Cancer Data

ADOLESCENTS AND YOUNG ADULTS IN AUSTRALIA

Youth Cancer Service | canteen

University of South Australia

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GLOSSARY OF ABBREVIATIONS

ACD	Australian Cancer Database
ACIM	Australian Cancer Incidence and Mortality
AIHW	Australian Institute of Health and Welfare
ALL	Acute lymphoblastic leukaemia
AML	Acute myeloid leukaemia
ASIR	Age Standardised Incidence Rate
ASMR	Age Standardised Mortality Rate
AYA	Adolescents and Young Adults
CLL	Chronic Lymphocytic Leukaemia
CML	Chronic Myeloid Leukaemia
CNS	Central Nervous System
CRUK	Cancer Research UK
ED	Emergency Department
HL	Hodgkin lymphoma
HP	Health Professional
HPV	Human Papilloma Virus
IARC	International Agency for Research on Cancer
ICD	International Classification of Diseases
MDT	Multidisciplinary Team
NHL	Non-Hodgkin lymphoma
PECCS	Patterns and Experiences of Care and Cancer Study
YCS	Youth Cancer Services
YCS DAG	Youth Cancer Services Data Advisory Group
SAHMRI	South Australian Health and Medical Research Institute
STaR	Staging, Treatment and Recurrence

EXECUTIVE SUMMARY

CanTeen established the Youth Cancer Services Data Advisory Group in 2013 to provide strategic advice on national data collection and use with wide recognition for the need to improve data availability on adolescent and young adult cancers in Australia.

These data are critical to guide service planning for young people, service evaluation and quality improvement, for research studies, feedback to stakeholders, and to guide and support advocacy.

Following a national AYA dataset workshop attended by clinicians, health administrators, consumer representatives, researchers and other stakeholders in 2014, a stepped plan was developed to a) determine the current availability and accessibility of data on AYA cancers and b) to consider future opportunities for data collection and linkage.

This report presents the initial pathfinder work undertaken to date in collaboration with the University of South Australia.

Each year in Australia, approximately 900 adolescents and young adults (15-24 years) are reportedly diagnosed with cancer (2007-2011 annual mean). This accounts for 0.8% of all reported cancer incidence and compares with 0.5% for children (0-14 years) and 2.1% for the older age group (25-34 years). In the region of 100 AYAs die from cancer every year (2008-2012 annual mean). Cancer is the most common cause of non-accidental death among young people (15-24 years), second after injuries which predominantly caused fatal burden in this age group. AYA deaths from cancer account for 0.24% of all reported cancer deaths. This compares with 0.21% for children aged 0-14 years and 0.57% for the 25-34 year age group.

According to international data, Australia has a high estimated age-adjusted incidence rate for all invasive cancers in the AYA 15-24 year age group, 92% higher than the global estimate and higher than rates in Canada, the United Kingdom and New Zealand. Those cancers contributing to the elevated incidence estimates include melanoma, testicular cancer, Hodgkin lymphoma, colorectal and brain cancer. For melanoma in particular, Australia had a very high incidence rate, 15 times the global estimate.

In contrast, Australia's estimated AYA age-adjusted mortality rate was exceedingly low compared with the rest of the world, 50% below the global estimate and lower than for AYAs in the US, Canada, New Zealand and the UK. However, the mortality rate for invasive melanoma when compared globally are high at 6 times the global estimate (albeit lower than in New Zealand).

An analysis of trends in AYA cancers in Australia over the last three decades (1980s-2000s) suggests an increase of 15% in the age-adjusted incidence of AYA cancers for all invasive cancers combined. The most commonly reported cancer incidence in AYAs was for melanoma followed by Hodgkin lymphoma, testicular cancer, thyroid cancer, non-Hodgkin lymphoma, brain cancer, bone cancer, acute lymphoblastic leukaemia and acute myeloid leukaemia. A slightly higher proportion of AYA males are diagnosed with cancer than females, with the incidence of the most commonly reported cancers differing by sex.

Excluding melanoma from the analysis of all cancers reveals a clear increase in incidence (approximately 30%). While a decrease in the incidence of melanoma of the skin in AYAs is evident, this cancer still remains the most common AYA cancer reported (albeit accounting for a decreasing proportion of all cancers over time). Melanoma incidence rates in older age groups have not fallen to the same extent. There are some suggestions of a decrease in the age-adjusted incidence rate for AYA cervical cancer although further data are required to confirm this trend. Data indicate increasing age-adjusted incidence in other cancers with the largest increases applying to colorectal cancer, thyroid cancer, testicular cancer, Hodgkin lymphoma, non-Hodgkin lymphoma and acute myeloid leukaemia.

In contrast to the increased incidence, a marked reduction in mortality was evident with the age-adjusted mortality rate in the 2000s being 30% lower than in the 1980s, and 55% lower than the 1990s. Data do not provide clear evidence of increasing mortality rates for specific cancer types. A potential increase in mortality for colorectal and soft tissue cancers (other than bone) may be occurring though increases were small and not statistically significant when taking into account 95% confidence intervals. The highest mortality to incidence ratios in the AYA age group were for bone cancer, acute lymphoblastic leukaemia, acute myeloid leukaemia, brain cancer, soft tissue cancer (other than bone) and lung cancer.

A downward trend in all AYA cancer admissions was observed from 1999 to 2013 in contrast with increasing admissions for all ages combined. Lymphoid, haematopoietic and related malignant neoplasms were the most common cause of AYA patient admissions to hospital, with a high admission to incidence ratio for these cancers. Bone cancer, male genital cancer, melanoma and brain cancer were also responsible for a high proportion of AYA cancer hospital admissions with the admission to incidence ratios highest for bone, respiratory, haematological and soft tissue cancers.

CanTeen is committed to improving data availability on AYAs with cancer in Australia. Collaboration and discussions will continue with national data custodians and key stakeholders to access further data and to advocate the need for data and research specifically focusing on this age group. Gaps in data include survival, late effects, multiple primaries and patterns/experience of care. CanTeen is further progressing a national data initiative to collect a highest priority patient dataset to improve outcomes, both in terms of survival quality and duration.

BACKGROUND

CanTeen provides a range of support services for youth and young adults with cancer, their families and carers. Primarily the focus is on young people with a cancer diagnosis aged 15-25 years. While most have special clinical needs and often require specialised support to address physical, emotional and social impacts of their cancers and treatments, many are treated in adult or paediatric settings that are unsuited to these needs.

CanTeen obtains data for service planning and evaluation from its Youth Cancer Services (YCS) but generally not on services provided elsewhere and broader epidemiological aspects of cancers affecting this age group. Although state and territory registries can provide data on cancer incidence, mortality and survival in young people (non-melanoma skin cancer excepting), some of which have been included in a special Australian Institute of Health and Welfare (AIHW) report, further analyses of updated and ancillary data would be beneficial. Comparisons with corresponding international estimates of incidence and mortality can add value by indicating where Australia sits in league tables and by offering opportunities for international benchmarking. Also analyses of time trends in Australian incidence and mortality rates indicate the progress being made with cancer control in prevention and treatment.

While limited population-based data have been collected in Australia on cancer stage and other prognostic factors, treatment and support, and clinical and self-reported outcomes, there is a patchwork of data repositories that include relevant data that could be analysed to gain insights.

CanTeen established an advisory group in 2013 (the YCS Data Advisory Group) to give strategic advice on national data collection and use. The Group recognises that CanTeen data requirements are broad. In addition to routine cancer incidence, mortality and survival data, there is a need for data on treatment settings and pathways, clinical management, educational and psychosocial support needs, and side effects of care, including toxicity, and effects on relationships, educational and occupational aspects. Data are needed for defining and monitoring intermediary and late effects of treatments, especially in the context of the introduction of new pharmaceuticals.

Data are important to guide service planning for young people, service evaluation and quality improvement, for research studies, feedback to stakeholders, and to guide and support advocacy.

The development of systems to collect the broad range of data required was discussed at a CanTeen sponsored workshop of clinicians, health administrators, consumer representatives, researchers and other stakeholders in March 2014.

It was evident from workshop discussions that Cancer Australia was already collaborating with State and Territory cancer registries and the AIHW to develop a national monitoring of cancer rates by cancer stage at diagnosis, and stage-specific treatment and recurrence rates, which could be analysed by age, sex, socio-economic status, geographic remoteness and ethnicity. Such monitoring would include data on young people with cancer and would be of direct relevance to CanTeen's needs. In addition, a national dataset specification for collecting data on cancer, its management and outcomes in young people was in the process of gaining national government endorsement.

The purpose of the national dataset was to promote the use of common core data for research and for identifying the needs of young people with cancer, their treatment patterns and outcomes. These and ancillary data would be relevant for: (1) identifying unmet patient needs; (2) mapping patterns of care across geographic areas, centres and cancers; (3) monitoring emerging patterns of cancer and cancer treatment complications; (4) assessing clinical and patient-reported outcomes; (5) the costing of treatments and out-of-pocket expenses; and (6) enabling collaborative research. Inevitably, through the use of such data, remaining data gaps would be identified. The national dataset was intended to be a population-based and service-based statistical tool rather than to inform individual patient management for which medical records were required.

The CanTeen workshop discussion canvassed data collection options and participants indicated a clear preference, where possible, for the use of data extracts from existing databases rather than establishing a new data-collection system(1). It was considered that data from diverse sources could be integrated using privacy-protecting data linkage methods to produce a linked database to support research and service delivery. The cost-effectiveness of supplementary data collection would need to be considered to add value to existing data. The Cancer Australia and State & Territory cancer registry initiative to collect stage and linked treatment and recurrence data was regarded as fundamentally important for delivering core data, to which additional special-purpose data could be linked of specific relevance to youth cancer.

It was decided that initial pathfinder work would involve exploring and presenting data from existing data sources, prior to assessing progress with the Cancer Australia STaR (Staging, Treatment and Recurrence) project around March/April 2016 as a basis for future planning of data collection, integration and use. Such existing data sources examining cancer rates, cancer management and outcomes in young Australians, include: data from the AIHW Australian Cancer Database, including already published data, melanoma thickness and thickness-specific survival data, and follow-up data on multiple primary cancers; corresponding incidence and survival data by degree of spread (akin to SEER Summary Stage) collected through the NSW Cancer Registry; self-reported data on experiences with cancer and psychosocial outcomes gained through surveys and MDTs; and MDT data on broader health issues experienced by young people with cancer. Workshop participants agreed that the process should be a national collaborative effort, with co-authorship of report contributions by relevant data custodians and project collaborators. This pathway was supported at the CanTeen workshop as the preferred initial approach. Further developments of Australian data infrastructure, including recording of stage and other prognostic markers on population registries, further development of data linkage capacity to link registry data with treatment and treatment outcomes data, and other data collection options would be explored over the next three years.

This report describes initial steps in this pathfinder work. A range of data are presented that have been extracted from: International (GLOBOCAN) and national (ACD) population-based databases; the NSW Cancer Registry (separate publication); AIHW cancer incidence and mortality workbooks; AIHW Australian Cancer Database projected incidence rates; and AIHW Principal Diagnosis Data Cubes. The steps taken to develop a broader YCS data collection process to address data gaps are also described. For the purposes of this report, Adolescents and Young Adults (AYAs) are defined as young people aged 15-24 years old, preceding their 25th birthday.

CHARACTERISTICS OF YOUNG PEOPLE IN AUSTRALIA

It is widely recognised that Adolescents and Young Adults (AYAs) have distinct needs and requirements, different to those for other population groups. It is a period of immense change, adapting to crucial developmental tasks of psychosocial, physical and sexual maturity while acquiring skills needed to carry out adult roles, taking responsibility for their own lifestyle choices with increased autonomy from caregivers, and developing relationships with peers and partners (2). In addition to a growing level of independence, they can be at a critical stage of their education or early career.

The experiences of young adults today can be quite different to those in previous decades with transition affected by social, economic, environmental and technological changes which have occurred more recently.

Pathways from education to work, and from the family home to independent living, have become more varied and complex for young people.

The Australian Bureau of Statistics undertook an analysis of the 2011 census data and the 2011-13 Australian Health Survey to provide a picture of young people in Australia today and, where possible, compared with data from previous years. These data were presented by Justine Boland, Program Manager: Health & Disability Branch of the Population & Social Statistics Division of the Australian Bureau of Statistics, at the Inaugural International Oncology Congress in December 2015.

The 2011 Census counted 2.9 million AYAs (15-24 year olds) in Australia, equating to 13% of the total population (21.5 million), a similar proportion to 10 years ago but slightly lower than the 16% recorded in 1991. Of these 15-24 year olds, 51% were male and 49% female. Compared with 2001, the number of people aged 15-19 years had increased by 6%, and the number of 20-24 year olds had increased by 17% with the differences largely a reflection of fertility patterns in the 1970s and 1980s.

Of all Australian AYAs aged 15-24 years, the highest proportion were living in NSW/ACT (33%), followed by Victoria/Tasmania and Queensland. The lowest proportion were in South Australia/Northern territory (8%).

Table 1- AYA Population by Jurisdiction – 2011 Census Data

Jurisdiction	15-19 years	20-24 years	15-24 years	% of Australian AYAs
New South Wales / Australian Capital Territory	467,415	480,435	947,850	33%
Victoria / Tasmania	378,026	404,685	782,711	27%
Queensland	293,917	293,845	587,762	21%
Western Australia	148,208	159,010	307,218	11%
South Australia / Northern Territory	118,068	122,425	240,493	8%
Total	1,405,634	1,460,400	2,866,034	100%

Source: Australian Bureau of Statistics Census Data(3)

On a jurisdictional basis, the proportion of young people relative to each jurisdiction's total population was highest for the ACT with 15.3% and lowest for Tasmania with 12.6%.

Aboriginal and Torres Strait Islander people made up 2.5% of the total population but the age structure of this group was quite different from the non-Indigenous population. According to the 2011 Census, Aboriginal and Torres Strait Islander people have a younger age profile than non-Indigenous people with approximately 55% under the age of 25 years compared with around 30% for the total population. For the 15-24 year age group, these proportions were approximately 19% for indigenous people compared with 13% for the total population.

Australia's population is spread across a diverse range of places including major metropolitan cities to isolated outback locations. In terms of where these young people live, 72.3% were living in major cities. Very remote areas, on the other hand, had the highest percentage of young people as a proportion of the population. The high proportion of younger age Indigenous Australians, who make up nearly half the population in very remote areas, is likely to be a factor. The industry structure of very remote areas may also affect age structure with some mining towns having relatively young populations while major cities attract and retain young people by offering greater opportunities for higher education, employment and social interaction(4).

Young adults are one of the most mobile population groups with the mobility rate for females being higher than that for males. In 2011 around 42% of 18-34 year olds lived with a partner and of these around half had children. Comparing this back to 1976, around 65% of this age group lived with a partner and nearly 75% had children. Young adults in 2011 were more likely than those in 1976 to be living without a partner or child but with one or both of their parents.

The proportion of young people (18-34 years) born overseas has increased from 23% in 1976 to 27% in 2011. The countries in which they were born also changed reflecting changing migration patterns. In 1976, most young people born overseas were born in either the United Kingdom/Ireland (35%) or the rest of Europe (40%) with only 11% born in Asia. The 2011 census reveals that over half (53%) of this age group born overseas were born in Asia and only 10% in the United Kingdom/Ireland and 7% in the rest of Europe.

ANALYSES OF INTERNATIONAL AND NATIONAL AYA CANCER INCIDENCE AND MORTALITY DATA

Data Sources and Methods

International

The International Agency for Research on Cancer (IARC) has produced cancer incidence and mortality estimates for all countries globally for 2012 (GLOBOCAN). These estimates were drawn from registry data where they existed, and for countries without registries, from like countries with registries and associated mortality data. Multiple-projection methods were used to generate these estimates. Data were extracted from the GLOBOCAN database for 15-24 year olds for this project. These international data should be regarded as approximations only, although the Australian estimates would be reasonably precise given the availability of comprehensive registry data.

Annual incidence and mortality rates for 15-24 year olds are provided in this report for all invasive cancers collectively and for leading types, as applying to Australia, the World in total and global regions, for comparative purposes. Rates were adjusted by age by weighting rates for each age group equally (i.e: 15-19 and 20-24 year olds). Where applicable, rates are presented for males and females collectively in this report (due to small numbers). Results and interpretational comments are provided for all cancers collectively and for those types common enough to have been diagnosed in at least 10 young Australians in 2012. Appendix A[1] provides a full analysis of all GLOBOCAN data available, including a separate analysis for both males and females.

Australia

Australian incidence and mortality data are available through web-based ACIM spreadsheets (Australian Cancer Incidence and Mortality books(5)), published annually by the Australian Institute of Health and Welfare. Incidence data were available at the time of analysis for 1982-2011 and mortality data for 1968-2012. Age-adjusted incidence and mortality data are presented in this report for the 15-24 year age range per 100,000 persons along with 95% confidence limits approximated using the standard formula described in earlier AIHW reports. For the purposes of this report, differences in rates are interpreted as unlikely to be chance events where confidence intervals do not overlap.

Appendix C[1] includes results of a full analysis of all cancers in total and separate analyses for 44 specific cancer types, including decade and 5 year annual means and separate analysis for male and females. Supplementary survival data for 15-29 year olds available from a 2011 AIHW publication, Cancer in Adolescent and Young Adults in Australia(6) are also presented (Appendix B[1]). An analysis of the most common cancers in Australian AYAs is presented in Appendix D[1].

Mortality to incidence ratios are calculated based on age-adjusted rates for the AYA age group. While this gives an indication of comparative case fatality by cancer type, it does not take into account deaths which occur in the AYA age group from cancers diagnosed in children aged 0-14 years, or deaths occurring over the age of 25 years from AYAs diagnosed with cancer. Therefore, cancers which are common in children may result in an elevated AYA mortality to incidence ratio while cancers more common in the AYA age group, with deaths occurring in young adulthood (25 years and over), may present with a lower mortality to incidence ratio. Nonetheless, mortality to incidence ratios are commonly used around the world and generally provide good markers of comparative case fatality.

Projections for incidence and mortality rates are extracted from the Australian Cancer Database (2007) and the National Mortality Database (2012) respectively using population projections from the Australian Bureau of Statistics Population Projections – Series 2 (2012). Projection data are based on historical trend data with the assumption of no change in past trends.

AIHW published a report on Cancer in Adolescents and Young Adults in Australia in 2011(6) providing valuable survival data.

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1 Appendices are available on request from CanTeen.

Only invasive cancer data are presented throughout this report; non-melanoma skin cancers are excluded.

Introduction

Each year in Australia, approximately 900 AYAs are diagnosed with cancer and 100 lose their lives to cancer (2007-2011 annual mean).

This accounts for 0.8% of all reported cancers and compares with 0.5% for children (0-14 years) and 2.1% for the older age group (25-34 years). In the region of 100 AYAs lose their lives to cancer every year (2008-2012 annual mean). Cancer is the most common cause of non-accidental death among young people (15-24 years), second after injuries which predominantly caused fatal burden in this age group(7). AYA deaths from cancer account for 0.24% of all reported cancer deaths. This compares with 0.21% for children aged 0-14 years and 0.57% for the 25-34 year age group.

All Invasive Cancers

International

These data indicate that Australia had a high estimated incidence for AYA cancers in 2012, with only a slightly lower rate than for North America as the lead incidence region. The Australian incidence was about 91% higher than the global estimate and between approximately 4% and 18% higher than for Western Europe, Northern Europe and Southern Europe. Estimated rates in Australia were 5%, 15% and 16% higher than in Canada, UK and New Zealand respectively, although 3% lower than for the US. Comparatively low rates were estimated for Northern, Western and Middle Africa and Eastern Asia. The age-standardised incidence rate (ASIR) estimate was also elevated in Australia for all ages combined, using the global population as the reference population for age standardization, at 77% higher than the global estimate.

In contrast to the high incidence rate for all cancers collectively in adolescents and young adults in Australia, Australia's AYA cancer mortality rate was lower than for all comparative regions at about 50% below the global estimate, and approximately 4% to 24% lower than for Northern Europe, Western Europe, New Zealand, North America and Southern Europe. The age-standardised mortality rate (ASMR) in Australia was lower than that for the US (20% lower), Canada (16% lower), New Zealand (14% lower) and UK (12% lower). The ASMR estimate was also lower in Australia for all ages combined, using the World population as the reference population, but only marginally (6% below the global estimate).

Figure 1 - All Invasive Cancers – Global estimates of Incidence

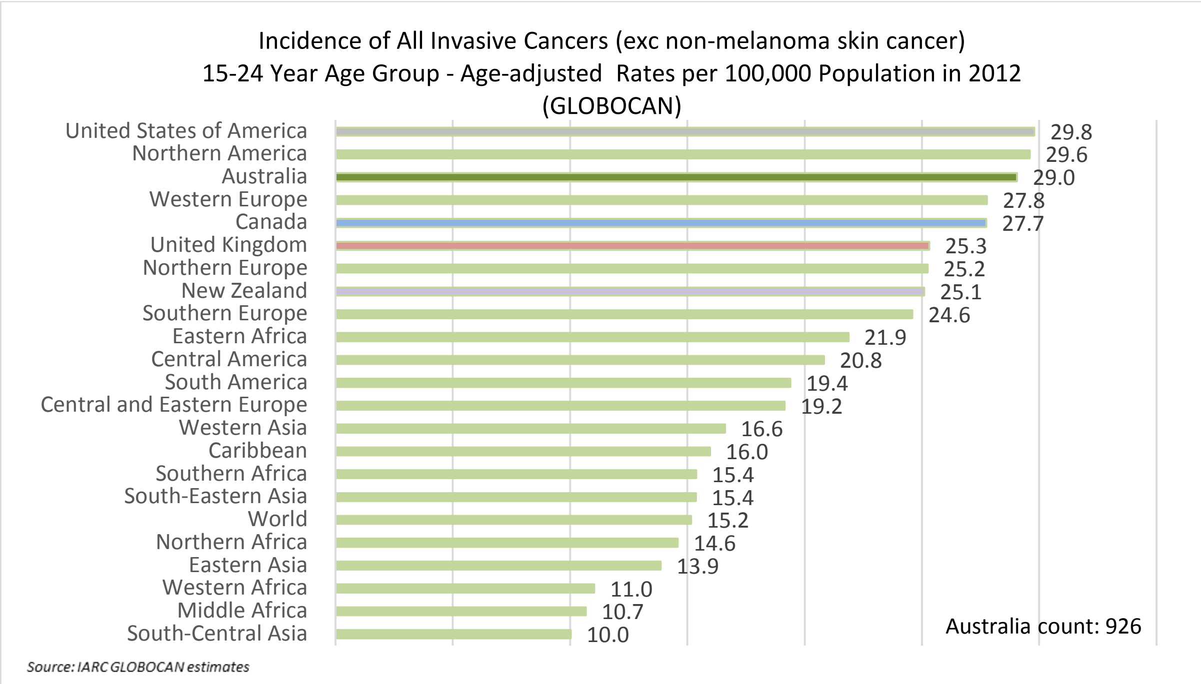
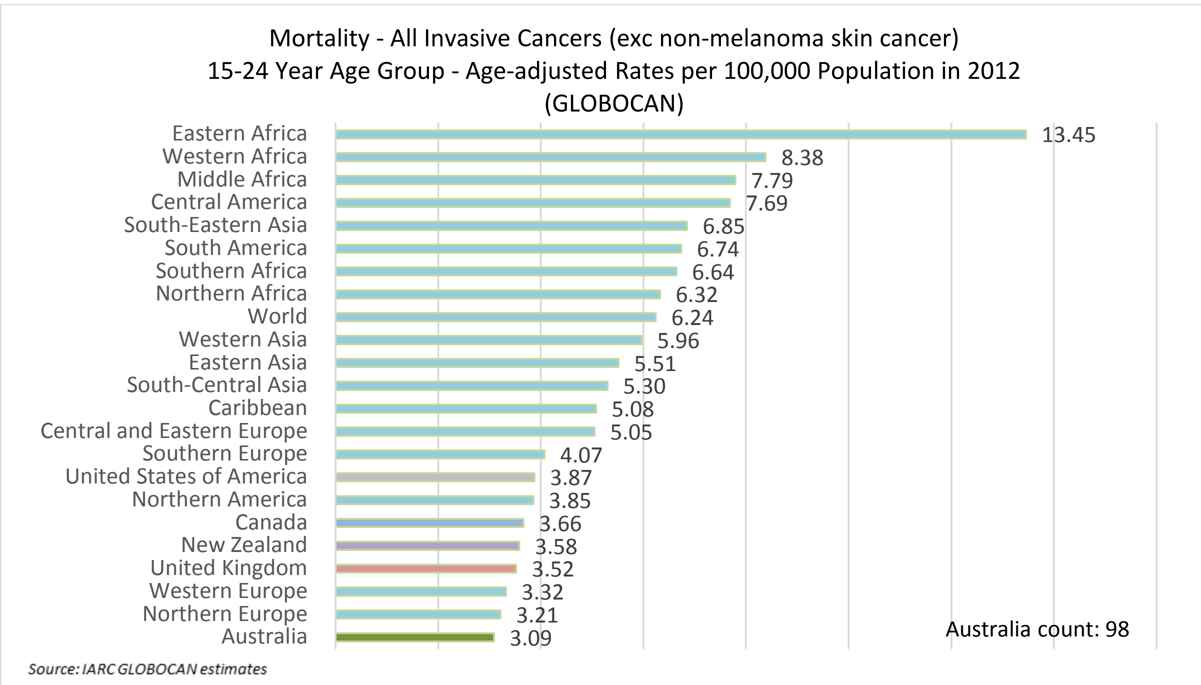


Figure 2 - All Invasive Cancers – Global estimates of Mortality



Comments

The higher incidence in Australia for AYAs was influenced by elevated incidence for melanoma, lymphoma, brain (CNS) tumours, and colorectal cancers. The elevation for melanoma is likely to reflect acute sun exposure in childhood. It is also possible that it is partly artificial due to raised levels of detection in response to campaigns to increase awareness. The reasons for the raised lymphoma and brain (CNS) cancer rates are not known. Increasing rates of lymphoma have been recorded around the world leading to speculation about possible contributions from viral infections, hair dyes, immunosuppressive states and exposures to herbicides and other environmental agents. Meanwhile the high colorectal cancer incidence in young Australians has been reported before and possible contributing factors considered (including poor diets, lack of exercise, obesity and excess alcohol consumption).

