



Statewide Cancer Control Plan 2011 - 2015

February 2011



Foreword

About 1 in 3 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.

All the evidence shows that the early detection plus new and innovative treatment of cancers over the past decade has led to much better outcomes for people in the community. More than half of all cancers are successfully treated, and survival rates for some common cancers have increased by more than 20 per cent in the past two decades.

This reflects well on the quality of treatment services and the positive effects of screening and other initiatives to find cancers early at a more treatable stage. South Australian cancer survivals are at the high end of the international range and are improving progressively over time.

Nevertheless cancer continues to be a growing public health problem with South Australia's ageing population and the increasing number of people with cancer posing a real challenge for our health system and our community.

An additional concern is the difficulty in developing and sustaining an adequate cancer workforce the lack of which has the potential to limit progress made in all other areas of cancer control.

The Statewide Cancer Control Plan 2010–2015 incorporates further developments in our knowledge and understanding of all aspects of cancer risk, incidence, workforce and control as well as reflecting improvements which have been achieved in the management of cancer in South Australia since the launch of the 2006–2009 Plan. Many professionals who are experts within the cancer sector as well as consumers have again contributed significantly of their time, knowledge and expertise to develop this updated Statewide Cancer Control Plan. The goodwill and dedication of these people is reflected in the plan.

Hon John Hill
Minister for Health

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Introduction

In February 2006, South Australia launched the Statewide Cancer Control Plan 2006–2009. The Plan was developed by The Cancer Council South Australia and SA Department of Health working in partnership. The Plan was developed under the auspices of the Clinical Senate which comprised consumer and community representatives and professionals working across all areas of cancer control: cancer prevention and early detection programs, cancer treatment and care settings, infrastructure and workforce planning, research and evaluation. The Statewide Cancer Clinical Network was formed in 2007 to take this work forward, as part of the SA Health Care Plan.

The new Statewide Cancer Control Plan 2010–2015 builds on the comprehensive work that was done to develop the original Plan. It reflects the considerable progress that has already been made under the leadership of the Cancer Clinical Network and in the regional health services. It provides updated information and recommendations to provide a way forward.

Like the document that preceded it, the Statewide Cancer Control Plan 2010–2015 calls for the systematic application of current knowledge and investment to generate new knowledge, to reduce the impact of cancer. It 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.

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 between more and less advantaged sectors of the community in cancer risk and cancer outcome 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.



Professor Brenda Wilson
Chief Executive, Cancer Council SA



Professor Dorothy Keefe
Chairman, Cancer Clinical Network

Executive summary

This plan is the second SA Cancer Control Plan developed to guide the provision of cancer control and care in SA. The first plan, released in 2007, combined high level, aspirational direction and targets with operational actions designed to prevent lifestyle-attributed cancers and to improve the cancer journey for people diagnosed with cancer.

This next plan has been produced as a collaborative effort between Cancer Council SA and the SA Cancer Clinical Network. Its development and the achievements in cancer control to date reflect the value of the partnership between SA Health and Cancer Council SA in achieving cancer prevention and better outcomes for people with cancer. This partnership will continue in response to the directions outlined in this plan and as new opportunities arise. Within this partnership, the differing roles and responsibilities are acknowledged.

The outcomes to be achieved and the motivation behind this second SA Cancer Control Plan remain consistent with the first plan; to reduce the incidence of cancer occurring in SA's population; improve the cancer journey for those diagnosed with cancer; and increase long term survivorship after diagnosis.

The collaborative relationship between SA Health and the Federal Government in advancing cancer care is acknowledged. Cancer service development in SA will be supported with new funding secured from both state and federal sources. SA has been the beneficiary of a series of significant Federal investments including:

- funding to expand and develop cancer services across country SA
- funding, in partnership with CanTeen, to establish a Youth Cancer Service
- project funding through Cancer Australia supporting development of the cancer network and development of evidence based pathways and protocols.

It is recognised that the nature of the relationship between the Federal Government will continue to evolve, and SA will continue to work with its national and jurisdictional partners to maximise opportunities to improve cancer care.

There have been many significant achievements in improving cancer control since the release of the Statewide Cancer Control Plan 2007-2009. These achievements are summarised below, and many represent the first stages of longer term strategies.

Achievements to date

Cancer Prevention

- Implementation of the SA Tobacco Control Strategy
- Implementation of the community-based healthy weight program – OPAL and the Right Bite healthy food in schools program
- Implementation of SunSmart skin cancer prevention initiatives in schools and social marketing campaigns
- Implementation of the National Bowel Cancer Screening program
- Appointment of Bowel Cancer Screening coordinators

Optimising Care

- Establishment of the Cancer Clinical Network
- Development of a series of evidence based tumour stream pathways to guide clinical care
- Establishment of multidisciplinary team cancer care planning meetings across many tumour streams
- Establishment of Regional Cancer Services
- Development of the Country Health SA model of cancer care
- Establishment of a statewide Adolescent and Young Adult cancer service

- Funding secured to establish additional chemotherapy units across country SA
- Expansion of the public radiotherapy services to Lyell McEwin Hospital

Infrastructure

- Construction of the radiotherapy unit at Lyell McEwin Hospital completed
- Funding secured to build a new cancer centre at Whyalla
- Funding secured to expand the Lyell McEwin Hospital single radiotherapy unit to two Linear Accelerator capacity
- Funding secured to improve information and communication technology linkages between country health services and metropolitan specialist services
- Building of the Children's Cancer Centre at The Women's and Children's Hospital
- Creation of Adolescent and Young Adult space in Royal Adelaide Hospital
- Funding secured for the establishment of an online chemotherapy prescribing system

Workforce

- Appointment of new cancer care coordinators in major tumour stream specialties
- Appointment of Cancer Directors to regional services

Quality

- Development of a cancer quality framework with a series of performance indicators for monitoring targeted priority areas
- Development of standards for administration of chemotherapy

Research

- Establishment of the SA Cancer Research Collaborative
- Secured \$20million in cancer research funding over the next five years
- Establishment of the Flinders Centre for Innovation in Cancer

Information

- Upgrading of Cancer Registries due for completion in 2011
- Establishment of the Data Linkage program

Future directions and opportunities

The next phase of cancer development is focussed on embedding and completing work that has commenced, as well as implementing those pieces of newly funded work that are still in planning or design stages. The Cancer Pathway developed by the Cancer Clinical Network, provides the framework for identifying the next phase of improving cancer outcomes.

This new plan identifies key areas of focus for action over the coming years. These areas are:

- Cancer prevention
- Optimising care
- Service development
- Infrastructure
- Workforce
- Quality
- Research
- Information.

Recommendations

Cancer Prevention

- 1 Cancer prevention strategies that focus on health protection and health promotion are continued
- 2 Early detection strategies to promote participation in cancer screening programs are continued

Optimising Care

- 3 The Cancer Clinical Network continues its advisory role to ensure that the provision of cancer care is optimised and to monitor the impact of the cancer model of care
- 4 Consumer engagement in cancer service planning and the design of implementation strategies continues

Service Development

- 5 Regional Health services, through their regional cancer service, continue to work collaboratively with the Cancer Clinical Network and Cancer Council SA to implement the 2nd SA Cancer Control Plan and oversee provision of quality cancer care
- 6 The model of cancer care is consistently applied across public SA Health services
- 7 Improved access for people in country SA to specialist cancer care across the care modalities, including chemotherapy and radiotherapy
- 8 Aboriginal and Torres Strait Island peoples with cancer feel better supported throughout their cancer journey

Infrastructure

- 9 Capital works programs to expand cancer services are completed as follows:
 - Whyalla Cancer Centre
 - Chemotherapy units in 10 country sites
 - Expansion of the radiotherapy facility at Lyell McEwin Hospital.
- 10 Implementation of the SA Health Information and Communication Technology Strategy to develop information and communication technology linkages that allow real-time communication/information flow between the specialist metropolitan cancer centre 'hubs' and the rural cancer unit 'spokes'
- 11 Expansion of the South Australian Cancer Registry to enable timely collection of comprehensive cancer clinical data from all hospitals

Workforce

- 12 Scope of practice guidelines which include core competencies and training requirements for the cancer workforce, including the nurse practitioner role, are developed
- 13 Programs that maintain the skills and competencies of the cancer workforce across metropolitan and country areas are implemented

- 14 A detailed analysis of the impact of cancer service development on the cancer workforce, including the applicability of advanced practice roles, is undertaken at a point when service changes become clearer

Quality

- 15 The cancer care quality framework is implemented across regional cancer services
- 16 Information systems are in place to collect data to monitor and evaluate cancer outcomes

Research

- 17 A Cancer Research Collaborative develops high quality cancer research programs in SA across the fields of biomedical research, clinical research, population health research and health services research and evaluation
- 18 A research translation and evaluation program is developed to ensure research findings are communicated and incorporated into service delivery and programs

Information

- 19 A comprehensive range of cancer information that is readily accessible is developed
- 20 The project to expand South Australian Cancer Registry data is completed

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 SA Health collates this data for South Australia. Incidence refers to the number of new cases which are found and reported in a specific time period.

In 2006 there were 8,592 invasive cancers reported to the South Australian Cancer Registry, 57% of them in males and 43% in females.¹ The ten leading types of cancer in 2006 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.

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.² Overall 3,436 cancer deaths were notified to the South Australian Cancer Registry for 2006, of which 55% were in males and 45% in females.¹ The ten leading causes of cancer death in 2006 are shown in Figure 2.¹

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.³ 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.³ In general, incidence rates are higher in metropolitan than non-metropolitan areas, partly due to higher rates for lung cancer and non-Hodgkin lymphoma in urban settings.¹

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.⁴ 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

Figure 1 Cancer incidence—ten leading cancers notified to the South Australian Cancer Registry in 2006, numbers by site (non-melanoma skin cancers excluded)

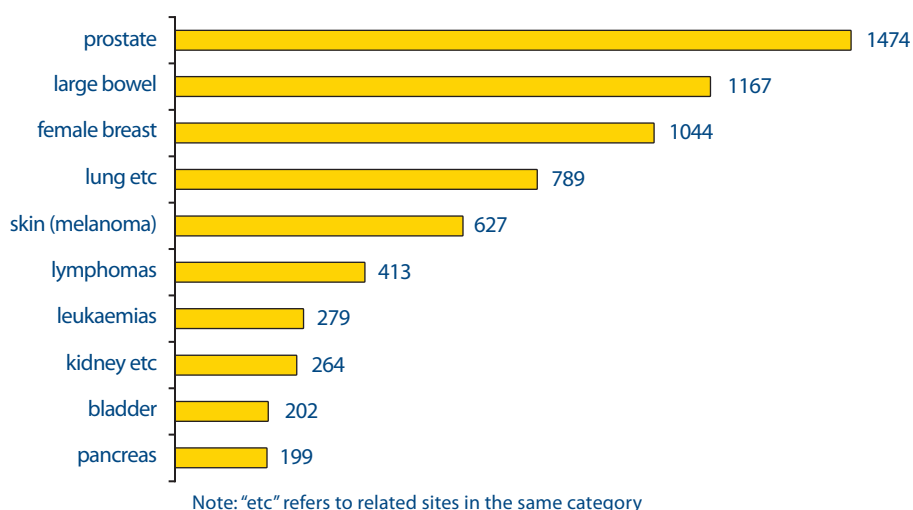
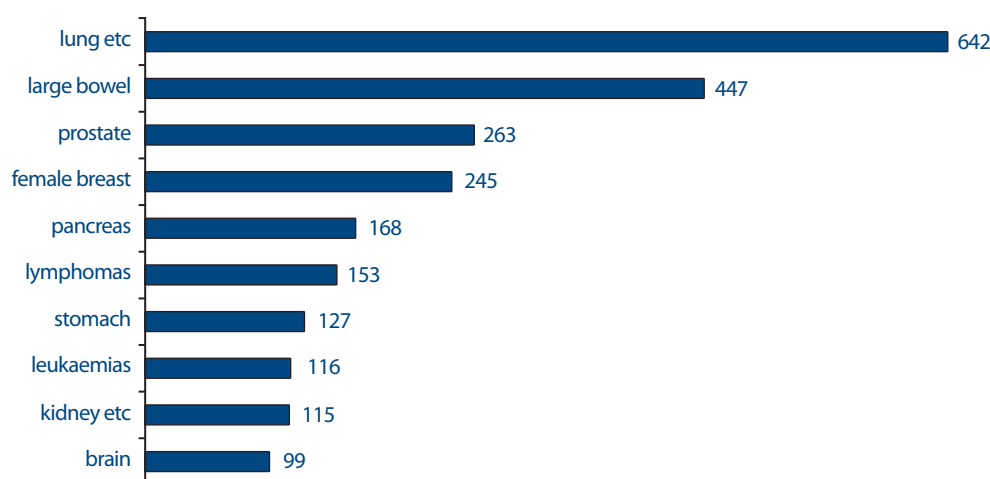


Figure 2 Cancer mortality—ten leading causes of cancer deaths notified to the South Australian Cancer Registry in 2006, numbers by site (non-melanoma skin cancers excluded)



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

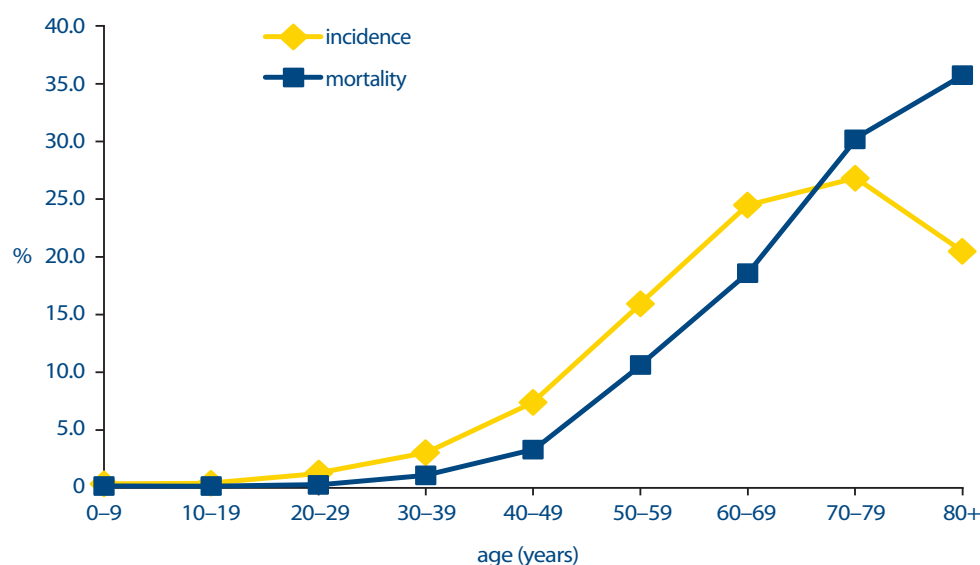
treatment access, quality and compliance; as well as major social and environmental challenges that would need to be overcome for effective prevention.

