

cancerinstitute  
NSW



# NSW Rural Cancer Services Review

Commissioned by: **Cancer Institute NSW**

Conducted by: **Health Outcomes International**

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# 1. Introduction

## 1.1 Background

The Cancer Institute NSW was established in August 2003 with the primary objectives of:

1. Increasing cancer survival.
2. Reducing cancer incidence.
3. Improving the quality of life of cancer patients and their carers.
4. Providing expert advice to patients, the public, health care professionals and the Government.

In addressing these objectives, the Cancer Institute NSW established a consultation process to develop the NSW Cancer Plan 2004-2006 in conjunction with the NSW Department of Health, the cancer community and the public. The NSW Cancer Plan 2004-2006 was released in July 2004.

The NSW Cancer Plan 2004-2006 (Program 17.1) identified the need for a review of cancer services in rural Area Health Services (AHS). After expression of interest and request for quotation processes, the Cancer Institute NSW engaged a team of specialised external healthcare systems reviewers at Health Outcome International Pty Ltd (HOI) to undertake the review and descriptive overview of cancer services for people living in rural areas of NSW.

Collection of data for the review was completed in August 2005 and includes data up to 2003. Additional comments on cancer incidence and trending to include data up to 2004 are included in section 4.5 of this review.

## 1.2 Objectives

The overall objective of the review was to provide an overview of cancer services in rural and remote New South Wales. The outcomes are intended to inform future strategic initiatives to improve access to services.

The project objectives are listed below:

1. review and document cancer services currently available to cancer patients in rural areas in New South Wales, including interstate services;
2. review and identify any obstacles for rural cancer patients in accessing specialist cancer services;
3. review and identify gaps in the travel support and accommodation needs of rural NSW patients in accessing cancer services;
4. identify current accommodation facilities for patients and carers and identify any issues affecting utilisation;
5. identify possible partners such as government, non-government, community and other organisations to develop programs to close gaps identified in Objectives 2, 3 and 4; and
6. identify issues in the access of rural practitioners to an oncology team and vice versa in metropolitan based continuing education programs and in participating teaching hospitals.

While information relevant to objectives five and six was collected over the course of the review, it became clear as the review developed, and following extensive consultation with rural stakeholders, that these objectives would require additional investigation, beyond the scope of this review. More detailed analysis of these areas will form the basis of further research and projects under the NSW Cancer Plan 2007-2010. Key areas will include a review of outreach services.

Information regarding cancer services in each area was current at the time of the review, and verified with each participating area. However it is expected that some changes in the service and network details will have occurred since the data collection for this report was finalised.

## 1.3 Methodology

The evaluation methodology for the review was built around the collection of qualitative data from a range of stakeholders involved in the planning, provision and access of cancer services in rural and remote locations across New South Wales. Consultation strategies were designed to engage with patients and carers, service providers, rural communities and Divisions of General Practice. Information was gathered directly through one-on-one interviews, in group sessions, or via teleconference. Surveys were distributed to targeted individuals by mail or email.

Prior to the commencement of this review, the Cancer Institute NSW had completed a round of consultation forums with a number of communities in rural NSW. Outcomes of these consultations were compared to those of the review to ensure that all qualitative findings were included. Rather than duplicate the process underpinning the rural forums, alternate strategies were developed to engage with cancer patients and their families and carers on an individual level. A self administered patient survey (refer Appendix A) was developed and approved by the Cancer Institute NSW Ethics Committee.

The patient surveys were distributed to the Cancer Nurse Co-ordinators across each AHS covered by the scope of the study. Each nurse was briefed on the objective of the review and the survey itself. Up to ten surveys were left at each radiotherapy and chemotherapy waiting area for patients to complete at their leisure. Pre-paid postage was made available. A total of 200 patient surveys were distributed. At the completion of this report, a total of 30 responses had been received.

Engagement with Divisions of General Practice was also undertaken in recognition of the pivotal role of General Practitioners in the detection, treatment and follow up of cancers in rural communities. Additionally GPs play an important role in the referral processes between rural and metropolitan locations. A survey (refer Appendix B) was sent to each Division of General Practice within the scope of the review. Five responses were received (from a total of 13 surveys sent), including one from the Alliance.

The survey of service providers (refer Appendix C) was developed through several draft stages, with input from the Cancer Institute NSW staff and a number of service providers. A total of 220 responses were received.

In addition to information collected from the surveys, the Cancer Institute NSW provided cancer service inventory details that had been collected prior to the AHS amalgamation at the beginning of 2005. This information was verified with the respective Cancer Development Managers within each newly formed AHS and updated where appropriate.

Cancer incidence and projection information, maintained by the Cancer Institute NSW through the NSW Central Cancer Registry, was accessed by the project team and is included in the review.

To substantiate the findings of the patient/carer survey, given the low response rate, the review team considered other Australian studies / papers involving rural cancer patients / carers and their access to cancer services. Various papers / studies were considered and the following issues around the improvement of rural cancer services extracted.<sup>1, 2, 3</sup>

- Transport and the need to remove variations under the IPTAAS system
- Improved patient support in both regional centres and townships with appropriate population sizes
- Workforce planning to ensure adequate future cancer services staffing to be regarded as a Statewide priority;

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<sup>1</sup> Palliative Care Australia (The Social Impact of Caring for Terminally Ill People in Australia, 2004);

<sup>2</sup> University of Western Sydney Nepean (Support Needs of Rural Families of Cancer Patients [undated]), and

<sup>3</sup> Commonwealth Department of Health and Aged Care (Cancer in the Bush: Optimising Clinical Services, 2001)

- Training for cancer services professionals be planned and undertaken with state-wide co-ordination;
- Review of existing consumer resources available for rural palliative care;
- Review of bereavement models and services in rural and regional areas;
- Education of all members of the rural health care teams to assist cancer information needs of patients and their families;
- Ongoing development, use and updating of telemedicine facilities to provide access to specialist medical services for rural general practitioners, specialist palliative care nurses and involving patients;
- Consideration of the use of other workforce models such as nurse practitioners to deliver cancer care services in remote locations;
- Development of information kits for rural patients, families and health professionals on the various stages of the cancer journey.

The themes from the literature were consistent with the qualitative feedback from the patient/carer survey of this review.

## **1.4 Geographical Scope of the Review**

### **1.4.1 Criteria used to define Rural and Remote**

Two main criteria are currently used by health service planners to classify geographic localities as rural or remote, the Accessibility/Remoteness Index of Australia (ARIA) and the Rural, Remote and Metropolitan Areas (RRMA.) A third measure, used less frequently is the Australian Standard Geographical Classification (ASGC) indicator. While all three are sound indicators of remoteness, there is ambiguity surrounding the differentiation of outer metropolitan and rural areas.

The ARIA classification is based on an index score derived from the road distance to the closest service centre. This classification categorises areas into highly accessible, accessible, moderately accessible, remote and very remote. Under this classification system, the majority of the Greater Western Area Health Service is classified as remote or very remote. The remaining locations within the project scope of this study would be categorised between accessible and moderately accessible, with a few in the highly accessible group.

The RRMA classification allocates each statistical local area (SLA) within capital cities and metropolitan centres (defined as having a population of 100,000 or more) to a category of metropolitan. All other SLAs are classified as rural or remote zones based on an index score calculated by combining the SLA population density with the distance of the centroid of the SLA to the nearest urban centre.

The Australian Institute of Health and Welfare indicates that remoteness can be interpreted as “access to a range of services, some of which are available in smaller and others in larger centres: the remoteness of a location can thus be measured in terms of how far one has to travel to centres of various sizes”.<sup>4</sup>

Dependent upon which classification system is used in health service planning, quite different conclusions can be reached about the status of access to appropriate health services.

### **1.4.2 Geographical definition**

After consultation with each NSW AHS by the Cancer Institute NSW, it was agreed to utilise the working definition of rural used by NSW Health, which uses the ARIA system with a few variations. Under this definition, the following AHSs (or parts thereof) were included:

1. Greater Southern AHS;

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<sup>4</sup> Rural, regional and remote health: A guide to remoteness classifications, March 2004, AIHW Cat. No. PHE 53

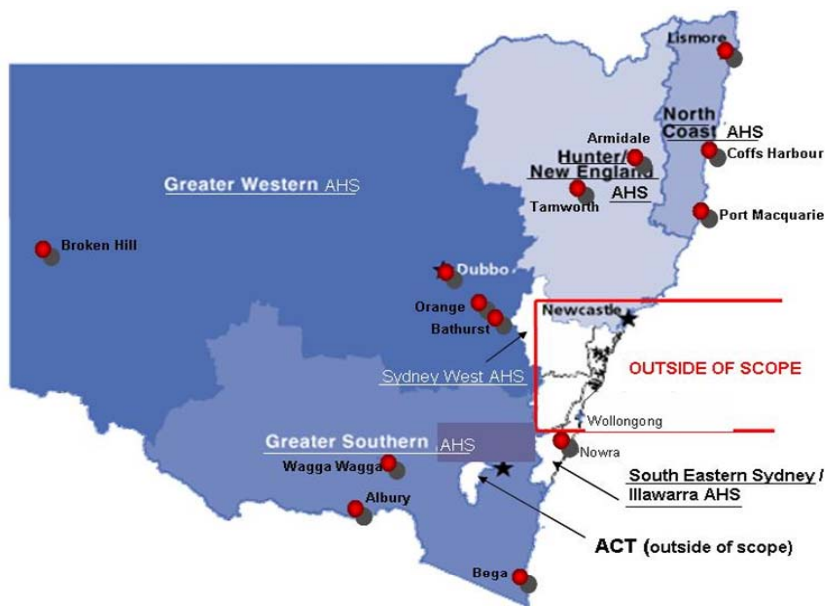
2. Greater Western AHS;
3. North Coast AHS;
4. Hunter New England AHS, excluding the Newcastle LGA;
5. Sydney West AHS, west of Mount Victoria; and
6. South Eastern Sydney/Illawarra AHS, south of Wollongong.

For South Eastern Sydney/Illawarra AHS an additional area outside the NSW Health definition was incorrectly included by the review team, between Wollongong and Nowra. On the understanding that this difference provided more information rather than less, and the adjustments would significantly delay the finalisation of the review, the extra information for SESIAHS remains in the final review as part of the project scope. Figure 1.1 depicts the regions falling within and outside of the scope of this study.

Sydney West, east of Mt Victoria and Northern Sydney/Central Coast Area Health Services were classified as metropolitan and were therefore outside the scope of this review.

Using the NSW Health definition the population of NSW living in rural settings is 22%.<sup>5</sup> The population represented by the area reviewed by the project consultant is 47.9%.

Figure 1.1: Map of within/outside scope by Area Health Service and location major regional hospitals



## 1.5 Area comparisons – cancer projections and incidence

This section provides information on projected cancer cases on the Areas studied, together with a summary of the five most frequently occurring cancers in each of the Areas.

Table 1.1: Summary of projected number of new cases of cancer<sup>6</sup>

	2006	2011	2016
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<sup>5</sup> Tracey E (HOIST populations old Area Health Services – actual and estimated, 2006)

<sup>6</sup> Tracey EA, Roder D, Bishop J et al. Cancer in New South Wales: Incidence and Mortality 2003. Sydney: Cancer Institute NSW, 2005.

NSW total	35,193 (100%)	40,116 (100%)	45,715 (100%)
Greater Southern AHS	2,707 (7.7%)	3,134 (7.8%)	3,633 (7.9%)
Greater Western AHS	1,714 (4.9%)	1,913 (4.8%)	2,175 (4.8%)
Hunter New England AHS (whole area)	4846 (13.8%)	5533 (13.8%)	6317 (13.8%)
North Coast AHS	3,266 (9.3%)	3,863 (9.6%)	4,549 (10.0%)
South Eastern Sydney/ Illawarra AHS (whole area)	6407 (18.2%)	7180 (17.9%)	8045 (17.6%)
Sydney West AHS (whole area)	5,609 (15.9%)	6,428 (16.0%)	7,389 (16.2%)

Table 1.2: Comparative summary of the five most frequently occurring cancers.<sup>7</sup>

AHS	Greater Southern	Greater Western	Hunter New England	North Coast	South Eastern Sydney/ Illawarra (whole area)	Sydney West (Hawkesbury, Blue Mountains & Greater Lithgow LGAs)
1	Prostate cancer	Prostate cancer	Breast cancer	Melanoma	Prostate cancer	Breast cancer
2	Breast cancer	Breast cancer	Prostate cancer	Prostate cancer	Breast cancer	Prostate cancer
3	Lung cancer	Melanoma	Melanoma	Breast cancer	Melanoma	Lung cancer
4	Melanoma	Lung cancer	Colon cancer	Lung cancer	Colon cancer	Colon cancer
5	Colon cancer	Colon cancer	Lung cancer	Colon cancer	Lung cancer	Melanoma
Total %	54.0%	55.0%	54.0%	57.0%	54.0%	54.5%

## 2. Cancer Services Overview per Area Health Service

The following is a summary of the available cancer services for each AHS reviewed. The information in these summaries is current as at the finalisation of the review in May 2006.

<sup>7</sup> ibid

## **2.1 North Coast Area Health Service (NCAHS)**

### **2.1.1 Demographics**

The NCAHS consists of 35,570 square kilometres, extending from the Port Macquarie-Hastings Council in the south to the Queensland border in the north, and westward to the Great Dividing Range. NCAHS is comprised of 12 Local Government Authorities, and a population of 470,908 (2004), comprising 7.0% of the NSW population. Added to this are 45,377 people accessing services in the Tweed region from south-eastern Queensland. Approximately 3.4% of the local population identified themselves as Aboriginal and Torres Strait Islanders (NSW average 1.9%). The area office is located at Lismore.

### **2.1.2 Cancer incidence**

The five most frequently occurring cancers in NCAHS are melanoma, prostate, breast, lung and colon cancer, accounting for 57% of all cases within the AHS. There is a higher incident rate for melanoma in this region compared to other rural areas of NSW. The LGAs with the highest average number of cancer cases per year in the period 1999-2003 include Tweed, Hastings, Coffs Harbour, and Ballina.

### **2.1.3 Cancer services**

There are 5 public and 1 private hospitals/facilities providing cancer services in the NCAHS. These are located at Coffs Harbour, Grafton, Lismore, Port Macquarie, and Tweed Heads. Radiotherapy services are being established at Port Macquarie and Coffs Harbour, with facilities also to be established at Lismore in the future. Currently people living within the NCAHS travel to Brisbane, Newcastle or Sydney for radiotherapy treatment. NCAHS people requiring specialised cancer surgery are treated in Sydney, the Gold Coast and Brisbane.

### **2.1.4 Screening services**

Screening services are offered by general practitioners (pap tests and bowel screening examinations) and a cervical screening program at Port Macquarie Hospital. Rotary is actively involved in bowel cancer screening across the AHS. There are 29 active NSW BreastScreen sites across the NCAHS, including regular visits from mobile services to sites within the Area Health Service. Women located near the interstate border can also access Queensland BreastScreen.

### **2.1.5 Specialist diagnostic services**

A range of diagnostic services exists in the hospitals across the North Coast Area Health Service, some of which are also accessed by people from Queensland. Lismore Base and St Vincent's Hospitals provide surgery and biopsies (Base only), MRI, ultrasound/x-ray, pathology (Base only), colonoscopy and urology diagnostic screening. The Tweed and Coffs Harbour hospitals also undertake biopsies, with biopsies from Coffs reviewed in Sydney and re-rated in Coffs Harbour. Coffs Harbour Hospital also provides MRI, urology, colonoscopy, pathology and ultrasound/x-ray/bone density screenings. Maclean Hospital provides BCG and ultrasound/x-ray/bone density screenings. Port Macquarie Hospital provides MRI and ultrasound/x-ray/bone density screenings. Grafton Hospital provides CT scans and colonoscopy diagnostic services. The Mayne group of private facilities provide radiology and pathology services. Out of Area screening is provided on the Gold Coast (MRI), Brisbane (PET scans) and CT scans at Royal North Shore and the Newcastle Mater hospitals.