In general, ratios of deaths to cases are very low in young people, due in part to high case survivals for these cancers. Five-year relative survivals reported for 15-29 year old Australians were 88% for 2004-10, up from 80% in 1983-89 (Appendix B). Comparative five-year survivals were 81% for 0-14 year olds in 2004-10, up from 68% in 1983-89, and 86% for 30-39 year olds, up from 76% in 1983-89 (Appendix B). The reasons for the higher survivals in 15-29 year olds likely include the mix of cancers involved, and potentially earlier cancer detection, and youthful resilience. Differences by individual cancer types are discussed in this report.

Australia

The incidence rate of all AYA cancers was approximately 15% higher in 2000-09 than the 1982-89 reference years for males and females collectively, but then decreased by approximately 10% in 2010-11 when it no longer differed significantly from the reference years (Table 2). A similar pattern applied by sex although the reduction in males in 2010-11 compared with 2000-09 was smaller and attributable to chance. By comparison, marked reductions in mortality rates occurred (Table 3), with the 2010-12 rate being 56% lower than for 1968-69, 54% lower than for the 1970s, 45% lower than for the 1980s, 36% lower than for the 1990s, and 21% lower than for 2000-09. Pronounced reductions occurred in both males and females, although appearing to be larger in males. Further analyses, including 5-year annual data and a separate analysis of male and female data, are provided in Appendix C.

Table 2- All Invasive Cancers - Annual Incidence for 15-24 year olds by decade

All Cancers		Age-adjusted Rates per 100,000 AYAs		
Male & Female		Annual Mean	Lower	Upper
Incidence	Count	Age 15-24	95% CI	95% CI
1982-1989	5915	**27.6**	26.9	28.3
1990-1999	8394	**31.3**	30.6	31.9
2000-2009	8840	**31.7**	31.0	32.3
2010-2011	1752	**28.6**	27.2	29.9

Source: AIHW ACIM 2015

Table 3 - All Invasive Cancers - Annual Mortality for 15-24 year olds by decade

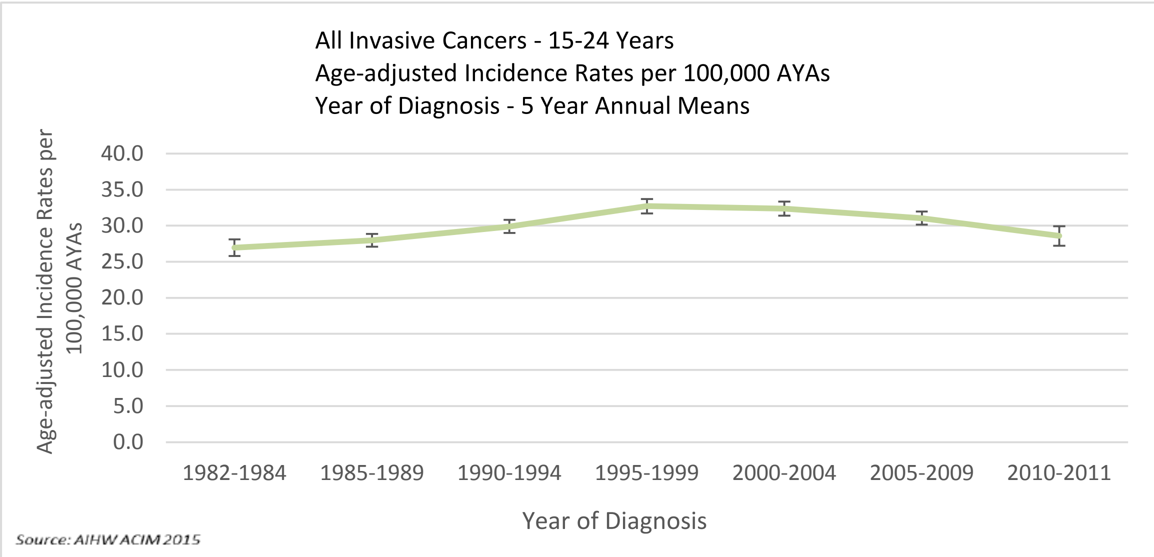
All Cancers		Age-adjusted Rates per 100,000 AYAs		
Male & Female		Annual Mean	Lower	Upper
Mortality	Count	Age 15-24	95% CI	95% CI
1968-1969	310	**7.42**	6.59	8.24
1970-1979	1679	**7.05**	6.71	7.39
1980-1989	1573	**5.91**	5.62	6.21
1990-1999	1353	**5.04**	4.77	5.31
2000-2009	1141	**4.09**	3.85	4.33
2010-2012	298	**3.23**	2.87	3.60

Source: AIHW ACIM 2015

Comments

Changes in incidence over the study period were generally small although, reviewing the five year annual means (Figure 3), a peak in 1995-1999 is suggested, followed by a slight decline. An analysis of cancer incidences, all cancers excluding melanoma, shows an increase to 2000-09 (Figure 3). No subsequent decline in age-adjusted incidence was evident for males, although a small decline was suggested for females in 2010-11. Further analysis of data for the period beyond 2011 will be required to confirm these latest trends in incidence.

Figure 3 - All Invasive Cancers - Trends in Annual Incidence for 15-24 year olds by five-year period



In contrast to incidence trends, large reductions in mortality from all cancers were attributable to gains in survival. Data for people diagnosed when 15-29 years old indicate an increase in 5-year relative survival from 80% for 1983-89 to 88% for 2004-10 Appendix B). Reasons for these increases in survival are likely to include earlier cancer detection and treatment advances, including gains in systemic therapies and stem cell transplantation.

AIHW projections of age-adjusted incidence rates (per 100,000) for 2011-2020 (8, 9) for all cancers combined, both males and females (mean), suggest little change for the AYA age group (2% decline).

This is comparable with changes for the 0-14 and 25-39 year age groups. Applying projected increases in population(5, 10), which indicate a 5% expected increase in the AYA population by 2020, results in a 3% overall increase in the number of incident cancers for all cancers combined. Projections of age-adjusted mortality rates (2013-2025), however, indicate an expected 22% decline from 2013 to 2025, a lower decline than rates for the 0-14 year age group (-32%) and 25-39 year age group (-26%). Taking account of the predicted increase in the AYA population during this period, there is an expected decline of 14% in projected numbers of male and female deaths arising from all cancers combined.

Differences by individual cancer types are discussed in relevant sections of this report.

Melanoma (Skin)

International

Australia had a very high melanoma incidence estimate for AYAs at about 15 times the global estimate and about 45% higher than for New Zealand (Figure 4). The highest incidence rates were for European countries and other regions predominantly of European extraction. The estimated rate for Australia exceeded rates for the UK (by 46%), US (by 131%) and Canada (by 210%), all of which were higher than the global estimate. The Australian melanoma mortality estimate was about 6 times the global estimate, exceeded only by New Zealand (Figure 5) but higher than for the UK (by 6%), US (by 64%) and Canada (by 200%). Again, the highest rates were estimated for European countries and other populations of predominantly European extraction.

The ASIR was also elevated in Australia for all ages combined (using the World population for age standardization) at about 12 times the global estimate and the corresponding Australian mortality was about six times the global estimate.

Figure 4 - Melanoma – Global estimates of Incidence

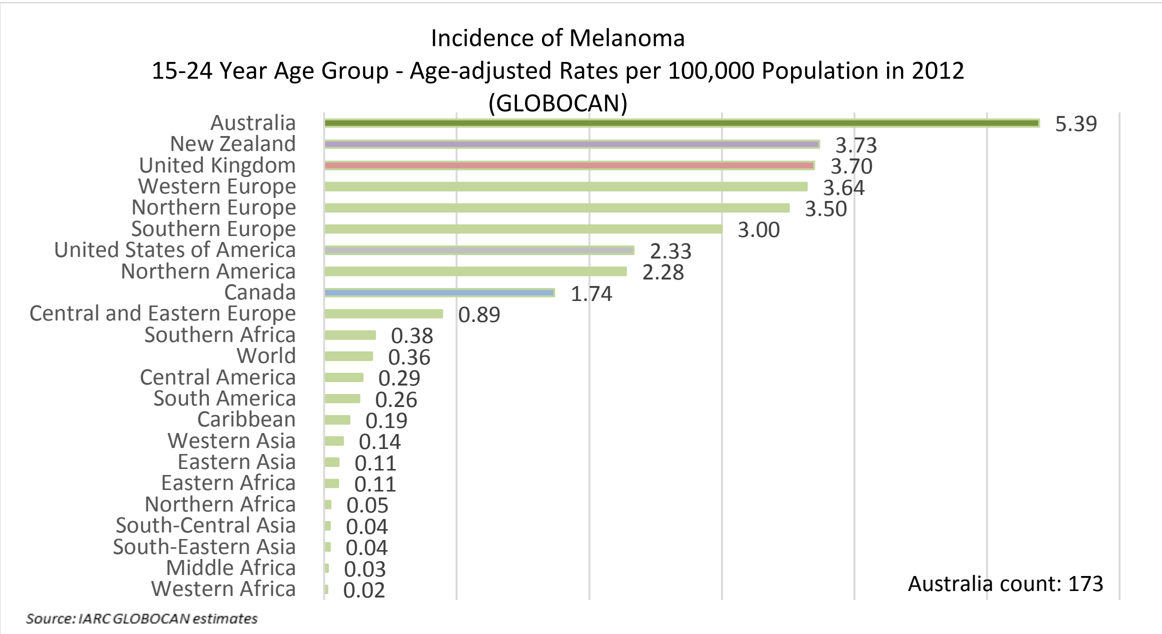
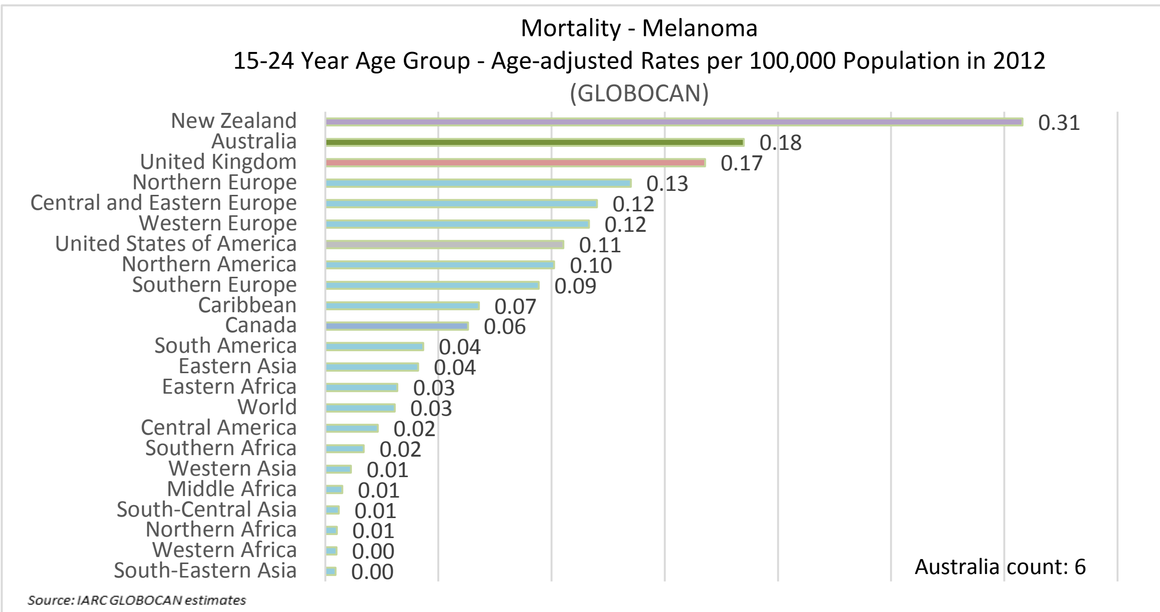


Figure 5 - Melanoma – Global estimates of Mortality



Comments

The elevated incidence in Australia likely reflects sun exposure, particularly in childhood, of a mostly fair-skinned population, plus high cancer detection from raised awareness. The lower elevation in mortality than incidence in Australia compared with the global estimate may reflect the emphasis in Australia on early detection and adherence to recommended treatment protocols to optimise survivals. Five-year survivals in young adults aged 15-29 years at diagnosis are reported to have increased from 93% in 1983-89 to 96% in 2004-10 (i.e. a reduction in mortality of around 43% in the five years from diagnosis) (Appendix B). The emphasis placed on sun protection to reduce incidence may be having an effect. Although elevations in incidence and mortality estimates applied to young Australians, these elevations were not as high as for older Australians.

Australia

Invasive melanoma was the most common cancer reported for AYAs during 1982-2011, accounting for 28% of the reported incidence for all cancers (non-melanoma skin cancers excluded) (Appendix D). According to incidence figures for the last complete decade of 2000-2009, melanoma remained the most common reported cancer (for AYAs overall and for males/females separately) but equated to 23% of all reported cancers, falling to just 17% for the latest period of 2010-11. Melanoma was the sixth most common cause of AYA cancer mortality for the period of 1968-2012 at 6% of all cancers, 6% for the last complete decade 2000-2009 but falling to 4% in 2010-12 (Appendix D).

Table 4- Melanoma - Annual Incidence for 15-24 year olds by decade

Melanoma		Age-adjusted Rates per 100,000 AYAs		
Male & Female		Annual Mean	Lower	Upper
Incidence	Count	Age 15-24	95% CI	95% CI
1982-1989	1925	**9.0**	8.6	9.4
1990-1999	2674	**10.0**	9.6	10.3
2000-2009	2064	**7.4**	7.1	7.7
2010-2011	294	**4.8**	4.2	5.3

Table 5 – Melanoma - Annual Mortality for 15-24 year olds by decade

Melanoma		Age-adjusted Rates per 100,000 AYAs		
Male & Female		Annual Mean	Lower	Upper
Mortality	Count	Age 15-24	95% CI	95% CI
1968-1969	18	**0.43**	0.23	0.63
1970-1979	119	**0.50**	0.41	0.59
1980-1989	110	**0.41**	0.34	0.49
1990-1999	71	**0.26**	0.20	0.33
2000-2009	68	**0.24**	0.19	0.30
2010-2012	11	**0.12**	0.05	0.19

Source: AIHW ACIM 2015

The age-adjusted incidence was approximately 47% lower in 2010-11 than the 1982-89 reference years, with the reduction mostly occurring from 2000 onwards, for males and females collectively (Table 4). There was a higher incidence in female than male AYAs with a decade annual mean age-adjusted rate per 100,000 for females in the 1980s of 10.6 compared to 7.4 for males. Corresponding rates reduced to 5.5 and 4.1 respectively per 100,000 in 2010-11. A higher incidence of melanoma in female AYAs was also reported in a study of melanoma in adolescents and young adults aged 15-39 in the US (11).

Even greater reductions in mortality rates occurred, with the 2010-12 rate being 72% lower than for 1968-69, 76% lower than for the 1970s, 71% lower than for the 1980s, 54% lower than for the 1990s, and 50% lower than for 2000-09. In all decades, with the exception of 2010-12, the mortality rate for males was higher than for females (by approximately 30%). Pronounced reductions in mortality occurred in both sexes, although tending to be larger in males (the 2010-12 rate being 84% lower than for 1968-1969 for males compared with 53% lower for females). Similar findings were reported using UK registry data, with malignant melanoma being more common in young females than males, but with higher mortality rates in males(12).

Comments

Changes in incidence over the study period were marked and mortality reductions were more marked again. The reduction in incidence is welcomed and likely reflects improved sun protection following national campaigns such as Slip, Slop, Slap and SunSmart (13). There is probably also an effects change in susceptibility with changes in the ethnic composition in the Australian population since the 1970s (but particularly during 1980s-90s), with increasing immigration of people from low risk areas such as Asia, the Middle East and the Pacific Islands(14). Incidence rates in older age groups have not fallen to the same extent, which could be partly a result of the higher proportion of high risk people in these age groups (where less immigration from low risk people has taken place).

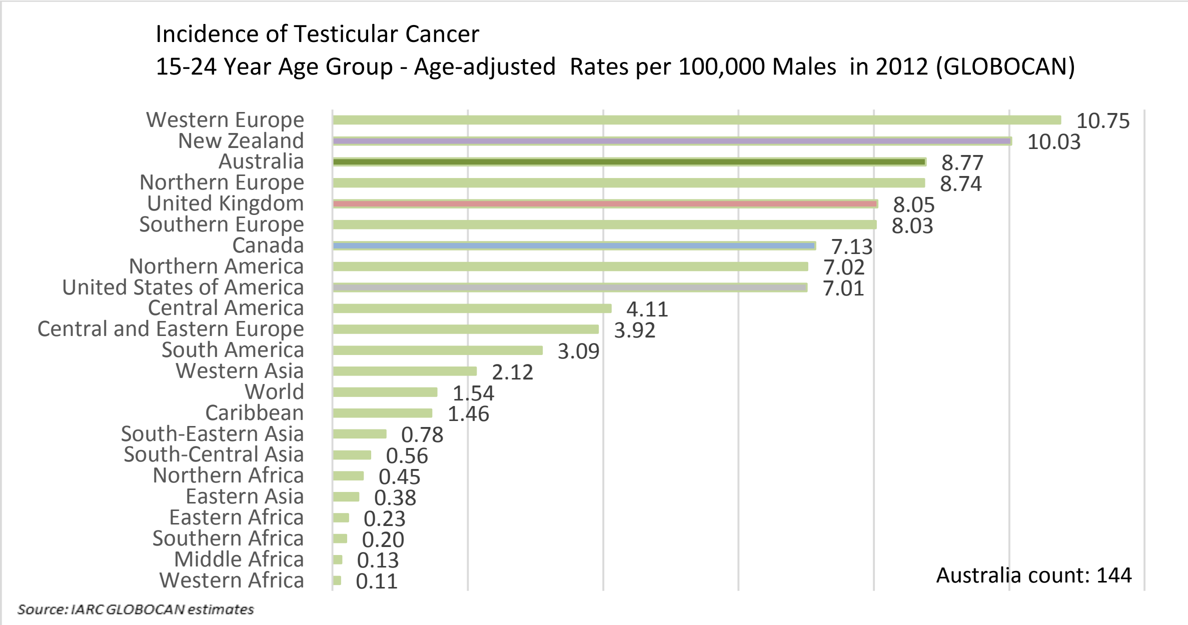
Reasons for the greater mortality than incidence reduction reflect survival gains (Appendix B), possibly resulting from earlier cancer detection and to some extent, new systemic therapies.

AIHW projections of AYA age-adjusted incidence rates (2011-2020) suggest a continued decline in reported invasive melanoma of the skin (particularly for ages 15-19) with a 17% decline for the 15-24 year AYA age group, the largest decline in projected AYA incidence by cancer type. This compares with an estimated 8% and 5% decline for the 0-14 and 25-39 year age groups. Taking account of anticipated increases in the AYA population, this results in a 12% decrease in predicted incidence numbers. AYA deaths resulting from invasive melanoma are extremely low. A decrease of 4% in the age-adjusted mortality rate is predicted between 2013 and 2025.

Testicular Cancer

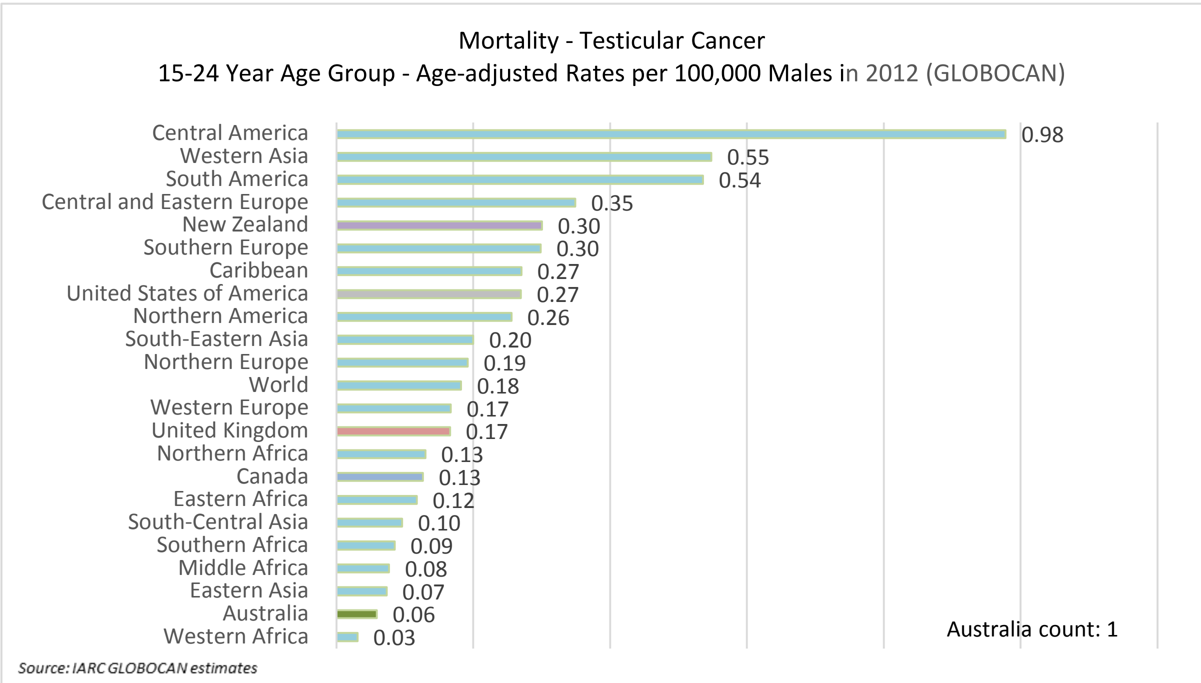
International

Figure 6 - Testicular – Global estimates of Incidence



Australia's incidence estimate (Figure 6) for young males was similar to that for Northern Europe and exceeded only by Western Europe and New Zealand (by 23% and 14% respectively). The Australian incidence was about six times the World figure and higher than that for the UK, Canada and US. Again, the highest estimates applied for European countries, with low rates applying for most Asian and African regions. By comparison, death rates in Australia were at the bottom of the league ladder at about a third of the global estimate and below estimates for New Zealand, the US, UK and Canada (Figure 7). The age-standardised estimates for all ages combined followed a similar pattern (using the World population as the reference population) with the incidence for Australia about 4-5 times the global estimate and the mortality rate only about a third of the corresponding World figure.

Figure 7 - Testicular – Global estimates of Mortality



Comments

The highest rates of testicular cancer have generally been reported for white Caucasian populations (and New Zealand Maoris)(15, 16), with lower rates for African-Caribbean and Asian men(17). Rates have increased in many western industrialized countries (including the US, Canada, UK and other European countries)(18).

An evaluation of trends in incidence in Ontario, Canada over a 30-year period reported an increase in rate of about 60% overall (2% annual increase), with the increase being greatest in 15-29 year olds(19). Similarly high average annual increases were also seen in Denmark, Norway and Sweden.

