

Statewide

Cancer Control Plan

2006 – 2009



Government of South Australia
Department of Health



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Cancer Control Plan

2006 – 2009

Prepared in collaboration by The Cancer Council South Australia and the SA Department of Health

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Foreword

About one in three South Australians experience cancer during their lifetime. The impact of cancer extends well beyond the person directly affected and touches family members, friendship groups, work colleagues and in the case of children, school communities.

Despite much progress in prevention and treatment over the recent decades, cancer continues to be a growing public health problem. South Australia's ageing population and increases in numbers of people with cancer pose a real challenge for our health system and our community. We must ensure that our current management of cancer is as effective as possible and plan for the future to reduce the personal, social and economic impacts of cancer. This can be achieved through effective cancer control.

Comprehensive cancer control planning requires investing in cancer prevention and early detection and implementing well documented strategies to reduce rates of new cancers. It is also about improving the way we provide cancer treatment and care; enhancing coordination and communication between sectors and services; and implementing strategies we know will improve cancer outcomes and quality of life.

South Australians can be justifiably proud of our cancer services. Survival rates for people diagnosed with cancer are high and treatment options are consistent with those offered in the best cancer centres around the world. But there is still more that can be achieved. This Statewide Cancer

Control Plan sets out a broad range of actions that encompass prevention, diagnosis, treatment, supportive care, workforce and infrastructure needs and research. The Plan is centred on the needs of the South Australian population, and aims to reduce the impact of cancer in the community.

The government is committed to improving cancer control in South Australia. Many professionals who are experts within the cancer sector as well as consumers have contributed significantly of their time, knowledge and expertise to develop this Statewide Cancer Control Plan. The goodwill and dedication of these people who have given freely of their time and knowledge is reflected in this Plan. I commend all those who have made such a tremendous effort in developing this Cancer Control Plan for South Australia.

Improving on what we already have is an ambitious undertaking. The cancer journey is an expression often used in relation to the path that people with cancer take. This Statewide Cancer Control Plan reflects another cancer journey – one that we as a government, the health care sector and the people of South Australia collectively must take together if we are to be successful in improving our control of cancer.



Hon John Hill
Minister for Health

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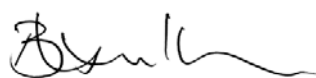
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Introduction

Under the auspices of the Clinical Senate, the South Australian Department of Health and The Cancer Council South Australia have worked in partnership with health professionals and community representatives to develop a Statewide Cancer Control Plan. Many professionals who work in cancer prevention and early detection programs, in cancer treatment and care settings, as well as experts in infrastructure and workforce planning, in research and evaluation as well as consumer and community representatives have been involved in the Plan's development.

The Statewide Cancer Control Plan calls for the systematic application of current knowledge and investment to generate new knowledge and to reduce the impact of cancer. The Plan articulates principles and sets goals against which strategies in cancer control should be considered and measured. It recommends priority programs and services which will accelerate cancer control by reducing

the incidence of cancer, improving cancer survival, and improving the quality of experience and life for people with cancer, their carers and families.



Associate Professor Brenda Wilson

Chief Executive
The Cancer Council South Australia



Dr Denes Marantos

Chairman, Cancer Control Plan Committee
Member, Clinical Senate

The vision for the Statewide Cancer Control Plan is to:

- 1** Save more lives by reducing the number of new cases of cancer and improving rates of survival when cancer does occur.
- 2** Ensure people receive effective support as well as the best treatment and care.
- 3** Improve the quality of life of people with cancer, cancer survivors and carers.
- 4** Address inequalities in cancer risk and cancer outcomes, between more and less advantaged sectors of the community, by addressing the causes.
- 5** Build for the future through investment in the cancer control workforce, infrastructure and strong cancer research.
- 6** Provide and improve information for cancer control.

Leading Change in Cancer Control

About cancer control

One in three South Australians experience cancer during their lifetime. While this includes melanomas, it excludes many other less lethal skin cancers that affect around 60% of South Australians during their lives.¹

Many other people are also affected indirectly by cancer when a family member or someone else close to them has cancer. Despite advances in treatment and cure, people in the community report a greater fear of cancer than of any other illness.² The demands of treatment and under-met need for psychosocial and practical support for people living with cancer can place a large burden on people in our community.

Cancer control is the universal term used to define the comprehensive strategies aimed at reducing the impact of cancer. These include strategies to prevent cancer from occurring, population screening to detect cancers and pre-cancerous lesions early, treatment, psychosocial care, palliation and research.

Reducing cancer risk, increasing cancer prevention and early detection

Over half of all cancers could be prevented if we acted on the knowledge we already have available about not smoking, healthy diet, increasing physical activity, weight control, appropriate sun protection and reduced alcohol consumption.

In the absence of effective primary prevention of cancer, secondary prevention by means of screening is an alternative for some cancers. Screening for and early detection of cancer is based on the premise that earlier diagnosis of the disease, either in a pre-cancerous state or at an earlier stage than that at which clinical presentation would otherwise take place, leads to a reduction in risk of mortality, morbidity or development of invasive disease.

All South Australians should be helped to understand the factors that contribute to the risk of cancer, know how to reduce their own risk of cancer through appropriate lifestyle and behaviour modifications and be enabled to act on this knowledge. Resourcing and implementing well-documented, evidence-based strategies, will have significant impact by reducing cancer risk, increasing cancer prevention and early detection.

In order to reduce cancer risk, increase cancer prevention and early detection:

- Legislative frameworks are required that provide the South Australian community with living and working environments that are conducive to cancer prevention and early detection (e.g. smoke-free workplace and public places laws).
- High-quality, affordable, evidence-based cancer prevention, early detection and screening programs, services and information should be implemented so that all South Australians are enabled to access them.

Optimising cancer care

South Australians with cancer generally experience quality cancer care and this is reflected in survival rates that are comparable with those in other parts of Australia and for people with cancer treated at the best treatment centres overseas. However, there are still opportunities to enhance service delivery in South Australia and, in particular, to improve service accessibility, coordination and alignment with primary health care.

There are also opportunities to improve cancer care in South Australia by ensuring that:

- Cancer care is people-centred and meets the needs of people with cancer, their carers and families.
- Cancer, or its precursors, is detected as early as possible, and people with cancer receive appropriate diagnostic tests and timely referral to appropriate specialist cancer care.

- Accessible and timely care is provided to people with cancer, their carers and families.
- Cancer care is multidisciplinary, fully integrated and coordinated.
- Clinical practice and psychosocial care in cancer are based on best practice and with a research base that informs future care.
- Cancer services include monitoring of safety, effectiveness, efficiency, satisfaction, accessibility and equity of outcomes.

A Statewide Integrated Clinical Cancer Service is proposed. The goal of the clinical service delivery model is to optimise the experience and outcomes of people with cancer and their carers by maximising co-ordination and integration of cancer services. It will provide accessible, high-quality, people-centred, coordinated, and multidisciplinary cancer services for all South Australians.

Support for cancer control

Effective cancer control requires a workforce and infrastructure that supports high quality services and programs. The importance of clear directions for service planning cannot be overstated. It is essential that the cancer workforce, which includes professionals, volunteers and carers is adequate across the spectrum of cancer control. Educational, learning and recruitment strategies need to be aligned with cancer control workforce projections.

Good quality research and evaluation should be integral to the whole cancer control pathway and underpin all cancer control programs and services. Research needs to be oriented to deliver information to inform cancer control programs and services and research findings need to be communicated and incorporated into service delivery and programs. In order to facilitate this, South Australia needs to support and develop high quality cancer research. It is recommended that a Cancer Control Research Collaborative be established to develop research capacity in South Australia. This would comprise of researchers from all fields from basic to clinical, population health and health services research, including supportive research, which would focus on translational research.

Statewide Cancer Control Advisory Group

Implementing the changes recommended in this Plan will require strong leadership, resources and better systems for planning cancer control services. A Statewide Cancer Control Advisory Group is recommended to provide a leadership structure for cancer control programs and services in South Australia.

The establishment of this Advisory Group will ensure that all sectors involved in cancer control, across the cancer continuum and both public and private, are represented in a central coordinating body, to enable service planning to be integrated across the spectrum of cancer control and across the state. Effective linking of these sectors would also provide greater opportunity for policy and practice to inform and be informed by research.

The aims of the Statewide Cancer Control Advisory Group are to:

- a. Facilitate direct links with government and promote bilateral communication and strategic planning of cancer control services.
- b. Ensure that all sectors involved in cancer control in South Australia, including clinical services, prevention and early detection programs, and research, are represented in a coordinating body. This will promote communication, integration and avenues for reform and accountability across the spectrum of cancer control in South Australia.

The objectives of the Statewide Cancer Control Advisory Group would be to achieve and coordinate quality standards, investment, research and reform through:

1. Ensuring a statewide approach to the delivery of cancer control services and programs.
2. Providing leadership in the ongoing development of standards and continuous improvement.
3. Advocating to the Department of Health regarding the need for future investment.
4. Monitoring agreed outcomes related to cancer incidence and mortality, service and program effectiveness and quality of life indicators.
5. Monitoring the implementation of the Statewide Cancer Control Plan.
6. Engaging with all sectors involved in cancer services in South Australia, including the state government, the federal government, private health and relevant community sectors.

Membership will be small and will not aim to have representations from all potential agencies or disciplines. However, membership will be broadly based, and include:

- Metropolitan and rural regions
- Cancer services, in the public and private sectors
- Cancer prevention, cancer screening and research
- The Cancer Council South Australia
- Consumers.

The Statewide Cancer Control Advisory Group will report to the CEO, Department of Health.

A leader in cancer control or cancer services will chair the Statewide Cancer Control Advisory Group. The Chair will be for a fixed term and will rotate across the cancer control sectors.

Implementing the Statewide Cancer Control Plan (SCCP)

A major focus of the Statewide Cancer Control Advisory Group, in the short term, will be to support and monitor the progress of the implementation of the SCCP. The broad scope of cancer control is such that this may be done through a series of task groups that focus on integrated cancer prevention and early detection, cancer care, infrastructure planning, workforce planning and research and evaluation.

Cancer prevention and early detection programs and service delivery

While Regional Health Services have an important role in cancer prevention, much of the programs and services which support cancer prevention and early detection are undertaken at a statewide level. For example, comprehensive SunSmart and Quit programs are centrally coordinated by The Cancer Council South Australia working with its non-government and government partners. Various activities which contribute to health promotion strategies to promote healthy eating, physical activity, healthy body weight and reduce alcohol consumption are undertaken by The Cancer Council South Australia, different State Government departments as well as a number of other agencies with converging agendas, such as the Heart Foundation.

Population breast and cervix cancer screening programs are linked with national programs and coordinated at a statewide level. BreastScreen SA, for example, is administered by the Central Northern Adelaide Health Service, but is responsible for providing services to women, primarily aged 50–69 years, across all of South Australia.

Cancer care delivery

Policy development in health is largely the responsibility of the Department of Health. Broad cancer control policy development can be undertaken with the Statewide Cancer Control Advisory Group. The Statewide Cancer Control Advisory Group will have a key role in setting standards for cancer care in South Australia. Within South Australia's revised health structure, much cancer care delivery will be the responsibility of Regional Health Services, and it will be their responsibility to interpret standards, and decide how best to deliver care which meets those standards to the population for which they are responsible. Regional Health Services are developing Primary Health Care Networks and Chronic Disease Management models. These may also serve as effective models to ensure cancer care service delivery standards are met.

Private organisations and practitioners as well as non-government and community organisations deliver significant components of cancer care. It is intended that the statewide standard setting, agreed key indicators, accreditation and credentialing processes in the government sector, plus communication and collaboration will promote equivalent standards in private care settings.

Key recommendations to lead change in cancer control

- 1** Establish a Statewide Cancer Control Advisory Group to coordinate cancer control across the state and to promote and monitor the implementation of the Statewide Cancer Control Plan.
- 2** Establish sub-committees or entities to oversee progress of recommendations relating to different areas of cancer control, namely:
 - Cancer Prevention and Early Detection Operations Group
 - Cancer Care Operations Group
 - Infrastructure Planning Operations Group
 - Workforce Planning Operations Group
 - South Australian Cancer Control Research Collaborative

The Operations Groups would operate as sub-committees of the Statewide Cancer Control Advisory Group. The Chair of the South Australian Cancer Control Research Collaborative would report and make recommendations to the Statewide Cancer Control Advisory Group.
- 3** Establish and adopt key indicators of cancer control (e.g. through Regional Health Service funding agreements) and monitor progress.



Recommendations to reduce cancer risk, increase cancer prevention and early detection

1. Establish a Cancer Prevention and Early Detection Operations Group. This group would have within its remit to:
 - Advocate for the importance of cancer prevention within a cancer control framework, and for increased investment in cancer prevention in a population health context.
 - Advocate for evidence-based policies and programs in cancer prevention and for investment to generate evidence where it does not yet exist.
 - Bring together key experts in cancer prevention in South Australia with a view to developing an organised approach to improving cancer prevention outcomes across the State.
 - Promote coordination between state government, local government, non-government organisations and community agencies involved in cancer prevention.
 - Develop a whole of government approach to cancer prevention.
 - Promote the participation of agencies outside of health in cancer control, including, Education, Transport, Recreation and Sport, the Environmental Protection Agency, Treasury, Primary Industries, Employers and Employee associations.
 - Link actively with national programs.
 - Encourage long-term financial commitment by government and non-government organisations to increase evidence-based strategies that result in significant reduction in the incidence of cancer.
 - Collaborate with the National Cancer Strategies Group and Cancer Australia to establish priorities in Cancer Control.
 - Facilitate interface between clinical aspects of cancer prevention and community programs; specifically develop a strategy aimed at coordinating management of high-risk groups.



Recommendations to reduce cancer risk, increase cancer prevention and early detection (continued)

2. Implement legislative, public policy and structural initiatives for cancer prevention, including:
 - Implementation of legislative, public policy and structural strategies listed within National and State Plans and Frameworks.
 - Expansion of smoke-free public places and workplace legislation.
 - Financial incentives to promote cancer risk reduction (e.g. price of tobacco, sun protection, vegetables and fruit and formal physical activity programs).
 - Policies in schools and pre-schools to promote healthy eating choices, participation in physical activity and sun protection.
 - Programs and policies for workplaces that impact on cancer risk (e.g. reduction of exposure to carcinogens, sun protection and healthy eating).
 - Policies for shade provision and safe environments for physical activity in public places.
 - Advertising regulations on tobacco products and investigation of restrictions on food marketing to children.
 - Creation of environments that make healthy choices easy choices and support individual decision-making.
 - Improve access to intensive surveillance programs for high risk individuals.
3. Provide evidence-based information about the environmental, behavioural and familial risks of cancer, cancer prevention and early detection. Provide tailored information to people with special needs and diverse groups.

Recommendations 1-3 provide the immediate focus for broad statewide cancer prevention outcomes. The following points focus on the progress of specific successful cancer prevention initiatives or established programs.
4. Develop state and support national social marketing campaigns promoting and motivating cancer risk reduction behaviours (e.g. National SunSmart Campaign, Fruit and Vegetable Campaign, Quit campaigns, Physical Activity Campaign). Ensure that integrated health promotion programs support these campaigns.
5. Support (or establish where not in place) national approaches to assist primary health care providers to offer high quality, appropriate assessment of risk, assistance in behavioural change for risk reduction and detection of cancer (e.g. SNAP (Smoking, Nutrition Alcohol and Physical Activity program) and lifestyle scripts).
6. Maintain and expand efforts to prevent the uptake of smoking and assist people to quit by comprehensive implementation of the second *South Australian Tobacco Control Strategy* and in line with the second *National Tobacco Control Strategy*.
7. Maintain and expand efforts related to reducing exposure to ultraviolet radiation in order to prevent skin cancer by comprehensive implementation of The Cancer Council South Australia *Cancer Prevention Plan*, and in line with The Cancer Council Australia *National Cancer Prevention Policy*.
8. Support the development, dissemination and uptake of national consumer guidelines on skin cancer detection targeting older Australians.
9. Increase investment in strategies to promote healthy eating, physical activity and healthy weight including comprehensive implementation of state strategies, '*be active*', *Physical Activity Strategy for SA*, *The Eat Well South Australia Fruit and Vegetable Action Plan*, *the Promoting Healthy Weight Action Plan* and in line with The Cancer Council Australia's *National Cancer Prevention Policy*.
10. Implement strategies to reduce alcohol consumption in line with the Cancer Council Australia *National Cancer Prevention Policy*.
11. Increase investment to increase participation in breast screening to achieve after 5 years, a 70% participation rate in BreastScreen SA by women in the target group (50–69 years) and access on request to the program for women aged 40–49 years and 70 years or more. Re-screen all women in the program at two-yearly intervals, in keeping with best evidence.



Recommendations to reduce cancer risk, increase cancer prevention and early detection (continued)

12. Improve participation in cervical screening, in particular in women in under-screened populations e.g. Aboriginal and Torres Strait Islander women. Advocate for policy and program development in line with emerging evidence, cultural sensitivity and in keeping with best practice e.g. investigation of new technologies.
13. Advocate for and support the implementation of an effective and efficient screening or early detection program for bowel cancer in Australia. People at high risk for colorectal cancer should be able to access colonoscopic screening and genetic testing, where appropriate.
14. Continue to monitor research outcomes on efficacy of population screening for prostate cancer mortality reduction. In recognition of strong public interest in prostate cancer testing and the associated demand on GPs, develop expert clinical information and community education programs.
15. Support the Familial Cancer Service of South Australia, in recognition that at least 5% of all cancers have an inherited origin.
16. Strengthen the collection and publication of cancer data:
 - Strengthen the collection of cancer data in South Australia through population and hospital based registry collections.
 - Strengthen the collection of population monitoring data on risk factors for cancer including individual behaviour.
 - Underpin cancer prevention activities with resources for quality monitoring and evaluation.
 - Support research to promote development of evidence-based strategies to reduce risk.



Recommendations to optimise cancer care

1. Establish a Cancer Care Operations Group. This Group would provide government as well as the non-government and community sectors with standards and priorities for enhancing cancer control, including clinical cancer services in South Australia. Its role will also include the development of cancer care guidelines, standards and outcome measures.

Ensuring cancer care is people-centred and meets the needs of people with cancer, their carers and family

2. Implement structures to ensure that all people with a diagnosis of cancer have a well-defined and understood care plan that is used and regularly updated.
3. Implement structures to ensure that people with cancer, family members and carers should have access to accurate, relevant and timely information on cancer, prognosis, treatment options, likely treatment side effects and availability of allied services.
4. Ensure that Aboriginal and Torres Strait Islander people and people from culturally and linguistically diverse backgrounds have timely and consistent access to trained interpreters when appropriate.
5. Implement structures to ensure that cancer services are culturally appropriate.
6. Develop and implement care coordination service delivery models to ensure that all people with cancer have appropriate coordination of care.
7. Implement structures to ensure that psychosocial support is integrated with routine care.

Detecting cancer early, diagnosis and referral

8. Expand education programs to inform the community about signs and significant symptoms which could be related to cancer.
9. Develop a directory of specialist cancer services in South Australia, which is readily available to people in the community and health practitioners.

10. Develop and disseminate guidelines on most appropriate referral pathways for all referrers, including GPs and other primary health care providers.
11. Develop (where they do not already exist) and implement evidence-based guidelines regarding the investigation and diagnosis of symptoms and signs related to major cancers.
12. Expand access to affordable transport and accommodation for rural based people with cancer and their accompanying carers in order to facilitate access to diagnostic services.
13. Increase the capacity of services to identify and manage people at increased genetic risk of cancer.

Accessibility and timeliness of cancer care

14. Implement proposed model of service delivery (see page 38).
15. Implement NMRC *Clinical Practice Guidelines for the Psychosocial Care of Adults with Cancer* across South Australia.³
16. Implement *Standards for Providing Quality Palliative Care for all Australians*, developed by Palliative Care Australia.⁴
17. Develop and implement programs to improve access to appropriate treatments for all people with cancer. This includes addressing specific practical support mechanisms such as child-care, transport, and accommodation for people from country areas.
18. Establish a program to ensure South Australia meets the national standard for delivery of radiation oncology. This will include implementing the *SA Plan for Radiation Oncology Services 2005–2010*. A component of this will be to develop a plan for radiation oncology services that addresses the lack of services in outer northern Adelaide and the lack of publicly funded services in Southern Adelaide.
19. Metropolitan and rural and remote health services should explore options for access and delivery of chemotherapy services in country areas, and implement guidelines where they exist.



Recommendations to optimise cancer care (continued)

20. Explore and implement the best model for delivering care to adolescents and young adults (age 15–25 years) with cancer. This will include establishing an appropriate infrastructure to support the transition of young people with cancer, or the consequences of childhood cancer, from paediatric to adult services.

Multidisciplinary, fully integrated and coordinated cancer care

21. Implement the Statewide Integrated Clinical Cancer Service (see page 38) to ensure equitable access to cancer services in South Australia and to provide coordination between metropolitan hospital-based cancer care services, to rural and remote cancer care services and to emerging primary health care networks.
22. Enable Health Services to lead and coordinate local cancer services with networks between public and private sectors.
23. Develop and implement a strategy to incorporate multidisciplinary care as an essential component of cancer services.
24. Identify and address specific barriers to multidisciplinary care in certain settings, such as in the private sector and in rural settings, for example, the Medicare Benefits Schedule needs to change to facilitate multidisciplinary care in the private sector.
25. Expand the use of technologies such as teleconferencing as a means of improving access to multidisciplinary care.
26. Incorporate the principles of multidisciplinary care in the undergraduate and postgraduate training of all disciplines involved in multidisciplinary care.

Evidence and research in clinical practice and psychosocial care

27. Determine the current level of participation in clinical trials in South Australia including participation of rural people, adolescents and young adults and people treated in the private sector, and increase participation.

28. Provide to people with cancer clear and accessible information to support their ability to make informed decisions about participation in clinical trials.
29. Create or participate in a centralised clinical trials management program that provides information about available clinical trials to clinicians and for people with cancer, and promotes access for people with cancer, where appropriate.
30. Develop and implement a strategy to attract more clinical trials to South Australia.
31. Increase research that supports and improves cancer care, particularly health service research and psychosocial research.

Monitoring of safety, effectiveness, efficiency, satisfaction, accessibility and equity outcomes

32. Ensure that information systems are in place to collect data to monitor and evaluate outcomes.
33. Adopt appropriate quality indicators at all points of the cancer continuum.
34. Undertake statewide monitoring of key outcomes such as patient satisfaction, cancer incidence, staging, mortality and survival.
35. Support the Cancer Registry to provide timely and up-to-date information and the expansion of hospital cancer registries to enable collection of clinical data from all hospitals.
36. Commit to benchmarking of services to monitor compliance with standards and achievement of quality.
37. Support, develop and implement processes for accreditation of services and credentialing of practitioners to ensure that quality outcomes are met and recognised standards are adopted.
38. Develop pathways to incorporate feedback from people with cancer and their carers into quality of care.
39. Implement a process whereby quality measures are made known to people with cancer, primary health care providers and other members of the care team.



Recommendations for infrastructure planning

Implementing a comprehensive infrastructure strategy for South Australia

1. Establish an Infrastructure Planning Operations Group to oversee development of a staged comprehensive infrastructure strategy.
2. Develop an comprehensive infrastructure strategy for cancer control, giving particular attention to:
 - Enhancing infrastructure to support cancer care service delivery to people with cancer in the country, to Aboriginal and Torres Strait Islander people, to people who choose to die at home and to other sectors of the population where shortfalls are pronounced.
 - Increasing service availability closer to home where appropriate, increasing access to palliative care and end-of-life care, and further developing transport and accommodation services to facilitate access to metropolitan treatment services, for people with cancer living in the country.
 - Addressing infrastructure needs to provide cancer screening services to rural and remote sections of the population, especially Aboriginal and Torres Strait Islander people, where screening coverage is relatively low and treatment outcomes are poor.

Infrastructure for cancer prevention and cancer screening

3. Provide adequate infrastructure support for cancer prevention and population cancer screening, with particular attention to:
 - Prevention initiatives identified above.
 - Capacity for screening services to meet national targets, and to provide services to sections of the population, where screening coverage is relatively low.
 - The development of IT systems to support preventive initiatives as part of individual patient care, such as recall systems.

Infrastructure for diagnostic services

4. Audit and review diagnostic services.
5. Address needs for PET/CT scanning, diagnostic mammography, MRI and CT imaging, and for broader diagnostic infrastructure, as relating to tissue pathology, cytology, and chemical pathology.

Infrastructure for radiation oncology services

6. Support the *SA Plan for Radiation Oncology Services 2005–2010*, including recognition of the needs for public services to the north and in the south of Adelaide.
7. Ensure sufficient capacity of radiation oncology infrastructure for service provision to at least half of all people with cancer and proactive monitoring of infrastructure to assess needs for new equipment, ongoing maintenance and repair.
8. Monitor rates of use of radiation oncology services by the whole community, people from the country, and Aboriginal and Torres Strait Islander people and other groups at risk of under-representation. Investigate and address barriers to use.

Infrastructure for medical oncology and haematology services

9. Address the need for an equitable access to multidisciplinary care and anti-cancer drugs by all people with cancer, irrespective of place of residence.
10. Address the issue of rationing and funding of expensive drugs and the need for infrastructure for monitoring systems to ensure that anti-cancer drugs, particularly the more expensive ones, are used in accordance with evidence-based protocols.

Infrastructure for surgical oncology services

11. Develop infrastructure to monitor surgical caseloads, practice variations and treatment outcomes.



Recommendations for infrastructure planning (continued)

12. Provide funding and technical support for the development of infrastructure for surgical audits, taking account of the model used in the RACS breast surgery audit.

Infrastructure for palliative care services

13. Address the infrastructure requirements needed to support service delivery to people with cancer in rural and remote areas, including Aboriginal and Torres Strait Islander people, to other metropolitan and country sectors of the population where shortfalls are pronounced and to people who choose to die at home.
14. Addresses the need for IT infrastructure to monitor and audit the timely referral of patients for palliative care.

Infrastructure to deliver the information required by service providers and administrators

15. Develop an information infrastructure program for cancer services delivery, with emphasis on clinicians' needs for information for appropriate treatment planning, population health practitioners needs for surveillance data and to health administrators' needs for information for appropriate cancer-service planning and evaluation.

Infrastructure program for information and support services

16. Enable the provision of a broad range of information and support services for the community as a whole and for people with cancer.

Infrastructure for cancer research

17. Develop infrastructure to support the establishment of a South Australian Research Collaboration, to support the integration of research into all aspects of cancer-service delivery, increased participation of people with cancer in clinical trials, the availability of tissue sample data, the coordination of research to develop new monitoring and treatment strategies, the access of researchers and health administrations to cancer and cancer-services data, and the streamlining of ethics committee processes.

