Australian Government
Australian Institute of Health and Welfare

*Authoritative information and statistics
to promote better health and wellbeing*

James Nelson
Committee Secretary
Standing Committee on Health
House of Representatives
PO Box 6021
Parliament House
Canberra ACT 2600

Dear Mr Nelson

The Australian Institute of Health and Welfare (AIHW) welcomes the opportunity to make a submission to the House of Representatives Standing Committee on Health's inquiry into skin cancer in Australia: awareness, early diagnosis and management.

The AIHW is a major national agency set up by the Australian Government in 1987 as an independent statutory authority within the Health portfolio. Our mission is to provide authoritative information and statistics to promote better health and wellbeing. We provide timely, reliable and relevant information and statistics on health, aged care services, child care services, services for people with disabilities, housing assistance, child welfare services and other community services.

We collect data and manage national data collections in these areas, producing over 100 public reports each year. Our work is frequently referenced by the media. We also provide information to other government bodies, such as the COAG Reform Council, the Productivity Commission and cross-jurisdictional councils, to external researchers and also directly back to data providers. We report in formats that suit their purposes and allow them to place their service provision in a wider context.

We also develop, maintain and promote data standards to ensure that data collected are nationally consistent. In all these activities we enable governments and the community to make better informed decisions to improve the health and wellbeing of Australians.

The AIHW has a strong track record in reporting on issues relating to both cancer and cancer screening. The AIHW compiles the *Australian Cancer Database* annually which contains national data on cancer incidence which is collected from cancer registers in each state and territory. Other major contributions AIHW makes to the understanding of cancer include the biennial publication of *Cancer in Australia: an overview* as well as the release of numerous reports on specific cancer-related topics, such as a report on skin cancer which is scheduled for release in July 2014. The AIHW also produces annual monitoring reports for the Commonwealth government-funded bowel, breast and cervical screening programs as well as various other reports related to Australia's cancer screening programs.

Background on skin cancer data

Skin cancer can be categorised as follows:

- Melanoma of the skin
- Non-melanoma skin cancer (NMSC):
  - Common NMSC, of which there are two types:
    - Basal cell carcinoma (BCC)
    - Squamous cell carcinoma (SCC)
  - Rare NMSC, of which there are numerous types.

Melanoma can start in organs other than the skin, for example the eye. In what follows,

- 'melanoma' refers only to melanoma of the skin
- 'NMSC' refers to all NMSC combined, that is to both common and rare NMSC, unless otherwise specified.

All cancers except common NMSC are notifiable diseases in Australia. This means that registration of these diseases in a central cancer registry is legally required in each state and territory. The main notifiers are hospitals and pathology laboratories but there are others. Notifiers must send the specified information about each cancer case to the central cancer registry of their state or territory. Each cancer registry puts together all this information and once a year supplies agreed data items to the AIHW, where the data are standardised and compiled into the Australian Cancer Database. The International Association for Research on Cancer, of the World Health Organization, rates the quality of Australia's cancer incidence data as 'A', which is the highest of their seven categories. The most recent year for which national incidence data are currently available is 2010. Some states have more recent data available but most are presently nearing completion of their 2011 data sets.

With respect to skin cancer mortality data, the number of deaths caused by melanoma and NMSC is known, however it is not possible to break the number of NMSC deaths into those caused by common NMSC and those caused by rare NMSC. The most recent year for which national cause of death data are available is 2011.

The NMSC surveys

Unlike melanoma and rare NMSC, common NMSC is not a notifiable disease. Its incidence has been estimated on the basis of four national surveys, conducted in 1985, 1990, 1995 and 2002 (Staples et al. 2006). The surveys were conducted through a collaboration of Australian researchers and the same methodology was used in each survey. Their survey method has some drawbacks, centred around the fact that the researchers had no way to verify respondents' claims of having had or not had skin cancer in the past 12 months if the respondent did not consent to the researchers being able to follow up with their GPs, or if those GPs did not respond to the researchers' requests for confirmation.

