Cancer in the Bush conference⁷
- recognises that, although hospitalisation and specialist treatment are critical components of combating cancer, a large part of the journey for people with cancer takes place in the community, where primary care providers, such as GPs and community nurses, are the cornerstones of continuing care
- identifies Critical Intervention Points, which provide an opportunity for improving cancer control; the Critical Intervention Points are based on the best available evidence.

THE NATIONAL SERVICE IMPROVEMENT FRAMEWORK FOR CANCER

The Framework and its scope

The Framework is illustrated in **Figure 1** (page 9).

It indicates that people and services range across a continuum from well people in their communities, through detection and diagnosis to people living with cancer. Five main phases are identified as follows:

People want to:

- reduce their risk of developing cancer
- find cancer as early as possible, if early treatment is effective
- have the best treatment and support during active treatment
- have the best treatment and support after and between periods of active treatment
- have the best care at the end of life if the cancer is not cured.

Although the Framework does not address specific tumour sites or target groups (for example Aboriginal and Torres Strait Islander populations or paediatric cancers), it does draw upon the available evidence—most of which comes from the national priority cancers. The priority cancers are breast cancer, bowel cancer, lung cancer, skin cancer, melanoma, prostate cancer, cervical cancer and non-Hodgkin's lymphoma. The Framework also recognises the strong track record of paediatric oncology in relation to best practice care, for example patient enrolment in clinical trials, effective care coordination and multidisciplinary care.

The analysis

The Framework applies a systematic analysis of evidence and consensus to consideration of each phase along the continuum of care by asking:

What are optimal person-centred cancer services?

The optimal services are defined by an analysis of:

- the needs of people, families and communities affected by cancer
- what is known about the effectiveness of different types of service provision.

What is happening now?

Current care is described in relation to both needs and service provision. In some areas, this analysis is limited by a lack of data about many aspects of current care.

What is needed for change to occur?

The Framework identifies system level changes that should assist in improving cancer control. It also identifies, where possible, some models of good and innovative practice.

What are the priorities for improving care?

The Framework identifies 19 opportunities for improving cancer control in Australia by comparing optimal services with current provision. The opportunities for improving care or Critical Intervention Points represent those aspects of care where Australia might most usefully invest to reduce death and distress from cancer. The identification of priorities is based on consideration of whether the aspect of care:

- is important in terms of death, suffering or health care costs
- is currently suboptimal given what is known about optimal services and about current care, and
- can be significantly improved.

What are the national priority actions for change?

There are eight priority actions which underpin the Critical Intervention Points. If these actions were undertaken by national and state/territory governments, the basis for establishing many of the optimal services identified in the Framework would be in place.

FIGURE 1: NATIONAL SERVICE IMPROVEMENT FRAMEWORK
Cancer

Organising matrix for service improvement

		Condition of Cancer			
		Well Community (including those at increased risk)		People with the condition (and their families and carers)	
	Reduce Risk	Find the condition early	Have the best treatment and support during active treatment	Have the best treatment and support between and after active treatment	Have the best care at the end of life
AIM— People will be able to:					
WHAT ARE THE OPTIMAL PERSON OR PATIENT CENTRED SERVICES FOR THE CONDITIONS?					
People's needs		↓ The needs of people who have or are at risk of the condition →			
Optimal Services					
WHAT IS HAPPENING NOW?					
Current practice in meeting people's needs and providing optimal services		↓ Gaps in current care →			
WHAT ARE THE PRIORITIES FOR IMPROVING CARE?					
		↓ Where do the gaps between the optimal services and current practice matter? →			
WHAT ACTIONS ARE NEEDED FOR CHANGE TO OCCUR?					

Making Change from the needs of individuals

To Systems Change

Key Considerations

There are several considerations in interpreting the Framework:

- the analysis is limited by a lack of evidence about the costs, benefits and feasibility of different models of service provision in Australia; it is often difficult to generalise strategies and approaches from Europe or North America because of the different organisation of health services, different geography and different populations
- similarly, the analysis is limited by a lack of data about many ways in which current cancer care is provided in Australia—there have been few patterns of care studies about the provision of treatment and there is very little information about approaches to diagnosing cancer; there are very few studies that have examined the organisation of cancer services and the absence of this information limits the ability to describe current practice or to identify gaps in service provision
- people with cancer typically spend most time being cared for in the community by their general practitioners, community nurses, family or other care providers; however, most available information relates to the provision of acute treatment services—there is very little information about the care provided to people with cancer between or after periods of active treatment, or indeed about their needs
- the Framework shown in **Figure 1** (page 9) identifies four components of cancer control; it is not intended that these components be interpreted as discrete elements—in an effective cancer control program seamless linkages and integration between components are important; the improvement of integration between the components of cancer care through the establishment of integrated cancer services is identified by the Cancer Strategies Group's priorities for action.

CRITICAL INTERVENTION POINTS FOR CANCER CONTROL

The Critical Intervention Points and their derivation are described in **Chapter 7**. The 19 Critical Intervention Points for cancer are placed in order of the continuum of care and are as follows:

Reduce risk

1. Establish national, state/territory and local plans to further reduce rates of smoking using evidence-based public health strategies and government actions.
2. Establish national, state/territory and local plans to increase rates of skin protection from solar and solarium radiation using evidence-based public health strategies and government actions.
3. Establish national, state/territory and local plans to promote healthy eating and active living including healthy weight in collaboration with other national health priorities and policies.

Find cancer early

4. Improve strategies (particularly via primary care) to increase participation in breast cancer screening, and to increase participation by under-screened groups in cervical screening.
5. Improve programs to provide more appropriate and accessible breast and cervical screening services for Aboriginal and Torres Strait Islander women.
6. Complete and evaluate the bowel cancer screening pilot, which will assist in informing governments about the acceptability, feasibility and cost effectiveness of introducing a national bowel screening program.

7. Develop and disseminate support and information for general practitioners and people with cancer about the diagnosis of symptoms which may be cancer, including recommendations about appropriate investigation and referral pathways.
8. Improve systems so that all people with suspected cancers are referred appropriately and assessed promptly and effectively.

Management and support during active treatment

9. Improve access to treatment services for all Australians, particularly those living in regional, rural and remote areas and Aboriginal and Torres Strait Islander people.
10. Develop systems to improve the coordination of care for people with cancer including defined referral pathways and designated coordinators of care.
11. Develop and implement strategies to encourage multidisciplinary care.
12. Implement clinical practice cancer guidelines.
13. Develop and implement strategies to encourage cancer services and people with cancer to participate in clinical trials.
14. Provide information through accreditation of services, credentialing of practitioners or other strategies to help people with cancer assess the quality of care being provided.
15. Work towards improving supportive care for people with cancer by implementing the psychosocial clinical practice guidelines.

Management and support after and between periods of active treatment

16. Develop and implement strategies so that the needs of people with cancer after and between periods of active treatment are met.
17. Provide appropriate information for people with cancer about follow up, practical issues, support services and self care.

Care at end of life, if cancer is not curable

18. Improve timely and appropriate access to adequate palliative care services and medications and monitor the impact.
19. Develop models of end of life care that ensure integration with treatment services and coordination among community services and palliative care teams.

NATIONAL PRIORITY ACTIONS FOR CHANGE

There are eight priority actions which underpin the Critical Intervention Points. If these actions were undertaken by Australian and State/Territory governments, the basis for many of the changes identified in the Framework would be in place.

1. Establish integrated and networked cancer services to improve continuity of care from reducing risk to care at the end of life.
2. Establish accreditation for cancer services and credentialing of practitioners using as a basis the recommendations about optimal services outlined in the Framework.
3. Develop funding structures which support multidisciplinary care in hospitals and the community through specialist and general practitioner payment schedules.
4. Develop national, state/territory and local approaches to monitoring all aspects of cancer control including performance indicators.

5. Provide evidence-based consumer information about the environmental, behavioural and genetic risks of cancer, prevention, early detection, diagnosis and treatment, and supportive care.
6. Establish national approaches to assist primary care providers especially general practitioners to offer high quality and appropriate assessment of risk, detection of cancer, referral to treatment, coordination of treatment and supportive care (from diagnosis to palliative care).
7. Implement and evaluate culturally appropriate programs to improve cancer control with special emphasis on the needs of disadvantaged groups, particularly Aboriginal and Torres Strait Islander people.
8. Review the evidence, gaps in research and opportunities for action within a specific timeframe, at least every three years.

CHAPTER 2. Reduce the Risk of Cancer

The risk of developing some cancers can be reduced by modification of lifestyle or the environment. We do not yet know what causes some cancers and, for others, the factors that are known to increase risk cannot be changed (e.g. genetic inheritance).

PEOPLE'S NEEDS

People want to:

- understand their risk of developing cancer
- know how to reduce their risk of cancer
- have a safe environment
- be able to access risk prevention programs that are affordable and appropriate
- understand how their family history affects their risk of cancer
- access highly credible nationally consistent evidence-based information about the risk of cancer and the ability to reduce cancer risk.

OPTIMAL SERVICES

People in the community will have access to consistent and evidence-based information about opportunities for risk reduction:

- Nationally consistent evidence-based information about the risk of cancer and opportunities to reduce cancer risk will be available to the community, health professionals and the media. This information could be provided by existing organisations. The information will
 - enable individuals to assess whether they are at increased risk of developing a particular cancer because of their family history or other factors
 - indicate the amount of risk reduction that might occur from adopting the recommended behaviours so that individuals can make informed choices where possible
 - indicate its source and the approach used to assess the evidence so that individuals can be sure of the quality of the information
 - be provided in an integrated manner across cancers (and, where possible, with other diseases) so that people can readily understand how to take action to reduce their risk of cancer
 - be appropriate for different groups in the community particularly disadvantaged groups, notably those from lower socioeconomic status, culturally and linguistically diverse and Aboriginal and Torres Strait Islander backgrounds.

People will be provided with an environment that encourages risk reduction:

- People will be confident that their environment supports risk reduction. They will know that their governments have a coordinated plan to reduce the most important cancer risks through application of legislation; financial incentives and disincentives and policy.
- To reduce rates of smoking, the plan will include:
 - strategies to provide smoke free environments
 - financial disincentives for smoking
 - limitations on advertising.
- To increase rates of skin protection, the plan will include
 - policies for shade provision in public places
 - safe and affordable skin protection
 - policies in schools, child care centres and workplaces to support skin protection.
- To increase rates of healthy physical activity, the plan will include
 - policies for the establishment of appropriate public spaces for physical activity (e.g. walk and bike ways)
 - policies in schools to encourage healthy physical activity
 - reduction in financial disincentives to participate in formal physical activity programs.
- To increase healthy eating, the plan will include
 - policies in schools and workplaces to encourage healthy eating choices
 - strategies to ensure that all people have access to good quality fruit and vegetables at an affordable price.

People will be encouraged to take action to reduce their cancer risks:

- There will be regular media information programs promoting the value of cancer risk reduction behaviours.
- The media programs will be accompanied by community based programs.
- Health professionals will assist individuals to identify their own cancer risk and relevant risk reduction behaviours and will have the knowledge and skills to assist individuals to reduce their risk of cancer.
- Smokers will have access to cessation programs which are appropriate to their needs and affordable.
- Individuals who are overweight or obese will have access to weight reduction programs or strategies to achieve a healthy weight.

People with special needs and disadvantaged groups will have access to appropriate, tailored information and programs:

- People will have access to information and programs for reduction of cancer risk that meet their needs including
 - people from lower socioeconomic backgrounds
 - Aboriginal and Torres Strait Islanders
 - people from culturally and linguistically diverse communities.

RATIONALE FOR THE COMPONENTS OF OPTIMAL SERVICES AND CRITICAL INTERVENTION POINTS

Information about risk reduction

Optimal Services: People in the community will have access to consistent and evidence-based information about opportunities for risk reduction. The information will be provided in an integrated manner across cancers so that people can readily understand how to take action to reduce their risk of cancer. It will indicate the degree of risk reduction that might occur from adopting the recommended behaviours (where possible) so that individuals can make informed choices. The information will be developed to be appropriate for different groups in the community, particularly those with lower socioeconomic status, people from culturally and linguistically diverse communities and Aboriginal and Torres Strait Islander peoples, and the media will be encouraged to use evidence-based information. Information will be available to enable individuals to assess whether they are at increased risk because of their family history. People will feel confident that they will receive accurate information about new opportunities for risk reduction in cancer.

Opportunities to reduce cancer risk

Research over the past 40 years has identified opportunities to reduce the risk of cancer as follows:

Reduce smoking: Tobacco smoking causes the following cancers: lung; oral; nasal cavity and paranasal sinuses; naso-, oro- and hypopharynx; larynx; oesophagus; bowel; pancreas; stomach; liver; kidney; urinary tract; cervical; myeloid leukaemia; vulva; penis; bladder; renal parenchyma and renal pelvis.⁸⁻¹¹ In 2001, 19.5% of Australians (3.07 million) aged 14 years and older smoked daily and 3.6% (0.57 million) smoked less than daily.¹²

Limit alcohol intake: Alcohol is a causal factor for cancer of the mouth; pharynx; liver; bowel; larynx; oesophagus¹³ and breast cancer in women.^{8,11} The Australian Institute of Health and Welfare (AIHW) has estimated that 12% of breast cancer may be attributable to alcohol intake. In 2001, 9.9% of people consumed alcohol in a manner that put them at risk of long term harm, while 34.4% put themselves at risk of short term alcohol related harm on at least one drinking occasion.¹²

Increase protection of skin from the sun: Basal cell carcinoma, squamous cell carcinoma and melanoma are caused by sun exposure.¹⁴ In 1999, 78–82% of Australian secondary students, aged 12–17 years reported being sunburnt last summer. Amongst this age group, 42–56% regularly wore hats, 18–25% regularly wore protective clothing and 56–61% regularly wore maximum Sun Protection Factor sunscreen.¹⁵

Improving diet mainly by increasing the intake of fruit and vegetables: The expert panel of the World Cancer Research Fund concluded that inappropriate diets cause around one-third of all cancer deaths.¹⁶ It recommended dietary diversity to maximise the likelihood of more balanced as well as more adequate diets, noting that there was convincing evidence of dietary protection against cancer of many sites. The evidence was strongest and most consistent for diets high in fruits and vegetables. In 1995 in Australia approximately 44% of males and 34% of females did not consume fruit in the 24 hours preceding the National Nutrition Survey, and 20% of males and 17% of females did not consume vegetables.¹⁷ The 1995 National Nutrition Survey results show that only one in five Australian adults met the recommended '5 or more serves of vegetables per day' and around one in two met the '2 serves per day' recommended for fruit.¹⁸

Reduction in rates of overweight and obesity: There is sufficient evidence that avoidance of weight gain has a cancer preventive effect for cancer of the bowel, breast (postmenopausal), endometrium, kidney (renal-cell) and oesophagus (adenocarcinoma).¹⁹ For premenopausal breast cancer, the available evidence does not suggest a cancer preventive effect. In 2001, an estimated 2.4 million Australian adults were obese (16% of men and 17% of women aged 18 years and over). A further 4.9 million Australian adults were estimated to be overweight but not obese (42% of men and 25% of women).²⁰

Increased physical activity: There is sufficient evidence that physical activity has a cancer preventive effect for cancer of the bowel and breast, and limited evidence for an effect for cancers of the endometrium and prostate; there is no adequate evidence in relation to other sites¹⁹. In 2000, 57% of Australian adults aged 18–75 years were spending sufficient time being physically active to achieve health benefits (i.e. at least 150 minutes of walking, moderate and/or vigorous activity per week).²¹

Increased rates of safe sex: Prevention of Human Papilloma Virus (HPV) infection would prevent cervical cancer.²² However, there is inconsistent evidence about whether condoms can reduce the risk of HPV infection.²² Meta-analyses of completed research suggest there is little benefit^{23,24}, but ongoing randomised trials suggest there may be some value.²⁵

Understanding familial risk: Genes and the environment cause cancer. A person's family history is a way of knowing about their genetic inheritance.

People understand that cancer can run in families and can, understandably, be anxious and want more information if they have a family history of cancer. In general, people tend to overestimate the importance of family history²⁶ and they need accurate information to help them understand their risk. Testing is available for some genetic mutations linked with some cancers. However, even when an individual is known to carry a relevant genetic mutation, there is often little that can be done to reduce potential risk. People with a strong family history and some high risk mutations may have the option of preventive strategies such as surgery.

There is currently a considerable research effort to understand the mechanisms underlying the development of cancer, and the genetic characterisation of specific cancer types. It is likely that this research will enable the development of drugs targeting specific parts of the cancer pathway and result in other benefits which are unforeseen at this point in time. At present, the broader implications of developments in genetics for clinical practice and health service delivery are unclear. However, services should be developed in a planned manner to provide care in accordance with the best available evidence, such as that outlined in the Australian Cancer Network and National Health and Medical Research Council's Familial aspects of cancer: a guide to clinical practice.²⁷

Emerging issues: Australia should monitor research to identify emerging opportunities for prevention. For example, there may be opportunities to reduce the risk of cancer through the use of non-steroidal anti-inflammatory drugs or aspirin to prevent bowel cancer, vaccines against HPV to prevent cervical cancer, the reduction of hepatitis B and the prevention of *Helicobacter pylori* infection to reduce stomach cancer. It will be of value to continue to monitor and control exposure to ionising radiation, occupational exposures, medicinal drugs and environmental pollution.