Infrastructure to address other health-system needs

18. Address particular health services infrastructure needs for:
 - Familial Cancer Service.
 - Services for paediatric cancer cases, which include follow-up monitoring of late effects, and services for older teenagers and young adults, who are neither the focus of existing paediatric or adult oncology services.
 - Cancer care networks across specialist centres and primary health care practitioners.



Recommendations for workforce planning

Broad and structural

1. Establish a Workforce Planning Operations Group, linked to a broader Health Workforce Inquiry, to oversee a systematic review to:
 - Develop comprehensive categories of cancer control workers across the continuum of cancer control. This would include, but not be limited to medical staff (e.g. oncologists, haematologists, surgeons, pathologists, paediatrics, general practitioners, nurses, radiation therapists, palliative care), allied health (e.g. pharmacists, psychologists, nutritionists, occupational therapists), social workers, cancer prevention workforce (e.g. policy managers, health promoters), researchers, carers and volunteers.
 - Develop a mechanism for workforce data collection and monitoring, including gauges of time spent in the cancer control workforce.
 - Audit cancer control workforce systems in all public hospitals, private hospitals and other relevant agencies.
 - Facilitate discussions or workshops specific to workforce groups where information is scarce (e.g. allied health and palliative care), taking the opportunity to investigate where and why there are shortages in certain areas of cancer control.
 - Undertake surveys to understand better the career intentions of those currently in the cancer control workforce.
 - Undertake studies that project future cancer control workforce requirements based on epidemiological predictions of cancer incidence in South Australia and anticipated models of care and practice.
2. It is also recommended that the Workforce Planning Operations Group:
 - Support the implementation of the workforce component of the *SA Plan for Radiation Oncology Services 2005–2010*.
 - Ensure that workforce deliberations are guided by the *Generational Health Review* recommendations and the health services reform underway in South Australia.
 - Investigate what research is being done locally, nationally and internationally about cancer control workforces and seek to link local and national taskforces on workforce issues.

Workforce reform, recruitment and retention

3. Implement reform of the existing cancer control workforce, to be consistent with a model placing more emphasis on primary health care, but understanding implications for the acute care systems, consistent with the health services reform underway in South Australia.
4. Introduce workforce reform and training to promote a shift to multidisciplinary care, as proposed in *Optimising Cancer Care in Australia* leading to significant improvements in patient outcomes, cost reductions and productivity gains.
5. Develop approaches for recruitment, training and retention for the cancer control workforce.
6. Investigate reasons for workforce attrition and develop incentives to keep people in the cancer control workforce for longer than currently experienced.
7. Develop a strategic plan to recruit more Aboriginal and Torres Strait Islander people into the cancer workforce, and that in parallel, benchmarks for improved cancer outcomes in Aboriginal and Torres Strait Islander people be set and pursued to help prevent widening of the gap in cancer mortality rates.



Recommendations for workforce planning (continued)

Workforce curriculum, education and training

8. Routinely include a cancer module in appropriate health professional education and training. This could include: primary and secondary cancer prevention, risk management and familial risk, the primary referral, psychosocial and supportive care, palliative care and pain management. An example for implementation is via GP Divisions' strategic plans.
9. Develop strategies for credentialing of medical practitioners in cancer, in line with recommendations of the *National Services Improvement Framework for Cancer*.
10. Enlist the Australian Medical Council to assist in incorporating The Cancer Council Australia's Ideal Oncology Curriculum into undergraduate medical education and the accreditation process for undergraduate medical training, both in South Australia and nationally.
11. Maximise opportunities for training volunteers and carers e.g. via the TAFE sector, non-government organisations and by inclusion in training provided to paid staff where relevant.
12. Develop incentives for nurses to undertake relevant post-graduate training in cancer nursing.
13. Develop strategies to increase post-graduate training in psychology as well as specialist training in psycho-oncology for health professionals.
14. Include access to psycho-oncological support services as one of the accreditation criteria in any cancer service accreditation scheme.
15. Increase provision of affordable, effective alternatives to psychological counselling such as peer-support.
16. Establish a capacity building workforce alliance with all non-government organisations and community organisations working in cancer control.
17. Educate the entire cancer control workforce in understanding cultural sensitivities relevant to Aboriginal and Torres Strait Islander people and culturally and linguistically diverse communities.



Recommendations for cancer control research

1. A Cancer Control Research Collaborative should be established and resourced in South Australia that will provide an enabling structure for integrated research programs that foster quality, are directed to definable community benefit and focus on areas of South Australian strengths and important populations. This recommendation is of the highest priority and will have far-reaching benefits.
2. The Cancer Control Research Collaborative should be funded to provide support for teams of excellent researchers with international recognition, focussing on areas of priority and state strengths, as well as providing support for the training, retention and career development of talented young researchers and the development and maintenance of essential research infrastructure. This is necessary to support high quality cancer research in South Australia and to retain and attract researchers.
The Collaborative would fund research through:
 - Programs
 - Fellowships
 - Training Awards
 - Infrastructure grants
 The Collaborative would fund research infrastructure, including:
 - Tissue bank
 - Linked database
 - Cancer staging data
 - Quality of life data
 - Links to the SA Birth Cohort
 - Bio-informatics and bio-specimen support
3. The Cancer Control Research Collaborative should:
 - Develop collaborative networks of researchers, policy makers, service providers, community representatives and commercial partners in areas of relative strength, in order to build critical mass, attract research funding, and facilitate translation.
 - Develop training opportunities for researchers in these collaborative networks, and employment opportunities for early-career researchers, that will sustain a research workforce of appropriate skill mix.
 - Establish and facilitate interaction between cancer funding agencies and cancer research organisations such as The Cancer Council South Australia and Child, Adolescent and Family Health Research Institute (CAFHRI).
 - Support and foster collaborations with interstate and international research partners.
 - Address priority cancer issues, monitor cancer research in South Australia and provide links with national and international research programs.
 - Develop de-identified databases, with approval for use from an ethics committee, for generic research purposes.
 - Work to streamline ethics application processes, to reduce duplication and promote communication and co-operation between the various local ethics committees operating within South Australia, whilst continuing to safeguard ethical research principles.
4. Conduct a review of cancer research currently being undertaken in South Australia, in order to establish the range of research and identify gaps, areas of overlap and areas of strength. Monitor cancer research to assist in planning and co-ordination of research.
5. Develop and implement a comprehensive program of research that addresses the entire spectrum of cancer control. Elements of the research program will include research activities that support the following:
 - Optimising cancer prevention
 - Detecting cancers early, particularly those where evidence exists that survival benefits will follow
 - Learn more about the causes and characteristics of solid and blood cancers in order to develop additional treatments



Recommendations for cancer control research (continued)

- Providing evidence-based clinical services that maximise the potential for cure and attend to psychosocial needs and requirements for palliation
 - Providing support for families and carers in non-clinical environments
 - Providing clinical and psychosocial support to people with cancer during the terminal stages of their disease, through the delivery of hospice and other community services.
6. As part of comprehensive cancer control research planning, incorporate policy to practice research that is underpinned by collaboration between researchers, policy makers, practitioners and community representatives.
 7. Improve coordination of programs for the evaluation and monitoring of existing cancer services to enable continuing quality improvement.
 8. Explore existing international models for knowledge translation in cancer research and support the implementation and resourcing of an appropriate model in South Australia.
 9. Develop, in partnership with Aboriginal and Torres Strait Islander communities and health agencies a research program that will focus on cancer control amongst Aboriginal people and translate research findings into improving health-service provision and reducing health inequities.
 10. Maintain a focus on health inequities in order to increase access and improve outcomes of cancer services.
 11. Develop a mechanism to enable research agendas to be responsive to community concerns that may not be addressed in mainstream research programs, as for example, in the role and impact of complementary and alternative therapies.



Recommendations for cancer information

1. The Statewide Cancer Control Advisory Group oversee the development, implementation and periodic review of a comprehensive cancer information strategy. The strategy will address the information needs of all stakeholders and in relation to cancer, cancer services, and outcomes of cancer services, after a systematic evaluation of present information availability.
2. Develop and implement targeted information programs within the context of this broad information strategy, including information for:
 - The general community that systematically addresses shortfalls in information.
 - People with cancer, their families and carers that systematically addresses shortfalls in information.
 - Clinicians and other health professionals that will enable the provision of high-quality services.
 - Population health professionals and health-service planners, policy makers and administrators to address gaps in existing information.
 - Researchers that addresses the range of research activity from basic through to clinical, population health, and health services research.
 - For parliamentarians to inform them annually of cancer control performance in South Australia.
3. Include the provision of question prompts and information on planned care and allied service needs, for people with cancer.
4. Address the needs of clinicians and other health professionals for generic and patient-centred information and for statistics for profiling practices for quality monitoring and audit.
5. Provide increased access for researchers to existing databases, re-engineer the South Australian Cancer Registry, re-engineer and extend clinical cancer registration across the State, and add value through linkage of existing data systems.
6. Streamline and simplify research ethics committee processes so as to reduce barriers to research data, while maintaining high ethical standards.

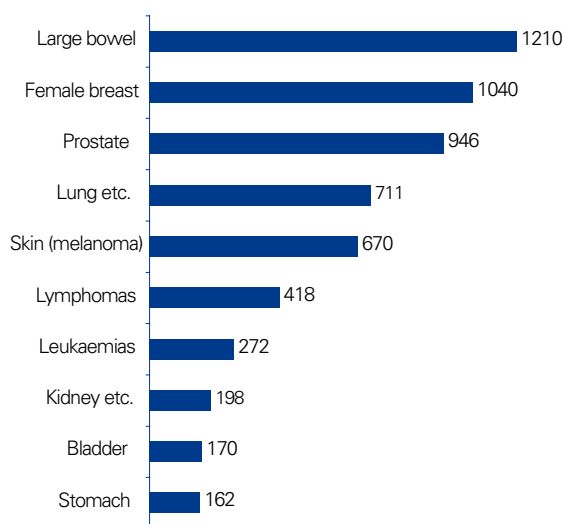
Background

Cancer is the abnormal and uncontrolled growth of cells which invade and destroy local tissues and eventually may spread to other parts of the body. The term covers more than 100 medical conditions. Cancer is a reportable disease in Australia and in many other western countries, meaning that when cancer is detected, it is mandatory for it to be recorded and reported. The South Australian Cancer Registry at the Department of Health collates these data for South Australia. *Incidence* refers to the number of new cases, which are found and reported in a specific time period.

In 2002, 7,708 invasive cancers were reported to the State Cancer Registry, 53% of them in males and 47% in females.⁵ The 10 leading types of cancer in 2002 are shown in Figure 1. South Australians have a similar incidence of cancer to other Australians, which is at the high end of the international scale.

Figure 1: Cancer Incidence – 10 leading cancers notified to the South Australian Cancer Registry in 2002, number by site.

(Non-melanoma skin cancers excluded)



Note: "etc" refers to related sites in the same category

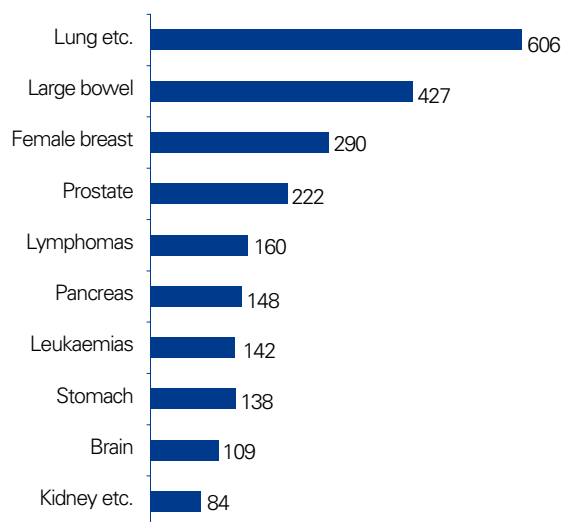
About 28% of all deaths in South Australia are due to cancer and more years of life are lost prematurely to cancer than to any other cause. Overall, 3,324 cancer deaths were notified to the State Cancer Registry for 2002, of which 55% were in males and

45% in females.⁵ The 10 leading causes of cancer death in 2002 are shown in Figure 2.⁵

Rates of new cancers and of deaths from cancer are not distributed evenly across the South Australian community. There are differences between men and women. South Australian males in lower socio-economic areas have a higher incidence of cancer than males in upper socio-economic areas. This is largely due to more cancers caused by tobacco, alcohol, and poor diet in lower socio-economic areas.⁶ By comparison, a reverse trend is observed for females, with higher rates of cancers of the breast, colon and skin (melanoma) occurring among women in the upper socio-economic areas.⁶ In general, incidence rates are higher in metropolitan than non-metropolitan areas, partly due to higher rates for lung cancer and non-Hodgkin's lymphoma in urban settings.⁵

Figure 2: Cancer Mortality – 10 leading causes of cancer death notified to the South Australian Cancer Registry in 2002, number by site.

(Non-melanoma skin cancers excluded)



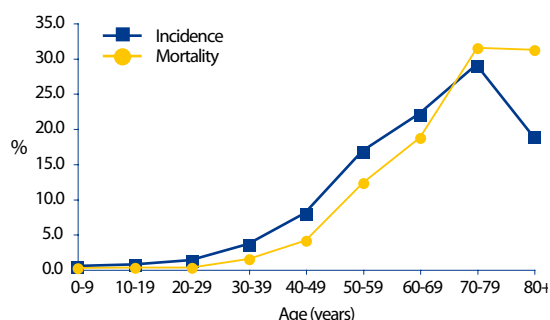
Note: "etc" refers to related sites in the same category

Aboriginal and Torres Strait Islander people living in South Australia have a similar overall rate of new cancers to the rest of the population, although with a different distribution of cancer types.⁷ Aboriginal and Torres Strait Islander residents of South Australia encounter more lethal types of cancer and have much higher rates of death from cancer.

Even for individual cancer types, Aboriginal and Torres Strait Islander people are more likely to die of their cancers. This is partly due to later diagnoses when prospects for cure are reduced. Yet, even for individual cancers of equivalent stage of progression at diagnosis, death is more likely in Aboriginal and Torres Strait Islander people than other people with cancer. This raises serious questions about treatment access and quality as well as major social and environmental challenges that would need to be overcome for effective prevention.

Whilst cancer occurs across all age groups, cancer is predominantly a disease of ageing. The older the age group, the more commonly cancer occurs. Cancer occurs much less commonly in children and people aged under 30 years. Figure 3 demonstrates the percentage distribution across different age groups of the cancers which were diagnosed and the deaths due to cancer in 2002.

Figure 3: Percentage distribution of cancers diagnosed in 2002 and cancer deaths occurring in 2002 in South Australia. (Non-melanoma skin cancers excluded)



Numbers of new cancers and deaths from cancer are increasing. Globally, the World Health Organization reports that more than 10 million people are diagnosed with cancer every year, and estimates that there will be 15 million new cases every year by 2020.⁵ In the 25 years to 2002, the number of South Australians diagnosed with cancer each year more than doubled.^{5,6} It is projected that the number of cancers diagnosed in South Australia each year will increase by at least 18% between 2002 and 2011.⁸ The number of deaths from cancer has also increased over the past 20 years and is predicted to increase by at least 13% between 2002 and 2011.⁸

However, this does not mean that the risk of cancer or of dying from cancer at any given age, is increasing, as these trends are largely due to population changes. The size of the population has increased and as other diseases are becoming better managed, more people are living longer and

entering older age brackets where cancer is more common.

Other factors influence the observed increases in numbers of new cancers, such as improved detection of new cancers. A significant amount of the increase in incidence observed in South Australia has been *artificial*, reflecting increased detection of cancer through breast (mammography) screening, the early detection of melanoma and prostate testing. However, *real* increases have also occurred for cancers of the female breast, skin (melanoma), large bowel (colon/rectum), lung (in females), and non-Hodgkin's lymphoma.

Figures 4 and 5 contain age-adjusted rates of cancer incidence and cancer deaths, published by the South Australian Cancer Registry. Age-adjusted rates control for changes in the profile of the population and allows comparisons in rates of cancer incidence and cancer death, if there were no changes to the age distribution. Stated another way, Figure 5 shows that we would now have seen a reduction in the cancer death rate since the early 1990s, were it not that South Australians are living longer. This indicates that we are making headway.

Figure 4: Annual age-adjusted incidence of cancer per 100,000; South Australia, 1977 to 2002. Age-standardised to the Australian Population (2001). (Non-melanoma skin cancers excluded)

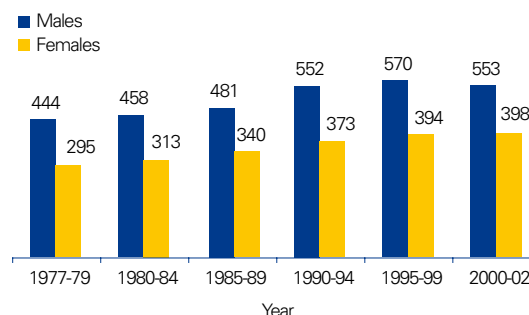
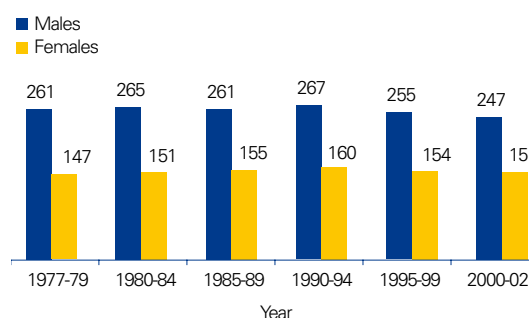


Figure 5: Annual age-adjusted cancer death rates per 100,000; South Australia, 1977 to 2002. Age-standardised to the Australian Population (2001).



Reducing Cancer Risk, Increasing Cancer Prevention and Early Detection

Summary

Over half of all cancers could be prevented if we acted on the knowledge we already have about tobacco control, improvements in diet, physical activity, weight control, sun protection and avoidance of excess alcohol consumption. Cancer prevention, within a population health framework, aims to influence the economic, social and physical environments in which people live and work to minimise exposure to contributors to cancer risk, and to facilitate cancer-preventing behaviours. It also aims to ensure that people's knowledge is sound about all sources of cancer risks and ways to reduce cancer risk, and that cancer risk reducing behaviours are promoted and enabled. This also involves providing a range of services and programs that are accessible and affordable to the community.

In the absence of effective primary prevention of cancer, secondary prevention by means of screening is an alternative for some cancers. Screening for and early detection of cancer is based on the premise that earlier diagnosis of the disease, either in a pre-cancerous state or at an earlier stage than that at which clinical presentation would otherwise take

place, leads to a reduction in risk of mortality or development of invasive disease.

The Statewide Cancer Control Plan goals for reducing cancer risk, increasing cancer prevention and early detection, within a population health framework, are that:

- Legislative frameworks exist that provide the South Australian community with environments in which to live and work that are conducive to cancer prevention and early detection (e.g. smoke-free workplace and public places laws).
- All South Australians understand the factors that contribute to the risk of cancer, know how to reduce their own risk of cancer through appropriate lifestyle and behaviour modifications and act on these.
- High-quality affordable, evidence-based cancer prevention, early detection and screening programs, services and information are implemented and all South Australians are enabled to access them.

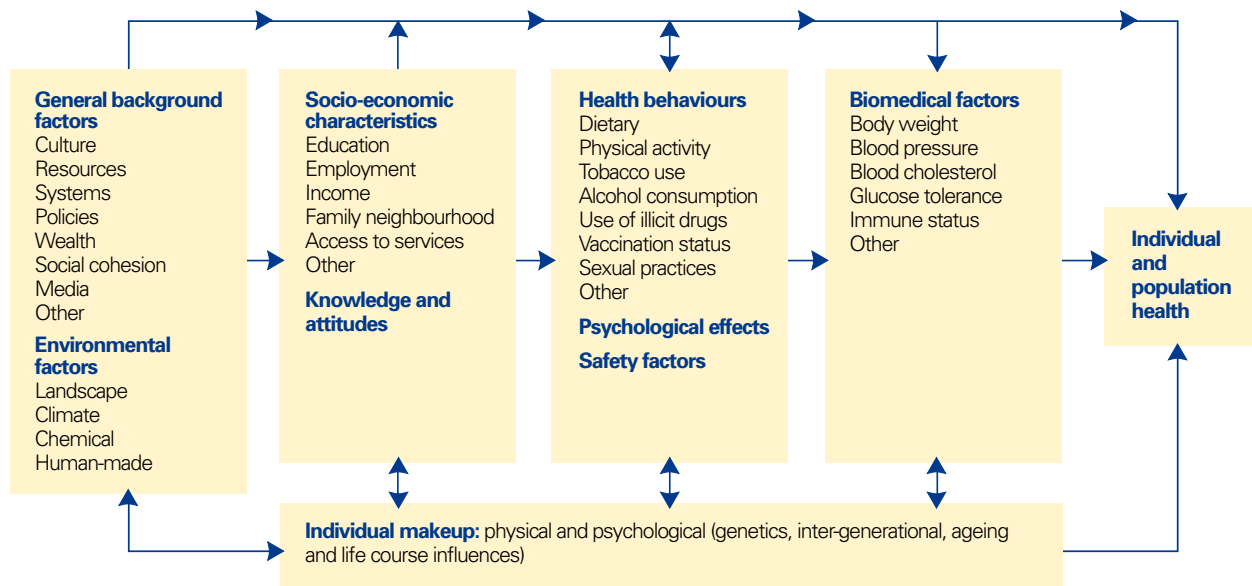
Population health and determinants of health

"Population health... is concerned with improving the health of whole populations or specific populations, particularly to reduce inequalities, through policies, programs, research and interventions designed to protect and enhance health".⁹

Many different factors impact on individual health and population health. The Australian Institute of Health and Welfare (AIHW) acknowledges "Australia's levels of health and wellbeing, including diseases and disability, are influenced to varying degrees by a range of determinants that are in

complex interplay". These determinants can be socio-economic, environmental, behavioural (such as tobacco use), biomedical (such as blood cholesterol or blood pressure) or genetic factors (see Figure 6).¹⁰

Examining the spectrum of determinants of health informs our understanding of the health of our community and the individuals within it. It broadens our perspective from one focussing predominantly on individual illness and health, to one with a greater emphasis on population health. It also informs ways to improve population health.

Figure 6: A conceptual framework for the determinants of health. (Source: AIHW 2004)

The AIHW argues that “these causes and their effects on health and wellbeing can be modified to various degrees by prevention and health promotion, treatment, rehabilitation and other health care. Such interventions are supported by human and material resources and associated systems, including essential information via research, monitoring and evaluation.”¹⁰

An essential component of cancer control is the treatment and care of people with cancer. This element of cancer control is predominantly focussed at an individual health or disease level. Cancer prevention in a population health context, on the other hand, seeks to reduce the incidence, morbidity and mortality of cancer, by influencing the social, environmental and behavioural determinants of health.

Inequity and inequality in health

Addressing health inequities and inequalities is an often-cited aim of health promotion and public health. “Health inequality is about measurable variations in health status. Health inequity ‘refers to those inequalities in health that are deemed to be unfair or stemming from some form of injustice.’”⁹ Within the context of cancer prevention, health equity is about reducing the observed inequalities in the incidence, early detection, treatment and outcomes of cancer for people in all socio-demographic groups. This is achieved by enabling people to have equitable access to relevant and affordable programs and services, on the basis of need. Reducing inequalities is also about enhancing the capacities and power that people need to act upon the circumstances of their lives that determine their health.

There are differences in exposure to the social and physical factors which impact on risk and in the health behaviours which impact on cancer risk and participation in cancer screening. This contributes to the observed inequalities in the prevalence of different cancers and stages at which cancers are detected in different groups across South Australia.

Reducing risk, increasing prevention and early detection in South Australia

Uncertainties and myths led to a common belief in the past that cancer was generally incurable. Over the years, there has been an increase in understanding of the nature, causes and means of controlling cancer. In particular, familial or inherited factors, environmental exposures and lifestyle factors have become clearer as causes of cancer. Prevention can often be achieved and cure, through treatment, has become more common, especially when the cancer is detected early.

Cancer risk

Cancer risk refers to the chances that a person will get a certain type of cancer. Some factors increase people’s risk of getting cancer above the risk of the population as a whole, while other factors decrease risk. For example, a person who smokes cigarettes and has done so for many years is at far greater risk of getting lung cancer than a person who has never smoked tobacco.

The relationships between different cancers, cancer risk factors and the strength of evidence of association, are outlined in Table 1 overleaf.

Table 1: Strengths of associations between lifestyle factors and cancer^{11,12}

Factors that may INCREASE risk of cancer						
	Tobacco	Ultra-violet radiation	Alcohol at any level #	Alcohol at unsafe levels #	Obesity	Diet: Charred or burnt or processed meats
Oesophageal	+++		+++	+	+++	
Laryngeal	+++		+++	+		
Oropharyngeal	+++		+++	+		
Bladder	+++					
Lung	+++					
Liver			+++	+		
Skin – non-melanoma		+++				
Skin – melanoma		+++				
Endometrial						
Colorectal	+				+	?
Renal	++				++	
Breast			+	?	+	
Stomach	+					
Anal	++					
Cervical	++					
Penile	++					
Vulval	++					
Pancreatic	+					
Leukaemia	?					
Ovarian						
Prostate						
Thyroid						

+ Reduction or increase in risk from 10–19%

++ Reduction or increase in risk from 20–29%

+++ Reduction or increase in risk at or above 30%

? Indications of decreased or increased risk but data base too small or variable to be definitive or to assign risk level

Table 1: Strengths of associations between lifestyle factors and cancer^{11,12} (continued)

Factors that may DECREASE risk of cancer			
	Physical activity	Diet: Specific nutrients	Diet: Fruits and vegetables
Oesophageal			+
Laryngeal			+
Oropharyngeal			++
Bladder			?
Lung	?	Folate?	
Liver			?
Skin – non-melanoma			
Skin – melanoma			
Endometrial	+++		?
Colorectal	+++	Calcium, Vitamin D status and Selenium?	++ (High fibre, whole grain foods?)
Renal			?
Breast	++	Folate?	+
Stomach		Anti-oxidants?	++
Anal			
Cervical			?
Penile			
Vulval			
Pancreatic			?
Leukaemia			
Ovarian			?
Prostate		Selenium?	?
Thyroid			?

For alcohol, one set of estimates was based on comparing consumption at levels consistent with limits set by health authorities (i.e. 1–2 drinks per day or less) compared to higher levels of consumption; the other estimate compares risk for any level of drinking to non-drinking. The estimates indicate higher relative risk for any level of alcohol consumption compared to non-drinking.

Note: Other relationships between behavioural factors and cancer risk have been noted in some studies. The strength of the association may not have been documented.