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 2006.

Numbers of new cancers and deaths from cancer are increasing. Globally, the World Health Organization reports that more than ten million people are diagnosed with cancer every year, and estimates that there will be 15 million new cases every year by 2020.¹ In the 30 years to 2006, the number of South Australians diagnosed with cancer each year more than doubled.¹ It is projected that the number of cancers diagnosed in South Australia each year will increase by around

Figure 3 Percentage distribution of cancer diagnosed in 2006 and cancer deaths occurring in 2006 in South Australia



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

22% between 2006 and 2016.⁵ The number of deaths from cancer has also increased over the past 30 years and is also predicted to increase by around 22% between 2006 and 2016.⁵

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.

There are other factors that influence the observed increases in numbers of new cancers, such as improved detection of new cancers. Increases in the incidence observed in South

Australia reflects increased detection of cancer through breast (mammography) screening, the early detection of melanoma and prostate testing. However increases in incidence have also occurred for cancers of the female breast, skin (melanoma), large bowel (colon/rectum), lung (in females) and non-Hodgkin lymphoma.

Figures 4 and 5 contain age-adjusted rates of cancer incidence and cancer deaths, as published by the South Australian Cancer Registry. Age-adjusted rates control for changes in the profile of the population and allow for comparisons in rates of cancer incidence and cancer death. As evident in Figure 5, when controlling for the increasing longevity of the South Australian population, mortality from cancer has decreased since the early 1990s.

Figure 4: Annual age-adjusted incidence of cancer per 100,000; South Australia, 1977 to 2006 Age-standardised to the Australian Population (2001) (Non-melanoma skin cancers excluded)

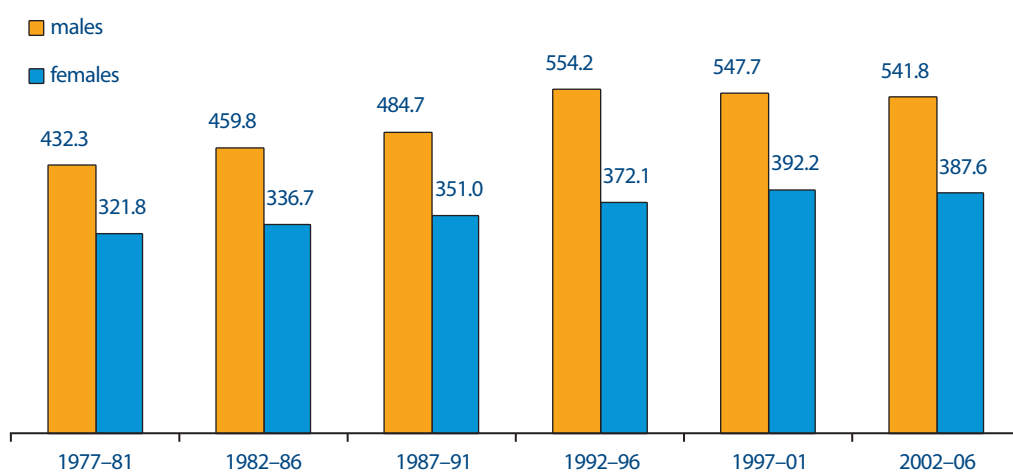
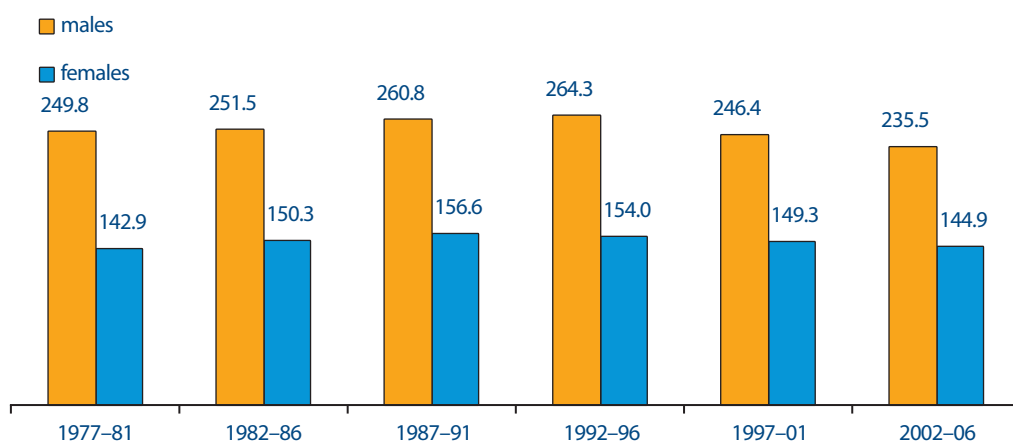


Figure 5: Annual age-adjusted cancer death rates per 100,000; South Australia, 1977 to 2006, Age-standardised to the Australian Population (2001)



Cancer prevention and early detection

Summary

Cancer prevention and early detection of cancer are essential components of cancer control. Primary prevention of cancer aims to prevent as many cancers as possible from ever occurring. This is achieved by minimising people's exposure to cancer-causing agents; and by promoting and facilitating cancer-preventing behaviours. Over half of all cancers could be prevented by acting on existing knowledge about tobacco control, improvements in diet, physical activity, healthy body weight, sun protection, and reduced alcohol consumption. 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 a stage preceeding clinical presentation, leads to a reduction in risk of development of invasive disease and mortality.

There are many cancer prevention and early detection strategies with demonstrated effectiveness. Effective cancer prevention and early detection involves ensuring that people understand what causes cancer and encourages people to change their behaviour so they can reduce their risk. It involves legislation and other public policy measures to ensure that people live and work in environments that reduce cancer risk and facilitate cancer-preventing behaviours. It involves social marketing to promote and motivate cancer-preventing behaviours. It also involves providing a range of services and programs that are accessible and affordable to the community.

The goals for reducing cancer risk, increasing cancer prevention, and increasing early detection are:

- South Australians live and work in environments that minimise exposure to carcinogens (cancer-causing agents) and are conducive to cancer-preventing behaviours
- South Australians understand how to reduce the risk of cancer through healthy lifestyle and act on this information
- South Australians have ready access to high-quality, evidence-based, affordable cancer prevention, early detection and screening programs, services, and information.

Cancer prevention, like much of health promotion, requires a comprehensive approach and long-term commitment.

Achievements to date

- Implementation of the SA Tobacco Control Strategy
- Implementation of the community-based healthy weight program – OPAL and the Right Bite Healthy Food in Schools program
- Implementation of SunSmart skin cancer prevention initiatives in schools and social marketing campaigns
- Implementation of the National Bowel Cancer Screening program
- Appointment of Bowel Cancer Screening coordinators

Recommendations

1. Cancer prevention strategies that focus on health protection and health promotion are continued.
2. Early detection strategies to promote participation in cancer screening programs are continued.

Population health and cancer prevention

Many different factors impact on individual health and population health. These determinants can be socio-economic, environmental, behavioural (such as tobacco use), biomedical (such as blood cholesterol or blood pressure) or genetic factors.⁶ The socio-economic, environmental and behavioural factors which precede or predict rates of cancer also predict many other chronic diseases, such as heart disease and diabetes. Intervening to prevent cancer will also improve other health outcomes.

Cancer prevention is commonly referred to as either primary prevention or secondary prevention. Primary prevention is about preventing illness, in this case cancer, before it happens. This is done through reducing exposure to risk factors for cancer. Secondary prevention is about early detection of cancer and intervention to stop or slow existing disease.

The conceptualisation of health recognises that a range of social, economic, cultural, political and physical environmental factors contribute to health. Thinker in Residence Ilona Kickbush recognised that "...social gradients in our society make it difficult for large sections of the population to make healthy choices and to navigate the health system".⁷ Inequalities exist in the incidence, early detection, treatment and outcomes of cancer for people in all socio-demographic groups. There are differences in exposure to the social and physical factors which impact on health. There are also differences in health behaviours and participation in cancer screening. These differences contribute to the observed inequalities in the prevalence of different cancers and stages at which cancers are detected in different groups across South Australia. Reducing inequalities requires that people have equitable access to relevant and affordable programs and services. Reducing inequalities is also about enhancing the power that people have to act upon the circumstances of their lives that determine their health. 'Health literacy' initiatives are designed to address these inequalities.⁷

Addressing legislative, policy and structural issues requires whole of government input

and collaboration as many factors are beyond the jurisdiction of the health sector (see Health in All Policies approach).⁷ However, there is a place for leadership from SA Health in advocating for cancer control programs. Local governments are responsible for many public spaces, and local planning has a role in providing shade and environments conducive to physical activity.

At national level, Cancer Australia, the Australian Government's national cancer agency, is providing national leadership in cancer control to ensure national cancer control, prevention, treatment and care are evidence-based.

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. The Cancer Council Australia National Cancer Prevention Policy Document also advocates for a concerted and comprehensive national approach to the prevention of cancer.

The multiple poor health effects caused by a small cluster of very important risk factors has prompted the development of overarching chronic disease management strategies. The SA Health Primary Prevention Plan provides a comprehensive framework to address primary prevention of multiple diseases, including many cancers.

Over the years, there has been an increase in understanding the nature, causes and means of controlling cancer. An increasing evidence base links lifestyle factors, environmental exposures and familial or inherited factors with cancer. This increased understanding has led to increased detection, control, and prevention.

Understanding cancer risk

Cancer risk refers to the chance that a person will develop 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 reduce risk. Current estimates indicate that around half of all cancers are due to lifestyle factors and therefore are largely preventable.⁸ The

relationships between different cancers and many cancer risk factors amenable to behaviour change are outlined in Table 1. There are also predisposing conditions which contribute to cancer risk, such as infection with Human Papilloma Virus and the likelihood of cervical cancer, and Hepatitis B and C and the likelihood of 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 predisposition to common cancers have been identified. Around 5% of specific types of cancer are considered to involve the inheritance of a strong genetic predisposition. 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.

There are factors in the environments in which people live and work that also contribute to cancer risk. Estimating the proportion of cancer attributable to occupational exposures is complicated and difficult, as the effects can be subtle and the timeline between exposure and cancer diagnosis can be long. A number of estimates have been made, with some researchers suggesting that as little as 2% of new cancer cases are due to workplace exposures. Other estimates are as high as 11%. Primary prevention is the most reliable way to reduce occupational cancer. Occupational health and safety legislation and employers have important functions in eliminating cancer-causing agents in industry, and introducing physical controls to isolate and otherwise separate cancer-causing substances from workers. Examples of primary prevention include: eliminating workplace exposure to

Table 1: Factors known to increase and decrease cancer risk^{10,11}

	tobacco	UV radiation	alcohol	body fatness	physical activity	diet		
						fruit & vegetables	specific nutrients in foods	meat
colorectal			↑↑ men ↑ women	↑↑	↓↓	↓ garlic	- fibre - calcium	↑↑ red meat ↑↑ processed meat
breast (plus ↓↓ lactation)			↑↑	↓ premenopausal ↑↑ postmenopausal	↓ post-menopausal			
prostate							↓ lycopene ↓ selenium ↑↑ calcium	
lung	↑↑					↓ fruit	↑↑ beta-carotene	
skin		↑↑						
leukaemia	↑↑							
kidney	↑↑			↑↑				
bladder	↑↑							
stomach	↑↑					↓	↑ salt	
pancreas	↑↑			↑↑			↓ folate	
oesophageal	↑↑		↑↑	↑↑		↓		
mouth, pharynx, larynx	↑↑		↑↑			↓		
liver								
endometrial				↑↑	↓			

↑↑ Evidence of increased risk is convincing ↓↓ Evidence of decreased risk is convincing

↑ Evidence of increased risk is probable ↓ Evidence of decreased risk is probable

Note: Other relationships between behavioural factors and cancer risk have been noted in some studies.

tobacco smoke; reducing exposure to UV radiation; and ensuring adherence to asbestos removal procedures.

Awareness and understanding of the relationship between different factors and cancer risk vary. As might be expected, after 30 years of community education, community awareness that tobacco smoking and sun exposure increase the risk of cancer is high. Community awareness of other factors such as healthy body weight and alcohol exposure is far lower by comparison. Frequently there is disproportionately high concern about factors that have a relatively low risk of causing cancer. The Health Omnibus Survey⁹ is a representative survey of approximately 3,000 South Australians aged 15 and over. In 2006 respondents were asked a number of questions about their perceptions of cancer risk. Figure 6 shows South Australians' perceptions about the importance of a range of factors and contribution to cancer risk.