Latest AIHW data on skin cancer

Overall numbers and rates

Latest AIHW skin cancer incidence and mortality data as at March 2014

	Incidence in 2010		Mortality in 2011(a)	
	Number of cases	**ASR**	**Number of deaths**	**ASR**
Melanoma	11,405(b)	48.5	1,544	6.2
Non-melanoma skin cancer				
Common NMSC	416,000(c)	1,719(c)	n.a.	n.a.
Rare NMSC	766(b)	3.2	n.a.	n.a.
Total NMSC	*417,000*	*1,722*	*543*	*2.1*
Total	**428,000**	**1,771**	**2,087**	**8.3**

n.a. – not available.

ASR – age-standardised rate using the 2001 Australian standard population and expressed per 100,000 persons.

Notes:

(a) 2011 mortality data are based on the year of registration of death. The data are from the preliminary version of the Cause of Death Unit Record File and subject to revision.

(b) Cancer incidence data include AIHW estimates for NSW and ACT.

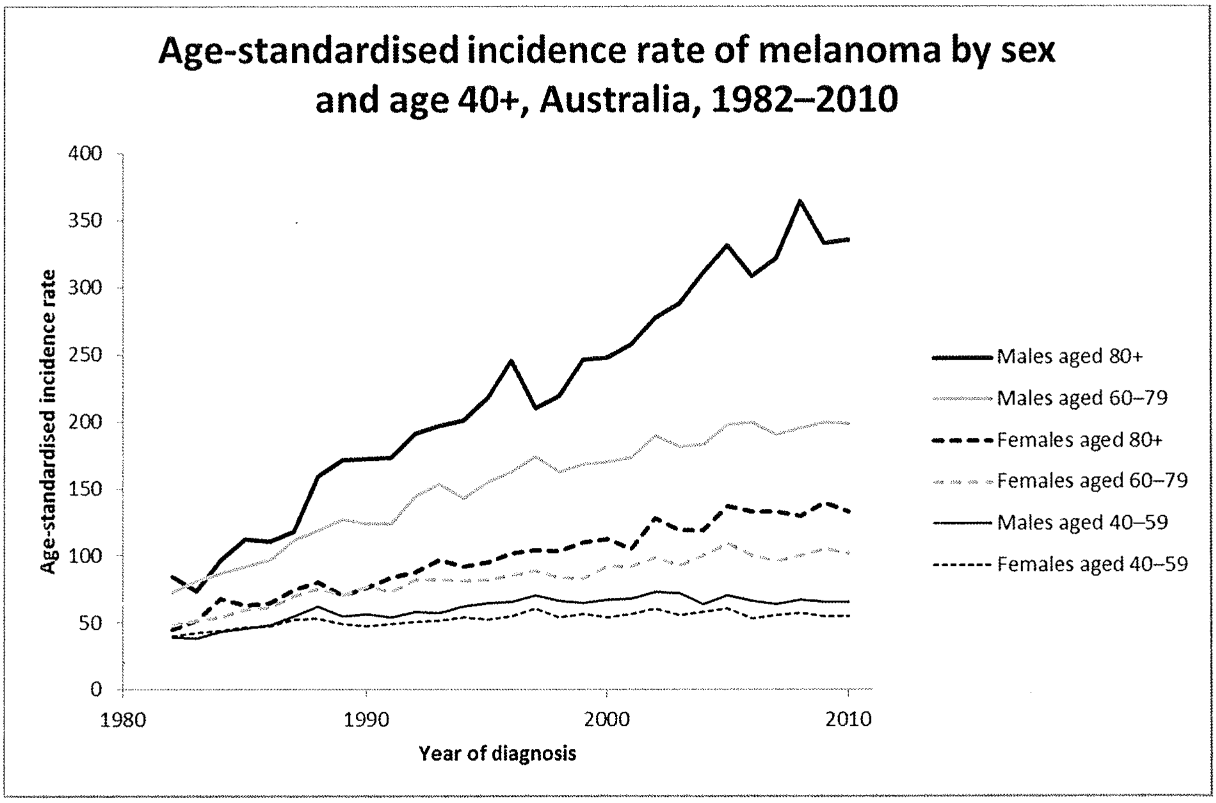
(c) Estimate based on a survey conducted in 2002 (Staples et al. 2006).