Research evidence in western countries have shown that although testicular cancer incidence in young boys (0-4 years) has generally remained constant, high average annual increases applied to adolescents (15-19 years) at around 6% per year(20). It suggests that the increase could be due to a secular trend towards earlier age at puberty.

A worldwide review of the increasing incidence of testicular cancer found a birth cohort effect in the US and European countries, although the incidence rates between neighbouring countries varied significantly (Finland 2.5/100,000 cases versus Denmark 9.2/100,000 for all ages) as well as among regions of the same country (2.8 to 7.9/100,000 across various regions of France for all ages)(21).

Despite elevated risks of testicular cancer, young Australians have a comparatively low risk of dying from their cancer.

Mortality rates in Australia were below those in New Zealand, the US, UK and Canada. This may reflect treatment quality in Australia through surgery and adjuvant radiotherapy and/or chemotherapy. Marked increases in five-year survivals have occurred across all age ranges with a 91% five-year survival for 1982-87 increasing to 98% by 2004-10.

Australia

Testicular cancer was the second most common incidence cancer reported for AYA males in Australia (and third overall for males/females combined) for 1982-2011, accounting for 19% of all reported AYA male cancer incidence, second behind melanoma. However, for 2000-09 it was the most commonly reported cancer for AYA males, accounting for 21% of the total count, compared with 19% for melanoma (Appendix D). In contrast, testicular cancer accounted for only 4% of the total number of all AYA deaths for 1968-2012 (6% for males only) but fell to just 1% for the period of 2000-09. It was the 7th most common cause of AYA cancer deaths for males during 1968-2012.

Table 6- Testicular - Annual Incidence for 15-24 year olds by decade

Testicular		Age-adjusted Rates per 100,000 Male AYAs		
Male Only		Annual Mean	Lower	Upper
Incidence	Count	Age 15-24	95% CI	95% CI
1982-1989	499	**4.57**	4.17	4.97
1990-1999	779	**5.69**	5.29	6.09
2000-2009	996	**6.99**	6.55	7.42
2010-2011	237	**7.53**	6.57	8.49

Source: AIHW ACIM 2015

Table 7 - Testicular - Annual Mortality for 15-24 year olds by decade

Testicular		Age-adjusted Rates per 100,000 Male AYAs		
Males only		Annual Mean	Lower	Upper
Mortality	Count	Age 15-24	95% CI	95% CI
1968-1969	27	**1.26**	0.79	1.74
1970-1979	115	**0.95**	0.78	1.12
1980-1989	53	**0.39**	0.29	0.50
1990-1999	26	**0.19**	0.12	0.26
2000-2009	17	**0.12**	0.06	0.18
2010-2012	4	**0.08**	0.00	0.17

Source: AIHW ACIM 2015

The incidence rate was approximately 65% higher in 2010-11 than the 1982-89 reference years, but with this increase occurring progressively through the study period. In contrast, the mortality rate reduced, such that the 2010-12 rate about was 94% lower than for 1968-69, 92% lower than for the 1970s and 79% lower than for the 1980s. The sharply declining mortality, despite the incidence increase, reflects survival gains (Appendix B), are possibly attributed to improvements in surgery and adjuvant therapies.

Comments

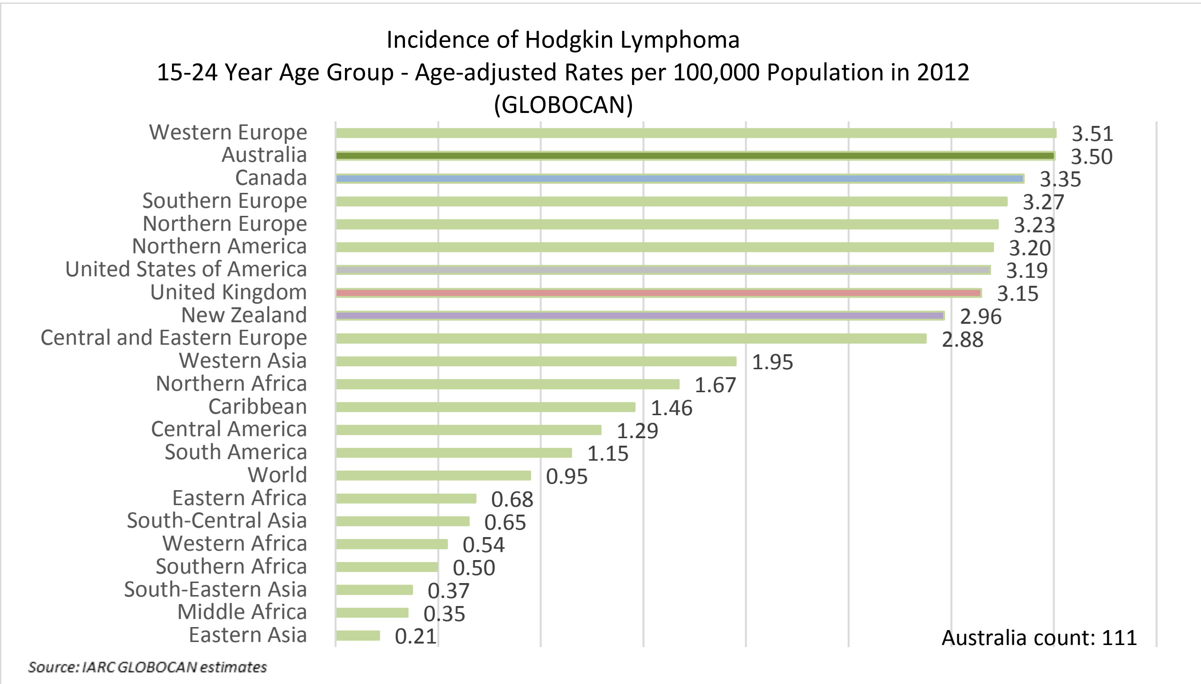
Testicular cancer incidence is strongly related to age but unlike many other cancers, it does not follow a pattern of increasing incidence with age but rises sharply from the age of 15 and peaks in the 30s before declining (22). Reasons for the increasing rates of testicular cancer are unclear, although many hypotheses have been proposed, including trends towards earlier age at puberty, endocrine disrupters, HIV/Aids and height. Failed testicular descent, family history and ethnic grouping (white Caucasian men) are known to increase the risk of testicular cancer. There are no proven measures to prevent testicular cancer.

The AIHW predict a continued increase in the male AYA age-adjusted incidence rate for testicular cancer, with an estimated increase of about 14% between 2011 and 2020. Taking into account projected increases in the AYA population during this period, an approximate 20% increase in the number of patients diagnosed with this cancer is estimated. Given the extremely low mortality rates for this cancer type, numbers are too low to estimate any predicted changes in age-adjusted rates by 2025.

Hodgkin lymphoma

International

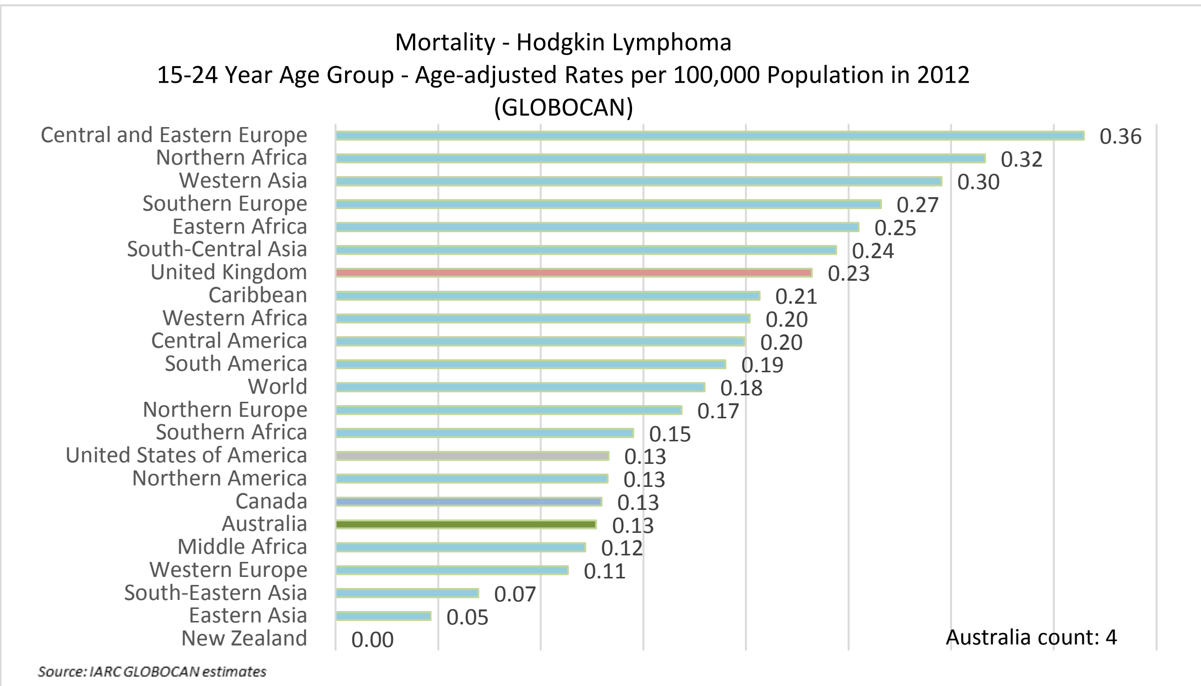
Figure 8 – Hodgkin lymphoma – Global estimates of Incidence



International

Australia's incidence of Hodgkin lymphoma in young people was similar to that estimated for Western Europe, which was about 4 times the global estimate (Figure 8) and higher than estimated for Canada, the US, UK and New Zealand. Again, the highest estimates applied for European countries and other populations of predominantly European extraction. By comparison, the corresponding mortality rate was very low in Australia, with only four deaths estimated for 2012, with a rate below the global estimate and those for the UK, US and Canada (Figure 9). The age-standardised estimates for all ages combined followed a similar pattern, using the World population as the reference population, with the incidence rate for Australia about 167% higher and the mortality rate about 33% lower than the global estimate.

Figure 9 – Hodgkin lymphoma – Global estimates of Mortality



Comments

Despite considerably elevated risks of these cancers in Australia, young Australians and those of all ages have a comparatively low risk of dying from Hodgkin lymphoma.

This may reflect high quality treatment through combined chemotherapy and radiotherapy, or chemotherapy alone, and advances from the use of stem cell transplantation. Marked increases in Australia in five-year survivals have occurred in young adults aged 15-29 years at diagnosis where an increase from 84% in 1983-89 to 97% in 2004-10 has been recorded (Appendix B).

Australia

Hodgkin lymphoma was the second most common AYA cancer reported during 1982-2011, accounting for around 11% of all reported cancer incidence (Appendix D). This percentage increased to approximately 12% for 2000-09 and 14% for the latest period of 2010-11. In terms of mortality, Hodgkin lymphoma was the 8th most common, accounting for 4% of all AYA cancer deaths in 1968-2012 and 2% in 2000-09.

Table 8- Hodgkin lymphoma - Annual Incidence for 15-24 year olds by decade

Hodgkin lymphoma		Age-adjusted Rates per 100,000 AYAs		
Male & Female		Annual Mean	Lower	Upper
Incidence	Count	Age 15-24	95% CI	95% CI
1982-1989	570	**2.66**	2.44	2.88
1990-1999	815	**3.04**	2.83	3.24
2000-2009	1105	**3.96**	3.73	4.19
2010-2011	238	**3.88**	3.38	4.37

Source: AIHW ACIM 2015

Table 9 – Hodgkin lymphoma - Annual Mortality for 15-24 year olds by decade

Hodgkin lymphoma		Age-adjusted Rates per 100,000 AYAs		
Male & Female		Annual Mean	Lower	Upper
Mortality	Count	Age 15-24	95% CI	95% CI
1968-1969	32	**0.77**	0.50	1.03
1970-1979	106	**0.45**	0.36	0.53
1980-1989	70	**0.26**	0.20	0.32
1990-1999	42	**0.16**	0.11	0.20
2000-2009	23	**0.08**	0.05	0.12
2010-2012	9	**0.10**	0.03	0.16

Source: AIHW ACIM 2015

The incidence rate among Australian AYAs was approximately 46% higher in 2010-11 than the 1982-89 reference years, with about a 41% increase occurring in males and 51% increase in females. The male to female age-adjusted incidence ratio is now close to 1 to 1 (Appendix E). UK cancer registry data indicate that Hodgkin lymphoma incidence rates for all ages have remained relatively stable for males but, as in Australia, have increased for females. The trend in the UK for both males and females was a decrease in the 1970s-1980s followed by an increase in the 1990s and 2000s.

The UK trends are said to probably reflect changes in diagnosis, classification and registration practices. Age specific data from Ireland suggest rates in children aged less than 15 years have remained more or less constant, with the greatest increase in incidence observed in 15-34 year old patients during 1994-2011. Females have shown a higher proportion among 15-34 year olds diagnosed with Hodgkin lymphoma than have males(23). The incidence of Hodgkin lymphoma shows a clear bimodal age distribution with the first peak in incidence rates occurring for young adults and the second peak in older men and women.

In contrast, the mortality rate for Hodgkin lymphoma reduced, such that the 2010-12 rate was 87% lower than for 1968-69, 78% lower than for the 1970s and 62% lower than for the 1980s (Appendix B). These improvements in mortality are consistent with international trends. The mortality reduction has tended to be more pronounced for males.

Comments

Reasons for the marked increase in incidence of Hodgkin lymphoma are not known, although it is thought that contributions may be include viral infections (including EBV acquired in adolescence and HIV), increases in obesity, immunosuppressive states, medication (as for example following organ transplantation), marginal effects of secular increases in height and possibly changes in diagnosis/classification. The sharply declining mortality, despite the incidence increase, is due to survival gains (Appendix B), attributed to improvements in systemic therapies and stem cell transplantation, with or without radiotherapy.

Based on AIHW projections of the AYA age-adjusted rates, an approximate 6% mean increase in incidence per 100,000 (2011-2020) in the 15-19 and 20-24 year age groups is expected, with the increase attributed to the younger age band. This would result in the 15-19 and 20-24 year age groups having the highest age-adjusted incidence rate per 100,000 of all ages (although mortality rates are low). Accounting for the predicted increase in AYA population, estimates are of an 11% increase in the number of AYAs diagnosed with Hodgkin lymphoma. Hodgkin lymphoma mortality in AYAs is too low to estimate predicted changes in age-adjusted rates by 2025.

Non-Hodgkin lymphoma

International

Australia's non-Hodgkin lymphoma (NHL) incidence for AYAs tended to be middle-ranking among comparison regions, although exceeding the global estimate by 21%. The rate was lower than estimated for the US, Canada and New Zealand but slightly higher than for the UK. By comparison, the corresponding mortality rate was very low in Australia at about 63% below the global estimate. The ASIR for all ages combined showed a marked elevation in Australia at 2.4 times the global estimate, when using the World population for age standardization. By comparison, the corresponding mortality rate, although raised, was only about 20% higher than the world average.

Figure 10 – Non-Hodgkin lymphoma – Global estimates of Incidence

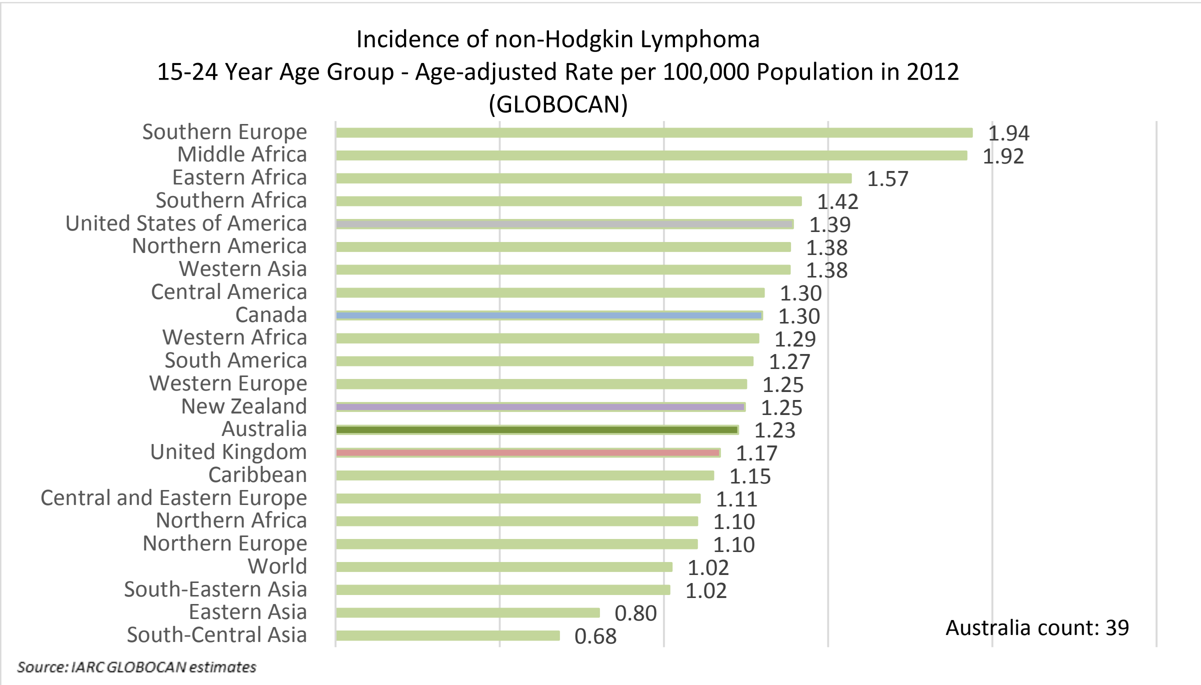
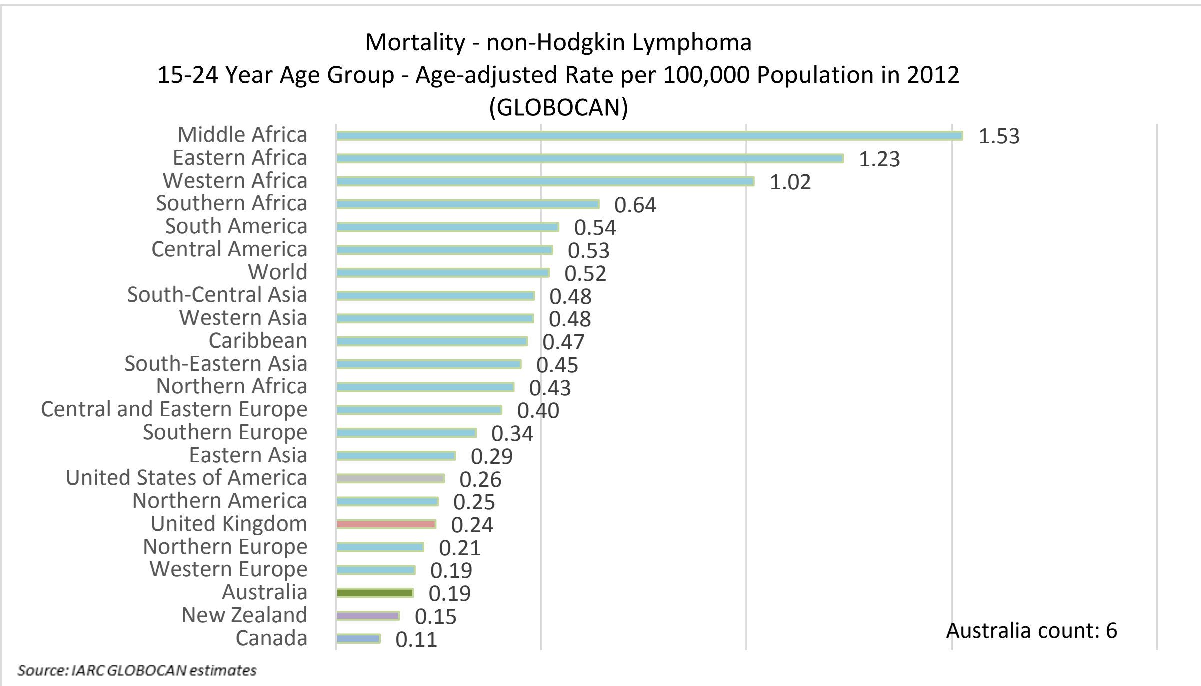


Figure 11 – Non-Hodgkin lymphoma – Global estimates of Mortality



Comments

The lower mortality than incidence ranking for AYA Australians indicates a higher survival than generally applying for other populations. Five-year survival has increased markedly in 15-29 year old Australians from 65% for 1983-89 to 84% for 2004-10 (Appendix B). This is consistent with increases observed for all ages combined from a 47% five-year survival for 1982-87 to a 70% survival for 2004-10. These increases are thought to reflect improved chemotherapy, including high-dose therapies supported by stem cell transplant, plus radiotherapy and biological therapy.

Australia

Non-Hodgkin lymphoma was the fifth most commonly reported AYA cancer accounting for 6% of all incidence cancers reported during 1982-2011, and during 2000-09 (Appendix D). For males and females separately, NHL was the 4th most common reported cancer for each accounting for 8% and 5% of all reported cancers respectively (2000-09). Non-Hodgkin lymphoma accounted for 8% of all AYA cancer deaths (1968-2012), comprising the 5th most common for males/females, but falling to the 6th most common for 2000-09 (Appendix D).

Table 10- Non-Hodgkin lymphoma - Annual Incidence for 15-24 year olds by decade

Non-Hodgkin lymphoma		Age-adjusted Rates per 100,000 AYAs		
Male & Female		Annual Mean	Lower	Upper
Incidence	Count	Age 15-24	95% CI	95% CI
1982-1989	275	**1.28**	1.13	1.44
1990-1999	464	**1.73**	1.57	1.89
2000-2009	573	**2.05**	1.88	2.22
2010-2011	117	**1.91**	1.56	2.25

Source: AIHW ACIM 2015

Table 11 – Non-Hodgkin lymphoma - Annual Mortality for 15-24 year olds by decade

Non-Hodgkin lymphoma		Age-adjusted Rates per 100,000 AYAs		
Male & Female		Annual Mean	Lower	Upper
Mortality	Count	Age 15-24	95% CI	95% CI
1968-1969	22	**0.53**	0.31	0.75
1970-1979	151	**0.63**	0.53	0.74
1980-1989	118	**0.44**	0.36	0.52
1990-1999	131	**0.49**	0.40	0.57
2000-2009	84	**0.30**	0.24	0.37
2010-2012	12	**0.13**	0.06	0.20

Source: AIHW ACIM 2015

The incidence of non-Hodgkin lymphoma increased such that the 2010-11 rate exceeded the 1982-89 reference rate by about 49%. A larger increase was suggested for females than males although the rate for males still remained considerably higher than for females (approximately 62% higher). Increasing incidence rates are evident worldwide and are believed to be partly artificial, reflecting improvements in diagnostics and changes in classification and registration practices.

Despite this incidence increase, the mortality rate reduced, with the 2010-12 rate around 75% lower than for 1968-69, 79% lower than for the 1970s and 70% lower than for the 1980s. A larger mortality reduction was suggested for males than females. Five year survival rates for 15-29 year old Australians have increased from 65% for the 1983-1989 to 84% for 2004-2010.

The number of AYA people diagnosed with non-Hodgkin lymphoma was around half that for Hodgkin lymphoma for 1982-2011 (1429 compared with 2,728 respectively). However, the number of deaths from non-Hodgkin lymphoma was higher than for

Hodgkin lymphoma (i.e. 518 compared with 282 for 1968-2012). The percentage increase in incidence rate for non-Hodgkin lymphoma was slightly higher than for Hodgkin lymphoma (60% from the 1980s to 2000s compared with 49%). Meanwhile mortality rates for Hodgkin lymphoma fell by around 69% for the same period compared with 32% for non-Hodgkin lymphoma.

Comments

Reasons for the marked increase in incidence of non-Hodgkin lymphoma are not known. A broad range of contributing factors have been considered, including chronic antigenic stimulation, immune suppression, autoimmunity, immunodeficiencies, viral and bacterial infections, and exposures to chemicals, herbicides and hair dyes. Blood transfusions have also been raised as a possible cause. The divergent incidence and mortality trends are consistent with reported survival gains (Appendix B) which are attributed to improved chemotherapy, including high-dose therapies, supported by with stem cell transplant, plus radiotherapy and new biological therapies.

AIHW projections of AYA age-adjusted incidence rates (2011-2020) indicate an approximate 6% increase, attributed to the 20-24 year age group. This compares with no change for the 0-14 year age group and a decrease of about 11% for the 25-39 year age group. Applying increasing populations suggests an overall approximate 12% increase in the number of AYAs diagnosed with NHL by 2020. A decline in the age-adjusted mortality rates is predicted for all age groups (2013-2025), including AYAs (at about 16%, although numbers are very low).