There are factors in the environments in which people live and work that also contribute to cancer risk. Determining the consequences of workplace and other environmental hazards can be difficult as the effects can be subtle and the timeline between exposure and cancer diagnosis can be long. Cancer authorities have focussed on reducing passive smoking and excessive sun exposure in workplace settings. Frequently, they have advocated regulatory processes for this purpose. Other improvements in environmental hygiene have also been beneficial. For example, initiatives to decrease inhalation of asbestos in occupational and other settings will have impacted on rates of cancers of the lung and pleura. There are other pre-disposing conditions, which contribute to cancer risk, such as infection with Human Papilloma Virus and cervix cancer, and Hepatitis B and C and liver cancer.

Significant developments in cancer genetics have occurred in the past decade. Cancer results from the progressive accumulation of genetic changes in cells due to instability of the genome and consequent effects on gene function and cell behaviour. Accumulation of such changes with progression through the cancer development pathway (oncogenesis) usually spans years and in some cases decades. Some of the genes involved in the inherited pre-disposition to common cancers have been identified. Around 5% of specific types of cancer are considered to involve the inheritance of a strong genetic pre-disposition. For some cancers, weaker inherited factors might play a large role. There is also an improved understanding of cancer risk based on family history of the disease outside of these defined familial syndromes. What is not well appreciated, is that most cancers do not

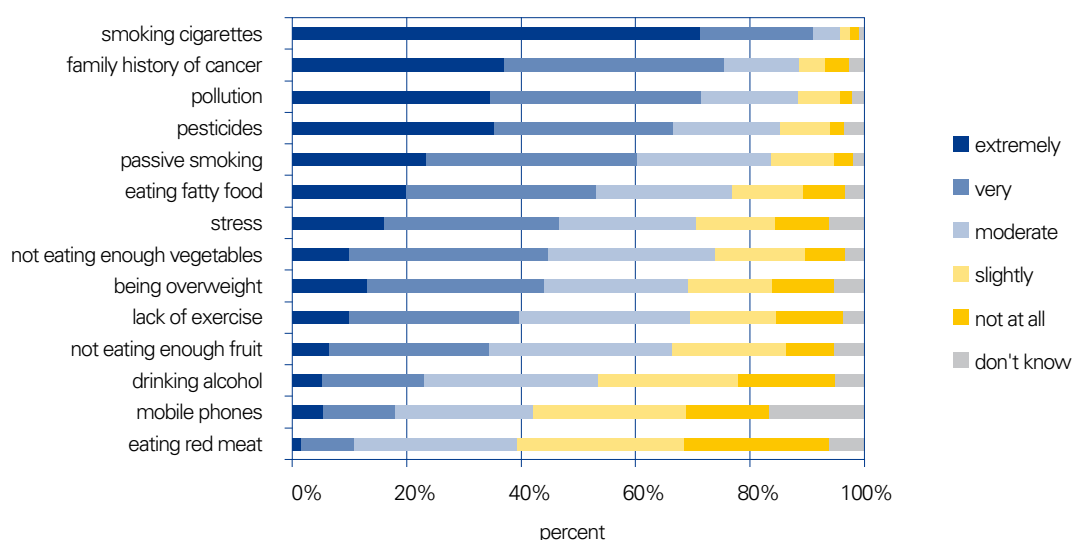
involve inheritance but are acquired, meaning that environmental factors (e.g. tobacco smoking, sun exposure) play a major role in the causation and progression of these.

General community understanding of cancer risk is not well aligned with current evidence. Frequently, there is disproportionately high concern about factors that are far less likely to create excess risk of cancer. The public has strong concerns in relation to environmental exposures and cancer risk. For example, there have been concerns that increased exposure to non-ionising radiation from power lines and other sources may be increasing the risk of childhood cancers. Yet the incidence of these cancers is not increasing in South Australia, nor is there convincing evidence, currently, of a cancer link with non-ionising radiation. Other public concerns relating to ionising radiation include the future storage of nuclear waste that may pose health risks. Radio frequency radiation from cellular phones and electromagnetic radiation have also been of concern to the public.

The Health Omnibus Survey is a representative survey of 3,000+ South Australians aged 15 and over. In 2004, respondents were asked a number of questions about their perceptions of cancer risk. Figure 7 shows South Australians' perceptions about the importance of a range of factors and contribution to cancer risk.

Awareness and understanding of the relationship between different factors and cancer risk vary. As might be expected, after 20 years of community education, community awareness that tobacco smoking and sun-exposure increase the risk of cancer is high. Community awareness of other

Figure 7: Perceived importance of cancer risk factors



factors such as healthy body weight and alcohol exposure is far lower by comparison.¹³

Cancer risk-reducing behaviours

While there is a range of risk factors related to cancer, the following are paramount: tobacco use, exposure to ultraviolet radiation, poor nutrition, physical inactivity, being overweight or obese and alcohol use. As with cancer incidence, the behavioural and environmental risk factors for cancer are not distributed evenly across the population. Disadvantaged populations experience higher rates of certain cancers, and often have higher rates of the factors that contribute to cancer risk. For example, rates of smoking are higher in less advantaged groups and lower in more advantaged groups.

Tobacco smoking

Tobacco contributes significantly to cancer causes and deaths.⁵ Apart from causing cancer, tobacco smoking is an important cause of cardiovascular disease, chronic respiratory disease, low birth-weight and associated adverse outcomes of pregnancy, and many other conditions.¹⁴ There have been major advances in reductions of tobacco smoking over recent decades. For example, after the Second World War, 75% of men smoked while in 2004, only 25% of Australian men smoked.¹⁵ Tobacco exposure also occurs from passive smoking. Many South Australians are still routinely exposed to passive smoking, at work, in enclosed public spaces and at home.¹⁵ Quitting smoking and avoiding exposure to second hand tobacco smoke can reduce the risk of cancer considerably.

Sun protection

Excess sun exposure and a high prevalence of fair skins are responsible for Australia's exceedingly high levels of melanoma and non-melanoma skin cancers.^{16,17} To reduce exposure to ultraviolet radiation, the Cancer Council South Australia promotes the wearing of protective clothing, hats and sunscreens. It also promotes sun-protective environments and avoidance of direct sun exposure is encouraged, especially between 10.00 am and 3.00 pm. When people are outside, The Cancer Council South Australia advises that shade be used as much as possible. In 2002, the proportion of South Australian adults (aged 15+ years) reporting use of sunscreens was 44%, a decline from 1999.¹³ Meanwhile, a recent decline also was suggested in the proportion using hats and clothing worn for protective purposes. Nonetheless, the proportion of people reporting sunburn in the preceding summer period reduced from about 38% in 1999

to 29% in 2002.¹³ A corresponding downward trend in frequency of sunburn also was reported by secondary students, although the change was marginal and sunburn was still reported more frequently than in the early 1990s.¹³

Non-melanocytic skin cancers (NMSC) are the most common cancers diagnosed in Australia¹⁸ and comprise squamous cell carcinomas (SCC) and basal cell carcinomas (BCC). While mortality rates associated with NMSC are low, the treatment of these cancers places a significant burden on the health budget.¹⁹ SCC rates have increased by 133% in the period 1985 to 2002 and BCC rates have increased by 35% in the same period.¹⁸ In spite of these increases, there is evidence of a reduction in incidence of BCC in cohorts aged 49 years or less.²⁰ This suggests that public health campaigns to reduce sun exposure, that have been running for over 20 years, may be having a beneficial effect.²⁰

Melanoma remains the fourth most commonly diagnosed cancer in South Australian males and the third most commonly diagnosed cancer in South Australian women.²¹ While the incidence of melanoma has been increasing over the past 20 years there has been a plateau more recently.²¹ Unlike incidence, the mortality rate for melanoma has remained stable over the past 20 years.¹⁷ This is due mostly to earlier diagnosis and the five-year survival rate for invasive melanoma has increased.¹⁷ Melanoma remains a major cause of cancer death in the 15–44 age-group.²¹

Nutrition

Nutrition has a major effect on cancer incidence, with a high intake of vegetables and fruit generally being associated with a lower incidence.^{22,23,24}

Dietary guidelines recommend two serves of fruit, five serves of vegetables and five or more serves of cereal per day.²⁵ Against these standards, most South Australians have a poor quality diet. Only 11% of those aged 15 years and over are reported to have an adequate intake of vegetables, and only 24% and 46% have adequate intakes of cereals and fruit respectively.¹³ In general, more women are eating recommended levels of vegetables and fruit than men. Fruit and vegetable consumption is lower in younger adult groups, than in older groups.¹³

Physical activity

Lack of physical activity has also been identified as an important and widespread contributor to cancer risk.^{23,24} A survey of South Australian adults undertaken in 2004, showed that 54% had undertaken 'sufficient' physical activity for general health in the past week (equivalent to

150 minutes walking), however, 17% were classified as sedentary, in that they had little or no physical activity.²⁶ Recommendations about the amount of physical activity required to reduce cancer risk vary. The International Agency for Research in Cancer notes that 30 minutes per day of moderate intensity activity is recommended for good general health, although some evidence suggests 60 minutes per day including some vigorous intensity physical activity is more likely to reduce the risk of cancer.²⁷

Body weight

Maintenance of a healthy body weight is recommended, as excess body weight is known to be a risk factor for many cancers.^{23,28,29,24} The prevalence of obesity in Australia has more than doubled in the past 20 years.³⁰ The proportion of South Australians aged 18 years or more, who have been classified on the basis of their body mass index as overweight or obese, approximates 50%.²⁶ This is similar to the corresponding national figure. Males are more likely than females to be overweight or obese.¹³ Higher proportions are overweight or obese in the age range of 45–64 years than in younger or older sections of the population.¹³ National data indicate that more people are becoming overweight and obese.²⁶

To achieve and maintain a healthy weight, The Cancer Council Australia recommends regular physical activity and eating to meet energy needs. Eating patterns should be consistent with the *National Healthy Eating Guidelines*. Making vegetables, fruit, cereals and other low energy density foods the basis of an individual's diet may assist with achieving and maintaining healthy body weight.

Alcohol

The latest Australian review of the health effects of alcohol, confirms the association between alcohol consumption and an increased risk of cancer. The Cancer Council Australia recommends that people limit or avoid alcohol to reduce cancer risk. Adult males are regarded to be at increased risk of cancer if they average more than two standard alcohol drinks (i.e. >20gms) per day.¹¹ Females are regarded to be at risk if they consume half this amount. These standards are more stringent than previously employed.¹¹ Notably, applying this definition, up to one in five South Australians aged 15 years or more would be at risk from excess alcohol consumption.¹³

Primary prevention of cancer

Over half of cancers of the type occurring in South Australia could be prevented through cessation of tobacco smoking, improved diet including increased vegetable and fruit consumption, increased physical activity, weight control, limiting or avoiding alcohol consumption and appropriate sun protection.¹¹ Reduced exposure to environmental carcinogens at work and in other settings (e.g. tobacco smoke, asbestos, industrial chemicals) would also assist in the prevention of cancer. Prospects for cure can be increased through screening and other early detection initiatives. In particular, premature mortality can be reduced through breast, cervix and large-bowel screening, which are of proven efficacy. Furthermore, screening programs that detect pre-cancer lesions (dysplasia) for cervix and the colorectum can also reduce incidence by preventing cancer.

There is growing evidence (strong in some areas, weaker in others) about the effectiveness of different strategies to bring about changes that reduce cancer risk. It is important to inform and educate the community about ways that they can reduce their cancer risk. However, awareness raising about behavioural and environmental risks for cancer to change knowledge and attitudes is only one component of a comprehensive cancer prevention program. Strategies to encourage and facilitate behaviour change to reduce cancer risk are also essential.

Population health broadens the focus for intervention from the individual to the whole of the population, and sub-groups at risk within the population. It seeks to make sustainable changes to social and physical settings, as well as health systems. This broader conceptualisation of health recognises a range of social, economic, cultural, political and physical environmental factors which contribute to health. To make change, it is also essential to influence these factors, as part of a comprehensive approach to cancer prevention.

There is considerable potential for cancer prevention through initiatives aimed at social and physical environmental factors. These include initiatives to reduce exposure to carcinogens in workplaces and other environments (including ultraviolet radiation, tobacco smoke and industrial carcinogens), initiatives to alter the environment to make it more conducive to physical activity participation and fiscal mechanisms to promote cancer-preventing behaviour and to reduce cancer-causing behaviours (e.g. taxation on tobacco).

Addressing legislative, policy and structural issues requires whole of government input and collaboration, as many factors are beyond the jurisdiction of the health sector. However, there is a place for leadership from the Department of Health and Regional Health Services. Local Government has responsibility for many public spaces and local planning, and has a role in providing shade and environments conducive to physical activity. There is also an important role for non-government organisations, community and other agencies engaging in cancer control to promote, inform and advocate for legislative, policy and structural changes.

Many initiatives which could reduce cancer through behavioural, social and physical environmental mechanisms are documented in already endorsed state and national strategy documents. These include: the *National Services Improvement Framework for Cancer* (Department of Health and Ageing); the *National Cancer Prevention Policy Document* (TCCA); The Cancer Council South Australia's *Cancer Prevention Strategy*; state and federal governments' Tobacco Control Strategies; Drug and Alcohol Strategies; physical activity, nutrition and healthy weight policy documents (*be active, Physical Activity Strategy for SA, Eat Well Australia, Eat Well South Australia and The South Australian Action Plan for Promoting Healthy Weight, The South Australian Fruit and Vegetable Coalition Action Plan*).

Cancer screening and early detection

In the absence of effective primary prevention of cancer, secondary prevention by means of screening is important for those cancer sites where there is strong evidence of benefit. Screening for and early detection of cancer is based on the premise that earlier diagnosis of the disease either in a pre-cancerous state or at an earlier stage than that at which clinical presentation would otherwise take place, leads to a reduction in risk of morbidity, mortality, and for some cancers, a reduction in development of invasive disease.

Screening refers to the application of a test to a population which has no overt signs or symptoms of the disease in question, to detect precursor conditions or unsuspected disease while a cure is still possible. The screening test does not diagnose illness, but is used to identify people who require further investigation to determine the presence or absence of disease.¹¹ At the public health level, it is important that uptake of screening within a population be maximised, so as to increase the benefit.

The conceptual framework for implementing a screening program was proposed by Wilson and Junger for the World Health Organization, as summarised in Figure 8.³¹

Figure 8: Evidence-based cancer prevention
(Source: International Union Against Cancer (UICC))

The classic conceptual framework for implementing a screening program

- 1** The condition should be an important health problem.
- 2** There should be an accepted treatment for patients with recognised disease.
- 3** Facilities for diagnosis and treatment should be available.
- 4** There should be a recognisable latent or early symptomatic stage.
- 5** There should be a suitable test or examination.
- 6** The test should be acceptable to the population.
- 7** The natural history of the condition, including development from latent to declared disease, should be adequately understood.
- 8** There should be an agreed policy on whom to treat as patients.
- 9** The cost of case-finding (including diagnosis and treatment of patients in whom disease is diagnosed) should be economically balanced in relation to possible expenditure on medical care as a whole.
- 10** Case finding should be a continuing process and not a 'one off' project.

Familial cancer testing

Approximately 18% of individuals with cancer report family clustering (i.e. similar cancer in other members of their family). Often this would be due to chance, or shared lifestyles or environmental factors, but in approximately 5% of cases there is a strong genetic element, with an inherited predisposition to cancer due to gene mutation.³² It is established that some cancers are hereditary and that some relatives of a person who has or has had cancer will be at greater risk of developing the disease themselves. The identification of cancer genes has opened up a new field of cancer screening, and services exist to counsel such people about their increased risk and the options for management.

Breast screening

Mammography screening can reduce breast cancer mortality by 30% or more in screened women.³³ Biennial screening with mammography is advocated for Australian women in the 50–69 year age range.³³ Approximately 64% of South Australian women in this age range received mammography screening in the public sector during a 2-year period ending 31 December 2004. The proportion receiving mammography investigations through the private health sector is not known exactly, although from previous surveys, it would be expected that in excess of 70% of women of this age would receive mammography screening or other mammography testing within a 24 month period.³⁴ Thus, up to 30% of women in this age range would be at risk through a lack of exposure to earlier diagnosis through mammography. This proportion is higher in Aboriginal and Torres Strait Islander women than other women.⁷

Cervix screening

Cervical screening can reduce the risk of squamous cell carcinoma of the cervix by 90%.³⁵ Approximately 65% of South Australian women aged 20–69 years, who have an intact uterus, receive a Pap test within a given two-year period, whereas about 78% do so within a three-year period.³⁵ Lowest screening coverage relates to women under 30 years of age and those over 65 years of age.³⁵ Comparatively low screening rates apply in the Flinders and Far North Division of General Practice and in the Northern Division. Screening should be promoted actively among those sectors of the population at high risk of cervical cancer. These include Aboriginal and Torres Strait Islander women and those from low socio-economic areas.³⁶

Colorectal screening

Bowel (colorectal) cancer is prevalent in Australia. With the ageing South Australian population it is expected that the total number of new cases of bowel cancer will increase substantially. Rates of bowel cancer are higher among people with a family history of this type of cancer.¹¹

In recent decades there has been considerable interest in identifying modifiable risk factors associated with bowel cancer. The main focus of research into preventable risk factors associated with bowel cancer has been in relation to diet and other lifestyle factors such as physical activity, intake of aspirin and not smoking.³⁷ As yet, it is not confirmed which interventions to influence all of these factors will be feasible and effective. Some evidence from people with adenomas suggests that calcium, vitamin D status, dietary fibre and certain non-steroidal anti-inflammatory drugs (NSAID) are protective, but the cost-benefit and impact on cancer remain unclear.

There is evidence from population trials that annual or biennial screening of the normal population by faecal occult blood testing could lead to reductions in disease-specific mortality. In those who use the test, mortality can be reduced by approximately 40%.³⁸

The Australian Health Technology Advisory Committee (AHTAC) report on colorectal cancer screening noted that a national approach to population screening for people without symptoms would need to be complemented by a national policy for groups potentially at increased risk for bowel cancer, i.e. individuals with a family history of bowel cancer, or a personal history for bowel adenoma, bowel cancer or inflammatory bowel disease.³⁹ Following the AHTAC recommendation that Australia undertake a pilot study to evaluate feasibility, acceptance and cost-effectiveness of screening, a trial program including about 69,000 Australians aged 55–74 years has been undertaken. A decision to proceed with a national program has now been made.

Prostate cancer testing

In 2002, prostate cancer was the most commonly diagnosed cancer (apart from non-melanoma skin cancer) in Australian men. Proven means of preventing prostate cancer do not exist, although the typical Western diet, high in fat, red meat, milk and dairy products, and low in vegetables, is suspected to be a risk factor.²⁹ Population-based screening of asymptomatic men is not being advocated by most Australian health authorities in advance of the results of current field trials, due

to uncertainties about benefits and adverse side effects.²⁹ Even so, there is widespread community concern about prostate cancer reflected in the high rates of Prostate Specific Antigen (PSA) testing in general practice. Most clinical practice guidelines recommend that such testing only take place after patients are adequately informed about the risks and benefits.^{39,40,41} However, Australian studies suggest that this frequently does not occur.^{42,43,44}

Prostate cancer is a widespread disease where research is urgently needed to find opportunities for prevention, screening and more effective treatments.

Self-screening

There are also opportunities to promote the earlier detection of disease within a population either by increased awareness or by self-screening, for example, encouragement of awareness about changes in skin spots through health education programs.

Issues in cancer screening and early detection

There are outstanding issues in cancer screening, including the issue of what to do when there is uncertainty about the effectiveness of a screening test. To date, this is approached in a public health context by not funding and not offering the test. However, in a clinical context there remain issues which need to be resolved. These include:

- a. the possibility that the test may help the person with cancer as well as harm him/her, and whether clinical information about the patient helps refine those risks
- b. the patient's anxiety about the particular disease – the anxiety becoming the clinical issue
- c. the patient's own attitude towards the uncertainties or risks about testing and the disease
- d. strong public demand for the test generating a need to support General Practitioners to respond appropriately.

In the case of prostate cancer, screening may eventually be proven to save lives. So in dealing with an individual patient, if a medical practitioner does not offer testing, there is potential for harm. This clinical context is not the same as a population context in that it is possible to obtain additional information from the patient that may change their possibility of benefit or harm from the test. Information might include age, family history and the patient's own anxiety or desire for testing.

This refines the decision although it does not dispel uncertainty.

Many clinical practice guidelines suggest a useful strategy in this situation to be 'informed choice'. Ideally the informing process includes the individualisation of risk, the consideration of related clinical issues and the patient's own concerns. The responsibility for the decision is shared. However, informed choice itself is expensive, involving a cost in terms of doctors' time, training and other resources. Without adequate resourcing, it can be influenced by vested interests. Informed choice as a recommendation needs careful consideration for this reason. Informed choice is a response to an ethical dilemma where there is uncertainty surrounding a decision with potentially major impacts on a patient's well being and where patient's preferences will vary. It should not be used as a universal strategy for managing screening tests about which there is uncertainty.

Screening can be undertaken in two dimensions: the individual and the population. In the individual dimension, screening is negotiated with a health-care provider, risk is assessed, symptoms appropriately dealt with, and duty of care is exercised such that it is likely that the best test gets done. In the population setting, there is little opportunity for individualisation, a test must be simple and doing anything must be better than nothing. In our society there is a tension between these two approaches, but each has its place. We need to improve overall uptake of proven screening methods but we also should ensure that in working towards this goal, the needs of individuals, especially those at high risk are not overlooked.

The aim of population cancer screening is to reduce morbidity and mortality from the disease.³¹ There is evidence on the effectiveness of screening for cancers of the breast, cervix and colorectum. Population participation is the key to successful screening. More behavioural research aimed at overcoming barriers is essential.

There is still no conclusive evidence that population based screening for cancers of the prostate, head and neck or melanoma reduces the mortality rates from those sites. Population-based screening for cancers at sites other than breast, cervix and large bowel will not be recommended until health benefits have been shown. The screening tests currently being tested are prostate specific antigen (PSA) for prostate cancer; and Computerised Action Tomography (CAT) for lung cancer. No other cancer is currently regarded as a good candidate for population cancer screening at this time.³¹

How will we reduce cancer risk, prevent cancer and detect cancer early?

National cancer priorities

The National Cancer Strategies Group has nominated priority areas for cancer control in Australia.⁴⁵ They include cancers of the large bowel (colon and rectum), female breast, prostate, lung, skin (melanoma), cervix, non-Hodgkin's lymphoma, and skin (non-melanoma). Control measures identified by the National Cancer Strategies Group directed at reducing cancer risk, increasing cancer prevention and early detection of these cancers include the following:

Lung cancer: promoting cessation of tobacco smoking; decreasing exposure to environmental tobacco smoke; and reducing occupational exposures to respiratory carcinogens, such as asbestos, inorganic arsenic, chloromethyl ethers, polycyclic aromatic hydrocarbons, radon products and ionising radiation.⁴⁶

Large bowel cancer: promoting healthy diets rich in vegetables and low in fat, weight control, moderate levels of physical activity, and avoidance of excess alcohol consumption; and advocating population screening with faecal occult blood testing and endoscopic follow-up, and endoscopic monitoring of high-risk groups, including those with inherited risk factors.²³

Female breast cancer: promoting early detection, primarily through mammography screening of 50–69 year olds, but also through screening other women over 40 years of age; encouraging medical (physical) examinations and breast self-awareness as precautionary measures; advising medical surveillance of those with inherited risk factors; and promoting healthy diets rich in vegetables and fruit, weight control and avoidance of excess alcohol intake.²⁸

Prostate cancer: promoting healthy diets (as a precaution and for broader health reasons) and seeking early results of field trials of PSA testing, in order to better reconcile potential benefits and side effects.²⁹

Skin cancers (melanoma and non-melanoma): promoting protection against excess sun exposure; and advising on prompt medical checks when lesions show early signs of possible malignancy.¹⁷

Cervical cancer: promoting Pap-smear screening of all women with a history of sexual intercourse and assessing results of trials of Human Papilloma Virus vaccination.²⁸

Non-Hodgkin's lymphoma: undertaking research into possible causes, including: exposures to various viral infections; chemotherapies; medications for suppressing immunological rejection of organ transplants; radiation; solvents; pesticides; herbicides; and water-born nitrates.⁴⁷

Cancer is an increasing public health problem. An ageing population and increasing rates of cancer pose a challenge for our health system and our community. We need to plan for the future to reduce the personal, social and economic impacts of cancer. A comprehensive and coordinated approach to cancer prevention and early detection within a population health framework is required to reduce the overall impact of cancer. Preventing cancer means that the pain, inconvenience and distress of cancer are avoided, not only for the people with the disease, but also for their families and friends. Our health system also benefits; resources and time can be allocated elsewhere as the burden of treating the disease reduces.



Recommendations

1. Establish a Cancer Prevention and Early Detection Operations Group. This group would operate as a sub-committee of the Statewide Cancer Control Advisory Group. This group would have within its remit to:
 - Advocate for the importance of cancer prevention within a cancer control framework, and for increased investment in cancer prevention in a population health context.
 - Advocate for evidence-based policies and programs in cancer prevention and for investment to generate evidence where it does not yet exist.
 - Bring together key experts in cancer prevention in South Australia with a view to developing an organised approach to improving cancer prevention outcomes across the State.
 - Promote coordination between state government, local government, non-government organisations and community agencies involved in cancer prevention.
 - Develop a whole of government approach to cancer prevention.
 - Promote the participation of agencies outside of health in cancer control, including, Education, Transport, Recreation and Sport, the Environmental Protection Agency, Treasury, Primary Industries, Employers and Employee associations.
 - Link actively with national programs.
 - Encourage long-term financial commitment by government and non-government organisations to increase evidence-based strategies that result in significant reduction in the incidence of cancer.
 - Collaborate with the National Cancer Strategies Group and Cancer Australia to establish priorities in Cancer Control.
 - Facilitate interface between clinical aspects of cancer prevention and community programs; specifically develop a strategy aimed at coordinating management of high-risk groups.
2. Implement legislative, public policy and structural initiatives for cancer prevention, including:
 - Implementation of legislative, public policy and structural strategies listed within National and State Plans and Frameworks.
 - Expansion of smoke-free public places and workplace legislation.
 - Financial incentives to promote cancer risk reduction (e.g. price of tobacco, sun protection, vegetables and fruit and formal physical activity programs).
 - Policies in schools and pre-schools to promote healthy eating choices, participation in physical activity and sun protection.
 - Programs and policies for workplaces that impact on cancer risk (e.g. reduction of exposure to carcinogens, sun protection and healthy eating).
 - Policies for shade provision and safe environments for physical activity in public places.
 - Advertising regulations on tobacco products and investigation of restrictions on food marketing to children.
 - Creation of environments that make healthy choices easy choices and support individual decision-making.
 - Improve access to intensive surveillance programs for high risk individuals.
3. Provide evidence-based information about the environmental, behavioural and familial risks of cancer, cancer prevention and early detection. Provide tailored information to people with special needs and diverse groups.

Recommendations 1-3 provide the immediate focus for broad statewide cancer prevention outcomes. The following points focus on the progress of specific successful cancer prevention initiatives or established programs.