### **2.1.6 Support services**

The review identified 149 support services for people living with cancer in NCAHS including services offered in South Eastern Queensland. These included community health services, support groups (bereavement, bowel cancer, breast cancer, prostate cancer, carers, palliative care, colostomy, financial, leukaemia, multiple myeloma), prosthesis and special clothing/wigs, transport, holiday retreat for cancer patients and their families, living with cancer education programs, "Look Good Feel Better" programs and lymphoedema/physiotherapy clinics.

### **2.1.7 Patient referral pathways**

To receive complex cancer care services apart from radiotherapy, patients are referred to Sydney or south-eastern Queensland (n=638 to Brisbane or Gold Coast in 2003/04). These included referrals to PET scans, specialised surgery, specialised chemotherapy, medical oncology, stem cell transplants, paediatrics and specialised clinical trials. For radiotherapy, patients are referred to Brisbane, Newcastle or Sydney.

### **2.1.8 Outreach services**

Medical specialist services are provided between centres within NCAHS and also from out of area. Intra-area cancer services include radiation oncology, haematology, palliative care and medical oncology specialist services from Lismore or Coffs Harbour to other NCAHS locations. Cancer services received from out-of-area are from South Eastern Sydney/Illawarra AHS (gynae oncology and palliative care), Sydney South West AHS (cardiothoracic surgery) and from Tugun, Qld, (radiation oncology).

### **2.1.9 Telehealth and Multidisciplinary teams**

There are 33 telehealth sites across the NCAHS. Multi-disciplinary care is supported at a service provider level at the Tweed, Lismore, Port Macquarie and Coffs Harbour hospitals. These include participation from a range of health professionals including nursing, medical and allied health care professionals where possible, as well as general practitioners at Lismore. In addition there are a number of breast cancer specific multi-disciplinary teams at Port Macquarie, Tweed and Coffs Harbour hospitals. Urology cancer MDT's exist at Port Macquarie and Coffs Harbour with colorectal/GIT cancer MDT's at Port Macquarie and Coffs Harbour.

## **2.2 Greater Western Area Health Service (GWAHS)**

### **2.2.1 Demographics**

The GWAHS consists of 444,586 square kilometres (approximately 55% of the geographical coverage of NSW), with a population of approximately 294,000 people (4.35% of the NSW population). 7.3% of the population is identified as Aboriginal and Torres Strait Islander. 42% of the GWAHS population reside in the local government areas of Bathurst, Orange, Dubbo and Broken Hill. The remaining population is dispersed in small rural and remote towns. The Area Health Service office is located at Dubbo.

### **2.2.2 Cancer incidence**

The five most frequently occurring cancers in GWAHS are prostate, breast, melanoma, lung and colon cancer, accounting for 55% of the cancer incidence in GWAHS, and 4.9% of the cancer incidence in NSW.

### **2.2.3 Cancer services**

The majority of hospital cancer services for the AHS are located in Orange, Dubbo, Bathurst and Broken Hill. Inpatient and outpatient medical oncology and chemotherapy services and surgical services are available at Bathurst, Broken Hill (limited surgical), Dubbo, Cowra (limited surgical), Orange and Parkes (outreach chemotherapy treatment clinic, no surgical). The only identified lymphoedema clinic in GWAHS is at Dubbo (Lourdes Hospital).

### **2.2.4 Screening services**

There are 26 Breast Screen locations within GWAHS for routine visits, including regular visits from mobile services to sites within the Area Health Service. Colonoscopy is provided at Orange and Broken Hill, genetic counselling at Broken Hill, skin clinic or visiting dermatologist at Broken Hill, Dubbo and Mudgee.

Colonoscopy services are provided at: Bathurst, Cowra, Orange, Parkes, Forbes, Dubbo and Broken Hill.

Genetic counselling is available at Bathurst, Orange and Broken Hill. There are resident dermatologists in Bathurst and Orange with visiting services and/or skin clinics available at Dubbo, Mudgee and Broken Hill.

### **2.2.5 Specialist diagnostic services**

Orange provides CT, diagnostic ultrasound, MRI, ultrasound and specialist pathology services. Bathurst provides CT, diagnostic ultrasound and specialist pathology services. Broken Hill provides CT, diagnostic ultrasound and specialist pathology services. Dubbo provides CT, diagnostic ultrasound, MRI and specialist pathology services.

Nuclear medicine is offered at Dubbo, Orange and Broken Hill.

### **2.2.6 Support services**

The review identified 115 support services provided across GWAHS including psychologists and social workers, support groups, specialists counselling services, rehabilitation services, palliative care and community care services. Patient accommodation facilities are available in Dubbo (n=3). Accommodation facilities not available at Orange (private facilities exist in all regional centres across GWAHS, with subsidy available from IPTAAS if patients qualify)

### **2.2.7 Patient referral pathways**

People in the GWAHS requiring complex cancer treatments are referred to Sydney or Adelaide. Adelaide is the major referral centre for Broken Hill patients and is the major provider for outreach services to Broken Hill.

The major Sydney centres utilised for outreach services include:

- Royal Prince Alfred Hospital –surgical services, haematology, medical oncology, radiation oncology, palliative care, PET scan, sentinel node mapping – links with Dubbo Oncology and Palliative Care services)
- Note: Haematology also provided to Orange (clinician was formerly based at POW)
- St Vincent’s Hospital – surgical services, medical oncology, radiation oncology, palliative care – links with Bathurst and Orange Oncology and Palliative Care services
- Liverpool Hospital - PET scan
- St George Hospital - liver surgery
- Prince of Wales – haematology – links with Bathurst

The main relationships are St Vincent’s with Bathurst and Orange, Royal Prince Alfred with Dubbo and Adelaide hospitals with Broken Hill.

### **2.2.8 Outreach services**

Cancer services are provided between centres within GWAHS and also from out of area.

Intra-area services include:

- Chemotherapy nursing treatment clinic
  - Orange to Parkes
  - Dubbo to Mudgee
- Psycho-Oncology Counsellor
  - Orange to Bathurst, Cowra, Forbes and Parkes
  - Dubbo to Mudgee, Coonabarabran and other small towns as required

- Broken Hill to Dareton, Wentworth and Menindee
- Rural Cancer Care Coordinator
  - Orange to Bathurst
  - Dubbo to Mudgee, Coonabarabran and other small towns as required
  - Broken Hill to Dareton, Wentworth and Menindee
- Palliative Care RNs, CNS and CNC
  - Bathurst to Oberon, Blayney and Rylstone
  - Orange to Canowindra, Cowra, Cudal, Eugowra, Grenfell, Molong and Yeoval
  - Parkes to Peak Hill, Trundle, Tullamore and Tottenham
  - Forbes to Condobolin and Lake Cargelligo
  - Dubbo to Mudgee, Coolah, Dunedoo, Gulgong, Wellington, Narromine, Trangie, Nyngan, Cobar and Warren
  - Broken Hill (CNC) to Bourke, Brewarrina, Collarenebri and Goodooga
  - Dareton to Wentworth, Euston and Balranald
  - Walgett to Lightning Ridge
- Private medical specialists from Dubbo (a paediatrician to Walgett, and a general surgeon to Bourke).

Out-of area outreach services:

- SSWAHS (RPAH) – haematology, medical oncology, radiation oncology, palliative care, to Dubbo Oncology and Palliative Care  
NB: Haematology also provided to Orange (clinician was formerly based at POW)
- SES/Illawarra ( St Vincents Hospital) – medical oncology, radiation oncology, palliative care – to Bathurst and Orange
- SES/Illawarra ( Prince of Wales) – haematology to Bathurst

## **2.2.9 Telehealth and Multidisciplinary teams**

There are 35 Telehealth sites across GWAHS, which appear to be mostly used for administrative purposes. There is a breast cancer specialist meeting in Orange and a cancer multidisciplinary team meeting at Dubbo, with limited GP involvement.

## **2.3 Greater Southern Area Health Service (GSAHS)**

### **2.3.1 Demographics**

The GSAHS covers 166,000 sq km (approximately 21% of NSW), and has a population of approximately 468,000 persons (6.9% of the NSW population). There are six main areas of population density each located at Albury, Deniliquin, Goulburn, Griffith, Queanbeyan and Wagga Wagga, with many smaller rural towns in the AHS. The GSAHS shares borders with Victoria and the Australian Capital Territory. Border issues contribute to the complexity of cancer services and patient referrals in the GSAHS.

### **2.3.2 Cancer incidence**

The top five reported cancer types in the GSAHS are prostate, breast, lung, melanoma and colon cancer. These represent 54% of all cancers within the AHS. As a proportion of the total new

cancer cases projected for NSW, the number of new cancer cases expected across the GSAHS remains relatively steady at 7.9% of the NSW total by 2016. The AHS head offices are in Queanbeyan.

### **2.3.3 Cancer services**

Cooperative arrangements exist between the public and private sectors in the provision of cancer services in GSAHS. The base hospitals are located in Albury, Goulburn, Griffith and Wagga Wagga (public facilities as well as the private Riverina Cancer Care Centre), and district hospitals at Bega, Moruya, Goulburn and Young. The Murray Valley Private Hospital (Wodonga, Vic) also provides chemotherapy for private patients. Prostate surgery is provided by 3 urologists in Albury-Wodonga and a general surgeon in Wagga Wagga with an interest in urology. Radiotherapy is offered at the Riverina Cancer Care Centre (Wagga Wagga) and Radiation Oncology Victoria (Wodonga, Vic). Radiotherapy is also accessed at Canberra Hospital with approximately 35% of their clients from GSAHS.

### **2.3.4 Screening services**

Cancer screening services are provided by GPs throughout the AHS. Facility (public) screening is predominantly provided in Albury, Griffith and Wagga Wagga. Endoscopy and colonoscopy screening are available at 14 hospital sites across the AHS. Bowel cancer screening is a current project with the Riverina Division of General Practice (recruiting 3,000 participants). There are 27 BreastScreen sites across the GSAHS, including regular visits from mobile services to sites within the Area Health Service.

### **2.3.5 Specialist diagnostic services**

The majority of hospitals in the GSAHS provide basic services associated with general surgery, pathology and general radiology. More complex or specialised services are provided by the base hospitals including nuclear medicine, interventional radiology (except at Goulburn), fluoroscopy (also at Bega private) and MRI (Albury and Wagga Wagga Base Hospitals only). Complex tumour marker testing is undertaken at Newcastle, Royal Melbourne Hospital, Royal Children's Hospital (Melbourne) and at the ICPMR at Westmead.

### **2.3.6 Support services**

The review noted 177 support services with additional services provided outside the area as part of cross-border arrangements.

### **2.3.7 Patient referral pathways**

Cancer patients from GSAHS comprise 30-40% of the patients in the Canberra Oncology Unit at Canberra Hospital. Referrals are also made to hospitals in Sydney and Melbourne as required, e.g. for specialised cancer surgery. In Sydney these include Prince of Wales, Royal Prince Alfred, St Vincent's and the Children's Hospitals. In Melbourne these include the Royal Women's Hospital, Melbourne Children's Hospital, St Vincent's Hospital, Austin Hospital and Royal Melbourne.

Chemotherapy is provided across the GSAHS at 7 sites, as well as in Canberra, Wodonga, Sydney and Melbourne. Radiotherapy is provided within the area at Wagga Wagga. It is also offered at Radiation Oncology Victoria (Wodonga, Vic), Canberra and at Sydney and Melbourne for some tumour specific treatment. The GSAHS provides funding for residents (inpatients only) receiving treatment in Canberra and Wodonga through cross-border arrangements. Genetic counselling is available in Goulburn.

### **2.3.8 Outreach services**

In Greater Southern Area Health Service there are a number of intra area Cancer Services (details to be added later).

These are provided predominantly by specialists from Canberra or South Eastern Sydney/Illawarra AHS. The Canberra Hospital provides medical oncologists, haematologists and a urologist to Bega; a radiation oncologist and medical oncologists to Goulburn; and a medical oncologist to Young. SESIAHS provides a medical oncologist and haematologist & RCCC provide Radiation Oncology consultation to Griffith; and a radiation oncologist, haematologist and palliative care specialist to Wagga Wagga; as well as a palliative care specialist to Albury. RCCC also provide a radiation oncologist to Young.

In Greater Southern Area Health Service, ACT Health provides out reach Medical Oncology, Radiation Oncology consultation and Haematology Services to Bega, Moruya, Goulburn and Young, also Albury Wodonga Medical Oncologists provide a Service to Finley. St George provide medical oncology, urology and general surgical services. St Vincents provide haematology services to Griffith. Wagga provide GI, General surgery services to Young. Urology from ACT Health is provided to Bega, Palliative Care specialists from Sacred Heart Hospice provide monthly and fortnightly services to Albury and Wagga.

### **2.3.9 Telehealth and Multidisciplinary teams**

There are 28 telehealth sites across the GSAHS, with Albury, Goulburn and Queanbeyan having more than one facility. Multidisciplinary cancer team meetings are held in Albury, Bega, Griffith (Palliative Care) and Wagga Wagga. Meetings are also held in Canberra where there is a GSAHS patient load. There are also some tumour specific meetings including breast cancer, urology cancer and gastrointestinal cancer (Albury); gynaecological cancer and head and neck cancer (Wodonga).

## **2.4 Hunter New England Area Health Service (HNEAHS)**

### **2.4.1 Demographics**

The HNEAHS covers a geographical area of 130,000 sq kms, and has a population of 840,000 people (12.4% of NSW). There are 34 LGAs within the HNEAHS, of which 33 are within scope of this review. The HNEAHS provides health services to 20% of the NSW Aboriginal population.

### **2.4.2 Cancer incidence**

The top five cancers are breast, prostate, melanoma, colon and lung cancer, which account for 54% of all cancers within the AHS. The count of cancer cases in the scope LGAs for the period 1999-2003 was 17,057. The LGAs within scope with the highest average number of cancers cases per year over the period 1999-2003 are Lake Macquarie, Port Stephens, Greater Taree and the Great Lakes LGAs.

### **2.4.3 Cancer services**

The majority of cancer services are located within the Base Hospitals or in locations close to the Base/regional hospitals. There are also a number of private hospitals offering cancer services within the HNEAHS including Lingard, Lake Macquarie, Toronto and Warners Bay private hospitals. Outpatient chemotherapy is provided at Muswellbrook, Armidale and Manning Base hospitals, Tamworth, Moree and Inverell (public) and Lingard Private Hospital. Radiotherapy services are provided by Newcastle Mater Hospital, located outside of the scope of this review but within the AHS. Referrals for radiotherapy are also made to the Royal Brisbane (Queensland), Prince of Wales (SESAHS), Royal North Shore (NSCCH), St Vincents (SESAHS), Liverpool (SSWAHS) hospitals and Mater Hospital Crows Nest.

### **2.4.4 Screening services**

Cancer screening services are provided by GPs throughout the AHS. Facility (public) screening is provided mostly in Armidale and Tamworth. There are 45 Breast Screen sites in the HNEAHS scope area, including regular visits from mobile services to sites within the Area Health Service.

### **2.4.5 Specialist diagnostic services**

Specialist diagnostic services are available in Armidale and Tamworth for CT scan, ultrasound, MRI (Tamworth only), pathology and biopsies.

The Mater and John Hunter Hospitals (HNEAHS but outside review scope) are utilised for CT scans, ultrasound, bone and nuclear scans. Out-of-area services are accessed at Royal North Shore Hospital (CT scan, bone and nuclear scan), Royal Prince Alfred and Royal Brisbane Hospitals (PET scans).

### **2.4.6 Support services**

The review identified 38 support services for cancer patients and their families including volunteer organisations such as the Dungog Palliative Care Volunteers & Linen Service.

### **2.4.7 Patient referral pathways**

Cancer patients living in the HNEAHS access a range of cancer screening, treatment, follow up and support services locally, many of which are located within the public or private hospitals. However for more complex procedures or diagnostic services requiring access to advanced technology patients are referred out of area to facilities located in Sydney or in Brisbane.