Understanding risk of cancer

Australians understand that cancer is a major health issue.²⁸ People consistently overestimate the lifetime risk of developing cancers by a margin of 20–25% for most cancers.²⁸

There appears to be high community awareness of some modifiable risk factors of cancer. For example, in a NSW study the majority of a community sample was aware of smoking (96%) as a risk factor for lung cancer and of sun exposure (80%) for melanoma.²⁸ However, a substantially smaller proportion indicated that diet (35%), consuming too little fibre (22%) or too much fat (12%) were risk factors for bowel cancer.²⁸

Most people have an accurate understanding of the extent to which cancer can be prevented. A survey of NSW residents reported that 37% thought they could reduce their cancer risk greatly or completely.²⁸ Approximately half believed that lung cancer; melanoma and other forms of skin cancer are very or completely preventable. Cervical cancer and bowel cancer were perceived to be very or completely preventable by about 20% of respondents. Less than 20% thought breast cancer and prostate cancer are very or completely preventable.²⁸

Availability of information

There has been a lack of consistency in the information given to the community about the risk of cancer. For example, a national review conducted over a decade ago of written educational material relating to the prevention of cancers highlighted a lack of consistency in the messages generated by cancer organisations.²⁹

More recent research has identified partial and inconsistent information available from cancer organisations, government health departments, and mammographic screening programs throughout Australia about the benefits of mammography.³⁰

Recently, The Cancer Council Australia has made substantial attempts to develop nationally consistent information about risk reduction through its National Cancer Prevention Policy.³¹ Information for the community is also available through The Cancer Council Australia's website and through printed and other information disseminated through its member organisations.

Information is also available through the National Cancer Helpline, which is used by more than 120 000 Australians each year.³² An evaluation of the breast cancer information provided by the Helpline found that consistent and accurate information was provided.³³ However, more could be done to ensure that the community is aware of the service—39% of NSW residents were not aware of the Cancer Helpline in 2001 (according to personal communication with Associate Professor Afaf Girgis, Centre for Health Research and Psycho-oncology).

Information is available to the major non-English speaking background groups through a number of sources, including translated printed materials (available nationally) and the Cancer Helpline, which provides access to bilingual information officers (currently available in Victoria and NSW only). There have been some limited attempts to provide more appropriate information to Aboriginal and Torres Strait Islander people about cancer risk reduction.

However, inconsistent and inaccurate information about risk and cancer continues to be widely available. There are many websites with information about cancer risk and it is difficult for people to judge which of these are providing accurate and dependable information. There are often reports about 'new' risk factors for cancer in the media which can be very misleading. For example, in an analysis of media reporting on breast cancer it was noted that there was a predominance of stories about young women with breast cancer—despite the fact that it is primarily a disease of ageing. The report noted there was no consistency in the information given about risk factors for breast cancer, with more than 28 different risk factors for breast cancer mentioned. Age was mentioned as a risk factor in only 4% of articles.³⁴

Epidemiological research about risk factors can be complex and requires careful analysis before conclusions about the real impact on cancer risk can be drawn. Opportunities exist to integrate information about risk factors for cancer with those for other diseases (e.g. cardiovascular disease and diabetes).

There are opportunities to reduce the risk of cancer among Australians. Overall, there is a need to increase the consistency and accuracy of information about risk and cancer.

ENVIRONMENTS TO REDUCE CANCER RISK

Optimal Services: People will be provided with an environment that encourages risk reduction. People will be confident that their environment supports risk reduction. They will know that their governments have a coordinated plan to reduce the most important cancer risks through application of legislation, financial incentives and policy. To reduce rates of smoking, the plan will include strategies to provide smoke free environments, financial disincentives for smoking, and limitations on advertising. To increase rates of skin protection, the plan will include policies for shade provision in public places, safe and affordable skin protection, and policies in schools, child care centres and workplaces to support skin protection. To increase rates of physical activity, the plan will include: policies for the establishment of public spaces for physical activity (e.g. walk and bike ways), policies in schools to encourage physical activity, and reduction in financial disincentives to participate in formal physical activity programs. To increase healthy diet, the plan will include policies in schools and workplaces to encourage healthy eating choices and strategies to ensure that all people have access to good quality fruit and vegetables at an affordable price.

Cancer risk can be reduced by ensuring that the environment limits exposure to risks through the application of legislation, financial incentives and disincentives and policy approaches. Over the past 40 years, many strategies to modify cancer risk have been implemented and evaluated including the following.

Environmental strategies to reduce rates of smoking

Other non-environmental strategies to reduce smoking rates are included under Encouraging risk reduction below.

Strategies to provide smoke free environments: Comprehensive, multi-component strategies for smoke free environments effectively reduce smoking in public places.³⁵ Policies, regulations and laws banning smoking in workplaces and other public venues have been successful in reducing exposure to environmental tobacco smoke³⁶ and smoke free workplaces encourage smokers to quit or reduce their tobacco consumption.³⁷ In Australia, there is state and territory legislation and/or regulations for smoking in enclosed public areas.³⁸ There are variations to legislation in each jurisdiction, with some banning smoking in all enclosed public places with few exceptions, and others only prohibiting smoking in specified venues.

Financial disincentives for smoking: Higher tobacco prices significantly reduce tobacco use.³⁹ In Australia large price increases on cigarettes occurred in the 1990s⁴⁰, in particular in 1999 when the method for calculating excise was changed.

Limitations on tobacco advertising: Comprehensive bans on tobacco advertising can reduce tobacco consumption.⁴¹ However, more limited partial advertising bans will have little or no effect.⁴¹ In Australia there is a complete ban on all forms of tobacco advertising in print, television, radio and in cinemas.⁴² The *Tobacco Advertising Prohibition Act 1992* is currently being reviewed to ensure it remains an effective tobacco control measure.

Labelling of tobacco products: Health warnings on cigarette packets have been shown to be effective in reducing cigarette consumption.⁴³ In Australia there has been labelling of tar and nicotine levels on cigarette packages since 1982, with stronger warnings implemented in 1994.⁴²

Sales to minors: Interventions with retailers can lead to large decreases in the number of outlets selling tobacco to young people.⁴⁴ In Australia, efforts to reduce the access of minors to tobacco products include a minimum age of purchase of 18 years in all jurisdictions, with penalties imposed on those selling to minors or in some cases, supplying to minors.⁴²

Restrictions on the location of vending machines also apply in most jurisdictions.⁴² Despite this policy, the sale of cigarettes to minors is still prevalent. In 2001, 82.6% of underage smokers most commonly obtained tobacco from a shop or retail outlet.¹²

School based programs: There is inconsistent evidence about the value of school based programs in discouraging smoking.⁴⁵

Promoting cessation of tobacco use: Smoking cessation is a major means of reducing smoking related mortality as it prevents the occurrence of disease and reduces the risk of further disease in those who quit.⁴⁶ Strategies such as mass media campaigns, medical practitioner interventions, offers of support to smokers and effective Quitline services all play critically important roles in reducing the proportion of people in the population who smoke on a regular basis.

Environmental strategies to increase rates of skin protection

Policies for shade provision in public places: Guidelines for shade planning and design have been published by The Cancer Council NSW and NSW Health.⁴⁷ There are opportunities to improve shade in public places. For example, in 2001 only 25% of Victorian local government authorities had a shade policy applying to parks and gardens⁴⁸, 38% of council parks and gardens were estimated to have high levels of shade, 41% moderate levels and 23% inadequate levels of shade.⁴⁸

Safe and affordable skin protection: Australia has rigorous standards related to skin protection. It is less clear that skin protection measures are affordable for all Australians.

Policies in schools, child care and workplaces to support skin protection: Most sun protection interventions increase knowledge and attitudes, although they are less effective in producing behaviour change, particularly amongst adolescents.⁴⁹ There is evidence that childcare⁵⁰ and worksite⁵¹ interventions have some impact on sun protection behaviours as well as attitudes. NSW Health with The Cancer Council NSW has developed and is implementing a strategic plan to encourage sun protection, including a collaborative inter-sectoral approach.⁵² The strategy focuses on environmental and policy changes in primary schools and child care centres. The SunSmart Accreditation Program has been operating in Victorian primary schools, preschools and childcare centres since 1993 and has been adopted throughout most of Australia.⁵³

In Victoria, 49% of preschools, 44% of childcare centres, 73% of primary schools and 20% of secondary schools had accredited sun protection policies in 2002.⁵³ In 2001, 76% of Victorian local government authorities had a written sun protection policy for council outdoor workers and 26% for contract outdoor workers.⁴⁸

Environmental strategies to increase rates of physical activity

Policies for the establishment of public spaces for physical activity (e.g. walk and bike ways): Interventions to alter environments by removing barriers and providing more opportunities for physical activity can be effective.⁵⁴ It is recognised that more could be done to improve access to public spaces for physical activity in Australia.⁵⁵

Policies in schools to encourage physical activity: There is inconsistent evidence about the impact of school based programs in encouraging physical activity.⁵⁶

Reduction in financial disincentives to participate in formal physical activity programs: There is no evidence about the role of financial barriers in preventing participation in formal physical activity programs in Australia.

Environmental strategies to increase healthy diet

Policies in schools and workplaces to encourage healthy eating choices: There is some evidence that school based programs can improve diet among school children⁵⁷ and good evidence that worksite interventions are effective in increasing fruit and vegetable consumption.^{58,59}

Eat Well Australia: an agenda for action for public health nutrition⁶⁰ provides direction for improvements in diet in Australia. The document outlines the need to equip educators, such as teachers and health professionals, with the knowledge, skills, framework and tools to encourage healthy changes in diet.

Strategies to ensure that all people have access to good quality fruit and vegetables at an affordable price: Price reductions are an effective strategy to increase the purchase of healthy foods in community based settings such as worksites and schools.⁶¹ In Australia lower income adults are more likely than their higher income counterparts to report that price is a barrier to increasing their fruit and vegetable consumption.¹⁷ Socioeconomic differences in fruit and vegetable consumption are apparent in Australian adults.¹⁷

There is an opportunity to reduce the risk of cancer by providing environments that better prevent smoking, exposure to tobacco smoke, and encourage skin protection, healthy diets and physical activity.

ENCOURAGING RISK REDUCTION

Optimal Services: People will be encouraged to reduce their cancer risk. There will be regular media and community information programs promoting the value of cancer risk reduction behaviours. Health professionals will assist individuals to identify their own cancer risk and relevant risk reduction behaviours and will have the knowledge and skills to assist individuals to reduce their risk of cancer. Smokers will have access to cessation programs that are appropriate to their needs and affordable. Individuals who are overweight or obese will have access to weight reduction programs.

In addition to safe environments, people and communities can be encouraged to take active steps to reduce their own risk of cancer. Over the past 40 years several strategies have been implemented and trialed to encourage people to reduce their cancer risk.

Mass media campaigns

Mass media campaigns have been found to be effective in reducing smoking among both adults^{62,63} and adolescents^{64,65}, with enduring effects noted when the campaign is part of a comprehensive tobacco control program including legislative change and community based programs.^{66,67}

Launched in 1997, Australia's National Tobacco Campaign featured televised graphic advertisements portraying the certain, as opposed to probabilistic, damage smoking inflicts on the body.⁶⁸ Evaluation of the campaign over a four year period showed increases in ad specific learning, more favourable anti-tobacco attitudes, increased intentions to quit, quit attempts and positive changes in smoking behaviour among adults^{69,70} as well as positive effects on adolescents.⁷¹ Skin cancer control programs have been running for more than 20 years—the Slip! Slop! Slap! Campaign from 1980–1988; the SunSmart program from 1988 to the present.⁷² The Life. Be in it Campaign, was launched at a national level in 1977 to promote an active lifestyle. State-wide campaigns have been implemented to promote increased consumption of vegetables and fruit.

Health professionals advice

There have been mixed results of health professional advice about risk reduction. A review of the effectiveness of promoting lifestyle change in general practice suggested that although many general practice based lifestyle interventions show promise in producing small changes in behaviour, substantial changes in behaviour are not apparent.⁷³ There is evidence that brief smoking cessation advice from doctors has a small but significant increase on quit rates among people who smoke.⁷⁴ More intensive advice is marginally more effective than minimal advice.⁷⁴

If general practice based interventions are to have an impact, more general practitioners will need to provide programs on a routine basis. A survey of general practitioners in NSW reported that only 34% provide smoking cessation advice during every consultation with a smoker.⁷⁵ However, health care professionals who receive smoking cessation training are more likely than their untrained counterparts to provide advice.⁷⁶ Specific evidence-based approaches recommended in national guidelines are underutilised.⁷⁵ Other health professionals are also important in providing consistent advice about the benefits of cessation.⁷⁷

Smoking cessation programs

With regard to specific interventions, there is some evidence that individual and group counselling^{78,79} and nicotine replacement therapies⁸⁰ increase the chance of quitting, although most smokers who quit will not use any specialist services. Telephone counselling can be an effective and economic way of providing smoking cessation advice.^{79,81} In Australia, the Quitline telephone service is available for the cost of a local phone call in metropolitan areas and no charge to callers outside of metropolitan areas.⁸² A Quit pack can be sent to individuals free of charge. Quit resources are available in 13 languages: Arabic; Cambodian; Chinese; Croatian; Greek; Italian; Macedonian; Polish; Russian; Serbian; Spanish; Turkish and Vietnamese; and bilingual workers are available to provide telephone support in a language other than English to those who contact the Quitline.

There is an opportunity to reduce risk of cancer by continuing media awareness programs and increasing advice from health professionals.

REDUCING RISK IN SPECIAL NEEDS COMMUNITIES

Optimal Services: People with special needs will have access to appropriate, tailored information and programs. People from lower socioeconomic groups, Aboriginal and Torres Strait Islander people and those from culturally and linguistically diverse communities will have access to information and programs that meet their needs. Communities and individuals with special needs will have access to appropriate information and programs to help them reduce their risk of cancer.

The risk profile is different for different communities. For example:

- people from lower socioeconomic groups have higher rates of many cancers; lower socioeconomic status, for example, is associated with higher rates of smoking and of obesity⁸⁴ and lower rates of physical activity and of fruit and vegetable consumption^{17,83}
- Aboriginal and Torres Strait Islander people have much higher incidence rates than other Australians of cancers of the lung, liver, and cervix⁸⁵; lower rates of cervical cancer screening have been reported in Aboriginal and Torres Strait Islander women in some populations⁸⁶; Aboriginal and Torres Strait Islander peoples are twice as likely as other Australians to smoke⁸⁷

- there are some studies reporting that people from different cultures and different countries have higher rates of some cancers⁸⁸, but more research in this area is required.

Relatively little is known about how to develop information and programs for different communities, although some strategies are in place:

- information resources are developed to be comprehensible to those with limited reading ability
- the state and territory cancer organisations provide information about risk in languages other than English; translated printed materials are available nationally to major non-English speaking background groups through a number of sources, and the Cancer Helpline provides access to bilingual information officers in Victoria and NSW
- the difficulties faced by Aboriginal and Torres Strait Islander people include affordability, distance and appropriateness of information and services; it is recognised that there is poor access to culturally appropriate services for Aboriginal and Torres Strait Islander people and that much more needs to be done to provide acceptable programs to reduce smoking and encourage participation in screening.

Better understanding of and improved programs for risk reduction in special communities is a priority. While these programs may be resource intensive, they represent an opportunity to significantly impact on communities where risk may be much higher than the Australian norm.

There is an opportunity to reduce risk of cancer through programs that meet the special needs of people from lower socioeconomic, Aboriginal and Torres Strait Islander, and culturally and linguistically diverse backgrounds.

CHAPTER 3.

Find Cancer Early

For many cancers, the chances of survival and quality of life are better if the cancer is found early. For some cancers, like breast cancer, it may be possible to find the cancer before it has spread to other parts of the body and when an effective cure is possible. For other cancers, like ovarian cancer, it may be difficult to find the cancer early because symptoms are either diffuse or may not be present. For other cancers, even when they are found early, it may not be possible to treat them effectively.

Cancer can be found while a person has no signs or symptoms by participation in a screening program; it can also be found by investigation of a change that may be diagnosed to be cancer. This section covers both approaches to finding cancer.

PEOPLE'S NEEDS

People want to:

- have cancer found as early as possible, if early treatment is beneficial
- have enough information to decide whether to participate in population screening programs
- be able to access appropriate population screening and diagnostic services
- be confident that population screening programs and diagnostic services are providing high quality care
- understand their test results,
- if they are diagnosed with cancer, to be told appropriately and provided with support.

OPTIMAL SERVICES

Screening

People will have access to high quality population screening programs:

- All screening programs will be set up to meet national and international benchmarks and will have quality improvement programs.
- People will know that there is a system in place to ensure the quality of screening, including accreditation and public reporting mechanisms.

People will have information about population screening programs for cancer including:

- The purpose of screening, its benefits, downsides and limitations, and differences between cancers.
- Which cancers can be detected early.

- Information to assist in their decision about whether to participate in population screening programs including the
 - criteria for eligibility or the people who may benefit from participating in screening
 - absolute benefit of participation, including reference to population risks
 - downsides and limitations of screening, including information about false positives, treatment of in situ disease or disease which would not have become evident in their lifetime, with specific reference to their own circumstances
 - steps involved in screening and diagnosis, including any discomfort, cost, time and possible need for further tests and treatment.
- Information appropriate for people from disadvantaged groups, especially Aboriginal and Torres Strait Islander people and people from culturally and linguistically diverse backgrounds.

