Australian Government
Australian Institute of Health and Welfare

26 Thynne Street
Fern Hill Park
Bruce ACT

GPO Box 570
Canberra ACT 2601

Ph 02 6244 1000
Fax 02 6244 1299

The Secretary
Senate Community Affairs References Committee
Suite S1 59
Parliament House
Canberra ACT 2600

Inquiry into services and treatment options for persons with cancer

Thank you for the opportunity to provide information to the Committee on national cancer data, current gaps in that data in respect of services and treatment, and support provided by the AIHW to research into services and treatment.

1. Australian Institute of Health and Welfare (AIHW) national datasets containing cancer data

Cancer screening

The Institute is funded by the Department of Health and Ageing for monitoring and other statistical services for the National Cervical Screening Program, the BreastScreen Australia Program, and development of a national bowel screening program. The program performance indicators include numbers of cancers which are diagnosed within two years of screening; hence a complete set of data for reporting does not become available until 2 years after screening.

Most recent published reports

Cervical screening in Australia 2001–2002.

BreastScreen Australia monitoring report 2001–2002.

Cancer incidence (new cases of cancer)

The AIHW and the Australasian Association of Cancer Registries jointly operate and publish statistics from the National Cancer Statistics Clearing House, which is the national cancer registry database from 1982 to 2002 compiled from records of all new cases of malignant cancer provided by the state and territory cancer registries.

The dataset includes demographic characteristics, type of cancer, and date of death and causes of death where applicable. Notification is required by law and so the information notified is a minimum dataset to enable population monitoring. Hence treatment and service information is not required to be notified.

Most recent published report

Cancer in Australia 2001 and interactive data cube.

for health and welfare statistics
www.aihw.gov.au

National Death Index and mortality data

The Institute holds:

- the National Death Index, containing all deaths in Australia since 1980 (sourced from the Registrars of Births Deaths and Marriages). This is used primarily for record linkage in research studies to determine mortality outcome and to assist researchers avoid writing to deceased persons.
- the National Mortality Database, a repository of cause of death data sourced from the ABS, with records from 1964 to 2003. The Institute has ABS cancer statistics in varying detail back to 1907.

Most recent published reports

Cancer in Australia 2001.

GRIM books, national: Interactive workbooks containing cause-specific national mortality information from 1907 (for some causes) to 2003, indexed by year of registration, sex, and five-year age groups.

GRIM books, State and territory: Interactive workbooks containing cause-specific Australian mortality information from 1968 (for most causes) to 2003, nationally and by State/Territory, indexed by year of death, sex and five-year age groups.

Cancer survival

Linking cancer incidence and the National Death Index enables the calculation of cancer survival. The next national survival analysis will be conducted later this year.

Most recent published reports

Cancer survival in Australia 2001: Relative survival data for selected cancers for the period 1982 to 1997

Cancer survival in Australia 1992–1997: Geographic categories and socioeconomic status

General practitioner consultations

The AIHW General Practice and Statistics Unit collects and publishes statistics from a sample of 100,000 GP consultations per year, with data currently available from 1998 to 2004. There are an estimated 2 million GP consultations per year and the data includes types of treatment and referrals.

Most recent published report

Cancer in Australia 2001.

Hospital inpatient statistics

The AIHW National Hospital Morbidity Database is a rich source of episode-based inpatient data on cancer treatment. In 2001-02 one in ten hospital admissions were cancer-related and hospital inpatient admissions for cancer have been increasing at 4.7% per year in recent years.

Most recent published report

Australian hospital statistics 2002–03.

Palliative care

Data are currently available on palliative care for admitted patients in Australia. However, work has been undertaken to develop a national data collection for community-based palliative care.

Most recent published reports

Admitted patient palliative care in Australia 1999–00

National palliative care information collection: A way forward for community-based palliative care (AIHW 2004)

Cancer expenditure

The AIHW disease expenditure database includes breakdowns of allocatable direct expenditure on cancer in Australia.