### **2.4.8 Outreach services**

Cancer services are provided between centres within HNEAHS and also from out of area. Intra-area arrangements include a geneticist, medical oncologist and palliative care specialist (Newcastle Mater Hospital to Taree and Muswellbrook); and palliative care specialists (Newcastle Mater Hospital to Westlake, Cessnock-Singleton, Port Stephens).

Services received from out-of-area are from the Children's Hospital Westmead (palliative care to Taree), a private Sydney dermatologist to Taree, a medical oncologist to Armidale (Royal North Shore Hospital), a radiation oncologist to Armidale (Mater Hospital Sydney), a paediatric oncologist to Armidale (Children's Hospital Randwick) and a medical oncologist and radiation oncologist to Tamworth (Prince of Wales Hospital).

### **2.4.9 Telehealth and Multidisciplinary teams**

There are 25 telehealth sites located across the regions of the HNEAHS within review scope. A professional multi-disciplinary general oncology team meeting is held at Manning Base Hospital (Taree). There are no tumour specific multi-disciplinary team meetings in scope, though these are conducted within the HNEAS at the Newcastle Mater Misericordiae Hospital (lung cancer, breast cancer, head and neck cancer, oesophageal cancer, and lymphoma) and at the John Hunter Hospital (gynecological, urological and GI cancer).

## **2.5 South Eastern Sydney/Illawarra Area Health Service (SESIAHS)**

### **2.5.1 Demographics**

The SESIAHS is comprised of 6,331 square kilometres. SESIAHS is identified by NSW Health as a metropolitan AHS and is unique in the number of significant referral hospitals within one AHS. Of these facilities, only the hospitals at Shoalhaven, Shellharbour, and Milton-Ulladulla fall within the scope of this review.

The Area population is 1,164,580 (2004), comprising 17% of the NSW population. 1% people in the SESIAHS identify themselves as Aboriginal or Torres Strait Islander. The population of the 3 scope LGAs is 177,096 (15.2% of the SESIAHS population). Shoalhaven and Kiama LGAs have the highest proportion of residents aged over 70 years of age, while Shellharbour LGA has the highest proportion of children less than 5 years of age.

## **2.5.2 Cancer incidence**

The top five cancer types in the SESIAHS include prostate, breast, melanoma, colon and lung cancer. These were responsible for 54% of all reported cancers with the AHS. The average annual number of new cases diagnosed in the period 1999-2003 was 3,069 cases. In the 3 LGAs in scope, there were 4,703 cases of cancer notified to the Central Cancer Registry in the period 1999-2003.

## **2.5.3 Cancer services**

There are two district hospitals in the scope LGAs; Shoalhaven (Nowra) and Shellharbour. Wollongong Hospital is the closest tertiary referral facility and cancer centre (inc. radiotherapy). Cancer services are also located at Kogarah (inc. radiotherapy) and Randwick in the SESIAHS. Palliative care is provided at the David Berry Community Hospital near Nowra and Port Kembla Hospital. Chemotherapy is offered in Shoalhaven at both the public (Shoalhaven Oncology Day Care Centre) and at the private hospital. The community had raised funds to open a chemotherapy clinic in Milton, which remained in the planning stages at the time of the review.

## **2.5.4 Screening services**

There are two 'relocatable' BreastScreen sites located at Nowra and Ulladulla. GPs and rotary (bowel only) are involved in cancer screening. Shoalhaven District Hospital has a skin cancer screening program. All screening is available at Wollongong and the Sydney based hospitals.

## **2.5.5 Specialist diagnostic services**

There are no specialist diagnostic services in the scope areas. They are mainly available at Wollongong, or in the Sydney based facilities of SESIAHS.

## **2.5.6 Support services**

The review noted 22 support services in the scope LGAs. Stomal therapy in Canberra was noted to be accessed by cancer patients in the scope LGAs.

## **2.5.7 Patient referral pathways**

Patients within SESIAHS are generally referred to Wollongong Hospital, St George, Prince of Wales or St Vincent's Hospitals within SESIAHS for radiotherapy and specialised surgery or chemotherapy. Chemotherapy is provided at Sutherland Hospital and also within the scope hospitals. Anecdotally during the review it was suggested that patients in the southern part of the AHS access services in Canberra.

## **2.5.8 Outreach services**

These are provided both across/within SESIAHS, as well as from other AHSs. The outreach services to the rural areas of the SESIAHS from within the area include medical oncologists (Prince of Wales and Wollongong Hospitals), a haematologist (Wollongong Hospital) and chemotherapy (Nowra to Milton).

External service provision to the rural areas of the SESIAHS is via Nowra and is provided by a medical oncologist from the Mater Hospital (Sydney), a private palliative care specialist (from Berry), a gynaecological oncologist (Westmead Hospital) and private urologists (Liverpool Hospital).

## **2.5.9 Telehealth and Multidisciplinary teams**

Five telehealth sites were identified in the scope LGAs. Shoalhaven Hospital holds monthly multidisciplinary team meetings and uses telehealth facilities. Quarterly BreastScreen meetings are also held at Shoalhaven Hospital.

## **2.6 Sydney West Area Health Service (SWAHS)**

### **2.6.1 Demographics**

The SWAHS is defined by NSW Health as a metropolitan AHS. It is comprised of nine LGAs comprising 8,094 square kilometres. The scope of this review includes three LGAs, Hawkesbury, Blue Mountains and Greater Lithgow. The population of these LGAs is 154,590 which represent 13.9% of the SWAHS population and approximately 2.3% of the NSW population. There were 3,333 new cases of cancer in the period 1999-2003 in this group (17.7% of the whole AHS reported cases).

### **2.6.2 Cancer incidence**

In the 3 LGAs of SWAHS reviewed, the top five cancer types were responsible for 54.5% of all cases of cancer in that region and included breast, prostate, lung, colon cancer and melanoma. The average annual number of new cases of these cancers diagnosed in the period 1999-2003 was 363.

### **2.6.3 Cancer services**

Services for the population in this area are provided from within the AHS and also from hospitals in other AHSs. Lithgow District Hospital provides limited cancer services (outpatient chemotherapy and medical oncology, minor surgical services). There are no private facilities in this area. The primary cancer services provider is Nepean Hospital, Penrith, which houses a fully comprehensive cancer centre. Radiotherapy is primarily provided at Nepean and Westmead Hospitals. Other cancer services are also accessed at Bathurst and Orange.

### **2.6.4 Screening services**

Cancer screening services across SWAHS are offered through a number of venues including general practitioners, hospitals located within the AHS, private screening services such as through Mayne Health, and non-government organisations such as Rotary. There are 24 BreastScreen sites in SWAHS. There are no sites west of Katoomba though breast screening is provided at Bathurst Hospital.

### **2.6.5 Specialist diagnostic services**

Specialist diagnostic services for people in SWAHS are provided at Nepean Hospital, though PET scans are accessed at Royal Prince Alfred Hospital. Residents in the scope LGAs either travel to Penrith or access services at Orange and Dubbo Base hospitals.

### **2.6.6 Support services**

The review identified 12 support services for the three rural LGAs, including ten at Lithgow and one each at Bathurst and Portland.

### **2.6.7 Patient referral pathways**

Residents in Hawkesbury, Blue Mountains and Greater Lithgow LGAs are usually referred to Nepean Hospital for a range of cancer screening, treatment and follow-up services. This is especially the case for complex cancer care. Some routine cancer screening, treatment and follow-up services are also accessed in Bathurst.

### **2.6.8 Outreach services**

Specialist oncologists and haematologists from St Vincent's and Nepean visit Lithgow and Bathurst. This may encourage people with cancer in Hawkesbury, Blue Mountains and Greater

Lithgow LGAs to access the Bathurst specialist outreach rather than traveling to Penrith. There are no outreach services provided by Lithgow District Hospital to surrounding areas.

### **2.6.9 Telehealth and Multidisciplinary teams**

There are two telehealth sites in Lithgow. There is also a multi-disciplinary team at Lithgow, but similar teams have not been developed beyond this locality within the rural regions of GWAHS.

## **3. Summary of survey results**

### **3.1 Consumer surveys**

Responses to the consumer surveys were primarily from people living with cancer (93%), with 7% completed by carers. The majority of respondents to the consumer survey indicated that they had been diagnosed with cancer within the last twelve months, and that they had breast cancer (41.4%), bowel cancer (13.8%) and lung cancer (10.0%). Key issues identified in the consumer survey included:

- Information
  - dissemination by internet and e-health not always an effective medium for rural cancer patients;
- Access to cancer services
  - travel and accommodation financial support issues were important with numerous responses on the Isolated Patients Travel and Accommodation Assistance Scheme (IPTAAS)
  - limited access to after hours nursing services;
  - patient 'out-of-pocket expenses was a secondary issue when considering treatment issues.
- Care planning
  - Underestimates of the time needed for cancer treatment and recovery from treatment, affecting both the course of treatment and access logistics, such as transport and accommodation.

### **3.2 Service provider and rural Divisions of General Practice surveys**

Key issues from service providers and the rural Divisions of General Practice included:

- Area Health Service restructure (01/01/05) issues including:
  - conflicting cultures, practices and service delivery models as a result of mergers;
  - informal and inconsistent reporting between cancer service providers within the merged Area Health Services;
- Informal service delivery and referral cancer patient pathway networks:
  - cancer services are mostly built on informal referral relationships rather than on formal hub and spoke or other service delivery models;
- Development of regional and rural facilities:
  - newly introduced cancer services may require support from metropolitan linkages to ensure optimal service provision ;
- Telemedicine system links:

- widespread infrastructure has the potential to be used more widely and effectively;
- technical issues around equipment and/or equipment failure , such as “drop-outs” during a telemedicine session;
- Data management:
  - value in more comprehensive and standardised databases
  - Continuing challenges in data management around palliative care and Allied Health services
- Research and clinical trials:
  - time and human resource requirements to develop competitive grant applications may present a challenge for many rural Areas
  - participation in clinical trial may be limited due to variations in appropriately skilled staff;
- Workforce issues:
  - involvement and knowledge of General Practitioners about available cancer services could be improved,
  - recruitment and retention of cancer specialists (medical, surgical), nurses and allied health professionals to rural areas remains an issue;
  - most rural cancer services are being run on small staffing numbers which can impact on staff morale and health (limited ability to take annual leave or participate in professional development)
- Support services for children who have a parent with cancer;
- Transport and accommodation issues:
  - Challenges related to access and administrative issues related to IPTAAS were noted by service providers;
  - accommodation for people receiving cancer treatments in rural and urban locations appears limited and does not always accommodate children;
- Information regarding available cancer services;
- Variation in access to pharmaceuticals and diagnostic Services;
  - access to some new drugs may be limited compared with metropolitan services.

## 4. Rural Cancer Incidence and Mortality

When conducted in 2005, the NSW Rural Cancer Services Review extracted cancer incidence and mortality data for the period of 1999 – 2003 from the NSW Central Cancer Registry. This data is presented in the report as it remains relevant to the context and timing of the review.

However since the initial data extraction and finalization of the review, this data has been superseded. Therefore additional information regarding rural cancer incidence and mortality trends for the 2000 – 2004 period is also included and can be referenced in section 4.5.

### 4.1 National Cancer Incidence

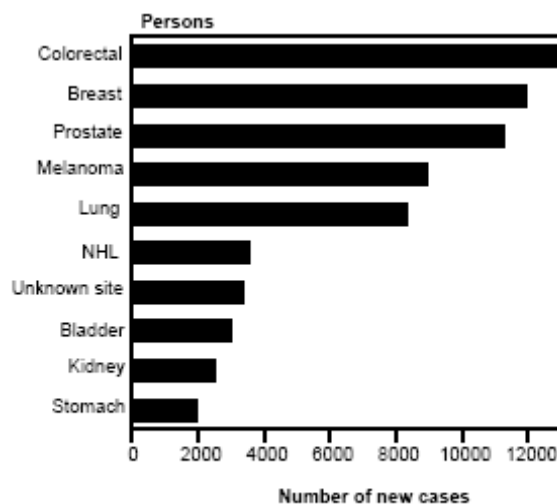
In 2001, the Australian Institute of Health and Welfare (AIHW) reported 88,398 new cancer cases and 36,319 deaths due to cancer across Australia, excluding non-melanoma skin cancers (NMSC). This represents a significant increase compared to the previous decade in which there were 65,966 new cases and 30,928 deaths. Based on these figures, 1 in 3 men and 1 in 4 women in Australia will be diagnosed with cancer in the first 75 years of life. Cancer currently accounts for 31% of male deaths and 26% of female deaths.

Further, an estimated 257,458 potential years of life will be lost to the community each year in Australia as a result of cancer deaths before the age of 75.

Figure 4.1 is an extract from the AIHW report and depicts the cancers with the highest national incidence rates, where the incidence rate is defined as the number of new cases of cancer divided by the population at risk in a specified time period. Based on this figure the five cancers with highest incidence rates across Australia correspond to:

- Colorectal cancer
- Breast cancer
- Prostate cancer
- Melanoma, and
- Lung cancer

**Figure 4.1: Incidence Rates of Cancers, Australia 2001**



Source: *Cancer in Australia 2001* (AIHW & AACR 2004).

Table 4.1 breaks down the most frequently occurring cancers by gender for Australia and shows that for males the five most frequently occurring cancers are prostate cancer, colorectal cancer, lung cancer, melanoma and cancer of the bladder. For females, the five most frequently occurring cancers are breast cancer, colorectal cancer, melanoma, lung cancer, and Non-Hodgkin's Lymphoma.

**Table 4.1: Most frequently occurring cancers in Australia, 2001**

Cancer site	New cases					Deaths				
	Number	% of all new cancer cases	ASR (A)	ASR (W)	Lifetime risk <sup>(a)</sup>	Number	% of all cancer deaths	ASR (A)	ASR (W)	PYLL <sup>(c)</sup>
<b>Males</b>										
Prostate	11,191	23.4	128.5	88.1	1 in 11	2,718	13.3	35.2	20.2	5,665
Colorectal	6,961	14.6	79.0	55.4	1 in 17	2,601	12.7	30.5	20.4	17,183
Lung	5,384	11.3	61.4	42.3	1 in 22	4,657	22.8	53.7	36.4	28,948
Melanoma	5,024	10.5	55.2	42.4	1 in 25	684	3.4	7.8	5.5	7,568
Bladder	2,258	4.7	26.6	17.5	1 in 60	633	3.1	8.0	4.8	2,155
NHL	1,923	4.0	21.4	16.1	1 in 64	787	3.9	9.2	6.3	6,628
Unknown site	1,736	3.6	20.5	13.6	1 in 80	1,213	5.9	14.7	9.4	7,173
Kidney	1,514	3.2	16.9	12.3	1 in 78	540	2.6	6.3	4.3	4,425
Stomach	1,202	2.5	13.8	9.5	1 in 104	753	3.7	8.9	5.9	5,140
Pancreas	958	2.0	11.0	7.6	1 in 133	946	4.6	11.0	7.4	6,465
<i>All cancers</i>	<i>47,820</i>	<i>100.0</i>	<i>541.4</i>	<i>387.6</i>	<i>1 in 3</i>	<i>20,417</i>	<i>100.0</i>	<i>241.2</i>	<i>160.0</i>	<i>139,913</i>
<b>Females</b>										
Breast	11,791	29.1	117.2	93.1	1 in 11	2,594	16.3	24.8	18.2	28,540
Colorectal	5,883	14.5	55.4	38.9	1 in 26	2,153	13.5	19.7	13.1	12,585
Melanoma	3,861	9.5	38.3	31.6	1 in 34	390	2.5	3.7	2.7	4,300
Lung	2,891	7.1	27.7	20.0	1 in 46	2,382	15.0	22.6	15.9	16,030
NHL	1,576	3.9	15.1	11.3	1 in 88	715	4.5	6.5	4.4	3,935
Unknown site	1,568	3.9	14.3	9.5	1 in 117	1,217	7.7	10.9	6.9	5,640
Uterus	1,537	3.8	15.1	11.7	1 in 77	299	1.9	2.8	2.0	2,225
Ovary	1,295	3.2	12.6	9.8	1 in 104	857	5.4	8.1	5.7	6,598
Kidney	944	2.3	9.1	6.8	1 in 142	386	2.4	3.6	2.4	1,923
Pancreas	900	2.2	8.2	5.5	1 in 207	865	5.4	7.8	5.1	3,908
<i>All cancers</i>	<i>40,578</i>	<i>100.0</i>	<i>393.3</i>	<i>300.3</i>	<i>1 in 4</i>	<i>15,902</i>	<i>100.0</i>	<i>147.8</i>	<i>102.2</i>	<i>117,545</i>
<b>Persons</b>										
Colorectal	12,844	14.5	66.2	46.6	1 in 21	4,754	13.1	24.5	16.5	29,768
Breast	11,886	13.4	61.2	48.0	1 in 20	2,620	7.2	13.5	9.7	28,733
Prostate	11,191	12.7	57.6	40.6	1 in 22	2,718	7.5	14.0	8.3	5,665
Melanoma	8,885	10.1	45.8	36.5	1 in 29	1,074	3.0	5.5	4.0	11,868
Lung	8,275	9.4	42.6	30.1	1 in 30	7,039	19.4	36.3	25.1	44,978
NHL	3,499	4.0	18.0	13.6	1 in 74	1,502	4.1	7.7	5.3	10,563
Unknown site	3,304	3.7	17.0	11.4	1 in 96	2,430	6.7	12.5	8.0	12,813
Bladder	2,954	3.3	15.2	10.3	1 in 96	908	2.5	4.7	2.9	2,930
Kidney	2,458	2.8	12.7	9.3	1 in 101	926	2.5	4.8	3.2	6,348
Stomach	1,902	2.2	9.8	6.8	1 in 143	1,209	3.3	6.2	4.2	8,133
<i>All cancers</i>	<i>88,398</i>	<i>100.0</i>	<i>455.3</i>	<i>337.6</i>	<i>1 in 3</i>	<i>36,319</i>	<i>100.0</i>	<i>187.1</i>	<i>127.3</i>	<i>257,458</i>

(a) Rates are expressed per 100,000 population and age-standardised to the Australian 2001 Standard Population (ASR (A)) and to the WHO 2000 World Standard Population (ASR (W)). The rates age-standardised to the two populations (World 2000 and Australia 2001) differ due to the age distributions of these populations. For example, the world population gives more weight to younger age groups where there are fewer cancers, and consequently the rate is lower compared with the Australian 2001 population. A greater weight is given to the older age groups in the Australian 2001 population where there are more cancers, and consequently these rates tend to be higher.