Cost effective population screening programs will be readily accessible to all Australians and their participation will be facilitated:

- People eligible for screening will not be prevented from participating by cost or access barriers. Population screening programs will be available to people close to where they live throughout Australia.
- Aboriginal and Torres Strait Islander people and people from culturally and linguistically diverse backgrounds will have access to services that are appropriate to their needs. There will be targeted programs to address special barriers to participation for people from disadvantaged groups, especially Aboriginal and Torres Strait Islander people and people from culturally and linguistically diverse backgrounds.
- Health professionals will provide advice about participation in population screening programs to eligible people.
- Information about the reasons for screening and screening intervals will be provided to all participants in screening programs. Reminders will be sent to participants to notify them when screening is due.

Diagnosis

All people in the community will have access to information about what might be an early sign of cancer:

- Balanced information about early signs of cancer will be available in the community through a number of sources including general practice, mass media and community programs.
- Appropriate information will be available for people from disadvantaged groups, especially Aboriginal and Torres Strait Islander people and people from culturally and linguistically diverse backgrounds.
- People with a sign or symptom that may be cancer will have access to information and the chance to discuss: the likelihood that their sign or symptom is cancer and other possible causes of the changes; where to go for diagnosis and the time frame during which they should seek to receive treatment; what is involved in treatment; and what to do if they have questions.

People with a sign or symptom that may be cancer will have access to high quality diagnostic services regardless of where they live:

- People with a sign or symptom that may be cancer will know where to get appropriate care including: where to go as a first step to have the symptom investigated; how to be sure that they are receiving best care at this first step; information about how to access diagnostic services, the costs and the procedures involved.
- There will be support and information for general practitioners about the investigation of signs and symptoms that may be cancer, providing appropriate investigation pathways and information about referral. Similar information will be available for people with signs and symptoms when they attend for investigation.
- There will be a planned approach to ensuring that diagnostic services are available throughout Australia to provide adequate care to those living in regional, rural and remote areas. People will know about the quality of diagnostic services through a process of accreditation or credentialing.

People will have information about, and be supported through the process of diagnosis regardless of whether they have an abnormality detected by a population screening program or a sign or symptom that may be cancer:

- People will have information that helps them understand that the process of diagnosis is one of increasing certainty rather than a moment of truth.
- People will know about the steps in the pathway of diagnosis, what is involved in each test and what the results mean. This will include information about the likelihood of false positives and false negatives.
- People will be provided with support throughout the process of diagnosis recognising that this is a time of increased anxiety.

People will be provided with their results in an appropriate and timely manner:

- Both positive and negative results will be provided in an appropriate manner meeting best practice guidelines about breaking bad news.
- People will be provided with information about the short and long term significance of their diagnosis.
- People diagnosed with cancer will be provided with information about the next steps in treatment, and critical timeframes.
- People diagnosed with cancer and their families will be provided with appropriate support and counselling.

People with cancer will be appropriately referred to treatment:

- There will be established referral pathways between diagnostic and treatment services. People will experience the transition between diagnosis and treatment as seamless and continuous care.
- People will know that they are being referred to a high quality treatment service. This might be established through accreditation and links to major treatment centres as outlined in the next section.

RATIONALE FOR THE COMPONENTS OF OPTIMAL SERVICES AND CRITICAL INTERVENTION POINTS

High quality screening programs

Optimal Services: People will have access to appropriate and high quality population screening programs. All screening programs will be provided to meet national and international benchmarks with quality improvement programs. People will be able to judge whether the screening service is of high quality through mechanisms like accreditation and public reporting.

Australia's population based breast cancer and cervical screening programs, BreastScreen Australia and the National Cervical Screening Program, have been in operation since 1991. A pilot is currently underway to examine the acceptability, feasibility and cost effectiveness of bowel cancer screening.

Breast cancer screening

There is evidence from randomised control trials that mammography screening reduces deaths from breast cancer at least among women aged 50–69 years.⁸⁹ BreastScreen Australia provides high quality screening, performing at a level consistent with international benchmarks in relation to small cancer detection rate and interval cancers.⁹⁰ Information about the program is available to the community and there is a formal accreditation process.

Cervical screening

Screening for pre-cancerous abnormalities and cancer of the cervix has reduced both mortality and morbidity from the disease.⁹¹ In Australia, the population screening program performs at a level consistent with international benchmarks. Information about the program is available to the community; laboratories are formally accredited by National Association of Testing Authorities; those who take smears for the Pap test are not usually accredited but are well trained.

Bowel cancer screening

There is evidence from randomised trials that targeted screening for bowel cancer using the faecal occult blood test reduces the incidence of and mortality from bowel cancer.⁹² A national screening program for bowel cancer is currently being piloted.

Prostate cancer

Although there is a screening test for prostate cancer, the current evidence is not adequate to demonstrate that its use will reduce deaths from prostate cancer.⁹³ The most thorough systematic review of screening for prostate cancer has been conducted and recently updated by the United States Preventive Services Taskforce. It concluded that 'current evidence is insufficient to recommend for or against routine screening for prostate cancer using the Prostate Specific Antigen (PSA) test or digital rectal examination'.⁹⁴ There are substantial side effects from the treatment of prostate cancer, which must be considered in the introduction of a population based screening program. Since screening is not occurring as part of an organised population based program, it is not possible to assess its quality. There is no accreditation program for providers.

A large randomised controlled trial of prostate cancer screening, the European Randomised Study of Screening for Prostate Cancer⁹⁵, is currently being undertaken. The aim of the trial is to determine whether the effect of early detection and treatment of prostate cancer will reduce deaths from prostate cancer. The first results from the study are expected before 2010; it will be of value to monitor the results of this trial.

There is an opportunity to reduce mortality from cancer through organised population based screening programs for breast, cervical and bowel cancer.

Information about screening programs

Optimal Services: Information will be readily available about population screening programs for cancer generally, including the purpose of screening, its benefits, downsides and limitations, and which cancers can be screened for currently. People will be able to access information to assist in their decision about whether to participate in screening programs, including: information about the issues to be considered for each cancer and screening program; the criteria for eligibility or the people who may benefit from participating in screening; the absolute benefit of participation including reference to population risks; the downsides and limitations of screening including information about false positives and treatment of in situ disease; the steps involved in screening and diagnosis including any discomfort; cost; time and possible need for further tests and treatment; and an opportunity to discuss the benefits and downsides of screening given individual circumstances.

Population screening for cancer is the systematic application of a suitable screening test to identify individuals with (i) pre-cancerous changes that increase their risk or (ii) early stage disease where treatment can be effectively implemented. It is undertaken amongst asymptomatic individuals. Importantly, population screening is an organised process that involves call and recall of the population to regular screening as an aid to early detection and appropriate follow up of people requiring further treatment.

There has been a significant shift in views regarding the type of information that people need in considering whether or not to participate in population screening programs. Persuasive communication strategies that downplay the disadvantages of screening are being replaced by more explicit sharing of information concerning the benefits and risks of entering screening programs. The latter approach is now considered more ethical, as it reduces the chances of negative outcomes such as increased anxiety, false alarms, false reassurance, unnecessary diagnostic tests, over-diagnosis and over-treatment.⁹⁶

The UK General Medical Council's guidelines⁹⁶ specify that informed consent should include information about:

- the purpose of the screening
- the uncertainties and risks attached to the screening process
- the likelihood of positive/negative findings and the possibility of false positive/negative results
- any significant medical, social or financial implications of screening for the particular condition or preposition
- a follow up plan, including the availability of counselling and support services.⁷⁸

There is increasing understanding about how best to convey information about screening, including the use of absolute risk reduction and visual displays of information.^{97,98}

Information about population screening programs is available to Australians from the screening programs and from the state and territory cancer organisations. However, misconceptions in the community about the purpose of screening and the accuracy of screening tests seem prevalent. Women are not aware of the limitations of breast screening tests and commonly overestimate their sensitivity and specificity.⁹⁹ Women in Australia and New Zealand misunderstand their risk of developing and dying from breast cancer, and the benefits of screening.¹⁰⁰ For instance, only 1% of women in an Australian study correctly stated that screening mammograms are for asymptomatic women.¹⁰¹ The information provided by the breast and cervical cancer programs does not provide information about absolute risk reduction.

Men experience particular difficulty in accessing accurate and balanced information about prostate cancer testing. There is some evidence that a decision aid may be of value in assisting men to decide whether to participate in being tested for prostate cancer.¹⁰²

There are opportunities to improve information available to people about population screening for cancer.

Access to and participation in screening programs

Optimal Services: Cost effective population screening programs of demonstrated benefit will be readily accessible to all Australians and their participation will be facilitated. People eligible for screening will be provided with information through a number of channels and will not be prevented from participating by cost or access barriers. Participation in screening will be facilitated. There will be appropriate programs for people from disadvantaged groups, especially Aboriginal and Torres Strait Islander people and people from culturally and linguistically diverse backgrounds.

Access to and participation in cervical screening

Australia's cervical screening program is provided in primary care and mainly by general practitioners. In those mainly rural areas where access to general practice is more limited, there will be poorer availability of cervical screening. For some women, the ability to access a female provider will be an important determinant of participation.

In 1999–2000, 62.6% of eligible women participated in cervical screening. Rates of screening were lower among women aged over 55 years although rates of cervical cancer are higher in this age group.¹⁰³ Rates of participation in cervical screening are lower among Aboriginal and Torres Strait Islander women and rates of cervical cancer are higher.⁸⁶ Australian screening recommendations are different to those of other countries—Australia recommends 25 screens in a woman's lifetime compared with seven in the Netherlands and Finland; the recommended screening interval is two years compared with five years in Finland and the Netherlands.¹⁰⁴

Access to and participation in breast cancer screening

BreastScreen provides screening to all Australian women with symptoms free of charge. Women aged 50–69 are targeted, although women aged 40–49 and 70 years and older are able to attend for screening. In 2000–01, 56.9% of eligible women participated in mammographic screening through BreastScreen Australia.⁹⁰ The proportion of women being screened outside the organised screening program is unknown. Aboriginal and Torres Strait Islander women are less likely to participate in population screening programs. There is little evidence that women from culturally and linguistically diverse backgrounds, lower socioeconomic groups or those living in regional, rural or remote areas are less likely to participate.⁹⁰

Barriers to and opportunities for improving participation in mammographic screening programs

The reasons people decide not to participate in screening have been extensively studied in Australia and internationally. A systematic review found the following factors were consistently identified: financial concerns; concern about radiation; embarrassment; poor access, including travel difficulties; anxiety about test results; inconvenience; forgetting or procrastination; and discomfort associated with the screening test.¹⁰⁵

There has also been considerable research about strategies to improve participation. The most effective strategies will be dependent upon the way in which the population screening program is organised. A Cochrane Collaboration review found that five strategies were effective in encouraging women to participate in population based mammographic screening: letter of invitation; mailed education material; letter of invitation plus phone

call; training activities plus direct reminders for women.¹⁰⁶ However, the involvement of primary care providers and letters of invitation and reminders are consistently identified as important.^{107;108} There is evidence that invitation letters from a woman's doctor with a fixed appointment time are more effective. In Australia, it is likely that primary care providers will be critical in increasing rates of screening for breast and cervical cancer among the targeted population.

Screening in Aboriginal and Torres Strait Islander women

Aboriginal and Torres Strait Islander women are less likely to take part in both cervical⁸⁷ and breast cancer screening in Australia.^{86,109} Primary care providers (both general practitioners and Aboriginal health workers) are central to improving participation rates for Aboriginal and Torres Strait Islander peoples. The national population screening programs for both breast and cervical cancer have developed, and are trialling approaches to encouraging Aboriginal and Torres Strait Islander women to take part in screening—it is too early to tell whether these approaches will be effective. A better understanding of how to make screening services appropriate for Aboriginal and Torres Strait Islander peoples will be important.

Good practice: increasing access to population screening programs

The recurrent problem of providing access to cervical and breast cancer screening and diagnostic services for people in regional, rural and remote areas has been recently addressed. In 1999, the Australian Government established a fly-in fly-out female GP program, now known as the Rural Women's GP Program, in conjunction with the Royal Flying Doctor Service for women who do not have access to a female GP. In some regional areas, the Cervical Cancer Prevention Program is being conducted by female Aboriginal health workers because personal invitations are believed to be more appropriate than mailed reminders.⁸⁶

There is an opportunity to decrease mortality from cancer by (i) increasing participation in mammographic population screening programs among women aged 50–69 and (ii) increasing participation in screening for breast cancer and cervical screening among under screened groups.

Information about signs and symptoms

Optimal Services: All people in the community will have access to information about early signs of cancer and their significance. People with a sign or symptom that may be cancer will have access to information about and the chance to discuss: the likelihood that their sign or symptom is cancer and other possible causes of the changes; the benefits of early treatment on length and quality of life; where to go for diagnosis and the time frame during which they should seek to receive treatment; what is involved in treatment and where to go to have the symptom investigated.

Although there is general agreement that the early diagnosis and treatment of cancer improves survival, there is a lack of evidence about the value of encouraging people or their doctors to search for possible symptoms. This seems paradoxical but may be because many symptoms are not sufficiently sensitive or specific for cancer or cannot be found early enough to make a difference in treatment effectiveness. This has resulted in confusing messages both for health professionals and for the community.

Skin cancer

There appears to be little current evidence that individual or general practitioner based population testing for skin changes that may be a sign of a skin cancer or melanoma improves outcomes.^{110,111}

Breast cancer

The International Agency for Research on Cancer working group on screening for breast cancer concluded that there is inadequate evidence for the efficacy of screening women by clinical breast examination⁸⁹ and that breast self examination does not improve outcomes and may contribute to additional tests.⁸⁹ However, there is some evidence that prompt investigation of breast symptoms results in improved outcomes.⁸⁹

Bowel cancer

There is inconsistent evidence about the value of recommending that people and their doctors seek prompt investigation of bowel symptoms. However, after considering the small amount of available evidence, both Australian¹¹² and UK¹¹³ guidelines conclude that earlier diagnosis of people presenting with rectal bleeding may be of value.

Prostate cancer testing

At present there is no generally accepted population screening test for prostate cancer. The decision to be tested for prostate cancer is a personal choice to be made by men in consultation with their doctor.

There is no organised population screening program for prostate cancer in Australia. However, from 1992–1996, 47% of men aged 60–69 years had one or more PSA tests. The age standardised rate of testing for PSA increased by 68% from 1994 to 2001¹¹⁴ (and personal communication with Dr David Smith, The Cancer Council NSW).

Information

Information about symptoms and cancer is available from the state and territory cancer organisations and other sources. The most appropriate public health messages based on available evidence appear to be that people should know that breast changes, bleeding from the bowel and a change in a mole may be signs of cancer and that they should seek advice if they notice such changes. However, it is not clear that the available evidence strongly supports major public health programs to encourage active checking for these symptoms.

There is an opportunity to improve information about signs and symptoms that may be cancer.

Access to high quality diagnostic services

Optimal Services: People with a sign or symptom that may be cancer will have access to high quality diagnostic services. They will know where to get appropriate care, including where to go as a first step to have the symptom investigated, and how to be sure that they are receiving best care at this first step. The diagnosis will be undertaken according to best evidence. People will know how to judge the quality of the diagnostic services through a process of credentialing and/or specialised clinics. They will also have access to information about the recommended approaches to diagnosis.

There is no systematic organisation of diagnostic services across Australia or within states and territories. The process of diagnosis will differ according to the cancer and according to the services available locally. It will often involve visiting a number of different and independent services. It can be difficult for people to know whether their symptoms have been investigated according to best practice.

There are few summaries of evidence or clinical practice guidelines which provide algorithms for the diagnosis of cancer. The National Breast Cancer Centre has published guidelines for general practitioners for the investigation of breast changes¹¹⁵ and some

guidance about the diagnosis of bowel cancer is provided in the clinical practice guidelines.¹¹² In the absence of agreement about appropriate strategies, it is difficult to judge the extent to which diagnosis is currently adequate in Australia.

There is little information about the diagnosis of cancer in Australia. The NSW patterns of care study of bowel cancer¹¹⁶ suggested that there are opportunities to improve the diagnosis of bowel cancer by increasing the rate of endorectal ultrasound, colonoscopy, and pre-operative histological diagnosis of rectal cancer.