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. The incidence of these cancers is not increasing in South Australia nor is there current compelling evidence 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, despite limited evidence of harm.

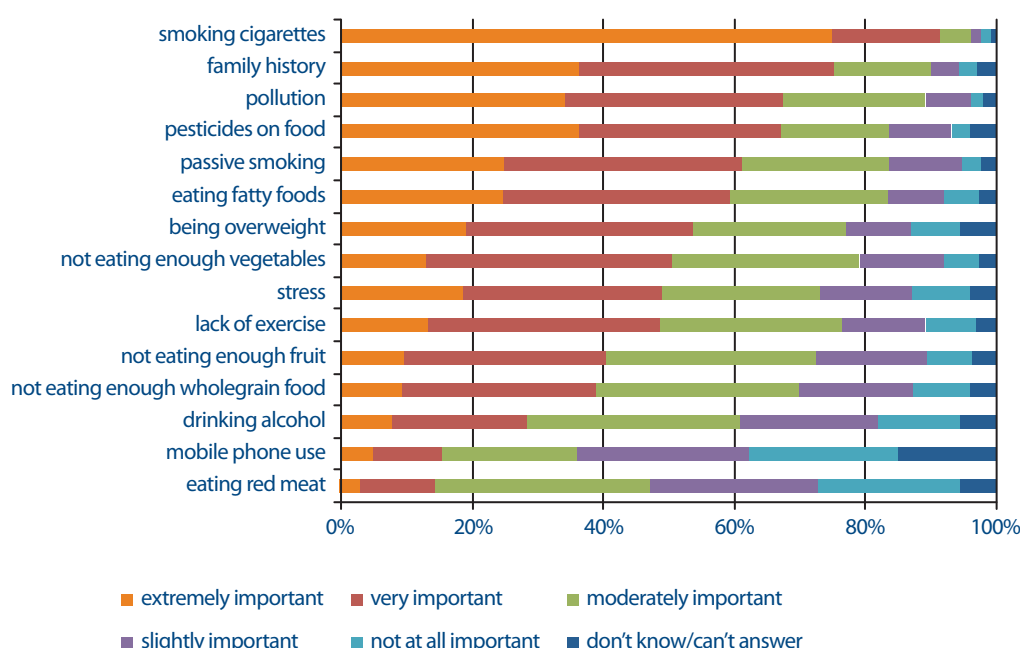
As noted in the National Health and Hospitals Reform Commission report, *A Healthier Future for All Australians*,¹⁰ an emphasis on prevention and the promotion of 'wellness' is seen as central to reform in health care in Australia. Within the report, a focus on developing health literacy and fostering community participation and engagement is acknowledged as a method to promote a focus on prevention and a healthier Australia.

Lifestyle risks

Tobacco smoking

Tobacco contributes significantly to cancer causes and deaths. 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.¹¹ Quitting smoking and avoiding exposure to second-hand tobacco smoke can reduce the risk of cancer considerably. There have been major advances in reductions of tobacco smoking over recent decades. For example, after the Second World War, 75% of

Figure 6: Perceived importance of cancer risk factors¹²



men smoked. In contrast in 2007 only 22% of South Australian men smoked.¹² Tobacco exposure also occurs from passive smoking. While legislation has reduced passive smoking in workplaces, enclosed public spaces and cars carrying children, many South Australians are still routinely exposed to passive smoking; for example, in confined public spaces and at home.¹²

Sun protection

Excess sun exposure and a high prevalence of people with fair skin is responsible for Australia's exceedingly high levels of melanoma and non-melanoma skin cancers.^{13,14} There is also increasing evidence that vitamin D, metabolised in the skin after UV radiation exposure, may protect against certain types of cancers¹³⁻¹⁶ and can be beneficial in reducing the risk of osteoporosis. Therefore a balance is required between avoiding an increase in the risk of skin cancer and achieving enough UV radiation exposure to maintain adequate vitamin D levels. More detailed information is available from Cancer Councils.¹⁷

Non-melanocytic skin cancers (NMSC) are the most common cancers diagnosed in Australia¹⁸ and are comprised of 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 Melanoma remains the fourth most commonly diagnosed cancer in South Australian men and the third most commonly diagnosed cancer in South Australian women.¹

To reduce exposure to ultraviolet radiation, Cancer Council SA promotes the use of five skin protection strategies when the UV radiation level is 3 and above. The use of the SunSmart UV Alert together with wearing protective clothing, hats, sunscreens, and sunglasses; and the use of shade is encouraged to protect the skin from overexposure to the sun. The SunSmart UV Alert also promotes sun-protective environments. In 2007 only 14% of South Australians adequately protected themselves when exposed to the sun by reporting they regularly used a combination of wearing a hat, cover-up clothing and applying SPF30+ sunscreen during summer. Some separate behaviours were more prevalent: shade seeking—80%; wearing 30+ sunscreen—57%; wearing a hat—49% and wearing covering

clothing—33%.⁹ Almost a third of South Australian adults and three quarters of secondary school students reported getting burnt in the last summer.^{9,20} The proportion of people reporting sunburn in the preceding summer period reduced from about 38% in 1999 to 31% in 2007.

Nutrition, physical activity and healthy weight

Nutrition, physical activity and healthy weight are all independent contributors to cancer risk. They also contribute to a number of other health conditions including heart disease and type-II diabetes.

Dietary guidelines recommend two serves of fruit, five serves of vegetables and five or more serves of cereal per day.²¹ Most South Australians do not meet these recommendations, with only 8% having an adequate intake of vegetables and 46% having adequate intakes of fruit. Increased intakes of vegetables, fruit and high fibre grain foods can lower a person's risk of developing some forms of cancer such as bowel and gastric cancers.^{22,23} High intakes of animal fats (saturated fats) and meat are considered to increase a person's risk of developing some forms of cancer such as bowel and breast cancers.²⁴

Physical activity recommendations have varied as evidence about cancer risk and physical activity has emerged. Most recently, the International Agency for Research in Cancer recommended that people be moderately physically active, (equivalent to brisk walking) for at least 30 minutes every day. As fitness improves, it is recommended that people aim for 60 minutes or more of moderate, or for 30 minutes or more of vigorous, physical activity everyday.⁸ In 2007, only 23% of South Australians were undertaking 60 minutes of physical activity per day; 57% were undertaking some activity but not sufficient to reduce cancer risk; and 20% were sedentary (undertaking no physical activity).

Physical activity and nutrition also contributes to weight control. The prevalence of obesity in Australia has more than doubled in the past 20 years.²⁵ Over half of South Australian adults are overweight or obese.⁹ Obesity increases the risk for bowel, breast, endometrial and kidney cancer. Obesity also increases the risk

of developing heart disease and diabetes.²⁴ To achieve and maintain a healthy weight, Cancer Council Australia recommends regular physical activity and eating to meet energy needs. Eating patterns should be consistent with national healthy eating guidelines. Making vegetables, fruit, cereals and other low energy density foods the basis of an individual's diet will assist with achieving and maintaining healthy body weight.

Alcohol

The latest international review of the health effects of alcohol confirms the association between alcohol consumption and an increased risk of cancer.⁸ Cancer Council Australia recommends that people limit or avoid alcohol to reduce cancer risk. The National Health and Medical Research Council has revised downwards its maximum consumption recommendations to two standard drinks per day for men and women. Notably, applying this definition, one in five South Australians aged 15 years or more would be at risk from excess alcohol consumption.⁹

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 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.¹⁷

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. The conceptual framework for implementing a screening program was proposed by Wilson and Junger for the World Health Organization (see Figure 7).²⁶

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. Current evidence demonstrates that premature mortality can be reduced through breast, cervix and large-bowel screening. It is important that uptake of screening within a population be maximised to increase the benefits. Of particular concern is the relatively low screening coverage among Aboriginal and Torres Strait Islander people.

Figure 7: 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.

It is recognised that population growth and the general ageing of the population will increase pressure on screening services.

Breast screening

Mammography screening can reduce breast cancer mortality by 30% or more in screened women.²⁷ Biennial screening with mammography is advocated for Australian women in the 50–69 year age range.²⁷ Approximately 56% of South Australian women in this age range received mammography screening in the public sector during a two-year period ending 31 December 2007. Estimates of the proportion receiving mammography investigations through the private health sector are not known. However on the basis of previous surveys, it would be expected that in excess of 70% of women of this age range would receive mammography screening or other mammography testing within a 24 month period.²⁷ 30% of women in this age range remain at increased risk of breast cancer. This proportion is higher in Aboriginal and Torres Strait Islander women than other women.⁴

Cervical screening and HPV vaccination

Cervical screening can reduce the risk of squamous cell carcinoma of the cervix by 90%.²⁸ Approximately 65% of South Australian women aged 20–69 years, who have an intact cervix, receive a Pap test within a given two-year period, whereas about 78% do so within a three-year period, and 88% within five years.²⁸ Lowest screening coverage relates to women under 25 years of age and those over 65 years of age.²⁸ Comparatively low screening rates apply in the far north of South Australia and in the northern metropolitan suburbs of Adelaide. 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.²⁹

Prophylactic vaccination against human papilloma virus (HPV) 16/18 has the potential to prevent up to 70% of cervical cancers. The uptake of the vaccines is influenced by perceived benefits and risks and needs to continue to be promoted through communication strategies with health

professionals, parents, women and adolescents, which are sensitive to culture, religion and age.¹⁷

Immunisation should positively impact on under-screened groups and populations with a higher incidence of cervical cancer. In Australia Aboriginal women are more than four times more likely to die of cervical cancer than other Australian women.³⁰ This difference is in part due to lower participation of this group in the National Cervical Screening Program. Vaccinating Aboriginal girls and women should reduce the incidence and mortality from cervical cancer but this will require better understanding of their barriers to participation. Targeted efforts are required for this at-risk population.

The HPV vaccine and Pap tests will remain important in preventing cancer of the cervix.

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.¹⁷ In recent decades there has been considerable interest in identifying modifiable risk factors associated with bowel cancer. Many modifiable risk factors have been identified, including diet, physical activity and alcohol consumption.⁸

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%.³¹ The two objectives of bowel cancer screening are:

- 1 to prevent cancer by identifying and removing pre-cancerous advanced adenomas
- 2 to diagnose and treat early stage curable cancer.

In 2006 the Australian Government started the first phase of a nationally coordinated, population-based bowel cancer screening

program. By 2009 people who turned 50, 55 or 65 were eligible to participate in this program. Expansion of the eligibility criteria and increased participation among those eligible will maximise the population benefit of bowel cancer screening.

Prostate cancer testing

In 2006 prostate cancer was the most commonly diagnosed cancer (apart from non-melanoma skin cancer) in South 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.³²

Population-based screening of asymptomatic men is not advocated for by most Australian health authorities. Preliminary results from two current randomised controlled trials,^{33,34} have reported mixed findings. The US trial of annual screening³⁴ reported no difference in prostate cancer deaths after seven years follow-up however the control group reported high levels of annual screening (increased to 52%). The European trial of four-yearly screening reported a 20% reduction in prostate cancer death rate with median nine years follow-up in the screened group but at the expense of a high rate of over-diagnosis. Widespread community concern about prostate cancer is 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.³⁵⁻³⁷ The latest results highlight the importance of this approach. However Australian studies suggest that this frequently does not occur.³⁸⁻⁴⁰

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

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, shared lifestyles, or environmental factors; however in approximately

5% of cases there is a strong genetic element, with an inherited predisposition to cancer due to gene mutation.⁴¹ 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.

High risk surveillance

Cancer types which are particularly amenable to high risk surveillance are those in which risk can be reliably stratified and which offer a treatment which is both cost-effective and demonstrates population level reductions in morbidity and mortality. Currently such systems are known to be very effective for those at high risk of breast, cervical and colorectal cancer and potentially for other cancers.

Best practice surveillance programs include:

- a comprehensive data base
- matching individuals to a risk profile for the specific cancer in question using their personal and family history and/or pathology reporting according to a risk protocol
- identifying and referring those who will benefit from genetic testing and counselling
- systematised recall and follow-up.

Issues in cancer screening and early detection

Population cancer screening aims to reduce morbidity and mortality from the disease.²⁶ There is evidence on the effectiveness of screening for cancers of the breast, cervix and colorectum.

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. No other cancer is currently regarded as a good candidate for population cancer screening at this time.²⁶

Population participation is the key to successful screening. Increasing participation by under-represented population sub-groups is also important. Behavioural research and interventions aimed at overcoming barriers to participation are essential.

Reducing cancer risk, preventing cancer and detecting cancer early

There is growing evidence about the effectiveness of different strategies to bring about changes that reduce cancer risk. Sustained social marketing of quitting smoking and sun protection messages have demonstrated their effectiveness in raising awareness and also motivating behaviour change.

Almost half of cancers that occur 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.⁸ Reduced exposure to environmental carcinogens at work and in other settings would also assist in the prevention of cancer. This provides an enormous opportunity to reduce the impact and burden of cancer on the community.

Promoting Healthy Living

Improving the health literacy of all South Australians is fundamental to the health reform program. Programs that promote healthy living and increase public awareness of the link between elements of healthy lifestyle and cancer risk will continued to be implemented:

- The SA Eat Well Be Active Healthy Weight Strategy aims to assist the community to make healthy lifestyle choices through progressing work in four key areas: community education; school and community programs; policy and legislation; and workforce development. Activities relating to nutrition, physical activity, body weight and alcohol consumption, and reducing children's exposure to the marketing of unhealthy food and drinks are included in this strategy.

- The Obesity Prevention and Lifestyle (OPAL) program is targeting improving the eating and activity patterns of children and increasing the proportion of 0 to 18 year olds in the healthy weight range.