(b) Non-melanoma skin cancers, known to be the most common cancer type, are excluded from this list as basal cell carcinoma and squamous cell carcinoma, the two most common types of non-melanoma skin cancer, are not notifiable cancers.

(c) These measures are calculated for ages 0–74 years; PYLL refers to person-years of life lost. Methods for the calculation of these measures are presented in Appendix B.

Note: NHL refers to non-Hodgkin's lymphoma. In this table colorectal cancer includes anus; kidney includes ureter and urethra; ovary includes other and unspecified female organs. Methods for calculation of these measures are presented in Appendix B.

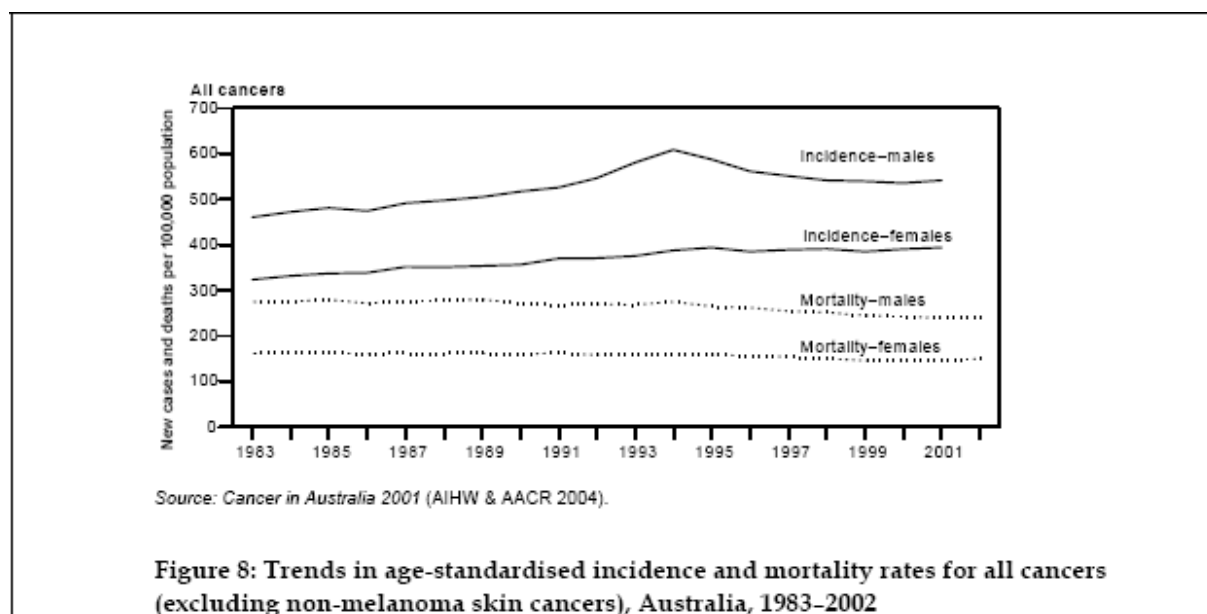
Source: *Cancer in Australia 2001* (AIHW & AACR 2004).

In considering this information it is important to acknowledge that small changes in the trend in the most common cancers (for example, breast, prostate) can mean a substantial shift in the numbers of new cases or deaths, whereas the same shift in less common cancers can have a relatively small impact. For example, a 1% increase in the breast cancer incidence rate results in an increase of approximately 118 new cases, whereas the same percentage increase in cervical cancer incidence would result in approximately seven new cases <sup>8</sup>.

Figure 4.2 shows that while there has been a steady increase in the incidence rates (age standardized) over the ten year period covered by 1991 to 2001, the same trend has not been observed in terms of the mortality rates for all cancers combined. The reduction in cancer mortality can be attributed to:

- monitoring of individuals at high risk;
- reducing external risk factors;
- detecting and treating cancers early in their development, and
- treating cancer in accordance with the best available evidence.

**Figure 4.2: Age standardized incidence rates and mortality rates for all cancers combined, Australia 1991 – 2001**



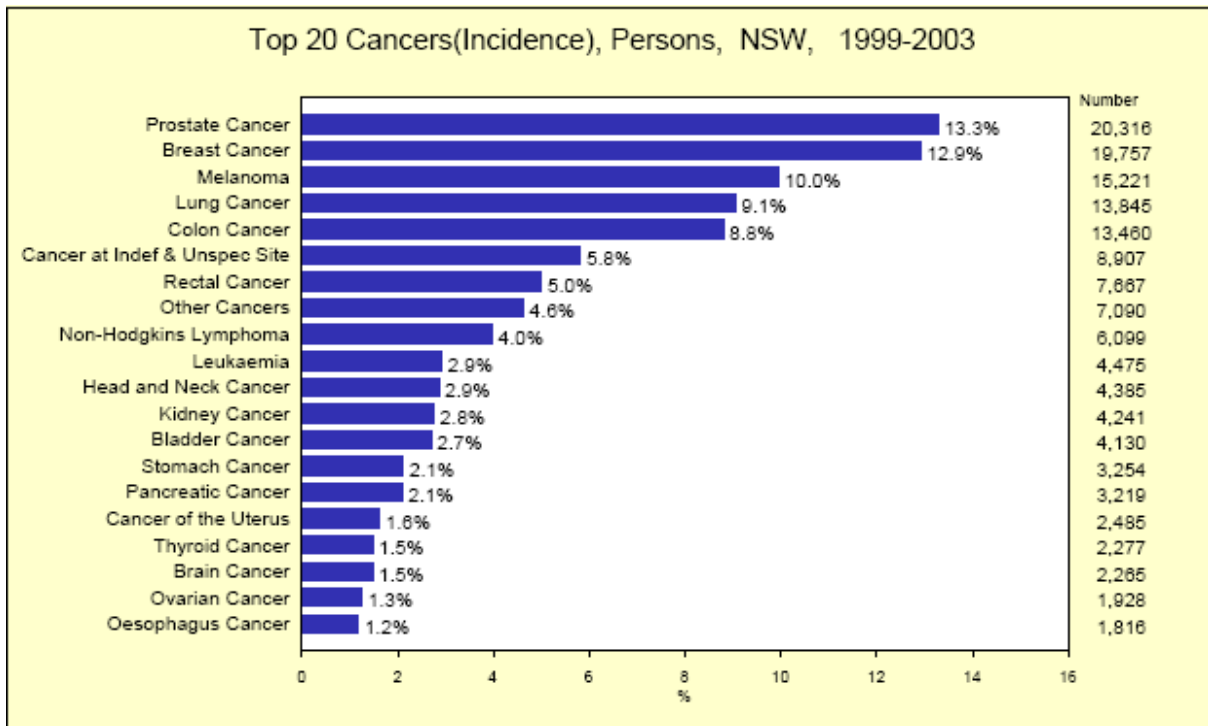
## 4.2 Cancer Incidence in New South Wales

New South Wales is the most populous state in Australia with a population of approximately 6.8million residents, one-third of the country's total population. The State covers a geographic area of 801,600 square kilometres.

Figure 4.3 depicts the top twenty cancers in NSW by incidence rates for the period 1999-2003 and indicates that the top five cancers are prostate cancer, breast cancer, melanoma, lung cancer, and colorectal cancer.

**Figure 4.3: Top Twenty Cancers across New South Wales 1999-2003**

<sup>8</sup> Ibid.



### 4.3 Cancer Incidence in Rural New South Wales

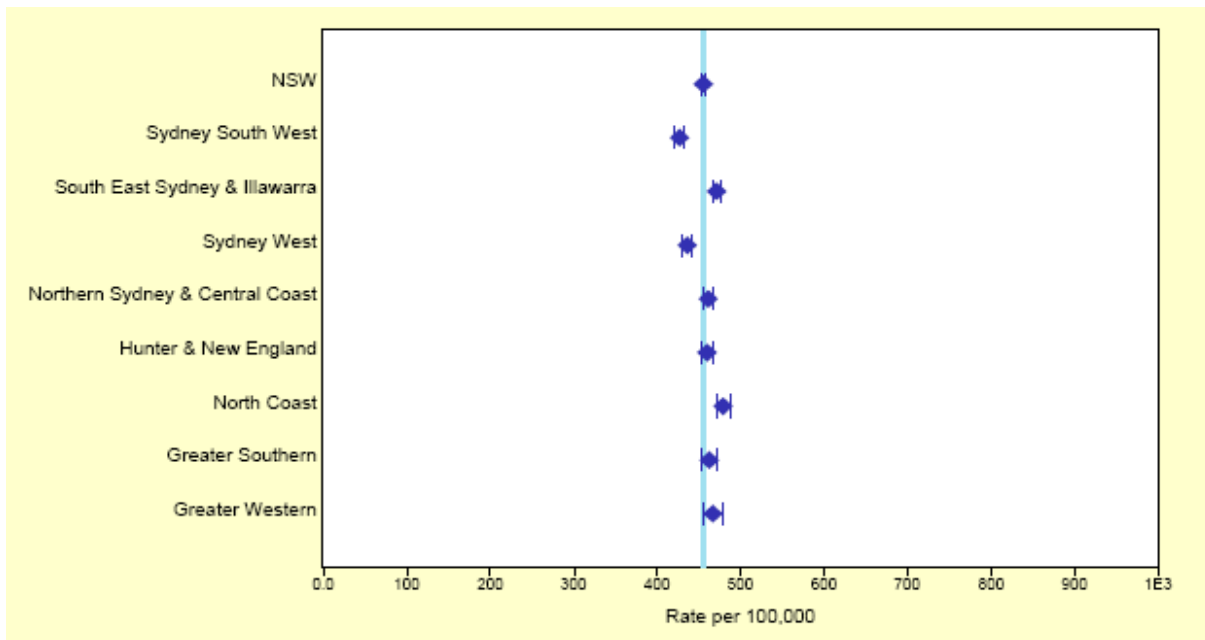
Based on the NSW Health definition of rural as applied in this review Table 4.2 identifies the top twenty cancers for the region covered by the project scope. This listing is based on incidence data for the period 1999-2003 as provided by the Cancer Institute NSW. Adjustments were made to the data to reflect incidence rates of the Area Health Services that have rural and metropolitan areas.

**Table 4.2: Top Twenty Cancers in locations within scope of the review – Incidence data 1999-2003**

Rank	Cancer Type	Observed Cases	Rank	Cancer Type	Observed Cases
1	Prostate Cancer	8298	11	Leukaemia	1789
2	Breast Cancer	7599	12	Bladder Cancer	1703
3	Melanoma	6808	13	Kidney Cancer	1659
4	Lung Cancer	5783	14	Pancreatic Cancer	1302
5	Colon Cancer	5596	15	Stomach Cancer	1196
6	Cancer at Indef & Unspec Site	3782	16	Cancer of the Uterus	987
7	Rectal Cancer	3221	17	Brain Cancer	882
8	Other Cancers	2665	18	Oesophagus Cancer	804
9	Non-Hodgkins Lymphoma	2292	19	Ovarian Cancer	756
10	Head and Neck Cancer	1839	20	Lip Cancer	573

## Comparisons to the State average for all cancers for each AHS covered by the review

Figure 4.4 All cancers - Age Standardised Incidence Rates by Area Health Service 1999-2003



From Figure 4.4 it can be seen that cancer incidence in a number of the rural AHSs, particularly North Coast, Greater Southern, Greater Western and South East Sydney and Illawarra AHSs is higher than the State average and metropolitan counterparts.

### 4.4 Effects of rurality / remoteness

Based on the Australian Bureau of Statistics (ABS) definition of remoteness and the Australian Standard Geographic Classification (ASGC), the AIHW found that cancer mortality outcomes by remoteness are likely to be affected by a complex range of factors including:

- the age structure of the population and of families;
- socioeconomic status;
- diet and lifestyle risk factors including tobacco smoking;
- ethnicity and Indigenous status;
- environmental, industry and occupational exposures to carcinogens;
- access to cancer screening and treatment services, and the extent to which cancers diagnosed are detected early; and
- Level of co-morbidities with other diseases such as cardiovascular diseases and diabetes.

Specifically, data from the AIHW (Table 4.3) indicates that:

- Lung cancer, cervical cancer and cancer of the uterus as a proportion of the cancer deaths in the population increase with remoteness.
- Breast cancer, leukaemias, ovarian cancer and stomach cancer as a proportion of the cancer deaths in the population decrease with remoteness.
- In very remote Areas, age-standardised death rates for colorectal and brain cancers and leukaemias were all significantly below the national average, and the lung cancer death rate was significantly above the national average".<sup>9</sup>

<sup>9</sup> Ibid.