A retrospective Victorian survey of people with lung cancer concluded that there was no evidence of any clear approach to disease assessment. In the judgment of the authors, diagnosis and staging was inadequate. Half of the people with lung cancer did not have the size of the primary tumour recorded, many had a chest X-ray but fewer (68%) had a Computer Tomography (CT) scan for evaluating mediastinal node involvement, and very few had mediastinoscopy (the gold standard for these nodes). Less than half of the people with lung cancer had investigations for distant metastases and 109 (12%) did not have a histological diagnosis.¹¹⁷

An Australian study compared the diagnostic strategies used by general practitioners with women presenting with a breast symptom with those in the guidelines 'Investigation of a new breast symptom'.⁹⁷ Practice differed from the guidelines in some significant respects, including lower than expected rates of surgical referral after an examination indicating suspicious or malignant changes; biopsy when imaging results were normal and clinical findings were not; surgical referral for a cyst with bloody fluid.¹¹⁸

There is agreement that prompt diagnosis and treatment of cancer improves treatment options and survival. For example, in one study of people with breast cancer, a delay of more than three months between noticing a symptom and treatment was associated with poorer survival.¹¹⁹

Delays in diagnosis contribute significantly to anxiety and concern for people with cancer. Two Australian studies have examined the timing of cancer diagnosis. Schofield et al. documented retrospective recollections of people with melanoma diagnosed approximately four months prior to the study.¹²⁰ The majority (66%) reported that the time interval from seeking help to diagnosis confirmation was 'about right', while one-third felt that it was 'far too long' or 'a bit long'. The actual time between first seeking medical advice and being told the diagnosis was not recorded in this study. Butow et al. documented recollections of, and satisfaction with, the delivery of the diagnosis of cancer for 187 people with breast cancer and melanoma diagnosed, on average, four years prior to the study.¹²¹ Most people reported receiving their diagnosis within one week of seeking medical help. However, a significant minority of people (16%) reported not receiving confirmation of diagnosis for more than one month after seeking medical help and the majority of these people (96%) felt that this was too long. Twenty six percent reported waiting for confirmation of the diagnosis for more than one week, and the majority of those (63%) felt this time period was too long. People with breast cancer were less satisfied with the amount of time taken to confirm diagnosis than people with melanoma.

There is little information to help people judge the quality of their diagnosis. The National Breast Cancer Centre has published a consumer guide¹²² that provides information about the recommended steps in investigating a breast symptom in parallel to the guideline for general practitioners.¹¹⁵ There is no credentialing or other program that enables people to know whether their general practitioner or other care provider is competent in the diagnosis of cancer.

There are opportunities to improve diagnosis by the establishment of guidelines and the audit of current practice.

Information and support in diagnosis

Optimal Services: People will have information about, and be supported through the process of diagnosis, regardless of whether they have an abnormality on screening or a sign or symptom that may be cancer. They will have information that helps them understand that the process of diagnosis is one of increasing certainty rather than a moment of truth. They will know about the steps in the pathway of diagnosis, what is involved in each test and what the results mean. This will include information about the likelihood of false positives and false negatives. People will be provided with support throughout the process of diagnosis, recognising that this is a time of increased anxiety.

Health professionals and consumers can approach population screening programs and the investigation of symptoms with different agendas—consumers seeking reassurance that they do not have a condition while practitioners are looking for a sign of possible disease or abnormality. Such differing agendas may often result in different information needs and discrepancies in information provision.¹²³ For example, consumers and health practitioners often do not differentiate between screening and diagnostic testing. The process of diagnosis can be more anxiety provoking than knowing that a cancer exists.

The information and support needs of people with abnormal test results include¹²⁴:

- receiving information about test results and planned diagnostic procedures
- receiving information about possible diagnosed conditions and their causes, effects and treatment
- being directed to reliable sources of information
- having an educational approach tailored to people's preferences
- feeling able to ask questions
- receiving emotional support from the person presenting results
- being referred to appropriate support services.

Most people find the uncertainty associated with an abnormal screening result or investigation of a symptom very stressful. It is important to minimise the delay between the findings of test results and a referral to further diagnostic tests or to a treatment team. Typically, people have very inaccurate knowledge about the pre-test and post-test probabilities of common diseases and about the characteristics of tests used to diagnose those diseases.^{98,125} For example, an Australian population based study of women's attitudes to information, and involvement in decisions, about test results found that most women were shocked to hear that mammograms are not 100% accurate.¹²⁶ Having experience with the disease does not improve people's knowledge about the disease characteristics and probabilities.¹²⁶ Many people do not understand the purpose of, and differences between, different tests and that the process of diagnosis is one of increasing certainty.¹²⁶

While people may vary in their need to understand this information, it is important that the key issues are clearly communicated so they can fully understand the meaning of their test results. There is growing research about how best to communicate information about test results, including the development of decision aids and visual guides.¹⁰²

There is little information about the adequacy of information for people undergoing cancer tests in Australia. One study assessed provision of the information about test accuracy and pre- and post-test probabilities related to cancer diagnostic and screening tests currently used in Australia. Most publications lacked the quantitative information women needed in order to make informed choices.¹²⁷ The failure to acknowledge that a test can give false-positive and false-negative results may mislead people when they are interpreting their own results.

Little is known about the special information needs of people with symptoms from disadvantaged groups, especially Aboriginal and Torres Strait Islander peoples and people from culturally and linguistically diverse backgrounds.

There is an opportunity to improve the information about diagnostic tests for cancer.

Access to diagnostic services for communities with specific needs

Optimal Services: People will have access to high quality and appropriate diagnostic services regardless of where they live. People from disadvantaged groups, especially Aboriginal and Torres Strait Islander peoples and people from culturally and linguistically diverse backgrounds, will have access to culturally appropriate diagnostic services.

There is little information about the availability of diagnostic services throughout Australia. However, regional, rural and remote areas are more poorly provided with diagnostic services; for example, diagnostic breast clinics are uncommon outside urban areas. A recent report by The Cancer Council of NSW noted that five year relative survival from all cancers, considered together for both men and women in NSW, was lower for people from remote areas. The reasons for this were not clear, but access to diagnostic services may be a contributing factor.^{128,129}

Little is known about the extent to which special communities can access appropriate diagnostic services. There is some evidence that cancer is diagnosed later among Aboriginal and Torres Strait Islander people.¹³⁰ A recent qualitative study examined Queensland Aboriginal and Torres Strait Islander women's perceptions of breast cancer diagnosis and treatment.¹³¹ The 101 women interviewed reported a number of barriers to timely presentation with breast symptoms, including the need for services to be central and easily accessible for women who lack access to public or private transport. The women preferred services to be available in known and familiar surroundings. Aboriginal Health Workers were said to be important for promoting a 'culturally safe' environment and increasing community awareness of breast cancer. Women saw the fixed appointment system as a major barrier to Aboriginal and Torres Strait Islander women attending services, as it conflicted with 'Aboriginal time' and precluded the possibility of women dropping in for a consultation.

There is an opportunity to improve diagnostic services for communities with special needs.

Provision of results

Optimal Services: People will be provided with their results in an appropriate and timely manner. Both positive and negative results will be provided in an appropriate manner, meeting published guidelines about breaking bad news. People will be provided with information about the short and long term significance of their diagnosis and about the next steps in treatment. People diagnosed with cancer and their families will be provided with appropriate support and counselling.

Test results

For people with cancer to fully understand test results, they need to know: what the test can test for; the range of possible test results (e.g. normal, benign disease, cancer, uncertain); what these results mean; that tests are not 100% accurate; the chance of a normal result in a person who does not have cancer (true negative) and the chance of normal result in a person who does have cancer (false negative); the chance of an abnormal result in a person who does have cancer (true positive) and the chance of an abnormal result in a person who does not have cancer (false positive); the next steps and test options. In practice, this amount of information is rarely given, either by the clinician or in written form.¹²⁷

A diagnosis of cancer

Guidelines for telling people that they have cancer or a recurrence of cancer have been developed in Australia. They emphasise that the doctor should clearly and honestly state the test results, and make it very clear that the diagnosis is now certain to avoid confusion and denial.¹³² Adequate preparation beforehand concerning possible outcomes of testing will make the final diagnosis less of a shock. Rapid clarification of the next steps will ease the emotional impact.

People have high needs for information and support at the time of diagnosis. Most people want a great deal of information—clear information about prognosis and treatment options has been found to assist adjustment after the shock of the diagnosis.¹²¹ However, many people report difficulty absorbing and processing information at this time, and benefit from having information staged, and repeated several times. The best approach is to tailor information to individual needs.

A large survey of people with different types of cancers found that they value the supportive aspects of health professional communication almost as much as the content.¹³³ The way in which a diagnosis of cancer is delivered affects not only the person's understanding of the illness, but can also impact on their long term psychological adjustment. For example, an Australian study linking people's reports of their experience of being told the cancer diagnosis to their subsequent adjustment¹³⁴ found that people were less anxious and more satisfied 4–13 months later if they: felt prepared for a possible diagnosis of cancer; had the people they wanted present to hear the diagnosis; had as much information about the diagnosis as desired; were provided with written information; felt the information was presented clearly; had their questions answered on the same day; and had an opportunity to talk about their feelings and felt reassured¹³⁴. People were less depressed if the doctor used the word 'cancer', discussed the severity of the situation, their life expectancy and how the cancer might affect their lives, and if they were encouraged to be involved in treatment decisions.

Few Australian studies have reported people's experiences of communication at the time of their diagnosis. In one study of people with melanoma¹³⁴, several disparities between people's experiences and preferences were reported, the most notable being perceived delays in receiving the diagnosis, and having inadequate opportunity to ask their clinician questions. Just over half the people reported receiving the amount of information they wanted at diagnosis. Most people appeared to be satisfied with the way their diagnosis was communicated, but would have liked more information, particularly about prognosis.¹³⁴ In a study of people with breast cancer and melanoma, 63% rated the communication at diagnosis as excellent or good, and a further 18% rated it as satisfactory.¹²¹

In another study, 25% of people with breast cancer and melanoma reported being told their diagnosis over the telephone, 34% reported that the situation lacked privacy, and 36% reported that the diagnosis was a complete surprise, suggesting a lack of adequate preparation.¹²¹ Some 76% reported that their doctor was caring and sympathetic, but only 46% reported being told about cancer support services. A population based study of women with early breast cancer in Australia found that most women were satisfied with the way they were told their diagnosis, and that they reported care in accord with most aspects of evidence-based guidelines.¹³⁵

There are opportunities to improve understanding of test results and their significance.

Referral to treatment

Optimal Services: People with cancer will be appropriately referred to treatment. There will be established referral pathways between diagnostic and treatment services. People will experience the transition between diagnosis and treatment as seamless and continuous care. People will know that they are being referred to a high quality treatment service. This might be established through credentialing and links to major treatment centres as outlined in the next section.

There is good evidence that for some cancers prompt referral to a multidisciplinary team or centre of expertise will increase survival.¹³⁶ The referral is usually made by a general practitioner either at the point of diagnosis of cancer or because of a high suspicion of cancer.

Referral pathways are often established historically or by personal knowledge of a specialist or specialist team. There is no detailed information available to general practitioners to assist them in providing advice to people with cancer about appropriate referral options. Likewise, there is no standard information available about the differences between services and the quality of care that they provide.

There is little information about referral pathways in Australia or the extent to which they result in optimal care.

There are opportunities to significantly improve referral pathways by providing information to primary care providers and to people with cancer about cancer services.

CHAPTER 4.

Treatment and Support during Active Treatment

The treatment of cancer will depend upon the type of cancer and its spread at diagnosis and upon the person's needs and wishes. For many people with cancer, surgery will be the first step in treatment. This may be followed by combinations of radiotherapy, chemotherapy and other treatments. For some people the cancer will not recur after the initial treatment while for others the cancer will recur after a period when it does not appear to be present. For some people with cancer the disease will continue to be active from the time of diagnosis. Issues for people after and between periods of active treatment are discussed in the next section.

Survival rates among people with cancer in Australia generally compare well with similar countries. Overall, Australia is second only to the US.¹³⁷ When treatment practices are compared with evidence-based guidelines or practice in similar countries, people with cancer in Australia are usually found to be receiving high quality care.^{4,138}

It is recognised that the opportunities to improve treatment and support for people with cancer lie mainly in modifying the ways in which cancer care is organised and services are delivered.⁴ Australia has a very complex health system—people with cancer often move between the private and public sectors and, also, care must be provided to people in regional, rural and remote parts of Australia. A more coordinated approach to cancer care is required which enables networked integrated services to be provided within a person centred and multidisciplinary framework.

PEOPLE'S NEEDS

People want to:

- Understand what may happen to them during active treatment.
- Trust their treatment team to provide them with best care.
- Know who is coordinating their care and who can answer their questions and that their care is well coordinated and seamless.
- Have access to the best and most appropriate care regardless of where they live or their cultural and linguistic background.
- Be told honestly and clearly about their disease and treatment options so they can make the best decisions.
- Limit the symptoms of the disease and the side effects of treatment to maintain the best possible quality of life.
- Limit the impact of the cancer and its treatment on their daily lives and that of their families and carers.
- Be able to discuss their concerns and feelings and receive support if needed for themselves and their families.

OPTIMAL SERVICES

People with cancer will have access to all relevant expertise and facilities regardless of where they live:

- The core treatment team will include but not be limited to surgery, medical oncology, radiation oncology, pathology, radiology, nursing and supportive care.
- Facilities for high quality radiology, pathology, surgery, medical oncology and radiation oncology will be available.
- People with cancer will also be able to access other care as relevant to their needs including genetic testing and counselling, psychiatry, physiotherapy, and nuclear medicine.
- Models of service provision will ensure that people with cancer in regional, rural and remote areas can access high quality care by linking smaller centres to large specialist centres; this might be achieved through personal visits, teleconferencing or multidisciplinary case conferencing.
- Adequate support for travel and accommodation will be provided for people who need to travel for treatment and consideration will also be given to the needs of their families.

People with cancer will experience the cancer journey as seamless and continuous care provided by one integrated service:

- People with cancer will move from one component of care to the next and from one treatment modality to another as though they are part of one service. The transition from screening or diagnosis to treatment, and from treatment to the community, will be experienced as phases of care rather than movement from one separate service to another. Likewise, people with cancer will experience the provision of surgery, radiation oncology and medical oncology services as integrated components of one organised service.
- This feature will require close liaison nationally and integration between different components of the screening, diagnostic, treatment and support services.
- Communication strategies will be in place to ensure that general practitioners and other community care providers are fully informed about the diagnosis, treatment and supportive care for each person with cancer in their care.
- People with cancer will have a designated coordinator of care who knows about all aspects of their disease, treatment and support. The care coordinator will help people with cancer move between treatment components, ensure that they have access to appropriate information and support and ensure that the treatment team is fully aware of a person's preferences and situation. The care coordinator might be a cancer nurse, general practitioner, case manager, cancer specialist or other health professional. The care coordinator may be a different person at different times in the cancer journey but the person with cancer should always be clear about who is their care coordinator.
- The care and referral pathways available to people with cancer will be clearly defined and any options identified.
- Referrals for diagnosis and treatment will be to individuals or centres with recognised expertise. This may include referral to smaller centres linked to larger centres of expertise. Referrals will ensure that diagnosis and treatment are provided within a time frame which will not cause people with cancer undue anxiety or compromise the effectiveness of their treatment.
- People with cancer will be provided with information about care and referral pathways so they understand what will happen next.

People with cancer will be confident that they are being treated according to the best available evidence:

- There will be agreed national clinical practice guidelines covering the diagnosis and management of the priority cancers.
- There will be agreed national psychosocial clinical practice guidelines covering information, support and counselling for the priority cancers.
- Processes will be in place to assess the extent to which clinical practice guidelines are adopted and to encourage their implementation.
- Services will have local protocols for the treatment and support of people with cancer based on agreed national guidelines (where they exist) and based on best available evidence in the absence of guidelines.
- Services will have audit systems for collecting information about the care of people with cancer which enable an evaluation of the extent to which care is in accord with the evidence and their protocols. Information from the audit will be provided to treatment teams and used to develop quality improvement programs.
- People with cancer will have access to information about the guidelines and/or the protocols used by their service providers.
- People with cancer will be invited to participate in clinical trials, when appropriate, and receive as much information as they need to enable them to make informed decisions about participation.
- Health professionals will have access to up to date information and continuing information about cancer treatment and support.

People with cancer will know that their treatment providers are working together with them as a team:

- People with cancer will know who is part of the team providing their care.
- The team will have strategies (such as local protocols and multidisciplinary case conferencing) for agreeing on the options for treating each person with cancer.
- People with cancer will know that there is good exchange of information among the team members, including their general practitioners.

People with cancer will receive care that is acceptable, accountable and appropriate:

People with cancer will be offered information about the extent to which their treatment facilities meet agreed national benchmarks and implement quality improvement and training programs.

People with cancer will have the opportunity to provide feedback and comment about the care provided and will be confident that it will be attended to.

Aboriginal and Torres Strait Islander people with cancer and people with cancer from culturally and linguistically diverse backgrounds will receive care that is culturally appropriate.

People with cancer will have the opportunity to contribute to the planning of cancer services.

People with cancer and their families will receive adequate information appropriate to their needs at all stages of the cancer journey and make decisions about their treatment:

- Both verbal and written information will be available about: prognosis, treatment options, benefits, risks and possible complications of treatment, pain and symptom management, reconstructive surgery, experience of the disease and its treatment and supportive care.

- People with advanced cancer will receive copies of letters/notes about treatment or be able to access their own health care record.
- Information will be suitable for people's educational status and cultural and linguistic background.
- People with cancer will be able to discuss their concerns openly with their treatment team. They should receive information that is given in a supportive, caring way and have the opportunity to express their feelings. Information should be given and discussed in a private environment, with plenty of time given for discussion.
- Adequate information about treatment options will be available.
- People with cancer will be able to be involved in decisions about their treatment to the extent that they wish.
- People with cancer will have a written treatment and follow up plan that takes account of individual circumstances.