Tobacco Control

The implementation of a South Australian Tobacco Control Strategy commenced in 2005 with a focus on:

- high-quality social marketing campaigns promoting quitting smoking
- providing access to effective cessation support for those wanting to stop smoking
- controlling tobacco promotion
- reducing involuntary exposure to second-hand tobacco smoke in confined outdoor spaces
- targeted tobacco control strategies to population groups with higher rates of smoking including Aboriginal and Torres Strait Island peoples.

The South Australian Tobacco Control Strategy was updated in 2010 and will continue to guide efforts to reduce tobacco smoking.

Sun Protection

The campaigns to achieve greater public awareness of the skin cancer risk associated with ultraviolet radiation should continue to be implemented. These include:

- continuing advocacy for comprehensive skin protection policies in South Australian schools
- monitoring of solariums to ensure compliance with legislation
- educating of older people about the importance of early detection of skin cancer
- working to increase general practitioner skills in diagnosis of early skin cancer.

Participation in screening programs

The promoting and fostering of participation in cancer control screening programs will continue through a series of targeted actions to:

- increase participation of women in the 50–69 years target group in screening mammography
- increase participation in cervical cancer screening and cervical cancer vaccination programs
- advocate for expansion of the National Bowel Cancer Screening Program
- increase participation in screening programs in targeted high risk groups, e.g. Aboriginal and Torres Strait Islanders, culturally and linguistically diverse groups, and familial cancers.

The positive impacts of change

The ultimate goal of cancer prevention and early detection is to reduce the morbidity and premature mortality associated with cancer via effective and efficient prevention and early detection strategies. The benefits will be for individuals whose disease is prevented and well-being improved; for the health system in reducing/levelling extreme demand for services; and for the population in terms of limiting health cost paid from taxes and increased community well-being.

Cancer prevention and early detection initiatives in South Australia are grouped into three key areas:

1. Health Protection:

- legislation is used appropriately to regulate for better population health
- cancer risk is reduced by healthy environments, organisations, products, policies and practices
- supportive environments exist to make healthy choices easier

2. Health Promotion:

- people increase control over and improve their health through use of lifestyle, societal and personal resources
- fewer people take up smoking and existing smokers are encouraged to quit
- harmful exposure to tobacco smoke among non-smokers is eliminated

- people of all ages protect themselves throughout life against harmful levels of solar UV radiation and avoid exposure to other sources of UV radiation
- people of all ages consume nutritionally adequate and varied diets based primarily on foods of plant origin such as vegetables, fruit, pulses and wholegrain cereals; as well as lean meats, fish and low fat dairy products
- people maintain minimum levels of physical activity: for adults at least 30 minutes of moderate-intensity activity on most days of the week, for children and adolescents at least 60 minutes
- South Australians maintain (or achieve) a healthy body weight through a balance of food intake and physical activity

3. Prevention and Early Detection:

- public health is improved through effective surveillance, screening and prevention programs
- cancer risk reducing behaviours are well recognised by health authorities, health professionals and the community
- eligible South Australians participate in bowel, breast and colorectal cancer screening programs
- access to cancer screening programs for South Australians is equitable
- the community is well informed about screening and prevention programs .

Optimising cancer care

Summary

Most Australians are affected directly or indirectly by cancer at some stage of their lives.⁴² For every person their 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 affected people should be provided with continuous and seamless care by an integrated service.

Opportunities to optimise cancer care in South Australia are constantly sought. To ensure that services are patient-centred and continue to meet the needs of people with cancer, their families and carers.

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.

Much work to optimise cancer care is in progress, under the auspices of the Cancer Clinical Network. A significant component of this work has been the development of an overarching cancer care pathway. This pathway is guiding the development of cancer services and informing the development of a series of tumour-specific clinical pathways. A pathway to guide the care of adolescents and young adults with cancer has also been developed.

The goals for optimising cancer care are:

- cancer care is patient-centred and is focused on meeting the needs of people with cancer, their families and carers
- the model of care in SA is evidence based and reflects best practice
- cancer care reflects consumer principles, in particular as described within the Cancer Australia consumer Group Consensus Values Statement and as described within the Charter of Paris Against Cancer, 2000

Achievements

- establishment of the Cancer Clinical Network
- development of a series of evidence based tumour stream pathways to guide clinical care
- establishment of multidisciplinary team cancer care planning meetings across many tumour streams

Recommendations

1. The Cancer Clinical Network continues its advisory role to ensure that the provision of cancer care is optimised and to monitor the impact of the cancer model of care.
2. Consumer engagement in cancer service planning and the design of implementation strategies continues.

Ensuring cancer care is patient-centred and meets need

There is opportunity to focus more closely on meeting the needs of people with cancer, their families and carers and ensure that services which deliver cancer care are patient-centred.^{42,43}

Increasingly Australian people, advocate for an active role in the design, provision, and evaluation of quality health care, incorporating cancer care. The National Health and Hospitals Reform Commission report, *A Healthier Future For All Australians*⁴⁴ emphasises the need for voice, choice, and the fostering of community participation to facilitate informed choice.

Cancer Australia's National Consumer Advisory Group (NCAG) Consensus Values Statement also describes principles and values concerning consumers' role in cancer care. The Consensus Values Statement also reflects the mission statement of the Charter of Paris Against Cancer; a ten point Charter containing directives and a commitment towards the worldwide treatment and prevention of cancer. Cancer Australia's NCAG endorses as part of its values statement the following Charter of Paris Against Cancer Articles:

- Article VII: advocate the rights of people affected by cancer to be comprehensively informed and to be engaged in all phases of cancer treatment, research and policy making
- Article VIII: stress the fundamental importance of the patient's quality of life regardless of the stage of the disease and its prognosis.

In addition to having a right to be fully informed and supported in decision making throughout the cancer experience, access to multidisciplinary treatment and the provision of a support plan is emphasised as a core value within the NCAG Consensus Values Statement. The support plan should incorporate the cultural, emotional social, physical, psychological, spiritual and sexual needs of people affected by cancer.

People with cancer express a desire to understand their care and treatment options.^{42,43} Cancer treatment or care plans need to be understandable, individualised,

and regularly reviewed. 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.

Addressing the psychosocial needs of people with cancer, their families and carers, is an integral component of cancer care. Its importance is recognised within the Clinical Practice Guidelines for the Psychosocial Care of Adults with Cancer,⁴⁵ the National Service Improvement Framework for Cancer⁴³ and international best practice guidelines such as those endorsed by the National Institute for Clinical Excellence.⁴⁶ The understanding and definition of supportive care is based upon the original definition proposed by the National Council for Hospice and Specialist Palliative Care Services:⁴⁷

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

As emphasised within the National Service Improvement Framework for Cancer,⁴³ supportive care should be:

- underpinned by open and sensitive communication
- provided to people with cancer and their carers throughout the cancer pathway
- given equal priority as with other aspects of clinical care
- integrated and coordinated
- informed by theories, models and frameworks drawn from diverse sources
- the responsibility of all health and social care professionals delivering care.

There is a particular need to improve mechanisms to address cancer diagnosis and cancer care delivery for Aboriginal and Torres Strait Islander people. This includes addressing the barriers that impair access to primary

health care, diagnostic services, treatment services, 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 are oriented to the needs of 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 includes 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 is presented in plain language and in languages other than English
- information for people with cancer and their carers is presented in a way that is appropriate and culturally sensitive and addresses the 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
- all people with cancer have an agreed verbal or written care plan.
- people with cancer have their care coordinated by an identified coordinator of care; a care coordinator may be cancer nurse, general practitioner or another member of the care team.

It was recognised that the needs of country South Australians are not fully understood, particularly in the area of diagnosis, referral to specialists, and access to a multidisciplinary team. In response to this, CanNET SA and Australian Better Health Initiative (ABHI) Cancer Care Coordinators collaborated to undertake a consultation process with rural consumers and clinicians to determine and prioritise their particular needs.

CanNET SA, with the Cancer Network, has also developed a consumer survey which will

be used at regular intervals to determine the cancer patients' perspectives of cancer care and service delivery within South Australia.

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.⁴⁸ 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 includes clear pathways for care so that the person with cancer and their professional and non-professional carers are able to identify appropriate pathways in their care.

Care coordinators have been identified as a way to enhance the coordination of care and assist people with cancer to move between treatment settings.^{42,43} 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.

People with cancer have identified gaps in the coordination of cancer services which include delays in treatment, lack of appropriate follow-up, and seeing different doctors at each visit.⁴² 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.

Comprehensive cancer care

The Cancer Clinical Network has developed a comprehensive cancer pathway model with the aim to improve and standardise cancer care for all South Australians, regardless of location, origin, age or financial status.

The cancer pathway model is based on available evidence and clinical expertise, with a strong emphasis on clinical and supportive care within the local South Australian context. It identifies key points across the cancer journey, factors that impact on patient care needs, as well as a series of pillars essential to supporting high quality care.

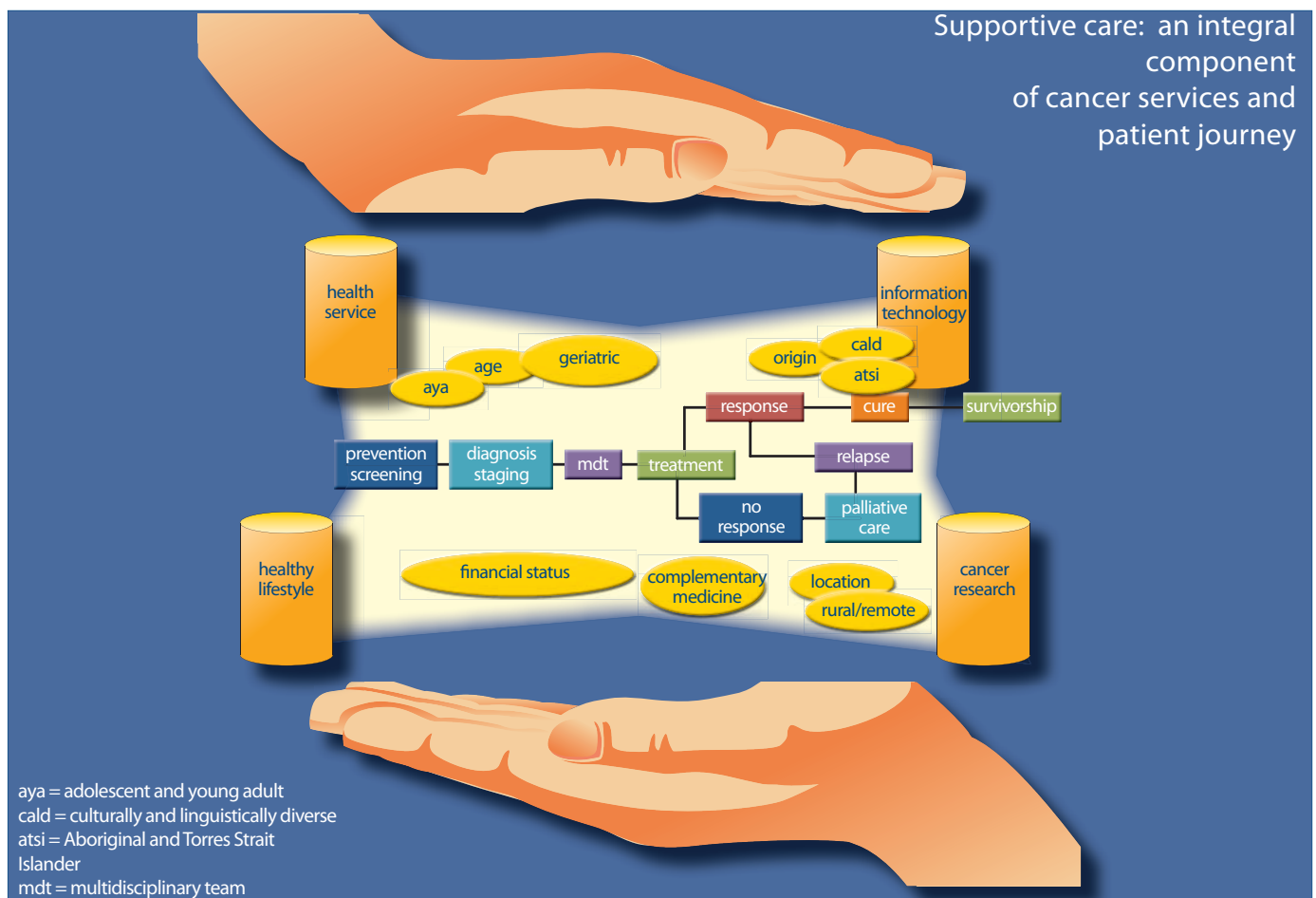
Clinical pathways

In addition to the cancer pathway model, a series of cancer type (tumour) specific pathways are being developed. These clinical pathways are developed by dedicated working parties including cancer specialists, multidisciplinary membership from across public and private health services, non-government organisations, general practitioners, and consumers.

The working party utilises the common cancer pathway model as a basis for individual pathway development to ensure consistency with the concept, as described in figure 8.

The pathways provide recommendations based on current evidence for best practice in the management of patients diagnosed with particular cancers. They include timeliness benchmarks for care provision

Figure 8: Cancer pathway



and recommend suitable key performance indicators to monitor practice. The pathways adopt a multidisciplinary approach with involvement of all professionals in the care of people with cancer.

The aims of the pathways are:

- to improve care and outcomes for patients with cancer
- to provide guidance in patient management in order to reduce the wide variations in current practice observed throughout South Australia
- to encourage appropriate referral and early diagnosis in the general population and in high-risk groups
- to ensure that all patients with cancer are offered the best chance of cure or palliation irrespective of where they present or are treated
- to optimise care delivery for cancer patients at all stages of their disease in South Australia.