Recommendations (continued)

4. Develop state and support national social marketing campaigns promoting and motivating cancer risk reduction behaviours (e.g. National SunSmart Campaign, Fruit and Vegetable Campaign, Quit campaigns, Physical Activity Campaign). Ensure that integrated health promotion programs support these campaigns.
5. Support (or establish where not in place) national approaches to assist primary health care providers to offer high quality, appropriate assessment of risk, assistance in behavioural change for risk reduction and detection of cancer (e.g. SNAP (Smoking, Nutrition Alcohol and Physical Activity program) and lifestyle scripts).
6. Maintain and expand efforts to prevent the uptake of smoking and assist people to quit by comprehensive implementation of the second *South Australian Tobacco Control Strategy* and in line with the second *National Tobacco Control Strategy*.
7. Maintain and expand efforts related to reducing exposure to ultraviolet radiation in order to prevent skin cancer by comprehensive implementation of The Cancer Council South Australia *Cancer Prevention Plan*, and in line with The Cancer Council Australia *National Cancer Prevention Policy*.
8. Support the development, dissemination and uptake of national consumer guidelines on skin cancer detection targeting older Australians.
9. Increase investment in strategies to promote healthy eating, physical activity and healthy weight including comprehensive implementation of state strategies, '*be active*', *Physical Activity Strategy for SA*, *The Eat Well South Australia Fruit and Vegetable Action Plan*, *the Promoting Healthy Weight Action Plan* and in line with The Cancer Council Australia's *National Cancer Prevention Policy*.
10. Implement strategies to reduce alcohol consumption in line with the Cancer Council Australia *National Cancer Prevention Policy*.
11. Increase investment to increase participation in breast screening to achieve after 5 years, a 70% participation rate in BreastScreen SA by women in the target group (50–69 years) and access on request to the program for women aged 40–49 years and 70 years or more. Re-screen all women in the program at two-yearly intervals, in keeping with best evidence.
12. Improve participation in cervical screening, in particular in women in under-screened populations e.g. Aboriginal and Torres Strait Islander women. Advocate for policy and program development in line with emerging evidence, cultural sensitivity and in keeping with best practice e.g. investigation of new technologies.
13. Advocate for and support the implementation of an effective and efficient screening or early detection program for bowel cancer in Australia. People at high risk for colorectal cancer should be able to access colonoscopic screening and genetic testing, where appropriate.
14. Continue to monitor research outcomes on efficacy of population screening for prostate cancer mortality reduction. In recognition of strong public interest in prostate cancer testing and the associated demand on GPs, develop expert clinical information and community education programs.
15. Support the Familial Cancer Service of South Australia, in recognition that at least 5% of all cancers have an inherited origin.
16. Strengthen the collection and publication of cancer data:
 - Strengthen the collection of cancer data in South Australia through population and hospital based registry collections.
 - Strengthen the collection of population monitoring data on risk factors for cancer including individual behaviour.
 - Underpin cancer prevention activities with resources for quality monitoring and evaluation.
 - Support research to promote development of evidence-based strategies to reduce risk.

Optimising Cancer Care

Summary

South Australians with cancer receive high quality cancer care, which is reflected in survival rates comparable with those in other parts of Australia and in the best treatment centres overseas. However, there are still opportunities to enhance service delivery in South Australia and, in particular, to improve service accessibility, coordination and integration with primary health care.

There are also opportunities to upgrade cancer care in South Australia by focussing more closely on meeting the needs of people with cancer, their families and carers and by ensuring that services are people-centred.

The Statewide Cancer Control Plan goals for effective cancer diagnosis, improving treatment and extending psychosocial care are that:

- Cancer care is people-centred and meets the needs of people with cancer, their carers and families.
- Cancer, or its precursors are detected as early as possible, and that people with cancer receive appropriate diagnostic tests and timely referral to appropriate specialist cancer care.
- Accessible and timely care is provided to people with cancer, their carers and families.
- Cancer care is multidisciplinary, fully integrated and coordinated.
- Clinical practice and psychosocial care in cancer are based on best practice and with a research base that informs future care.
- Cancer services include monitoring of safety, effectiveness, efficiency, satisfaction, accessibility and equity of outcomes.

Cancer incidence in South Australia is high by international standards, equating in broad terms with North American and New Zealand rates, and slightly exceeding incidence rates for the United Kingdom and Ireland and most other Northern European populations.⁴⁸ Lower cancer death rates are seen in Australia than in Europe and most other comparable countries.^{49,50,48} Australians have good outcomes of cancer care by world standards.

About 50% of people with cancer survive their cancer for 20 years or more. Furthermore this proportion of long-term survivors is increasing.^{51,52} This surpasses cancer survival in most populations.

Because of improved treatment outcomes and survival, cancer can be regarded as both an acute and chronic disease. Cancer Registry data show that among residents aged 70 years or more, about one in 14 are living with a history of cancer

diagnosed within the past 5 years.⁵³ Many of these people would still be in active phases of treatment, whereas others would be experiencing active follow-up surveillance to assess treatment outcomes. Managing cancer in its acute phase and as a chronic disease is a challenge for our health system.

Although great progress has already been made, there are many opportunities to advance cancer care by developing coordination of care, improving equity of access to cancer care and providing greater levels of psychosocial support.^{2,3}

The cancer experience

Most Australians are affected directly or indirectly by cancer at some stage of their lives.² For every person, the experience of cancer is unique, and their diagnosis and treatment will be different. For many, the experience is complex and difficult. While the outcomes for people with cancer can vary markedly, all people should be provided with continuous and seamless care by an integrated service.

People with cancer should be able to 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 should be experienced as phases of care rather than movement from one separate service to another. People with cancer should experience the provision of surgery, radiation oncology, medical oncology services, primary health care and supportive care as integrated components of one organised service.

There should be equity of access to all cancer services for all South Australians. Particular barriers such as those associated with age, ethnicity, geographical location and socio-economic status should be addressed. Services should meet standards for cultural safety and respect.

Ensuring cancer care is people-centred and meets the needs of people with cancer, their carers and family

There is opportunity to focus more closely on meeting needs of people with cancer, their families and carers and by ensuring that services, which deliver cancer care, are people-centred.^{2,54}

People with cancer express a desire to understand their care and treatment options.^{2,54} Information for people with cancer and their carers needs to be available in a range of languages and formats with quality systems to monitor comprehension and understanding. The resources needed and time commitment associated with supporting people to participate in decision-making also need to be recognised. People with cancer also want clear information about their treatment plans.⁵⁴ Cancer treatment or care plans need to be understandable, individualised and regularly reviewed.

Care coordinators have been identified as a strategy to enhance the co-ordination of care and assist people with cancer to move between treatment settings.^{2,54} Care coordinators will be familiar with that person's particular

circumstances. While currently, the delivery of cancer care is managed by the Oncologist, Physician or another relevant specialist, the position of cancer care coordinator may be fulfilled by a general practitioner, a specialist cancer nurse or another member of the cancer care team.

Addressing the psychosocial needs of people with cancer, their families and carers, is an integral component of cancer care,³ and an area of unmet need.

There is a particular need to improve mechanisms to address cancer diagnosis and cancer care delivery for Aboriginal and Torres Strait Islander people. This will include addressing barriers that impair access to primary health care, diagnostic services, treatment services and psychosocial support services and implementing structures to ensure that cancer services are culturally appropriate and culturally safe.

The following principles should be applied to ensure cancer care meets the needs of people with cancer, their families and carers:

- Cancer services should be oriented to the needs of the people with cancer, their families and carers.
- Carers and family are recognised and the participation of carers is supported across the entire cancer journey.
- Care should include the range of support services that facilitates and encourages involvement of people with cancer, their families and carers in decision-making and care planning.
- Information for people with cancer and their carers needs to be presented in plain language, and in languages other than English.
- Information for people with cancer and their carers should address the special needs of people from culturally and linguistically diverse backgrounds, Aboriginal and Torres Strait Islander people, and others with special needs including people with mental health needs and under-privileged groups. This information should be presented in a way that is appropriate and culturally sensitive.
- All people with cancer should have an agreed verbal or written care plan. Where this is a written plan, it should be in plain language.
- People with cancer should have an identified coordinator of care. This care coordinator may be cancer nurse, general practitioner or another member of the care team.

- It is recognised that many people with cancer use complementary and alternative therapies (see page 40). People with cancer should be encouraged to inform their professional carers if they are using these therapies.

Detecting cancer early, diagnosis and referral

For many cancers, early diagnosis, through early recognition of cancer symptoms, appropriate and timely investigation, and an efficient referral process for accessing specialised care, will improve the experience and optimise outcomes for people with cancer.⁵⁴ Barriers to early diagnosis of symptomatic cancers include lack of recognition of symptoms and signs of cancer and delays in access to primary health care. Problems with access to appropriate diagnostic services and unclear or inefficient pathways for referral to specialist cancer services may also impede timely diagnosis of cancer.^{2,54}

The following principles should be applied to ensure cancer, or its precursors, are detected as early as possible, and that people with cancer receive appropriate diagnostic tests and timely referral to appropriate specialist cancer care:

- Access to GPs, primary health care services, diagnostic services and specialist cancer services should be equitable for all South Australians, including those from rural and remote locations, Aboriginal and Torres Strait Islander people and those from culturally and linguistically diverse backgrounds.
- People in the community should have access to information and education to facilitate improved recognition of significant cancer related symptoms.
- GPs should have access to information and education to facilitate improved recognition of significant cancer related symptoms.
- Clinical guidelines related to appropriate investigation and diagnosis of significant cancer related symptoms for frequently encountered cancers should be utilised and developed where they do not exist.
- Acceptable timelines and appropriate standards should exist for diagnosis and referral for frequently encountered cancers and compliance with these standards should be monitored.
- GPs and other medical specialists and people in the community should have ready access to information about the most appropriate specialist cancer services that are available for a particular cancer diagnosis.

- GPs and people in the community need to be aware of familial factors that place a person at substantially increased risk of developing cancer and of the benefits of targeted surveillance.

Accessibility and timeliness of cancer care

The care of people with cancer depends on the type and extent of cancer at diagnosis. The preferences of the person with cancer will also be a factor in determining cancer treatment. Treatment may consist of surgery, radiotherapy, chemotherapy or a combination of these. Other disciplines involved in cancer treatment will include pathology, nursing, pharmacy, psychological therapy, physiotherapy, occupational therapy and psychosocial and palliative care. General Practitioners and other primary health care providers have a role in care throughout the cancer care continuum. Cancer care is provided in a range of settings including home, the community, hospitals, residential aged care facilities, or palliative care units.

People require care during active phases of their disease, such as at diagnosis and episodes of recurrence, as well as between episodes of active treatment. For the person with cancer, most of their time will not be spent in acute treatment settings, but rather in the community. It is important to recognise the role of the community setting, and primary health care in ensuring quality cancer care and cancer outcomes for people with cancer.

People with cancer need frequent and easy access to their family and locally based support networks. These factors are integral to reducing the negative impacts of the disease and it is essential that cancer care service providers be cognisant of this when planning these services for a community. Geographical isolation is recognised as an access issue and subsequent disincentive to the optimal management of health. There should exist a balance between providing care close to home and achieving quality patient outcomes. Collaboration between metropolitan and country services should be enhanced to benefit people with cancer in rural and remote settings.

People with cancer experience a range of physical, practical, psychological and emotional challenges. Similarly, partners who may play an integral part in the care, experience levels of stress reported to be comparable to, or higher than, that of the person with cancer. Families are also vulnerable to cancer-related distress.³ Psychosocial care must recognise the individual needs of people with cancer, their carers and families, and may include spiritual care, community support services, financial assistance,

cancer support programs, relationship and sexual counselling and grief, loss and bereavement counselling.

Palliative care is “care provided for people of all ages who have a progressive life limiting illness with little or no prospect of cure, and for whom the primary treatment goal is quality of life”.⁴ This is non-curative therapy but defined in terms of comfort, survival or avoiding predictable problems for a person with cancer. This can include chemotherapy and radiotherapy. Adequate care during the end of life period is based upon the provision of psychosocial care and the development of effective relationships with health professionals as early as possible. Primary health care providers may provide this care for some people with cancer, 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. Barriers may include health professionals’ reluctance to broach the issue of palliative care early in the cancer journey and/or people with cancers’ varying interest in exploring it.

Children with previously life-limiting cancers now frequently survive through to adolescence and into adulthood because of advances in clinical care. The increasing number of older adolescents referred to children’s hospitals has important implications for paediatric, and, in turn, adult health services in terms of the specialist services required, the way in which developmentally appropriate care is delivered, and the design of physical environments. The transition from paediatric to adult services needs to be carefully coordinated particularly as there is an increasing body of evidence suggesting that better outcomes for some young people with some cancers can be achieved using paediatric treatment protocols.

Particular access issues that have been identified include: access to care for people in rural and remote South Australia; access to care for Aboriginal and Torres Strait Islander people; cancer care services for adolescents and young adults (aged 15–25 years); services for cancer survivors; access to radiation oncology services, notably waiting lists and public services in the South and outer North of Adelaide; access to cancer drugs, including delivery of drugs outside of metropolitan Adelaide; lack of appropriate accommodation for people whose palliative care needs may extend over a longer period of time but whose care requirements exceed the capacity of residential care facilities.

In order to ensure equity of access and timeliness of cancer care, the following principles can be applied:

- People with cancer should have appropriate and timely access to high quality of care, irrespective of where they live. Metropolitan and rural and remote service planning will ensure coordination of cancer care across the continuum of care.
- Accessible, effective and culturally safe systems of care should be available for groups within the community which may have differing needs, e.g. Aboriginal and Torres Strait Islander people and people from culturally and linguistically diverse backgrounds.

Multidisciplinary, fully integrated and coordinated cancer care

Integrated and coordinated cancer care

Integrated and coordinated cancer care should extend across the full continuum of care, including prevention, risk assessment and management for at-risk relatives, early detection, staging evaluation, initial and subsequent treatment, psychosocial therapies, long-term follow-up, rehabilitation, palliative care and bereavement services.

Well-integrated and coordinated cancer services will improve continuity of care for people with cancer.⁵⁴ Integrated services rely on effective communication and coordination between the various disciplines involved in cancer treatment and effective links between all groups involved in care, including services in the private and public sectors, and in community settings. A well coordinated model will include clear pathways for care, so that the person with cancer, their professional and non-professional carers will be able to identify appropriate pathways in their care.

People with cancer have identified gaps in the co-ordination of cancer services, which include delays in treatment, lack of appropriate follow-up and seeing different doctors at each visit.² Also noted is a gap in the transition from childhood to adult cancer services.

Care of cancer survivors is an essential part of cancer care, and there is a need for long-term follow-up services. Some people with cancer will require specialist long-term care, whilst for other people care may also be provided in a primary health care setting. The need to provide services for long-term follow-up and care of adult survivors of childhood cancer is also recognised.

There is a need for a well-articulated cancer care service delivery model to ensure coordination and integration of care across the spectrum of cancer care; for people in active and in more chronic

phases of the disease; for people in all treatment and care settings; and for people from all sectors of the South Australian community. Such a model is proposed (see page 38). The proposed Statewide Integrated Cancer Care Service is based on the current configuration of services and focuses on defining how existing services could inter-relate, as a first step. A next step would be evolving towards an 'ideal' model that is more closely aligned with population needs and in delivering services closer to the community. The financial cost of developing and implementing this model will need to be established.

Multidisciplinary care

Multidisciplinary care refers to a team approach to cancer care, whereby a team including specialists with all of the relevant expertise considers the treatment options. The team develops the treatment plan together, rather than sequential input by individual specialists.⁵⁴ Members of the multidisciplinary team may include surgical oncology disciplines, radiation oncology, medical oncology, palliative care, pathology and imaging, general practitioners, oncology nurses, psychologists, dietitians and other allied health professionals. Multidisciplinary care is widely advocated and can improve outcomes in cancer.

There is insufficient information about the location and extent of multidisciplinary services in South Australia and about how people access these services. However, barriers to widespread delivery of multidisciplinary care have been reported in cancer care delivery in the private sector and for people living in rural areas, notably the inadequacy of the Medicare Benefits Schedule. In addition, in the private sectors there is little or no recompense for psychological and other allied health services. A need has been identified for education and advocacy to expand the availability of multidisciplinary care.

In order to ensure cancer care is multidisciplinary, fully integrated and coordinated, the following principles can be applied:

- All people with cancer should have access to a multidisciplinary team of providers and cancer care delivery should be planned and coordinated with input from this multidisciplinary team.
- Effective and timely communication should occur between the person with cancer, the specialist oncology team, the general practitioner and community based health care professionals involved in that person's care.
- Cancer survivors should be able to access comprehensive rehabilitation, including physical reconstruction, and long-term follow up.

Evidence and research in clinical practice and psychosocial care

The strongest evidence available, and systematic reviews of evidence, are used to define best practice and the evidence-base to support it. Clinical practice guidelines are a means of translating this evidence-base into cancer care. Utilisation of clinical guidelines can improve outcomes for people with cancer and will also promote uniformity of care across different treatment settings.⁵⁴ Evidence-based clinical guidelines have been developed for many cancers but it is critical that such guidelines are disseminated and implemented in order to have an impact on cancer care.

Clinical trials are integral to the delivery of cancer clinical services. Involvement in clinical trials brings benefits in care and outcomes for people with cancer and contributes to and strengthens new knowledge about cancer treatment options.² It is estimated that between 2–3% of adults with cancer participate in clinical trials throughout Australia, although 20–30% may be eligible.⁵⁴ It is difficult to establish the participation rates in South Australia.

Facilitating greater involvement of people with cancer in clinical trials is an important part of enhancing clinical cancer services. Participation in national and international trials has benefits for the cancer care of South Australians. Attracting clinical trials to South Australia, enhancing non-industry sources of funding for clinical trials, ensuring adequate infrastructure to support clinical trials and fostering an academic environment have all been identified as factors which will optimise involvement in clinical trials. Collaboration between treatment centres is also important. The Adelaide Cancer Trials and Education Collaborative (ACTEC) currently provides a vehicle for networking and communication about clinical trials across institutions in Adelaide.

Research into other areas of cancer care, particularly psychosocial and health service research will also improve quality of care.²

Providing infrastructure to support research into cancer service delivery and participation in research within cancer service settings is an essential investment in the future of care.

In order to ensure clinical practice and psychosocial care in cancer are based on best practice and with a research base that informs future care, the following principles can be applied:

- Diagnosis, investigation and management of cancer should be based on the best available evidence, including cancer treatment guidelines.

- Utilisation of clinical guidelines should be maximised through promotion of guidelines, addressing barriers to their implementation, developing guidelines in areas where they do not currently exist, and monitoring their implementation.
- People with cancer should have access to verbal and written information about the guidelines and/or protocols relevant to their care.
- People with cancer, their families and carers should have clear and accessible information about appropriate clinical trials.
- Participation in clinical trials should be increased through improved awareness of clinical trials by people with cancer as well as members of the professional team delivering cancer care, by maximising equity of access and consideration of infrastructure required to support clinical trials, such as Clinical Trials Registers.
- The importance of research, including clinical trials, in delivering services must be acknowledged and adequate funding provided to support this.

Monitoring of safety, effectiveness, efficiency, satisfaction, accessibility and equity outcomes

People with cancer should receive appropriate and acceptable care, which is transparent and accountable. Decision-makers, clinicians, people with cancer and the general community also need access to information about the quality of cancer care in South Australia. This includes the credentials of their service providers, and the extent to which the service facility is accredited, meets standards and agreed national benchmarks and implements quality improvement programs.⁴ Clear pathways should also exist so that people with cancer can provide feedback about their care.

The National Service Improvement Framework for Cancer advocates accreditation for cancer services and credentialing of practitioners.⁴ Models currently exist in the areas of radiation oncology and breast cancer surgery. A system of voluntary accreditation of cancer services across Australia is also recommended in *Optimising Cancer Care in Australia*.²

Monitoring the quality of cancer services is a critical component of cancer care. Quality indicators evolve over time, will be context specific and need to be reviewed regularly. Adequate monitoring of quality indicators will require information resources. The

Cancer Registry and hospital-based registries have a critical role in collecting and maintaining data that is essential for the monitoring and evaluation of cancer and cancer control services in South Australia.

In order to ensure cancer services include monitoring of safety, effectiveness, efficiency, satisfaction, accessibility and equity of outcomes, the following principles can be applied:

- There should be monitoring of outcomes of all services.
- Indicators of quality should exist and be monitored and reviewed regularly.
- There should be a process of continuous improvement within services providing cancer care.
- There should be a transparency and a clear path of accountability for all services provided.

Proposed Statewide Integrated Cancer Care Service

The proposed clinical service model describes a Statewide Integrated Cancer Care Service that will provide accessible, quality, patient centred, coordinated, and multidisciplinary cancer services for all South Australians.

The goal of the clinical service delivery model is to optimise the experience and cancer outcomes for people with cancer, their families and carers by maximising co-ordination and integration of cancer services.

The principles underpinning the Statewide Integrated Cancer Care Service include:

1. The type of treatment setting accessed by the person with cancer will be determined by a range of factors including the type and stage of cancer, the type of treatment and the preferences of the person with cancer.
2. Different levels of treatment and expertise will be provided in different treatment settings. Regional Health Services and local cancer care services will be accountable for the types and levels of services provided and the population for whom those services are responsible.
3. There will be very clear links between all treatment settings and well-defined corridors for communication.
4. All services, public and private, will be encouraged to operate within the multidisciplinary, coordinated model.

The structure will be influenced by:

- The relatively small size of the South Australian population.
- The need to maximise the efficiency of the current service structure rather than redesign the entire service structure.
- The value of having a small number of centres of excellence in cancer care, rather than multiple smaller volume centres where quality outcomes are less likely to be achieved.
- The need to meet national standards regarding activity and quality targets required to achieve best practice.
- Recognition of the level of quality outcomes already being achieved by the current construct of services and service providers.

The *Statewide Integrated Cancer Care Service* will function as a coordinated service, delivering quality cancer care for the whole of South Australia. The Statewide Integrated Cancer Care Service will comprise *Comprehensive Cancer Centres* and *Cancer Services*. A Comprehensive Cancer Centre will be based in a major metropolitan hospital and develop collaborative links with affiliated Cancer Services which will comprise smaller metropolitan and country hospitals, primary health care services and associated health services. The levels of care provided within the Cancer Services will vary, with larger services providing some of the more complex cancer treatment modalities.

Highly specialised services

Given South Australia's population size and regional health profile, some highly specialised services would not be duplicated across Regional Health Services and may only be provided at certain sites (e.g. major metropolitan hospitals) which would provide for the whole of South Australia. This would include highly specialised services, services for the management of rarer cancers and services where there are small numbers of specialists. Largely, this formalises what already exists, but this may require rationalisation of existing services to concentrate high-level expertise and specialised facilities as effectively and efficiently as possible. Such specialised services may include the following:

- gynaecology oncology
- allogeneic bone marrow transplantation services
- radiation oncology: such as brachytherapy services

- paediatric oncology
- some diagnostic services (e.g. Positron Emission Tomography (PET) and Computerised Tomography (CT)).

Comprehensive Cancer Centres

Comprehensive Cancer Centres will provide highly specialised, complex and sophisticated levels of medical care. Comprehensive Cancer Centres will provide, or ensure access to, the range of specialised surgical, radiation and medical oncology services, plus imaging and pathology. Given the need for some of the highly-specialised services to be managed as statewide services provided in a single site, the Comprehensive Cancer Centres will need to work collaboratively and develop formal links to facilitate access to these services for all South Australians.

Cancer Services

The level and type of cancer care provided in the Cancer Services will vary. The range of care available will vary from core services, such as limited chemotherapy, to progressively more sophisticated care including major surgery, experimental drug treatments and total parenteral nutrition. Cancer Services providing lower levels of care will link to other Cancer Services providing higher levels of cancer care to ensure people with cancer, first accessing cancer care at these points have access to the full continuum of cancer care.

Operational guidelines for the Statewide Integrated Cancer Care Service

The responsibility for operational management of cancer service delivery will occur predominantly at a Health Service (regional) level, as well as in private tertiary institutions, private practice and other settings. The model is based on the following operational guidelines:

- Formal links will be created between Comprehensive Cancer Services and their affiliated Cancer Services, respecting current linkages but working toward developing more structured relationships between services providing cancer care.
- Where a Comprehensive Cancer Service does not provide a specific specialist service, it will develop links with the Comprehensive Cancer Service that does.
- Existing hospitals and cancer services will have their role within the model clearly identified to ensure they know what services they are

- accountable for providing and where their 'up-links' are for referral purposes. The linking corridors between services need to be clearly defined and constructed.
- In country areas, existing Cancer Services may initially retain existing links with one or more Comprehensive Cancer Services. However, specified relationships and arrangements between geographically proximate services will be encouraged to enable defined referral pathways to be developed and promote more effective local coordination of care for people with cancer.
 - Regardless of the point of entry into the cancer care system and the level of the Cancer Service in which they receive treatment, all people with cancer and their carers will be provided with information and have access, either on site or by referral, to rehabilitation, psychosocial support and palliative care services.