People with cancer and their families will receive appropriate support:

- People with cancer will receive detailed information about supportive care services.
- People with cancer and their families will have the opportunity on repeated occasions to discuss their needs with a member of the treatment team and with community health providers.
- People with cancer will have access to supportive care services including psychologists, psychiatrists and physiotherapists, if needed.
- People with cancer will have access to services to assist in managing the side effects of their disease and its treatment.
- People with cancer will be provided with information about entitlements to financial assistance for costs associated with treatment including travel, accommodation and prostheses.
- People with advanced cancer will have access to specialist palliative care advice and services when required and in accordance with the National Palliative Care Strategy.²⁶³

RATIONALE FOR THE COMPONENTS OF OPTIMAL SERVICES AND CRITICAL INTERVENTION POINTS

Access to treatment

Optimal Services: People with cancer will have access to all relevant expertise and facilities regardless of where they live. The core treatment team will include, but not be limited to, expertise in surgery, medical oncology, radiation oncology, pathology, radiology, nursing and supportive care. Facilities for high quality radiology, pathology, surgery, medical oncology and radiation oncology will be available. People with cancer will also be able to access other care as relevant to their needs, including genetic testing and counselling, psychiatry, physiotherapy and nuclear medicine.

Models of service provision will ensure that people with cancer in regional, rural and remote areas can access high quality care by linking smaller centres to large specialist centres. This might be achieved through personal visits, teleconferencing or multidisciplinary case conferencing. Adequate support for travel and accommodation will be provided for people who need to travel for treatment and their families.

Access to expertise and services

The treatment and support of people with cancer requires many different types of services and skills including expertise in surgery, medical oncology, radiation oncology, pathology, radiology and supportive care. People with cancer may also need to be able to access other care as relevant to their needs, including genetic testing and counselling, psychiatry, physiotherapy, nuclear medicine.

There is evidence of poor access to some components of care throughout Australia. Poor access to specialist psychiatrists and psychologists is a barrier to the provision of adequate supportive care services¹³² and the lack of radiation oncology services has been repeatedly identified. The Baume Inquiry Report on Radiation Oncology⁶ noted that only 80% of the desirable number of people with a new diagnosis of cancer receive radiotherapy and that waiting times for treatment are too long. The Inquiry concluded that there are shortages in the critical workforce and a lack of modern machines, resulting in considerable waiting times.⁶

Access in regional, rural and remote areas

The provision of services close to where a person with cancer lives is inevitably limited by the local population density and the distance from major centres of population. Some services, such as radiotherapy, are not available outside capital cities and a few major towns. It is estimated, however, that around 30% of people with cancer live outside a major population centre.⁷

Health services in regional areas have lower caseloads than services in metropolitan centres. Caseload is not simply a count of the number of procedures performed or the people treated, but is associated with several complex interacting factors, each of which may affect outcomes, including: the relevant experience and training of the provider; processes of care in the institution in which care is delivered; institutional characteristics, including infrastructure and equipment; the availability of multidisciplinary expertise; and the appropriateness of people selected for the procedure performed. The association between caseload and outcomes varies with the type of cancer and the type of procedure performed.¹³⁹⁻¹⁴¹

The evidence about caseload, care provision and outcomes in the treatment of cancer in Australia is somewhat inconsistent. The national survey of breast cancer care found that surgeons with small caseloads provided similar care to those with large caseloads.¹³⁸ Although women seen by clinicians who treated a large number of women with breast cancer were more likely to receive breast conserving surgery than those managed by surgeons with a lower caseload, this does not in itself constitute poorer care.¹³⁸ In contrast, it appears that women with ovarian cancer who are treated in units that care for a smaller number of cases have poorer survival.¹⁴²

Within Australia, providing adequate access to care for people in regional, rural and remote areas will depend upon resolving two challenges.

Providing local high quality access for some services

Many people with cancer will continue to receive components of their care outside major treatment centres and close to where they live. There is evidence that, for some cancers, people treated by multidisciplinary teams have care more in accord with evidence, and better survival.^{136,143} The challenge is to provide services in regional, rural and remote areas using a multidisciplinary approach with specialist input as required.

Services outside major treatment centres should be encouraged to develop links with centres of expertise. This might be achieved in a number of ways, including visiting specialists and participation in multidisciplinary case conferencing through videoconferencing or by telephone. Links already exist between many regional, rural and remote areas and major centres of cancer expertise. These links have developed historically and are often based on relationships between individual health professionals.

A more systematic and planned approach to linking all regional, rural and remote facilities to centres of expertise would appear to be of value. It is anticipated that these links will include the development of extended teams which enable professionals working in regional, rural and remote areas with specialist teams in major hospitals to work together as one multidisciplinary team. Some models for this distance linkage already exist.¹⁴⁴

There may also be the opportunity to improve specific aspects of care in rural areas. For example, studies have reported considerable variation in standards and policies in the administration of chemotherapy in rural settings.^{145,146} Improved education and training for health professionals from rural Australia and the accreditation of chemotherapy services may also improve access to this component of care. There are some models for improving education for regional, rural and remote health professionals in administering chemotherapy.¹⁴⁷

Good practice: Linking centres of expertise with regional, rural and remote areas

A video conferencing link has been established for some time between Adelaide and Darwin to enable Darwin clinicians to participate in multidisciplinary oncology meetings at the tertiary referral centre in Adelaide. This is supplemented by regular visits by the Adelaide oncologists. An evaluation of the videoconferencing link reported that all clinicians found the link to be useful enabling remote area clinicians to participate in multidisciplinary cancer meetings, better support of isolated clinicians, decreased travel for people with cancer and enhanced education and peer review.¹⁴⁴

Support for people who need to travel

It is unlikely that people treated in regional, rural and remote areas will ever be able to access all services locally and there will be an ongoing need for people to travel for some components of their care. There is also often a competing tension about access to services and quality of care. A recent review of studies of the impact of travel on people with cancer and their experiences of treatment identified eleven studies which consistently described travel to cancer treatment as inconvenient and a practical hardship for many people with cancer and their families.¹⁴⁸ These issues may cause some patients in remote areas to choose not to have some treatments.

Financial schemes are available to help subsidise the costs of travel and accommodation for people with cancer needing to travel long distances for treatment. However, these schemes have been criticised on grounds of equity and affordability and they do not always work well for the people who need them. People with cancer report that they are often given insufficient information about financial assistance schemes. For example, in one population based study, less than half (47%) of 204 women with breast cancer from rural areas who travelled for treatment received financial assistance, and 13% of these women had difficulty organising or claiming financial assistance.¹⁴⁹ Similarly, one-quarter of 192 people with haematological malignancies surveyed in Queensland who travelled for treatment had never heard of the patient access and travel schemes.¹⁵⁰

Other people who are required to travel long distances may encounter discrimination in being eligible for financial assistance schemes, because of variations that exist within and between jurisdictions for the patient access and travel schemes. Some states and territories will provide assistance for people living more than 100km away (the majority of states/territories) while one state sets the cut off at 50km, and another at 200km. People who want an escort/family member to accompany them may also face difficulties receiving financial assistance for travel and accommodation.⁴ A national review of travel support has been suggested.⁴

The problem: the impact of cancer

I had my first blood tests on a Tuesday morning and that afternoon I was told I had cancer. During my first few nights in hospital my husband slept in a chair beside my bed. My parents were forced to stay in a guesthouse nearby at \$120 per night. My sister lived 40 minutes from the hospital, so her household grew from three to 10 people ... tension was high and relationships strained. These living arrangements meant that no one had any routine or normality to their lives. It would have been a load off my mind had my family been able to stay somewhere close by, without being a burden on anyone, or on their savings. I went from wondering if I had many tomorrows left, to stressing about where my family would stay.

Janelle, living in regional Victoria and travelling into Melbourne for treatment.¹⁷⁷

Appropriate access for special populations

The provision of standard services may not be sufficient to create appropriate access for some groups. For example, Aboriginal people living in regional, rural and remote areas, or even in Darwin, are reported as being particularly disadvantaged in accessing cancer services, especially radiotherapy.⁴ 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.⁴ Indigenous health workers with cancer training might assist in navigating the system. The gender of the clinician may be a barrier to having symptoms investigated or the provision of treatment.

The diagnosis of cancer is often regarded as meaning death and the person may be 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—that 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.

Little is known about how to provide appropriate cancer care for Aboriginal and Torres Strait Islander people or for people from culturally and linguistically diverse backgrounds.

There is an opportunity to improve access to services (especially radiotherapy), particularly for people living in regional, rural and remote areas and from Aboriginal and Torres Strait Islander backgrounds.

Seamless and continuous care

Optimal Services: People with cancer will experience the cancer journey as seamless and continuous care, provided by one organised service. They will move from one component of care to the next and from one treatment modality to another as though they are part of one service. The transition from screening or diagnosis to treatment and from treatment to the community will be experienced as phases of care rather than movement from one separate service to another. Likewise, people with cancer will experience the provision of surgery, radiation oncology and medical oncology services as integrated components of one organised service. This will require close liaison and integration between different components of the screening, diagnostic and treatment services, and communication to ensure that GPs and other community care providers are fully informed about the diagnosis, treatment and supportive care for each person with cancer. People with cancer should have a care coordinator who knows about all aspects of their disease, treatment and support. The care coordinator will help people with cancer move between treatment components, ensure they have access to appropriate information and support and that the treatment team is fully aware of the person’s preferences and situation. The care

coordinator might be a cancer nurse, GP, case manager or other health professional. The care coordinator may be a different person at different times in the cancer journey but the person with cancer should always be clear about who is their care coordinator. The care and referral pathways available to people with cancer will be clearly defined and any options identified and referrals for diagnosis and treatment will be to individuals or centres with recognised expertise. This will include referral to smaller centres linked to larger centres of expertise. Referrals will ensure that diagnosis and treatment are provided within a time frame that will not cause people with cancer undue anxiety or compromise the effectiveness of their treatment. People with cancer will be provided with information about care and referral pathways so that they understand what will happen next.

Continuity of care for people with cancer requires linkages and coordination:

- among different modalities (surgical, radiation and medical oncology)
- among providers from different professions and disciplines (e.g. general practitioners and specialist doctors, nurses, allied health practitioners, technical personnel, and psychologists)
- among different individuals within the same discipline (e.g. medical or nursing staff on rosters)
- within any single service, over time
- across the full spectrum of comprehensive cancer care, from cancer detection through treatment and follow up to palliative care
- across different service types and settings (public and private, inpatient and ambulant, general and specialist hospitals).

There is some evidence from international studies that continuity of care results in better outcomes^{151,152} It is also suggested it plays a role in reducing medical errors and improving patient safety.¹⁵³ However, it is not clear how these studies relate to care in Australia.

The establishment of continuity of care is particularly difficult in the Australian health care system where people may be treated in both the private and public sectors and at different geographic locations. The components of care (screening, diagnosis, treatment and ongoing care) may be provided by different and separate services with different funding and governance arrangements. Even within one component of care, like treatment, people with cancer may move between a number of different services.

There is evidence from international studies that some strategies improve continuity of care. For example, specialist breast nurses have been found to effectively function as coordinators of care and improve continuity of care.^{154,155} There is also some evidence that patient held records can contribute to improving the continuity of care.¹⁵⁶

However, relatively little is known about approaches to ensuring continuity of care in Australia or the extent to which people with cancer currently experience continuity of care. The lack of continuity of care is a common complaint of people with cancer in Australia.^{4,157,158} In one survey, women with breast cancer reported that they saw a different doctor every time they visited the hospital and that they did not clearly understand who in the treatment team did what.¹⁵⁷ However, a report of a national consumer survey of women with early breast cancer found that 94% of women said they understood who was coordinating their care, although 42% said they would have liked to have had access to one main contact person.¹⁵⁸ This study also reported that only about one in five women reported access to a specialist breast nurse. Patient held records for people with cancer are uncommon in Australia.

In Australia's diverse health system, it seems likely that other approaches will be needed to improve continuity of care between services such as diagnosis and treatment. It has been proposed that population based integrated cancer services may be a potential approach.

The integrated cancer service would create an overarching framework for a number of separate services. These services would remain separate entities but be linked through common approaches to quality assurance, protocol development, education, and monitoring. The integrated cancer service would be established to provide all cancer care including public information, screening, diagnosis, treatment, support and special services. The service would be built to provide a seamless transition between services, to provide care to a defined population, and include both public and private sector services.

The integrated cancer service would seek to provide a doorway to quality care; once people enter an integrated cancer service (e.g. at the point of attending for screening or investigation of a symptom) they would be assured of an organised, integrated and high quality approach to all aspects of care. The integrated cancer service would be well defined with named facilities and health practitioners who provide care within the service.

Information would be readily available in the community and to health practitioners about the integrated service's approach to care and facilities that are part of the service.

The integrated service might have a coordination centre responsible for fostering communication, linkages and the overall model within an area. It should be noted, however, that as yet there has been no evaluation of this concept.

There is an opportunity to improve continuity of care within service components and to improve continuity of care between service components through the development of integrated cancer services.

EVIDENCE-BASED TREATMENT

Optimal Services: People with cancer will be confident that they are being treated according to the best available evidence. There will be agreed national clinical practice guidelines covering the diagnosis and management of cancer and the provision of information, support and counselling. Services will have local protocols for the treatment and support of people with cancer based on guidelines where they exist and based on best available evidence in the absence of agreed national guidelines. Services will have systems for collecting information about an individual's care which enable an evaluation of the extent to which care is in accord with the evidence and their protocols. Information from the audit will be provided to treatment teams and used to develop quality improvement programs. People with cancer will have access to information about the guidelines and/or the protocols used by their service providers. People with cancer will be invited to participate in clinical trials and receive as much information as they need to enable them to make informed decisions about participation.

Clinical practice guidelines

There is substantial evidence that cancer care varies across services and settings¹⁵⁹ and that it is not always in accord with the best available evidence.^{160,161} Clinical practice guidelines are summaries of evidence and are often a first step in encouraging evidence-based practice. There is considerable research demonstrating that evidence-based clinical practice guidelines are effective in improving the quality of clinical practice and the outcomes of care for people with cancer.^{162,163} A targeted review of the impact of clinical practice guidelines on oncology treatment processes and outcomes showed that improvements have been demonstrated in compliance with guidelines, in short term length of stay, complication rates and financial outcomes.¹⁶⁴

However, implementation strategies are usually required to ensure the full adoption of clinical practice guidelines. The specific strategies will depend on the guidelines and the barriers to evidence-based practice. Intervention strategies may include those targeting change in the systems, funding or policies, knowledge, attitude or skills of health

professionals or consumer knowledge.¹⁶⁵ Implementation programs that use more than one method tend to be more successful.^{162,165,166}

In Australia, substantial effort has been directed at the development of clinical practice guidelines for cancer, and NHMRC endorsed guidelines are available, or soon will be, for most of the priority cancers including:

- early breast cancer (NHMRC endorsed)¹⁶⁷
- advanced breast cancer (NHMRC endorsed)¹⁶⁸
- skin cancer and melanoma (NHMRC endorsed)¹⁶⁹
- non-melanoma skin cancer (NHMRC endorsed)¹⁷⁰
- bowel cancer (NHMRC endorsed)¹¹²
- prostate cancer (NHMRC endorsed)¹⁷¹
- familial aspects of cancer (NHMRC endorsed)²⁷
- lung cancer (NHMRC endorsed);
- ovarian cancer (NHMRC endorsed).

Guidelines for non-Hodgkin's lymphoma are under development.

Guidelines for the psychosocial care of people with cancer¹³² have also recently been endorsed by the NHMRC.

However, the dissemination, implementation, evaluation and maintenance of these guidelines have generally not been sufficiently well supported and resourced, with the possible exception of breast cancer.

Clinical practice guidelines, or agreed standards of care, also make it possible to evaluate the extent to which current practice is in accord with the evidence. Population based patterns of care studies have been undertaken at the national and state levels. There have been two national invasive breast cancer patterns of care studies^{138,163}; a national colorectal study¹⁷²; and two lung cancer studies.^{117,173} There has also been a state based prostate cancer study.¹⁷⁴ Other patterns of care studies, including a skin cancer survey, are in progress. The completed studies have indicated aspects of care that require further attention. There have been no similar surveys for some other priority cancers and it is therefore not possible to know whether care is in accord with the evidence.

Good practice: measuring current care

A national survey of care¹⁷² involving 2 015 people with bowel cancer indicated that care for people with this cancer was overall of high quality and in accord with the guidelines.

However, several aspects of care emerged as possibly requiring additional attention:

- increasing rates of referral of people with lower third rectal cancer to specialist bowel surgeons
- increasing rates of adjuvant chemotherapy in node positive colon cancer and combined modality therapy in high risk rectal cancer
- increased participation in clinical trials.

Local protocols, audit and quality improvement

Clinical practice guidelines are used at the service level to develop protocols about the delivery of care. The audit of practice against local protocols and clinical practice guidelines assists services in understanding where care could be strengthened. The establishment of strategies to modify practice can be developed from this information.