Leukaemia

International

Australia's leukaemia incidence for young people was similar to that estimated for Southern Europe and South America and only slightly higher (9% higher) than the global estimate. Comparisons by country indicated that Australia had a higher age-adjusted incidence than Canada, the UK and New Zealand but lower than for the US. The corresponding mortality rate for Australia was at the very low end of the scale at about 62% below the global estimate and below the mortality rates for the US, Canada, the UK and New Zealand. The age-standardised estimate for all ages combined followed a different pattern, using the World population as the reference population for age standardization. Although the incidence estimate for Australia was about twice the global estimate, the mortality rate estimate was about the same (i.e. about 3% higher).

Figure 12 – Leukaemia – Global estimates of Incidence

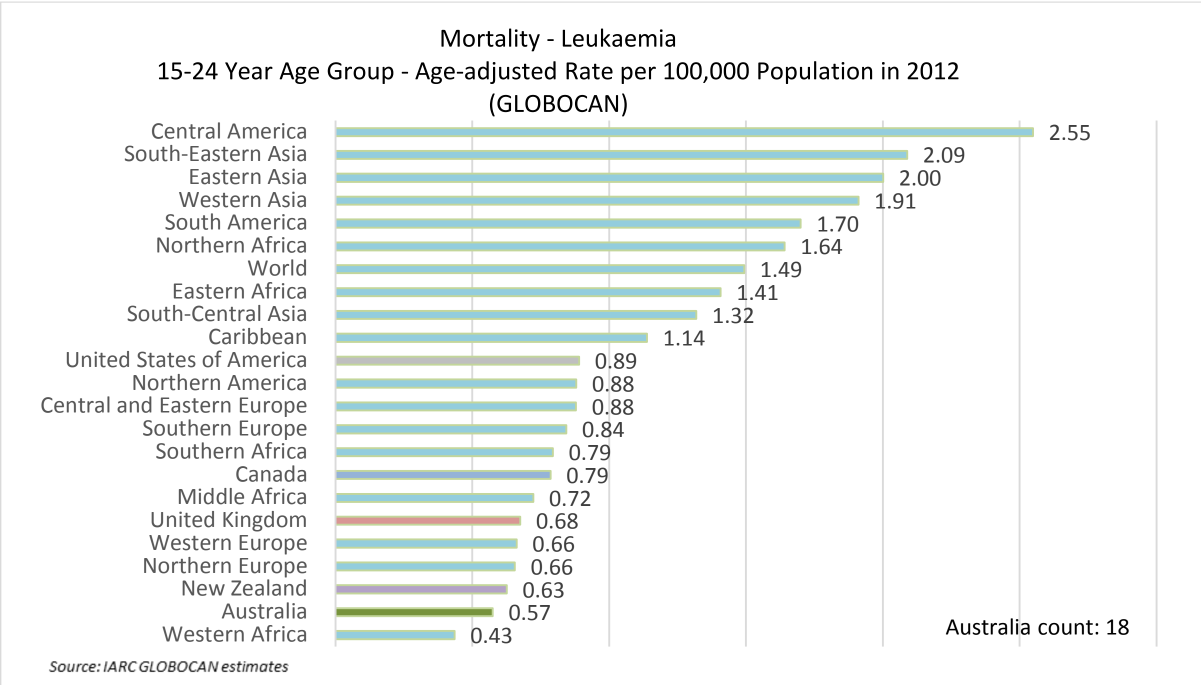
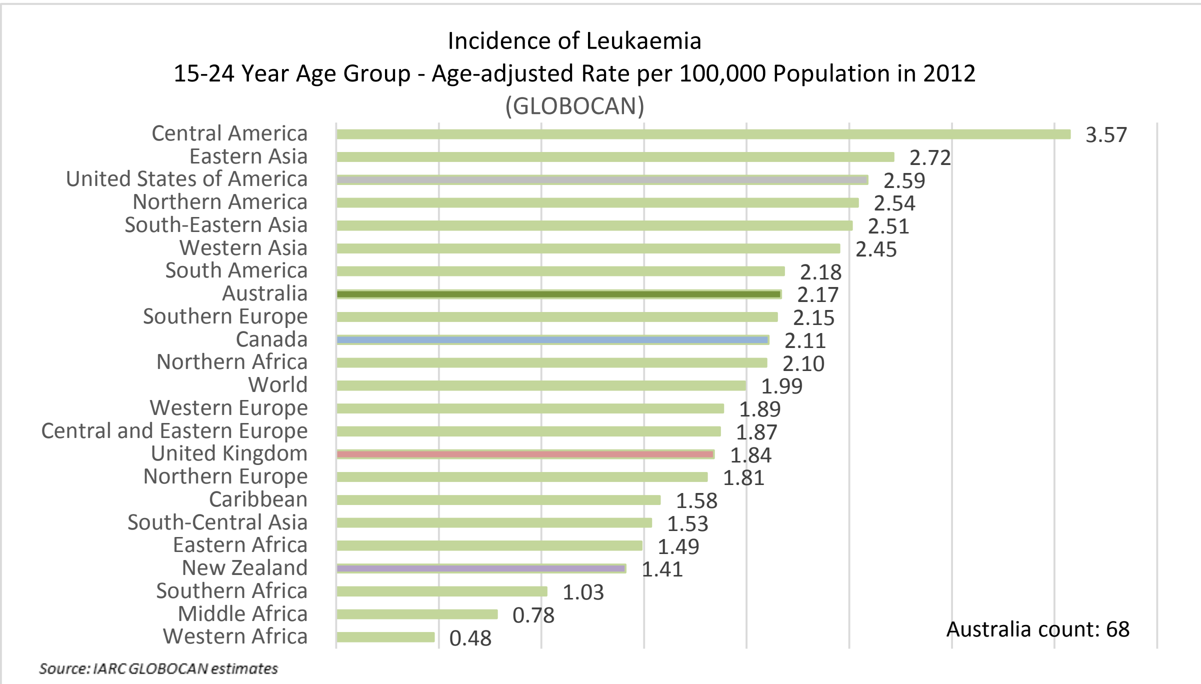


Figure 13 – Leukaemia – Global estimates of Mortality



Comments

Despite a marginally elevated incidence of leukaemias in young Australians, they have a comparatively low risk of dying from their cancer. This may reflect high quality treatment through chemotherapy, supported in selected cases by bone-marrow transplantation. A marked increase in five-year survival has occurred in young adults aged 15-29 years at diagnosis (from 36% in 1983-89 to 68% in 2004-10), with equivalent gains recorded for ALL and AML (Appendix B).

Australia

With 926 incidence cases diagnosed between 1982 and 2011, acute lymphoblastic leukaemia (ALL) was the 8th most common AYA cancer reported in Australia, accounting for 4% of all reported AYA cancers (it remained at 4% of all reported AYA cancers in 2000-09). Acute myeloid leukaemia (AML) was the 9th most common reported AYA cancer, at 3% of all reported AYA cancers during 1982-2011. When incidence data for ALL and AML are combined, they represent the 4th most commonly reported AYA cancer

In contrast, ALL was the leading cause of AYA cancer deaths, accounting for about 13 % of deaths in 1968-2012, and the same proportion for subsequent periods but no longer the leading cause (Appendix D). Among male AYAs, ALL was the leading cause of cancer death with AML ranked 4th. However, the converse was seen in females with a higher proportion of AYA deaths resulting from AML than ALL (2nd and 3rd most common cause of AYA cancer deaths respectively after brain cancer).

Table 12- Acute lymphoblastic leukaemia - Incidence for 15-24 year olds by decade

ALL		Age-adjusted Rates per 100,000 AYAs		
Male & Female		Annual Mean	Lower	Upper
Incidence	Count	Age 15-24	95% CI	95% CI
1982-1989	218	**1.02**	0.88	1.15
1990-1999	322	**1.20**	1.07	1.33
2000-2009	319	**1.14**	1.02	1.27
2010-2011	67	**1.10**	0.83	1.36

Source: AIHW ACIM 2015

Table 13 – Acute lymphoblastic leukaemia - Annual Mortality for 15-24 year olds by decade

ALL		Age-adjusted Rates per 100,000 AYAs		
Male & Female		Annual Mean	Lower	Upper
Mortality	Count	Age 15-24	95% CI	95% CI
1968-1969	25	**0.60**	0.36	0.83
1970-1979	173	**0.73**	0.62	0.83
1980-1989	239	**0.90**	0.78	1.01
1990-1999	221	**0.82**	0.71	0.93
2000-2009	148	**0.53**	0.44	0.62
2010-2012	40	**0.43**	0.30	0.57

Source: AIHW ACIM 2015

Table 14- Acute myeloid leukaemia - Annual Incidence for 15-24 year olds by decade

AML		Age-adjusted Rates per 100,000 AYAs		
Male & Female		Annual Mean	Lower	Upper
Incidence	Count	Age 15-24	95% CI	95% CI
1982-1989	167	**0.78**	0.66	0.90
1990-1999	259	**0.96**	0.85	1.08
2000-2009	298	**1.07**	0.95	1.19
2010-2011	62	**1.01**	0.76	1.27

Source: AIHW ACIM 2015

Table 15 – Acute myeloid leukaemia - Annual Mortality for 15-24 year olds by decade

AML		Age-adjusted Rates per 100,000 AYAs		
Male & Female		Annual Mean	Lower	Upper
Mortality	Count	Age 15-24	95% CI	95% CI
1968-1969	36	**0.86**	0.58	1.14
1970-1979	195	**0.82**	0.70	0.93
1980-1989	182	**0.68**	0.58	0.78
1990-1999	139	**0.52**	0.43	0.60
2000-2009	105	**0.38**	0.30	0.45
2010-2012	24	**0.26**	0.16	0.36

Source: AIHW ACIM 2015

The incidence rate for ALL remained relatively constant, although with suggestions of upward trends from the 1982-89 reference years to 2010-11. The incidence rate for ALL, although rising in the 1990s, was similar in 2010-11 to 1982-89. Higher incidence rates were evident in males than females with a decade annual mean adjusted rate per 100,000 for males in the 1980s of 1.37 compared to 0.66 per 100,000 for females, and with these rates increasing to 1.60 per 100,000 for the period of 2010-11 for males and decreasing to 0.57 per 100,000 for females. A clearer upward trend was evident in AML with incidence rates increasing by about 30% from the reference years of 1982-1989 to 2010-11. Similar rates and increases were seen between males and females. There were too few instances of chronic lymphatic leukaemia or chronic myeloid leukaemia to reveal trends (note: the combined total number of these AYA cancers was 266 between 1982 and 2011, representing just 1% of the total AYA cancer incidence).

AYA ALL mortality appeared to increase during the 1980s and 1990s before falling in the periods of 2000-09 and 2010-11. The 2010-12 ALL mortality rate was approximately 28% lower than the 1968-1969 rate, 52% lower than for the 1980s and 48% lower than for the 1990s. The higher incidence in AYA males led to double the number of deaths as in females.

There were much more marked reductions suggested for AML mortality, however, such that the 2010-12 mortality rate was about 70% lower than for 1968-69, 68% lower than for the 1970s and 62% lower than for the 1980s. Mortality in males was similar to that in females. Too few deaths were available to assess mortality trends for chronic lymphatic leukaemia (CLL) or chronic myeloid leukaemia (CML). Note: 98 AYA CLL or CML deaths occurred in total between 1968 and 2012.

Comments

The marked mortality decline despite no corresponding incidence decline, particularly for AML, is indicative of survival gains (Appendix B), which are attributed to improvements in systemic therapies, supported in selected cases by bone marrow transplantation. AIHW data on incidence projections are not available for ALL or AML. For mortality, it is predicted that the age-adjusted rate per 100,000 AYAs for ALL will continue to decline by a further approximate 18% by 2025 (mainly in the 20-24 year old age group). Greater declines in mortality are anticipated for children (0-14 years) and no change for adults aged 25-39 years. Declines in mortality are also predicted for AML, at about 11% for AYAs (compared with 8% for the 0-14 and 16% for the 25-39 year age groups).

Brain & Nervous System Cancer

International

Australia's invasive brain cancer incidence for AYAs tended to be lower than for North America and Europe (including the US, Canada and UK) but about 44% higher than the global estimate and 20% higher than for New Zealand. Again, the highest mortality estimates applied for European countries and other regions of predominantly European extraction. By comparison, the corresponding mortality rate was very low in Australia at about 19% below the global estimate and 30% below New Zealand.

The age-standardised estimate for all ages combined followed a similar pattern for incidence (using the World population as the reference for age standardization), with the Australian incidence about 59% higher than the global estimate. The mortality pattern for all ages combined differed from that for young people, however, in that the mortality rate estimate was about 56% higher than the global estimate.

Figure 14 – Brain – Global estimates of Incidence

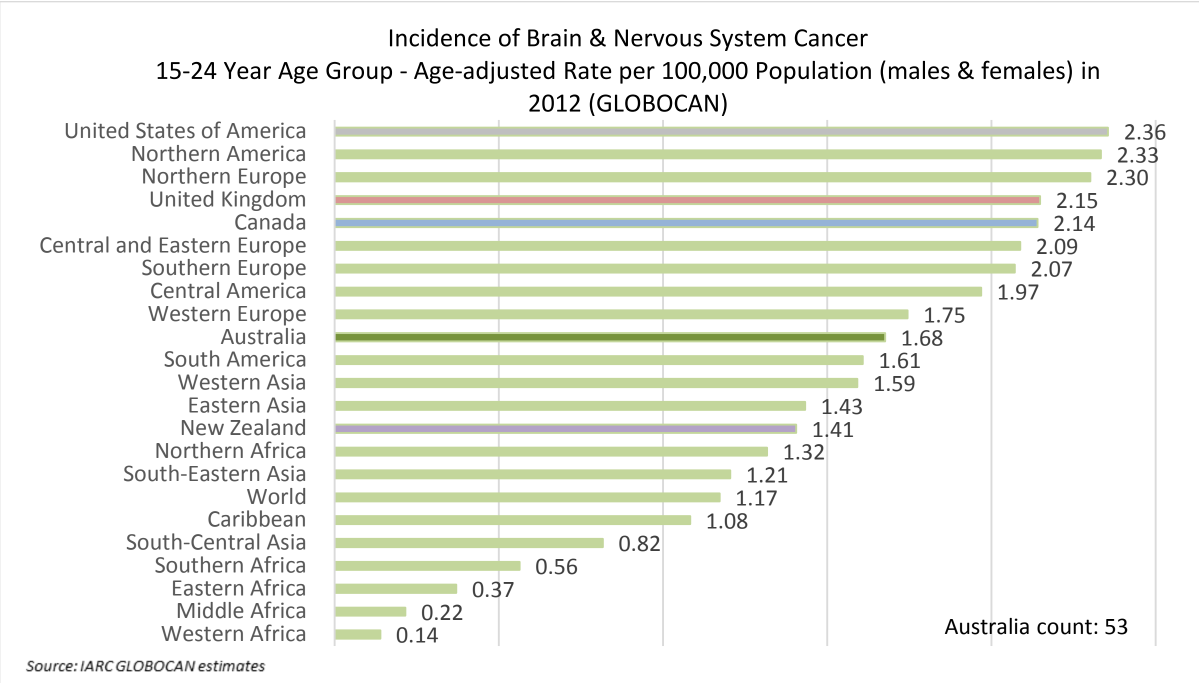
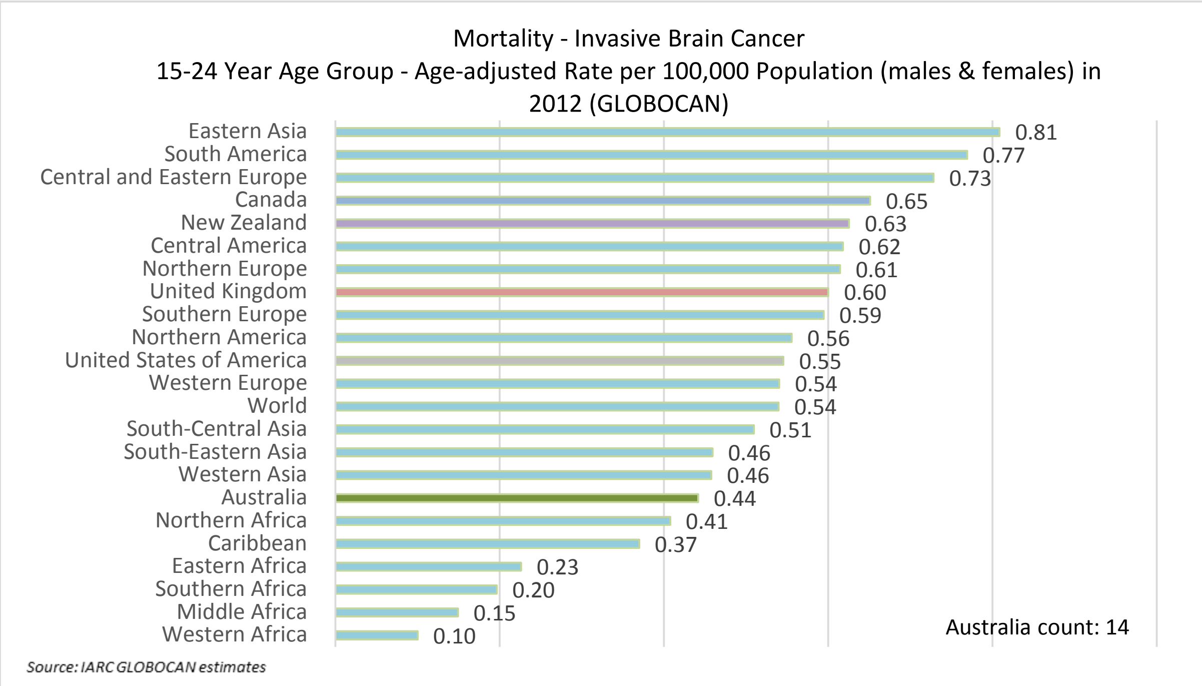


Figure 15 – Brain – Global estimates of Mortality



Comments

Despite considerably elevated risks of brain cancers, young Australians have a comparatively low risk of dying from this cancer. There is little evidence of secular gains, however, with five-year survivals of 65% for 1983-89 and 66% for 2004-10 (Appendix B). Similarly there is little evidence of gains in survival for all ages combined, with five-year survivals in the 19% to 22% range between 1982-87 and 2004-10.

Australia

Between 1982 and 2011, there were 1,332 reported newly diagnosed AYA brain cancers. They represented 5% of all AYA cancers in Australia in this period and in 2010-2011. Brain cancer was the 6th most common AYA cancer by incidence for males/females, 5th for males and 4th for females (Appendix D). However, brain cancer was the second leading cause of all AYA cancer deaths, behind ALL (note: it was the leading cause for females and third leading cause for males). Brain cancer accounted for around 12% of all AYA cancer deaths from 1968-2012 and 13% of AYA cancer deaths in 2000-09. The latest data for the three year period 2010-12 suggest brain cancer now accounts for approximately 15% of all reported AYA cancer mortality.

Table 16- Brain - Annual Incidence for 15-24 year olds by decade

Brain		Age-adjusted Rates per 100,000 AYAs		
Male & Female		Annual Mean	Lower	Upper
Incidence	Count	Age 15-24	95% CI	95% CI
1982-1989	367	**1.71**	1.54	1.89
1990-1999	458	**1.71**	1.55	1.86
2000-2009	416	**1.49**	1.35	1.63
2010-2011	91	**1.49**	1.18	1.79

Source: AIHW ACIM 2015

Table 17 – Brain - Annual Mortality for 15-24 year olds by decade

Brain		Age-adjusted Rates per 100,000 AYAs		
Male & Female		Annual Mean	Lower	Upper
Mortality	Count	Age 15-24	95% CI	95% CI
1968-1969	25	**0.60**	0.36	0.83
1970-1979	173	**0.73**	0.62	0.83
1980-1989	239	**0.90**	0.78	1.01
1990-1999	221	**0.82**	0.71	0.93
2000-2009	148	**0.53**	0.44	0.62
2010-2012	40	**0.43**	0.30	0.57

Source: AIHW ACIM 2015

Incidence and mortality rates for brain cancers were broadly similar in 2010-11 to the reference 1968-69 years, although possibly a little lower, particularly in females. Trends in mortality suggest an increase in age-adjusted mortality during the 1970s and 1980s before a slight decline since. This reflects relatively stable survivals.

Comments

Both incidence and mortality rates for AYA brain cancer have remained relatively constant over recent decades, as has survival. The mortality to incidence ratio (Appendix E) for brain cancer is high at 0.36, the third highest after Bone and ALL, and equal to that of AML.

Exposure to radiation is a risk factor for brain cancer but causes are largely unknown. Other possible causes include previous cancers, genetic conditions and family history, other medical conditions, medicines and body weight.

Based on AIHW projections, an increase in the age-adjusted incidence rate for the over 75 age group is predicted between 2011 and 2020. No change in incidence rates are expected for all other age groups with the exception of the 10-14 and 15-19 years where a decrease in the rates of around 7-8% is estimated. Taking into account increases in population during this period, the proposed number of AYA diagnosis by 2020 will be similar to 2011. For mortality, declining AYA age-adjusted mortality rates are expected, particularly in the 20-24 year age group but, combined with 15-19 year olds, this decline is small (about 3%). Mortality rates are also expected to fall for the 10-14 and 25-39 year age groups, by around 10%.

Bone Cancer

International

International AYA data on bone cancer are not available from GLOBOCAN. Age-adjusted incidence rates for Australia appear to be slightly higher than published for the UK for AYA ages. The Australian age-adjusted rate for 15-24 year old males was around 1.59 per 100,000 (2010-11) compared with 1.45 per 100,000 for the UK (2009-11) (source: CRUK). For females, the Australian AYA age-adjusted rate was 0.77 per 100,000 compared with 0.65 per 100,000 for the UK. A higher age-adjusted mortality rate was evident in Australian males at 0.83 per 100,000 compared with a corresponding 0.70 per 100,000 for the UK (2010-12). For females, the corresponding Australian and UK rates were 0.42 per 100,000 and 0.40 per 100,000 respectively.

Australia

Bone cancer was the 7th most common AYA cancer reported between 1982 and 2011, with 970 cancers notified (Appendix D). This accounted for approximately 4% of all reported AYA cancers (note: this proportion remained at 4% for 2000-09). By comparison, bone cancer was the third most common cause of AYA cancer death, accounting for about 12% of these deaths in 1968-2012. Its ranking increased, such that it was the most common cause of AYA cancer death in 2000-09 and 2010-12, accounting for 14% and 19% of cancer deaths respectively (Appendix D).

Table 18- Bone - Annual Incidence for 15-24 year olds by decade mean

Bone		Age-adjusted Rates per 100,000 AYAs		
Male & Female		Annual Mean	Lower	Upper
Incidence	Count	Age 15-24	95% CI	95% CI
1982-1989	249	**1.16**	1.02	1.31
1990-1999	313	**1.17**	1.04	1.29
2000-2009	335	**1.20**	1.07	1.33
2010-2011	73	**1.19**	0.92	1.46

Table 19 – Bone - Annual Mortality for 15-24 year olds by decade

Bone		Age-adjusted Rates per 100,000 AYAs		
Male & Female		Annual Mean	Lower	Upper
Mortality	Count	Age 15-24	95% CI	95% CI
1968-1969	35	**0.84**	0.56	1.11
1970-1979	164	**0.69**	0.58	0.79
1980-1989	189	**0.71**	0.61	0.81
1990-1999	153	**0.57**	0.48	0.66
2000-2009	157	**0.56**	0.47	0.65
2010-2012	58	**0.63**	0.47	0.79

Source: AIHW ACIM 2015

The age-adjusted incidence rate was relatively unchanged over the period of analysis, being approximately 3% higher in 2010-11 than 1982-89 (3% higher for males and 1% higher for females). The incidence of bone cancer in AYA males was significantly higher than in females (1.45 and 0.77 per 100,000 respectively), which gave a similar male/female ratio to that seen in the UK.

Mortality rates also remained relatively constant, with around a 9% reduction in the 2010-12 rate compared to rates in the 1970s (both for males and females). The age-adjusted mortality rate for males was double that of females (0.83 compared with 0.42 per 100,000 AYAs, 2010-12), again giving a similar male/female ratio to that seen in the UK.

Five-year survivals for 15-29 year olds with bone cancer increased only marginally, from 63% for 1983-89 to 66% in 2004-10 (Appendix B).