Figure 9: Statewide Integrated Cancer Care Service delivery model

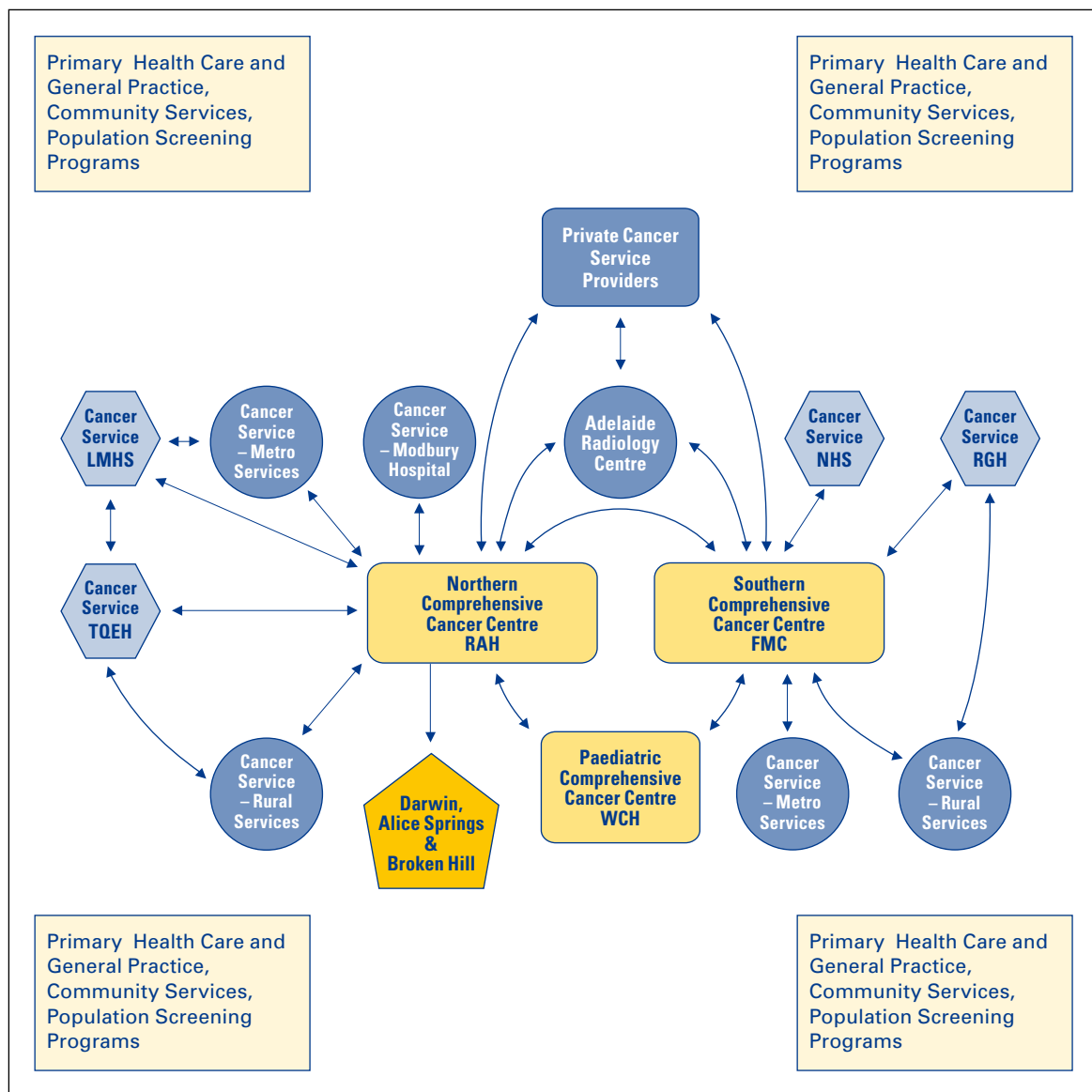


Figure 9: Statewide Integrated Cancer Care Service delivery model (continued)

	Nature of services	Location of service and links
Super Specialty Services	Gynaecology oncology	Single site based at Royal Adelaide Hospital (RAH) with outreach at Flinders Medical Centre (FMC).
	Allogeneic bone marrow transplantation services	Single site based at RAH
	Radiation oncology: brachytherapy services	- Limited number of providers - Single public service and single private service - Each provider may have multiple facilities - All brachytherapy services based at RAH
	Paediatric oncology	Single site based at WCH
	Some diagnostic services (e.g. PET-CT)	RAH
Comprehensive Cancer Centres	- High level, tertiary, highly specialised care across the range of treatment modalities. - Core services plus specialties/plus or minus some super specialties. - Provide, either onsite or by referral, to full range of specialised surgical, radiation and medical oncology services, plus imaging and pathology. - Not all super specialty services available at all sites.	There will be 3 publicly managed Comprehensive Cancer Centres (CCC): - Northern CCC; based at Royal Adelaide Hospital - Southern CCC; based at Flinders Medical Centre - Paediatric CCC; based at Women's and Children's Hospital
Cancer Service	Mid level services - Cancer Services will be affiliated with Comprehensive Cancer Centres. - Generally be a major health care centre. - Provide more sophisticated levels of care. - Core plus some specialties e.g. surgery, chemotherapy. - May act as an affiliate for lower level cancer services.	Cancer Services affiliated with <i>Northern CCC</i>: - The Queen Elizabeth Hospital - Lyell McEwin Health Service - Modbury Hospital - Larger health units in Eyre, Northern and Far Western, Wakefield and Riverland country regions e.g. Whyalla Hospital Cancer Services affiliated with <i>Southern CCC</i>: - Noarlunga Health Service (NHS) - Repatriation General Hospital (RGH) - Larger health units in country regions HMS, South East, e.g. Mt Gambier Country based Cancer Services may also have links with <i>Paediatric CCC</i>. Private Cancer Services: - Private cancer service providers - Adelaide Radiation Centre (ARC)
Cancer Service	Low level services - Cancer Services will be affiliated with Comprehensive Cancer Centres. - Low level services may also be affiliated with Mid level Cancer Services to ensure access across the continuum of cancer care. - Provide core cancer care only (e.g. limited or pre determined chemotherapy). A nurse with training in the administration of chemotherapeutic agents would be on site. - May be a primary care service (e.g. screening service, primary health care centre). - No surgical or radiation oncology services available.	Cancer Services aligned with <i>Northern CCC</i>: - St Margaret's Hospital - Gawler - Smaller health units in Eyre, Northern and Far Western, Wakefield and Riverland country regions e.g. Ceduna Cancer Services aligned with <i>Southern CCC</i>: - Smaller health units in HMS, South East Country based Cancer Services may also have links with <i>Paediatric CCC</i>. Private Cancer Services: - Private cancer service providers - Adelaide Radiation Centre (ARC)
	Population Screening Programs, Primary Health Care, General Practice and Community Services	Links with all levels of Cancer Services

Conventional, complementary and alternative therapies

Types of therapies

Complementary therapies are used together with evidence-based conventional treatments. They do not cure cancer but may help to relieve symptoms or side-effects and improve well-being. Examples include acupuncture, aromatherapy, art therapy, massage therapy, meditation, visualisation and yoga.⁵⁵

Conventional therapies are evidence-based treatments that have been tested following a strict set of scientific guidelines and shown to be safe and effective at curing cancer, slowing its growth or providing relief from symptoms. The main conventional therapies are surgery, radiotherapy, chemotherapy and immunotherapy. Conventional therapies are sometimes referred to as mainstream, medical or orthodox treatments.

By definition, *alternative therapies* are used *instead* of conventional therapies to treat cancer. Most of these have not been scientifically tested or have little evidence supporting their safety and effectiveness. Examples include shark cartilage, special diets and herbal treatments.⁵⁵ Alternative therapies are sometimes called unproven or 'disproven' treatments.

Community use of non-conventional therapies

The vast majority of research exploring the use of complementary and alternative medicines by cancer patients has been conducted in the United States, and there is little information about their use among Australian people with cancer. An important shortcoming of the literature is that most studies fail to distinguish between "complementary" and "alternative" medicines, despite the important distinctions noted here.

A systematic review of the literature suggests that between 7 and 64% of adult cancer patients use some form of non-conventional treatment.⁵⁶ The complementary and alternative medicines most commonly used are special diets or food supplements and mind-body techniques such as meditation and relaxation. Studies generally indicate that cancer patients who use complementary and alternative medicines tend to be younger, female, better-educated and those with more advanced disease.^{57,58,56,59}

In the largest Australian study published to date, 22% of 319 cancer patients reported using non-conventional therapies, with meditation/relaxation, diet and megavitamins the most prevalent.

Furthermore, three quarters of patients reported using more than one non-conventional therapy.⁵⁷

A more recent study found that 52% of 156 cancer patients at one Australian hospital reported using at least one non-conventional therapy since their cancer diagnosis and more than one quarter used three or more. Meditation/relaxation, change in diet and multivitamins were the most commonly used therapies.⁵⁹

Supporting evidence-based medicine

The only difference between therapies that are supported by conventional practitioners and those that are not is evidence. Acquiring the level of evidence needed to show efficacy is time-consuming and resource-intensive, and should be done on the basis of demonstrated interest and clear guidelines.

Given the high level of community interest, it has been recommended that the National Health and Medical Research Council fund well-designed scientific studies examining the safety and effectiveness of promising and commonly used complementary and alternative cancer medicines.⁶⁰ This could enable people with cancer and healthcare providers to differentiate between treatments that are dangerous and those that may be helpful.

Conventional practitioners should nonetheless welcome open discussion about non-conventional therapies. People with cancer should be encouraged discuss their use of non-conventional therapies with their professional carers.



Recommendations

1. Establish a Cancer Care Operations Group. This Group would provide government as well as the non-government and community sectors with standards and priorities for enhancing cancer control, including clinical cancer services in South Australia. Its role will also include the development of cancer care guidelines, standards and outcome measures. This group would operate as a sub-committee of the Statewide Cancer Control Advisory Group.

Ensuring cancer care is people-centred and meets the needs of people with cancer, their carers and family

2. Implement structures to ensure that all people with a diagnosis of cancer have a well-defined and understood care plan that is used and regularly updated.
3. Implement structures to ensure that people with cancer, family members and carers should have access to accurate, relevant and timely information on cancer, prognosis, treatment options, likely treatment side effects and availability of allied services.
4. Ensure that Aboriginal and Torres Strait Islander people and people from culturally and linguistically diverse backgrounds have timely and consistent access to trained interpreters when appropriate.
5. Implement structures to ensure that cancer services are culturally appropriate.
6. Develop and implement care coordination service delivery models to ensure that all people with cancer have appropriate coordination of care.
7. Implement structures to ensure that psychosocial support is integrated with routine care.

Detecting cancer early, diagnosis and referral

8. Expand education programs to inform the community about signs and significant symptoms which could be related to cancer.
9. Develop a directory of specialist cancer services in South Australia, which is readily available to people in the community and health practitioners.

10. Develop and disseminate guidelines on most appropriate referral pathways for all referrers, including GPs and other primary health care providers.
11. Develop (where they do not already exist) and implement evidence-based guidelines regarding the investigation and diagnosis of symptoms and signs related to major cancers.
12. Expand access to affordable transport and accommodation for rural based people with cancer and their accompanying carers in order to facilitate access to diagnostic services.
13. Increase the capacity of services to identify and manage people at increased genetic risk of cancer.

Accessibility and timeliness of cancer care

14. Implement proposed model of service delivery (see page 38).
15. Implement NHMRC *Clinical Practice Guidelines for the Psychosocial Care of Adults with Cancer* across South Australia.³
16. Implement *Standards for Providing Quality Palliative Care for all Australians*, developed by Palliative Care Australia.⁴
17. Develop and implement programs to improve access to appropriate treatments for all people with cancer. This includes addressing specific practical support mechanisms such as child-care, transport, and accommodation for people from country areas.
18. Establish a program to ensure South Australia meets the national standard for delivery of radiation oncology. This will include implementing the *SA Plan for Radiation Oncology Services 2005–2010*. A component of this will be to develop a plan for radiation oncology services that addresses the lack of services in outer northern Adelaide and the lack of publicly funded services in Southern Adelaide.
19. Metropolitan and rural and remote health services should explore options for access and delivery of chemotherapy services in country areas, and implement guidelines where they exist.



Recommendations (continued)

20. Explore and implement the best model for delivering care to adolescents and young adults (age 15–25 years) with cancer. This will include establishing an appropriate infrastructure to support the transition of young people with cancer, or the consequences of childhood cancer, from paediatric to adult services.

Multidisciplinary, fully integrated and coordinated cancer care

21. Implement the Statewide Integrated Clinical Cancer Service (see page 38) to ensure equitable access to cancer services in South Australia and to provide coordination between metropolitan hospital-based cancer care services, to rural and remote cancer care services and to emerging primary health care networks.
22. Enable Health Services to lead and coordinate local cancer services with networks between public and private sectors.
23. Develop and implement a strategy to incorporate multidisciplinary care as an essential component of cancer services.
24. Identify and address specific barriers to multidisciplinary care in certain settings, such as in the private sector and in rural settings, for example, the Medicare Benefits Schedule needs to change to facilitate multidisciplinary care in the private sector.
25. Expand the use of technologies such as teleconferencing as a means of improving access to multidisciplinary care.
26. Incorporate the principles of multidisciplinary care in the undergraduate and postgraduate training of all disciplines involved in multidisciplinary care.

Evidence and research in clinical practice and psychosocial care

27. Determine the current level of participation in clinical trials in South Australia including participation of rural people, adolescents and young adults and people treated in the private sector, and increase participation.

28. Provide to people with cancer clear and accessible information to support their ability to make informed decisions about participation in clinical trials.
29. Create or participate in a centralised clinical trials management program that provides information about available clinical trials to clinicians and for people with cancer, and promotes access for people with cancer, where appropriate.
30. Develop and implement a strategy to attract more clinical trials to South Australia.
31. Increase research that supports and improves cancer care, particularly health service research and psychosocial research.

Monitoring of safety, effectiveness, efficiency, satisfaction, accessibility and equity outcomes

32. Ensure that information systems are in place to collect data to monitor and evaluate outcomes.
33. Adopt appropriate quality indicators at all points of the cancer continuum.
34. Undertake statewide monitoring of key outcomes such as patient satisfaction, cancer incidence, staging, mortality and survival.
35. Support the Cancer Registry to provide timely and up-to-date information and the expansion of hospital cancer registries to enable collection of clinical data from all hospitals.
36. Commit to benchmarking of services to monitor compliance with standards and achievement of quality.
37. Support, develop and implement processes for accreditation of services and credentialing of practitioners to ensure that quality outcomes are met and recognised standards are adopted.
38. Develop pathways to incorporate feedback from people with cancer and their carers into quality of care.
39. Implement a process whereby quality measures are made known to people with cancer, primary health care providers and other members of the care team.

Infrastructure Planning for Cancer Control

Summary

Infrastructure refers to the equipment and systems required to support the programs and services for cancer control. In order to achieve the objectives of the Statewide Cancer Control Plan, infrastructure planning is required.

The goals of such planning are that:

- A comprehensive health infrastructure strategy will be implemented in SA, with particular focus on:
 - rural and remote sections of the population
 - delivery of the information required by service providers and administrators
 - addressing other health system needs.
- Infrastructure programs will be implemented for cancer control:
 - prevention services and programs
 - screening services
 - diagnostic services, including early diagnostic resources and programs
 - radiation oncology services
 - medical oncology services
 - haematology
 - surgical oncology services
 - palliative care services
 - support services
 - cancer research.

Effective cancer control requires an infrastructure that supports high quality services and programs. The importance of clear directions for service planning cannot be understated. Infrastructure development will need to complement and facilitate the proposed Statewide Integrated Clinical Cancer Service model.

An Infrastructure Strategy is required to address infrastructure requirements for cancer control in South Australia. The infrastructure strategy should span all aspects of cancer control from prevention to screening, diagnosis, therapy (surgical, medical, radiation and other services), and palliative and end-of-life support. The strategy should place due emphasis on infrastructure planning development and ongoing auditing of infrastructure, its maintenance and replacement, and periodic re-evaluation.

The following provides a framework for considering issues of relevance to priority setting and broader decision-making for infrastructure development for cancer control, with specific goals, operational principles for achieving these

goals, and recommendations. The development of this framework has been informed by the results of a survey of 90 service providers, community representatives and health administrators in South Australia in January 2005, which yielded 270 recommendations for infrastructure development.

Implementing a comprehensive infrastructure strategy for South Australia

Key infrastructure required to achieve the objectives of the Statewide Cancer Control Plan to reduce the impact of cancer in South Australia includes:

- Facilities and equipment for comprehensive cancer education, cancer prevention, population screening.
- Facilities and equipment for comprehensive cancer care including diagnosis, primary health care and specialist health care, palliative and end-of-life care, and psychosocial support.

- Support services, such as service directories, booking systems, transport assistance, accommodation, home nursing, telemedicine and other technologies to facilitate service provision, systems for quality improvement such as accreditation and credentialing, and health insurance.
- A comprehensive cancer information plan that addresses the information needs of the general community, people with cancer, their family members and carers. It must also address the information needs of people delivering cancer prevention programs and cancer care services, as well as researchers working to enhance cancer control. Information must also be available for administrators and decision-makers.
- Information technology support to enable implementation of the cancer plan and associated service and program delivery.
- Research infrastructure for randomised trials and basic, clinical, health-services and population health research, including a structure for appropriate and efficient ethics committee clearance.
- Databases for population-based and clinical cancer registration, bio-specimen data, information on service activity, workforce statistics, finances and human resources.

Cancer facilities are unevenly distributed across South Australia directly impacting on access to services and treatment. Addressing the imbalance requires significant planning and implementation likely to take a number of years.

It is essential that investment is targeted in the right places and delivers optimal outcomes, consistent with service planning priorities for any funds invested. The infrastructure strategy should include targeted priority-driven initiatives to meet identified gaps and special needs, including those of culturally and linguistically diverse groups, Aboriginal and Torres Strait Islander people, and people living in rural and remote areas. The needs of rural and remote Aboriginal and Torres Strait Islander people will need to receive particular attention, due to their poorer cancer outcomes.

As far as possible, specialised services should be available close to the places of residence of rural populations. The proposed Statewide Integrated Cancer Care Service presents a model for better integrated and coordinated service delivery, and provides a structure in which means of increasing service provision through country hospitals and general practitioners can be explored,

with appropriate support from metropolitan-based specialists. Telemedicine and other information technologies should be available for case conferencing and radiotherapy planning for rural patients.

As far as possible, palliative care, end-of-life, and bereavement services for rural populations should be equivalent in scope and quality to corresponding metropolitan services. To facilitate this, training should be provided to country practitioners, nurses and social workers, and country service providers should receive support from metropolitan-based palliative care specialists, using telecommunication and other communication infrastructure.

Transport and accommodation services should be adequate for rural people with cancer who need metropolitan oncology services. Transport links are required between sites of metropolitan accommodation and specialist cancer centres to facilitate service access. The availability of accommodation in the metropolitan area for country patients is limited and needs to be extended.

The infrastructure strategy should cover both public and privately funded services. Accreditation programs should be developed for health services that require compliance with prescribed infrastructure standards.

It is considered that a sub-group of the Statewide Cancer Control Advisory Group should provide oversight to development of the Infrastructure Strategy. The initial strategy with indicative cost implications should be prepared in further consultation with network stakeholders and should be facilitated by appointment of an appropriately qualified consultant. While the strategy will need to be staged across a number of years and will require ongoing review in line with service planning developments, Stage 1 addressing immediate priorities should be developed for consideration in the 2006/07 budget deliberations.

The priorities for infrastructure development and investment include:

- Improved access to appropriate treatment modalities.
- Establishment of radiotherapy facilities to ensure national standards for delivery of radiation oncology are met.
- Access to locally provided chemotherapy services.
- Development of infrastructure to support transition of young people to adult care.
- Expansion of the use of technologies to facilitate multi-disciplinary care.

- Information systems development to collect data and facilitate monitoring and evaluation of outcomes.

Infrastructure for cancer prevention and cancer screening

Infrastructure is also required to support population-based prevention programs and services and resource allocation for prevention should be commensurate with its relative value in cancer control.

As far as possible, all members of the population who are targeted for screening should have access to screening and to follow-up services for investigation and management of screening results. The infrastructure capacity of BreastScreen SA appears to be insufficient to screen the target age range and this gap is increasing due to population growth. Screening coverage is relatively low among Aboriginal and Torres Strait Islander women. The Infrastructure Strategy must ensure that BreastScreen SA, has sufficient infrastructure to meet national accreditation requirements to screen 70% of the target population, including under-represented groups.

It is expected that the introduction of a national bowel screening program in 2006 will over-stretch colonoscopy services, due to the need for investigation of screen-detected abnormalities. Colonoscopy capacity also will be given attention to ensure that it will meet diagnostic needs arising from the forthcoming national bowel-screening program. Furthermore, the screening program will result in identification of significant numbers of people who fall into the high risk categories and require screening by higher technology processes such as colonoscopy and perhaps genetic testing. These require state resourcing.

In all cases where a high-risk setting is identified in an individual and ongoing surveillance is justified from the evidence base, there is a duty of care to ensure that recall systems are established to bring such people back for surveillance procedures. Health care facilities that conduct surveillance in high risk groups must be resourced to establish effective recall systems.

As far as possible, screening services should be coordinated, to increase public convenience and encourage screening participation. The Infrastructure Strategy should investigate opportunities to coordinate cancer screening services better.

Clinical protocols for general practice and other clinical services should cover preventive as well as treatment requirements. Information Technology (IT) infrastructure for clinical management information systems could provide service prompters and facilitate the auditing and monitoring of preventive service delivery as part of clinical care. Service reminders would be particularly important for people at increased risk.

Infrastructure for diagnostic services

Imaging services need adequate capacity to meet requirements for prompt diagnosis and treatment. The capacity of existing Magnetic Resonance Imaging (MRI) and CT diagnostic equipment to meet South Australian population needs should accord with international benchmarks. Currently, diagnostic mammography services in the public sector appear not to be meeting service demands, leading to delays and the potential for reduced service quality. The Infrastructure Strategy should ensure that diagnostic mammography services in the public sector have sufficient infrastructure capacity to avoid delays and reductions in quality of service.

Access to the PET and CT imaging is required for accurate staging and treatment planning, and use is increasing. Locations of existing PET, MRI and CT facilities are mapped in the proposed Statewide Integrated Cancer Care Service. At present, isotopes are transported daily by plane from interstate, a practice which is unreliable and insensitive to fluctuations in need. These materials have short half-lives, which complicates supply. Airline staff members sometimes express concern about safety aspects. The need to produce these isotopes locally will increase with the establishment of a new PET and CT scanner at the Royal Adelaide Hospital in 2005. This will require a broader range of isotopes than could be transported by air. The Infrastructure Strategy should address the capacity of PET and CT imaging and the need to establish a cyclotron facility in South Australia for the production of isotopes. The need for a second PET/CT device also should be reviewed in the context of service requirements.

In order to achieve successful treatment outcomes, prompt access is also required to a broad range of diagnostic services, as relating to tissue pathology, cytology, and chemical pathology. Emphasis should be placed on the capacity of other diagnostic infrastructure to meet existing and projected cancer loads. This will include infrastructure for tissue pathology, cytology, chemical pathology and other diagnostic services.

Infrastructure for radiation oncology services

Evidence-based standards indicate that radiotherapy services should have the capacity to treat at least half the cancer patients in SA, either with curative or palliative intent. Currently, South Australia is not meeting this standard. Radiotherapy facilities are mapped in the Statewide Integrated Cancer Care Service and a statewide five-year radiation oncology plan has been developed, to address this need and future requirements for facilities.

Cancer care infrastructure planning involves proactive monitoring of needs for equipment, new equipment, ongoing maintenance and repair. There should be ongoing quality assurance systems to monitor the appropriate use of radiation oncology services, using evidence-based guidelines, so as to optimise the therapeutic benefits gained from available infrastructure capacity.

Special attention should be given to access and use of radiation oncology services by rural and remote populations, including Aboriginal and Torres Strait Islander people. Case conferencing and treatment planning through telemedicine and other information technologies should be used to encourage the appropriate use of radiation oncology services. There should be adequate transport services and metropolitan accommodation of rural patients who need metropolitan-based radiation oncology services.

Infrastructure for medical oncology and haematology services

Medical oncology and haematology services of a high quality should be available to all cancer patients. Depending on the cancer type, these services can be crucial for cure, increased survival duration and palliation. New drugs that offer therapeutic benefits should be available to all people with cancer, when appropriate. These drugs can be very expensive and their benefits applicable to restricted numbers of people with cancer. Infrastructure is needed for ongoing monitoring systems to ensure that the use of all anti-cancer drugs, particularly the more expensive ones, accords with evidence-based protocols. Infrastructure support is also required to advance services addressing leukaemia, lymphoma and multiple myeloma, mostly managed by haematologists.

People living in rural and remote areas, including Aboriginal and Torres Strait Islander people, have less access to specialist oncology centres,

which can compromise their care. By definition, anti-cancer drugs are toxic and can have serious side effects that need to be monitored. Rural practitioners would need adequate experience in order to administer these drugs, and most are not equipped to substitute for specialist oncologists. In addition the availability of blood products for use in the event of complications from chemotherapy or surgery is limited. Safety issues are therefore an important consideration. The potential to increase access of rural and remote patients to these drugs, through the use of more remote specialist support via telecommunication, warrants research and development.

Infrastructure for surgical oncology services

High quality surgery is required for good outcomes from cancer care. Increased emphasis is being placed on surgical sub-specialisation and ongoing audit of practice and treatment outcomes. The Royal Australian College of Surgeons (RACS) breast surgery audit is one example. Quality also can be assessed indirectly through monitoring caseloads, practice variations and clinical outcomes. An appropriate information technology infrastructure is needed for this auditing and monitoring process. Infrastructure planning should address the need for infrastructure to monitor surgical caseloads, practice variations and clinical outcomes. Emphasis should be placed on the infrastructure needed for surgical audit and quality control for all cancers, based on the model used by the RACS breast surgery audit.

Infrastructure for palliative care services

Palliative care and pain control should be available to reduce the burden of cancer and cancer deaths for people with cancer, their families and their carers. Fifty percent or more of people with cancer eventually die of their disease. The current capacity of palliative care services is insufficient to cope with increasing numbers of cancer deaths. While there is a general shortfall, special needs have been identified in country areas, such as the South Coast, Murray Mallee, Wakefield Region, and Gawler, and in metropolitan areas such as Modbury and other northern suburbs. Hospice and other end-of-life services are in short supply. Structures also are needed for the provision of palliative care in rural and remote areas, including the provision of services to Aboriginal communities. Telemedicine and other communication links between specialist palliative care centres in metropolitan areas and rural practitioners should be available for this purpose.

Palliative care and pain control should be available to people with cancer who choose to die at home. Approximately 60% of South Australians express a preference to die at home, but few do so, partly because of fear of pain and the resulting burden on them and their families. Pain relief is often required at night and nursing services should have access to morphine or alternative drugs like midazolam, hyoscine or clonazepam for this purpose. Means of providing palliative care at home is required for uninsured patients. Community social workers have an important role to play in providing community support.

The drugs available for palliative care should be appropriate for effective service delivery. Medicare Benefits Scheme items and private health insurance items should be extended to cover palliative care needs more effectively. This aspect requires review, so that there will not be structural impediments to effective palliation and pain control.

Appropriate infrastructure is required to monitor the use of palliative care services. Timely referral of patients for palliative care should be included in clinical protocols, audited, and addressed in professional and institutional accreditation systems. An appropriate IT infrastructure is needed to support this monitoring and auditing process.

Infrastructure to deliver the information required by service providers and administrators

Clinicians need to be informed about their patients' health status and the prior services received by them to plan appropriate care. There is a need for electronic health records, unique patient ID numbers, means of electronic transfer and integration of patient records from separate service outlets, the extension of the Open Architecture Clinical Information Service (OACIS) to country hospitals and the introduction of patient held records. Electronic prompts should be included in management systems for systematising preventive care, screening, promotion, and follow-up checks at primary health care and tertiary levels. The nursing clinical information system, Exelcare, should be replaced with a suitable system. Means of electronic transfer of hospital record information at discharge to primary health care practitioners should be strengthened.

Health administrators need to be informed about cancer trends, and existing service availability and performance, in order to plan appropriate services. The State Cancer Registry should provide up-to-date data on cancer incidence, survival, and

prevalence across the population. Clinical cancer registration should be extended across all service outlets for monitoring quality and safety of care and care outcomes. Linking and integration of clinical databases within and across service outlets are required for service planning and monitoring, and for assessing patterns of care. All hospitals should be included in Admission, Transfer and Discharge data systems that cover inpatient and outpatient clinics. Standardised laboratory and other diagnostic reporting should be introduced, to increase accessibility of that information. Laboratory databases should be introduced, akin to the Cervical Cytology Back-up Record System, for more general quality assurance and for monitoring of laboratory performance. National data dictionary definitions should be applied to facilitate national benchmarking. An inventory of cancer databases should be available.