There is little information about the extent to which services currently develop protocols, audit and review practice or implement quality improvement programs. In a survey of 60 hospitals, written protocols covering multiple aspects of care for women with breast cancer were reported in 45% of high caseload hospitals only. In 40% of low, 25% of medium and 15% of high caseload hospitals there were no protocols for the management of women with breast cancer.¹⁷⁵ All high caseload hospitals had some form of data collection, but 60% had no process for review of data. Forty percent of low and 20% of medium caseload hospitals had no data collection system.¹⁷⁵

One Australian study has explored the impact of a systematic approach to quality improvement in cancer services. It demonstrated in a randomised trial that a quality improvement program based on analysis of local data and needs was effective in improving care.¹⁷⁶ The extent to which such processes are routinely in place is unknown.

Clinical trials

There is also a need to continue to develop the evidence base for improving care. Clinical trials are fundamental to establishing whether there is benefit in new treatments. There is also evidence that people with cancer enrolled in clinical trials receive better care and have longer survival. It has been estimated that around 2–3% of people with cancer participate in clinical trials, with around 20–30% eligible for current trials.⁴ Among people with breast cancer, participation is somewhat higher at around 6%.¹³⁸ In a recent population based survey, 12% of women with breast cancer reported being offered an opportunity to participate in a clinical trial with 6% of women agreeing to participate.¹³⁵

There are opportunities to encourage greater adoption of clinical practice guidelines and to better support participation in clinical trials.

MULTIDISCIPLINARY CARE

Optimal Services: People with cancer will know that their treatment providers are working together with them as a team. They will know who is part of the team providing their care and the team will have strategies for agreeing on the options for treating each individual. People with cancer will know that there is good exchange of information among the team members including their general practitioners.

The problem: multidisciplinary care¹⁷⁷

My surgeon told me that I wouldn't need radiotherapy but I ended up having to have it (woman with breast cancer: National Multidisciplinary Care Demonstration Project).

My surgeon told me that my cancer was oestrogen receptor negative but my oncologist said it was positive and prescribed tamoxifen (woman with breast cancer: National Multidisciplinary Care Demonstration Project).

There are many different disciplines involved in the treatment and support of people with cancer. There is evidence from overseas studies that care is more in accord with the evidence and survival is improved when treatment is provided by experts working together as a team rather than by individual clinicians seeing people with cancer sequentially.

This team approach to care is often referred to as multidisciplinary care. In a multidisciplinary approach to care, the treatment options are considered by a team including specialists with all of the relevant expertise. The treatment plan is developed by the team together rather than through sequential input by individual specialists.

A summary of evidence about the benefits of multidisciplinary care is provided in a recent publication by the National Breast Cancer Centre.¹⁷⁷ There is evidence that people with

cancer treated in large centres with a multidisciplinary approach are provided with better care and have better outcomes.^{136,143} For example, Gillis & Hole reported that the five year survival rate of women with breast cancer was 9% higher and the 10 year survival rate 8% higher if they were treated by specialist teams.¹⁴³ In Australia, women not treated within three months of diagnosis of ovarian cancer in a principal referral hospital (and therefore presumably without access to multidisciplinary care) were found to have lower survival.¹⁴² There is also evidence that treatment recommendations made by a multidisciplinary panel are more in accord with the evidence than those made by individual doctors.¹⁷⁸ A recent study found that in the UK multidisciplinary care improved survival, recruitment of people with cancer into clinical trials, personal satisfaction, and the mental wellbeing of team members.¹⁷⁹

A multidisciplinary model of care is increasingly common in the UK where most treatment of people with cancer occurs in designated cancer clinics. It is not clear how these findings apply in the more diverse delivery systems in Australia or indeed how multidisciplinary care might be defined in this context. In Australia, clinicians believe that a multidisciplinary care approach will provide better care.¹⁸⁰ Multidisciplinary approaches to the treatment of cancer are recommended in Australian clinical practice guidelines.¹⁶⁷

Different approaches to implementing multidisciplinary care in Australia will be required. In Australia, multidisciplinary care is more difficult to achieve because specialists treating a person with cancer may work in geographically separate places and a person with cancer may be treated in the private and/or public sectors. Innovative service delivery models will need to be developed to provide multidisciplinary care to all people with cancer in Australia. It is likely that the models will be different in different parts of Australia. The National Breast Cancer Centre has developed a set of principles to describe an operational definition of multidisciplinary care in Australia.^{180,181} Service delivery models should be developed to achieve these. There is evidence that a multidisciplinary approach to care can be facilitated even in remote areas. Olver & Selva-Nayagam have described the development of a multidisciplinary approach to treating women with breast cancer based on the team at the Royal Adelaide Hospital and linking with clinicians in Alice Springs and Darwin through videoconferencing and visits.¹⁴⁴

The National Multidisciplinary Care Demonstration Project followed three multi-site collaborations who were implementing strategies to foster increased multidisciplinary care. The collaborations were able to establish regular multidisciplinary treatment planning meetings, often across geographically separate sites. Multidisciplinary care was found to improve supportive care, improve communication between clinicians and provide clinicians with greater emotional and intellectual support. The participating clinicians also reported that the multidisciplinary strategies were worthwhile and had improved the care of women with breast cancer.¹⁷⁷

Little is currently known about the extent to which care for people with cancer in Australia is provided using a multidisciplinary approach. There are no simple indicators of multidisciplinary care. Treatment in a larger centre does not necessarily mean that care is multidisciplinary and treatment in a rural centre may be multidisciplinary through the use of videoconferencing, specialist visits or other approaches.¹⁸² The only study that has specifically examined service organisation surveyed 60 hospitals providing care for women with breast cancer. While 70% of large case load hospitals had regular multidisciplinary meetings, only 50% considered all women with breast cancer. Fifty five percent of medium caseload hospitals held regular treatment planning meetings but only 35% considered all cases. Only one hospital in the low caseload category had regular multidisciplinary meetings.¹⁷⁵

Several strategies may facilitate the establishment of multidisciplinary care for people with cancer in Australia, including:

- the establishment of population based cancer services that link smaller facilities with larger centres for treatment planning and multidisciplinary education
- development of accreditation processes for cancer services that include the provision of multidisciplinary care as a criterion
- financial support for videoconferencing in regional, rural and remote areas, and for coordination of the meetings
- reimbursement for participation in multidisciplinary meetings.

There is the opportunity to improve multidisciplinary care in Australia.

ACCEPTABLE, ACCOUNTABLE AND APPROPRIATE CARE

Optimal Services: People with cancer will receive care that is acceptable, accountable and appropriate. People with cancer will have access to information about the extent to which their treatment facilities meet agreed national benchmarks and implement quality improvement and training programs, will have the opportunity to provide feedback and comment about the care provided, and will be confident that it will be attended to. Aboriginal and Torres Strait Islander people with cancer and people with cancer from culturally and linguistically diverse backgrounds will receive care that is appropriate.

The provision of person centred care implies that services are seen as acceptable and appropriate by people with cancer. There should be methods in place to ensure that people with cancer can find out about the quality of care being provided, and feedback on those aspects of care that they do not find acceptable. Care for all people with cancer should be appropriate to their needs. Given the cultural diversity of the Australian population, particular attention should be paid to ensuring that services meet the needs of Aboriginal and Torres Strait Islander people and people from culturally and linguistically diverse backgrounds.

Feedback from people with cancer will help to indicate whether the cancer services are seen as acceptable and appropriate. Feedback can either be solicited from the person with cancer, or generated spontaneously. Giving people with cancer the opportunity to express their views and preferences, and the incorporation of those views and preferences are integral parts of person-centred care.

There should be opportunities to provide feedback to local services. This will require commitment from senior management and service providers, and the skills to respond effectively to the feedback received. Mechanisms must be in place to ensure that appropriate communications and interactions occur with people with cancer (and any other party concerned), that the feedback or complaint is responded to in a timely manner, and that any actions or changes implemented as a result of the feedback are monitored and evaluated. Most importantly, people with cancer should feel that they have really been heard. In Australia there are several other mechanisms for people with cancer to address complaints or concerns about medical treatment: directly to the doctor involved or the hospital or practice management; state based medical ombudsmen; the Medical Board, the police, or civil litigation through the courts.¹⁸³

Evidence suggests that people with cancer are aware of their rights as consumers, and that they welcome opportunities and avenues to provide feedback and make complaints.¹⁸⁴ While it has been claimed that most people who make a complaint simply want an apology or acknowledgement of harm, in a sample of 290 complainants to the NSW Health Care Complaints Commission, only 16% would have been satisfied with such a response. In addition, most complainants were disappointed with both the process for handling and

the outcome of their complaint.¹⁸⁴ Most complaints fell into two groups: complaints about clinical care and allegations of incompetence or negligence (64%); and poor or inadequate communication, including rude and inconsiderate behaviour (22%).¹⁸⁴

For services to be fully accountable, people with cancer need to be able to judge the standard of service provided. It is difficult, if not impossible, for people with cancer to know whether they are receiving high standard clinical care. Accreditation of services and credentialing of health professionals provide a mechanism through which individuals can be confident that their treatment service meets agreed standards of practice.

There are opportunities to improve the quality and accountability of cancer services through accreditation and credentialing.

INFORMATION ABOUT TREATMENT

Optimal Services: People with cancer and their families will receive adequate information appropriate to their needs at all stages of the cancer journey to assist them to make decisions about their treatment. Both verbal and written information will be available about: prognosis, treatment options, benefits, risks and possible complications of treatment, pain management, and reconstructive surgery, experience of the disease and its treatment and supportive care. People with advanced cancer will receive copies of letters/notes about treatment or be able to access their own health care records. Information will be appropriate to the educational and cultural/linguistic background of individuals. People with cancer will be able to discuss their concerns openly with their treatment team. They will receive information that is given in a supportive, caring way and have the opportunity to express their feelings. Information will be given and discussed in a quiet and private environment, with plenty of time given for discussion. Adequate information about treatment options will be available and people with cancer will be able to be involved in decisions about their treatment to the extent that they wish. People with cancer will have a written treatment and follow up plan that takes account of individual circumstances.

Most people with cancer would like access to a considerable amount of information about their disease and its treatment.¹⁸⁵ A good understanding of their choices and what may happen to them improves people's satisfaction with care, psychosocial well being and compliance with treatment.⁴

There is somewhat inconsistent evidence about the extent to which people with cancer in Australia currently receive adequate information; it is very likely that information is better for some cancers than others. In a population based survey of women with breast cancer, most women reported that they had enough information about all aspects of their disease and its management.¹³² However, other reports noted that people with cancer were dissatisfied with the information they received.⁴

People can be assisted to understand their disease and its treatment through the provision of written information, their own treatment plans and through good communication with their treatment team.

Written information

There is some research about how best to provide written information for people with cancer. For example, with regard to treatment decisions, information should include evidence-based statements about the benefits and harms associated with treatment options and the quality and consistency of the empirical studies underlying these statements. Information should also be presented in a balanced way using concise, jargon-free language.¹⁸⁶

For several cancers, consumer guides have been developed to provide evidence-based information in parallel to the clinical practice guidelines.

The consumer guides include evidence about treatment effectiveness. The guides appear to be judged by people with cancer as very useful. Among people with early breast cancer, 66–90% reported receiving a copy of the consumer guide.¹³⁵

Patient held records and treatment plans

The recall of information by people with cancer increases when they are provided with individualised information.¹⁸⁷ Patient held records are relatively uncommon in Australia, as is written information about an individual's own treatment. In a population based survey of women with early breast cancer, only 22% were provided with written information about their diagnosis. Only 5% received a written follow up plan.¹³⁵

Communication with the treatment team

Substantial evidence confirms that good communication has many positive effects on adjustment to cancer and its treatment.^{188,189} Several Australian publications provide guidance to clinicians on good communication practices with people with breast cancer, most of which are likely to be relevant to people with other cancers.^{189,190} There is evidence that people with cancer prefer audiotapes of consultations to written material.¹⁹¹

Interactive training can improve clinicians' communication skills.¹⁹² There is some evidence that Australian clinicians recognise the need for communication skills training, with only 29% of a sample of 143 surgeons believing they are very competent in skills like breaking bad news.¹⁹³

There are opportunities to improve the information available to people with cancer and their families through the provision of consumer guides for cancer and individualised information and by improving the communication skills of health professionals.

APPROPRIATE SUPPORT

Optimal Services: People with cancer and their families will receive appropriate support. They will receive detailed information about supportive care services and have the opportunity on repeated occasions to discuss their needs with a member of the treatment team and with community health providers. People will have access to supportive care services including psychologists, psychiatrists and physiotherapists and to consumer support groups and services to assist in managing the side effects of their disease and its treatment. People will be provided with information about entitlements to financial assistance for costs associated with treatment including travel, accommodation and prostheses.

Supportive care can be defined as care that helps a person with cancer and their family to cope with cancer and the treatment of it from pre-diagnosis, through the process of diagnosis and treatment, to cure, continuing illness or death and into bereavement. It helps the person with cancer to maximise the benefits of treatment and to live as well as possible with the effects of the disease. It is given equal priority alongside diagnosis and treatment.¹⁹⁴

Supportive care is provided to people with cancer and their carers throughout the cancer pathway. It should be given equal priority with other aspects of care and be fully integrated with diagnosis and treatment. It is not stage-of-disease dependent; people have supportive care needs from the time that the possibility of cancer is first raised. Supportive care is not a distinct specialty but is the responsibility of all health and social care professionals delivering care that is informed and driven by theories, models and frameworks drawn from diverse sources.

It is underpinned by open and sensitive communication and by organisations and teams who work in a coordinated way to ensure the smooth progression of people with cancer from one service to another.

The recently published *Clinical practice guidelines for the psychosocial care of adults with cancer*¹³² provide evidence that enhanced psychosocial support is associated with improved outcomes for a person with cancer and their family, including early recognition of support needs, and improvements in psychosocial adjustment, decision making, treatment compliance, satisfaction with care, and physical recovery.¹³² The guidelines make over 30 recommendations with supporting evidence from meta-analysis or randomised trials. There is evidence to support the benefit of:

- effective communication skills, including discussions about prognosis; 'breaking bad news'; information about treatment options; and preparing people with cancer for potentially threatening procedures and treatment; there is demonstrated benefit from communication skills training^{195,196}
- offering information and the opportunity to participate in decision making¹⁹⁵
- providing emotional counselling and support using a range of different strategies^{195,197}
- coordinators of care, particularly specialist breast nurses^{154,155}
- the identification and treatment of those with more serious anxiety or depression; evidence suggests that the prevalence of long term psychological distress in people with cancer ranges from 20–66%, and 12–30% experience clinically significant anxiety problems^{198,199}; only a very small proportion will be referred for professional assistance.²⁰⁰

Supportive care in cancer also includes a range of practical assistance: for example, the provision of wigs, prostheses, assistance with travel or child minding. These issues are often identified in people's comments about care. People with cancer want to know that different types of support services are available to them and also their families.

Consumer groups recognise the important role cancer support groups have in assisting many people with cancer to deal with the psychosocial impact of diagnosis, treatment and recurrence.²⁰¹

People with cancer also note the value of various forms of peer support, including self help groups for men with prostate cancer, and one-on-one programs for women with breast cancer.²⁰²

A central concern for many people is how their family, carers and friends will cope with cancer. As family and friends are often an integral part of a person's cancer care, the person with cancer will want to ensure that the impact on their family is minimal and that their family can access support services. Partners of people with cancer may experience comparable or even higher levels of distress than the person with cancer themselves.¹³²

There is little information at the population level about the extent to which people with cancer in Australia receive adequate supportive care. One population based survey of women with breast cancer found that most people reported receiving adequate care for themselves but not for their families.¹³⁵ However, complaints about lack of support are often received from people with cancer. People with cancer report that they want opportunities to discuss their feelings and concerns during and after treatment has concluded. For example, a study of more than 800 people with cancer in NSW demonstrated that they experience high levels of unmet needs, particularly in the psychological area, including concerns such as knowing whether their cancer would return or spread.²⁰³

People with cancer want their health care providers to be aware of and respond to their emotional concerns and provide appropriate support. Australian evidence has suggested that oncologists' awareness of their patients' physical and psychosocial wellbeing is less than optimal. A study of medical oncologists showed that clinicians tended to overestimate

patients' levels of perceived supportive care needs but underestimated the levels of their anxiety and depression.²⁰⁴ Similarly, a study of 298 Australians with cancer found that oncologists were less observant of and less able to address their cues for emotional support compared to cues for information.¹²¹ The Specialist Breast Nurse Project found that 36% of women recently diagnosed with breast cancer were depressed, as defined by the General Health Questionnaire, but few had sought professional help.²⁰⁰ In this study, specialist breast nurses were found to be skilled in identifying individuals with high levels of distress.

Strategies for improving supportive care have been implemented through the recent national program Strengthening Support for Women with Breast Cancer. Some of the implementation issues include:

- lack of funded positions for specialist cancer nurses
- limited access to specialist psychiatry and psychology services
- lack of knowledge and coordination of support services at the local level.

There is the opportunity to improve supportive care for people with cancer and their families, including the implementation of the 'Psychosocial clinical practice guidelines: providing information, support and counselling to adults with cancer'.

CHAPTER 5.

Management and Support after and between Active Treatment

The time after and between periods of active treatment is a distinct phase for people with cancer. During this time there may be different needs to those experienced during the period of active treatment, and the person will be adjusting to living with a chronic condition. People will be resuming their daily lives and making adjustments necessary to cope with the ongoing side effects of the disease and its treatment. They will also be dealing with uncertainty and fear of recurrence. They will access many health professionals and other agencies in the community and it is likely their general practitioner and community services will be key reference points for all aspects of their care.