Three pathways have been completed: Upper Gastrointestinal (GI) Cancer; Lymphoma; and Adolescents and Young Adults (AYA). These pathways were chosen as a starting point for a cancer pathway development program as they included the major clinical components of cancer care including surgery, medical oncology, radiation oncology, and supportive care. They required consideration of a broad range of factors which influence care such as age, location, culture, and family. Major themes of focus for the pathways have included equity in access, referral processes, links within regions and primary care and access to multidisciplinary teams for all diagnoses.

The development of these three pathways has been supported by the Cancer Service National Network Program of South Australia (CanNET SA); a Cancer Australia initiative and funded by the Australian Government.

Creation of standards, monitoring of benchmarks and key performance indicators has been a central concept in the development of the pathways. This includes developing standard operating procedures for pre-chemotherapy nursing assessment across rural and metropolitan areas, and commencement

of similar procedures to guide medical assessment.

Utilising the pathway approach for Upper GI Cancer, Lymphoma, and AYA has enabled considerable progress against the original Statewide Cancer Control Plan 2006–2009. These achievements include: establishment of two evidence based multidisciplinary teams; trialling of MDT Administrative Coordinator roles; Cancer Care Coordinator projects (in partnership with the Australian Better Health Initiative project and CanNET); and SA pathology implementing synoptic pathology reports for an increasing number of cancer types.

In addition to the clinical pathways there are dedicated pathway documents for consumers, for people from culturally and linguistically diverse backgrounds, and for Aboriginal and Torres Strait Islander people.

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.⁴³ Members of the multidisciplinary team may include diagnostic clinicians in each area, surgical oncology disciplines, radiation oncology, medical oncology, palliative care, pathology and imaging, general practitioners, oncology nurses, psychologists, dieticians and other allied health professionals. Multidisciplinary care is widely advocated as a method to improve clinical outcomes in cancer.⁴⁹

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

- all people with cancer 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 occurs 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 are able to access comprehensive rehabilitation including physical reconstruction and long-term follow-up.

Types 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, molecularly targeted anti-cancer therapy, 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, 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.

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.⁴⁵ Psychosocial care must recognise the individual needs of people with cancer, their families and carers, and may include spiritual care, community support services, financial assistance, cancer support programs, relationship and sexual counselling, and grief, loss and bereavement counselling. People with cancer should be made aware of and encouraged to utilise available cancer support services.

The use of clinical practice guidelines relevant to the continuum of care across the cancer pathway needs to be consistently applied across all cancer services. Examples of such guidelines are *Clinical Practice Guidelines for the Psychosocial Care of Adults with Cancer*,⁴⁵ and *Standards for Providing Quality Palliative Care for all Australians*.⁵⁰

End of Life care

End of life care is non-curative and defined in terms of maximising comfort and providing psychosocial supportive care. Primary health care providers may provide some end of life care for some people with cancer, while for others specialist palliative care services may be needed. Palliative care can include chemotherapy and radiotherapy. Adequate care during the end-of-life period includes the development of effective relationships with health professionals as early as possible, a seamless transition between services, and a high level of communication and collaboration between the health professionals involved. Significant barriers include health professionals' reluctance to broach the issue of palliative care early in the cancer journey and/or people with cancer's varying interest in exploring it. The SA Palliative Care Service Plan⁵¹ provides the framework for improving and expanding the provision of end of life and palliative care in South Australia. Effective palliative care provision is also informed by Palliative Care Australia's Standards for providing quality palliative care and their Strategic Plan.^{50,52}

Children, adolescents, and young adults with cancers

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 evidence that better outcomes for some young people with some cancers can be achieved using paediatric treatment protocols.

Cancer in adolescents and young adults (AYA) requires particular attention because of the potential for this group to fall in a 'gap' between paediatric and adult services. There are psychosocial differences between this age group, children, and adults. In addition, there is a lack of clinical research data about this group, and low participation rates in clinical trials. There is evidence of delayed diagnosis and referral as well as lower improvements in survival rates than are being seen in other age groups. It is recognised that what is required is appropriate, safe, and effective services delivered as locally as possible, rather than local services as safely as possible.

As the types of cancer that occur in AYA are quite unique, the signs and symptoms often differ from those seen in older adults or younger children. There is a need to raise awareness of the possibility of cancer as a diagnosis with adolescents and young adults themselves, and also to educate health professionals regarding the symptoms and signs of cancers in this age group. An education program to promote this issue is required for both consumers and health professionals. This work is underway. The clinical referral system can be more complex for adolescents and young adults who are often treated in both a paediatric and an adult setting.

There is a need for a simplified referral system for these patients to make negotiation of a complex system easier. Based on the model developed by the Statewide Cardiology Clinical Network, it is envisaged that referrals for AYA with cancer can be made through a single statewide telephone access number i.e. a resourced '1800 AYA cancer' referral line.

Older people with cancer

Cancer is predominantly a disease of older people. Just as children are not 'adults but smaller', older people are not just 'adults but older', and cancer in older people brings with it added complexities. Onco-geriatrics is an emerging field recognising that patients benefit from accessing the combined expertise in the fields of oncology and geriatrics. The Royal Adelaide Hospital Cancer Centre, in partnership with the hospital's Department of Geriatric and Rehabilitation Medicine, and as a pilot project for the South Australian Cancer Network, has set up a screening service for geriatric patients with cancer.⁵³

Cancer services development

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, opportunities must continually be sought to enhance service delivery by improving service accessibility and better coordinating and integrating with primary health care.

The goals for developing cancer services include that:

- comprehensive care is multidisciplinary, fully integrated and coordinated
- care is based on best practice, with a research base that informs future care
- cancer, or its precursors, are detected as early as possible and people diagnosed with cancer experience timely referral to appropriate specialist cancer care
- care is delivered as close to home as safely as possible, recognising that some specialised treatments need to be given in a tertiary level setting
- cancer services include monitoring of safety, effectiveness, efficiency, satisfaction, waiting times, accessibility and equity of outcomes
- equitable access to services is provided for people from all areas of SA

Achievements

- Establishment of Regional Cancer Services
- Appointment of Cancer Directors to regional services
- Development of the country health SA model of cancer care
- Establishment of a statewide Adolescent and Young Adult cancer service

Recommendations

1. Regional Health services, through their regional cancer service, continue to work collaboratively with the Cancer Clinical Network and Cancer Council SA to implement the 2nd SA Cancer Control Plan and oversee provision of quality cancer care.
2. The model of cancer care is consistently applied across public SA health services.
3. Access to specialist cancer care across the care modalities for people in country SA is improved by increasing cancer services provided in country general hospitals and larger country hospitals.
4. Aboriginal and Torres Strait Island peoples with cancer feel better supported throughout their cancer journey.

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.⁵⁴ However, Australians have good outcomes of cancer care by world standards, with lower cancer death rates seen in Australia than in Europe and most other comparable countries.^{54–56}

About 50% of people with cancer survive their cancer for 20 years or more. Furthermore this proportion of long-term survivors is increasing.^{48,57} 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 fourteen people are living with a history of cancer diagnosed within the past five years.⁵⁸ 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.

Cancer service delivery model

There has been 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 chronic phases of the disease; for people in all treatment and care settings; and for people from all sectors of the South Australian community. The Statewide Cancer Control Plan 2006–2009 included a model for a statewide integrated cancer care service based on the existing configuration of services. The model focused on defining how existing services could initially interrelate, and then evolve toward an ‘ideal’ model more closely aligned with population need and delivering more services locally.

The cancer service delivery model continues to be one aimed at optimising the experience and cancer outcomes for people with cancer, their families and carers. The cancer service model maximises coordination and integration of cancer services to provide accessible, high

quality, multidisciplinary, patient-centred cancer services for all South Australians.

The cancer service model, illustrated in figure 9, describes all cancer service delivery points function as elements within an integrated service, delivering quality cancer care for the population. This includes clear links between treatment settings and well-defined corridors that facilitate ongoing communication.

The cancer service model will facilitate consistency of standards of care. It will also ensure that regardless of where a person with cancer first enters the ‘system’, they have access to the same quality of care and options for care.

The model of cancer service delivery is being consistently applied across public SA health services. It includes a focus on the following areas:

- patient cancer care regimes, including their supportive care needs, are planned by a multi-disciplinary team
- statewide, standardised protocols for administration of chemotherapy are in place
- clinical practice guidelines are consistently applied in all cancer services
- tumour stream clinical pathways are implemented
- cancer care is delivered by a skilled and credentialed cancer workforce.

The cancer service delivery is being applied within the health reform environment that has emerged since the release of the SA Health Care Plan 2007–2016. The SA Health Care Plan includes a clinical service delivery matrix that is directing changes in health care provision across metropolitan and country health care infrastructure.

With the service profiles of hospitals and health services across SA being refocused, different levels of treatment and expertise are being provided in different treatment settings.

The comprehensive cancer centres based in the major metropolitan hospitals have collaborative links with other cancer service delivery points in smaller metropolitan and country hospitals, primary health care and

associated health services. Cancer services in country general hospitals are being expanded to increase the amount of cancer care that is delivered in country SA.

Given South Australia's population size and regional health profile, some highly specialised cancer services will continue to be provided in a single location as statewide services. This will include the management of rarer cancers, and services where there are small numbers of specialists. 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).

The treatment setting accessed by the person with cancer will continue to be determined by

a range of factors including the type and stage of cancer, the type of treatment required and the preferences of the person with cancer.

The treatment setting for the level of cancer services is described in table 2.

Figure 9: Statewide Integrated Cancer Service Delivery Model

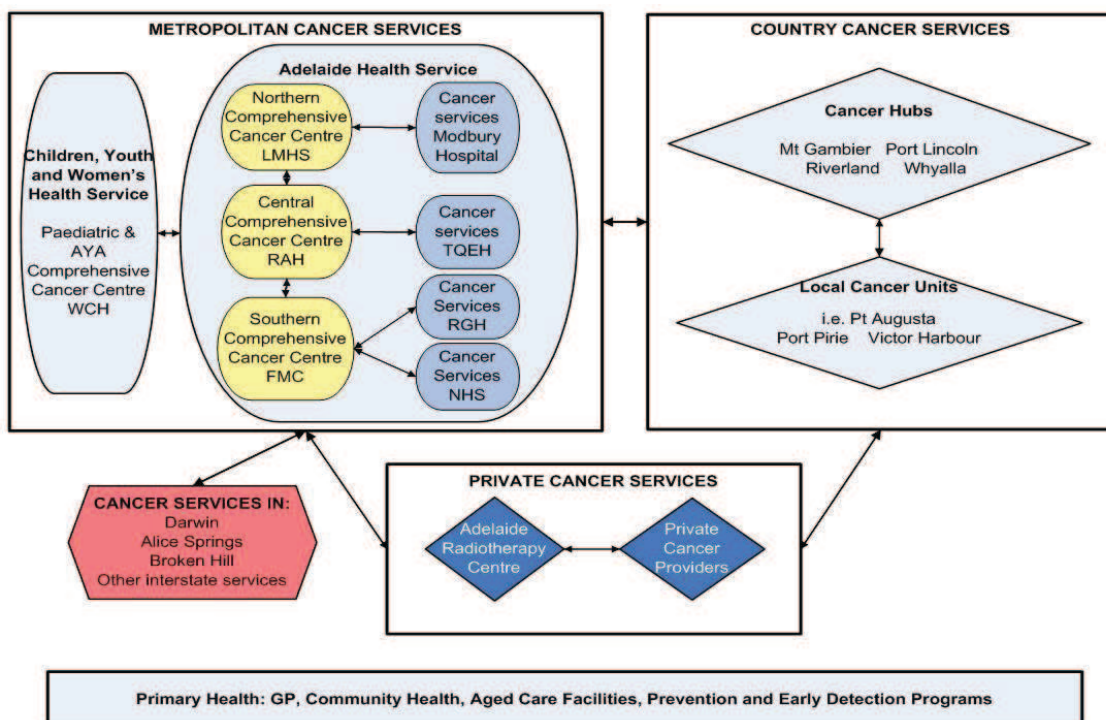


Table 2: Statewide Integrated Cancer Service delivery model

	Nature of services	Location of service and links
Super Specialty Services	Allogeneic bone marrow transplantation services	Single site based at RAH
	Radiation oncology: brachytherapy services	<ul style="list-style-type: none"> Limited number of providers - a single public and single private service public provider - RAH, with linked service at LMH private provider - Adelaide Radiation Centre (ARC) Each provider may have multiple facilities Brachytherapy services based at RAH
	Paediatric oncology	Single site based at WCH
	Some diagnostic services (e.g. PET)	RAH
Comprehensive Cancer Services	<ul style="list-style-type: none"> High level tertiary, specialised care across the range of treatment modalities. Provide (either onsite or by referral) a full range of cancer services: specialised surgery, radiation oncology, medical oncology, clinical hematology, cancer clinical pharmacy plus imaging and pathology. Not all super specialty services available at all sites. 	<p>Based in Major metropolitan hospitals</p> <ul style="list-style-type: none"> Central Adelaide Cancer Service - based at Royal Adelaide Hospital Northern Adelaide Cancer Service - based at Lyell McEwin Hospital Southern Adelaide Cancer Service - based at Flinders Medical Centre Paediatric Cancer Service - based at Women's and Children's Hospital
Cancer Service	<p>Mid level services</p> <ul style="list-style-type: none"> Affiliated with Comprehensive Cancer Service. Provide access to a limited range of cancer services i.e. primarily chemotherapy and some surgical specialties. Radiation oncology consultation in some country centres 	<p>Based in metropolitan and country General hospitals</p> <ul style="list-style-type: none"> The Queen Elizabeth Hospital Modbury Hospital Noarlunga Health Service (NHS) Repatriation General Hospital (RGH) Larger country and local hospitals in nominated country areas <p>Country based services will have links with Paediatric CCC.</p>
Cancer Service	<p>Low level services</p> <ul style="list-style-type: none"> 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 basic cancer care only e.g. limited or pre determined chemotherapy. A nurse with training in the administration of chemotherapeutic agents would be on site. No surgical or radiation oncology services available. 	Local hospitals in nominated country areas
	Population Screening Programs, Primary Health Care, General Practice and Community Services	Links with all levels of Cancer Services

Private Cancer Services other than radiation oncology are not included in this table.