Bone cancer incidence is strongly related to age but unlike many cancers, it does not follow a pattern of increasing incidence with age. Rather, like Hodgkin lymphoma, a bimodal age distribution presents, with a small peak in incidence in young people aged 10-24 years (particularly in the 15-19 year age group) followed by a decline and then a second higher peak in older men and women. Age-adjusted mortality rates show a similar pattern with a peak in deaths in 15-19 year olds and a secondary peak in older
age groups.

Comments

The incidence of bone cancer has remained relatively constant over the last 3-4 decades, as has mortality rates. This is consistent with observations in other parts of the world, including the United Kingdom, particularly for the AYA age group. However, the mortality to incidence ratio, based on age-adjusted rates for AYAs, is one of the highest of all cancers at 0.46 (equal to that of ALL), as indicated by 2000-09 data (Appendix E). Notably, as a proportion of all AYA cancer deaths in Australia, bone cancer deaths are increasing. The risk factors associated with bone cancer are unclear. CRUK suggests that less than 1% of bone sarcoma cases each year in the UK are linked to major lifestyle and other investigated risk factors. The evidence for associated risk factors is limited due to the rare nature of bone cancer and its many subtypes. It is suggested that some forms of ionising radiation, previous cancer treatment, larger body size and certain medical conditions may relate to higher risk, and that the peak in incidences in adolescents could be due to rapid bone growth at this age.

AIHW data on incidence projections are not available for bone cancer. Age-adjusted mortality rates, for all ages with the exception of the over 85s, are expected to remain constant or decline. For the under 45s, declines are predicted in the 10-14 and 15-19 year age groups. When projected increases in AYA populations are applied, an increase of approximately 7% in the number of AYA deaths is estimated (2013-2025).

Other Soft Tissue Cancer

International

GLOBOCAN international AYA specific data are not available for "other soft tissue cancers". AYA age-adjusted incidence rates appear to be lower in Australia than in the UK however. Incidence data reported by CRUK indicate a male AYA age-adjusted incidence of 1.39 per 100,000 (2008-10) compared with 0.95 per 100,000 in Australia (2010-11). For females, the corresponding figures are 1.29 and 0.97 per 100,000 respectively.

Australia

Other soft tissue cancers represents the 10th most commonly reported AYA cancer in Australia, with 773 cases notified between 1982 and 2011 (note: 3% of all AYA cancer notifications). It was also the 10th most commonly notified cancer in 2000-9 but the 11th for the latest period of 2010-11, after colorectal. In contrast, it was the 7th most common cause of cancer death between 1968 and 2012 and the 5th for 2000-09, the latter representing 8% of all AYA cancers deaths.

Table 20- Other Soft Tissue - Annual Incidence for 15-24 year olds by decade

Other Soft Tissue		Age-adjusted Rates per 100,000 AYAs		
Male & Female		Annual Mean	Lower	Upper
Incidence	Count	Age 15-24	95% CI	95% CI
1982-1989	173	**0.81**	0.69	0.93
1990-1999	271	**1.01**	0.89	1.13
2000-2009	270	**0.97**	0.85	1.08
2010-2011	59	**0.96**	0.71	1.21

Source: AIHW ACIM 2015

Table 21 – Other Soft Tissue - Annual Mortality for 15-24 year olds by decade

Other Soft Tissue		Age-adjusted Rates per 100,000 AYAs		
Male & Female		Annual Mean	Lower	Upper
Mortality	Count	Age 15-24	95% CI	95% CI
1980-1989	82	**0.31**	0.24	0.37
1990-1999	96	**0.36**	0.29	0.43
2000-2009	96	**0.34**	0.28	0.41
2010-2012	23	**0.25**	0.15	0.35

NB: Other Soft Tissue mortality data only available since 1979 Source: AIHW ACIM 2015

The age-adjusted incidence rate was approximately 19% higher for AYAs in 2010-11 than for the 1982-89, but remained relatively stable between 2000-09 and 2010-11. While incidence rates were higher for males during the 1980s-90s, the rates since then have been equivalent or higher for female AYAs. The 2010-11 rates were 0.95 per 100,000 for males compared with 0.97 per 100,000 for females. It is uncertain whether the increases reported in incidence since the 1980s is real or an artefact due to increased awareness/diagnosis and reporting.

Unlike other cancers, mortality data for these soft tissue cancers has only been available for Australia since 1979. Mortality rates since the 1980s have remained relatively constant, although they appear to have fallen in 2010-12 (Table 21). Further data for this last decade will be required to confirm this trend.

Comments

Unlike bone cancer, other soft tissue cancers do not show a bimodal pattern of incidence. Incidence increases with age (following a small peak in children under the age of 4 years). These soft tissue cancers comprise varying types, some of which are more prominent in AYAs. Incidence data by type of soft tissue cancer are not readily available for Australia. However, data from the UK National Cancer Intelligence Network suggest that rhabdomyosarcoma is more common in children and adolescents, whereas synovial sarcoma has a higher incidence in young adults. Leiomyosarcoma and liposarcoma are more common in older age groups.

The mortality to incidence ratio for these soft tissue cancers is the 5th highest for all AYA cancers at 0.35 (2000-09), lower than for ALL, bone cancer, AML and brain cancer (Appendix E). This is due to relatively low survivals when compared with other common cancers. Notably the ratio experienced some improvement since the 1980s, particularly for 2010-12. More data for this decade are required to confirm this recent trend.

The risk factors associated with soft tissue cancers are not fully known due to the rare nature of the cancer comprising of many subtypes. Only a very small proportion of incidence cases are believe to be linked to lifestyle. Possible risk factors may include exposure to chemicals, previous radiation treatment for cancer and viruses (such as Human Immunodeficiency Virus and Kaposi Sarcoma Herpes Virus).

AIHW data on incidence projections are not available for "other soft tissue cancer". Age-adjusted mortality rates, for all ages with the exception of the over 85s, are expected to remain constant or decline. For the under 45s, a small decline in the mortality rates (2013-25) is predicted for the 25-29 age group with no change in age-adjusted rates for other age groups. However, with increasing populations, increase in the number of deaths from other soft tissue cancers is still expected.

Thyroid Cancer

International

International AYA data on thyroid cancer are not available from GLOBOCAN. There is recognition worldwide, however, that thyroid cancer is increasing in many countries, including the US, Canada, UK, France, Italy, and Spain, and that this trend is often more pronounced in women and young people. According to CRUK, the thyroid AYA age-adjusted rate per 100,000 for UK males is 0.65 per 100,000 (2009-11) as compared with 2.4 per 100,000 for females. Corresponding rates for Australia are 1.23 and 3.55 per 100,000 respectively (2010-11). Mortality remains low worldwide.

Australia

Thyroid cancer was the 4th most commonly notified AYA cancer between 1982 and 2011 (1,532 cases notified) (Appendix D). Of these cases, 1,214 affected AYA females. Thyroid cancer accounted for 6% of all AYA cancers notified, increasing to 8% of the total for 2000-09. Mortality was extremely low however (the 29th ranked AYA cancer), with only 10 deaths applying between 1968 and 2012.

Table 22- Thyroid - Annual Incidence for 15-24 year olds by decade

Thyroid		Age-adjusted Rates per 100,000 AYAs		
Male & Female		Annual Mean	Lower	Upper
Incidence	Count	Age 15-24	95% CI	95% CI
1982-1989	292	**1.36**	1.21	1.52
1990-1999	430	**1.60**	1.45	1.75
2000-2009	665	**2.38**	2.20	2.56
2010-2011	145	**2.36**	1.97	2.74

Source: AIHW ACIM 2015

Table 23 – Thyroid - Annual Mortality for 15-24 year olds by decade

Thyroid		Age-adjusted Rates per 100,000 AYAs		
Male & Female		Annual Mean	Lower	Upper
Mortality	Count	Age 15-24	95% CI	95% CI
1968-1969	3	**0.07**	0.00	0.15
1970-1979	1	**0.00**	0.00	0.01
1980-1989	2	**0.01**	0.00	0.02
1990-1999	3	**0.01**	0.00	0.02
2000-2009	1	**0.00**	0.00	0.01
2010-2012	0	**0.00**	0.00	0.00

Source: AIHW ACIM 2015

Australian AYA data show an increasing age-adjusted incidence of 74% between 1982-89 and 2010-11, with increases affecting both males and females. The incidence rate for females was three to four times that for males throughout the study period. For 2010-11, the female rate per 100,000 was 3.55 compared with 1.23 per 100,000 for males.

In contrast, mortality rates are extremely low with only 10 AYA deaths presenting in Australian AYAs between 1968 and 2012. This reflected the extremely high case survivals. The five year survival increased slightly from 98.5% for 1983-89 to 99.8% for 2004-10 (Appendix B).

Comments

The pronounced increase in thyroid cancer incidence in Australia accords with international trends, as does the much higher incidence in females. Reports indicate that around 80% of thyroid cancers in AYAs are reported in females in the UK(24, 25), US(26) and Australia.

The reasons for the rapid increase in incidence are thought to include greatly increased detection (including incidental detection during unrelated ultrasound and imaging). Possible risk factors for thyroid cancer are thought to include exposure to female hormone factors (possibly including increasing abortions/miscarriages), radiation exposure (particularly in childhood), iodine supplementation and family history.

AIHW projections of the age-adjusted incidence rates (per 100,000) for thyroid cancer, both males and females (mean), suggests an increase of around 25-44% for Australians aged between 30 and 80 years of age (2011-2020). A higher increase is anticipated for females than males. However, for the under 30 age groups, no change in the age-adjusted rate is expected, with the exception of AYAs aged 20-24 years where a decline is predicted (about 26%). Further data will be required to confirm this decrease which is not in line with trends in thyroid incidence in the AYA age groups in Australia or globally over the last 30 years.

A clear time trend did not present for mortality given exceeding low numbers and no change in the age-adjusted rate is anticipated by 2025, for all age groups.

Colorectal Cancer

International

Australia has a very high colorectal cancer incidence and mortality, which also applies to young people where the incidence estimate is second only to that for Western Europe, about 51% higher than the global estimate and higher than for Canada, the UK, New Zealand and the US. By comparison the corresponding mortality rate for Australia was about 24% lower than the global estimate, although still higher than for New Zealand, the US, Canada and the UK. For all ages combined, the ASIR estimate for Australia was about 2.2 times the global estimate, whereas the corresponding elevation in mortality rate was only about 8%.

Figure 16 – Colorectal – Global estimates of Incidence

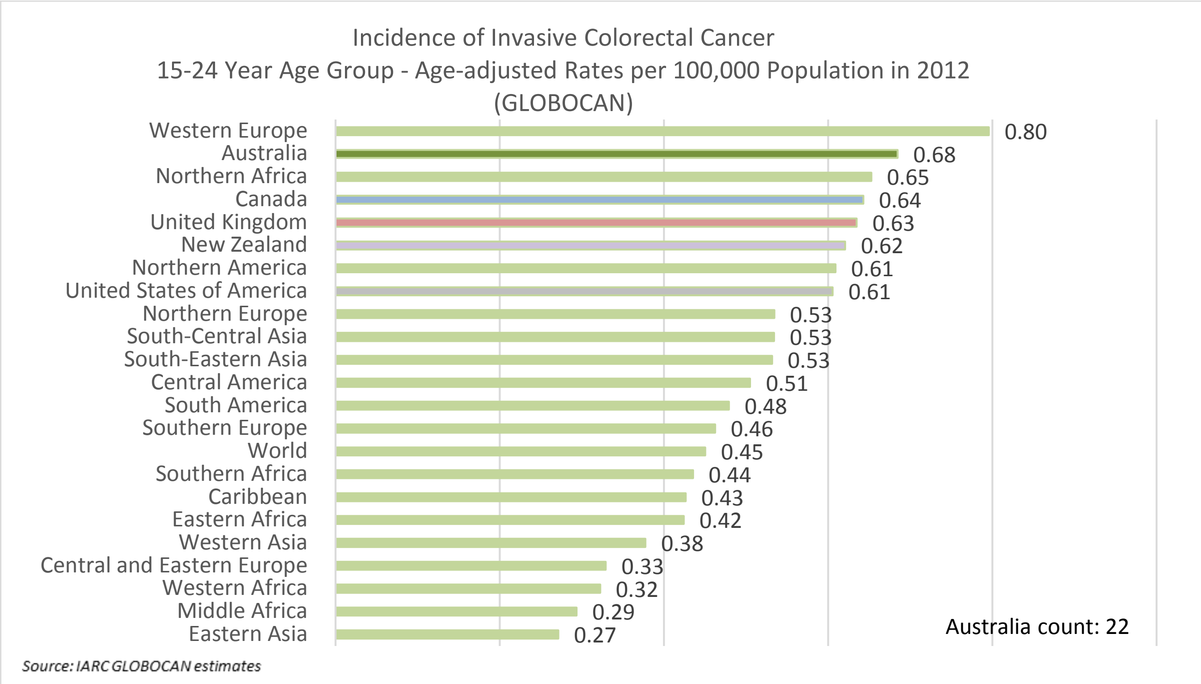
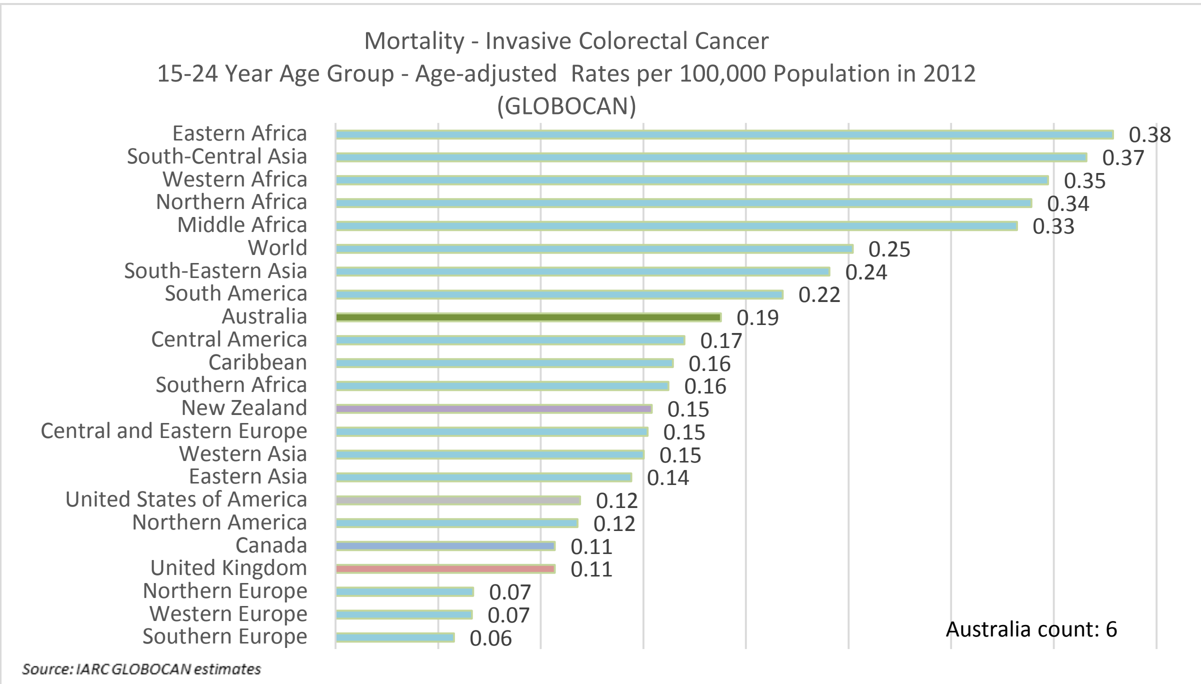


Figure 17 – Colorectal – Global estimates of Mortality



Comments

The markedly higher world ranking of incidence than mortality estimates for Australia, irrespective of age, are due to high colorectal cancer survivals in Australia. Five-year survivals for 15-29 year olds increased from 62% for 1983-89 to 72% for 2004-10 (Appendix B). For all ages combined, the five-year survivals increased from 48% for 1982-87 to 65% for 2004-10. This is mostly attributed to gains from adjuvant therapies for non-localised disease and increased surgical specialization.

Australia

Colorectal cancer was the 12th most commonly notified AYA cancer (1982-2011) with 550 notified cases (Appendix D). They accounted for 2% of all notified AYA cancers, increasing to 3% of the total for 2000-09. Mortality was also the 10th highest (1968-2012) but this increased to the 8th highest for 2000-09 (accounting for 4% of AYA cancer deaths). Initial data for the latest decade (2010-2012) show colorectal now as the 6th most common cause of AYA cancer death.

Table 24- Colorectal - Annual Incidence for 15-24 year olds by decade

Colorectal		Age-adjusted Rates per 100,000 AYAs		
Male & Female		Annual Mean	Lower	Upper
Incidence	Count	Age 15-24	95% CI	95% CI
1982-1989	90	**0.42**	0.33	0.51
1990-1999	123	**0.46**	0.38	0.54
2000-2009	276	**0.99**	0.87	1.11
2010-2011	61	**0.99**	0.74	1.24

Source: AIHW ACIM 2015

Table 25 – Colorectal - Annual Mortality for 15-24 year olds by decade

Colorectal		Age-adjusted Rates per 100,000 AYAs		
Male & Female		Annual Mean	Lower	Upper
Mortality	Count	Age 15-24	95% CI	95% CI
1968-1969	10	**0.24**	0.09	0.39
1970-1979	32	**0.13**	0.09	0.18
1980-1989	33	**0.12**	0.08	0.17
1990-1999	31	**0.12**	0.07	0.16
2000-2009	46	**0.16**	0.12	0.21
2010-2012	13	**0.14**	0.06	0.22

Source: AIHW ACIM 2015

The age-adjusted incidence rates for colorectal cancer increased such that the rate for 2010-11 was 2.4 times that for 1982-89. During 2000-09, the rate for females was 36% higher than for males (1.14 compared with 0.84 per 100,000). However, the rates for 2010-11 suggest a more equal incidence (1.00 and 0.98 per 100,000 for females and males respectively). Further data are required to confirm this recent trend.

Despite increases in incidence, the mortality rates have remained relatively low due to the offsetting effects of survival gains (Appendix B). From the 1980s to 2000s the decade annual age-adjusted mortality rate per 100,000 AYAs increased by 33% (0.12 to 0.16 age-adjusted mortality rate per 100,000 AYAs) compared with a corresponding increase in incidence of 136%. Meanwhile five-year relative survivals for AYAs increased from 61.5% for 1983-1989 to 71.7% for 2004-10.

Comments

Reasons for the marked incidence increases are not known but environmental factors that may be contributing include alcohol consumption, tobacco smoking, poor diet (e.g., high consumption of red meat, increases in dietary fat, and lack of fibre), increased obesity and lack of physical activity. Diseases of the bowel lining are also thought to increase the risk of bowel cancer (such as ulcerative colitis and Crohn's disease) as well as hereditary dispositions. Bowel Cancer Australia suggests that a third of colorectal cancers diagnosed before 35 years old are hereditary.

The noticeable increases in colorectal cancer incidence in AYAs are not evident on the same scale in older age groups.

From the 1980s to 2000s, the approximate age-adjusted incidence increased by around 16% in the 25-39 age group, decreased by 12% for those aged 40-59 years, and increased by 11% for the over 60s (although the age-adjusted incidence for all these age groups is higher than for AYAs). This compares with a corresponding increase of 136% for the AYA group (15-24 years), with the increase mainly attributed to the 20-24 year age group. A higher 200% increase was evident for those under 14 years of age, but this related to very small numbers.

Increases in colorectal cancer incidence are also seen in younger people around the world, including the UK and the US (27, 28). Again, the reasons for these trends are not known.

Increases in survival are attributed to advances in recognition of familial colorectal factors, increased public awareness, improved screening and diagnostic techniques leading to early diagnosis, adjuvant therapies and greater surgical specialization. Research for the US also suggests that younger age patients (under 40 years of age) with metastatic colorectal cancer have poorer outcomes than other age groups, with evidence of distinct genetic differences between younger and older patients with colorectal cancer(29, 30).

AIHW projections of AYA age-adjusted incidence rates (2011-2020) suggest an increase for all five year age groups between 10 and 39 years. The largest increase in age-adjusted rate is in the AYA age group with an estimated 37% increase by 2020, with a greater increase in males than females. An approximate 13% increase is projected for 0-14 year olds and 6% for the 25-39 year age group. AIHW estimate a decrease in the age-adjusted rate for the 40-64 ages, of around 3-12% and then relatively small increases of around 2% for the over 65s. Despite predicted increases in incidence, projected mortality rates suggest no change in the rates for the under 45s, with the exception of the 25-29 age group where an approximate 86% increase in mortality is estimated (a greater increase for females than males). Further data will be required to confirm this large estimated rise in young adult mortality. A decrease in the age-adjusted mortality rates for the five year age groups over 45 years is predicted, ranging from around 14-51%.

Female Breast Cancer

International

Australia does not have a high incidence of breast cancer in 15-24 year olds, in contrast to all ages combined where the incidence is at the high end of the international range. Among 15-24 year olds, the incidence estimate for 2012 was about 22% below the global estimate, higher than the rate for Canada and New Zealand but lower than rates for the UK and US (Figure 18). Whereas the mortality ranking was low (the rate about 84% below the global estimate), and lower than for New Zealand, it was higher than in the US and UK (Figure 19).

Figure 18 – Female Breast – Global estimates of Incidence

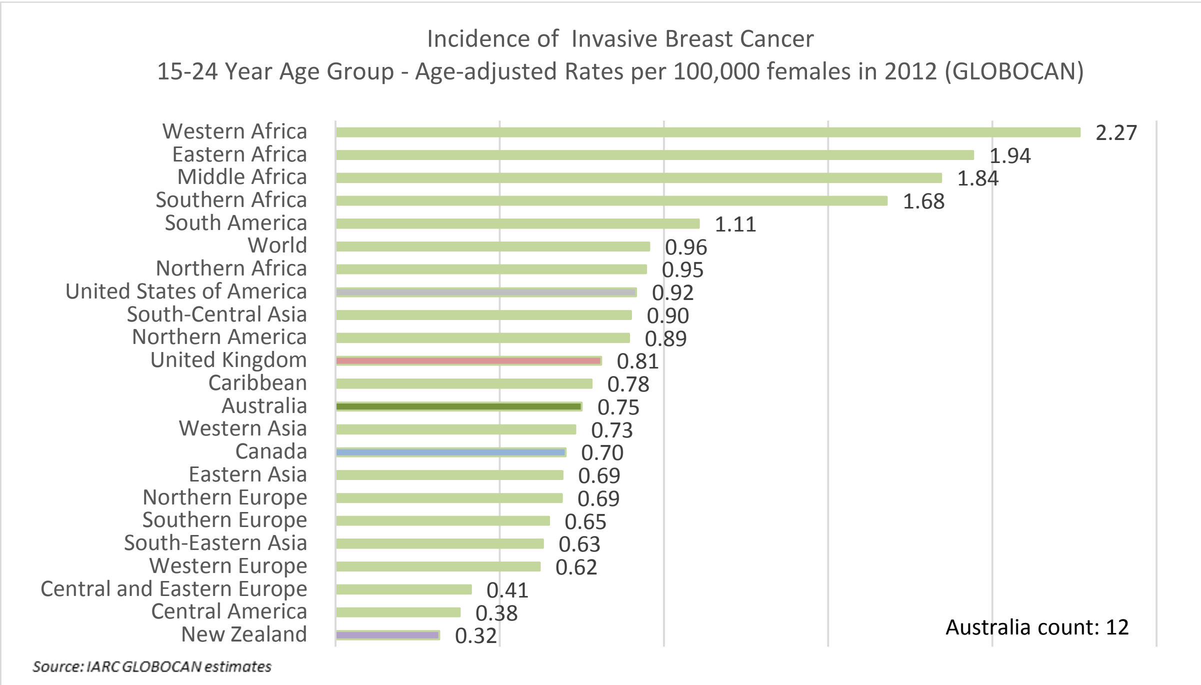
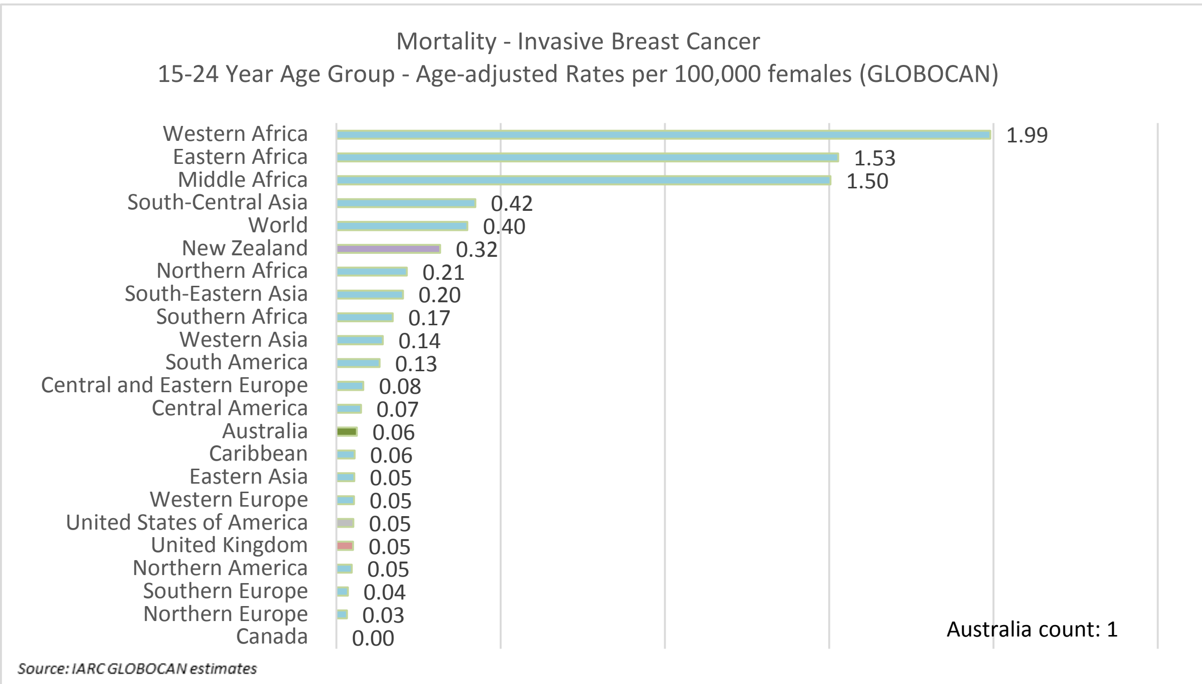


Figure 19 – Female Breast – Global estimates of Mortality



Comments

The lower mortality than incidence estimate ranking is indicative of higher case survival. The five-year survival in 15-29 year olds increased from 71% for 1983-89 to 86% for 2004-10 (Appendix B).