PEOPLE'S NEEDS

People want to:

- know what may happen to them at and following the completion of treatment
- have information about and help dealing with uncertainty and fear of recurrence
- have information about and help preventing and dealing with ongoing side effects of treatment and disease
- understand how they can tell if the cancer has come back or is progressing
- know who is coordinating their care, or who they can use as a reference point or system navigator
- know how to take care of themselves and to maintain optimal health
- have help to maintain a maximum level of independence and physical, psychological and social functioning.

OPTIMAL SERVICES

People with cancer and their families will receive appropriate management and support after, and between, periods of active treatment:

- Systems will be in place to ensure that people with cancer have an effective transition between care at the treatment centre and in the community. People will know about the plan for the transition of their own care. There will be effective liaison and integration between service providers in the treatment setting and community.
- People with cancer will have a care plan for treatment and support which will include identification of a coordinator of care or system navigator. The system navigator might be a general practitioner, cancer nurse or other health professional.

- There will be good communication between the patient's hospital and community based health professionals.
- Systems will be in place to promote communication and liaison among health professionals providing care and support in the community.
- People will know how to access high quality and reliable information about all aspects of their disease, management and support.
- People will have access to services, support and information including general practitioners, allied health services and community based organisations to help them
 - take care of themselves, including advice about diet and lifestyle
 - manage the side effects resulting from the disease or its treatment to maximise their quality of life
 - cope with fears of recurrence
 - resume their daily lives, as far as possible.
- Appropriate systems and services will be in place to identify recurrence or progression of disease. People will understand the approach to surveillance of their own cancer. People will have information about possible signs and symptoms of their cancer progressing and know where to seek help.
- Services will focus on maintaining and improving quality of life and the concept of palliative care will be considered if appropriate throughout this period.

RATIONALE FOR OPTIMAL SERVICES AND CRITICAL INTERVENTION POINTS

Issues in cancer survivorship and living with cancer

“Cancer survivorship is a tumultuous experience of balancing the elation of surviving [a] life-threatening illness with the demands of chronic health concerns and altered life meaning.”²⁰⁵

More than half of all people diagnosed with cancers will be cured of their disease, excluding non-melanoma skin cancers. Non-melanoma skin cancers, if treated early, are much less life threatening than most other cancers. Another substantial percentage will have time without the effects of cancer troubling them after initial treatment.

The time after and between periods of active treatment is a distinct phase for people with cancer. During this time there may be different needs to those experienced during the period of active treatment and the person will be adjusting to living with a chronic condition. People will be resuming their daily lives and making adjustments necessary to cope with any ongoing side effects of the disease and its treatment. They will also be dealing with uncertainty and fear of recurrence. They will access many health professionals and other agencies in the community, and it is likely that their general practitioner and community services will be key reference points for all aspects of their care.

People want to be able to get on with their lives after recovering from cancer. Although there has been little research regarding the needs of people who have survived cancer, a review of studies of people with cancer who had survived five years or more reported that many continued to experience negative effects of cancer and/or treatments on their daily lives.²⁰⁶ Issues of concern for cancer survivors include physical symptoms such as fatigue, impaired sexual function, specific emotional issues related to survival, and concerns about recurrence. Other themes described by cancer survivors include the struggle between independence and dependence, a sense of wholeness, life purpose, reclaiming life, dealing with multiple losses, having control, the altered meaning of health, and surviving cancer from a family perspective.²⁰⁷

Research in this area highlights the need to be aware of the physical, emotional and social impact of cancer, even in the longer term, and the importance of understanding the unique meaning of the cancer experience to the individual.

Quality of life in survivors of cancer includes physical, psychological, social and spiritual wellbeing.^{208,209} Physical issues impinge least on quality of life after the treatment of cancer, while spiritual and psychological issues have the most impact.²⁰⁹ Survivors of cancer use mental health services more often than people of the same age who have not had cancer, with rate of use increasing further with co-morbid illnesses.²¹⁰ These rates rise further with younger age at diagnosis of cancer. At a population level, survivors of cancer have poorer global health ratings, more limited activities of daily living or other function limitations and more psychological problems. For younger people after treatment for cancer, working was less likely when compared to similar groups in the population as a whole.²¹¹ Two decades after diagnosis, health problems are still frequently encountered in survivors of cancer, including treatment specific and global health issues.²¹²

There is a perception that the diagnosis of cancer is a life changing event. Survivors of cancer often change lifestyle after the diagnosis in areas such as smoking or diet. At least one study by contrast also documented a decrease in physical activity in survivors of cancer.²¹³

Caregiver anxiety is also an issue. Caregivers of survivors of cancer have levels of distress about a diagnosis of cancer or a diagnosis of recurrence that may be higher than the person who has the diagnosis of cancer.²¹⁴

There have been few studies in Australia about the needs of people between and after active treatment for cancer.

Transition from active treatment

The concept of making a transition from a person with cancer undergoing active treatment to a survivor of cancer (after and between episodes of active treatment) is one that has not been widely explored. People making that transition reflect on the fact that it is a time of anxiety and uncertainty after a period of relatively intense support. Understanding this transition will be important to developing services that adequately meet the needs of people at this time in their lives.²¹⁵

A heightened form of this transition is from treatment to no treatment because of progressive disease. Health professionals must balance the withdrawal of active treatment while still providing supportive care.²¹⁶ Excellent communication will be necessary to ensure that people do not feel abandoned because of changes in their treatment. Health professionals may need special training to deal with this transition and to optimize outcomes for people with cancer and their carers.

Care planning for follow up of cancer survivors

Clinical practice guidelines often include recommendations about the frequency of and approach to follow up.¹⁶⁷ There is little information about the extent to which follow up recommendations are implemented. In breast cancer there is some evidence that, in practice, follow up schedules are more frequent than the recommendations.¹³⁸ Again, for people with breast cancer, it has been demonstrated that follow up by general practitioners is at least as effective as follow up by specialist teams. However, follow up in primary care is not routine practice in Australia. There are similar issues for other cancers—for example, follow up schedules for many solid tumours fail to account for the fact that if a diagnosis of recurrence is made, it is likely to be incurable. Intense follow up for many solid tumours is expensive without delivering improved health outcomes.

There are likely to be complex reasons for more frequent and more intensive follow up. These may be as much to do with individual's concerns about recurrence as about benefit in terms of outcomes.

Managing effects resulting from treatment

Adult survivors of adult cancers

Site specific long term problems are defined for most cancers where cure has been achieved, especially in the setting of systemic chemotherapy and/or curative doses of radiotherapy. Each cancer specific treatment has its own side effect profile. For example, people who have been treated for Hodgkin's disease have problems with lung and thyroid disease later in life.²¹² In women who have been treated for breast or ovarian cancers, specific advice on long term bone health should be routinely given, although limited data suggests that it is given in less than one-third of cases.²¹⁷ Women treated for Hodgkin's disease should be provided with advice about ongoing surveillance for breast cancer.²¹⁸ Women may experience early menopause following chemotherapy. This has wide implications, including decreased bone density with the risks of increased fractures later in life. Infertility for males and females remains a significant issue. Even with the availability of sperm/ova storage and fertility services, the emotional impact of treatment induced infertility cannot be underestimated.²¹⁹ Memory loss may cause problems for people after treatment.²¹² Neuro-psychological impairment following systemic chemotherapy is well documented. The magnitude of decline for each individual affected may not be enormous, but the total effect is substantial and may affect between one-quarter and one-third of all people who have systemic chemotherapy.²²⁰ Second tumours are a major concern for people who have been treated for cancer.

People have concerns about survivorship, regardless of their age. Older people frequently express concern about the effects on family of the diagnosis and treatment of cancer and about their survival.²²¹

There is a psychological impact of surviving cancer, including increased rates of depression and stress. A small number of people experience post traumatic stress disorder.^{222,223} However, most people surviving cancer, in the absence of residual or recurrent disease, have quality of life comparable to that of the rest of the population.²²⁴ For some people, the diagnosis is a transforming process with positive outcomes ultimately.²²⁵

Adult survivors of childhood cancers

One in every 1000 people reaching the age of 20 will have had treatment for cancer.²²⁶ Every system in the body has long term effects from systemic chemotherapy and childhood cancer, and its treatment may also impact on growth and body composition.^{226,227} Health generally, mental well being, level of function and limited activity are worse in adult survivors of childhood cancers than age matched controls. There may also be long term effects on social function including lower highest educational qualification and lower income in those who have had cancer.²²⁸

Second cancers, including leukaemia and thyroid cancer, are also more common. Rates of solid tumours among survivors of childhood cancers are seven times those of the population as a whole before the age of 40. Living with bone marrow transplantation and its long term effects, if graft-versus-host disease is present, is an ongoing issue for many children who are being treated successfully for a number of malignancies with intense treatment regimens.²¹⁷ The need for life long follow up generates its own burden.²²⁷ Complications later in life will be increasingly described as the cohort of people cured of malignancies, such as acute lymphoblast leukaemia, ages. The full extent of late side effects of treatment has not yet been realised.²²⁹ The long term effects of high dose chemotherapy and ionising radiation in the children of people who suffered from childhood cancer is largely unknown.

The need to cope with uncertainty about the future and challenges in transition to independence are concerns of survivors of childhood cancer entering adulthood. Body image and the impact of treatment on it is also a concern in this group of people.²³⁰ The transition from childhood through adolescence to adulthood is potentially a more difficult transition than for people who have not had childhood cancers. An appropriate balance of reasonable vigilance against increased anxiety is required.

Resumption of daily life after treatment

There are significant long term health problems following the successful treatment of a cancer, including persistent fatigue years after therapy is completed.^{211,231} Many cancer treatments increase fatigue. There are prospective randomised trials that indicate aerobic exercise improves the rating of quality of life, and physical and functional well being.²³²⁻²³⁴ Fatigue and other symptoms persist in populations with cancer treated with curative intent, and fatigue at six months after commencing treatment predicts the ability of people to ultimately return to work.²³⁵ Increasing age and physical complaints lessen the likelihood of returning to a previous level of function. There is evidence that rehabilitation for people after cancer treatment increases the likelihood of returning to the previous level of function (including work).²³⁶

In Australia, treatment of people after active treatment for cancer is increasingly likely to include individually tailored programs to specifically address fatigue.^{237,238}

Previous treatment for cancer also impacts on other clinical conditions. For example, people who had been treated for cancer had more pre- and post-operative problems during hip replacement and were significantly more likely to be overweight at the time of surgery when compared to an age matched cohort.²³⁹

Service provision

In the Australian context, issues of transition from treatment to observation appear to be managed on an ad hoc basis. A rehabilitation paradigm is rarely present despite good evidence that intervention can improve function, quality of life and likelihood of returning to work.

The National Institute of Clinical Excellence has developed draft guidelines on supportive care for people with cancer.²⁴⁰ These guidelines demonstrate that a considerable part of the cancer journey occurs between and after active treatment.

Very little is known about the best ways to provide care during this period. As described in the next section, there is some evidence that discharge planners, written care plans and coordinators of care can improve outcomes during this period. Care planning and communication between health professionals is described in the next section on end-of-life care.

There is little or no information about the adequacy of services in Australia during this period. There is no planned approach to ensuring that services are available to meet the needs of people between and after active treatment for cancer. It seems likely that some people receive excellent care coordinated by their general practitioner (or other health professional) while others are left to seek support, information and management where they can. Non-government, community based and consumer organisations also play a major supportive role for people with cancer after treatment is completed. There is likely to be a great deal of variation in terms of quality of information and support provided by these groups and their availability.

The absence of research about good practice, guidelines for care provision or data about current practice in Australia illustrates the relative lack of attention outside the treatment context. There is an urgent need for increased research data and the development of organised and coordinated approaches to care.

CHAPTER 6. Care and Support at End of Life

In this document, the term ‘end of life’ has been used to describe the point where people with incurable cancer come to feel that the cancer is preventing them from leading the life they would like to live and that this will not improve. They may feel that either physically or psychologically they are not living as actively as they would like or experiencing the quality of life that they would like.

In using this definition, it is recognised that people will reach this point in differently. For some individuals, this will occur at the time of diagnosis while others may not feel this way until very close to death. Individuals will move along a continuum rather than between discrete phases of treatment and end of life care.

It therefore follows that adequate care during the end of life period is fundamentally based upon the provision of supportive care and the development of effective relationships with health professionals much earlier in the cancer journey. For some people with cancer, these services may be provided by generalist health providers while for others specialist palliative care services may be needed. There should be a seamless transition between services and a high level of communication and collaboration between the health professionals involved. Health professionals may be reluctant to broach the issue of palliative care early in the cancer journey.

INDIVIDUAL AND FAMILY NEEDS

People want to:

- have the best possible quality of life
- be free of pain and have their symptoms under control
- be able to prepare for death and feel a sense of completion
- find a sense of meaning in their life and illness
- be involved in decision making about their care as much as they wish
- know that their family is being supported
- not feel like a burden
- feel able to cope with the disease in the way that feels right to them
- have their practical needs met
- be treated by a team (which might be virtual) that is built around their needs and has good communication
- understand what is happening to them and what may happen in the future as their disease progresses
- be cared for in an environment of their choice, be it at home, hospital or hospice.

Families want to:

- be supported during their family member's illness
- be able to maintain their own quality of life while caring for their family member
- be confident their family member is receiving the best care

- be able to access information specific to their needs (which may differ from those of their family member)
- receive help when needed in caring for their family member, physically and psychologically
- be supported through the bereavement period.

OPTIMAL SERVICES

People with cancer and their carers will have access to:

- Supportive care services from the time of diagnosis, to provide continuous and seamless care into the end of life period.
- Care which is coordinated and multidisciplinary including partnerships between specialists, primary care providers and the community.
- Treatment and palliative care services which are coordinated and integrated.
- Services that assist in meeting their physical, psychological, social, sexual, spiritual and practical needs.
- Services that are accessible to primary clinical carers 24 hours a day.
- Services that are person centred and enable the person and their family to be in control of decisions about their care.
- Information in formats that are easy to understand and meet their needs, taking into account that these may change over time, and that the person with cancer and the family may have different needs.
- A specific primary care coordinator, often their general practitioner and/or community nurse, who will assess needs and preferences and plan care taking into account the fact that these may change over time.
- A care plan which is based on management by a team which will be developed to meet the specific needs of each individual. The teams may be virtual, and may include individuals to meet special cultural or other needs.
- A choice about where they will die taking into account that preferences may change over time. This will require adequate palliative care services and adequate community based support for those who choose to die at home.
- Adequate bereavement services, including the active identification of needs.
- Professional carers who are adequately trained and supported.

RATIONALE FOR THE COMPONENTS OF OPTIMAL SERVICES AND CRITICAL INTERVENTION POINTS

Needs of people with a life limiting illness

The needs of people with cancer at the end of life are complex. In a large cross-sectional study in the US, there was strong agreement about priorities among people who were aware that they had advanced cancer, family members between six and 12 months after the death of a relative with cancer, their doctors, nurses and allied health staff. Issues that were rated as important by all groups included:

- pain and symptom management
- the ability to prepare for death (psychologically and getting affairs in order)
- the ability to achieve a sense of completion (in relation to relationships and life goals)

- being able to be involved in decision making
- the need to be treated as a whole person.

Issues that were far more important to people with cancer than their families or carers included:

- not being a burden
- coming to peace with God
- helping others and maintaining a sense of humour.

Similar issues were identified in a prospective study in the UK.²⁴²

In Australia, information about end of life care has been obtained from carers after the death of the person with cancer. Most people indicate that they were satisfied with the care received, but that more easily available practical support would be valued. The place of care was felt to be appropriate.²⁴³

Organisation of services: palliative care, coordination and integration

Palliative care

Specialised palliative services can improve outcomes for people at the end of life. These improved outcomes include patient and carer satisfaction, improved symptom control, improved provision of family information needs and shorter hospital stays.²⁴⁴ In adequately randomised trials, benefits also include greater satisfaction with information transfer, improved likelihood of being cared for in the place of choice, fewer hospital admissions.²⁴⁴

The WHO refined its 12 year old definition of palliative care in 2002.²⁴⁵ Among the very significant changes that reflect the worldwide evolution in end-of-life care across the 1990s, the new definition emphasises:

- the need for timely involvement of palliative services—the issue of timeliness will vary from person to person, and be informed by their needs, those of their carers and family, and also the health professional involved in their care
- a smooth transition from active treatment to palliative and supportive care, with substantial shared care between treating teams and the palliative care team²⁴⁶
- the breadth of palliation to include the prevention of suffering (where possible) and bereavement follow up
- the need for palliative care teams to have sufficient depth of skill for ‘impeccable assessment’ of the person with the life limiting illness in the context of their life and illness.

There is no evidence at this time that one particular model of service provision in palliative care optimises outcomes and resource utilisation.^{247,248} For example, the benefits of hospital based palliative care teams are not well defined in the literature. The studies that have been done generally use end points that may well fail to capture the breadth of the practice that is carried out in hospitals. The few studies available need to be interpreted with caution²⁴⁹, although a more recent study concluded that there were overall benefits.²⁵⁰ Prospective evaluations of the impact of community teams have been carried out around the world. The presence of a palliative care community team may decrease the duration and frequency of hospital admission at the end of life for people with cancer.²⁵¹ The extent of benefit and the key elements that need to be in place for this benefit are not well defined in the literature.²⁵²

There are currently 260 specialised palliative care teams in Australia. However, there is little information about access to and use of palliative care services or the extent to which there is a seamless transition from other services to palliative care.