**Table 4.3: Age standardized average annual cancer death rates by remoteness category 1998-2002 selected cancers**

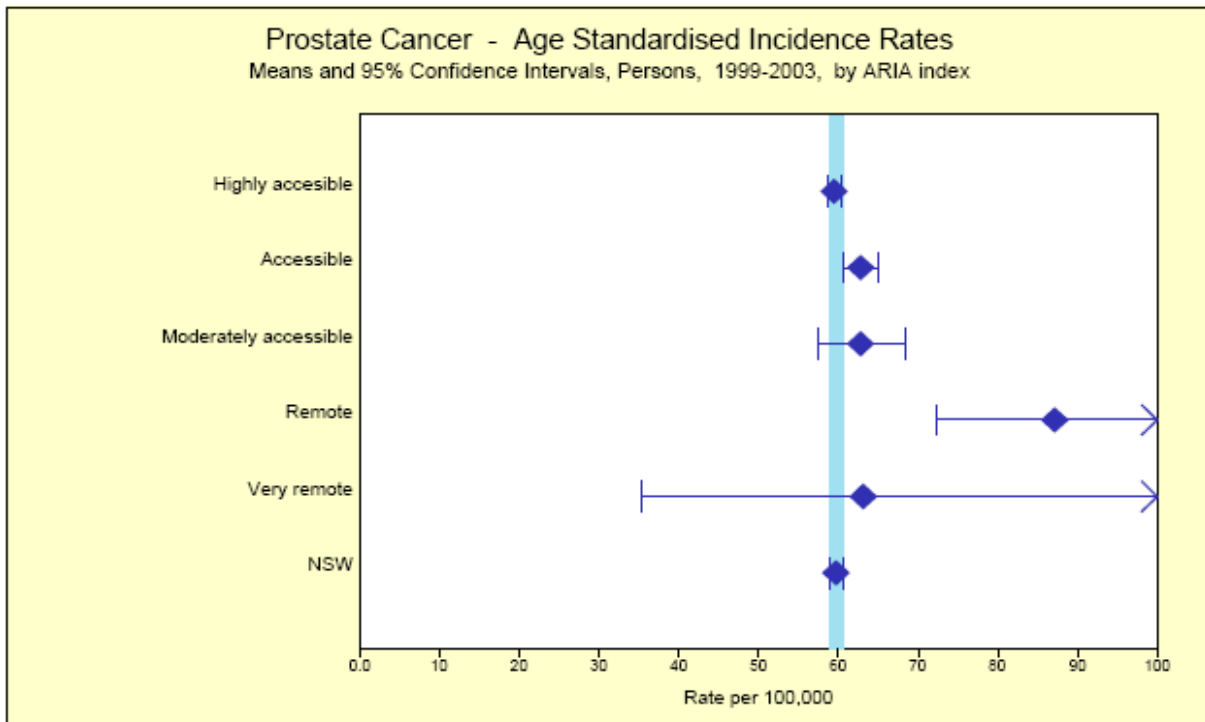
Cancer site	Major cities	Inner regional	Outer regional	Remote	Very remote	Australia
Age-standardised number per 100,000 population						
Colon & rectum	24.0	26.0	26.9	24.6	16.5	24.7
Breast	13.9	13.7	13.3	11.2	10.6	13.7
Prostate	13.0	15.7	17.6	17.5	14.8	14.1
Lung	35.8	36.8	40.2	41.4	47.2	36.7
Melanoma	5.1	6.1	5.7	4.7	4.1	5.3
Non-Hodgkins lymphoma	8.1	8.0	7.9	6.9	6.2	8.1
Cervix	1.3	1.1	1.7	1.9	2.2	1.3
Unknown site	12.9	13.6	14.7	15.6	17.5	13.3
Leukaemias	7.3	7.2	7.0	6.0	4.6	7.2
Pancreas	9.1	9.6	9.2	8.6	10.0	9.2
Uterus	1.5	1.5	1.4	1.4	3.0	1.5
Brain	5.6	5.7	5.5	5.5	2.2	5.6
Ovary	4.3	4.1	3.9	3.5	3.1	4.2
Stomach	6.6	5.8	6.3	6.0	5.2	6.4
Other cancers	38.7	39.0	41.2	42.6	51.1	39.2
<b>All cancers</b>	<b>187.0</b>	<b>193.8</b>	<b>202.6</b>	<b>197.5</b>	<b>198.2</b>	<b>190.8</b>
Confidence interval						
Colon & rectum	23.6–24.3	25.3–26.6	25.9–27.9	21.7–27.6	12.5–20.5	24.4–25.0
Breast	13.6–14.2	13.2–14.2	12.5–14.0	9.3–13.1	7.7–13.5	13.5–14.0
Prostate	12.7–13.3	15.1–16.2	16.8–18.5	14.9–20.1	10.8–18.8	13.9–14.4
Lung	35.4–36.3	36.0–37.7	38.9–41.4	37.7–45.1	40.7–53.6	36.4–37.1
Melanoma	4.9–5.2	5.7–6.4	5.2–6.2	3.4–5.9	2.1–6.0	5.2–5.5
Non-Hodgkin's lymphoma	7.9–8.4	7.6–8.3	7.4–8.5	5.4–8.4	3.9–8.5	7.9–8.3
Cervix	1.2–1.4	1.0–1.3	1.5–2.0	1.2–2.7	0.8–3.6	1.2–1.4
Unknown site	12.6–13.1	13.1–14.1	13.9–15.5	13.2–18.0	13.4–21.7	13.1–13.5
Leukaemias	7.0–7.5	6.9–7.6	6.5–7.6	4.6–7.4	2.6–6.5	7.1–7.4
Pancreas	8.8–9.3	9.2–10.0	8.6–9.8	6.9–10.3	6.9–13.1	9.0–9.4
Uterus	1.4–1.6	1.3–1.7	1.2–1.7	0.8–2.1	1.3–4.7	1.4–1.6
Brain	5.4–5.8	5.3–6.0	5.1–6.0	4.2–6.8	0.9–3.5	5.4–5.7
Ovary	4.1–4.4	3.8–4.4	3.5–4.3	2.4–4.6	1.5–4.8	4.0–4.3
Stomach	6.4–6.8	5.5–6.2	5.8–6.8	4.5–7.4	3.1–7.3	6.2–6.5
Other cancers	38.2–39.2	38.2–39.9	39.9–42.5	38.8–46.4	44.3–57.9	38.8–39.6
<b>All cancers</b>	<b>185.9–188.1</b>	<b>191.9–195.7</b>	<b>199.8–205.4</b>	<b>189.2–205.7</b>	<b>184.8–211.7</b>	<b>189.9–191.7</b>

Source: AIHW National Mortality Database.

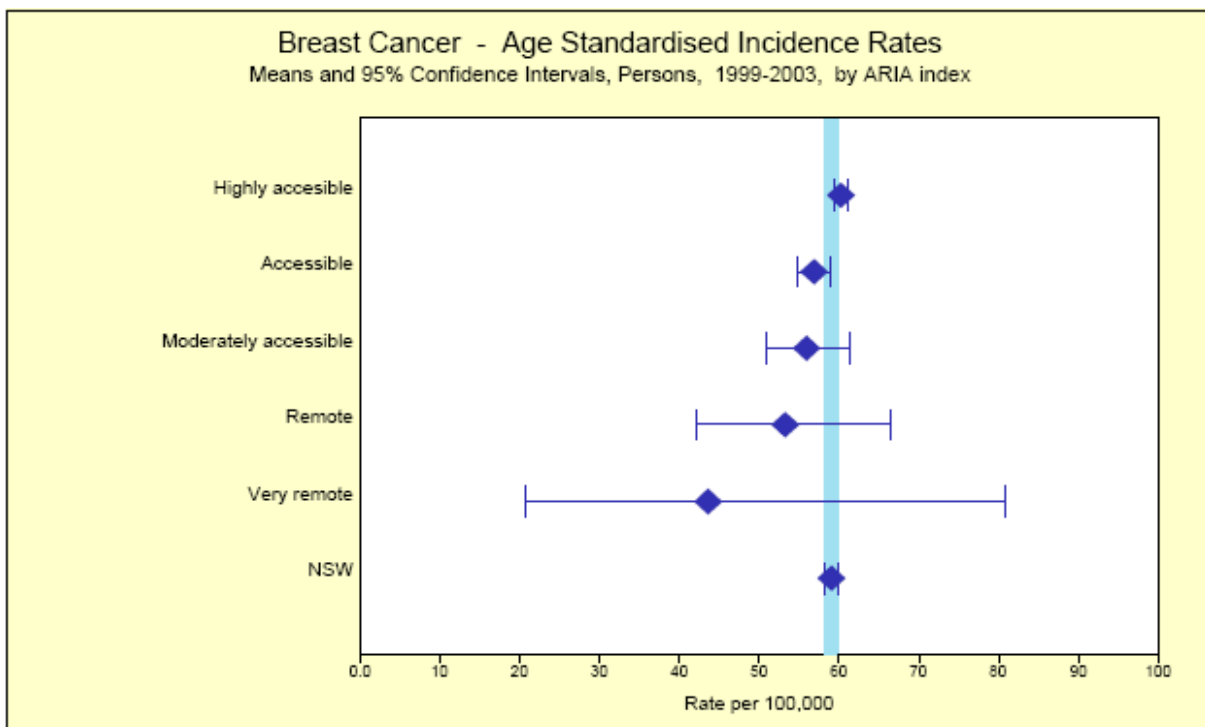
The Cancer Institute NSW uses an alternate classification system to define rurality, namely the ARIA classification. Under this definition, the order for the top five cancers is different compared to the AIHW sequence. Specifically, for breast cancer and melanomas of the skin (Figures 4.6 and 4.7) there is an inverse relationship between incidence rates and remoteness.

Figures 4.5 to 4.9 show the variation in incidence rates for each of the top five cancers in NSW, factoring rurality into the calculation.

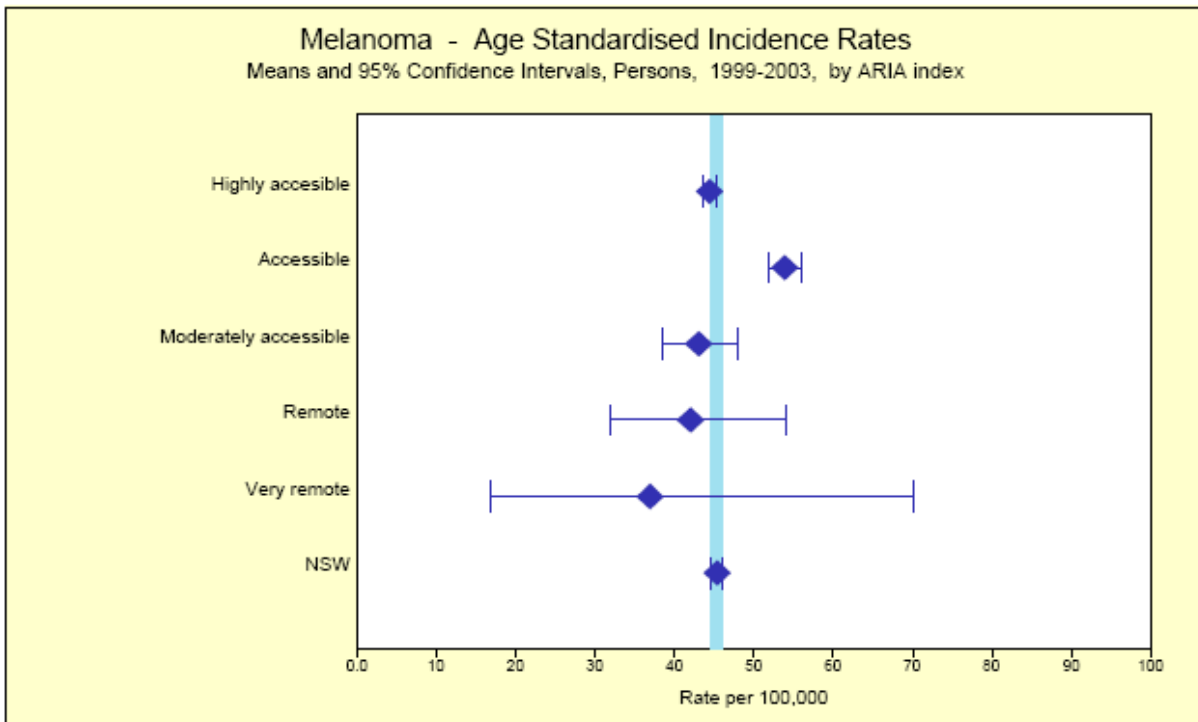
**Figure 4.5: Incidence rate for Prostate Cancer by rurality (ARIA) index, New South Wales, 1999-2003**



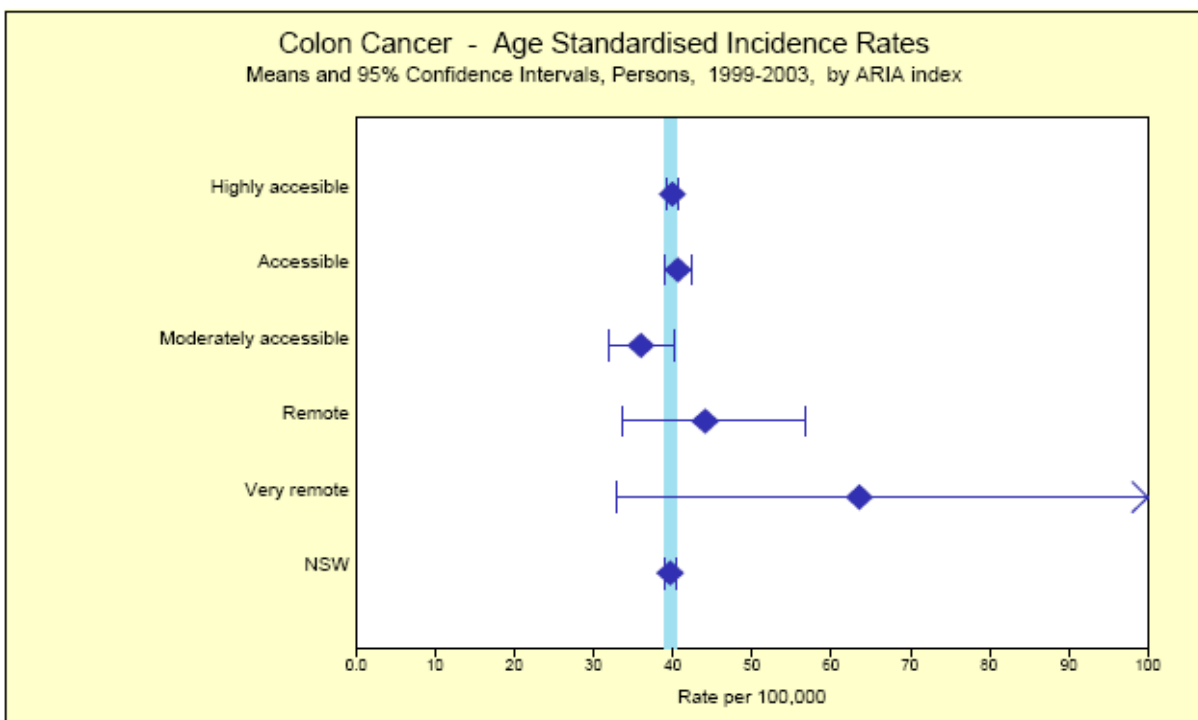
**Figure 4.6: Incidence rate for Breast Cancer by rurality (ARIA) index, New South Wales, 1999-2003**



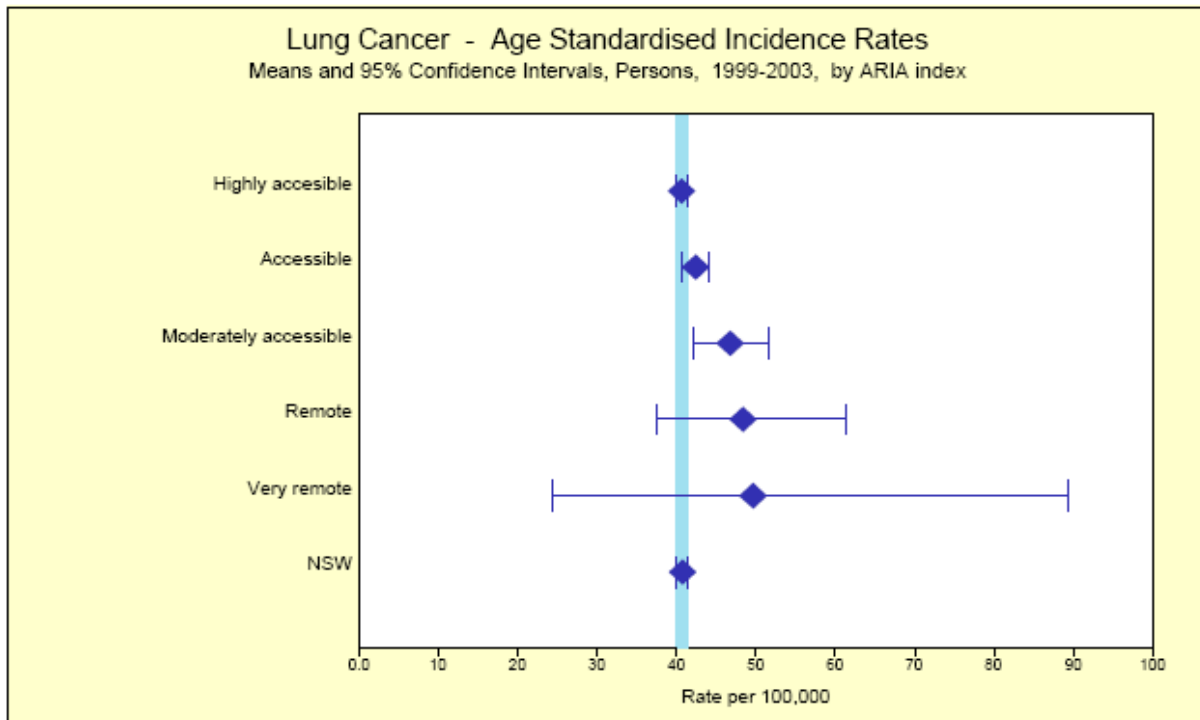
**Figure 4.7: Incidence rate for Melanoma by rurality (ARIA) index, New South Wales, 1999-2003**



**Figure 4.8: Incidence rate for Colon Cancer by rurality (ARIA) index, New South Wales, 1999-2003**



**Figure 4.9: Incidence rate for Lung Cancer by rurality (ARIA) index, New South Wales, 1999-2003**



#### 4.5 Rural Cancer Incidence and Mortality (2000 – 2004)

As an adjunct to this project, further analysis on cancer incidence and mortality patterns in rural areas over 2000-2004 has been performed. The analysis was done using previous Area Health Service boundaries.

