

8. Methods and terminology

This section sets out the issues involved in and terms used in cancer registration, and highlights practices adopted by the South Australian Cancer Registry (SACR) staff over its history. While this is not a listing of all the issues, it highlights those that are of significance. The explanation of technical terms used in the report which follows, will assist the reader in interpreting tables and graphs.

8.1 Coding issues in cancer registration

Demographic and cancer-related information is entered by SACR staff from the sources described and following the procedures explained in Section 1.1. The SACR staff currently use the International Classification of Diseases (9th Revision) to describe the topographic cancer site. The Systematized Nomenclature of Medicine and Modifications (SNOMED II) is used to classify histopathology. For particular cancer sites there are coding rules and issues which need to be highlighted:

❖ Exclusions

The non-melanocytic skin cancers are not included in the cancer registry collections, with the exception of such lesions of skin immediately adjacent to the lip and anus. “In-situ” cancers and neoplasms of uncertain behaviour are not included, except where otherwise stated in Section 1.1 of this report.

Sites for metastatic disease are not coded as such, but are assigned to the original primary sites or as “unknown primary” where applicable.

❖ Coding options

- ◆ Soft-tissue cancers such as sarcomas and Merkel cell tumours of the intra-thoracic, breast or abdominal organs are coded to the relevant organ. Others are coded to the ICD-9 soft tissue site 171.
- ◆ Bladder tumours diagnosed prior to 1982 were all recorded as invasive cancers. These would have included some “in-situ” carcinomas and papillary non-invasive tumours.
- ◆ Urinary-tract tumours are counted as one primary when they are multifocal transitional cell carcinomas.

8.2 Cancer registry terminology

A number of terms are used to define concepts in cancer registry work. Some of the most common ones are discussed below.

❖ Cancer incidence

Cancer incidence is defined as the number of new cases of cancer notified for a specified period and for a specified population (e.g. South Australia for 2003 or 1977-2003). It is usually presented as either the number of new cases or as a rate per 100,000 population (see below).

❖ Cancer prevalence

Cancer prevalence is a measure of the number of people with cancer at a specified point in time. There are two measures of prevalence used in this report – five year prevalence and care prevalence. Five year prevalence is the number of people who

were alive on a certain day and had had a diagnosis in the preceding five year period. Care prevalence is an estimate of the prevalent cases that are still under care.

❖ Cancer mortality

Cancer mortality is defined as the number of deaths where cancer is specified as the underlying cause of death. The underlying cause of death is derived from the death certificate issued by a certified medical practitioner and is based on the World Health Organisation's rules for attribution of cause of death. Information about death and its cause may form part of the mandatory notification made when cancer cases die in hospitals. Such information may also be retrieved by linking the SACR records to the Registry of Births, Deaths and Marriages. Non-cancer deaths are also recorded on the Registry however these are not coded specifically to their cause of death, only to a generic non-cancer death code.

❖ Age-specific rates

Age-specific incidence or mortality rates were calculated by dividing the number of new cases or deaths in each age group by the at risk population for that age group and multiplying by 100,000. These rates are usually presented in five year age groups and by sex.

❖ Crude rates

A crude incidence or mortality rate is defined as the number of new cancer cases or deaths (usually across all ages) divided by the population at risk in a specified time period. Crude incidence and mortality rates in this report were calculated using the estimated resident South Australian population for 2004 and are expressed as cases or deaths per 100,000 population per annum.

❖ Age-standardised rates

Summary incidence or mortality rates across all ages can be calculated to provide an overview of the impact of cancer. These rates are either expressed as crude rates (see above) or standardised rates (sometimes referred to as adjusted rates). Standardised rates enable comparisons of cancer rates between populations with different age distributions - an important advantage as the risk of cancer increases with age. Age-standardised incidence or mortality rates highlight the differences in cancer risk between populations that would be observed, had their age distributions been the same.

The age-standardised method used in this report is the direct method where a standard (or reference) population is used.

❖ Standard populations

There are two standard populations used in this report - the New World Population and the Australian Standard Population 2001. The New World Population is an estimate of the proportional age distribution of the whole world and the Australian Standard Population is the actual Australian population from the 2001 Census.

❖ Risk

Cumulative risk is the risk an individual would have of developing or dying from a particular cancer, over a defined life span, if that person were not to die beforehand from another cause. Cumulative risk is usually calculated using the following formula:

$$\text{Cumulative risk} = (1 - e^{-\text{cumulative rate}/100})$$

The cumulative rate (a component of the calculation) is the sum of the age-specific incidence or mortality rates over a certain specified age range (life expectancy or other specified range). It is calculated by using the formula:

$$\text{Cumulative rate} = \frac{5 \times (\text{sum of age specific rates}) \times 100}{100,000}$$

This formula assumes that age groups are arranged in five yearly blocks. Typically this rate ranges from less than 1 per cent for rare cancers to around nine per cent for common cancers.

Lifetime risk is another common way of expressing risk, where the risk is expressed as a 1 in x chance of being diagnosed with or dying of a cancer. It is calculated by the following formula:

$$\text{Lifetime risk} = 1 / \text{cumulative risk}$$

For example a cumulative rate of, say, 4.4 percent for lung cancer in males would mean that one out of every 23 males would be expected to be diagnosed with lung cancer by age 75 years if he were not to die before that age from another disease.