Clinicians and health administrators need efficient access to evidence-based protocols, and to the broader scientific database, for informed decision-making. Computer-aided decision-making has an important role in this regard.

Infrastructure planning should address the infrastructure needed to provide information to service providers for individual patient care and to health administrators for service planning, implementation and evaluation. Emphasis could be given to efficient means for clinicians to gain access to integrated patient records from separate service outlets to inform decisions at point of care; health administrators to assess data on cancer trends, service needs, and the performance of health services; and clinicians and health administrators to access the scientific evidence base required for assessing service options.

Infrastructure program for information and support services

Cancer leads to concern and stress at a community level and particularly so among those affected by the disease and their family members and carers. There is a general educational requirement at a community level, plus a need for telephone help-lines and emergency services for individual patients through nursing and allied personnel on call. These services are needed outside as well as inside normal working hours.

A diverse range of information and support should be provided. Services should attend to broad community needs, plus the special needs of Aboriginal and Torres Strait Islander people and culturally and linguistically diverse groups.

They should cover information on cancer and its management, service directories, access to psychosocial support, community support groups, and support for patients with disabilities, as well as broader information and support needs.

A diverse infrastructure is needed to support this service delivery through multiple outlets, including printed media, the Internet, radio, television, schools, pharmacies, general medical practices and other health services and community agencies.

Infrastructure for cancer research

A strong research capacity is important for generating new knowledge for cancer control and for translation of knowledge into practice. It is also important for attracting and retaining professional leaders in local employment and enhancing the quality of health-service delivery. The proportion of national health research funding attracted to South Australia has been declining. This threatens local research capacity, weakens the position of South Australia as an employment option for professional leaders, and threatens the quality of health services.

Research collaborations of basic and applied researchers, policy makers and health-service practitioners should attract research funding, strengthen research and increase translation of research results into practice. National funding now favours broader multi-disciplinary research collaborations. South Australian researchers have been slow to form research collaborations and have become less competitive in national funding bids.

Applied research should be integral to all aspects of cancer control from disease surveillance to service planning, monitoring, evaluation and quality audit. The *Generational Health Review* emphasised the need for applied research as part of health-service delivery. Results of this research are important for identifying cancer trends, planning service responses, and evaluating service performance.

Clinical trials provide the highest level of evidence of benefits of new clinical interventions and should be part of routine service delivery. Quality of clinical care is acknowledged to be better in services that incorporate clinical trials. Other health jurisdictions have set an initial target of participation in clinical trials of at least 10% of cancer patients. To include sufficient numbers of patients, trials generally must cover multiple treatment centres. An administrative and technical infrastructure is needed to facilitate this process and to monitor levels of participation of South Australian cancer patients in trials.

Rapid progress is being made in molecular science, which increasingly will set future directions for cancer control. South Australia needs to develop bio-specimen databases for integration with clinical and population data for research into cancer aetiology, prognosis and treatment efficacy. Without bio-specimen databases, South Australia will increasingly lose competitiveness with interstate researchers in bids for national research funding.

Ready availability of cancer and cancer-service data is important for research and health administration. Data availability is less readily available in South Australia than in other jurisdictions, such as New South Wales and Western Australia. De-identified (anonymous) cancer and cancer-service databases, including linked databases, should be made available to authorised researchers and health planners, after generic approval for release by ethics committees and stakeholders. This would encourage descriptive research and provide training opportunities for junior researchers. The data could be used in South Australian bids for competitive research funds.

Ethics committees have a central role in ensuring the ethical conduct of health research. They should operate within an efficient administrative framework. The present need for multiple ethics committee approvals in South Australia is wasteful of resources, increases the administrative burden on South Australian research, and reduces competitiveness. The process should be streamlined.

South Australia should be able to describe its cancer research activity in the context of research strategies and targets. Research activity and funding is dispersed and not well defined. Infrastructure is needed to monitor this activity, identify gaps and assess performance in the context of research strategies and targets. For example, while health-service research, including palliative care research, is known to be deficient, benchmarking is not possible without data from a monitoring system of this type.

There are benefits if public facilities collaborate with drug companies and other commercial bodies in cancer research, in the context of contractual arrangements that minimise risk exposure. The Australian health environment has become more litigious. Contractual arrangements for research need to address risk exposure appropriately. The Department of Health could lead in the development of minimum requirements for contractual arrangements between commercial funders of research and public-sector facilities, so as to minimise risk.

The Infrastructure Strategy needs to address infrastructure requirements to strengthen cancer research in South Australia. Emphasis should be placed on infrastructure requirements for establishing:

- A Cancer Control Research Collaboration, comprising researchers from all fields from basic to clinical, population health and health services research, including supportive research, which would focus on translational research.
- Research as an integral part of all aspects of cancer care.
- Clinical trials.
- A bio-specimen database and facility.
- De-identified cancer and cancer-service databases generically approved by ethics committees for use by authorised researchers and health administrations.
- A more efficient means of ethics committee clearance for multi-centre and population health research.
- A system for identifying and monitoring cancer research in South Australia in the context of strategic directions and targets.

Cancer care is increasingly subject to sub-specialisation as sophistications in treatment increase. Complete cancer care needs collaborative input from an increasing number of specialists and primary health care practitioners. Networks of specialist cancer centres and primary health care providers are required to provide integrated cancer care. Organisational networks are needed to ensure the coordination of this activity. These networks need relevant staffing and information-system infrastructures.

Infrastructure to address other health-system needs

Advances in genetic testing and the management of genetic risk should be incorporated into cancer services. The costs of these services are substantial and influenced by international patency laws and trade agreements. Increased attention to infrastructure requirements of these services will be important, so that South Australians will not be disadvantaged.

Cancers in children, teenagers and young adults need special attention. Special grief is associated with cancer and cancer deaths at a young age. The management of these cancers is generally different from those affecting older adults. In particular, there is the need for customised care of older teenagers and young adults who are the focus of neither existing paediatric nor adult oncology services. Organisational arrangements and infrastructure need to make special provision for this group.



Recommendations

Implementing a comprehensive infrastructure strategy for South Australia

1. Establish an Infrastructure Planning Operations Group to oversee development of a staged comprehensive infrastructure strategy. This group would operate as a sub-committee of the Statewide Cancer Control Advisory Group.
2. Develop an comprehensive infrastructure strategy for cancer control, giving particular attention to:
 - Enhancing infrastructure to support cancer care service delivery to people with cancer in the country, to Aboriginal and Torres Strait Islander people, to people who choose to die at home and to other sectors of the population where shortfalls are pronounced.
 - Increasing service availability closer to home where appropriate, increasing access to palliative care and end-of-life care, and further developing transport and accommodation services to facilitate access to metropolitan treatment services, for people with cancer living in the country.
 - Addressing infrastructure needs to provide cancer screening services to rural and remote sections of the population, especially Aboriginal and Torres Strait Islander people, where screening coverage is relatively low and treatment outcomes are poor.

Infrastructure for cancer prevention and cancer screening

3. Provide adequate infrastructure support for cancer prevention and population cancer screening, with particular attention to:
 - Prevention initiatives identified above.
 - Capacity for screening services to meet national targets, and to provide services to sections of the population, where screening coverage is relatively low.
 - The development of IT systems to support preventive initiatives as part of individual patient care, such as recall systems.

Infrastructure for diagnostic services

4. Audit and review diagnostic services.
5. Address needs for PET/CT scanning, diagnostic mammography, MRI and CT imaging, and for broader diagnostic infrastructure, as relating to tissue pathology, cytology, and chemical pathology.

Infrastructure for radiation oncology services

6. Support the *SA Plan for Radiation Oncology Services 2005–2010*, including recognition of the needs for public services to the north and in the south of Adelaide.
7. Ensure sufficient capacity of radiation oncology infrastructure for service provision to at least half of all people with cancer and proactive monitoring of infrastructure to assess needs for new equipment, ongoing maintenance and repair.
8. Monitor rates of use of radiation oncology services by the whole community, people from the country, and Aboriginal and Torres Strait Islander people and other groups at risk of under-representation. Investigate and address barriers to use.

Infrastructure for medical oncology and haematology services

9. Address the need for an equitable access to multidisciplinary care and anti-cancer drugs by all people with cancer, irrespective of place of residence.
10. Address the issue of rationing and funding of expensive drugs and the need for infrastructure for monitoring systems to ensure that anti-cancer drugs, particularly the more expensive ones, are used in accordance with evidence-based protocols.

Infrastructure for surgical oncology services

11. Develop infrastructure to monitor surgical caseloads, practice variations and treatment outcomes.
12. Provide funding and technical support for the development of infrastructure for surgical audits, taking account of the model used in the RACS breast surgery audit.



Recommendations (continued)

Infrastructure for palliative care services

13. Address the infrastructure requirements needed to support service delivery to people with cancer in rural and remote areas, including Aboriginal and Torres Strait Islander people, to other metropolitan and country sectors of the population where shortfalls are pronounced and to people who choose to die at home.
14. Addresses the need for IT infrastructure to monitor and audit the timely referral of patients for palliative care.

Infrastructure to deliver the information required by service providers and administrators

15. Develop an information infrastructure program for cancer services delivery, with emphasis on clinicians' needs for information for appropriate treatment planning, population health practitioners needs for surveillance data and to health administrators' needs for information for appropriate cancer-service planning and evaluation.

Infrastructure program for information and support services

16. Enable the provision of a broad range of information and support services for the community as a whole and for people with cancer.

Infrastructure for cancer research

17. Develop infrastructure to support the establishment of a South Australian Research Collaboration, to support the integration of research into all aspects of cancer-service delivery, increased participation of people with cancer in clinical trials, the availability of tissue sample data, the coordination of research to develop new monitoring and treatment strategies, the access of researchers and health administrations to cancer and cancer-services data, and the streamlining of ethics committee processes.

Infrastructure to address other health-system needs

18. Address particular health services infrastructure needs for:
 - Familial Cancer Service.
 - Services for paediatric cancer cases, which include follow-up monitoring of late effects, and services for older teenagers and young adults, who are neither the focus of existing paediatric or adult oncology services.
 - Cancer care networks across specialist centres and primary health care practitioners.

Workforce Planning for Cancer Control

Summary

Workforce refers to the people required to deliver cancer control programs and services, and other cancer care. Like many other areas of health, shortages have been reported in the cancer control workforce and they are predicted to worsen. Other issues are likely to influence the make-up of the future workforce, including workforce accountability, greater flexibility within the workforce roles, finding ways to use the workforce more efficiently, keeping people in the workforce longer and providing relevant training programs.

It will be more efficient to address cancer control workforce issues within the context of a broader health workforce enquiry.

The goals for workforce planning to support the Statewide Cancer Control Plan are that:

- The cancer workforce, which includes professionals, volunteers and carers is adequate across the spectrum of cancer control.
- Educational, learning and recruitment strategies are aligned with cancer control workforce projections.
- Cancer control workers are able to participate in accredited continuing education programs and equipped to participate in research projects to enhance cancer control.
- The curriculum content of tertiary courses provides optimal cancer education.

Cancer control is a broad domain. Therefore, the workforce engaging directly in cancer control is large and diverse. It includes workers in health promotion agencies, screening services, primary health care, tertiary institutions, and allied health. There is also a sizable community based workforce, delivering social services as well as a large unpaid workforce of carers and volunteers.

Workforce planning for cancer control, like any aspect of health, is essential if agencies are to deliver efficient and effective programs and services to the South Australian community. As well as examining current requirements and the extent to which they are met, it is also critical to be forward-looking to ensure that there will be enough people with the necessary skills and knowledge to deliver appropriate programs and services into the future. However, workforce planning in the health sector is not an exact science, but rather an attempt to predict and determine the future needs on the basis of information available in the present.⁶¹

There is good reason for concern about the supply of labour in the current health workforce and the need for labour in the future. *The National Health Workforce Strategic Framework* endorsed by the Australian Health Ministers in 2004 reported that in Australia, the national workforce grows at an annual rate of around 170,000 persons per year.⁶² By 2020 this is predicted to be just 12,500 per year. Unless this outlook changes, the next 20–30 years will see a decreasing rate in supply of workforce. This will lead to an unprecedented focus on obtaining and keeping the Australian workforce, including the health workforce.

In March 2005, the Federal Treasurer indicated that the Productivity Commission intended to examine issues affecting the health workforce including the supply of, and demand for, health professionals. Submissions were invited to inform the study which would be undertaken in the context of the need for efficient and effective delivery of health services in an environment of demographic change, technological advances and rising health costs.

The study would take a broad whole of government perspective, including health and education considerations and will cover the full range of health workforce professionals. In considering these issues, the paper would look at the particular health needs of rural areas.

Beyond basic volume, other issues likely to influence the make-up of the future workforce will include: clearer articulation of the role accountabilities for workforces – what it is we need the workforce to do; greater flexibility in role designation – who can do what; productivity and finding ways to utilise the workforce more efficiently; retaining people in the workforce longer; and the length of initial training programs.

Optimising Cancer Care in Australia reports consistently that there are already workforce shortages in all areas of cancer care.² Either there are instances of professionals but no positions available or, much more commonly, positions, but no professionals to fill them, particularly outside the capital cities. This is true of medical oncologists, radiation therapists, radiation oncologists, nurses with experience and or qualifications in cancer, and pharmacists. Also reported is considerable risk of burnout of the staff presently in the field. A widespread view is that the situation is likely to get worse as the South Australian population ages and the prevalence of cancer continues to rise.

The Government of South Australia, in response to the *Generational Health Review* recommendations, is committed to rebuilding a better health system of care.⁶³ Some of the first steps in the South Australian Health Reform focus on:

- building better governance;
- building better services; and
- building better system support.

More specifically steps are being introduced to provide services for people that are closer to home, to increase prevention and early intervention and to strengthen primary health care services by creating opportunities for health professionals to work in local teams. This is intended to create better opportunities for general practitioners, allied health workers and nurses to work together giving people easier access to health services. There is also a step aimed at developing a health workforce with the right skill balance and the required training, recruitment and retention strategies to support the new system.

Cancer is not the only sector of health with workforce shortage issues and it is recognised that the need for efficiency and effectiveness will necessitate many health professional roles

stretching across chronic diseases, with cancer as one component. Therefore, it will be more efficient to investigate cancer control workforce issues within the context of a broader health workforce inquiry.

General cancer control workforce background information

Apart from the Radiation Therapy workforce data,^{64,65} currently in South Australia there is a shortage of coherent baseline data to document the existing Cancer Control workforce, or education and training opportunities. This highlights the need for:

- Consistent methodological tools for collecting and classifying workforce data.
- Known and agreed cancer care and cancer prevention standards, models of care or practice, to provide benchmarks for workforce requirements.
- Delineation of time spent in cancer control work. Identification of the cancer control workforce is complicated by the broad roles of those working in the discipline. This makes the defining, identifying and recording of time spent in cancer control work more difficult.
- Systematic information about the magnitude of the training and education requirements and opportunities for the continuum of the cancer control workforce.

Other issues complicating data collection include:

- Extension of the professional health workforce in cancer control by a non-professional workforce of volunteers and carers, about which there are even less data.
- The broad scope of the workforce (potentially or actually) engaging in cancer control – the workforce influencing cancer control also extends to less obvious roles in: legislation; policy; local government; pre-school, school, TAFE and university level education; media; multicultural and community centres.

Specific cancer control workforce background information

There has been national recognition of current and future workforce shortages to service cancer care needs. Although comprehensive data to document the existing workforce in cancer control in South Australia is not available to the extent observed in radiation oncology, there is plenty of evidence of specific instances of workforce shortages in cancer screening and cancer care. There are also

opportunities for greater coordination in cancer care, cancer prevention and cancer control research.

Oncology specialists

The 2001 report of the Australian Medical Workforce Advisory Committee, examining specialist haematology and medical oncology workforce, indicated that the supply was deficient by at least forty practitioners and was going to worsen, particularly in regional areas.⁶¹ Some feel the Australian Medical Workforce Advisory Committee report significantly underestimated the future need for medical oncologists and haematologists.

The National Strategic Plan for Radiation Oncology suggests there is a current deficit of around twenty radiation oncologists, more acute in some places than others.⁶⁶ There are also documented deficits in the radiation physics workforce and the radiation therapy workforce. These are all important gaps in the capacity to improve cancer care.

In surgical oncology, there is a major drive by the Royal Australasian College of Surgeons (RACS) to recognise the importance and very specific nature of cancer surgery and to create training programs in cancer surgery across Australia and New Zealand.

General and Specialist Physicians play an important role in cancer diagnosis and in the management of co-morbidities.

Oncology nurses (including chemotherapy nurses)

Specialist oncology nurses (including chemotherapy nurses) make a substantial contribution in managing the burden of cancer care in Australia. Specialist cancer nurses can reduce psychosocial morbidity associated with cancer and its treatments, enhance early recognition of support needs and provide continuity of care. In Australia, studies in the context of breast cancer provide evidence that specialist cancer nurses are cost effective, acceptable to other health professionals and highly valued by consumers.⁶⁷ Cancer nurses workforce planning, both in numbers of staff and needs for professional development, should be a priority. Particular gaps in the specialist workforces need to be addressed such as specialist nurses for different cancers.

Registered nurses

Again, nurses make a substantial contribution to the cancer control workforce in tertiary institutions, but also in areas not directly aligned with the acute care setting. Nurses contribute to health promotion regarding cancer prevention in community settings and community care via the Royal District Nursing

Service and they provide a large proportion of the palliative and psychosocial care workforce.

Future models of care with an increased emphasis on Primary Health Care, Cancer Care Coordinators and specific roles for Nurse Practitioners are expected to enhance and influence the role of nursing in Cancer Control.

General Practitioners

General Practitioners (GPs) have a pivotal role as providers of care, with cancer increasingly treated in a community setting, ranging from health promotion within the clinical setting through to palliative care. They should be supported in conjunction with the rest of the multidisciplinary cancer care team. As well as numbers and skills development, there needs to be greater opportunity to practice in ways that offer consumers and GPs a better environment in which to provide treatment, for example more time and greater information.

Primary health care

In line with the South Australian Government's health reform agenda, there will be an increased emphasis on primary health care settings and structures for the delivery of health services. There is opportunity to ensure that the cancer control workforce in primary health care are skilled to manage cancer prevention and early detection (for example BreastScreen SA) in a population health context as well as cancer care in the community setting.

Breast cancer screening

Population based breast cancer screening through mammography is a highly technical and specialised field. There is a national and international shortage of radiographers and radiologists who specialised in this area. The workforce shortages are having a detrimental impact upon the ability of programs across the country to achieve their aim of reducing the mortality and morbidity attributable to breast cancer in women through early detection.

Psychosocial oncology

Psychosocial care includes physical, emotional and social support. The importance of psychosocial care is well recognised by many cancer care providers but others do not refer patients for support when it is required. This in part relates to lack of access to suitable services to which to refer people. The shortage of professional positions to provide psychosocial support is also well known. The Cancer Strategies Group of the Australian Government has recognised that an increase in the

number of psychologist positions is needed and will be cost effective.⁶⁷ It is reportedly hard to access psychosocial support in the private sector. Lack of sexual health counselling and rehabilitative services have also been reported as unmet needs.

Private professional psychological services are not eligible for Medicare subsidies. Ongoing professional psychological support can be costly for those with ongoing psychological difficulties related to cancer. While the evidence of effectiveness may not be clear for alternatives to a full psychological service, there is a need for broadly based support services that are readily available at low cost, to supplement professional services. Provided there is evidence for effectiveness, greater investment in, and use of community based interventions such as one-to-one peer support, self-help groups, or guided group therapy may be required.

Cancer Councils

Cancer Councils, locally and nationally, have expertise and experience in population health, research and cancer prevention, which provides an opportunity to coordinate these activities across the state. Cancer Councils can also provide authoritative, up-to-date and relevant information and support for primary health care workers.

Allied health

Allied health is a term used to describe a range of professional health-care providers who are not physicians (e.g. pharmacists, psychologists, physiotherapists, nutritionists, occupational therapists). Consultations undertaken with allied health workers, to inform the Statewide Cancer Control Plan, revealed their concern about inability to meet current demands and the significant concerns about their ability to support future cancer control programs and services. It is also noted that significant barriers to accessing allied health across South Australia include late referrals to allied health and poor levels of staffing.⁶⁸

Cancer registration

Population-based, hospital-based and other clinical registries are unique in the medical field in that they bridge an information gap, by capturing a summary of a patient's disease process and outcome through their lifetime. Cancer registries provide benchmarking services and information to monitor quality of care and clinical practice guidelines, assess patterns of care and referrals and monitor adverse outcomes including mortality and co-morbidity. Without an adequate staffing of cancer registries, accurate, dependable and timely cancer research and statistics reporting is compromised.⁶⁹

With the increased demand for current, comprehensive cancer data, and with changes within the health system itself, the need for cancer registries and cancer registry staffing has increased markedly, with a need for appropriate training.

Volunteers and carers

Consultations undertaken to inform the Statewide Cancer Control Plan recorded the demand for volunteer assistance alongside the developing and growing needs of the cancer care community. There is opportunity to collaborate around the future roles, functions and training of volunteers.⁶⁸ Carer and primary support roles need to be clearly defined and supported through improved training and engagement with the cancer care professionals and local community groups.

Public relations and marketing issues

The promotion of the benefits of working in the health and cancer control workforce could be developed to meet the demands of a competitive workforce market. These benefits include opportunities for lifelong learning, variety and diversity of work and contributions to community well being.

Many avenues exist to enter the cancer control workforce and these could be emphasised as part of a workforce promotional strategy. Alongside this is the opportunity to educate the general public about the changing face of the health and cancer control workforce, in line with future people shortages, increases in the incidence of cancer and changes in service delivery.

Cancer control background information specific to curricula and education

Credentialing of medical practitioners in cancer

The *National Services Improvement Framework for Cancer* recommends as a priority action for national change: "Establishing accreditation for cancer services, and credentialing for practitioners, using as a basis, the recommendations about optimal services outlined in the Framework."⁵⁴

Specialty training in oncology nursing

"There are a number of post-graduate nursing courses in cancer. There is a shortage of nurses who have such training, and those who undertake it have no assurances that they will receive additional salary because of the additional skill".²

Medical schools' curriculum content

The Cancer Council Australia has developed an Ideal Oncology Curriculum for medical schools.⁷⁰ The curriculum has been used in some universities for curriculum improvement but has not yet been adopted by the majority.

Population health

There is a need for ongoing training and development of the professional workforce in every domain of cancer control. Over half of all cancers are thought to be preventable so it is important to include Population Health and cancer prevention training routinely in all cancer workforce curricula.

Cancer as a chronic disease

The projections for the future indicate that numbers of people getting cancer, in South Australia and globally, will increase in the next decades. In part this is due to the ageing population. Rates of early detection and treatment methods are becoming increasingly effective and as a consequence rates of long-term survival are also improving. There is already, and increasingly will be, a need for policy makers, educators and the workforce to understand cancer as a chronic disease. Definition of cancer as a chronic, as well as an acute disease, and incorporation in cancer control workforce curriculum and professional development would build better future understanding and management.

Communication skills

People with cancer and many providers see great need for formal training and occasional re-training in communication skills with patients. Cancer centres should routinely train staff in communications skills. One way to bring about routine communication training is by including the requirement in the accreditation framework.

Cultural issues

Aboriginal and Torres Strait Islander people with cancer are much more likely to die from the disease than other Australians. The available evidence suggests that one of the key reasons for this unacceptable inequity is that Aboriginal and Torres Strait Islander people face numerous barriers to accessing treatment services including culture, language, location and poverty. Many Aboriginal people have requirements for successful communication that differ from the general populations due to cultural issues related to health and well being.⁷¹ Cultural awareness should also be part of communication training for current and future cancer control workforces. Targeted recruitment efforts to encourage Aboriginal and Torres Strait Islander people to undertake education and training and to enter the

cancer control workforce in greater numbers would also help lessen the cultural barriers, which contribute to the burden of cancer on Aboriginal and Torres Strait Islander people.

Psychosocial care

The importance of psychosocial care is well recognised but many cancer care providers fail to refer patients for support when it is required. This in part relates to poor communication; that is failure to elicit information that indicates psychosocial care is required. It is also because of lack of awareness about services to which to refer people. The shortage of professional positions to provide psychosocial support is also well known and the need for greater investment in broadly based support services is addressed above. Greater information about and referral to affordable, effective alternatives to psychological counselling may be the first step (e.g. via The Cancer Council Helpline).

Capacity to integrate research and evaluation

The incorporation of opportunities to participate in research within cancer control workforce roles was identified in consultations, to inform the Statewide Cancer Control Plan, as fundamental to improving service delivery and development. Enabling staff to facilitate participation in clinical trials is an example. Enabling population health staff to incorporate evaluation into programs routinely, and to translate research outcomes into practice is another.

Key gaps and emerging issues

Apart from the information collected about Radiation Therapy,¹³³ very little is clearly documented about the composition of the cancer control workforce in South Australia. A better understanding of the cancer control workforce is essential and will enable better-informed decision-making and the development of more accurate and effective workforce and education strategies.

Within the current environment of health reform, there is opportunity to articulate the role for the cancer control workforce and to educate the community about realistic expectations of the future cancer control workforce. These will be informed by standards and benchmarks for quality of cancer care and evidence about cancer control programs. Understanding what it is we want the workforce to do, ensuring that there are adequate education and training courses, and that places are filled, are all essential to ensuring that there will be an adequate workforce to meet future community needs.



Recommendations

Broad and structural

1. Establish a Workforce Planning Operations Group, linked to a broader Health Workforce Inquiry, and reporting to the Statewide Cancer Control Advisory Group, to oversee a systematic review to:
 - Develop comprehensive categories of cancer control workers across the continuum of cancer control. This would include, but not be limited to medical staff (e.g. oncologists, haematologists, surgeons, pathologists, paediatrics, general practitioners, nurses, radiation therapists, palliative care), allied health (e.g. pharmacists, psychologists, nutritionists, occupational therapists), social workers, cancer prevention workforce (e.g. policy managers, health promoters), researchers, carers and volunteers.
 - Develop a mechanism for workforce data collection and monitoring, including gauges of time spent in the cancer control workforce.
 - Audit cancer control workforce systems in all public hospitals, private hospitals and other relevant agencies.
 - Facilitate discussions or workshops specific to workforce groups where information is scarce (e.g. allied health and palliative care), taking the opportunity to investigate where and why there are shortages in certain areas of cancer control.
 - Undertake surveys to understand better the career intentions of those currently in the cancer control workforce.
 - Undertake studies that project future cancer control workforce requirements based on epidemiological predictions of cancer incidence in South Australia and anticipated models of care and practice.
2. It is also recommended that the Workforce Planning Operations Group:
 - Support the implementation of the workforce component of the *SA Plan for Radiation Oncology Services 2005–2010*.
 - Ensure that workforce deliberations are guided by the *Generational Health Review* recommendations and the health services reform underway in South Australia.
 - Investigate what research is being done locally, nationally and internationally about cancer control workforces and seek to link local and national taskforces on workforce issues.