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.⁴⁵ 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.^{42,43}

The following principles are relevant to developing services that ensure cancer, or its precursors, are detected as early as possible and 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 is 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 have access to information and education to facilitate improved recognition of significant cancer related symptoms
- GPs have access to information and education to facilitate improved recognition of significant cancer related symptoms
- clinical guidelines relating to appropriate investigation and diagnosis of significant cancer related symptoms for frequently encountered cancers are utilised, and developed where they do not exist
- acceptable timelines and appropriate standards exist for diagnosis and referral of frequently encountered cancers, and compliance with these standards is monitored
- GPs, other medical specialists, and people in the community 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 are aware of familial factors that place a person at substantially increased risk of developing cancer, and of the benefits of targeted surveillance.

Services for specific population groups

The particular needs of adolescents and young adults with cancer are being addressed through the establishment of the statewide Adolescent and Young Adult Cancer Service, with service establishment funding from the Australian Government and CanTEEN. This new service will have significant benefits in improving the cancer journey for this group of young people.

Older people with cancer, particularly those who also have co-morbidities, also have particular care needs. Cancer services are now being integrated with geriatric services to ensure that the care needs of this group are properly met.

Access to affordable transport and accommodation for rural based people with cancer and their accompanying carers is essential in achieving equitable access to specialist metropolitan based diagnostic and treatment services.

Aboriginal and Torres Strait Islander people and people from culturally and linguistically diverse backgrounds often find it difficult to have their cancer care needs met in culturally sensitive ways. Regional cancer services need to ensure that timely access to trained interpreters is available for non-English speaking Aboriginal and Torres Strait Islanders. This is also applicable for people from culturally and linguistically diverse backgrounds.

Survivorship

Advances in treatment, early detection, and screening have led to a decreased incidence and improved survival for many types of cancers.⁵⁹ The all-cancer five-year relative survival rate improved significantly for diagnoses made in 1998–2004 compared with 1982–1986.⁶⁰

The consequences of cancer and its treatment vary considerably between survivors but much can be predicted based on the type and location of the cancer, its treatment, and any adverse reactions or individual toxicity which occurred during the treatment phase.

As more people survive a cancer diagnosis, or live with the consequences of cancer treatment, survivorship programs have increased relevance. A significant component of implementing the cancer model of care and cancer pathway is an increased focus on survivorship and secondary prevention programs.

Children and young adults

Treatment results have steadily improved for a variety of cancers in the past decade. This is especially true for cancers in children and to a lesser degree in young adults. Cure is the likely outcome for 70–80% of childhood cancers today;⁶¹ consequently there is a new and increasing focus on reducing any long-term treatment effects and improving quality of life for survivors.

In general young cancer survivors are at an increased risk of developing adverse outcomes including early death, secondary cancers, cardiac, gonadal, and endocrine dysfunction, impaired growth and development, decreased fertility, impaired intellectual function, and overall reduced quality of life.

The new Adolescent and Young Adult Cancer Service will improve timely access to services, with the aim of improving longer term survival rates for young people with cancer.

Adults

Many adults are now living with cancer as a chronic condition. This can often be associated with reduced quality of life and continued psychological distress.⁶³

Recent research suggests that unmet psychological need may be greatest post-treatment, and may progress into survivorship.

A recent study involving participants recruited from a regional cancer treatment centre noted in its findings that length of time since diagnosis was often associated with greater

unmet need, particularly in the domains of physical/daily living, psychological and health system needs.⁶³

Data and monitoring

Currently in SA there is a lack of data with respect to monitoring for the long-term toxicities of particular treatments, the effects of new treatments/technologies, and patient centered outcomes such as quality of life.⁵⁹ Historically, the focus of data collection in cancer has been on indicators such as incidence, mortality, and survival which have typically been operationalised as survival according to a fiveyear time-line. Whilst data in South Australia with respect to these indices is relatively robust and reliable due to mandatory reporting requirements, data with respect to the areas important in 'survivorship' are lacking.

Efforts to facilitate the inclusion of data processes to monitor the long-term effects of treatment with respect to clinical and psychosocial outcomes, including quality of life, are needed.

Need for programs

When late effects of cancer treatment are predicted and managed early, and when survivors are offered timely vocational guidance and psychological support, they can contribute as members of the community for many years at a significantly reduced cost to our health and social system.

Whilst some programs exist to provide psychosocial support to survivors, the adequacy and efficacy of these programs in meeting the range of needs of 'survivors' is not well established.⁶⁴ For instance, due to a lack of data, the extent to which such programs impact on clinical outcomes and quality of life is largely unknown. Nevertheless there is a solid evidence base underpinning the delivery of psychosocial interventions to reduce distress at other points in the cancer continuum.^{64,65}

Therefore there should be a focus on appropriate data collection and monitoring for research, education, and the development of programs to address the unique needs of survivors. An approach to survivorship

programs that aim to decrease morbidity related to cancer and its treatment will ensure that cancer survivors are integrated into society, make informed and healthy lifestyle choices, and realise their full potential to lead 'normal' lives.

Conventional, complementary, and alternative therapies

Conventional therapies are evidence-based treatments that have been tested following a strict set of scientific guidelines, and are 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.

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.⁶⁶

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.⁶⁶ Alternative therapies are sometimes called unproven or disproven treatments.

It is recognised that many people with cancer use complementary and alternative therapies. People with cancer are encouraged to inform their professional carers if they are using these therapies.

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.⁶⁶ 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.^{67–70}

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.⁶⁷ 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.⁷⁰

Under the auspice of the Cancer Clinical Network, a Complementary Therapies Working Party is identifying priorities of work in the South Australian context.

Improving access

Improving the accessibility and timeliness of care provided to people with cancer, their families and carers continues to be a major aim of this cancer plan.

Strategies to improve access to care include a focus on the needs of people in rural and remote South Australia; access to care for Aboriginal and Torres Strait Islanders; cancer care services for adolescents and young adults (aged 15 to 25 years); services for cancer survivors; and access to palliative care facilities.

High-quality cancer care including medical oncology, haematology, surgery, radiation oncology, as well as palliative care services 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 and appropriate drugs that offer therapeutic benefits should be available to all people with cancer. These drugs can be very expensive and their benefits applicable to restricted numbers of people with cancer.

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.⁷¹

Fifty per cent or more of people with cancer eventually die of their disease. Palliative care and pain control should be readily available and accessible irrespective of where people live. The *SA Palliative Care Services Plan 2009-2015* has been developed to respond to the growing need for high quality palliative and end of life care.⁵¹

Access to all cancer services should be equitable for all South Australians. In order to ensure equity of access and timeliness of cancer care, the following principles have informed the model of cancer care in this Plan:

- people with cancer 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 is 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.

Recent service developments are also improving access to cancer care. The cancer model of care is being underpinned by the development and implementation of cancer tumour pathways for all major types of cancer. Particular barriers such as those associated with age, ethnicity, geographical location and socio-economic status have been considered in the development of the cancer pathway.

More accessible radiotherapy treatment for many people north of Adelaide is being achieved following the opening of the radiotherapy unit at the Lyell McEwin Hospital.

Advances such as oral chemotherapies are also making some treatments more accessible. However, they also bring with them new toxicities that need management by multidisciplinary teams.

While not all patients will have the same service in the same location, all patients have a right to care that is of the same high quality and provided by a competent workforce. Safety and quality must be key considerations, alongside increased provision of treatment closer to home for people in country settings.

The Cancer Clinical Network and metropolitan and country Health Services are collaborating to enhance the benefits to people with cancer in rural and remote settings.

Cancer services available in country general hospitals need to be increased where possible to minimise the need for travel to metropolitan Adelaide for cancer care. The statewide implementation of technologies such as tele- and web-conferencing will have a major impact on facilitating communication between metropolitan hospital based cancer care services and rural and remote cancer care services as well as emerging primary health care networks.

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.

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 need adequate experience in order to safely administer these drugs and most are not equipped to substitute for specialist oncologists. In addition to these challenges, is the limited

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 could be facilitated through the use of increased remote specialist support and appropriate communications infrastructure.

Transport and accommodation services should be adequate for rural people with cancer who need metropolitan cancer 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. Demand for accommodation will need to be re-assessed once the implementation of the country cancer care model is completed, and the impact of expanding cancer care in country locations on the need for travel is known.

Rural population palliative care, end-of-life, and bereavement services 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.

Infrastructure planning for cancer care

Summary

The provision of cancer care needs to be supported by appropriate and modern infrastructure that includes physical facilities and information support systems.

Significant infrastructure development has been achieved since the first Statewide Cancer Control Plan was launched, with many infrastructure development programs commenced and scheduled for completion over the coming years.

The goals underpinning the development of cancer infrastructure are that:

- health facilities enable the delivery of high quality cancer care, the support of the cancer care pathways, and the achievement of the cancer care model
- physical facilities are modern and enable the provision of contemporary cancer clinical practice
- information system infrastructure supports timely communication and information flow and data collection across cancer services.

Achievements

- Construction of the radiotherapy unit at Lyell McEwin Hospital completed
- Funding secured to build a new cancer centre at Whyalla
- Funding secured to expand the Lyell McEwin Hospital single radiotherapy unit to two Linear Accelerator capacity
- Building of the Children's Cancer Centre at Women's and Children's Hospital
- Creation of adolescent and young adult cancer care space in Royal Adelaide Hospital
- Funding secured for the establishment of an online chemotherapy prescribing system
- Funding secured to improve information and communication technology linkages between country health services and metropolitan specialist services

Recommendations

1. Capital works programs to expand and upgrade cancer services are completed as follows:
 - Whyalla Cancer Centre
 - Chemotherapy units in 10 country sites
 - Expansion of the radiotherapy facility at Lyell McEwin Hospital
2. The SA Health Information and Communication Technology Strategy implementation develops information and communication technology linkages that allow real-time communication/information flow between the specialist metropolitan cancer centre 'hubs' and the rural cancer unit 'spokes'
3. The South Australian Cancer Registry expansion to enable timely collection of comprehensive cancer clinical data from all hospitals is completed.

Effective cancer control requires quality infrastructure that encompasses both physical facilities and information support systems.

Infrastructure planning to support service development needs to complement and facilitate the cancer service model.

In 2008, the Cancer Network, with support from the CanNET SA project, completed a cancer infrastructure audit covering all South Australian private and public health services, and interstate services where South Australia has a service role. Building on the information generated by this audit is the development of a 'standards for cancer services' model to frame infrastructure, workforce and service needs to safely administer different cancer treatments and care. The model, along with the cancer service delineation profiles, is under creation and will enable the development and monitoring of cancer services within principles of safety, quality and timeliness.

The infrastructure base supporting safe administration of chemotherapy across South Australia has been an area of priority need within the cancer sector for some time. Progress has been made towards selecting and implementing chemotherapy prescribing software for South Australia.

State radiotherapy infrastructure planning is progressing, including infrastructure for digital mammography in various sites in South Australia.

Implementing a comprehensive infrastructure strategy

Infrastructure planning to improve cancer services has been informed by a series of recent reviews of cancer services in South Australia.⁷²⁻⁷⁴

Cancer care infrastructure planning includes proactive monitoring of demand for equipment, ongoing maintenance and repair of existing equipment, and planning for new equipment.

The key infrastructure required to achieve the objectives of the Statewide Cancer Control Plan and to reduce the impact of cancer in South Australia include:

- facilities and equipment for comprehensive population cancer screening
- facilities and equipment for comprehensive cancer care including diagnosis, specialist cancer treatment and follow-up care, primary health care, support of survivors, palliative and end-of-life care, and psychosocial support
- facility design that supports new cancer care technologies and multi-modal approaches to cancer care
- support services, such as service directories, booking systems, transport assistance, accommodation, home nursing, telemedicine, and other technologies to facilitate service provision
- telemedicine and other information technologies for case conferencing and radiotherapy planning for rural patients
- systems and information technology support for quality monitoring and reporting of process and outcome data.

Capital works programs to upgrade health facilities need to include consideration of the needs of cancer patients across treatment modalities. This includes current capital works programs expanding cancer services in Whyalla, developing chemotherapy units in 10 country sites, and expanding radiotherapy at the Lyell McEwin Hospital.

The SA Health Information and Communication Technology Strategy also needs to include system elements that support all stages of the management of cancer patients through their cancer journey including: screening and screening recall; diagnostic information including staging; tracking of patient care across treatment modalities and sites of care; and monitoring of clinical outcomes in the short, medium and long term. Additionally, the implementation of this strategy should develop information and communication technology linkages that allow real-time communication/information flow between the specialist metropolitan cancer centre 'hubs' and the rural cancer unit 'spoke'. This includes:

- the information and communication technology linkages between metropolitan and country services

- high-quality, multi-site, user-friendly communication technologies such tele- and web-conferencing are available to support multidisciplinary care.

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.

Infrastructure planning also needs to include consideration of cancer control research supports, including the infrastructure required to support clinical trials and bio-specimen collection and databases.