Australia

Breast cancer occurs predominantly in females with 275 incidence AYA cases reported from 1982 to 2011 compared with 6 AYA males.

Breast cancer was the 13th most commonly reported female AYA cancer in 1982-2011, accounting for 2% of all notified female AYA cancers. It remained the 13th most commonly notified cancer during 2000-09, at 2% of all cancers. For AYA females, breast cancer was the 12th most common cause of cancer death, accounting for 45 deaths between 1968 and 2012. It was the 14th most common in 2000-09.

Table 26- Female Breast - Annual Incidence for 15-24 year olds by decade

Female Breast		Age-adjusted Rates per 100,000 female AYAs		
Female Only		Annual Mean	Lower	Upper
Incidence	Count	Age 15-24	95% CI	95% CI
1982-1989	57	**0.54**	0.40	0.68
1990-1999	103	**0.78**	0.63	0.93
2000-2009	96	**0.70**	0.56	0.84
2010-2011	19	**0.62**	0.34	0.90

Source: AIHW ACIM 2015

Table 27 – Female Breast - Annual Mortality for 15-24 year olds by decade

Female Breast		Age-adjusted Rate per 100,000 female AYAs		
Female Only		Annual Mean	Lower	Upper
Mortality	Count	Age 15-24	95% CI	95% CI
1968-1969	2	**0.10**	0.00	0.23
1970-1979	17	**0.15**	0.08	0.21
1980-1989	7	**0.05**	0.01	0.09
1990-1999	10	**0.08**	0.03	0.12
2000-2009	7	**0.05**	0.01	0.09
2010-2012	2	**0.04**	0.00	0.11

Source: AIHW ACIM 2015

Age-adjusted incidence of female breast cancer has remained relatively stable over the last 30 years, also identified in the AIHW 2015 report on Breast Cancer in Young Women(31). Neither was a clear time trend evident for mortality although a reduction since the 1970s was suggested. This is consistent with the increase in survival reported in 15-29 year olds (Appendix B). Female AYAs are at relatively low risk with most breast cancer incidence occurring in post-menopausal women and with a clear trend of increasing incidence with age.

There are numerous risk factors that have been linked to breast cancer. They include age, family history, previous cancer diagnosis (links to specific cancers and also treatment including radiotherapy and chemotherapy), levels of sex hormones, hormone replacement therapy, contraceptive pill, not having children (or having children later in life), early puberty or late menopause, ethic group (white population groups have a higher risk than other groups), alcohol consumption, smoking, body weight, exposure to x-rays/radiation, other health conditions (such as diabetes, benign thyroid conditions and benign breast disease), diets high in fat and shift work/disturbed sleep patterns.

AIHW predictions for the age-adjusted incidence rates of female breast cancer suggest no change between 2011 and 2020 for the under 40s, including the AYA age group. No change in AYA age-adjusted mortality rates (2013-2025) is expected.

Lung Cancer

International

Although based on small numbers, 15-24 year old Australians were estimated to have a high incidence of lung cancer by world standards at 67% above the global estimate, 60% above the UK and 94% above the estimate for US. By comparison the mortality rate was very low (only one death estimated for 2012), 79% below the world average and also below rates in US, UK and Canada, albeit only by small margins.

Figure 20 – Lung – Global estimates of Incidence

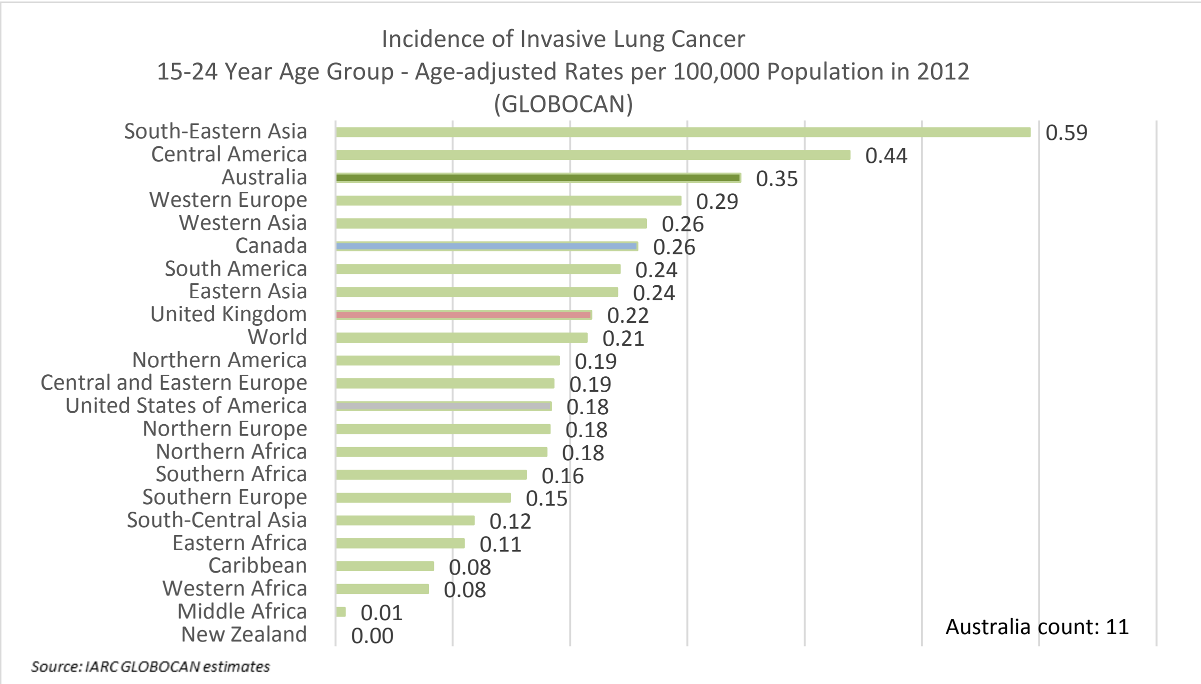
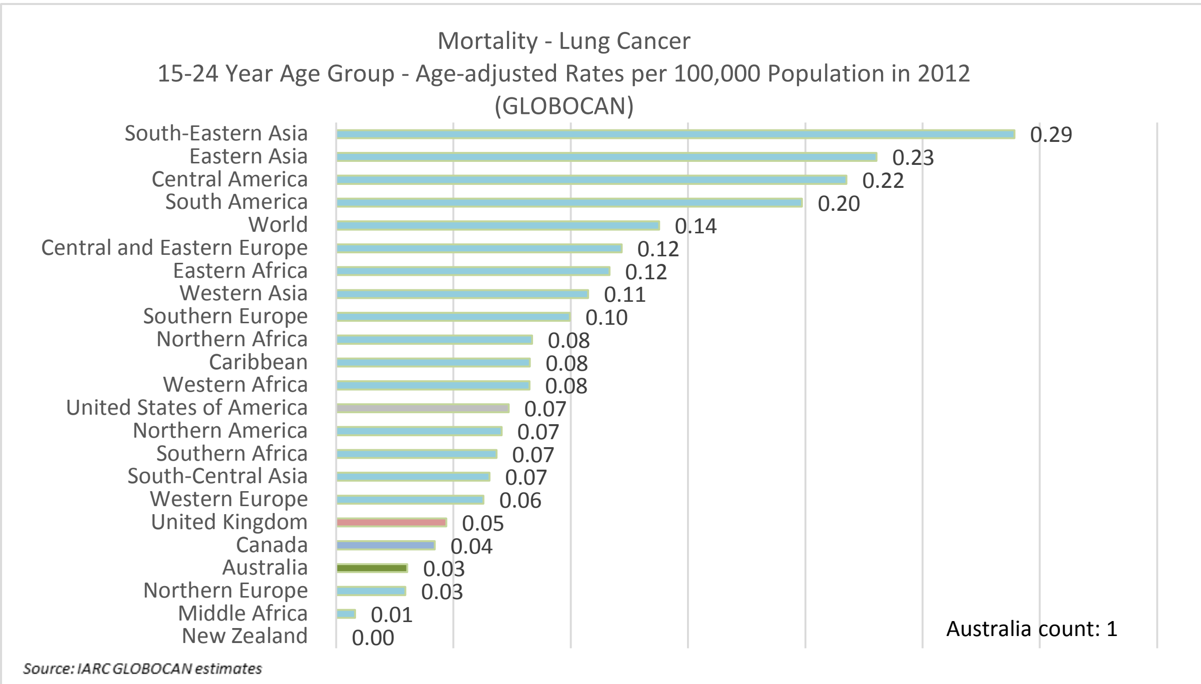


Figure 21 – Lung – Global estimates of Mortality



Australia

The incidence of lung cancer in AYAs is low. Between 1982 and 2011, 153 cases were notified in the 15-24 year age group. It represented the 19th most common notified cancer for AYAs, accounting for just 1% of all cancers. For mortality, lung cancer was the 18th most common cause of cancer death, with 53 deaths occurring between 1968 and 2012. This accounted for less than 1% of all cancer deaths for the same period.

Table 28- Lung - Annual Incidence for 15-24 year olds by decade

Lung		Age-adjusted Rates per 100,000 AYAs		
Male & Female		Annual Mean	Lower	Upper
Incidence	Count	Age 15-24	95% CI	95% CI
1982-1989	30	**0.14**	0.09	0.19
1990-1999	55	**0.20**	0.15	0.26
2000-2009	59	**0.21**	0.16	0.27
2010-2011	9	**0.15**	0.06	0.25

Source: AIHW ACIM 2015

Table 29 – Lung - Annual Mortality for 15-24 year olds by decade

Lung		Age-adjusted per 100,000 AYAs		
Male & Female		Annual Mean	Lower	Upper
Mortality	Count	Age 15-24	95% CI	95% CI
1968-1969	3	**0.07**	0.00	0.15
1970-1979	13	**0.05**	0.02	0.08
1980-1989	7	**0.03**	0.01	0.05
1990-1999	12	**0.04**	0.02	0.07
2000-2009	11	**0.04**	0.02	0.06
2010-2012	2	**0.02**	0.00	0.05

Source: AIHW ACIM 2015

There are no clear time trends in lung cancer apparent for this age range, with incidence and mortality rates remaining exceedingly low. However, the mortality to incidence ratio is relatively high, the 6th highest of all cancers.

For all ages in aggregate, CRUK suggests that around 90% of lung cancer cases in the UK are due to major lifestyle and other risk factors (more so in males than females). The predominant risk factor is smoking, although occupational exposures, ionising radiation, air pollution, increasing age and family history/genetics also can play a part.

Consistent and market reductions in both adolescent (aged 12-17 years) and young adults (aged 18-24 years) smoking in Australia from 2001 to 2013 is evident. The proportion of AYAs reporting that they were 'never smokers' increased by almost 20% with the average age of smoking initiation also increasing. Latest data from NSW shows the proportion of AYAs currently smoking as 6.7% in 2014, down from 23.5% in 1996(32).

Cervical Cancer

International

GLOBOCAN international AYA specific data are not available for cervical cancer.

Australia

Cervical cancer was the 7th most commonly notified female AYA cancer between 1982 and 2011, representing 4% of all cancers notified for this period and 3% for 2000-09. In contrast, cervical cancer was the 11th most common cause of female cancer mortality, accounting for 2% of all cancer deaths (Appendix D).

Table 30- Cervical - Annual Incidence for 15-24 year olds by decade

Cervical		**Age-adjusted Rates per 100,000 female AYAs**		
Female Only		**Annual Mean**	**Lower**	**Upper**
Incidence	**Count**	**Age 15-24**	**95% CI**	**95% CI**
1982-1989	138	**1.31**	1.09	1.53
1990-1999	126	**0.96**	0.79	1.12
2000-2009	115	**0.84**	0.69	1.00
2010-2011	32	**1.07**	0.70	1.44

Source: AIHW ACIM 2015

Table 31 – Cervical - Annual Mortality for 15-24 year olds by decade

Cervical		**Age-adjusted Rates per 100,000 female AYAs**		
Female Only		**Annual Mean**	**Lower**	**Upper**
Mortality	**Count**	**Age 15-24**	**95% CI**	**95% CI**
1968-1969	0	**0.00**	0.00	0.00
1970-1979	16	**0.14**	0.07	0.20
1980-1989	9	**0.07**	0.02	0.11
1990-1999	10	**0.08**	0.03	0.12
2000-2009	10	**0.07**	0.03	0.12
2010-2012	2	**0.04**	0.00	0.11

Source: AIHW ACIM 2015

Trend data suggests a decline in cervical cancer incidence from the 1980s to 2000s, from an age-adjusted rate of 1.31 to 0.84 per 100,000(36% decrease). The most recent data for 2010-11 gave an age-adjusted rate of 1.07 per 100,000.

Mortality from cervical cancer is low and has declined from a peak in the 1970s. This trend is likely a result of detection and treatment of pre-invasive abnormalities in response to cervical cytology screening. Improved treatments may also have assisted.

Human papilloma virus (HPV) is believed to be the major cause of the main types of cervical cancer (squamous cell cancer and adenocarcinoma). The National HPV Vaccination Program, introduced in Australia in 2007, has been credited with dramatically reducing the incidence of the HPV virus in Australia and is likely to further reduce incidence of cervical cancer(33). The program now targets both male and female 12-13 year olds through schools.

Further risk factors for cervical cancer include other sexually transmitted infections, smoking, weakened immune systems, long term use of oral contraception, early age first delivery and multiparity (34). AIHW project that both the age-adjusted incidence and mortality rates will remain fairly constant up until 2020 and 2025 respectively.

Bladder Cancer

International

GLOBOCAN international AYA specific data are not available for bladder cancer.

Australia

Bladder cancer is the 20th most common AYA cancer in Australia, accounting for less than 1% of all notified cancers (94 incidence cases notified between 1982 and 2011). Mortality is exceptionally low with only 7 deaths occurring between 1968 and 2012.

Table 32- Bladder - Annual Incidence for 15-24 year olds by decade

Bladder		Age-adjusted Rates per 100,000 AYAs		
Male & Female		Annual Mean	Lower	Upper
Incidence	Count	Age 15-24	95% CI	95% CI
1982-1989	35	**0.16**	0.11	0.22
1990-1999	44	**0.16**	0.12	0.21
2000-2009	14	**0.05**	0.02	0.08
2010-2011	1	**0.01**	0.00	0.04

Source: AIHW ACIM 2015

Table 33 – Bladder - Annual Mortality for 15-24 year olds by decade

Bladder		Age-adjusted Rate per 100,000 AYAs		
Male & Female		Annual Mean	Lower	Upper
Mortality	Count	Age 15-24	95% CI	95% CI
1968-1969	1	**0.02**	0.00	0.07
1970-1979	2	**0.01**	0.00	0.02
1980-1989	0	**0.00**	0.00	0.00
1990-1999	3	**0.01**	0.00	0.02
2000-2009	1	**0.00**	0.00	0.01
2010-2012	0	**0.00**	0.00	0.00

Source: AIHW ACIM 2015

Incidence in bladder cancer decreased by over 90% between 1982-89 and 2010-11. The reason for the reduction is unknown. A similar drop is evident in the UK for all ages combined, which is believed to be partially attributed to changes in classification. It is unknown whether this is a factor in Australia. Risks associated with bladder cancer include age (increasing incidence with age), smoking, certain occupational exposures and ionising radiation.

Mortality rates are exceeding low and no clear time trend has presented.

Other Cancers

Other cancers were investigated but showed no convincing evidence of changes in incidence or mortality. Often there were too few cases to meaningfully examine trends. These cancers included those with a primary site of ovary, head and neck, lip, kidney, tongue, stomach, mouth, uterine, pancreatic, anal and prostate (Appendix C).

Male and Female Comparison – Trends in Incidence and Mortality

A slightly higher proportion of male than female AYAs were diagnosed with an invasive cancer between 1982 and 2011 (52.9% males to 47.1% females). For the last decade (2000-2009) this proportion increased to 53.1% males to 46.9% females and to 56.1% and 43.8% respectively for the latest period of 2010-11. Further data are required for the current decade to confirm this increasing proportion of male AYAs diagnosed with cancer.

The age-adjusted incidence rate for males increased by 17% from the 1980s to 2000s compared with 13% for females, for all cancers combined (see Appendix E). Data for the latest reporting period of 2010-11 suggest a recent decline in both male and female incidence but further data are required for this last decade to confirm this trend.

The most commonly reported cancers differed between male and female AYAs. Cancers with the highest age-adjusted rate in males were testicular cancer, followed by melanoma, Hodgkin lymphoma, non-Hodgkin lymphoma, brain and acute lymphoblastic leukaemia. In contrast, the most commonly reported cancers in AYA females were melanoma, Hodgkin lymphoma, thyroid, non-Hodgkin lymphoma, brain and ovarian.

Melanoma was the most commonly notified cancer in males and females combined (2000-09) with a higher age-adjusted incidence rate for females (8.4 per 100,000) compared with males (6.4 per 100,000). However, over the 30 year period, the incidence in female AYAs fell by 21% compared with 14% in males.

Testicular cancer played a significant part in this increase in cancer incidence in males with the age-adjusted rate per 100,000 15-24 year olds increasing from 4.57 to 6.99. Excluding testicular cancer from all male cancers for the 2000-09 period, the increase in male incidence from the 1980s to 2000s was just under 10% (compared with 17% including testicular). Reviewing the male five year annual mean, the data for all cancers excluding testicular suggest a peak in incidence during the latter part of the 1990s followed by a small decline during the 2000s and into the latest decade. Further data for the last decade are required to confirm this trend.

While for many cancers, the age-adjusted incidence rate (2000-09 decade annual mean) was higher in males than females (specifically for non-Hodgkin lymphoma, brain, bone, acute lymphoblastic leukaemia, acute myeloid leukaemia, head & neck including lip, Chronic Myeloid Leukaemia, lung and bladder), trends since the 1980s indicate a greater increase in incidence in females than males for many cancers (specifically Hodgkin lymphoma, thyroid, non-Hodgkin lymphoma, bone, acute lymphoblastic leukaemia, acute myeloid leukaemia, colorectal, other soft tissue and head & neck including lip). Cancers more commonly reported in females than males included melanoma, thyroid, colorectal, other soft tissue and kidney.

In male AYAs, a decline in the age-adjusted incidence rate was evident for brain (19%) and melanoma (14%). In contrast, a decline in cervical cancer (36%) and melanoma (21%) was suggested for females.

Unlike cancer incidence, the six most commonly notified cancers for mortality in males mirrored those for females, namely bone, brain, acute myeloid leukaemia, acute lymphoblastic leukaemia, other soft tissue and non-Hodgkin lymphoma (although the order by age-adjusted rate varied). The age-adjusted mortality rate for males was higher for all of these cancers with the exception of AML. A higher proportion of male than female AYA deaths occurred from 1968-2012 (60% males to 40% females).

Observing trends in mortality, a reduction in rates over the three decades was evident for both males and females for melanoma, Hodgkin lymphoma, non-Hodgkin lymphoma, brain, bone, acute lymphoblastic leukaemia, acute myeloid leukaemia and the sex-specific cancers (testicular and ovarian). Increases in the age-adjusted mortality rate were observed for colorectal, other soft tissue and head & neck including lip for females and colorectal and other soft tissue for males. While the increase in the age-adjusted mortality rate for colorectal cancer was noteworthy (55% for females and 14% for males), this is in contrast to a corresponding increase in the age-adjusted incidence rate of 185% and 91% respectively during the same period.

Overall for all cancers combined, the age-adjusted mortality rate for males decreased by 37% from the 1980s to 2000s, compared with 21% decrease for females.

All Age Groups – Trends in Incidence and Mortality

The AYA age group account for about 0.8% of all cancer incidence in Australia (based on the average incidence for 5 year period 2007-2011) while accounting for 12.9% of the population. Approximately 0.3% of cancer mortalities in Australia occurred in the 15-24 year age group (2008-2012)

Reviewing the change in the decade annual mean age-adjusted incidence rate from the 1980s to 2000, a percentage increase is evident for all five year age groups from 0-4 years to the over 85s.

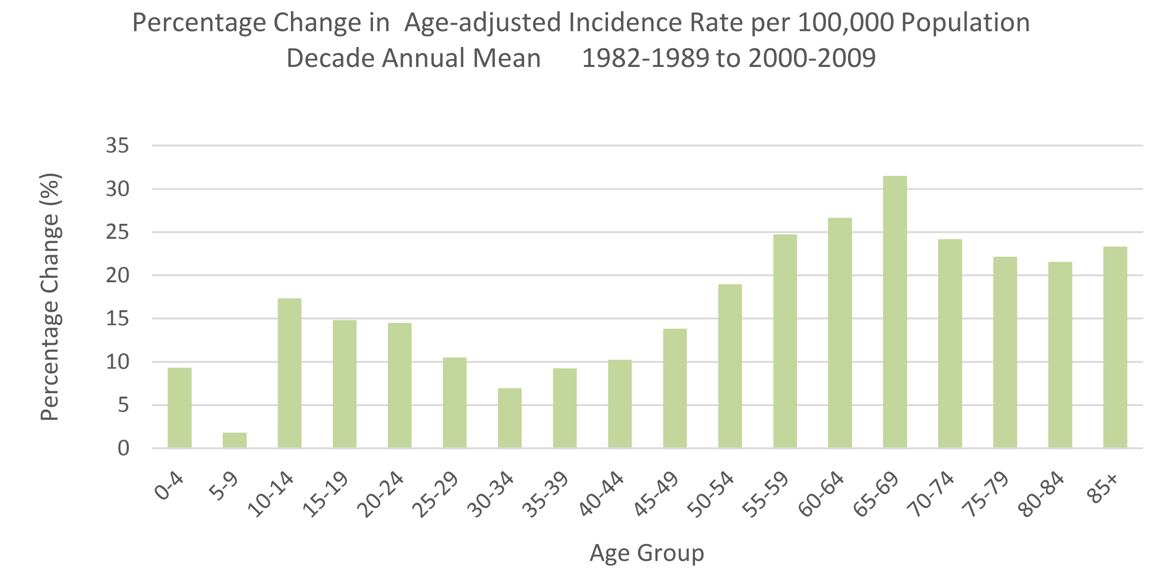
The largest percentage increase is suggested for the 65-69 year age group (31%). Regarding children, adolescents and young adults, a relatively small increase was apparent in the 0-4 and 5-9 age groups (<10%) and a more marked increases for the 10-14, 15-19 and 20-24 year age groups of 14-17%. The percentage increases in incidence rates for five year age groups between 25 and 50 years ranged from 7% to 14%, with larger increases between 19% and 31% applying in the older age range.