Over this period the analysis showed that the only rural health service with significantly lower mortality rates compared to NSW as a whole was Northern Rivers for males and females. All other rural area health services had mortality rates that were the same as the state average. (Figure 4.10)

There was no rural Area Health Service with significantly higher cancer mortality rates overall for the period 2000-2004 (all cancer types except NMSC) when compared to the state average.

When considered by specific cancer site, this analysis suggests that there were two “old” rural Area Health services with higher mortality rates than the State average. This was for oesophageal cancer in males in Southern and Greater Murray Area Health Services. This cancer relates to tobacco and alcohol consumption with a number of factors impacting on survival results.

The Northern Rivers Area Health Service had significantly lower mortality rates for breast and stomach cancer in females for the time period 2000-2004.

The following Area Health Services had significantly higher cancer incidence rates. (Figure 4.11) Northern Rivers (males and females) Greater Murray, Mid Western (males only), Mid North Coast and New England (females only). All other rural area health services had incidence rates that were the same as the state average.

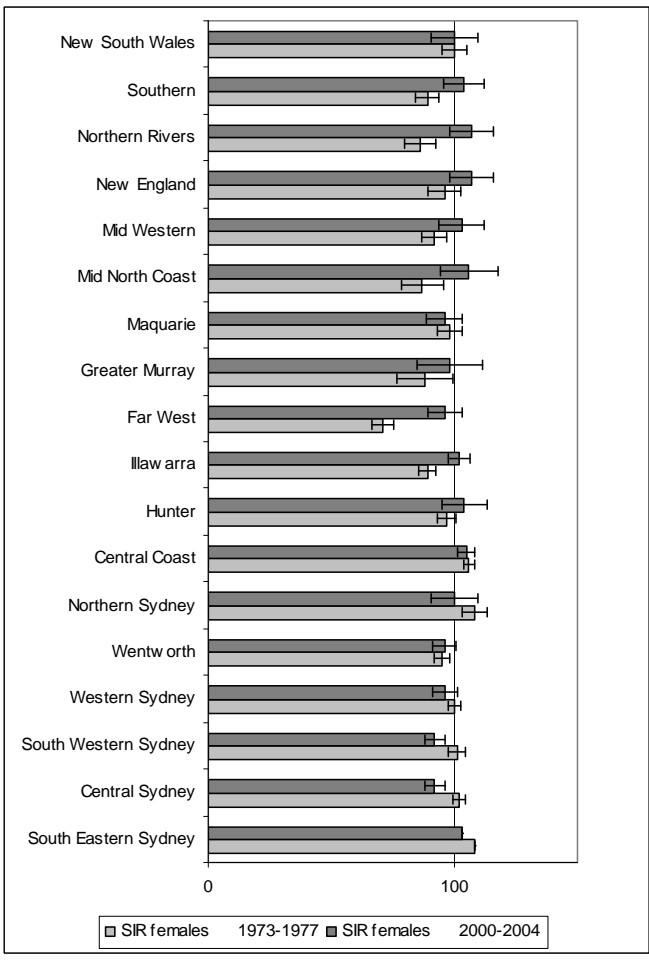
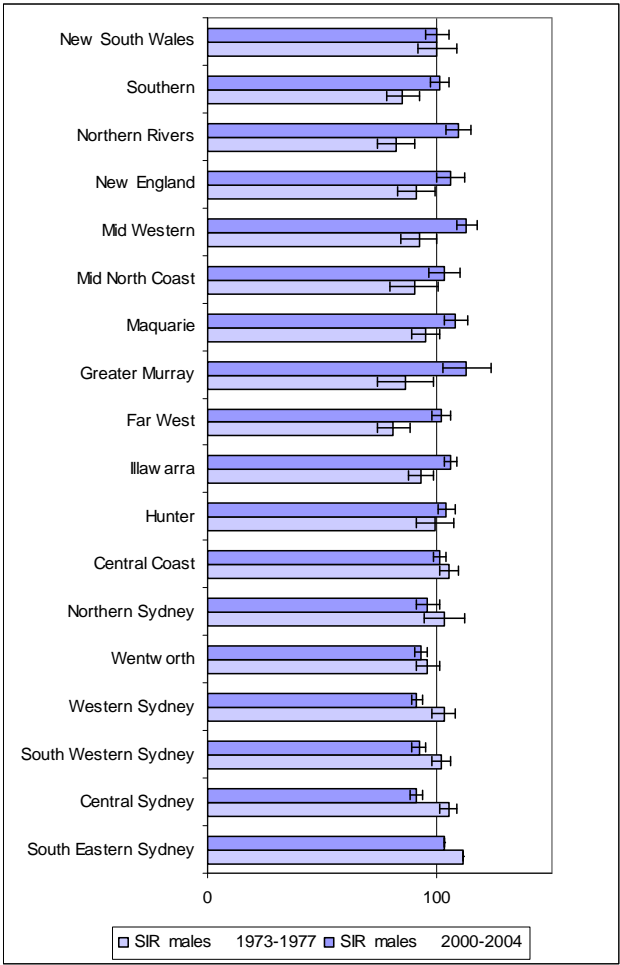
For specific cancers within rural area health services:

- Lip cancer remained significantly higher than NSW for Mid Western and New England (males only). In addition Greater Murray had significantly higher lip cancer rates in males.
- Melanoma incidence rates were significantly higher than the state in Mid North Coast, Mid Western and Northern Rivers (males and females) and New England (females only)
- Prostate cancer incidence rates were significantly higher in the Greater Murray, Macquarie and Mid Western Area Health Services.
- Head and neck cancer was higher in the Far West and New England (males only)
- Cancer of the uterus was higher in New England and large bowel cancer was higher in females in the Mid North Coast. Unknown primary cancer was higher in males resident in Macquarie.
- Thyroid cancer was significantly lower in females resident in Greater Murray and Southern Area Health services
- All other cancers in all other rural health services were not significantly different from the state average.

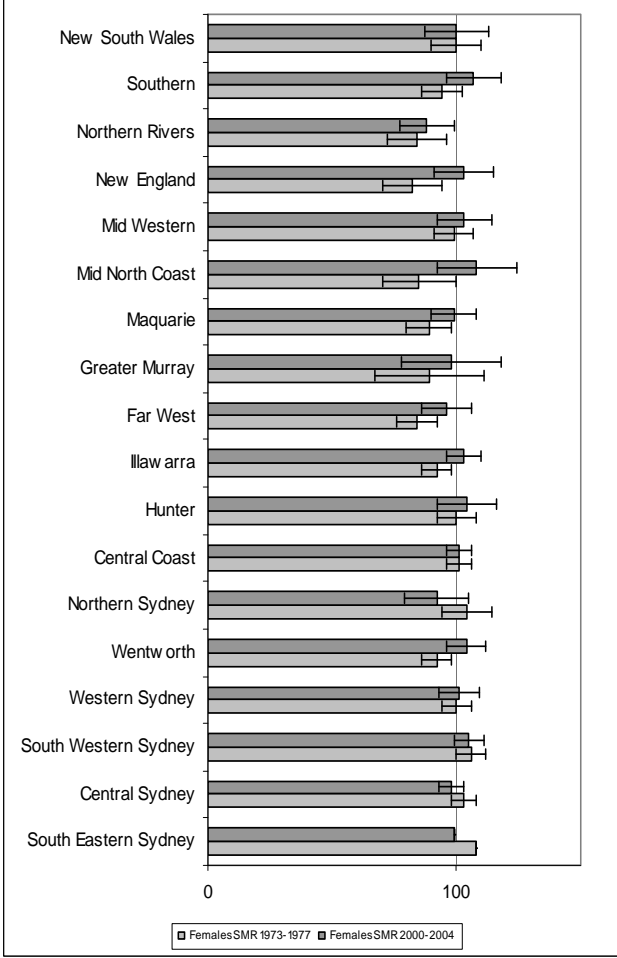
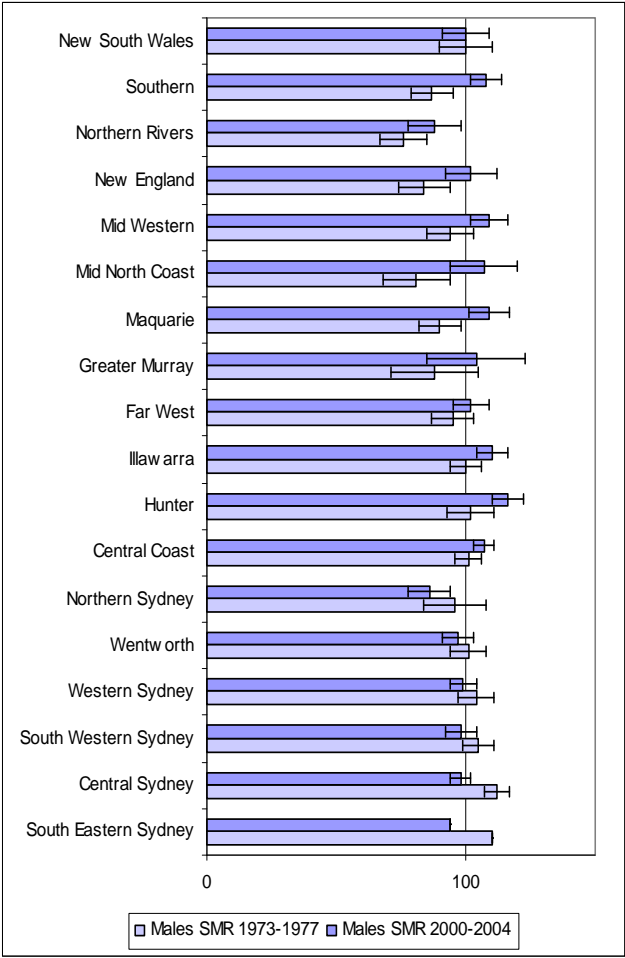
The analysis showed that Melanoma rates increase towards the north and towards the coast. Overall, patterns for smoking related cancers follow smoking prevalence distributions. These relate to 30 diseases including lip, oesophagus, head and neck cancer, lung cancer, and a proportion of stomach and urinary tract cancers.

It is important to note that mortality may vary between the Chief Health Officers report and AIHW publications and the Central Cancer Registry reporting of cancer deaths. The Australian Bureau of Statistics (ABS) reports cause of death for cancer by examining death certificates. The ABS is considered the official source of cause of death information, the NSW Department of Health reports cause of death using ABS data. The NSW Central Cancer Registry uses pathology reports, reports from doctors and other sources of notifications, as well as death certificates, which may improve specificity and accuracy of cause of death.

**Figure 4.10 Incidence rates and 99% confidence limits for all cancer types, NSW Area Health Services (old)**



**Figure 4.11 Mortality rates and 99% confidence limits for all cancer types, NSW Area Health Services (old)**



## 5. Issues identified by cancer patients, carers and families

The majority of the respondents to the consumer survey were patients in receipt of cancer services with 6.9% of respondents being carers or support people (refer Table 5.1). The majority of respondents were females (75.9% of respondents, refer Table 5.2).

**Table 5.1: Respondents to Consumer Survey**

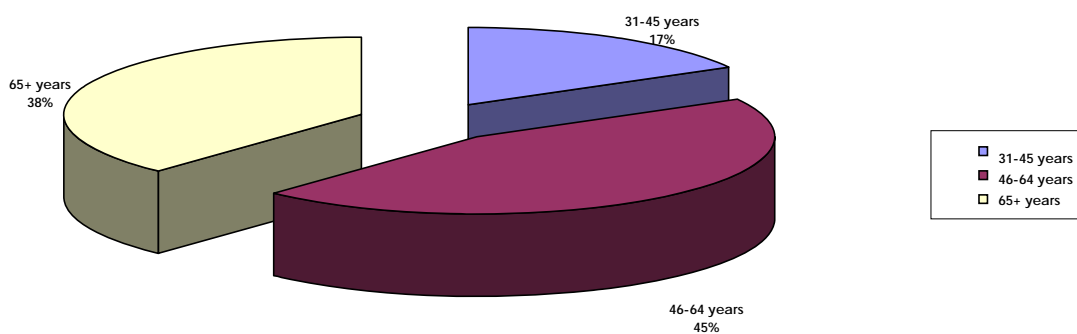
Respondent Type	No Respondents	%
Person living with cancer	28	93.1%
Carer or support person	2	6.9%
Total	30	100.0%

**Table 5.2: Gender distribution of respondents**

Gender	No of Respondents	%
Male	7	24.1%
Female	23	75.9%
Total	30	100.0%

The majority of the respondents were aged between 46 and 64 years of age (refer Figure 5.1) with most diagnoses presented within the last twelve months (refer Table 5.3).

**Figure 5.1: Age Ranges of Respondents**

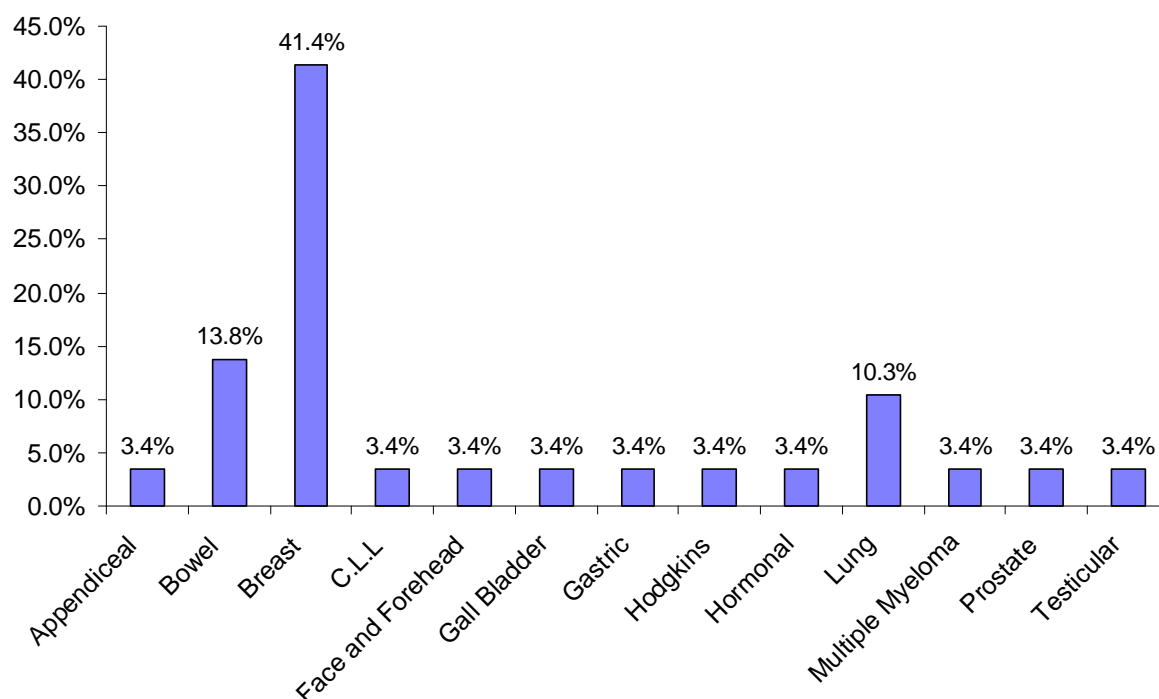


**Table 5.3: When Respondent was diagnosed with cancer**

When Diagnosed	No of Respondents	%
Less than 12 months ago	21	72.4%
Between 12 and 24 months ago	1	3.4%
Between 2 and 5 years ago	4	13.8%
More than 5 years ago	3	10.3%
Total	29	100.0%

The majority of respondents completing the patient/carer survey indicated that they had been diagnosed with breast cancer (refer Figure 5.2).