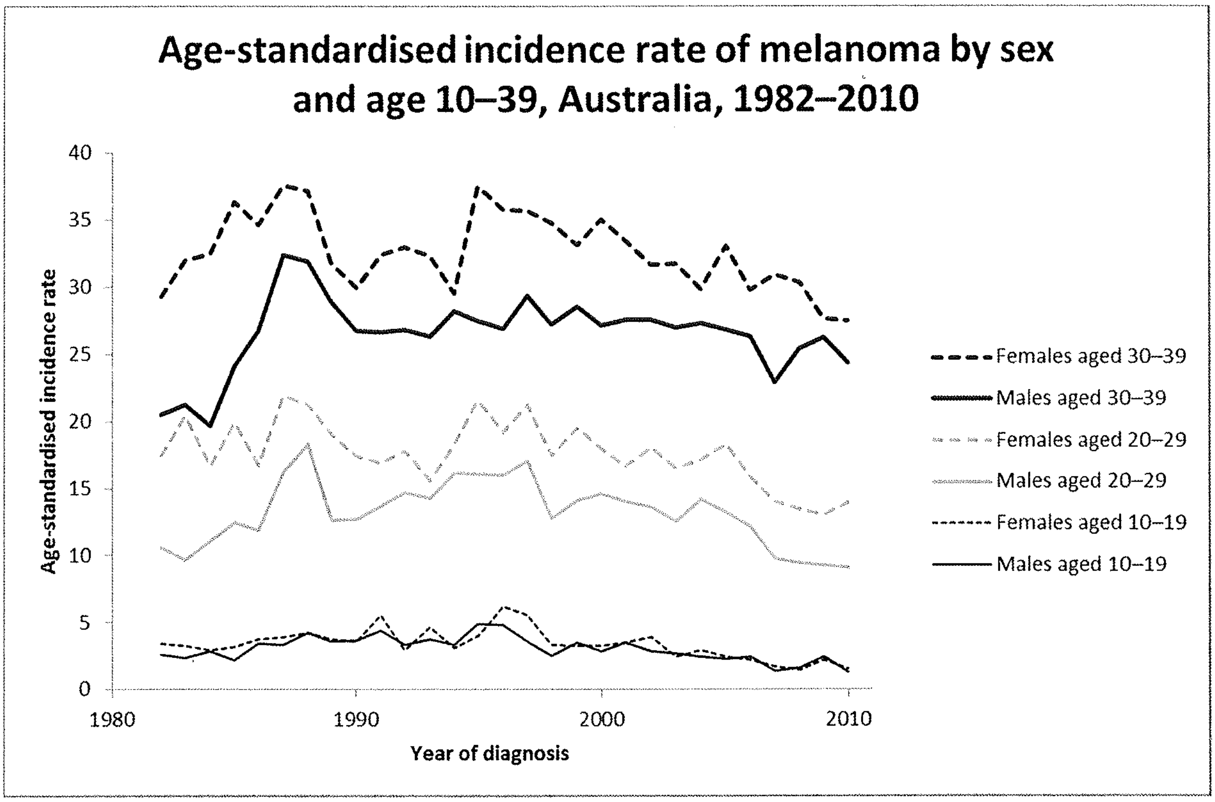
Sources: The incidence data are from the Australian Cancer Database, which is compiled by the Australian Institute of Health and Welfare (AIHW) from data provided by the state and territory cancer registries. The mortality data are from the National Mortality Database, which is compiled by the AIHW from data provided by the state and territory Registries of Births, Deaths and Marriages and the National Coronial Information System, and coded by the Australian Bureau of Statistics.

Melanoma: incidence

- In 2010, melanoma was the 5th most common cancer in Australia, with 11,405 new cases (6,700 males and 4,705 females) (AIHW 2014).
- The incidence rate of melanoma has been rising since national records began in 1982. It is projected that there will be 17,570 new cases of melanoma diagnosed in 2020, an increase of 54% over the 2010 figure (AIHW 2012a).
- Although the overall age-standardised incidence rate of melanoma is increasing, when the data are split into separate age groups as in the graphs and table that follow, it is evident that incidence rates are increasing in people aged 60 and over whereas they are decreasing in people under 60. Furthermore, rates are increasing fastest in the oldest age groups and decreasing fastest in the youngest age groups. These patterns correlate with how old people were when sun protection campaigns began in Australia. It is known that the major determinant of lifetime potential for skin cancer is sun exposure during childhood and adolescence (Armstrong 2004), although adult sun exposure does also have some effect. Sun protection campaigns began in Australia in the 1970s and were prominent from the 1980s onwards. People who turned 20 in or before 1970, i.e. those who were 60 or more in 2010, had already been exposed to the most critical sun damage during childhood and adolescence so could not benefit as much from subsequent sun protection behaviour. People under the age of 20 in 1970 (those aged under 60 in 2010) would have been increasingly exposed to sun protection campaigns, and changes in their behaviour would be expected to have a greater effect. The fact that incidence rates are