At a whole-of-health level, the two most comprehensive pictures of palliative service provision available currently in Australia are the national snapshot of palliative services carried out by Palliative Care Australia in 1998²⁵³ and the national sub-acute and non-acute patient casemix classification work done in the mid 1990s.²⁵⁴ Both studies drew data from the established funding services, rather than defining optimal service models. However, there are some estimates of the needs generated by people with cancer at the end of life and the resources needed to meet these needs.²⁵⁴⁻²⁵⁶

Few studies have evaluated the economic impact of palliative care.²⁵² Any evaluation needs to include the costs to the community of providing the care, benefits derived, and the costs if this care were not to be provided. The impact on carers in the longer term is a key issue that needs to be addressed in any economic model.

Referral to palliative care services

Optimal care requires timely referral from oncology services to palliative care early in the disease trajectory. Palliative care is referral based and therefore limited by how effectively the interface with other service providers identifies and refers the appropriate cases. It is a continuing challenge to achieve the current WHO recommendations about shared care.

In Australia, information about the proportion of people with cancer who are adequately referred is not available; however, the opinions of both professionals and people with cancer suggest that referral could be improved. There is some evidence that people are being referred earlier to palliative care services.²⁴⁵

Coordination of care, general practitioners and community care

In Australia, there is considerable variation in the extent to which a seamless service is provided from the time a life limiting illness is recognised through until death. Early studies in palliative care demonstrated that better coordination of existing resources can improve outcomes, including satisfaction with care and less time spent in hospital. Randomised trials support this role of specialised palliative services.²⁴⁴

Case conferencing is still being evaluated in health care in general, and in palliative care specifically, in randomised prospective studies in the Australian context.²⁴⁶ The role of case conferencing in palliative care has not yet been articulated. If bringing health practitioners together can improve patient outcomes in measurable ways, then their cost and the coordination difficulties may be worthwhile.

Continuity of care as people with cancer move into the community can be facilitated by discharge planners and by timely availability of information.²⁵⁵ The appointment of care coordinators would assist in improving continuity of care. In Australia, general practitioners often take this role. The interface between general practice (and by inference community nursing) and specialised palliative care services is not optimal.²⁵⁷

Despite the key role played by general practitioners in providing care and support for people at the end of life, it forms a very small part of their total workload.^{258,259} Engaging general practitioners in multidisciplinary care through case conferencing in the Australian context is not easy, with low uptake rates and the perception of time consuming processes to access reimbursement.²⁴⁶ There remains, however, little information about the ways in which general practitioners are involved in the provision of palliative care in Australia.

Multidisciplinary care

Optimal care at the end of life acknowledges the complexity of needs for people with cancer and their carers and, therefore, the range of different services required.²⁴⁵ *The Palliative Care Service Provision in Australia: A Planning Guide* articulates the disciplines required and the quantum of input for good palliative care across all care settings.²⁶⁰ Volunteers are widely used to complement professional clinical services in the provision of social, emotional and practical support.²⁶⁰ Acknowledged as being a vital component of many palliative care services²⁶¹, the provision of volunteer services requires support by way of training, supervision, and administration infrastructure.²⁶²

Multidisciplinary care must include the full spectrum of tools that can improve care; for example, improving the sense of wellbeing is an important goal and can be met with focused interventions including relaxation.²⁶³ It is not clear that Australian palliative care services are currently funded within models which enable multidisciplinary care and adequate use of allied health services.^{254,264}

Person-centred care

Services should be person-centred. The Palliative Care Australia guidelines²⁶⁰ point directly to ensuring that services are built around a person with cancer so that there is a virtual team to support each individual. People with cancer and their families should be involved in decision making about care to the extent to which they are comfortable. This is not always fully provided²⁶⁵

Supportive network: family, friends and other caregivers

Family, friends and other carers (referred to here as the 'primary carer') are the resource around which community based palliative care is built. In Australia, the strongest indicator of receiving home care and home death is the presence of a primary carer.^{266,267}

The roles that primary carers take on are broad²⁶⁸ and few are adequately trained or supported. Although rewarding, caring causes major life changes and is at times (especially with uncontrolled symptoms) very distressing.²⁵⁸ Caregiver outcomes depend on a number of variables, including the length of time for which care is given and the relationship to the person for whom care is given.²⁶⁹ There are significant health costs for carers. Adequate support for carers needs to include mechanisms for reducing anxiety through support and an ability to mobilise informal support networks.²⁷⁰ Carers find the role challenging and only half report finding the role rewarding, with the potential for many unmet needs while trying to maintain the role.^{258,271}

There are also economic costs associated with caring for someone at the end of their life. In a multi-site study in the US, there was a relationship between complexity of need at the end of life and economic costs. The more complex the care needs, the greater the rate of subjective economic burden reflected in higher rates of loans to pay for care, or where more than 10% of household income was spent on health care.²⁷² Overall, cost reductions to funded health services can be seen because of a shift to community care (and hence informal carers who are not costed in the models) with cost savings modest at best.^{244,248}

Research is only just beginning to explore approaches to addressing the needs of primary carers in a more comprehensive way. Interventions that may be of benefit include group support.²⁷³ There is also evidence that using a palliative care team may result in improved survival at 18 months for spousal carers²⁷⁴, improved satisfaction with care²⁴⁴ and shortened grief.²⁷⁵ Working with whole families can have a positive impact on outcomes.²⁷⁶

Respite care can do much to assist primary carers. However, Australia does not have a strong record in providing respite for carers, particularly in late disease where the physical burden and around-the-clock demands mean that carers tire.

Services that meet physical, psychological, social and other needs

Symptoms

Fear of uncontrolled symptoms is still the major fear of people facing end of life and of their carers.²⁶⁵ Major symptoms in order of magnitude and frequency include fatigue, pain, dyspnoea and nausea and/or vomiting. Data suggest that of these, significant benefits are derived from treatment for all but fatigue. Ongoing research with fatigue suggests that even this is amenable to tailored intervention. For the vast majority of people with cancer, symptoms can be substantially improved. Equally, despite best efforts, there will continue to be a small number of people with significant refractory symptoms.

Pain, however, is the second most frequently encountered symptom, and increasing evidence is that for the vast majority of people (> 98%), pain can be controlled so that sleep is not interrupted and people are able to be comfortable at rest during the day.²⁷⁷ Dyspnoea, when all reversible causes have been treated, can be improved with non-pharmacologic interventions such as breath control, functional pacing, relaxation and visualisation techniques and improved breathing habits. A meta-analysis and adequately powered study also indicate that low dose opioids are useful in opioid naive people with cancer in helping with dyspnoea.^{278,279}

The extent to which people with cancer in Australia receive adequate symptom control towards the end of their life is unknown.

Psychological issues

The psychological burden of cancer, its diagnosis and treatment is substantial. Towards the end of life, loss is a major issue and there can be demoralisation which is beyond simply sadness.²⁷⁶ A great range of emotions is encountered which may be out of character for the person with cancer, and may particularly challenge their primary caregivers.

Ensuring adequate psychological support within the Australian context is difficult as there are very few clinical psychologists employed in oncology and even fewer in palliative services. The costs for private psychology and psychological support are out of the reach of many people. The extent to which people in Australia receive adequate access to psychological support services during this period of their life is unknown.

Practical needs

Practical needs are of great importance. Declining functional status mirrors the disease course for most people with cancer. Needs at the end of life are complex²⁸⁰ and adequately supporting people in the activities of daily living, finances, wills and other legal issues is valued by people with cancer and their families.²⁶⁵

Other issues

The importance of social support, management of sexual issues and spiritual care are recognised as very important to the well being of people towards the end of life. However, little is known about the extent to which these aspects of care are provided in Australia at this time.

Providing care to groups with special needs

There are many people who have special needs that must be addressed during the end of life period. This includes people from culturally and linguistically diverse backgrounds, young children, those with Alzheimers or other types of dementia, people in communities where they have watched someone else die from this illness (particularly groups such as motor neuron disease or HIV/AIDS, and Aboriginal and Torres Strait Islander peoples).

There has been no systematic approach to developing appropriate services for groups with special needs and little is known about the care provided or the extent to which needs of people in these groups are met. However, the following comments can be made:

- Providing care for Aboriginal and Torres Strait Islanders is not about adapting models of care so much as examining with communities the care that they would expect at the end of life and, in close consultation, how those communities can best be supported to provide that care.²⁸¹
- For elderly people, managing symptoms encountered at the end of life will often be in the context of significant co-morbidities that will need special attention. In the setting of residential aged care facilities, adequate resources for staff development and deployment, and adequate time remain significant challenges.²⁸² The lack of identified carers will impact in coming decades on place of care for many Australians.

- Children with advanced cancer need to be supported in the context of their family.²⁸³ Both inpatient and home based care have advantages and disadvantages. These need to be weighed for each child at different times along their disease trajectory. Special needs exist for parents caring for children who are dying. Although there are advantages to home based care at the end of life, the challenge of providing adequate support across wide geographic regions remains.²⁸³
- The limited evidence available suggests that people from culturally and linguistically diverse backgrounds are less likely to access palliative care services.²⁸⁴ They may be less likely to derive the spectrum of benefits from the involvement of palliative services enjoyed by the rest of the community, including choice of place of care and physical symptom control.²⁸⁵ There is evidence that Australian palliative care workers could benefit from training in cross-cultural issues.²⁸⁶
- There is a major challenge of isolated practice for health professionals working in palliative care in Australia.²⁸⁷ Providing multidisciplinary care is possible even with Australia's dispersed population through tele-medicine and other strategies.²⁸⁸ Coordination of the resources already available is important particularly in regional, rural and remote areas to support outcomes that are focused around identified issues by people with cancer. This can be achieved even in those settings where members of the team may not meet face-to-face frequently.²⁸⁸

Information and choice for people with cancer

People with cancer and their families need appropriate information provided in a timely way as the disease progresses. For example, providing information on the physical care of the body at home after death is not appropriate early in the course of treatment but is imperative in the last few days to few weeks of life if carers are going to have confidence in providing that care later on. Care of the physical needs of people with cancer, particularly as they become debilitated, is a major focus for the caregivers. There are lots of information resources available but not a single resource that meets these complex needs.

Preference for place of care at the end of life may change over time.^{289,290} Eliciting from people with cancer and separately from their carers the key factors that influence these decisions may at times prove to be a difficult task. Choice of the place of care may be tempered by the resources available—the availability of health care professionals (both during the day and after hours), the availability of a primary caregiver in the household, and the concerns, skills and fears of those involved in the care.²⁹¹⁻²⁹³

Optimal care will enable open discussion about these issues. It will ensure that these decisions can be revisited comfortably without caregivers feeling they have failed the dying person.

Bereavement

Bereavement begins with the threat of loss; adequate support, often from the time of the diagnosis of advanced progressive disease, is necessary.²⁹⁴

For people at low risk of complicated bereavement, there is little evidence that any interventions will be of value. However, for those at high risk of chronic grief, there is some evidence to support interventions from trained health care providers with particular skills. There is as yet no agreed, validated screening tool to enable the identification of those likely to experience chronic grief and no evidence that early identification and management will improve outcomes.²⁹⁵

In Australia, there is diverse practice in the provision of bereavement care in terms of who provides assessment, who provides follow up, the qualifications and background discipline of the health professionals involved in bereavement and in the interventions offered. Bereavement services should be adequately resourced and work across the whole health spectrum.²⁹⁶

CHAPTER 7. Critical Intervention Points for Cancer Control

The Critical Intervention Points represent those aspects of care where Australia might most usefully invest to reduce death and distress from cancer. The identification of Critical Intervention Points is based on consideration of whether the aspect of care:

- is important in terms of death, suffering or health care costs
- is currently suboptimal, given what is known about optimal services and about current care, and
- can be improved.

SELECTION OF CRITICAL INTERVENTION POINTS

The Critical Intervention Points were selected as follows:

- The needs of people and the optimal services within the Framework shown in **Figure 1** were identified.
- A detailed review of the evidence about people's needs and the value of the optimal services were undertaken.
- Patterns of care in Australia were assessed to identify where services are currently different from the optimal. This analysis was hindered by the lack of data about many aspects of care and about service provision.
- The issues identified through these analyses were compared with priorities identified through a number of recent documents including: 'Optimising Cancer Care in Australia'⁴; 'Priority Actions for Cancer Control'⁵; the report of the Radiation Oncology Inquiry⁶; the report on the Cancer in the Bush conference⁷ and state plans for NSW and Victoria.
- The proposed Critical Intervention Points were reviewed by the National Service Improvement Framework Expert Panel; the National Health Priority Action Council; the Cancer Strategies Group; participants at the Clinical Oncological Society of Australia conference and consumer groups.

THE CRITICAL INTERVENTION POINTS

The 19 Critical Intervention Points for cancer are placed in order of the continuum of care and are as follows:

Reduce risk

1. Establish national, state/territory and local plans to further reduce rates of smoking using evidence-based public health strategies and government actions.
2. Establish national, state/territory and local plans to increase rates of protection of skin from the sun using evidence-based public health strategies and government actions.

3. Establish national, state/territory and local plans to promote healthy eating and active living including healthy weight in collaboration with other national health priorities and policies.

Find cancer early

4. Improve strategies (particularly via primary care) to increase participation in breast cancer screening, and to increase participation by under screened groups in cervical screening.
5. Improve programs to provide more appropriate and accessible breast and cervical screening services for Aboriginal and Torres Strait Islander women.
6. Complete and evaluate the bowel cancer screening pilot, which will assist in informing governments about the acceptability, feasibility and cost effectiveness of introducing a national bowel screening program.
7. Develop and disseminate support and information for general practitioners and for people with cancer about the diagnosis of symptoms which may be cancer, including recommendations about appropriate investigation and referral pathways.
8. Improve systems so that all people with suspected cancers are referred appropriately and assessed promptly and effectively.

Management and support during active treatment

9. Improve access to treatment services for all Australians, particularly those living in regional, rural and remote areas and Aboriginal and Torres Strait Islander people.
10. Develop systems to improve the coordination of care for people with cancer, including defined referral pathways and designated coordinators of care.
11. Develop and implement strategies to encourage multidisciplinary care.
12. Implement clinical practice cancer guidelines.
13. Develop and implement strategies to encourage cancer services and people with cancer to participate in clinical trials.
14. Provide information through accreditation of services, credentialing of practitioners or other strategies to help people with cancer assess the quality of care being provided.
15. Work towards improving supportive care for people with cancer by implementing the psychosocial clinical practice guidelines.

Management and support after and between periods of active treatment

16. Develop and implement strategies so that the needs of people with cancer after and between periods of active treatment are met.
17. Provide appropriate information for people with cancer about follow up, practical issues, support services and self care.

Care at end of life, if cancer is not curable

18. Improve timely and appropriate access to adequate palliative care services and medications and monitor the impact.
19. Develop models of end of life care that ensure integration with treatment services and coordination among community services and palliative care teams.

CHAPTER 8.

National Priority Actions for Change

OVERVIEW

Significant improvements in cancer control as outlined in the National Service Improvement Framework will require change at the local, state/territory and national levels.

A number of strategies may facilitate improvements in cancer control in Australia including: the establishment of state/territory cancer plans; the establishment of integrated networked cancer services; improvements in primary care management of cancer; improved access to services; the improvement of care for regional, rural and remote communities; establishment of accreditation systems; strengthening training and professional development; targeted funding systems; improvement of data and monitoring systems; strengthened approaches to research and planning strategies for the future.

The adoption of the National Service Improvement Framework for Cancer will require a systematic implementation plan developed in consultation with states and territories, professional colleges, non-government organisations, consumer groups and other key stakeholders.

Based on the consultations undertaken so far to develop the National Service Improvement Framework for Cancer eight initial priority actions are recommended. These national actions underpin the Critical Intervention Points and would provide the basis for many of the changes identified in the Framework.

PRIORITY ACTIONS

The priority actions are:

1. Establish integrated and networked cancer services to improve continuity of care from reducing risk to care at the end of life.
2. Establish accreditation for cancer services and credentialing of practitioners using as a basis the recommendations about optimal services outlined in the Framework.
3. Develop funding structures which support multidisciplinary care in hospitals and the community through specialist and general practitioner payment schedules.
4. Develop national, state/territory and local approaches to monitoring all aspects of cancer control, including performance indicators.
5. Provide evidence-based consumer information about the environmental, behavioural and genetic risks of cancer, prevention, early detection, diagnosis and treatment, and supportive care.
6. Establish national approaches to assist primary health care providers (especially general practitioners) to offer high quality and appropriate assessment of risk, detection of cancer, referral to treatment, coordination of treatment and supportive care (from diagnosis to palliative care).

7. Implement and evaluate culturally appropriate programs to improve cancer control with special emphasis on the needs of disadvantaged groups, particularly Aboriginal and Torres Strait Islander people.
8. Review the evidence, gaps in research and opportunities for action within a specific timeframe, at least every three years.

NEXT STEPS

An implementation plan for each of these priority actions will be developed based on the national consultations with states and territories.

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