Workforce reform, recruitment and retention

3. Implement reform of the existing cancer control workforce, to be consistent with a model placing more emphasis on primary health care, but understanding implications for the acute care systems, consistent with the health services reform underway in South Australia.
4. Introduce workforce reform and training to promote a shift to multidisciplinary care, as proposed in *Optimising Cancer Care in Australia* leading to significant improvements in patient outcomes, cost reductions and productivity gains.
5. Develop approaches for recruitment, training and retention for the cancer control workforce.
6. Investigate reasons for workforce attrition and develop incentives to keep people in the cancer control workforce for longer than currently experienced.
7. Develop a strategic plan to recruit more Aboriginal and Torres Strait Islander people into the cancer workforce, and that in parallel, benchmarks for improved cancer outcomes in Aboriginal and Torres Strait Islander people be set and pursued to help prevent widening of the gap in cancer mortality rates.



Recommendations (continued)

Workforce curriculum, education and training

8. Routinely include a cancer module in appropriate health professional education and training. This could include: primary and secondary cancer prevention, risk management and familial risk, the primary referral, psychosocial and supportive care, palliative care and pain management. An example for implementation is via GP Divisions' strategic plans.
9. Develop strategies for credentialing of medical practitioners in cancer, in line with recommendations of the *National Services Improvement Framework for Cancer*.
10. Enlist the Australian Medical Council to assist in incorporating The Cancer Council Australia's Ideal Oncology Curriculum into undergraduate medical education and the accreditation process for undergraduate medical training, both in South Australia and nationally.
11. Maximise opportunities for training volunteers and carers e.g. via the TAFE sector, non-government organisations and by inclusion in training provided to paid staff where relevant.
12. Develop incentives for nurses to undertake relevant post-graduate training in cancer nursing.
13. Develop strategies to increase post-graduate training in psychology as well as specialist training in psycho-oncology for health professionals.
14. Include access to psycho-oncological support services as one of the accreditation criteria in any cancer service accreditation scheme.
15. Increase provision of affordable, effective alternatives to psychological counselling such as peer-support.
16. Establish a capacity building workforce alliance with all non-government organisations and community organisations working in cancer control.
17. Educate the entire cancer control workforce in understanding cultural sensitivities relevant to Aboriginal and Torres Strait Islander people and culturally and linguistically diverse communities.

Cancer Control Research

Summary

Research has a vital role for cancer control, from prevention through to end-of-life care. Basic research provides the fundamental understanding of cancer behaviour at a cellular and sub-cellular level to develop breakthrough opportunities in cancer control. Clinical research discloses new therapies that lead to better outcomes for people with cancer. Health-services research shows where our health system is not functioning optimally and points the way to better delivery systems. Population health research indicates the social determinants of cancer and indicates where policy changes may reduce risk. It also reveals whether our cancer control efforts are having the effects intended. Translational research shows how best to translate research results into health policy and health-service

application and bridges the gap between the individual and laboratory research, clinical and population research. All research streams have necessary and complementary roles in the delivery of effective services.

The Statewide Cancer Control Plan goals for research and evaluation are that:

- South Australia supports and develops high quality cancer research.
- Good quality research and evaluation is made integral to the whole cancer control pathway and underpins all cancer control programs and services.
- Research findings are communicated and incorporated into service delivery and programs.

Research plays a vital role in cancer control, from prevention through to end-of-life care. Research is critical to improving the quality of services and must be a core element of health services. In addition to contributing to better health and health care, research also brings financial benefits to the State through the biotechnology pipeline, extra jobs and leveraging of research funding from the National Health and Medical Research Council (NHMRC).

It is of concern that there has been a steady decline in South Australian cancer research capacity in recent years. NHMRC statistics verify that South Australia's share of national health research funding has fallen. The effects are far reaching. Effective monitoring and evaluation of cancer services depends on research. Clinical and other health service leaders are attracted to positions where good opportunities exist for research. It is also recognised that involvement in clinical trials leads to a higher quality of care.

South Australia has a cancer incidence at the high end of the international scale. In 2002, the disease accounted for 28% of deaths, up from 17% in the early 1970s. Aboriginal and Torres Strait Islander people have a similar cancer incidence (that is, similar rates of new cases of cancer) to other members of the community, but are less likely to be cured or receive other benefits of care. South Australia's cancer control research capacity needs to be strong to address issues of this type.

Elsewhere in Australia, cancer service providers are strengthening cancer services. They are doing this through improved population health monitoring, adjusting clinical practice to follow what research shows to be the best way of treating people with cancer, building and training future generations of cancer care professionals and establishing strong programs of research. For example, New South Wales has established a multi-million dollar Cancer Institute to achieve these tasks. The Director of the NSW Cancer Institute oversees the State's cancer

control effort, and ensures that it has a strong research base. The Director reports directly to the State Minister for Cancer.

High quality research to support cancer control in South Australia

The overarching aim of a cancer control research policy is to reduce the impact of cancer in the community. In order to support and develop high quality research in South Australia, a lead organisation should be established, namely the South Australian Cancer Control Research Collaborative. The South Australian Cancer Control Research Collaborative would be responsible for co-ordinating the implementation and outcomes of the research components of the Statewide Cancer Control Plan.

The Research Collaborative would facilitate a collaborative network of researchers, policy makers, service providers, community representatives and commercial partners. Multidisciplinary networks of researchers, policy makers, service providers and commercial partners would be created to facilitate translation of research and to promote applied research. Community representatives would be included in these networks and additional mechanisms developed for community input.

An environment would be established, that facilitates access to data for research, health surveillance, policy development and service delivery, while protecting privacy and addressing legal and ethical issues.

The linking of population-based, clinical, health-service, and bio-specimen databases would facilitate research and service delivery. The Western Australian health services linked database serves as a model for determining linking pathways. There would be capacity to increase focus on bio-informatics and to expand a tumour tissue bank.

Translating research into practice

Basic, clinical, population health and health services research should all be linked to, and coordinated with, health policy formulation and service delivery, so as to achieve better health outcomes for the South Australian community.

Policy-and-practice focussed research contributes to knowledge that improves the delivery of services. Cancer care benefits in environments where there are clinical trials and other forms of clinical research. However, adult participation in clinical trials is low.

Research can help to identify and work towards addressing priority issues in cancer control such as how best to address health inequalities. A major issue for cancer control is the disparity in cancer outcomes between Aboriginal and Torres Strait Islander people and non-Aboriginal people.



Recommendations

1. A Cancer Control Research Collaborative should be established and resourced in South Australia that will provide an enabling structure for integrated research programs that foster quality, are directed to definable community benefit and focus on areas of South Australian strengths and important populations. This recommendation is of the highest priority and will have far-reaching benefits. The Chair of the Cancer Control Research Collaborative will report to the Statewide Cancer Control Advisory Group.
2. The Cancer Control Research Collaborative should be funded to provide support for teams of excellent researchers with international recognition, focussing on areas of priority and state strengths, as well as providing support for the training, retention and career development of talented young researchers and the development and maintenance of essential research infrastructure. This is necessary to support high quality cancer research in South Australia and to retain and attract researchers.

The Collaborative would fund research through:
 - Programs
 - Fellowships
 - Training Awards
 - Infrastructure grants
 The Collaborative would fund research infrastructure, including:
 - Tissue bank
 - Linked database
 - Cancer staging data
 - Quality of life data
 - Links to the SA Birth Cohort
 - Bio-informatics and bio-specimen support
3. The Cancer Control Research Collaborative should:
 - Develop collaborative networks of researchers, policy makers, service providers, community representatives and commercial partners in areas of relative strength, in order to build critical mass, attract research funding, and facilitate translation.
 - Develop training opportunities for researchers in these collaborative networks, and employment opportunities for early-career researchers, that will sustain a research workforce of appropriate skill mix.
 - Establish and facilitate interaction between cancer funding agencies and cancer research organisations such as The Cancer Council South Australia and Child, Adolescent and Family Health Research Institute (CAFHRI).
 - Support and foster collaborations with interstate and international research partners.
 - Address priority cancer issues, monitor cancer research in South Australia and provide links with national and international research programs.
 - Develop de-identified databases, with approval for use from an ethics committee, for generic research purposes.
 - Work to streamline ethics application processes, to reduce duplication and promote communication and co-operation between the various local ethics committees operating within South Australia, whilst continuing to safeguard ethical research principles.
4. Conduct a review of cancer research currently being undertaken in South Australia, in order to establish the range of research and identify gaps, areas of overlap and areas of strength. Monitor cancer research to assist in planning and co-ordination of research.
5. Develop and implement a comprehensive program of research that addresses the entire spectrum of cancer control. Elements of the research program will include research activities that support the following:
 - Optimising cancer prevention
 - Detecting cancers early, particularly those where evidence exists that survival benefits will follow
 - Learn more about the causes and characteristics of solid and blood cancers in order to develop additional treatments



Recommendations (continued)

- Providing evidence-based clinical services that maximise the potential for cure and attend to psychosocial needs and requirements for palliation
 - Providing support for families and carers in non-clinical environments
 - Providing clinical and psychosocial support to people with cancer during the terminal stages of their disease, through the delivery of hospice and other community services.
6. As part of comprehensive cancer control research planning, incorporate policy to practice research that is underpinned by collaboration between researchers, policy makers, practitioners and community representatives.
 7. Improve coordination of programs for the evaluation and monitoring of existing cancer services to enable continuing quality improvement.
 8. Explore existing international models for knowledge translation in cancer research and support the implementation and resourcing of an appropriate model in South Australia.
 9. Develop, in partnership with Aboriginal and Torres Strait Islander communities and health agencies a research program that will focus on cancer control amongst Aboriginal people and translate research findings into improving health-service provision and reducing health inequities.
 10. Maintain a focus on health inequities in order to increase access and improve outcomes of cancer services.
 11. Develop a mechanism to enable research agendas to be responsive to community concerns that may not be addressed in mainstream research programs, as for example, in the role and impact of complementary and alternative therapies.

Cancer Information

Summary

The workforce and agencies engaged in cancer control activities need information to perform their roles, and people with cancer need information. Systematic information planning will help to ensure that these needs are met. The goals for information planning to support the Statewide Cancer Control Plan are that:

- A comprehensive cancer information strategy be developed and implemented in South Australia.
- Cancer information programs be implemented for:
 - the South Australian population
 - people with cancer, their families and carers
 - clinicians and other health professionals
 - population health professionals and health-service planners, policy makers and administrators (state and regional)
 - researchers
 - parliamentarians.

All groups need information in a form that is readily understood. Comprehensive information planning is needed to ensure that all information requirements are addressed systematically within a comprehensive planning structure. The information planning recommended below is strategic. It provides a broad overarching framework for the development of more targeted operational plans that would specify who was to receive specified items of information, when, from whom, in what form, and for what purpose.

A comprehensive cancer information strategy for South Australia

The Statewide Cancer Control Advisory Group should oversee development of the information strategy. The cancer strategy should address information requirements for achieving key objectives of the Statewide Cancer Control Plan (see page 38). The Statewide Cancer Control Advisory Group should be responsible for collaboration with information units and initiatives to form a comprehensive information program.

The information strategy should cover both public and privately funded services, and address needs for information definitions, protocols and standards. Accreditation programs developed for health professionals and health services more generally, both public and private, should require compliance with these information protocols and standards.

The information strategy would cover all areas of information required by the population, high-risk sectors of the population, people with cancer, family members and carers, health professionals, population health experts, health-service administrators, planners, policy makers and researchers, state and regional health administrations, and parliamentarians, in order that they will be able to play their respective roles in cancer control. Information should be customised to the needs of all users. The type and depth of required information would vary with each group, but it would cover:

- Generic information about cancer, its risk factors and management.
- Information required by individuals at increased genetic risk on access to counselling services and genetic testing.

- The service options available to people affected by cancer and means of gaining access to these services.
- Specific information about a person with cancer's health, their prognosis, treatment options, plans and likely treatment side effects.
- Population-level information and statistics on cancer, cancer service availability, quality and utilisation, and projected service needs.
- Scientific information and databases for research.

Information provision should be timely, authoritative, user-oriented, concise, evidence based, easily accessible, and cost-effective. The information provided should be up-to-date and consistent across multiple outlets.

The broad information strategy should provide a context for more targeted priority-driven information programs. Special provision should be made to communicate effectively with high-risk sections of the population, such as the culturally and linguistically diverse, Aboriginal and Torres Strait Islander people, lower socio-economic and rural and remote.

Research is needed about information content needs and the best technology to use for information delivery. Information could be provided through a variety of sources, for example telephone help-lines, web-based technologies, electronic information systems, digital videoconferencing, print media, and other traditional paper-based systems, so as to reach all members of the population.

The information strategy and associated programs should be subject to periodic re-evaluation, as part of ongoing planning cycles, and be flexible in adopting new technologies.

Information systems should operate in a legal and ethical environment that fosters scientific enquiry, evidence-based service delivery and quality improvement, with due regard for people's privacy.

Cancer information program for the general community

People should have access to information about cancer as a disease, risk factors, cancer prevention, and how early diagnosis can be achieved, with special attention given to opportunities for mammography, cervical and large-bowel screening. Information should be available, through varied and accessible sources such as telephone help-lines and relevant web sites and print media.

The comprehensive information program would address population needs for generic information on cancer and its prevention, screening, and early detection. It should meet the needs of the population for statistics on cancer, cancer services, and outcomes of cancer services, thereby addressing public accountability requirements. Following a stock-take of information services, the program should address shortfalls in information availability to the population.

Cancer information for people with cancer, their families and carers

The comprehensive information program would address the needs of people with cancer, their families and carers for generic information on cancer management and support and for information that addresses their specific circumstances. Following a stock-take of information availability, it should address shortfalls in information.

People with cancer, their families and carers should have information on the person's cancer, prognosis, treatment options, likely treatment side effects, and allied service needs, provided sensitively with due regard for the patient's privacy.

People with cancer embarking on treatment should have information on the planned care, in order to be able to discuss this care and give informed consent. This is needed, irrespective of whether treatment is provided through public or privately funded centres. People should have access to lists of key prompting questions for use during clinical appointments.

People with cancer, their families and carers should have access to telephone help lines and service directories, including directories of psychosocial and other support services.

Cancer information for clinicians and other health professionals

The comprehensive information program would address the information needs of primary health care providers and specialists to provide individual patient care. This would include general information on cancer prevention, diagnosis, and treatment and specific information on individual patients' needs, their care and care outcomes. Health professionals would receive statistics on their practice profiles and outcomes for comparison with practice norms and evidence-based standards.

Primary health care providers and specialists should have up-to-date information on cancer prevention, detection and management, cancer genetics and familial cancer, evidence-based guidelines and

protocols, clinical trials, and service availability, and they should know how to access extra information sources. They also need information on individual patients, including their medical histories, diagnostic information, planned care, follow-up plans, service provision and outcomes of care.

Comprehensive integrated health-care information is needed at point of care in a timely manner. Appropriate information for cancer care should flow between separate public or privately funded centres.

More advanced electronic information systems are needed to provide prompt access to relevant generic and patient-centred information, and to synthesise this information rapidly for decision-making. Standardised reporting provisions are needed to facilitate the electronic synthesis of information from diverse sources.

Statistics are required to summarise practice profiles and outcomes, so that they can be compared with practice norms and evidence-based standards. These statistics are needed for service monitoring, auditing and accreditation. Hospital-based and allied clinical cancer registration systems are needed for this purpose.

Access to patient-centred information for service delivery and audits must comply with privacy laws and codes of ethical conduct. A balance is needed between the protection of people's privacy and the availability of information for quality health care.

Cancer information for population health professionals and health-service planners, policy makers and administrators, both state and regional

The comprehensive information program would address the needs of population health professionals for generic information and population-centred statistics on cancer risk, cancer trends, and cancer outcomes. The program would also address the needs of health-service policy makers, planners and administrators for data on service requirements, projected requirements, and service availability, quality and costs.

Population health professionals need generic up-to-date information on social and behavioural determinants of cancer. They require population statistics on:

- Tobacco smoking, poor diet, lack of physical activity, excess body weight, excess sun exposure, excess alcohol consumption and other cancer-risk behaviours and their social determinants
- Exposures to environmental carcinogens
- Participation in cancer screening
- Cancer incidence, prevalence and mortality
- Cancer stages at diagnosis, rates of treatment, rates of survival and other outcomes.

Health-service planners, policy makers and administrators require data on:

- Population service requirements for prevention, screening, treatment and support
- Projected service requirements
- Service availability and access
- Service participation by different sections of the population, including high-risk groups
- Service activity and costs
- Service quality, as reflected in service structures, processes and outcomes, and as indicated by:
 - Transition times from presentation to referral and for transitions along the treatment pathway
 - Extent of participation in clinical trials
 - Use of multidisciplinary care
 - Provision of palliative care
 - Referral practices for psychosocial and other support services
 - Extent of care coordination and integrated care planning.
- Resource availability and projected availability, as related to workforce, facilities, equipment, and funding.

Cancer information for researchers

Research should be an integral component of the State's cancer control effort, with an emphasis on translation of research findings into health policy and service delivery, and the realisation of commercial opportunities.

Clinical trials and other research activity should be an integral part of service delivery, such that the most effective and cost-effective service options can be determined. People with cancer need to have information on available clinical trials.

Research results from South Australia and elsewhere should be synthesised by expert groups in the future development of evidence-based guidelines and protocols for service delivery. The Department of Health and professional bodies should form expert groups to develop and endorse evidence-based guidelines and protocols, where they do not already exist.

There should be ongoing health-services research and audits in South Australia to assess quality of service delivery, efficiency of service, service outcomes, and service access and utilisation by all sectors of the population.

The cancer research workforce should be monitored in South Australia, together with the research undertaken, and research performance in the production of knowledge, health gain, and realisation of commercial opportunities.

The Department of Health should increase access to data for research and evidence-based practice by:

- Supporting the establishment of bio-specimen databases, blood and tissue banks that can be linked to population-based and clinical cancer registration systems.
- Updating the technology of the South Australian Cancer Registry and increasing access to registry data by the production of de-identified unit record files, cleared by the Human Research Ethics Committee, for use by authorised users in university departments and other research environments.
- Reconfiguring and promoting full coverage of cancer services by clinical cancer registration that includes data on stage, other prognostic indicators, treatment, and a range of quality indicators.
- Developing mechanisms for linking bio-specimen, population-based and clinical cancer registration, death registration, inpatient statistics, radiotherapy treatment, electoral roll, Health Insurance (MBS and PBS) and other relevant datasets.
- Working to streamline research ethics committee processes, such that administrative barriers to research data can be reduced, while maintaining high ethical standards.

The comprehensive information program would address data needs for basic, clinical, population health and health-services research.

Cancer information for parliamentarians

A better-informed political environment may give more appropriate support for cancer control initiatives. Performance indicators can be provided to strengthen accountability. National and international benchmarks would facilitate interpretation of these indicators.

The comprehensive information program would provide key performance indicators to parliamentarians annually. Performance indicators would cover trends in cancer, cancer-risk factors and their determinants, service access and utilisation, service quality and outcomes, consumer satisfaction with services, research performance, workforce and infrastructure statistics, and resource investment.



Recommendations

1. The Statewide Cancer Control Advisory Group oversee the development, implementation and periodic review of a comprehensive cancer information strategy. The strategy will address the information needs of all stakeholders and in relation to cancer, cancer services, and outcomes of cancer services, after a systematic evaluation of present information availability.
2. Develop and implement targeted information programs within the context of this broad information strategy, including information for:
 - The general community that systematically addresses shortfalls in information.
 - People with cancer, their families and carers that systematically addresses shortfalls in information.
 - Clinicians and other health professionals that will enable the provision of high-quality services.
 - Population health professionals and health-service planners, policy makers and administrators to address gaps in existing information.
 - Researchers that addresses the range of research activity from basic through to clinical, population health, and health services research.
 - For parliamentarians to inform them annually of cancer control performance in South Australia.
3. Include the provision of question prompts and information on planned care and allied service needs, for people with cancer.
4. Address needs of clinicians and other health professionals for generic and patient-centred information and for statistics for profiling practices for quality monitoring and audit.
5. Provide increased access for researchers to existing databases, re-engineer the South Australian Cancer Registry, re-engineer and extend clinical cancer registration across the State, and add value through linkage of existing data systems.
6. Streamline and simplify research ethics committee processes so as to reduce barriers to research data, while maintaining high ethical standards.

Appendix I – The Statewide Cancer Control Plan Committee and Expert Sub-committees

The production of this Plan was led by the Cancer Control Committee, with input from five expert sub-committees. The membership of the committees is listed below.

The Cancer Control Plan Committee

Dr Denes Marantos	Consultant Physician, Modbury Hospital	[Chairman]
Professor Ian Olver	Director, Cancer Services, Royal Adelaide Hospital	[Co-Deputy Chairman]
Professor Graeme Young	Director of Development, Flinders Centre for Innovation in Cancer, Flinders Medical Centre	[Co-Deputy Chairman]
Dr Michael Rice	Chairman – Clinical Senate Paediatric Oncologist Women's and Children's Hospital	[Clinical Senate Executive Sponsor]
Ms Danielle Nicolas	Community Representative	
Ms Louise Carroll/ Mr John Wishart	Health Consumer Alliance	
Ms Sandy Miller/ Mr Harold Stewart	Aboriginal Services Division, SA Department of Health	
Mr Nino DiSisto	Regional General Manager, Riverland Regional Health Service	
Dr Paul Jelfs	Director, Epidemiology Branch Department of Health	[Sub-committee Chairman]
Ms Jenny Richter	Executive Director, Strategic Planning and Service Development Southern Adelaide Health Service	[Sub-committee Chairman]
Ms Virginia Deegan	General Manager Royal Adelaide Hospital	[Sub-committee Chairman]
Ms Liz Hlipala	Director Human Resources Central Northern Adelaide Health Service	[Sub-committee Chairman]
Emeritus Professor Peter McDonald	Independent Consultant	[Sub-committee Chairman]
Associate Professor Brenda Wilson	Chief Executive, The Cancer Council South Australia (TCCSA)	[Chairman – Secretariat]
Ms Caroline Miller	The Cancer Council South Australia	[Executive Officer]
Ms Meryl Horsell	Acute Care and Clinical Services Department of Health	[Committee Secretariat]
Dr Linda Foreman	Group Executive, Research and Development, TCCSA	[Sub-committee Secretariat]
Ms Ellen Kerrins	Group Executive, Cancer Control Programs, TCCSA	[Sub-committee Secretariat]
Professor David Roder	Head, Cancer Statistics Unit, TCCSA	[Sub-committee Secretariat]

Ms Liz Abell	Manager, Cancer Support & Community Involvement Programs, TCCSA	[Sub-committee Secretariat]
Ms Sheryl Klingner	Manager, Communications, TCCSA	[Committee Secretariat]

The Cancer Control Plan Committee – Secretariat

Associate Professor Brenda Wilson	Chief Executive, The Cancer Council South Australia (TCCSA)	[Chairman]
Ms Caroline Miller	The Cancer Council South Australia	[Executive Officer]
Ms Meryl Horsell	Acute Care and Clinical Services Department of Health	
Dr Linda Foreman	Group Executive, Research and Development, TCCSA	
Ms Ellen Kerrins	Group Executive, Cancer Control Programs, TCCSA	
Professor David Roder	Head, Cancer Statistics Unit, TCCSA	
Ms Liz Abell	Manager, Cancer Support & Community Involvement Programs, TCCSA	
Ms Sheryl Klingner	Manager, Communications, TCCSA	

Population Health Expert Sub-committee

Dr Paul Jelfs	Director, Epidemiology Branch Department of Health	[Chairman]
Ms Lou Williamson	General Manager BreastScreen SA	[Deputy Chairman]
Ms Ellen Kerrins	Group Executive, Cancer Control Programs, TCCSA	[Sub-committee Secretariat]
Dr Katrine Baghurst	Division of Human Nutrition, CSIRO	
Dr Andrew Ellerman	Manager, QUIT SA	
Professor Janet Hiller	Department of Public Health, University of Adelaide	
Ms Barb Kirke	Manager, Cancer Prevention Unit, TCCSA	
Ms Sue Gilchrist/ Dr Lesley Shorne	Manager, Statewide Cervix Screening Program and Adelaide Bowel Cancer Screening Pilot Program/ Clinician, Statewide Cervix Screening Program	
Ms Dawn Thorp	Community representative	
Professor Graeme Young	Director of Development, Flinders Centre for Innovation in Cancer, Flinders Medical Centre	
Ms Michele Herriot	Director, Health Promotion SA, SA Department of Health	
Ms Catherine McKenzie	Local Government Project Officer, TCCSA	
Dr Carole Pinnock	Australian Prostate Cancer Collaboration	
Professor David Roder	Head, Cancer Statistics Unit, TCCSA	
	South Australian Divisions of General Practice	

Infrastructure Expert Sub-committee

Ms Virginia Deegan	General Manager Royal Adelaide Hospital	[Chairman]
Dr John Brayley	Acting Deputy Chief Executive Officer, Flinders Medical Centre	[Deputy Chairman]
Professor David Roder	Head, Cancer Statistics Unit, TCCSA	[Sub-committee Secretariat]
Mr David Johnston	Chief Information Officer, Health System Management – ICT Services, SA Department of Health	
Dr Linda Swaney	Adelaide Radiotherapy Centre	
Mr John Moss	Senior Lecturer, Department of Public Health, University of Adelaide	
Dr Michael Penniment	Department of Radiation Oncology, Royal Adelaide Hospital	
Dr Heather Tapp	Haematologist/Oncologist, Women's and Children's Hospital	
Dr Eric Yeoh	Director, Radiation Oncology Department Royal Adelaide Hospital	
Mr Brendan Hewitt	Acting Projects Director, Asset Services, Department of Health	
Dr Barry Chatterton	Director Medical Imaging, Department of Nuclear Medicine & Bone Densitometry, Royal Adelaide Hospital	
Ms Jenny Ball	Community representative	
Dr Murray Drummond	Community representative	

Clinical Services Expert Sub-committee

Ms Jenny Richter	Executive Director, Strategic Planning and Service Development Southern Adelaide Health Service	[Chairman]
Dr Leslye Long	Nursing and Patient Care Services, Royal Adelaide Hospital	[Deputy Chairman]
Ms Meryl Horsell	Acute Care and Clinical Services Department of Health	[Sub-committee Secretariat]
Dr Linda Foreman	Group Executive, Research and Development, TCCSA	[Sub-committee Secretariat]
Ms Liz Abell	Manager, Cancer Support & Community Involvement Programs, TCCSA	
Dr Robert Adams	Senior Lecturer, Department of Medicine, University of Adelaide The Queen Elizabeth Hospital Campus	
Dr Peter Bardy	Head, Department of Haematology-Oncology, The Queen Elizabeth Hospital	
Dr Martin Borg	Radiation Oncologist, Royal Adelaide Hospital	