**Figure 5.2: Type of Cancer diagnosed with or being treated for**



## 5.1 Information for rural cancer patients

The survey sought to explore the provision and suitability of information for people living in rural NSW following a diagnosis of cancer. The majority of respondents indicated that information about the type of cancer and available treatment options had been provided. However the provision of quality information about support services appeared to be less consistent, particularly with regards to transport and accommodation.

**Table 5.4: Provision of information about cancer and cancer services**

Information you have been given	Yes	No	Not Answered	Total
The type of cancer you have	29	1	0	30
How the cancer is treated	30	0	0	30
Where to go to get treatment	30	0	0	30
The type of travel support available	23	7	0	30
The type of accommodation support that is available	18	11	1	30
The type of support you can get to obtain equipment necessary for treatment	19	8	2	30
The type of support that your family can get	12	11	7	30
The types of follow up services that are available	21	7	2	30

The value of the information was also commented upon by the respondents. While information on the type of cancer, treatment options and location of treatment was rated highly, no single dimension scored a satisfactory rating from all respondents (refer Table 5.5).

**Table 5.5: Content provided sought for information**

The information told me what I needed to know	Yes	No	Not Answered	Total
The type of cancer you have	25	3	2	30
How the cancer is treated	25	2	3	30
Where to go to get treatment	25	0	5	30
The type of travel support available	16	8	6	30
The type of accommodation support that is available	15	10	5	30
The type of support you can get to obtain equipment necessary for treatment	14	9	7	30
The type of support that your family can get	12	11	7	30
The types of follow up services that are available	17	8	5	30

The survey allowed respondents to suggest how information provision could be improved and to identify what type of information they were hoping to find but felt was missing from the information provided. Table 5.6 illustrates the responses to these questions by information topic.

**Table 5.6: Responses identifying issues re information provided**

<b>Responses: Information about The type of cancer you have</b>
Did not know whether disease was active or treatable. Urgent surgery in Canberra hospital. Was not told by surgeon or other doctor what had been discovered. Ward nurse answered question about "how long was I out for" - 1.5 hours.
How it forms, how long it takes to become cancerous
I have never really been told much about my cancer or what to expect. Searching the internet myself has helped.
<b>Responses: Information about how the cancer is treated</b>
Just heaps of tests
Treatment teams have been very helpful and informative but I feel more paperwork on side effects would be advantageous
Whether the treatment is proving a success
<b>Responses: The type of travel support that is available to get to cancer treatment services</b>
I may have seen or been given one pamphlet during 4 years of treatment
I was told about IPTAAS but not about any other possible transport methods, ie public transport or community transport. I still don't know whether I could have used anything else other than private car to attend my chemotherapy sessions in Armidale.
Knowing what services I may be entitled to at the beginning of testing - surgery.
No information given on time tables, costs, etc
No transport available to treatment point
Not enough information, also have to travel over 200kms to find accommodation
The available support is not helpful. We must travel 300km return for every treatment and are not eligible for any assistance
<b>Responses: The type of accommodation support that is available to get to cancer treatment services</b>
Have to chase up certain people to get information and not always successful in finding same
I may have seen or been given one pamphlet during 4 years of treatment. I know of it but not about it
Knowing early on what accommodation available.
No accommodation available at treatment point
Was mentioned very late in treatment
What is available for accommodation away from home if I need to travel for treatment
<b>Responses: The type of support you can get to get equipment necessary for the treatment of your cancer</b>
I know of palliative care but feel their follow ups need to be looked at
Information was not adequate
There seems a lot of information for women's cancers, not much on skin cancer - men
Wasn't mentioned
<b>Responses: The type of support that your family can get such as carer respite services</b>
Didn't get much info on this but probably because not needed
I know about counselling for children but that's about it
No information given at first. Now aware they're available.
No mention of support for the husbands especially
This was not given in any info - but was relayed to us at the radiation session. It would have been more useful at the start of or after operation healing
Wasn't mentioned

Responses: the types of follow up services that are available
I get follow ups from community nurses and doctor. Guess I could find out information from them if I felt the need
I have failed to find any
Information ok. Quite brief but able to speak to nurse before requiring the service e.g. about how to get to service, when, where etc.
Limited resource in area
Not mentioned
Saw physio following operation.
Was hard to find - had to go to my GP and source it from there

The review also explored how rural cancer patients gained access to information. None of the respondents obtained information via workshops or information sessions and only a small number researched information on the Internet. For those who researched information on the internet the focus was on obtaining information on cancer types and treatments. While the sample size is relatively small, the responses suggest that the internet is not used by rural patients / carers to provide information on support services such as transport, accommodation, counselling, peak bodies, consumer groups, support groups etc. This finding may be influenced by the lack of access to the internet in rural / remote areas.

Freeform responses were also given on other information sources including the Cancer Council and the Breast Cancer hotline and nursing association.

**Table 5.7: How information was obtained**

How you got the information	Written Down	Was Told	Internet	Workshop
The type of cancer you have	55.2%	86.2%	17.2%	0.0%
How the cancer is treated	44.8%	86.2%	13.8%	0.0%
Where you have to go for treatment	27.6%	89.7%	0.0%	0.0%
The type of travel support that is available	20.7%	69.0%	0.0%	0.0%
The type of accommodation support that is available	20.7%	62.1%	0.0%	0.0%
The type of support you can get to obtain equipment	13.8%	48.3%	0.0%	0.0%
The type of support that your family can get	27.6%	34.5%	0.0%	0.0%
The types of follow up services that are available	31.0%	51.7%	0.0%	0.0%

The results showed that information about the type of cancer and treatment options was provided to rural cancer patients and their carers predominantly by general practitioners, nurses or specialist medical officers at the time of diagnosis. Information about support services was largely obtained from the Cancer Council, allied health professionals (such as social workers) and by nursing staff (refer Table 5.8).

**Table 5.8: Who provided the information to the consumer/carer of cancer services**

Who provided information	Type of cancer you have	How the cancer is treated	Where to go for treatment	Travel support available	Accommodation support	Equipment support available	Family support available	Follow up services available
General Practitioner	41.4%	20.7%	27.6%	10.3%	6.9%	6.9%	6.9%	3.4%
Nurse	17.2%	24.1%	27.6%	27.6%	20.7%	24.1%	10.3%	34.5%
Family Member	3.4%	6.9%	0.0%	6.9%	0.0%	0.0%	0.0%	0.0%
Internet	6.9%	6.9%	0.0%	3.4%	0.0%	0.0%	0.0%	0.0%
The Cancer Council NSW	20.7%	20.7%	10.3%	24.1%	20.7%	17.2%	13.8%	24.1%
Social Worker	3.4%	3.4%	6.9%	20.7%	20.7%	17.2%	24.1%	13.8%
The NSW Health Department	0.0%	0.0%	0.0%	6.9%	6.9%	3.4%	6.9%	0.0%
Specialist cancer doctor - Chemotherapy	48.3%	58.6%	55.2%	6.9%	3.4%	6.9%	0.0%	0.0%
Specialist cancer doctor - Radiation/Radiotherapy	37.9%	48.3%	41.4%	10.3%	13.8%	0.0%	0.0%	10.3%
Specialist cancer doctor - Surgery	44.8%	41.4%	31.0%	6.9%	0.0%	3.4%	0.0%	3.4%
Specialist cancer doctor - Haematology	6.9%	6.9%	6.9%	0.0%	0.0%	0.0%	0.0%	0.0%

## 5.2 Referrals and use of local cancer services in rural NSW

The majority of respondents in the review (89.7%) were referred to a specialist cancer service. However, only 37.9% indicated that issues of transport and/or accommodation were discussed as a factor in determining referral. Participants were also asked if issues such as time off work/school, money, home duties etc were considered or discussed as part of the referral process. Table 5.9 includes their responses.

**Table 5.9: Were impacts of referral on personal commitments discussed or considered as part of the referral process?**

Response	No of Respondents	%
Not Answered	2	6.9%
Yes	12	41.4%
No	10	31.0%
Not applicable	6	20.7%
Total	30	100.0%

The majority of respondents indicated that more consideration, discussion and provision of information about the time needed for the treatment and recovery is needed in planning and deciding on both the course and location of treatment.

58.6% of the consumer sample responded that they had accessed treatment facilities in their local area (within 15kms from home). The small sample size prevents an assumption that this is an accurate estimate of broader access.

### 5.3 Transport for rural cancer patients

Participants were asked to describe the types of transport they used to gain access to cancer treatment services. All respondents indicated that they used private transport at some stage. Only 34.5% indicated that they also used public transport.

A few of the respondents raised concerns about the costs of using private transport to access cancer services.

The majority of respondents (62.1%) indicated that public transport was difficult to access in their area, necessitating the use of private options. General issues relating to access to public transport as identified by the respondents is listed in Table 5.10.

**Table 5.10: Nature of the difficulties in accessing public transport to get to cancer services**

Responses
Am isolated in the bush. If catching the cancer bus there can be long delays and when ill is hard to endure
Have to drive half an hour to the transport. Might as well drive all the way. So don't have to wait for other patients which can extend a long day
I didn't have problems as I had private car available with a driver. I have not researched how I would have made it by public transport. Train and bus services would not have fitted in with my times so were not even considered.
I have not started my treatment yet where I have to travel to Wollongong 70 km away. The train service is unreliable and there is a bus but not sure of the details. The easiest way to travel is by private motor car
limited public transport from home address to treatment facility
Local bus service very inefficient, not good times. Train service to Wollongong unreliable, infrequent. Hospital run patient transport system good but you need to fit in with all patients and therefore takes much longer than driving yourself.
No direct service to treatment centre
No public transport - must drive to Nowra to catch Cancer Council bus
None direct to Canberra Hospital
Not available from Mollymook/Ulladulla. It would be helpful if a clinic could be established in Nowra, serviced by Wollongong Oncologists for follow up consults after treatment
There are no suitable public transport services
There is no public transport to get to Wollongong hospital from Nowra - but the service of the Nowra cancer bus is excellent
there is no public transport, between Inverell and Armidale
There is no public transport, however if daughter was unable to drive me I understand Inverell HACS transport would help out in an emergency
Wollongong - No public transport from home to railway station and Bonadonng. Time unavailable, service unreliable (often have to use buses supplied by railways - adds time to journey), unsatisfactory for keeping appointment times.

The survey sought to identify consumer and carer awareness and utilisation of the Isolated Patient Transport Accommodation Assistance Scheme (IPTAAS). Just over a third (34.5%) of respondents indicated they were aware of the scheme and 17.2% answered that they had actually used the scheme. Of those respondents that had used the scheme, 40% were not very satisfied with the experience and the remaining 60% did not rate the experience at all.

Comments provided by respondents indicated that the criteria used to determine eligibility criteria commonly appeared either inconsistent or unjust. Particularly, eligibility issues were faced by patients accessing treatment services in another state.

**Table 5.11: Comments provided about the IPTAAS scheme prior to 1 July changes under the “Transport for Health” reforms**

Comments
Only just provided information 6 months into treatment. Receipts for chronic/cancer patients should not be needed after initial ones as awkward when using other people’s cars
The combination of low payment rate per km and \$40 deducted from each claim makes this scheme useless to us even though each fortnight cycle involves over 600km travel in a private car
By reducing distance criteria to 50ks one way.
Have no idea who or what they are (if they can offer financial assistance it would be greatly appreciated, it is costing more than \$100 a week to get to Nowra and back)
I received a cheque for \$71 for 1 round trip to New castle each of 905 km; I don’t think this is very just. I used private accommodation at no cost to IPTAAS so in the circumstances suggest that in this case, the car allowance should be greater as the cost to the scheme is fairly minimal. The office girls were very courteous and helpful. Can't fault their service, only scheme itself. IPAAS also advised they take NSW ambulance distances which was 878km return not 905km. Pay \$111.50 less \$40 patient contribution as I am not on a pension.
make people aware of services
Not having to lodge separate forms for each cycle of treatment, i.e. space on form for several trips
Ok as is
Reduced mileage limit. My trip to Sydney was just short of the limit where assistance could be paid.

Since the review, the NSW government introduced a policy to reform health transport. Under “Transport for Health” implemented on 1 July, 2006, the administration of previously separate health transport services has been centralised. It is hoped that this approach will improve administration and allow better data collection.

Changes to IPTAAS have been included under this set of reforms, reducing the distance eligibility criteria from 200 kms to 100 kms and increasing the petrol allowance from 15c/km to 17c/km. The Cancer Institute NSW contributes a recurrent \$0.5 million to this initiative to improve access to transport for rural cancer patients.

## 5.4 Accommodation for rural cancer patients

As part of the consumer survey, participants were asked to describe the accommodation they used while away from home receiving cancer care.

The limited response to the consumer / carer survey made it difficult to draw concrete conclusions on the availability of suitable accommodation for rural cancer patients that fitted into treatment schedules. The lack of data held by accommodation facilities prevented analysis of cancer related utilisation rates.

## 5.5 Out of Pocket Expenses

In order to gauge out of pocket expenses incurred as a result of cancer treatment for rural patients, the review team sought information from service providers through case studies, IPTAAS and consumers through the consumer/patient survey.

Given the low sample size and the recent diagnosis of majority of the consumer survey respondees, the information relating to out of pocket expenses could not be considered representative. 29 of the 30 respondents answered this question and indicated they had

incurred some out of pocket expenses in accessing and obtaining treatment for cancer either within or outside their local area, ranging from \$20 to \$5,700.

While it may be expected that the cost of services is an important factor and would impact upon access to cancer services, feedback from the survey suggests that cost, and more importantly out of pocket expense is a secondary consideration when considering access to cancer services.

## **6. Issues identified by service providers and support services**

During the course of the review, consultations were undertaken with a range of cancer service providers and support services in each of the AHSs within the project scope.

Site visits were conducted in Albury/Wodonga, Armidale, Bega, Blue Mountains, Broken Hill, Coffs Harbour; Dubbo; Grafton, Griffith, Lismore; Milton, Moruya, Orange, Penrith, Port Macquarie, Queanbeyan, Tamworth, Tweed Heads, Wagga Wagga, Wollongong

Phone interviews were conducted with participants unable to attend the site meetings and surveys were also distributed to individual participants outside the site meetings. Surveys were also distributed to the Divisions of General Practice within the respective AHSs.

The following section presents the feedback on the major challenges in providing cancer services in remote areas.

### **6.1 Definition of Rural**

Both the evidence base and feedback from cancer patients and carers indicate that access to cancer services is significantly affected by the infrastructure supporting transport, accommodation and access to relevant equipment, pharmaceuticals etc. It was noted by several participants that confusion over the definition of metropolitan, rural and remote in health service planning can impact on the capacity of some areas to attract adequate resources.

For example, in one Area Health Service, a smaller town is located in an SLA rated as accessible by the ARIA classification and rural by the RRMA classification. There are no public transport facilities available connecting this town with its closest major regional centres. Health care planners can mistakenly conclude that the community in the town can readily access services as they live in an area that has been categorised as accessible. However, in order to access appropriate cancer treatment and services, people who live in this town travel in excess of two hundred kilometres one way to get to a chemotherapy or radiotherapy unit.