Physical infrastructure

Cancer screening

The health infrastructure planning program must ensure that screening demand and need are met in order to realise the benefits of early detection of cancers. This includes the management of people identified as at high risk, such as surveillance recall.

Screening service infrastructure must be well coordinated and maximise public access to encourage screening participation. This includes ensuring that screening service facilities are designed in ways that are culturally appropriate.

Infrastructure planning must ensure there is sufficient capacity within screening services to meet screening targets.

Diagnostic services

Diagnostic services need sufficient infrastructure capacity to avoid delays and reductions in quality of service.

Imaging services need adequate capacity to meet requirements for prompt cancer diagnosis and treatment.

The capacity of imaging facilities such as magnetic resonance imaging (MRI) and computerised tomography (CT) to meet cancer population diagnostic needs should accord

with international benchmarks.

Access to positron emission tomography (PET) and CT imaging is required for accurate staging and treatment planning, and their use is increasing. 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. Infrastructure planning 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.

Diagnostic infrastructure must also be sufficient to respond to the outcomes of increasing uptake of screening programs. For example bowel cancer screening increases demand for colonoscopy services to investigate screen-detected abnormalities.

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 while also working to facilitate access to diagnostic technologies for people from rural areas.

Radiation oncology services

Evidence-based standards indicate that radiotherapy services should have the capacity to treat at least half of all people diagnosed with cancer, either with curative or palliative intent.

A five-year radiation oncology plan is being developed to address this need and inform the planning of radiation oncology infrastructure requirements. This includes expanding the radiotherapy service at Lyell McEwin Hospital and Federal funding has been secured for this.

Medical oncology and haematologic oncology services

Medical oncology and haematology infrastructure must support the provision of

safe and timely chemotherapy.

Infrastructure support is also required to advance services addressing leukaemia, lymphoma and multiple myeloma, mostly managed by haematologists.

Information infrastructure also needs to include ongoing monitoring systems to ensure that the use of all anti-cancer drugs accords with evidence-based protocols.

The Communo review called for infrastructure initiatives to improve medication management and recommended the implementation of an online chemotherapy prescribing system across SA Health hospitals. Significant progress has been made, with funding secured to achieve this.

Surgical oncology services

Infrastructure planning must also address the need to monitor surgical caseloads, practice variations and clinical outcomes. Emphasis will 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.

This includes appropriate information technology to support this auditing and monitoring process.

Palliative care services

Palliative care infrastructure needs to support both inpatient hospice care as well as people who wish to die at home.

Inpatient facilities need to be designed in culturally sensitive ways to encourage access by Aboriginal and Torres Strait Island peoples.

Information and communication infrastructure also needs to support the mobility of the palliative care workforce, telemedicine, and other communication links between specialist palliative care centres in metropolitan areas and rural areas.

Cancer support services

Cancer leads to concern and stress at a community level; particularly so among those affected by the disease and their family

members and carers. There is a need for telephone helplines and emergency services for individual patients through nursing and allied personnel on call. These services are needed both outside and inside normal working hours.

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

Information infrastructure

Infrastructure requirements include supporting the provision of information to service providers for individual patient care and to health administrators for service planning, implementation, and evaluation.

An emphasis is needed on 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.

Information technology infrastructure for clinical management information systems needs to provide service prompts and facilitate the auditing and monitoring of preventive service delivery as part of clinical care. Service reminders are particularly important for supporting people at increased risk of cancers.

Electronic health records, unique patient ID numbers, 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 are all elements of a comprehensive information infrastructure program.

The implementation of the SA Health Information and Communication Technology Strategy which includes the provision of these elements will greatly enhance the delivery of coordinated cancer care.

The inclusion of electronic prompts in management systems will aid systematising preventive care, screening, promotion, and follow-up checks at primary health care and tertiary levels.

The ability for electronic transfer of hospital medical record information at discharge to primary health care practitioners greatly assists in achieving collaborative management of patient care.

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 for cancer control 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 are equipped to participate in research projects to enhance cancer control
- the curriculum content of tertiary courses provides optimal cancer education.

Achievements

- Appointment of new cancer care coordinators in major tumour stream specialties
- Appointment of Cancer Directors to regional services

Recommendations

1. Scope of practice guidelines that include core competencies and training requirements for the cancer workforce, including the nurse practitioner role, are developed.
2. Programs that maintain the skills and competencies of the cancer workforce across metropolitan and country areas are implemented.
3. A detailed analysis of the impact of cancer service development on the cancer workforce, including the applicability of advanced practice roles, is undertaken at a point when service changes become clearer.

Cancer control is a broad domain and 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.

In addition to 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, rather it is an attempt to predict and determine future need on the basis of information available in the present.⁷⁵

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 was growing at an annual rate of around 170,000 persons per year.⁷⁶ By 2020 this was predicted to be just 12,500 per year. Thus, in the next twenty to thirty years, the decreasing numbers in the available workforce will lead to an unprecedented focus on obtaining and keeping the Australian workforce, including the health workforce.

Optimising Cancer Care in Australia reports consistently that there are already workforce shortages in all areas of cancer care.⁴² Either there are instances of professionals but no positions available, or much more commonly, positions but no professionals to fill them. This is particularly the case outside the capital cities. This is true for medical oncologists, radiation therapists, radiation oncologists, nurses with experience and or qualifications in cancer, and pharmacists. Also reported is the considerable risk of burnout of staff presently in the field.

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 being stretched across chronic diseases, with cancer as one component.

The Council of Australian Governments has established the Australian Health Workforce Agency to manage and oversee major workforce reforms. The Agency will devise solutions that integrate workforce planning, policy, and reform with the necessary and complementary reforms to education and training. As part of its brief, the Agency will work with jurisdictions to develop and progress the demonstration, piloting, evaluation, and implementation of new workforce models and reforms. They will also assess the impact of these reforms on improving the efficiency and effectiveness of service delivery within a framework emphasising safety and quality of care.

The Agency will link into the National Registration and Accreditation Scheme to ensure sufficient regulatory protection for workforce redesign pilots, and to support changes to scopes of practice. It will work with the academic sector to increase university and vocational education and training places.

Intended workforce reform measures also include redesigning roles and creating evidence-based alternative scopes of practice, plus performance incentives for health professionals and multidisciplinary teams.

Apart from radiotherapy workforce data,^{77,78} there is a shortage of benchmarks⁷⁹ or baseline data to document the existing cancer control workforce, or education and training opportunities. This highlights the need for:

- consistent methodology and tools for collecting and classifying workforce data
- agreed cancer care and cancer prevention standards, models of care and clinical practice guidelines to provide benchmarks for workforce requirements
- delineation of time spent in cancer control work
- consideration of the scope of practice across the cancer workforce

- systematic information about the magnitude of the training and education requirements and opportunities across the entire cancer trajectory e.g. prevention, screening, diagnosis, treatment through survivorship or palliative care.

Other issues complicating cancer workforce data collection include extension of the professional health workforce in cancer control by a non-professional workforce of volunteers and carers, about which there is even less information.

The Cancer Clinical Network is pursuing collection and analysis of cancer workforce data including both qualitative and quantitative information in relation to all relevant clinical specialties and health workforce disciplines in the field of oncology. It is also developing projections about future workforce requirements and supply in key cancer workforce categories. Workforce benchmarks are being collated where available and are being adapted for Australian and South Australian conditions.

The skills and competencies of the cancer workforce need to be developed and maintained in order to support the delivery of the cancer model of care. This requires consistent and standardised education and training programs being available. Cancer control workers need to be able to participate in accredited continuing education programs and be supported to participate in research projects that enhance cancer control.

As advanced practice roles in cancer care across a range of disciplines are established the scope of practice for the cancer workforce, including the nurse practitioner role, will require development. This can best be achieved by undertaking a detailed analysis of the impact of cancer service development on the cancer workforce at a point when the impact of service changes become clearer.

Cancer control workforce

While there are workforce issues across the spectrum of oncology professions, priority is being given to improving recognised benchmarks or agreed minimum acceptable levels of staffing of the core professions of

medical oncology, radiation oncology, cancer pharmacy, and oncology nursing.

Oncology specialists

There are concerns that previous reports on the state of the oncology specialist workforce significantly underestimated the future need for medical oncologists and haematologists. Further benchmarking work needs to be undertaken to better inform workforce requirements. The Medical Oncology Group of Australia is currently leading work in this area.

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.

Previously deficits have been identified in radiation oncologists, radiation therapists, and medical physicists;⁸⁰ the three professions that are central to radiation oncology and fundamental to cancer care. A recent review involving radiotherapy services⁷² highlighted the need for increased workforce in radiotherapy, which is being addressed.

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

Oncology nurses (including chemotherapy nurses) and registered 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.⁸¹ 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.

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.

Cancer pharmacy

With the increasing age of the population and complexity of treatments the workload in cancer pharmacy has increased, as has the specialist knowledge required.

Specialist pharmacists with appropriate training, knowledge and skills are responsible for the safe provision of parenteral and oral chemotherapy and related medications in South Australian hospitals. In addition, clinical pharmacy services for admitted and ambulatory patients should be provided according to professional practice standards. New pharmacist roles in medication management, PBS medication supply, geriatric cancer patients and cancer outpatients have resulted in substantially increasing workload for cancer pharmacists without a corresponding increase in trained workforce. Staffing levels, where mentioned in the standards, are outdated and do not take into consideration the increasing use and complexity of cancer drug treatments during the past decade.

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. GPs have a pivotal role in cancer prevention, including the promotion of healthy behaviours and in early detection of cancer. 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.

Nurse practitioners

The Nurse Practitioners in South Australia review report recommends that Nurse Practitioner positions should be developed within sound clinical service plans consistent

with South Australia's Health Care Plan 2007–2016.

Nurse Practitioner role development and support in cancer should be consistent with associated health workforce strategies such as *Delivering the Future: Building a valued and sustainable nursing and midwifery workforce 2008–2011* and the *Aboriginal nursing and midwifery strategy 2008–2011*.⁸²

Other workforce planning issues

Primary health care

In line with the South Australian Government's health reform agenda, there is 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 is skilled to manage cancer prevention and early detection 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 specialise 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.

BreastScreen programs are targeted at women aged 50–69 and are subsidised under the Medicare Benefits Scheme as a diagnostic test. It is recognised that digital mammography has benefits over film mammography for the screening, surveillance and diagnosis of breast cancer. Digital mammography technology is being introduced to replace film mammography. Digital mammography permits additional functionality, including telemammography, which allows the transmission of mammographic images from a remote site to a radiologist for real-time assessment and interpretation. This opportunity is relevant given shortages of radiologists and radiographers.

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. It has been recognised that an increase in the number of psychologist positions is needed, but the overall benefit to long term health status will be cost effective.⁸³

Private professional psychological services are now eligible for some Medicare subsidies, assisting with the costliness of ongoing professional psychological support for those with continuing psychological difficulties related to cancer. Lack of sexual health counselling and rehabilitative services have also been reported as unmet needs.

Although there is not clear evidence of the effectiveness of alternatives to comprehensive psychological support services, there is a need for broad based support services that are readily available at low cost to supplement professional services. Provided there is evidence of effectiveness, greater investment in, and use of community based interventions such as one-to-one peer support, self-help groups or guided group therapy is required.

Cancer Councils

Cancer Councils provide authoritative, up to date and relevant information for primary health care workers and other health professionals. Cancer Councils also provide access to cancer support services such as counselling, one-to-one peer support, self-help groups and community education programs for people with cancer and can be a point for referral by health professionals.

Allied health

The Allied health workforce includes the range of professional health care providers who are not physicians, for example psychologists, physiotherapists, nutritionists, occupational therapists. To inform the Statewide Cancer Control Plan 2006–2009, consultations were

undertaken with a range of allied health workers. These consultations revealed that these health workers were concerned about their inability to meet current demands. They had significant concerns about their ability to support future cancer control programs and services and noted that significant barriers existed to accessing allied health across South Australia, include late referrals to allied health and poor levels of staffing.⁸¹

Cancer registries

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 throughout 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.⁸⁴ 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, along with appropriate training has increased markedly.

Volunteers and carers

Consultations undertaken during the development of the previous cancer plan recorded the demand for volunteer assistance alongside the developing and growing needs of the cancer care community. There are opportunities to facilitate discussion and collaboration with respect to defining the future roles, functions and training of volunteers.⁸¹ Carer and primary support roles need to be clearly defined and supported through improved training and engagement with cancer care professionals and local community groups.

Public relations and marketing

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; by reflecting on future people shortages, increases in the incidence of cancer and changes in service delivery.

Curricula and education background information

Credentialing of medical practitioners in cancer

The National Services Improvement Framework for Cancer recommended 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.”⁴³ The Communitio review into cancer services in South Australia⁷² made a number of specific recommendations about workforce development, including that medical staff standards, credentialing and scope of practice processes be defined, standardised, implemented and regularly reviewed. In particular it called for training and competence testing of radiation therapists and medical physicists to be benchmarked with interstate health services; credentialing of oncology nurses; and standardised training for oncology pharmacists and pharmacy technicians.

Specialty training in oncology nursing

“There are a number of postgraduate nursing courses in cancer. There is a shortage of nurses who have such training and those who undertake it have no assurances that they will receive additional salary because of the additional skill.”⁴² The Communitio review called for a statewide standard for the credentialing of chemotherapy nurses.⁸⁵

In addition, it is recommended that the National Professional Development Framework for Cancer Nursing be implemented and supported across health services and sectors to increase access to professional development

opportunities and ensure all nurses working in oncology meet required competencies to provide specialised cancer care.