This includes expenditure on hospital care, other medical services, pharmaceuticals, and research.

Most recent published report

Health system expenditure on disease and injury in Australia 2000-01.

Cancer expenditure in Australia 2000–01 (soon to be released).

Cancer workforce

The AIHW Labour Force Unit collects and publishes medical and nursing workforce statistics. However, although there is a large workforce providing cancer services, statistics are only available for occupations with cancer-specific titles such as Oncologist and Oncology nurse.

Most recent published report

Cancer in Australia 2001.

2. Other national datasets containing cancer data

MBS and PBS data

The Health Insurance Commission and the Department of Health and Ageing hold Medicare data on trends in the Medicare provider workforce, on MBS items related to cancer and on PBS drugs prescribed. These databases, on their own, provide only limited information about numbers of patients attending cancer specialists and about drugs which may used for treating cancer. There are in fact few drugs which are used exclusively for treatment of specified cancers.

However, if MBS and PBS records could be linked to hospital inpatient records of patients with a diagnosis of cancer, and with the AIHW National Death Index, to create a de-identified research data base protecting patient privacy, many different analyses could be undertaken of treatment outcomes for various cancers. These analyses could inform cancer service planning for rural and metropolitan areas, and for other population sub-groups. Such analyses would need to be specified in research protocols and approved by the ethics committees responsible for the databases.

ABS national health and disability surveys

These national survey databases of the Australian Bureau of Statistics include information on:

- Risk factors for cancer, including smoking, poor diet, and obesity.
- Self reported prevalence of cancer for the main cancers, and types of medication taken, including alternate medicines.
- Level of disability associated with the cancer.

Australian Paediatric Cancer Registry

This is a clinical cancer registry which has been collecting information on children's cancers and treatment since 1977. In 2003 it was transferred from the Brisbane Royal Children's Hospital to the Queensland Cancer fund where it is managed by the Queensland Cancer Registry.

Most recent report

Australian Paediatric Cancer Registry Report 2000 (APCR 2000).

Australian Mesothelioma Register

This Register has records of new cases of mesothelioma since 1986 and is managed by the former National Occupational Health and Safety Commission whose functions are now undertaken by the Department of Employment and Workplace Relations.

Most recent report

The Incidence of Mesothelioma in Australia 1999 to 2001. Australian Mesothelioma Register Report 2004 (NOHSC 2004).

3. AIHW support of research into cancer services and treatment options

The Australian Institute of Health and Welfare Act 1987 allows health researchers to link their research cohorts with the AIHW's national cancer database and National Death Index to determine cancer incidence and all-cause mortality outcomes, providing they have approval from their own institutional ethics committee, from the AIHW Ethics Committee, and, for the cancer database, all state and territory cancer registries.

This facilitates research into:

- Exposure to possible carcinogens and other risk factors;
- Effectiveness of treatments through the measurement of longer term survival/mortality post treatment.

4. Major gaps in national data on services and treatment options

Hospital outpatient services

There are no national data on hospital outpatient services for cancer. From July 2005 a collection of hospital outpatient occasions of service for chemotherapy and radiation oncology will commence for the principal referral and other major hospitals in each State.

Clinical cancer data

Currently only the NSW Cancer Registry has data on stage of cancer, a pre-requisite to interpreting changes in survival and to analysing the effects of changes in treatment and services.

To facilitate the development of clinical cancer registries to collect stage and treatment data consistently throughout Australia, the National Cancer Control Initiative developed a National Clinical Cancer Data Dictionary which was incorporated in the National Health Data Dictionary in 2004.

Most states are developing the infrastructure to set up clinical cancer registries; the Australian Department of Health and Ageing is best placed to advise on progress.

I trust that this information assists the Committee in its Inquiry. The Institute contact officer for further information is Mr John Harding, Head, Health Registers and Cancer Monitoring Unit on (02) 6244 1140, email john.harding@aihw.gov.au

Yours sincerely

Richard Madden
Director
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