Dr Peter Chapman	Chief Medical Advisor, Country Health, SA Department of Health
Ms Sandy Cleghorn	Clinical Nurse, Dept of Clinical Haematology and Oncology, Women's and Children's Hospital
Professor David Currow	Professor of Palliative and Support Studies, Flinders University Director, Southern Adelaide Palliative Services
Dr Bogda Koczwara	Head, Department of Medical Oncology, Flinders Medical Centre
Ms Courtney Oake	Consumer Representative
Professor Ian Olver	Director, Cancer Services, Royal Adelaide Hospital
Dr Graeme Suthers	Head, Familial Cancer Unit, SA Clinical Genetics Service Women's and Children's Hospital
Professor David Watson	Head, Department of Surgery, Flinders University
Associate Professor Helen Winefield	Clinical Program Director, Department of Psychology, University of Adelaide
Ms Liz Zwart	Clinical Lecturer, Department of Clinical Nursing, University of Adelaide
Dr Steve Birrell	Head, Surgical Oncology Unit, Flinders Medical Centre Senior Visiting Medical Officer, Dame Roma Research Laboratories, University of Adelaide
Dr Chris Bollen	General Practitioner Chair, South Australian Division of General Practice
Dr Margaret Davy	Director, Gynaecological Oncology Department, Royal Adelaide Hospital
Mr Nino DiSisto	Regional General Manager, Riverland Regional Health Service

Workforce Expert Sub-committee

Ms Liz Hlipala	Director Human Resources Central Northern Adelaide Health Service	[Chairman]
Ms Ellen Kerrins	Group Executive, Cancer Control Programs, TCCSA	[Sub-committee Secretariat]
Ms Maeve Downes	Nursing Unit Head, Dept of Clinical Haematology Oncology, Women's and Children's Hospital	
Associate Professor Eimear Muir-Cochrane	Division of Health Sciences, University of South Australia	

Ms Linda Saunders	Dean, School of Nursing and Midwifery, Flinders University
Dr Leon Bignold (proxy)	South Australian Salaried Medical Officers Association
Ms Jo Hoiles	Manager, Workforce Planning Unit, SA Department of Health
Associate Professor Dorothy Keefe	Senior Lecturer in Oncological Medicine, University of Adelaide
Ms Josie Kitch	Director, Allied Health, Flinders Medical Centre
Ms Lee Thomas	Branch Secretary, Australian Nursing Foundation (SA Branch)
Ms Debra Pratt	Principal Nursing Adviser, Nursing Services, SA Department of Health

Research and Evaluation Expert Sub-committee

Emeritus Professor Peter McDonald	Independent Consultant	[Chairman]
Professor Wayne Tilley	Dame Roma Mitchell Chair in Cancer Research, Hanson Institute	[Deputy Chairman]
Dr Linda Foreman	Group Executive, Research and Development, TCCSA	[Sub-committee Secretariat]
Professor David Roder	Head, Cancer Statistics Unit, TCCSA	[Sub-committee Secretariat]
Professor Robyn McDermott	Pro-Vice Chancellor, Division of Health Sciences University South Australia	
Dr Sandra Leggat	Senior Lecturer, LaTrobe University	
Professor Jim Bishop	Director, Cancer Institute NSW	
Professor Stephen Leeder	Public Health & Community Medicine, University of Sydney	
Professor D'Arcy Holman	School of Population Health, The University of Western Australia	
Mrs May Jackson	Community Representative	
Mr Barry Schultz	Managing Director, Schultz Pharmacy Group	
Professor Villis Marshall	Clinical Director, Surgical Specialties Service, Royal Adelaide Hospital	
Dr Jurgen Michaelis	Chief Executive Officer, Bio Innovation SA	
Mr Alwin Chong	Aboriginal Health Council of SA Inc	
Ms Kaye Hannaford	Consultant	
Ms Kate Castine	Community Representative	

Appendix II – Consultation Process

The developmental work for the Statewide Cancer Control Plan involved broad consultations. From the commencement it was noted that there were many people seeking involvement and so to facilitate the process a range of methods and opportunities were employed. During the course of chapter development, submissions were invited from several hundred individuals and agencies.

The following agencies and individuals were approached specifically and invited to contribute. Most of the groups listed accepted this invitation to provide information and feedback.

Targeted Consultations

- Department of Health: Health Portfolio Executive
- Central Northern Adelaide Health Service: Dr David Panter, Associate Professor Kaye Challinger
- Southern Adelaide Health Service: Mr David Swan, Ms Jenny Richter
- Children Youth and Women's Health Service: Ms Heather Gray, Associate Professor Victor Nossar, Dr Tom Revesz, Dr Scott Simmons
- Ms Gail Gago MP

Non-Government Organisations

- Palliative Care Council: Mr Andrew Taylor
- Leukaemia Foundation: Ms Angela Lawry-Jones, Mr Allan Hayward, Ms Dawn Thorpe
- Childhood Cancer Group: Mr Konrad Gawlick
- Canteen: Mr Lee Cooper
- Camp Quality
- Cancer Care Centre: Ms Sue Watchman
- Volunteering SA
- The Cancer Council South Australia: Ms Liz Abell, Ms Kate Cameron

Health Services / Service Providers

- Royal District Nursing Service: Palliative Care Group
- Lyell McEwin Health Service: Ms Dianne Rogowski
- The Queen Elizabeth Hospital: Ms Jan Hooper, Dr Peter Bardy
- Repatriation General Hospital: Ms Karen Glaetzer, Mr David Edwards
- Palliative Care Specialists: Professor David Currow, Ms Heather Broadbent
- Royal Adelaide Hospital: Dr Leslye Long, Dr Peter Robertson, Dr Ral Antic
- Noarlunga Health Service (NHS): Ms Heather Fraser
- Country Directors of Nursing
- Victor Harbour Health Service: Nurse Manager, Community Nursing Service Manager and Local GP
- Allied Health: Ms Josie Kitch
- Paediatric Oncologists
- Medical Oncologist Interest Group Chair
- Oncology Psychology RAH
- Population Health, Department of Health
- Carers Association
- Health Consumer Alliance

Private Oncology Groups

- Burnside War Memorial Hospital: Ms Jackie Thomson
- Ashford Hospital Cancer Centre
- Calvary Hospital
- St Andrews Hospital
- Flinders Private Hospital

Radiation Services

- Adelaide Radiotherapy Centre: Ms Katrina Rech
- Radiation Therapists Interest Group: Dr Adeline Lim

Aboriginal and Torres Strait Islander Groups

- Aboriginal Health Division, Department of Health: Ms Sandy Miller, Mr Harold Stewart, Ms Sonya Waters
- Aboriginal Health Council: Mr Alwyn Chong
- Nunkuwarrin Yunti: Ms Polly Sumner

Culturally and Linguistically Diverse Communities

- Multicultural Communities Council: Ms Vivian Hope
- Migrant Resource Centre of South Australia: Ms Cynthia Caird

Education Providers

- Department of Public Health, Flinders University: Dr Anne Johnson (representative of Professor Fran Baum)
- University of Adelaide: Professor Alison Tierney, Ms Liz Zwart
- TAFE: Ms Margaret Thornton
- Department of Public Health, University of Adelaide: Professor Janet Hiller

Professional groups

- Oncology Nurses Interest Group: Ms Liz Zwart
- Cancer Nurses Society of Australia: Ms Kate Cameron
- SA Divisions of General Practice: Dr Tori Wade
- South Australian Salaried Medical Officers Association
- Public Service Association
- Australasian College of Surgeons
- Australian Nursing Federation

Broader community consultation

Throughout the course of writing the Plan the community was kept informed about the work through The Cancer Council South Australia's *Progress Against Cancer* Newsletter and its website. A document entitled *Draft Cancer Control Plan – Summary for Community Consultation* was produced to facilitate further consultations with members of the broader community. Invitations were sent to 838 people who had involvement with The Cancer Council South Australia directly, or through other cancer community networks, the Health Consumers Alliance and Health Reform SA. Invitees were offered workshops or the option of completing a feedback form which could be returned by post or electronically. Interpreter services were available for people from culturally and linguistically diverse backgrounds.

Appendix III – Glossary

A

ADENOMA

A benign epithelial tumor having a glandular origin and structure. (Epithelium: Membranous tissue forming the covering of most internal and external surfaces of the body and its organs.)

AGE-STANDARDISED

Age distribution made comparable through statistical adjustment.

ALLOGENEIC BONE MARROW TRANSPLANT

Highly specialised treatment, used in the treatment of some malignancies.

ALTERNATIVE THERAPIES

Alternative therapies are used instead of conventional therapies to treat cancer. Most of these have not been scientifically tested or, have little evidence supporting their safety and effectiveness.

AT RISK

Describes an individual or group that is considered more susceptible to a certain health problem than the rest of the population, by virtue of their biological, social or economic status, behaviour or environment (contributing factors/risk factors).

B

BIOINFORMATICS

Refers to the use of electronic databases containing information on genomes, protein sequences and algorithms that are available to researchers to assist in solving information problems in the life sciences.

C

CANCER

A general term for abnormal cell growth and its uncontrolled spread. Cancer cells may grow into a lump called a malignant tumour. They may invade and damage surrounding tissue. Some may also break away from the original (primary) cancer and travel in the blood or lymphatic system to other parts of the body, where they form secondary tumours (metastases). The five main types of cancer are carcinomas, sarcomas, myelomas, lymphomas and leukaemia.

CANCER CONTROL

Cancer control is the universal term used to define the comprehensive strategies aimed at reducing the impact of this disease (research prevention, early detection, screening, treatment, support, palliation).

CARCINOGEN

Any substance that can cause cancer.

CARCINOMA

Cancer that starts in epithelial tissue, that is, tissue that forms the base of the skin and the lining of the body's inner surfaces (lungs, bowel, reproductive organs etc.)

CARE COORDINATOR

An identifiable coordinator of care who will know about the individual's disease, will assist the individual in moving between treatment settings, and ensure that all members of the treatment team are aware of the individual's situation. The care coordinator may be any member of the treatment team and may be a different person at different stages of the cancer journey.

CARE PLAN

Information provided to people with cancer about care and referral pathways so that they understand the pathways involved in their care.

CARER

A Carer is someone who provides care and support for their parent, partner, child or friend who has a disability, is frail aged, or who has a chronic mental or physical illness.

CHRONIC

Describing an illness that continues over a long time, with slow changes.

CHEMOTHERAPY

Drug therapy used to treat cancers that are known to have spread beyond the primary site, or as an addition to local treatment if there is a high probability that microscopic metastasis has occurred.

CLINICAL TRIAL

A clinical trial may be defined as a carefully designed, prospective medical study that attempts to answer a defined set of questions with respect to the effects of a particular treatment or treatments.

COMMUNITY PARTICIPATION (COMMUNITY INVOLVEMENT)

Involving people in the processes which affect their health. Some people use this term to refer to involving people in health promotion activities. Others use it to refer to involvement in decision-making structures that affect health, including intersectoral approaches to community health planning and promotion. Most effective participation occurs when a community's skills have been developed (community development), that is when a community is skilled in the processes of participation and decision-making.

COMPLEMENTARY THERAPIES

Complementary therapies are used together with conventional treatments. They do not cure cancer but may help relieve symptoms or side effects and improve well-being. Some examples of complementary therapies are acupuncture, aromatherapy, art therapy, massage therapy, mediation, visualisation and yoga.

CONTRIBUTING FACTOR

Any aspect of behaviour, society or the environment or anything else which contributes to a risk factor for a health problem, e.g. not having easy access to purchase condoms is a contributing factor for having sex without a condom, which is in turn a risk factor for contracting HIV. Contributing factors predispose, enable or reinforce risk factors, which are directly linked with the health problem. Some authors distinguish between risk factors and contributing factors on the basis that one is causally linked and the other is not but we prefer to maintain a distinction on the basis that a risk factor is directly linked with the health problem and a contributing factor is linked to the health problem via the risk factor – that is, it is a factor which contributes to or helps to explain the risk factor.

CONVENTIONAL TREATMENTS

Conventional cancer treatments have been through a wide range of tests to prove they are safe and have the effect of curing cancer, slowing its growth or providing relief from symptoms. The main conventional treatments are surgery, radiotherapy, chemotherapy and immunotherapy. Conventional treatments are sometimes called mainstream, medical, evidence-based or orthodox treatments.

CT

Computerised Tomography. Imaging technique involving taking cross-sectional images of the body by multiple small images that are built into a picture by a computer.

CULTURAL RESPECT

Cultural respect is the recognition, protection and continued advancement of the inherent rights, cultures and traditions of Aboriginal and Torres Strait Islander People.

D*DETECTION*

The discovery of abnormality or disease in the body. 'Early detection' is the discovery of an abnormality at an early stage when it is readily treated and in the case of cancer much more likely to be curable.

DIAGNOSTIC SERVICES

Tests and imaging services that assist in diagnosis and staging of cancer.

DNA

Deoxyribonucleic acid, the chemical in the nucleus of each cell that stores all of the genetic information for the body and is the inherited material that determines an individual's characteristics. It consists of a string of nucleotides strung together. Each nucleotide has a sugar and one of four different bases: adenine (a), thymine (T), guanine (G) and cytosine (C). The bases are like an alphabet and the sequence of bases spells three-letter words. The strand of DNA is a spiral shape and two strands twist around each other in what is called a double helix. The bases on one spiral are always paired to the same base on the other spiral, A with T and C with G. To read the code the strands unravel.

E*EPIDEMIOLOGY*

The study of factors that affect the incidence of disease. This is done by observing the variation in the incidence of disease under the differing conditions of life of different groups of people. Usually two large groups or populations of people are compared who are as similar as possible except for the characteristic being studied.

EVIDENCE-BASED GUIDELINES

A four-level rating system is recommended by the National Health and Medical Research Council in the 1999 publication: A guide to the development, implementation and evaluation of clinical practice guidelines, and is as follows:

Level I Evidence is obtained from a systematic review of all relevant randomised controlled trials.

Level II Evidence is obtained from at least one properly designed randomised controlled trial.

Level III-1 Evidence is obtained from well designed pseudo-randomised controlled trials (alternate allocation or some other method).

Level III-2 Evidence is obtained from comparative studies with concurrent controls and allocation not randomised (cohort studies).

Level III-3 Evidence is obtained from comparative studies with historical control, two or more single-arm studies, or interrupted time without a parallel group.

Level IV Evidence is obtained from case series, either post-test or pre-test and post-test.

F**G***GENETIC RISK*

The risk of cancer associated with the inheritance of abnormal gene/s from either or both parents.

GYNAECOLOGY ONCOLOGY

The field of oncology concerned with cancers of the female reproductive organs.

H*HEALTH BEHAVIOUR (HEALTH DIRECTED BEHAVIOUR)*

Any activity undertaken by an individual with the intention of maintaining, protecting or promoting health whether or not the activity is effective for that purpose.

HEALTH EDUCATION

Consciously constructed opportunities for learning which are designed to facilitate voluntary changes in behaviour towards a predetermined goal. It is closely associated with disease prevention and involves changing behaviours, which have been identified as risk factors for particular diseases. Targets individuals and groups, organisations and communities. In the past, health education was used to refer to the broad range of initiatives now covered by the term health promotion. The term health education now tends to refer to educational programs seeking to bring about voluntary changes in behaviour, but the reader should be aware that the broader meaning is still often used.

HEALTH INDICATOR

Health statistics selected for their capacity to summarize a larger body of statistics or to serve as indirect or proxy measures for a concept that cannot be directly measured e.g. infant mortality rate, life expectancy at birth. Health indicators purport to measure the health of a population. They are typically expressed as percentages, rates or ratios. Traditionally, health indicators have been seen as a subset of social indicators. More recently the distinction has become blurred, as the understanding of health and its concerns has broadened to overlap with social concerns. For example, population age profiles and employment rates are often used as indicators of levels of health.

HEALTH INTERVENTION

Any planned action, which is aimed at reducing a health problem by intervening in the existing causal chain. An intervention is the sum of all the strategies: that is, those events, circumstances or materials, which directly involve the target group or the community. An intervention may consist of one strategy or more than one.

HEALTH PROMOTION

The process of enabling individuals and communities to increase control over the determinants of health and thereby improve their health. Health promotion grew out of health education movement but can now be understood as an umbrella concept, which covers health education and a number of other approaches aimed at changing living conditions and lifestyles for the purpose of promoting health.

I*IMAGING*

Producing a representation of the form of the cancer. In relation to cancer, may use x-rays or scans (such as CT scans) to create an image of the cancer.

INCIDENCE

Rate of occurrence of new cases e.g. number of new cases per 100,000 members of population per year.

J**K****L***LEUKAEMIA*

Cancer that affects the bone marrow and organs that manufacture blood (lymph nodes, spleen). In leukaemia large numbers of abnormal white blood cells (known as leukaemic blasts) are produced and this suppresses the production of normal blood cells. Leukaemia may be acute, progressing rapidly over days or weeks, or chronic, progressing slowly over months or years.

LYMPHOMA

Lymphomas are divided into two major types: Hodgkin's disease and non-Hodgkin's lymphoma. Most arise in a lymph node but sometimes a non-Hodgkin's lymphoma may begin in lymph tissue in the stomach, bone or small intestine. Some non-Hodgkin's lymphomas tend to appear simultaneously in several parts of the body.

M*MAMMOGRAPHY*

Examination of the breasts using x-rays. The breast is compressed between two plates and can be x-rayed from above, from the side or obliquely.

MEDICAL ONCOLOGY

Medical specialty involved in managing cancer through use of chemotherapy.

MELANOMA

A very malignant form of skin cancer. Melanomas can occur anywhere on the body, including in the eye and the mucous membranes. A melanoma looks like a mole or freckle. It usually has an irregular outline and may vary in colour from black to almost white and in the early stages it is quite flat. The main symptom is a change in size, shape or colour over a period of weeks or months. A melanoma may start in an existing freckle or mole, but more often they start in normal-looking skin.

METASTASIS

An extension of the primary tumour. It develops in a part of the body away from the original (primary) cancer. When cancer cells break away from the original tumour and are carried by the lymph and blood systems to other parts of the body they are said to metastasise. Even though the metastasis may be far away it is not a new cancer. Also known as a secondary tumour or metastatic tumour.

MORBIDITY

Illness episodes. Morbidity data refers to data which describe the prevalence of different diseases and other health problems in the community. The main source of this is hospital admission records which include diagnosis, or reason for admission. Data collected by GP's, health centres, etc may also be used.

MORTALITY

Death. Mortality data on causes and number of deaths per year are collected by the Registrar General in each State. These are presented as proportions of the population by the Australian Bureau of Statistics.

MRI

Magnetic Resonance Imaging. A specialised imaging technique.

MULTIDISCIPLINARY CARE

In a multidisciplinary approach to care, a team, including specialists with all the relevant expertise, considers the treatment options, and the treatment plan is also developed by the team.

N**O***ONCOLOGY*

The study of cancer.

P*PAEDIATRIC ONCOLOGY*

The field of oncology concerned with cancer affecting children and adolescents.

PALLIATIVE CARE

Palliative care is the support of people who are suffering from an illness from which no cure can be anticipated.

The aim of palliative care is to maximise the quality of the person's life. This is achieved by coordinating and delivering a range of services in response to the individual needs of the person being cared for and the caregiver.

It is recognised that a range of problems, including physical, emotional, social and spiritual may need attention.

PATIENT CENTRED CARE

The care provided is organised around the individual's needs and wishes rather than for the convenience of organisations or their staff. This approach recognises that care can be improved by identifying and meeting the needs of the person throughout their journey. It also recognises that needs can be very different at different stages and therefore systems must be flexible in order to respond.

PET

Positron Emission Tomography. A medical imaging procedure.

PRE-CANCEROUS CONDITION

A growth that is not cancerous (malignant) but which may become a cancer if it is not treated, such as adenomas, which may develop into bowel cancer.

PRIMARY HEALTH CARE

Primary Health Care is both an approach to dealing with health issues as well as a level of health service. As an approach, there is a strong emphasis on working with communities and individuals to improve their health and well-being. It can include a range of strategies from health promotion, health protection, disease prevention, advocacy, social action and community development, through to screening for disease, early risk assessment, diagnosis, early intervention, treatment and rehabilitation, systematic chronic disease management and support for community living.

As a level of health service, Primary Health Care is often used to describe the first point of contact that a person has with the health system, such as general practice, community nurses, pharmacists, social workers and other health providers.

PRIMARY PREVENTION

Preventing disease occurrence by reducing risk factors for the disease.

PRIMARY TUMOUR

A malignant tumour (a cancer) starts in one site of the body where it is known as the primary tumour. At a later stage, cancer cells may break away from it and be carried to other parts of the body, where they may lodge and increase to form secondary tumours or metastases.

PROGRAM

A coherent series of activities, which together make up one strategy or more than one strategy, carried out with a group of participants for the purpose of improving the health status of the target group. This can be individual behaviour change, or environmental, legislative or other change. A program is usually planned in response to an established health need.

Note: Sometimes program is used synonymously with intervention program.

PSYCHOSOCIAL SUPPORT

Many people diagnosed with cancer face practical, emotional and psychological demands in addition to their physical health and similarly partners and families are also vulnerable to cancer-related distress. Psychosocial care/support aims to reduce this distress. Broad strategies include providing emotional, informational and practical assistance. Fostering an appropriate sense of well-being and hope is also an important part of this type of care.

PUBLIC HEALTH

Health and well being of whole population groups.

Q**R***RADIATION ONCOLOGY/RADIOTHERAPY*

Treatment with x-rays or gamma-rays.

RESOURCES

1. In terms of program planning – commitments of finances, staff time, expertise and energy and emotional commitments required to run a health program. Usually considered from the point of view of the providers of the program but may include resources from within the community or the program. Usually considered from the point of view of the providers of the program but may include resources from within the community of the program participants.
2. In terms of the health care consumer – personal, educational, financial, social and political capabilities to improve one's own situation, or to obtain help in doing so.

RISK

A measure of how likely a person is to develop a particular disease. Where people are at risk of developing a particular disease, this does not mean that the disease is certain to develop, but that they may have a greater-than-average chance of getting it. Similarly, people at low risk are less likely than others to develop it, though it could still occur. Therefore risk factors are any action that increases a person's chance of developing a particular disease, for example, overexposure to the sun is the major risk factor for skin cancer, and risk reduction describes techniques to reduce the chances of developing a particular disease, for example not smoking will reduce the risk of getting lung cancer.

RISK ASSESSMENT

Assessment of an individual's genetic risk of cancer on the basis of an evaluation of the family history of cancer.

RISK FACTOR

Something known to be associated with increased risk of a disease (may be genetic, environmental, behavioural or demographic).

RISK MARKER (RISK INDICATOR)

Any characteristic which signals where a problem is occurring and identifies individuals or groups as being at risk of a particular health problem. Risk markers are associated with the occurrence of the problem, but are not necessarily thought to cause the problem. Examples include age and sex. Risk markers usually cannot be changed or are not appropriate targets for intervention, but should be considered in planning the sort of intervention most likely to succeed.

S

SCREENING

Examining and/or testing a large number of people whom have no symptoms of a particular disease, to identify anyone who may have that disease. This enables the disease to be treated at an early stage, when cure is more likely. Examples include Pap tests to detect pre-cancerous changes of the cervix, and mammography to screen women for early breast cancers.

Screening refers to the application of a test to a population, which has no overt signs or symptoms of the disease in question, to detect unsuspected disease while a cure is still possible. The screening test does not diagnose illness, but is used to identify people who require further investigation to determine the presence or absence of disease. The purpose of screening an apparently healthy individual is to detect early evidence of an abnormality such as a risk factor (e.g. high blood pressure), pre-malignant changes (e.g. Pap test) or early malignancy (e.g. mammography) in order to recommend preventive strategies or treatment that will provide a better health outcome. It is a commonly held belief among health professionals and the community that 'early diagnosis' of a disease is beneficial and therefore screening is bound to be effective. However, it cannot be assumed that each person who is screened or diagnosed within a screening program for cancer will benefit from that diagnosis. Rather, sufficient lives will be altered by the early detection of the disease to result in a significant improvement in the health outcomes for the population in question.

Screening mammograms are used to look for signs of early breast cancer and may pick up small changes in the breast tissue often before the changes can be felt or noticed. It is an x-ray of a woman's breast using low dose radiation by compressing the breast between two plates for about 10-15 seconds while the x-ray is being taken. Screening mammograms do not cure breast cancer from developing in the future, nor are they 100% effective.

Diagnostic mammograms are for women who have a current breast symptom or breast change. A doctor's referral is required for which a Medicare rebate is available.

SECONDARY PREVENTION

Early detection and treatment to prevent further disease progression.

SKIN CANCER

The most common form of cancer in Australia. It affects all age groups from adolescence upwards. Skin cancer rates in Australia are higher than anywhere in the world. There are three main types: basal cell carcinoma (BCC), squamous cell carcinoma (SCC), and melanoma. All start in different parts of the outer layer of skin. Skin cancer is caused by the ultraviolet rays in sunlight.

SOCIAL EPIDEMIOLOGY

The study of the distribution and determinants of ill health, with particular and sophisticated reference to social phenomena and dependence on sociological theory. Social epidemiology emphasises that some health problems, such as depression, may have social causes, and may respond to a social solution.

SOCIAL INDICATOR

A directly measurable variable used as a measure of the wellbeing of individuals in a community, which is not directly measurable. For example, population age distribution, income levels, educational attainment, house or car ownership, and life expectancy.

Traditionally health indicators have been seen as a subset of social indicators.

SURVEILLANCE

Assessment for evidence of cancer or pre-malignant lesions in a healthy, asymptomatic person who is at increased genetic risk of developing cancer.

SURVEY

An investigation in which information is systematically collected from a population sample eg face-to-face inquiry, self completed questionnaire or telephone survey.

STAGING EVALUATION

Determining the extent of cancer by additional testing to see how far it has spread. The stage of cancer can be associated with its prognosis and can determine whether it can be adequately treated with local treatments such as surgery and radiotherapy.

T

TARGET GROUP

Those members of a community for whose benefit a health goal is constructed and a health intervention carried out. These people are usually the program participants or intervention group although in some cases the participants might be another group of people who will pass on the benefit to the target group. For example, a parent drug education program may be aimed at reducing drug abuse in children in which case the children are the target group and the parents are the intervention group.

TUMOUR

A new or abnormal growth of tissue in or on the body. A tumour may be benign (not cancer) or malignant (a cancer). The term 'neoplasm' usually describes malignant tumours.

U

V

W

X

Y

Z

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STATEWIDE CANCER CONTROL PLAN 2006 – 2009

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