Medical schools’ curriculum

Cancer Council Australia has developed an Ideal Oncology Curriculum for medical schools.⁸⁵ The curriculum has been used in some universities for curriculum improvement but has not yet been adopted by the majority. Ongoing work needs to be done to facilitate integration while ensuring that the curriculum content is relevant to the needs of medical students.

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 prudent to include cancer prevention training routinely in all cancer workforce and also public health 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 coming 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 both a chronic and acute disease, and incorporation of this in cancer control workforce curriculum and professional development, will build better understanding of the scope of cancer control 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. The need for communication training is supported by research which suggests that some oncologists perceive, inaccurately, the psychosocial concerns of patients.⁸⁶ Inadequate communication between doctor and patient has also been linked with increased distress for cancer patients and their families.⁸⁷

According to the Clinical Practice Guidelines for the Psychosocial Care of Adults with Cancer,⁴⁵ there is likely reliable (Level 1) evidence which links effective doctor-patient communication with improved patient outcomes such as increased satisfaction, improved adjustment, decision making and treatment compliance.

Moreover participation in structured communication training is linked with increased physician confidence (i.e. self-efficacy) for communicating bad news and/or managing difficult interactions with patients⁸⁸ and improved attitudes and knowledge of psychosocial issues impacting on patients.⁸⁹ In addition, physicians trained in communication express more empathy toward clients and present more open ended questions. A lack of training in effective communication training has been linked with job dissatisfaction and burnout.⁸⁷

The importance of communication training for professionals working in oncology is not new and since the 1960s considerable literature on the importance of communication training has been developed.⁸³ Nevertheless, further research is required to continue to develop and evaluate communication training programs designed for use in oncology.⁸³

Some communication training programs are available in Australia,⁹⁰ however the uptake of participation in these programs is not known. Furthermore the extent to which communication training is an integral part of oncological curriculum requires further review.

Training in effective communication may be required at various stages of career development and further research may link such training with improved outcomes for health professionals such as job satisfaction and reduced distress.

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.⁹¹ 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.

Quality cancer care

Summary

The cancer control quality program needs to be comprehensive and cover all aspects of cancer control and the cancer pathway. Approaches to the monitoring of quality should be flexible and include models that support the incorporation of consumer feedback. Assessments of patient centred outcomes such as patient satisfaction and quality of life, along with additional approaches for inclusion of consumer feedback, should be incorporated into statewide monitoring of the quality of cancer care.

Goals of the cancer quality program are that:

- patients receive care appropriate to their needs
- cancer care is high quality, safe and evidence based
- continuous improvement is a foundation of all cancer services.

Achievements

- Development of a cancer quality framework with performance indicators for monitoring targeted priority areas
- Development of standards for administration of chemotherapy

Recommendations

1. The cancer care quality framework is implemented across regional cancer services.
2. Information systems are in place to collect data to monitor and evaluate cancer outcomes.

Quality of care refers to safety, effectiveness and efficiency in care as well as consumer satisfaction, timeliness, accessibility and equity of outcomes. The following principles can be applied to facilitate quality in care:

- indicators of quality and outcomes should exist and be monitored and reviewed regularly
- there should be a process of continuous improvement within services providing cancer care
- there should be transparency and clear paths of accountability for all services provided.

The 2009 Communitio Review⁷² into cancer services in South Australia recommended the establishment of regional cancer management committees. It further suggested that these

committees implement standardised protocols and systems of care, specifically calling for a three-year quality improvement plan which included:

- a systematic audit schedule for radiation and cytotoxic therapies
- guidelines for multidisciplinary team function
- clinical case and peer review guidelines
- a suite of clinical indicators
- a targeted approach to improvement activities
- the requirement for mandatory regular reporting of the outcomes of these audits.

The review also called for the implementation of a cancer services accreditation model within the next three years that is consistent

with national accreditation frameworks and in particular with Australian Commission on Safety and Quality in Health Care recommendations. In addition to, or included in this accreditation model should be a regular and robust audit process against the national radiation oncology standards.

A review of safety and quality procedures in Country Health SA cancer services was also called for.

The Communio review also recommended a key role for regional cancer management committees in data collection systems development, data monitoring and reporting.

Monitoring quality cancer care requires:

- information systems to be in place to collect data for evaluation of clinical outcomes
- quality indicators at all points on the cancer continuum. These indicators may also include the Australian Council on Healthcare Standards (ACHS) radiation oncology indicators and clinical indicators currently under development by the Cancer Institute, NSW
- key outcomes to be achieved for patient satisfaction, timeliness of referral, cancer incidence, staging, mortality and survival
- service benchmarking of compliance with standards and achievement of quality.

The National Service Improvement Framework for Cancer⁴³ also advocates for accreditation for cancer services and credentialing of practitioners. Models currently exist in the areas of radiation oncology and breast cancer surgery. A system of voluntary accreditation of cancer services across Australia is recommended in *Optimising Cancer Care in Australia*⁴² with credentialing of clinical staff emphasised in the Communio review of cancer services in South Australia.⁷² The Delaney⁷³ and Kowalick⁷⁴ Reviews resulted in 18 recommendations about improved processes, incident reporting, protocols and workforce, which are supported and being pursued. They also highlighted the significant benefits from open disclosure to patients and the public in the event of an incident with potential quality or safety implications and draw attention to the importance of informing patients

appropriately and ensuring they receive follow-up support.

For example, the National Health Service in the United Kingdom and the Scottish Executive have recently adopted a patient-centred structured interview approach as a means of providing direct feedback on concerns about health service delivery and patient experiences to clinicians/service providers and those responsible for development of health policy.

The utilisation of these measures has been examined within an extensive literature review commissioned by CanNET SA for the network and will contribute to the development of a Quality and Safety Framework for Cancer Services for the state.

Clinical protocols for general practice and other clinical services should cover preventive as well as treatment requirements.

Quality can also be assessed indirectly through monitoring caseloads, practice variations and clinical outcomes.

Cancer control quality framework

A cancer quality framework which incorporates the elements of safety, effectiveness, efficiency, satisfaction, waiting times, accessibility and equity outcomes is required.

People with cancer require appropriate and acceptable care which is transparent and accountable. Decision makers, clinicians, people with cancer and the general community require access to information about the quality of cancer care in South Australia. This includes the credentials of service providers and the extent to which a service facility is accredited, meets standards and agreed national benchmarks and implements quality improvement programs.

Clear pathways are also required to ensure people with cancer can provide feedback about their care.

The South Australian 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.

The quality framework for monitoring cancer outcomes should:

- adopt appropriate quality indicators at all points of the cancer continuum, incorporating the collection of data to facilitate the monitoring of waiting times from suspected diagnosis to treatment
- monitor waiting times from suspected diagnosis to treatment, cancer incidence, staging, mortality, and survival
- benchmark services compliance with standards and achievement of quality
- include treatment standards and clinical guidelines across all cancer care modalities
- undertake statewide monitoring of key outcomes such as patient satisfaction and adherence to treatment pathways
- benchmark services to monitor compliance with standards and achievement of quality.
- 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.
- 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.
- include a process whereby quality measures are made known to people with cancer, primary health care providers, and other members of the care team.
- support the South Australian Cancer Registry to provide timely and up to date information and continue the expansion of hospital cancer registries to enable collection of clinical data from all hospitals.

Cancer control research

Summary

Research has a vital role in cancer control, from prevention through to end-of-life care.

All research streams have necessary and complementary roles in the delivery of an effective cancer control program.

- Basic research provides the fundamental understanding of cancer behaviour at a cellular and sub-cellular level and develops breakthrough opportunities in cancer care.
- Clinical research discovers 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 has a focus on the social determinants of cancer and indicates where policy changes may reduce risk. It also reveals whether 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, and clinical and population research.

The overarching aim of cancer control research is to reduce the impact of cancer in the community. The 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.

Achievements

- Establishment of the SA Cancer Research Collaborative
- Secured \$20million in cancer research funding over the next five years
- Establishment of the Flinders Centre for Innovation in Cancer

Recommendations

1. SA Cancer Research Collaborative develops high quality cancer research programs in SA across the fields of biomedical research, clinical research, population health research, and health services research and evaluation.
2. A research translation and evaluation program is developed to ensure 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).

The steady decline in South Australian cancer research capacity in recent years has been of particular concern. A review of the state of health and medical research in South Australia⁹² concluded that although SA has a proud history of excellence in health and medical research, this has been diminishing in recent years. This is most clearly demonstrated by the continuing reduction in the percentage of national research grants being won by SA researchers. NHMRC statistics verify that South Australia's share of national health research funding has fallen.

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 Australian Cancer Research Collaborative

The South Australian Cancer Research Collaborative was established in 2010 to support and develop high-quality research in South Australia. The establishment of the SA Cancer Research Collaborative is a significant milestone in improving cancer control and will enable SA to be a more competitive player in the field of cancer research.

The SA Cancer Research Collaborative will be integrated with the South Australian Health and Medical Research Institute and support the development of high quality cancer research programs in SA across the fields of biomedical research, clinical research, population health research, and health services research and evaluation.

The SA Cancer Research Collaborative will support the training, retention, and career development of talented young researchers, and the development and maintenance of essential research infrastructure.

The SA Cancer Research Collaborative will also enable research agendas to be responsive to community concerns that may not be addressed in mainstream research programs.

The new SA Cancer Research Collaborative is being supported by a research budget of \$20 million over a five year period provided jointly by the SA Government and Cancer Council SA.

Translating research into practice

A research translation and evaluation program is needed to ensure research findings are communicated and incorporated into service delivery and programs. 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.

Focused research contributes to knowledge that improves the delivery of cancer prevention and cancer care. Health services research helps to refine service delivery. Cancer care benefits from an environment where there are clinical trials and other forms of clinical research.

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.

Cancer control research in South Australia also requires a program that is developed in partnership with Aboriginal and Torres Strait Islander communities and health agencies to focus on better understanding the impact of cancer on Aboriginal peoples.

Supporting evidence-based medicine

The strongest evidence available, and systematic reviews of evidence, are used to identify best practice.

The 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 funds well-designed scientific studies examining the safety and effectiveness of promising and commonly used complementary and alternative cancer medicines.⁷⁰ This could enable people with cancer and health care 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 to discuss their use of non-conventional therapies with their professional carers.

Clinical practice guidelines are also a means of translating evidence into cancer care. Utilisation of clinical guidelines can improve outcomes for people with cancer and also promote uniformity of care across different treatment settings.⁴³ 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

Clinical trials are an integral component of the research that supports 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.⁴²

It is estimated that only 2 to 3% of adults with cancer participate in clinical trials throughout Australia, although up to 20 to 30% may be eligible.⁴³

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.

Participation in clinical trials can be increased through improved awareness of clinical trials among people with cancer, as well as members of the professional team delivering cancer care. This is of particular importance in ensuring that opportunities to participate in clinical trials for people living in country areas and adolescents and young adults are increased.

Clinical practice and psychosocial care

Research into other areas of cancer care, particularly psychosocial and health service research will also improve quality of care.⁴²

In order to ensure that clinical practice and the provision of psychosocial care in cancer are based on best practice, with a solid 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 is 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 have access to verbal and written information about the guidelines and/or protocols relevant to their care.

Cancer information

Summary

The workforce and agencies engaged in cancer control activities need information to perform their roles. People with cancer need information to be informed of their treatment options. Systematic information planning will help to ensure that these needs are met. The goals for information planning to support cancer control 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.

Achievements

- Upgrading of Cancer Registries due for completion in 2011
- Establishment of the Data Linkage program

Recommendations

1. A comprehensive range of cancer information that is readily accessible is developed.
2. The project to expand South Australian Cancer Registry data is completed.

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.

Much operational work is already underway. Priorities have been identified for improving the availability, access, and quality of cancer information for clinicians and consumers in South Australia. Investment has been made to enable development and redevelopment of cancer registries and related data infrastructure. The focus of this work is on information providing timely patient information to all clinicians as well as information which will support the quality and safety of cancer services.

A comprehensive cancer information strategy for South Australia

The South Australian Cancer Clinical Network should continue to oversee development of the information strategy. The South Australian Cancer Clinical Network 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 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. 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 with increased genetic risk regarding 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, 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 helplines, web-based technologies, electronic information systems, digital videoconferencing, print media and other traditional paper-based systems 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, the risk factors, cancer prevention, and how early diagnosis can be achieved. Special attention should be given to promoting mammography, cervical and large bowel screening.

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 stocktake 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 stocktake 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. This should be provided sensitively with due regard for the patient's privacy.

People with cancer embarking on treatment should have information on their 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. This could be achieved by developing key prompt questions for use during clinical appointments.

People with cancer, their families and carers should have access to telephone helplines 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 in providing 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, management, cancer genetics, familial cancer, evidence-

based guidelines and protocols, clinical trials, service availability and 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 public or privately funded centres.

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 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, politicians, 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 data needs of health service policy makers, planners, and administrators on service requirements, projected requirements, 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.

Politicians also require information on cancer control. A comprehensive information

program includes providing key performance indicators on cancer control outcomes to parliamentarians annually.

Relevant information includes information covering 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.

Cancer information for researchers

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

Clinical trials and other research activity is an integral part of service delivery, in determining the most effective and cost-effective service options. People with cancer need to have information on available clinical trials.

Research results from South Australia and elsewhere need to be synthesised by expert groups in the future development of evidence-based guidelines and protocols for service delivery.

Ongoing health services research and audits in South Australia will further add to the body of knowledge available to assess quality of service delivery, efficiency of service, service outcomes, and service access and utilisation by all sectors of the population.

Increased access to data for research and evidence-based practice can be achieved by:

- establishing biospecimen 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
- updating South Australian hospital cancer registries to improve data quality,

increase efficiency and timeliness of data provision, and facilitate greater access to data for authorised researchers

- 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 biospecimen, 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.

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