❖ Person-Years of Life Lost

Years of potential life lost (PYLL) is a measure of the number of years of life lost per annum due to premature death from a particular cause given a specified life expectancy. While life expectancy has changed, as discussed above, this report adopted the international approach of reporting this measure to age 74. There are a number of methods used to estimate cancer impact. This report used the simple approximation of:

$$\text{PYLL} = 75 - \text{age at death} \times \text{number of deaths at each age}$$

The calculation in this report was performed on five year age groups from 0-4 through to 70-74.

8.3 Projections of cancer rates for selected sites

The full time series of crude incidence rates was graphed separately for males and females for each site. From these graphs a subjective decision was made about which part of the series best reflected recent trends in incidence for these sites. For consistency, where the sites were in the top 15 for both males and females, the same part of the series was used for projection for each sex.

There was a discontinuity in the series for prostate cancer, which was reflected in the series for all sites for males. Thus cancers for all sites for males were only modelled based on data from 1996 onwards. The series for all cancers for females had no such problem, but for consistency this series was also modelled on data limited to 1996 onwards.

Key sites and appropriate years of diagnosis were selected as the base for projections. For each site, the age and sex specific crude rates were assessed for a linear trend. This was done by fitting a simple linear regression of the series against the year, and examining whether the coefficient of year was statistically significant at the 5% level. This model utilised the calculation of robust estimators of standard errors provided as an option by the Stata statistical package. The Huber/White/sandwich robust variance estimator produces consistent standard errors for Ordinary Least Squares regression coefficient estimates in the presence of heteroskedasticity.

Since the data are time series, it is possible that they are autocorrelated. Accordingly the errors in the regression model were tested for autocorrelation using the Durbin Watson alternative test for first order serial correlation in the disturbance. Where autocorrelation in the errors was detected, the model was refit using the Newey-West variance estimator, which handles autocorrelation up to and including a specified lag, as well as the presence of heteroskedasticity. The Newey-West model produces variance estimates that are exactly the Huber/White/sandwich robust variance estimates calculated by the robust regression estimator above when no lag is included in the model. Thus the two models used to assess linear trend are entirely consistent. Only first order correlation was allowed for in the fitting of the models.

Where a linear trend was established, projections were based on this trend. Where the trend was not statistically significant, projections were based on the mean crude rate of the series over that part of the series being applied.

9. Glossary

Age-specific rate

The number of new cases of cancer (incidence) or deaths (mortality) in a specified age group divided by the number of people at risk for that age group, multiplied by 100,000.

Age-standardised rate

Cancer rates vary with age. A crude (see below) or summary rate can therefore be a misleading way to characterise a population that includes people of different ages. This problem is even more challenging when summary rates of two populations are being compared. An age-standardised rate is a summary rate that has been constructed to reflect what would be the case if the population of interest had the age distribution of some other, known, population, eg an agreed standard population. Age-standardisation facilitates more logical comparison between populations.

Cancer

An abnormal, uncontrolled cell growth that invades parts of the body locally but also has the capacity to metastasise or spread to distant organs through the blood and lymphatic system.

Confidence intervals (95%)

A measure of variability in an estimate of the cancer rate in a particular population subgroup. A 95% confidence interval is an interval such that the probability is 0.95 that the interval contains the true value.

Crude Rate

Crude rates are calculated by dividing the number of new cases (incidence) or deaths (mortality) during a given period of time, by the number of people at risk. They are usually expressed per 100,000 people per annum.

Cumulative rate

The sum of the age-specific incidence or mortality rates over a certain specified age range. It is a good approximation to the cumulative risk & expressed as a percent.

Cumulative risk

The risk an individual would have of developing or dying of a particular cancer over a defined life span if no other causes of death were competing.

Incidence

The number of new cases of cancer occurring within a given population during a specified period. In this report, only invasive cancers are included and generally nonmelanocytic skin cancers (NMSC) are excluded.

Leukaemia

A progressive, malignant (cancerous) disease of the blood and blood-forming organs, characterised by over-proliferation and development of white blood cells.

Lifetime risk

The reciprocal of cumulative risk and is expressed as a 1 in x chance of being diagnosed with or dying of a cancer.

Lymphoma

Cancer of the lymphatic system, categorised as: Hodgkin's disease or Non-Hodgkin's lymphoma.

Melanoma

A very malignant form of skin cancer that begins in the pigment cells or melanocytes and spreads to other skin cells.

Multiple Myeloma

Cancer of the white blood cells found in the bone marrow.

Mortality

The number of deaths from cancer in a given population during a specified period.

Person-Years of Life Lost (PYLL)

A measure of the number of years of life lost due to premature death from a particular cause, given a specified life expectancy.

Prevalence

The proportion of people with cancer in a population at a single point in time.

Relative Survival

This is a net survival measure representing cancer survival in the absence of other causes of death. Relative survival is defined as the ratio of the proportion of observed survivors in a cohort of cancer patients to the proportion of expected survivors in a comparable set of cancer free individuals. The formulation is based on the assumption of independent competing causes of death.

Socioeconomic Status (SES)

Socioeconomic status is a measure of a person's relative level of advantage in the community, based on the person's income, education level, occupation and type of housing.

Statistical Local Area (SLA)

A statistical local area is the main geographical unit currently used by the Australian Bureau of Statistics. SLAs have populations in South Australia varying from 1,000 people to 33,000 people.

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