Table 34 – All Age Groups – Percentage change in All Invasive Cancer Incidence from 1980s to 2000s

Age Group	1982-1989 Age-adjusted Incidence Rate per 100,000 population Decade Annual Mean	2000-2009 Age-adjusted Incidence Rate per 100,000 population Decade Annual Mean	Percentage Change
0-4	19.3	21.1	**9.2%**
5-9	10.2	10.4	**1.7%**
10-14	10.4	12.2	**17.2%**
15-19	21.0	24.1	**14.7%**
20-24	34.2	39.2	**14.4%**
25-29	57.9	63.9	**10.4%**
30-34	90.0	96.1	**6.8%**
35-39	132.1	144.2	**9.1%**
40-44	204.5	225.3	**10.1%**
45-49	313.0	355.9	**13.7%**
50-54	464.7	552.4	**18.9%**
55-59	690.0	859.9	**24.6%**
60-64	991.3	1254.4	**26.5%**
65-69	1317.7	1731.2	**31.4%**
70-74	1684.1	2089.3	**24.1%**
75-79	2019.6	2464.5	**22.0%**
80-84	2226.7	2704.3	**21.5%**
85+	2210.1	2723.5	**23.2%**

Source: AIHW ACIM 2015

Figure 22 – All Age Groups – Percentage change in All Invasive Cancer Incidence from 1980s to 2000s



Source: AIHW ACIM 2015

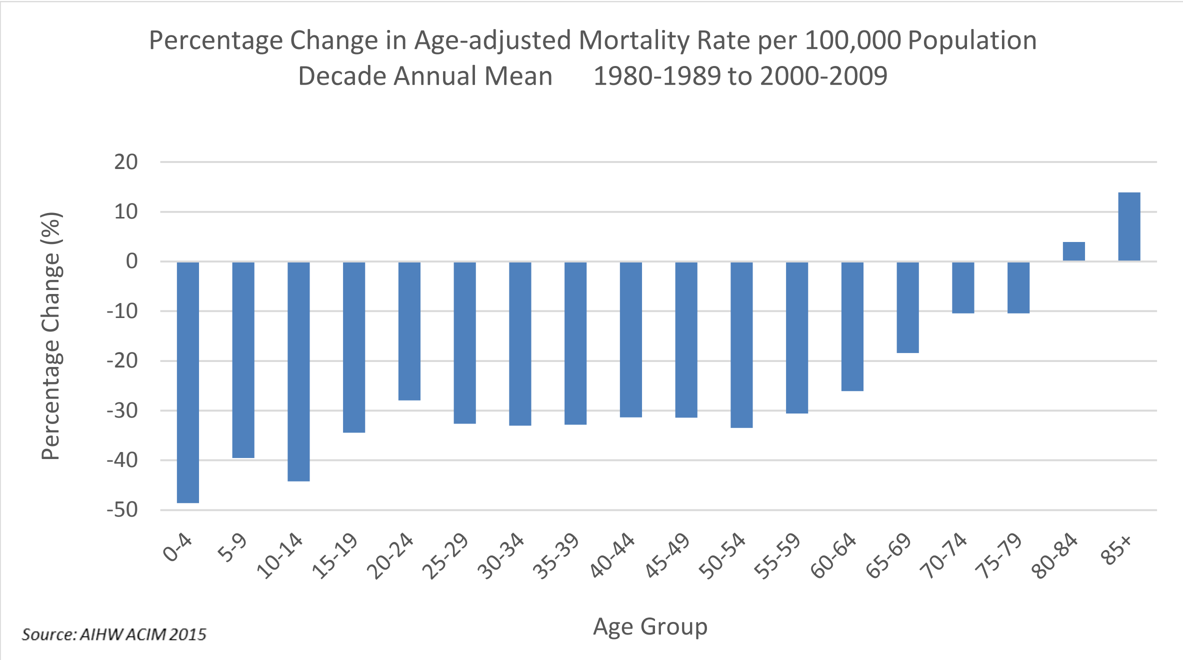
The age-adjusted mortality rates fell for all age groups from the 1980s to 2000s with the exception of the 80-84 and over 85 ages. There were noticeable declines in the mortality rate for children (0-4, 5-9 and 10-14 age groups) of 40-49%. Although the percentage decrease in age-adjusted mortality rates for 5 year age groups between the ages of 15 and 59 years were relatively similar (28-35%), the lowest decline in mortality rate was evident in the 20-24 year old age group.

Table 35 – All Age Groups – Percentage change in All Invasive Cancer Mortality from 1980s to 2000s

Age Group	1982-1989 Age-adjusted Mortality Rate per 100,000 population Decade Annual Mean	2000-2009 Age-adjusted Mortality Rate per 100,000 population Decade Annual Mean	Percentage Change
0-4	5.0	2.6	**-48.6%**
5-9	4.6	2.8	**-39.5%**
10-14	3.9	2.2	**-44.2%**
15-19	5.5	3.6	**-34.5%**
20-24	6.4	4.6	**-27.9%**
25-29	9.5	6.4	**-32.7%**
30-34	17.1	11.4	**-33.0%**
35-39	30.7	20.6	**-32.8%**
40-44	58.2	40.0	**-31.4%**
45-49	109.3	75.0	**-31.4%**
50-54	199.2	132.6	**-33.4%**
55-59	326.4	226.5	**-30.6%**
60-64	495.7	366.4	**-26.1%**
65-69	703.0	573.6	**-18.4%**
70-74	959.6	859.7	**-10.4%**
75-79	959.6	859.7	**-10.4%**
80-84	1543.7	1604.7	**4.0%**
85+	1839.6	2095.4	**13.9%**

Source: AIHW ACIM 2015

Figure 23 – All Age Groups – Percentage change in All Invasive Cancer Mortality from 1980s to 2000s



Key Findings/Summary

Global Comparisons

GLOBOCAN estimates indicate that Australia has a high incidence of AYA cancers compared with global estimates, for all cancers combined, and specifically for melanoma, testicular, Hodgkin lymphoma, brain, colorectal and lung cancer (NB GLOBOCAN data were not available for this report for all individual common AYA tumour sites such as bone, other soft tissue and thyroid cancers).

For all cancers combined, the age-adjusted incidence for Australia was 92% higher than the global estimate and, for individual cancer types, up to 15 times higher. However, with the exception of melanoma, AYA cancer mortality is relatively low in Australia, and below the global estimate. For all cancers combined, the mortality estimate for Australia was 50% lower than the global estimate. AYA breast cancer in Australia was the only cancer shown to have an incidence rate lower than the global estimate, coupled with a low mortality.

Trends in AYA Cancers in Australia

- Over the last three decades there has been little change in the incidence of **AYA cancers for all types combined**. Marked reductions in mortality are, however, evident.
- **Melanoma** is the most common AYA cancer but with a declining incidence and mortality, despite increasing incidence for all ages collectively (including non-AYA ages).
- A significant increase has occurred in **colorectal** cancer but without a corresponding increase in mortality.
- A high and increasing incidence of **testicular** cancer is occurring, but, in contrast, a low and declining mortality.
- A high and increasing incidence of **Hodgkin lymphoma** (HL) is taking place with a bimodal age distribution. There are clear reductions in mortality.
- A high and increasing incidence of **non-Hodgkin lymphoma** (NHL) is evident but with a declining mortality. A higher incidence applies to males than females.

- Little change in incidence of **acute lymphoblastic leukaemia** (ALL) is apparent. A reduction in mortality has occurred since the 1980s but this cancer remains one of the leading causes of AYA cancer deaths. A high mortality to incidence ratio applies.
- An upward trend in acute myeloid leukaemia (AML) incidence is suggested with more marked reductions in mortality than for acute lymphoblastic leukaemia. There is a higher incidence of AML in males than females and a high mortality to incidence ratio.
- Incidence and mortality rates for **brain cancer** have remained relatively constant over 30 years, possibly with a slight reduction, but the mortality to incidence ratio remains high and it is one of the leading causes of AYA cancer death.
- **Bone** cancer incidence and mortality have been relatively unchanged, with higher incidence rates in males. The mortality to incidence ratio remains high. This cancer is one of the most common causes of mortality, accounting for an increasing proportion of cancer deaths. Bimodal age patterns apply.
- **Other soft tissue** cancer incidence and mortality have remained relatively stable. The mortality to incidence ratio is high.
- A worldwide trend of increasing incidence of **thyroid cancer** is apparent, particularly in women and young people. Pronounced increase in AYA incidence is occurring in Australia, representing one of the most common AYA cancers, but mortality is extremely low.
- While incidence and mortality rates for lung cancer are low, the mortality to incidence ratio is relatively high.
- The incidence of **cervical** cancer declined from the 1980s to 2000s. A possible recent increase needs to be reviewed with further data, once available. Low mortality rates apply.
- No clear trends have emerged in **female breast** cancer although a possible decline in mortality from a peak in the 1970s is suggested. Incidence and mortality rates are low.
- A large decline in **bladder cancer** incidence rates has been recorded, along with exceeding low mortality rates.
- A higher proportion of male than female AYAs were diagnosed with invasive cancers.
- For all cancers combined, a greater increase in the age-adjusted incidence rate was evident in males compared with females.
- The most commonly reported cancers differed between males and females with the highest age-adjusted rates for male cancers evident for testicular, melanoma, HL, NHL, brain and ALL, and for females, melanoma, HL, thyroid, NHL, brain and ovarian.
- A decline in the male age-adjusted incidence rate was seen for brain and melanoma cancers, and for females, for cervical cancer and melanoma.
- A higher proportion of AYA male deaths occur than females.
- Declines in age-adjusted mortality rates were more pronounced in males than females.
- The most commonly notified cancers for mortality in males were similar to those in females, namely bone, brain, AML, ALL, other soft tissue and NHL cancers. Age-adjusted mortality rates for males were higher for these cancers, with the exception of AML.
- An increase in the age-adjusted mortality rates in females was observed for colorectal, other soft tissue and head and neck (incl lip). An increase in the male age-adjusted mortality rates were suggested for colorectal and other soft tissue.
- Comparing AYAs to other age groups, the age-adjusted incidence rates were significantly lower than for older age groups. However, the percentage increase in the decade annual mean age-adjusted incidence rate from 1982-1989 to 2000-2009 for people aged 15-19 and 20-24 years was higher than for the older 5 year age groups from 25 to 49 years.
- Between 1982-1989 and 2000-2009, the decade annual mean age-adjusted mortality rates decreased for all age groups with the exception of the over 80s. The lowest decline, however, was evident for the 20-24 years compared against the 5 year age groups from 0-59 years.

AYA CANCER SURVIVAL

Data Source

The AIHW report(6) on AYAs provides indications of survival for the 15-29 year old age group, including comparisons with other younger and older cancer patients.

Relative Survival

According to the AIHW, during the period of 2004-2010, 1-year relative survival for AYAs (15-29 years) with cancer was 95%, with a corresponding 5-year relative survival at 88%. The report found that those cancers that were most common in the AYA age group (namely thyroid carcinoma, testicular cancer, Hodgkin lymphoma and melanoma) were among those with the highest survival thereby contributing to the relatively high cancer survival in this age group. Cancers in the AYA age range with the lowest 5-year relative survival included brain, soft tissue and acute myeloid leukaemia (Appendix H).

AYA Survival Compared with Other Age Groups

Comparing the AYA age group (15-29 years) with younger (0-14 years) and older (30-39 years) ages indicated that at 1-year relative survival for AYAs for all cancers combined was higher than for children (95.1% compared with 91%) and broadly similar to that of older adults (94.6%). At 5-years after diagnosis, relative survival for AYAs was the highest of all three age groups (88%) compared with 81% for the younger age group and 86% for the older age group. Survival rates for AYAs, compared with other age groups, will be influenced by cancers with high survival being more common in AYAs than in children. This can mask lower survival for specific cancers in the AYA age group.

Given the relatively small numbers of AYA cancers, leading to broad 95% confidence intervals caution should be taken in interpreting some cancer specific data. However, the data suggests that AYA cancer patients may have poorer outcomes than children for leukaemia and bone cancers, but better for central nervous system and germ cell cancers. In comparison with the older age group (30-39 year olds), data suggest that AYAs have poorer outcomes for bone cancer and non-gonadal germ cell tumours, and have higher survival for CNS cancers, although these differences could be due to chance events. Further survival data for the 15-24 year age range are required for more specific analysis.

The recent findings from the EUROCARE-5 study of survival of European adolescents and young adults (aged 15-39 years)(35) are consistent with the Australian AYA survival data. European data indicated that 5-year survival was slightly better for the AYA age group than for children (0-14 years) mainly due to cancers with good prognosis being more frequent in AYAs than in children. The study also found that overall cancer survival improved during the period of 2000-2007, with similar improvements in both children (0-14 years) and AYAs and young adults (15-39 years). Survival remained significantly worse in AYAs and young adults than in children for eight cancers namely: acute lymphoid leukaemia; acute myeloid leukaemia; Hodgkin lymphoma; non-Hodgkin lymphoma; astrocytoma; Ewing's sarcoma; and rhabdomyosarcoma. For acute myeloid leukaemia, soft tissue sarcoma and fibrosarcoma, survival remained unchanged for AYAs and young adults over the study period.

AYA CANCER HOSPITAL ADMISSIONS AND PATIENT STAYS

Data Source

Data on hospital admissions were obtained from the Australia Institute of Health and Welfare Principal Diagnosis Data Cubes(36). The primary source was the AIHW National Hospital Morbidity Database where the data were classified according to the International Classification of Diseases (ICD) using tumour specific classification codes. While the data date back to 1993, prior to 1998, ICD version 9 was in use and these earlier data may not be directly comparable with data for subsequent years. The following analysis is restricted to 15 years of data from 1999 to 2013 inclusive (all coded using ICD version 10).

An admission to hospital, or separation from hospital, follows a decision that a patient requires in-patient management, treatment, care or assessment of need. It includes same-day admissions (i.e. those with discharges on the same day) and admissions involving overnight stays in hospital. According to the Australian Institute of Health and Welfare document 'Australia's Hospitals 2012-13 at a glance' (37), there were about 9.4m hospital admissions nationally in 2012-2013, of which 601,000 were directly related to cancer, equating to 6% of all hospital admissions for all age groups combined.

Data are presented for invasive cancer hospital admissions, patient days and average lengths of hospital stay for 15-19 and 20-24 year olds. Age-adjusted rates per 100,000 persons are calculated using AIHW ACIM workbook population figures. While a population figure was unavailable for 2013 from this source, a population projection prepared for the Australian Government Department of Social Services by the Australian Bureau of Statistics was used.

The analysis further includes calculations of 95% confidence limits, approximated using the standard formula. For the purpose of this report, differences in rates are interpreted as unlikely to be chance events when these confidence intervals do not overlap. Due to potential lack of independence of repeat admissions, however, these intervals may be under-estimated. They are not interpreted literally but used as a pointer to potentially non-random differences.

Appendix F presents the full analysis of the hospital data.

All Invasive Cancers Combined

During 2009 to 2013, 18,732 AYA patient admissions to hospital took place for invasive cancers. The proportions affecting 15-19 and 20-24 year olds were roughly equal, collectively comprising an average of 3,746 AYA admissions per year. The age-adjusted admission rate for 15-24 year olds combined was 122.2 AYA cancer admissions per 100,000s AYA (5 year annual mean).

A downwards trend in AYA invasive cancer admissions is evident with the annual mean age-adjusted rate for 2009-2013 being about 14% lower than for 1999-2008 when a relatively stable rate applied. For all ages and admissions, the AIHW Australia's Hospitals report indicates an increasing number of separations between 2008-9 and 2012-13 by 15% overall. An average increase of 3.6% each year occurred, which was larger than the corresponding population growth of about 1.4% per year.

The decline in AYA admissions for invasive cancer could be attributed, at least partly, to evidence of a possible decline in invasive cancer incidence during this period with the 5 year annual mean age-adjusted incidence rate falling by 12% during a similar period from 2000-2004 to 2010-2011, as evident in Figure 3. This follows a peak in incidence in 1995-1999. Other explanations could include a shift towards treatment taking place in outpatient departments or outside the hospital setting, strengthened and streamlined management of chronic disease, and a decrease in demand for elective procedures requiring hospital admission.

Table 36- All Invasive Cancers Combined - Trends in Hospital Admissions for 15-24 year olds – 5 Year Annual Mean

All Invasive Cancer Combined		Age-adjusted Rates per 100,000 AYAs		
Male & Female		Annual Mean	Lower	Upper
Yr of Admission	Count	Age 15-24	95% CI	95% CI
1999-2003	18,722	**142.0**	140.0	144.0
2004-2008	20,025	**140.6**	138.6	142.5
2009-2013	18,732	**122.2**	120.5	124.0

Source: AIHW Principal Diagnosis Data Cubes

The average length of stay for all AYA patients with invasive cancers approximated 4.5 days, for both AYA age groups combined, over the last 5 recorded years. This average length of stay had remained relatively constant since the late 1990s albeit with a slight increase during 2004-08 (mainly in the lower AYA age group).

Just under 95,000 patient days were recorded for all invasive AYA cancers between 2009 and 2013. This represents an age-adjusted rate for 15-24 year olds of 623.1 patient days per 100,000 AYA people. The rate is comparable for 2009-2013 and 1999-2003, but about 12% lower for 2009-2013 than the 2004-2008 peak. The increase in the rate of patient days during 2004-2008 is likely a result of the increasing average lengths of stay during this period. The subsequent decrease in patient hospital days could be a result of more limited hospital capacity, advanced treatments with shorter recovery times, improvements in the management of the disease, changes in incidence by cancer type, and improved patient support and care outside the hospital setting.

Table 37- All Invasive Cancers Combined - Patient Days for 15-24 year olds – 5 Year Annual Mean

All Invasive Cancer Combined		Age-adjusted Rates per 100,000 AYAs		
Male & Female		Annual Mean	Lower	Upper
Yr of Admission	Count	Age 15-24	95% CI	95% CI
1999-2003	83,728	**634.9**	630.6	639.2
2004-2008	101,197	**710.6**	706.2	714.9
2009-2013	94,966	**623.1**	619.1	627.0

Source: AIHW Principal Diagnosis Data Cubes

Lymphoid, Haematopoietic and Related Cancers

Lymphoid, haematopoietic and related cancers accounted, by a noticeable margin, for more AYA cancer admissions to hospital than for other cancer types. During 2009-2013, 48% of all AYA cancer admissions were reportedly for these cancers. This compared with 11% for bone and articular cartilage and less than 7% for each of the remaining tumour categories. The latest reported data for 2013 suggest that the proportion of all AYA cancer admissions applying to lymphoid, haematopoietic and related conditions is higher for males than females (48% compared with 37%).

A total of 8,947 admissions for lymphoid, haematopoietic and related cancers were reported for the AYA age groups from 2009 to 2013, equating to an age-adjusted rate of 59.2 per 100,000 15-24 year olds, the highest of all malignant cancers (Appendix F). This represented a 10% decline in admissions compared with the age-adjusted rate for 1999-2003 and a 13% decrease from a peak incidence in 2004-08.

Table 38- Lymphoid, Haematopoietic and Related Cancers - Hospital Admissions for 15-24 year olds – 5 Year Annual Mean

Lymphoid, Haematopoietic & Related Cancers		Age-adjusted Rates per 100,000 AYAs		
Male & Female		Annual Mean	Lower	Upper
Yr of Admission	Count	Age 15-24	95% CI	95% CI
1999-2003	8,644	**65.5**	64.1	66.9
2004-2008	9,696	**68.1**	66.8	69.5
2009-2013	8,947	**59.2**	58.0	60.4

Source: AIHW Principal Diagnosis Data Cubes

Age-adjusted incidence rates for both lymphomas and leukaemias, dating back to the early 1980s, suggest a high and increasing incidence of Hodgkin lymphoma, non-Hodgkin lymphoma and acute myeloid leukaemia (AML), but with little change in incidence for acute lymphoblastic leukaemia.

Although leukaemias and lymphomas represent high proportions of the total number of AYAs diagnosed with invasive cancer, 27% overall in 2000-09, the proportion of admissions for this cancer category was higher again at 46% of all admissions for invasive cancers.

A crude calculation of admission to incidence rate ratios was undertaken, based on age-adjusted rates for closely corresponding timeframes (2004-08 and 2005-09 respectively). The ratio was high for haematological cancer patients. After bone and soft tissue cancers, lymphoid, haematopoietic and related cancers had the third highest admission to incidence rate ratio (see Appendix F).

Data suggest an increase in length of stay for these AYA cancer patients. The average length of stay for AYA patients during 1999-2003 equated to 5.1 days, increasing to 5.8 and 6.0 for the later periods of 2004-2008 and 2009-2013. The average length of stay is broadly equivalent for 15-19 and 20-24 year age groups.

Approximately 53,500 patient days were attributed to AYA lymphoid, haematopoietic and related cancers between 2009 and 2013. This equated to an age-adjusted rate of 355.6 patient days per 100,000 AYAs. This rate was approximately 8% higher than for the 1999-2003 reference period, but 10% lower than the peak rate for 2004-08.

Table 39- Lymphoid, Haematopoietic and Related Cancers - Patient Days for 15-24 year olds – 5 Year Annual Mean

Lymphoid, Haematopoietic & Related Cancers		Age-adjusted Rates per 100,000 AYAs		
Male & Female		Annual Mean	Lower	Upper
Yr of Admission	Count	Age 15-24	95% CI	95% CI
1999-2003	43,586	**330.2**	327.1	333.3
2004-2008	56,251	**395.1**	391.8	398.4
2009-2013	53,578	**355.6**	352.6	358.6

Source: AIHW Principal Diagnosis Data Cubes

Bone and Articular Cartilage

Bone and articular cartilage malignant neoplasms were the second most common reason for AYA cancer admission to hospital, accounting for 11% of all admissions (2009-2013).

In all, 2,106 admissions for cancers of the bone and articular cartilage were recorded for the AYA age group, during 2009-2013. This represents an age-adjusted rate of 14.7 admissions per 100,000 AYAs, the second highest of all cancer categories after lymphoid, haematopoietic and related cancers.

Table 40- Bone and Articular Cartilage - Hospital Admissions for 15-24 year olds – 5 Year Annual Mean

Bone & Articular Cartilage		Age-adjusted Rates per 100,000 AYAs		
Male & Female		Annual Mean	Lower	Upper
Yr of Admission	Count	Age 15-24	95% CI	95% CI
1999-2003	2,092	**15.8**	15.1	16.5
2004-2008	2,255	**15.9**	15.3	16.6
2009-2013	2,106	**14.7**	14.0	15.3

Source: AIHW Principal Diagnosis Data Cubes

Relatively small changes in admissions were evident when comparing this rate with previous 5 year annual mean rates (not statistically significant). The incidence, and mortality, rates for bone cancer have also remained relatively unchanged for the last 30 years. The mortality to incidence ratio remains high and this cancer is one of the most common causes of mortality accounting for an increasing proportion of cancer deaths. When comparing age-adjusted ratios of admissions and incidence rates, the ratio for bone and articular cartilage is the highest of all AYA cancer categories indicating the highest levels of admissions per patient (see Appendix F).

Average length of stay has remained constant for the 15-19 year age group since 1999, fluctuating between 4 to 5 days with an average of 4.3 days. A longer length of stay is evident for the 20-24 year olds, with an average of 4.9 days during the same period albeit with a decrease in length of stay is suggested for the latest 5 year period.

Approximately 9,000 AYA hospital patient days were attributed to bone and articular cartilage malignant neoplasms between 2009 and 2013, with an age-adjusted rate of 62.2 per 100,000 AYAs - the second highest of all cancers (see Appendix F). A decline in patient days resulting from bone and articular cartilage cancers is evident with the rate for the most recent five year period about 14% lower than for 1999-2003.

Table 41- Bone and Articular Cartilage - Patient Days for 15-24 year olds – 5 Year Annual Mean

Bone & Articular Cartilage		Age-adjusted Rates per 100,000 AYAs		
Male & Female		Annual Mean	Lower	Upper
Yr of Admission	Count	Age 15-24	95% CI	95% CI
1999-2003	9,599	**72.6**	71.2	74.1
2004-2008	9,913	**69.9**	68.5	71.3
2009-2013	8,969	**62.2**	60.9	63.5

Source: AIHW Principal Diagnosis Data Cubes

Male Genital Organs

Cancers of the male genital organs (including the penis, prostate, testis and other/unspecified male genital organs) are the fourth most common cause of AYA cancer admissions in Australia (after the other ill-defined, secondary and unspecified cancer category), accounting for 6% in 2009-2013, similar to the corresponding proportion for Melanoma/other malignant neoplasms of skin. This proportion is, however, somewhat lower than the corresponding proportion for incidence cancers (accounting for 11% of all AYA incidence cases during 2000-2009 and a corresponding 21% of male cancers). The vast majority of male genital organs incidence cases comprise testicular cancer, with only a small percentage (0.06% of all AYA incidence during 2000-2009) attributed to prostate cancer.