During the review, service providers expressed concern that the current classification system used to determine status as rural or remote (and therefore imputed level of accessibility) is single in dimension and needs to be multi-dimensional.

### **6.2 Amalgamation of Area Health Services**

In 2005, AHSs across New South Wales were restructured with a number being amalgamated. In some instances, the amalgamation has resulted in the integration of metropolitan and rurally based health services, and in others, the integration of two rurally based areas. The amalgamation has presented AHSs across the State with a new set of challenges ranging from streamlining communication and administrative processes to the coalescing of different cultures. These issues appear to have created inefficiencies in current operations that will need to be addressed moving forward.

### **6.3 Service Delivery Models and Patient Referral Pathways**

Cancer services within rural New South Wales are frequently built on referral relationships between practitioners. Occasionally these are documented in formal contracts. However, at the time of the Review, there were no consistent service agreement procedures across AHSs, or in some cases within the same Area.

At the time of the review, no single AHS used a formalised service delivery model covering the entire patient pathway. Service providers suggested they were not always fully aware of the full suite of services available within their own AHS, or available services within other Areas that may be able to offer outreach or associated support services.

The contribution of clinicians providing services to the rural regions under current arrangements is most valuable. Referrals are often built on informal individual relationships and can present challenges to ongoing and future service delivery.

### **6.4 Telemedicine**

Evidence gathered through the site visits and consultations indicates that telemedicine facilities exist in all rural AHSs. As a solution to effectively communicating across distances, it appears that current facilities have capacity for more extensive use. There is evidence that the equipment is being used mostly to facilitate administrative and multi-disciplinary meetings. However at the time of the Review, no rural AHS was using telemedicine to relay pathology or radiology results. Additional applications such as genetic counselling or psycho-oncology support could be considered in the future.

The review team noted several observations around the limited uptake of telemedicine as a part of cancer services in rural NSW.

1. In some cases, the equipment is outdated and has not been adequately maintained or updated. For example, attempts to incorporate telemedicine by one AHS in communicating with a metropolitan hospital as part of virtual multi-disciplinary meetings failed due to frequent technology drop-outs.
2. The location of the telemedicine facilities within a number of the rural AHSs is less than optimal, the rooms either cannot hold the required numbers or do not have adequate supporting equipment (monitors, tables, white boards, etc.) The level of telemedicine facilities in the majority of rural AHSs is not conducive to the participation of carers or patients in the teleconferencing process.
3. Skill levels around the use of the technology vary. The reviewers found no evidence of formal training in the use of the equipment, particularly regarding the transmission of diagnostic information such as histopathology and radiology.

### **6.5 Appropriateness of Cancer Treatment Facilities**

The review team noted that a number of cancer treatment services require upgrading of space or small capital works.

A number of service providers indicated that some rural cancer service facilities are not sufficiently functional and would benefit from a planning review.

## **6.6 Awareness of Services**

Feedback was received from all rural AHSs that there is generally a low level of awareness of cancer services and support services within AHSs. The high level of reorganisation due to the amalgamation of Area Health Services at the time of this review may have contributed to this. A lower level of knowledge appears to exist about out-area-services to which cancer patients are referred.

## **6.7 Research and Clinical Trials**

It is well established that research opportunities attract quality senior medical staff. The chance to participate in cancer research and clinical trials in rural NSW were viewed by many of the respondents as “metro-centric”. Specific comments included:

- Rural AHS services facing service demands do not have the ability to develop competitive grant submissions.
- Often, rural hospitals are not able to meet the criteria requirements under the grant submission process.
- Follow-up services and facilities for clinical trial participants may be compromised by travel requirements for the patients to travel and lack of experience of some clinical trial staff.

The potential impacts on the rural cancer workforce include:

- Diminished up-skilling opportunities for rurally based clinicians;
- Decreased ability to attract and retain suitably qualified clinicians;
- Reduced access to more contemporary treatment regimes and pharmaceuticals on a cost neutral basis for existing rural cancer patients who could have benefited from participating in a clinical trial.

## **6.8 Rural Workforce Issues**

### **6.8.1 Recruitment and Retention**

Recruitment difficulties across the range of cancer services were reported in all rural AHSs, with some regions facing greater needs in specific vocational areas. Some areas identified a chronic shortage of general practitioners with reports of GPs in the area no longer able to see new patients. This has had significant impacts in terms of screening and early detection.

Some AHS reported particular problems in attracting clinical staff across the board, especially for the more remote regions.

### **6.8.2 Staffing Levels**

Due to smaller populations and recruitment difficulties in many rural and remote areas, small numbers of staff in cancer services is not uncommon. Staff working in these services is limited in their capacity to take annual leave or to participate in professional development activities as replacement relief is difficult. Staff leave often results in service closures in small centres.

### **6.8.3 Specialist medical practitioners**

Access to specialist medical practitioners is problematic across rural and remote AHSs, with Base Hospitals in the major regional centres finding it difficult to recruit and retain specialists. The more complex procedures, especially surgery, are usually performed at

metropolitan based hospitals. Outreach arrangements have been established in the majority of rural and remote AHSs to accommodate specialist consultations. The reviewers believed that these services could be consolidated with formal service level agreements to support these arrangements.

#### **6.8.4 Professional Development**

Participation in professional development for cancer services professionals in rural and remote areas appears to remain a challenge. In addition to pressures from fewer staff, attendance usually requires travel and at times overnight accommodation. This often presents additional out of pocket expenses for participants and has been reported as a deterrent.

For these reasons, professional development may be given a low priority. Reports indicating that professional development had yet to occur or had not occurred within the last two years were common.

Survey respondents indicated that professional updating via the internet is not adequate as a sole education source. Bringing education sessions to the hospital or health service was seen as preferable. Updates by visiting specialists were also suggested.

#### **6.8.5 Engagement with General Practitioners**

Many rural and remote cancer service providers reported that levels of engagement with general practitioners could be further improved. The current levels of involvement were thought to be dictated by demanding workloads of many rural GPs.

Rural General practitioners play a number of important roles:

- General practitioners in rural and remote areas provide a substantial level of cancer screening, particularly for prostate cancer and melanomas of the skin.
- The chances for the early detection of cancer are increased if rural patients are able to make an appointment with a GP.
- The quality of follow up for cancer treatment is improved if GP appointments are available.
- As opposed to metropolitan cancer specialists, local GPs have the potential to be an important point for information dissemination on local cancer services once treated patients return to their home town.

Service providers commented that rural GPs may have a limited awareness of the cancer support services and schemes available to their patients as part of the cancer care continuum.

Increased communication between rural Divisions of General Practice and cancer service providers was seen to be an effective mechanism for increasing GP awareness of local cancer services. It was also seen as an important mechanism for increasing GP involvement in multi-disciplinary teams and ongoing patient follow up.

Feedback from the rural Divisions indicated that they expected to play a role in the dissemination of information about cancer treatment services, and promoting the use of multi-disciplinary teams in the provision of cancer services, but need new strategies and support.

#### **6.8.6 Counselling Services**

The review found that counselling services for rural cancer patients exist in most AHSs, but vary in personnel available and the hours in which the services are provided.

### **6.8.7 Communication with Centrelink**

Feedback from a number of rural AHSs suggested that the quality of information given to rural cancer patients by Centrelink varied greatly, and in some cases affected decisions to undergo treatment.

At times nursing staff or allied health professionals such as social workers appeared to have more accurate advice on the financial aspects of cancer treatment.

The review showed that there may be a need to provide training for Centrelink staff in rural areas (if not in all areas) on the accurate and sensitive dissemination of information on the financial impacts of cancer treatment.

### **6.8.8 Transport**

For many rural cancer patients, distance from specialised treatment presents a major challenge. Some rural cancer patients may opt for treatment options associated with less travel, and accommodation needs to reduce family / business disruption.

The main transport options available to people living in rural and remote locations to access cancer services include:

- private car,
- public transport such as buses, trains,
- community transport including community transport organisations, not for profit organisations, charitable organisations and volunteer based service,
- AHS transport services,
- Isolated Patients Accommodation Assistance Scheme (IPTAAS), and
- taxis
- air transport

The review showed that private transport is most often chosen by patients and their families as it affords the greatest flexibility and maintains dignity and privacy during their treatment. However, the use of private vehicles presents a costly choice over what are often very long distances.

IPTAAS is the primary scheme that provides financial support for isolated patients using private transport to access cancer services. Need for some improvement in IPTAAS were reported. Main areas for improvement were:

- more readily available information about the scheme;
- consistent eligibility criteria applied especially for cross border patients;
- reduction in reimbursement delays
- reduction in the complexity of the application procedure

## **6.9 Reforms to IPTAASS under “Transport for Health”**

In May 2006, the New South Wales Government issued a statement describing reforms to IPTAAS under the Transport for Health policy.

The reforms, effective from 1 July 2006 focus on a reduction in the distance eligibility criterion and an increase in the vehicle allowance. Specifically the reforms are:

- reduction of eligibility distance for the IPTAAS scheme from 200 kilometres to 100 kilometres; and
- increase in vehicle allowance from 12.7 cents per kilometre to 15 cents.

- Centralization of IPTAAS within each AHS to provide a single point of access for information and assistance.

The total cost of these changes is estimated at \$2.6 million per year. NSW Health and AHSs will contribute \$2.1 million, while the Cancer Institute has committed \$500,000 to assist rural cancer patients.

The Cancer Institute NSW will be working with NSW Health to monitor improvements to IPTAAS under the Transport for Health reforms.

## **6.10 Accommodation**

Accommodation for rural cancer patients having to travel away from home to receive specialised treatment was identified as a significant issue by each surveyed group across all scope AHSs. The reviewers found that information on occupancy levels and waiting lists for accommodation facilities linked to cancer services is not readily available, making further analysis difficult. While there are variations between available levels of accommodation for different AHSs, common themes were noted:

- Accommodation for patients seeking treatment away from home is not restricted to cancer patients. Rural cancer patients compete with other patients for the small number of away from home accommodation facilities at the larger regional and metropolitan centres.
- The cost of accommodation was identified as an issue, particularly for cases in which subsidised accommodation is not available and treatment is required for long periods or on frequent occasions.
- There is little accommodation available for families of cancer patients who may need to accompany the patient, especially young children.
- Access to accommodation for cancer patients to coincide with treatment times is not always available. The capacity to book accommodation in advance may be limited by short treatment lead times.

## **6.11 Awareness of Available Services**

In assembling the profile of existing cancer services and support services available within each scope AHS it appeared that the level of awareness of existing services is highly variable. The following issues may contribute to this situation:

- Absence of documented referral pathways and mechanisms; and
- Absence of a central information repository across all scope AHSs.

## **6.12 Community Engagement**

One of the most significant enablers to accessing cancer services within the scope AHSs visited by the review team is the sense of community spirit in regional and rural areas. It is this level of involvement that has enabled the following outcomes in several rural areas:

- community transport services for cancer patients and their families;
- accommodation for patients and their families;
- development of satellite chemotherapy units.

## 6.13 Access to Pharmaceuticals

A number of clinicians reported that certain new TGA approved, but not PBS approved, cancer drugs are not available as quickly in some rural AHSs.

## 6.14 Out of pocket expenses

Out of pocket expenses were not quantified in this review. Service providers and patients in the review reported that out of pocket expenses are an issue for most rural cancer patients, usually to access appropriate cancer specialist services. The main areas where expenditure is outlaid include:

- Radiology / radiotherapy services from private providers where public services are not available or not convenient
- Travelling to and from specialist service providers
- Accommodation during the receipt of specialist cancer treatment.

A detailed health economic modelling of the out of pocket expenses for rural cancer patients would be of value.

## 7. Key findings

- There are many cancer services available to patients in rural NSW. These are centred on large regional or base hospitals located in more densely populated townships. Access to these services may be limited by patient travel and accommodation requirements, particularly for patients living some distance from the service.
- Outreach services in rural / remote NSW are generally not supported by formalised agreements with providers. Contingency planning may be required to better support outreach services.
- Rural health care providers or people living with cancer and their carers may not have a comprehensive understanding of all the cancer services that are available across their Area Health Service.
- Patient referrals from rural areas to metropolitan centres, are generally not underpinned by documented criteria, protocols or agreements but based on medical advice and practice and traditional referral patterns.
- Cross border flows occur on a regular basis in some rural areas. Some areas have developed innovative service delivery models that build on respective strengths of the bordering regions (e.g. the Border Cancer Care Coordination project at Albury-Wodonga).
- Many rural AHSs experience difficulties in the recruitment and retention of suitably qualified cancer services staff across all disciplines impacting on staff ratios, especially in the more remote areas.
- Rural cancer health care professionals may have limited access to professional development due to small staffing levels, travel and leave requirements.
- Involvement of general practitioners with state cancer services presents a significant challenge.
- There is an opportunity to improve the use of telemedicine to facilitate the transfer of clinical information and treatment strategies. Whilst telemedicine

facilities exist in all of the AHSs reviewed, they are often under used. Underutilisation appears to be a result of many factors including age of the equipment, inadequate training on use, location, and the drop out rate of some lines between rural and urban based services.

- At the time of the review, transport and accommodation subsidy criteria under IPTAAS was an issue, with eligibility and administrative variation across the areas. The scheme has subsequently been upgraded under the Transport for Health policy reforms. A variable range of accommodation and transport services are provided through community based organisations across the areas.
- Accommodation services generally are unable to provide utilisation statistics, and do not maintain data on the specific medical condition of the patient (e.g. cancer or dialysis patient) making analysis of utilisation for cancer patients difficult.

## 8. Conclusion

The issues identified in this review of cancer services in rural and remote NSW have led to a number of new rural initiatives through the Cancer Institute NSW.

The review includes a combination of quantitative and qualitative information sourced from a wide range of stakeholders across all AHSs within the project scope. The review is quite subjective, but where data was available those impressions and the qualitative findings were found to be consistent across the State.

The review found that the cancer services in rural / remote areas of NSW are sustained by high levels of dedication among the health professionals who work in them, often under challenging circumstances. In many cases support of the local community plays a significant part through the provision of transport and other voluntary support services.

The issues associated with providing better cancer services for rural patients are well captured in this review. It is not feasible to have specialist cancer services in every small town or population centre in New South Wales. However, innovative methods of networking and communication would assist some rural and remote service providers to overcome distance issues or affordability. Better communication and referral processes, enhanced use of communication technology and greater sharing of human resources are important as strengthening networks in some areas.

The outcomes of this review have been used by the Cancer Institute NSW to identify gaps in the current provision of cancer services in rural areas and to develop targeted and strategic projects to improve access. Rural initiatives developed following this report include programs across the priority areas of the NSW Cancer Plan.

Over the course of the two NSW Cancer Plans the Cancer Institute NSW will make a substantial investment in rural workforce and infrastructure initiatives, including funding for additional front line staff, specialised technology and telehealth grants, and other workforce initiatives such as the recently established registrar program fostering cancer related medical specialties in rural areas.

Other initiatives include supporting cancer training and continuing education for both rural cancer professionals and rural general practitioners. For example, programs offering cancer nursing education and training face-to-face in rural areas which are currently being piloted.

In 2006 the NSW Government announced reforms to the Isolated Travel and Accommodation Assistance Scheme (IPTAAS) and integration of all health related transport programs under the Transport for Health Program. As part of the reforms, the eligibility criterion was reduced to 100 kilometres and the vehicle allowance rate per kilometre was increased. The Cancer Institute NSW has committed funding to this initiative to assist rural cancer patients.

The Cancer Institute NSW will continue to develop and evaluate service models to improve cancer outcomes in rural NSW based on existing evidence of best practice. Current initiatives include: developing multidisciplinary team models; reviewing existing outreach cancer services and their sustainability; examining costs associated with rural cancer care services; developing managed clinical networks through the CanNET project; and the establishment of the Standard Cancer Treatment website (CI-SCaT) as a resource on cancer treatment protocols for cancer health professionals.