In all, 1,155 AYA admissions were a result of cancers of the male genital organs from 2009 to 2013. This represents an annual mean age-adjusted rate of 13.9 admissions per 100,000 male AYAs (the third highest rate exceeded by haematological and bone cancers).

Table 42- Male Genital Organs - Hospital Admissions for 15-24 year olds – 5 Year Annual Mean

Male Genital Organs		Age-adjusted Rates per 100,000 AYAs		
Males only		Annual Mean	Lower	Upper
Yr of Admission	Count	Age 15-24	95% CI	95% CI
1999-2003	1,167	**17.5**	16.5	18.5
2004-2008	1,160	**15.9**	15.0	16.8
2009-2013	1,155	**13.8**	13.1	14.6

Source: AIHW Principal Diagnosis Data Cubes

A clear decline in hospital admissions is observed, with a 21% reduction in the age-adjusted admissions rates in 2009-2013 when compared to the reference years of 1999-2003 (the second largest decline of all cancers) and 13% when compared to 2004-2008. This is in contrast to the high and increasing age-adjusted incidence rates of testicular cancer. However, an analysis of mortality data suggests a low and declining mortality, may be due to improvements in surgery and adjuvant therapies. Based on a crude admission to incidence rate ratios, and corresponding age-adjusted rates, patients with male genital organ cancers have a relatively low number of admissions per patient (see Appendix F).

The average length of stay for male genital organ cancers increased slightly in the last 5 year period from 3.2 to 3.5 days for both AYA age groups combined, with a longer length of stay evident for the 15-19 age range.

Cancers of male genital organs accounted for approximately 3,900 patient days between 2009 and 2013, with an age-adjusted rate of 47.6 per 100,000 male AYAs. This rate had declined from rates in the previous decade, but not to the extent of decline in admissions (due to increased length of stay). Age-adjusted rates fell by 14% compared with the reference years of 1999-2003.

Table 43- Male Genital Organs - Patient Days for 15-24 year olds – 5 Year Annual Mean

Male Genital Organs		Age-adjusted Rates per 100,000 AYAs		
Males Only		Annual Mean	Lower	Upper
Yr of Admission	Count	Age 15-24	95% CI	95% CI
1999-2003	3,684	**55.1**	53.3	56.8
2004-2008	3,826	**52.5**	50.8	54.1
2009-2013	3,888	**47.6**	46.1	49.1

Source: AIHW Principal Diagnosis Data Cubes

Melanoma and Other Malignant Neoplasms of the Skin

Melanoma and other malignant neoplasms of the skin (incorporating Merkel cell carcinoma and other/unspecified malignant neoplasms of the skin) are the fifth most common cause of AYA cancer admission to hospital in Australia, accounting for 6% of all admissions (2009-2013). This proportion is significantly lower, however, than the proportion of incidence cases due to melanoma (i.e. 24% of all AYA incidence cases during 2000-2009).

According to AIHW data, 1,118 AYA patient hospital admissions occurring between 2009 and 2013 were for melanoma/other malignant cancers, with an annual mean age-adjusted rate of 6.6 per 100,000 AYAs. This rate is almost half that occurring in the 1999-2003 period (a 45% decrease in age-adjusted rate).

Table 44- Melanoma and Other Malignant Neoplasm of the Skin - Hospital Admissions for 15-24 year olds – 5 Year Annual Mean

Melanoma & Other Malignant Neoplasms of the Skin		Age-adjusted Rates per 100,000 AYAs		
Male & Female		Annual Mean	Lower	Upper
Yr of Admission	Count	Age 15-24	95% CI	95% CI
1999-2003	1,594	**12.1**	11.5	12.7
2004-2008	1,402	**9.8**	9.3	10.3
2009-2013	1,118	**6.6**	6.2	7.0

Source: AIHW Principal Diagnosis Data Cubes

The decline in incidence is expected to have been a key contributor to the reduction in hospital admissions. A similar decrease is evident in incidence rates with a reduction in the age-adjusted rates of 44% between 2000-2004 and 2010-2011, from 8.5 to 4.8 incidence rate per 100,000 AYAs. This is in contrast to increasing incidence rates for all ages collectively (including non-AYA ages). Even greater reductions in mortality rates occurred with the 2000-2004 rate being 61% lower than for 2010-2012 (age-adjusted rates per 100,000 of 0.31 and 0.12 respectively). The admissions to incidence rate ratios suggest that the melanoma and other malignant neoplasms of the skin patients have the lowest ratio of admissions to incidence of all AYA cancers (see Appendix F).

The average lengths of stay for AYA patients with melanoma/other malignant neoplasm of the skin were exceptionally low, with an average of 1.3 days (1999-2013), for both the 15-19 and 20-24 year age group. A slight decline in length of stay is evident since the reference period of 1999-2003.

A total of 1,387 AYA patient days were reported for this cancer type for the period of 2009-2013, with an age-adjusted rate of 8.3 per 100,000 AYAs. This puts melanoma/other malignant neoplasm of the skin among the lowest four cancers in terms of age-adjusted patient days (see Appendix F) despite being in the top five for admissions (Appendix F). A significant reduction of 52% in age-adjusted patient days is evident when compared with the 1999-2003 reference years, when the patient day rate was 17.3 per 100,000.

Table 45- Melanoma and Other Malignant Neoplasm of the Skin - Patient Days for 15-24 year olds – 5 Year Annual Mean

Melanoma & Other Malignant Neoplasms of the Skin		Age-adjusted Rates per 100,000 AYAs		
Male & Female		Annual Mean	Lower	Upper
Yr of Admission	Count	Age 15-24	95% CI	95% CI
1999-2003	2,265	**17.3**	16.5	18.0
2004-2008	1,731	**12.0**	11.5	12.6
2009-2013	1,387	**8.3**	7.9	8.7

Source: AIHW Principal Diagnosis Data Cubes

Eye, Brain and Other Parts of the Central Nervous System

Cancers of the eye, brain and other parts of the CNS are the sixth most common reason for AYA cancer hospital admissions (2009-2013) accounting for 5.2% of all malignant neoplasm cancers for this age group (similar to the percentage for thyroid and slightly less than for male genitals and skin). Eye, brain and CNS cancers accounted for a higher proportion of AYA female than male cancer admissions - 7% and 4% respectively.

In all, 971 admissions for eye, brain and CNS cancers were reported for the AYA age group from 2009 to 2013 with a 5 year annual mean age-adjusted rate of 6.6 per 100,000 15-24 year olds. While the latest age-adjusted rate (2009-2013) was 14% lower than for 1999-2003, which was statistically significant, a smaller increase was suggested in from 2004-2008 (albeit not statistically significant).

Table 46- Eye, Brain and Other Parts of the Central Nervous System - Hospital Admissions for 15-24 year olds – 5 Year Annual Mean

Eye, Brain and other Parts of the Central Nervous System		Age-adjusted Rates per 100,000 AYAs		
Male & Female		Annual Mean	Lower	Upper
Yr of Admission	Count	Age 15-24	95% CI	95% CI
1999-2003	1,020	**7.7**	7.2	8.2
2004-2008	843	**5.9**	5.5	6.3
2009-2013	971	**6.6**	6.2	7.1

Source: AIHW Principal Diagnosis Data Cubes

Both incidence and mortality rates have remained broadly constant over the last 30 years, as has survival. The mortality to incidence ratio remains high, with these cancers among the leading causes of AYA cancer death. Eye, brain and CNS cancer admissions, as a proportion of all AYA cancer admissions, correlate with the proportion of incidence cases in this category. These cancers account for approximately 5% of both admissions and incidence cases. A mid-range admission to incidence rate ratio is observed.

The average annual length of stay has fluctuated greatly, particularly in the younger 15-19 year age group, ranging from 5 to 24 days since 1999. A peak length of stay is evident for both AYA age groups in 2004-2008, which was approximately 55% higher than for preceding and following two time periods (6.6, 10.3 and 6.7 days respectively).

There were 6,460 patient days attributed to AYA eye, brain and CNS cancers between 2009 and 2013. This equated with an age-adjusted rate of 43.5 days per 100,000 AYAs. The rate for the latest period was below the reference year, with a peak rate for 2004-2008. While a small decrease in admissions was reported in 2004-2008, this was more than offset by an increase in length of stay.

Table 47- Eye, Brain and Other Parts of the Central Nervous System - Patient Days for 15-24 year olds – 5 Year Annual Mean

Eye, Brain and other Parts of the Central Nervous System		Age-adjusted Rates per 100,000 AYAs		
Male & Female		Annual Mean	Lower	Upper
Yr of Admission	Count	Age 15-24	95% CI	95% CI
1999-2003	6,616	**50.1**	48.9	51.3
2004-2008	8,508	**59.9**	58.7	61.2
2009-2013	6,460	**43.5**	42.4	44.5

Source: AIHW Principal Diagnosis Data Cubes

Thyroid and Other Endocrine Glands

Cancers of the thyroid and other endocrine gland cancers were the seventh most common reason for AYA hospital admissions, accounting for a comparable number of admissions to eye, brain and CNS cancers (i.e. approximately 5% of all cancer admissions). This proportion is lower than that the proportion of incidence cases applying to these cancers (e.g., 8% for 2000-2009).

A total of 965 admissions with this cancer type were reported for the AYA age range for 2009-2013. This corresponds with an age-adjusted annual rate of 6.1 admissions per 100,000 AYAs.

Table 48- Thyroid and Other Endocrine Glands - Hospital Admissions for 15-24 year olds – 5 Year Annual Mean

Thyroid and Other Endocrine Glands		Age-adjusted Rates per 100,000 AYAs		
Male & Female		Annual Mean	Lower	Upper
Yr of Admission	Count	Age 15-24	95% CI	95% CI
1999-2003	806	**6.1**	5.7	6.6
2004-2008	850	**6.0**	5.6	6.4
2009-2013	965	**6.1**	5.7	6.5

Source: AIHW Principal Diagnosis Data Cubes

Age-adjusted hospital admission rates were relatively stable, with only 1% change from 2009-2013 and the 1999-2003 reference period, the smallest change observed for all AYA cancers. This is in contrast to the markedly increasing age-adjusted incidence rates for thyroid cancer, particularly in females, representing one of the most common AYA cancers. Mortality rates are, by comparison, extremely low and declining which likely would be reducing numbers of admissions for end-of-life care. Analysis of admissions to incidence rate ratios suggests a mid-range ratio for these cancers (see Appendix F).

The average length of stay for AYA patients with thyroid cancer declined from 3.2 to 2.7 days between 1999-2003 and 2009-2013. This decline mainly occurred in the younger AYA age group, although 20-24 year olds have a lower overall mean length of stay. These cancers accounted for 2,631 patient days during the five year period 2009-2013, with an annual mean age-adjusted rate of 16.9 per 100,000. There was little change in the age-adjusted rate from the previous five year period but an 11% decrease from the 1999-2003 reference year.

Table 49- Thyroid and Other Endocrine Glands - Patient Days for 15-24 year olds – 5 Year Annual Mean

Thyroid and Other Endocrine Glands		Age-adjusted Rates per 100,000 AYAs		
Male & Female		Annual Mean	Lower	Upper
Yr of Admission	Count	Age 15-24	95% CI	95% CI
1999-2003	2,507	**19.0**	18.3	19.8
2004-2008	2,442	**17.2**	16.5	17.8
2009-2013	2,631	**16.9**	16.2	17.5

Source: AIHW Principal Diagnosis Data Cubes

Mesothelial and Soft Tissue

Mesothelial and soft tissue cancers (including Kaposi's sarcoma and malignant neoplasm of peripheral nerves, autonomic nervous system, retroperitoneum, peritoneum and other connective and soft tissue) accounted for 3.8% of all AYA cancer admissions in 2009-2013, with a similar proportion for males and females.

A total of 720 admissions for these cancers were reported for the AYA age range from 2009 to 2013, equating with an annual mean age-adjusted rate of 4.8 per 100,000 15-24 year olds (Appendix F). Only small changes in rates were observed, not statistically significant.

Table 50- Mesothelial and Soft Tissue - Hospital Admissions for 15-24 year olds – 5 Year Annual Mean

Mesothelial and Soft Tissue		Age-adjusted Rates per 100,000 AYAs		
Male & Female		Annual Mean	Lower	Upper
Yr of Admission	Count	Age 15-24	95% CI	95% CI
1999-2003	711	**5.4**	5.0	5.8
2004-2008	698	**4.9**	4.6	5.3
2009-2013	720	**4.8**	4.5	5.2

Source: AIHW Principal Diagnosis Data Cubes

Soft tissue cancers make up around 3% of all AYA cancer incidences. Age-adjusted incidence rates were relatively stable over the last 30 years, as were mortality rates. The mortality to incidence ratio, however, remains high. Mesothelioma cases in the AYA age group are extremely rare and therefore the small numbers of patients do not provide sufficient data to determine trends. While admission rates for soft tissue appear low, soft tissue patients have the fourth highest admission to incidence ratio (see Appendix F) possibly correlating with the higher mortality rates for this cancer.

An increase in the average length of stay of patients with mesothelial and soft tissues cancers is evident, from an average of 4 days during 1999-2003 to 5.5 days during 2009-2013. While an increase is observed in both AYA age groups, it is more pronounced in the 20-24 year group.

Despite little change in admissions, patient days increased from 2,935 (1999-2003) to 3,843 days (2009-2013). This equated to an age-adjusted rate of 24.9 patient days per 100,000 AYAs (2009-2013) increasing by 11% from the reference year and up 17% from the central period.

Table 51- Mesothelial and Soft Tissue - Patient Days for 15-24 year olds – 5 Year Annual Mean

Mesothelial and Soft Tissue		Age-adjusted Rates per 100,000 AYAs		
Male & Female		Annual Mean	Lower	Upper
Yr of Admission	Count	Age 15-24	95% CI	95% CI
1999-2003	2,935	**22.3**	21.5	23.1
2004-2008	3,044	**21.3**	20.5	22.0
2009-2013	3,843	**24.9**	24.1	25.7

Source: AIHW Principal Diagnosis Data Cubes

Digestive Organs

Malignant neoplasms of the digestive organs (including the stomach, small intestine, colon, recto-sigmoid junction, rectum, anus/anal canal, liver/bile ducts, gall bladder, biliary tract, pancreas and other/ill-defined digestive organs) accounted for 2.6% of all AYA hospital admissions in 2009-2013. For the latest reporting year (2013), the proportion of all AYA female cancers comprising digestive organ cancers was higher at 5% compared with 2% for males, possibly reflecting the higher incidence, particularly of colorectal cancer, in AYA females.

There were 487 admissions for malignant neoplasms of the digestive organs for the AYA age group (2009-2013), giving an age-adjusted AYA rate of 2.8 admissions per 100,000.

Table 52- Digestive Organs - Hospital Admissions for 15-24 year olds – 5 Year Annual Mean

Digestive Organs		Age-adjusted Rates per 100,000 AYAs		
Male & Female		Annual Mean	Lower	Upper
Yr of Admission	Count	Age 15-24	95% CI	95% CI
1999-2003	359	**2.7**	2.4	3.0
2004-2008	547	**3.8**	3.5	4.1
2009-2013	487	**2.8**	2.5	3.0

Source: AIHW Principal Diagnosis Data Cubes

Five- year annual mean rates indicated little change in the age-adjusted admission rate between 2009 and 2013 and the reference years of 1999-2003 (2%) although a 27% elevation in rate for 2004-2008 following 1999-2003. AIHW incidence data indicate a significant increase in colorectal cancer incidence rate in AYAs since the 1980s (2.4 fold increase in age-adjusted rate) over the last 30 years but without a corresponding increase in mortality. Age-adjusted admissions to incidence rate ratios are low for this cancer (Appendix F).

Average length of stay has increased for the 15-19 year age group since 1999, from a 5 year annual mean of 4.7 days to 6.1 days. In contrast, a decline in length of stay is evident for the older age group (20-24 years) from 7 days to 6.3 days for the latest 5 year period. Lengths of stay for both age groups are now comparable.

Approximately 3,062 hospital patient days were attributed to AYA digestive organ cancers in 2009-2013, with an age-adjusted rate of 16.8 days per 100,000 AYAs. As with admissions, a peak in patient days is evident for the central period of 2004-2008 with a subsequent decline to a rate for 2009-2013, similar to that for 1999-2003.

Table 53- Digestive Organs - Patient Days for 15-24 year olds – 5 Year Annual Mean

Digestive Organs		Age-adjusted Rates per 100,000 AYAs		
Male & Female		Annual Mean	Lower	Upper
Yr of Admission	Count	Age 15-24	95% CI	95% CI
1999-2003	2,160	**16.5**	15.8	17.2
2004-2008	3,096	**21.6**	20.8	22.3
2009-2013	3,062	**16.8**	16.2	17.4

Source: AIHW Principal Diagnosis Data Cubes

Female Genital Organs

Cancers of the female genital organs (including the vagina, cervix, uterus, ovaries and other unspecified organs) were responsible for 2.4% of all cancer admissions in the AYA age range. 442 admissions took place in 2009-2013 for these cancers, with an annual mean age-adjusted rate of 5.6 per 100,000 females.

Table 54- Female Genital Organs - Hospital Admissions for 15-24 year olds – 5 Year Annual Mean

Female Genital Organs		Age-adjusted Rates per 100,000 AYAs		
Females Only		Annual Mean	Lower	Upper
Yr of Admission	Count	Age 15-24	95% CI	95% CI
1999-2003	394	**6.1**	5.5	6.7
2004-2008	456	**6.5**	5.9	7.1
2009-2013	442	**5.6**	5.1	6.2

Source: AIHW Principal Diagnosis Data Cubes

While an 8% decrease was evident between the reference years and 2009-2013, and suggestion of a peak mid-way, these changes were not statistically significant. Cervical cancer is the most common of the female genital organ cancers in the AYA age range, representing 3% of all cancers diagnosed in 2000-2009 and 2% of all AYA cancer deaths. Trend data for cervical cancer show a decline in incidence from the 1980s albeit with the suggestion of a possible increase in recent years which will need further review as more data become available. Low mortality rates apply.

The ratio of the age-adjusted admission to incidence rate is low and indicative of low numbers of hospital admissions per cervical cancer patients (Appendix F).

1,700 hospital patient days were reported for AYA patients with these cancers between 2009 and 2013, with an age-adjusted rate of 22.0 per 100,000. This represents a decrease of 23% from the reference years of 1999-2003 and a 32% decrease from 2004-2008.

Table 55- Female Genital Organs - Patient Days for 15-24 year olds – 5 Year Annual Mean

Female Genital Organs		Age-adjusted Rates per 100,000 AYAs		
Females Only		Annual Mean	Lower	Upper
Yr of Admission	Count	Age 15-24	95% CI	95% CI
1999-2003	1,846	**28.6**	27.3	29.9
2004-2008	2,256	**32.5**	31.1	33.8
2009-2013	1,700	**22.0**	21.0	23.1

Source: AIHW Principal Diagnosis Data Cubes

Respiratory and Intra-thoracic Organs

Respiratory and intra-thoracic organs include the nasal cavity, middle ear, sinuses, larynx, trachea, bronchus, lungs, thymus, heart, mediastinum, pleura and other ill-defined sites in the respiratory system and intra-thoracic organs. For the AYA age group, these cancers represented only 1.5% of all hospital admissions in 2009-2013.

According to AIHW principal diagnosis data cubes, only 273 AYA patient hospital admissions occurred for these cancers between 2009 and 2013, giving an age-adjusted rate of 1.8 per 100,000 AYAs. Referring to the 95% confidence interval ranges, no clear trend in admissions is observed.

Table 56- Respiratory and Intra-thoracic Organs - Hospital Admissions for 15-24 year olds – 5 Year Annual Mean

Respiratory and Intrathoracic Organs		Age-adjusted Rates per 100,000 AYAs		
Male & Female		Annual Mean	Lower	Upper
Yr of Admission	Count	Age 15-24	95% CI	95% CI
1999-2003	275	**2.1**	1.8	2.3
2004-2008	337	**2.4**	2.1	2.6
2009-2013	273	**1.8**	1.6	2.1

Source: AIHW Principal Diagnosis Data Cubes

Incidence and mortality rates for lung cancer are low, accounting for just 1% of all AYA cancer and less than 1% of cancer deaths. The mortality to incidence rate is high, consistent with a high case fatality. The admissions to incidence rate ratio for respiratory and intra-thoracic organs is also high, the second highest of all malignant neoplasms (second only to bone and articular cartilage and higher than for haematological cancers). This indicates a high rate of admissions per patient (Appendix F).

The average length of stay for AYA patients with respiratory and intra-thoracic organ cancers increased by approximately one day between the reference years of 1999-2008 and 2009-2013 for both AYA age groups. The latest 5 year annual mean for the 20-24 year age group is slightly higher than for 15-19 years olds at 6.0 compared with 5.4 days.

A total of 1,534 AYA patient days were reported for respiratory and intra-thoracic organ cancers for 2009-2013, with an age-adjusted annual rate of 10.3 per 100,000 AYAs (see Appendix F). No clear trend in patient days is observed.

Table 57- Respiratory and Intra-thoracic Organs - Patient Days for 15-24 year olds – 5 Year Annual Mean

Respiratory and Intra-thoracic Organs		Age-adjusted Rates per 100,000 AYAs		
Male & Female		Annual Mean	Lower	Upper
Yr of Admission	Count	Age 15-24	95% CI	95% CI
1999-2003	1,244	**9.5**	8.9	10.0
2004-2008	1,697	**11.9**	11.4	12.5
2009-2013	1,534	**10.3**	9.8	10.8

Source: AIHW Principal Diagnosis Data Cubes

Other Malignant Neoplasms

Data are available for other malignant neoplasm, namely: lip, oral cavity and pharynx; urinary tract; and breast cancers. However, hospital admissions are uncommon, representing 1%, 0.5% and 0.4% respectively of all admissions. These numbers are too low for meaningful analyses of admission trends.

Key Findings/Summary

- A downward trend in all **AYA cancer admissions** is observed in contrast with increasing separations for all ages.
- **Lymphoid, haematopoietic and related tissue** malignant neoplasms were, by a significant margin, the most common cause of AYA cancer patient admissions to hospital. Declining admissions but increasing lengths of stay are evident. The admission to incidence rate ratio is high.
- **Bone and articular cartilage** cancers represent the second most common cause of AYA cancer admissions. Admissions for these cancers have remained relatively constant, in line with trends in incidence and mortality. These cancers have the highest admission to incidence rate ratio of all cancers.
- The fourth most common contributor to AYA cancer admissions is **male genital organ** cancers (after other ill-defined, secondary and unspecified cancers). A significant decline in admissions is evident despite increasing incidence. A decline in patient days is suggested despite a slight increase in length of stay. A relatively low number of admissions is evident per patient.
- **Melanoma and other malignant neoplasms of the skin** were the fifth most common reason for AYA cancer admissions although the proportion of admissions attributed to these cancers was significantly lower than their proportional contribution to incidence. Marked decreases in admissions and patient days apply, along with an exceedingly low average length of stay. These cancers have the lowest admissions to incidence rate ratio of all AYA cancers in this study.
- **Cancers of the eye, brain and other parts of the CNS** represented the sixth most common reason for AYA cancer admissions, with little change in admission, incidence and mortality rates. Variations in lengths of stay and therefore patient days were observed. A midrange admission to incidence rate ratio applied in the context of other AYA cancers studied.
- Cancers of the **thyroid and other endocrine glands** were the seventh most common reason for AYA hospital admissions, with the attributable proportion being lower than for incidence. Stable admission rates applied, despite high and increasing incidence rates. A slight decline in length of stay and patient days was suggested.
- **Mesothelial and soft tissue** cancers formed a low proportion of all AYA cancer admissions. Declines in admissions rates, but increasing length of stay and patient days, were observed. These patients have a high admission to incidence rate ratio.
- **Cancers of digestive organs** accounted for a low proportion of all AYA cancer admissions, although a higher proportion for females than males (correlating with higher incidence rates in females). There were: variations in admission rates; increases in lengths of stay for 15-19 year olds; but decreases in lengths of stay for the older age group. Age-adjusted admission to incidence rate ratios are low.
- **Female genital organ** cancers represented a low proportion of all AYA cancer admissions. A decline in admissions and patient days applied for the most recent period. A low admission to incidence rate ratio was evident.
- Cancers related to the **respiratory and intrathoracic organs** formed a very small proportion of all AYA cancer admissions. No clear trends in admission rates or patient day rates were observed. There was a high admission to incidence rate ratio (second highest of all AYA malignant neoplasms).

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