decreasing fastest in the youngest age groups suggests that over the years a greater proportion of young people have followed the advice given in sun protection campaigns. While this is good news, the greatest number of cases—about 58%—occur in people aged 60 and over, for whom rates are increasing. Thus the overall incidence rate and the total number of cases are expected to continue to increase for many years to come, continuing to place an increasing burden on the health system.





Average annual change in age-standardised incidence rate of melanoma by sex and age group over the 10 years 2001–2010, Australia

	Sex	
Age group	**Male**	**Female**
80+	+3.0% p.a.	+2.2% p.a.
60–79	+1.3% p.a.	+0.9% p.a.
40–59	–0.9% p.a.	–0.7% p.a.
30–39	–1.4% p.a.	–1.8% p.a.
20–29	–5.4% p.a.	–3.4% p.a.
10–19	–8.1% p.a.	–9.0% p.a.

Melanoma: mortality

- While melanoma is much less common than NMSC, it results in about three times as many deaths, with 1,544 deaths in 2011 (1,071 males and 473 females) (AIHW 2014).

Melanoma: prevalence

- At the end of 2007 there were 45,753 living Australians who had been diagnosed with melanoma sometime in the previous 5 years, and 136,016 living Australians who had been diagnosed with melanoma sometime in the previous 26 years (from when national records began) (AIHW 2012b).

Melanoma: survival

- Survival from melanoma is among the highest of all cancers. In the period 2006–2010, 5-year relative survival from melanoma was 91% (89% for males and 94% for females). For comparison, the 5-year relative survival for other common cancers was 92% for prostate cancer, 89% for female breast cancer, 66% for bowel cancer and 14% for lung cancer (AIHW 2012b).
- The thickness of a melanoma at its time of removal is a good indicator of prognosis. As the following table shows, the thinner the melanoma, the greater the likelihood of survival.

5-year relative survival for melanoma, by melanoma thickness, Australia, diagnoses 2001–2007, period of follow-up 2006–2010 (calculated using the period method)

Melanoma thickness	5-year relative survival
0.01–1.00 mm	99.8%
1.01–2.00 mm	90.1%
2.01–4.00 mm	76.5%
4.01+ mm	55.0%

Melanoma: hospitalisations

- Among all hospitalisations in 2011–12 with a principal diagnosis of cancer, melanoma was the 10th most common, with 10,753 hospitalisations (unpublished data from AIHW National Hospital Morbidity Database).

Melanoma: primary care

- The prevention, management and treatment of melanoma beyond hospital settings cannot be examined in detail because there is very little or no information about the prevention of melanoma either at the population or individual level. With the exception of the data collected through the Bettering the Evaluation and Care of Health (BEACH) Survey of General Practice, there is very little information on primary health care activity (such as public and private allied health services, state-funded community health services, pharmacy, ambulance and tele-health services) or specialist consultations. The BEACH Survey has not been independently evaluated, relies on a paper-based rather than electronic surveying method and has relatively low GP response rates (between 23% and 33% responding to the initial invitation in the 10 years to 2010-11), and results therefore need to be interpreted with caution.

Melanoma: expenditure

- In 2008–09, the cost of treatment for melanoma was estimated to be $49.5 million (unpublished data from AIHW Disease Expenditure Database). Expenditure estimates are derived from combining information from the National Hospital Morbidity Database, the National Public Hospitals Establishments Database, the Health expenditure database, the National Hospital Cost Data Collection and the Bettering the Evaluation and Care of Health (BEACH) Survey of General Practice. Note that it is not possible to allocate all expenditure on health goods and services to specific diseases, e.g. capital expenditure and health administration. The AIHW's model produces conservative estimates of health expenditure and equates to about 70% of total recurrent health expenditure.

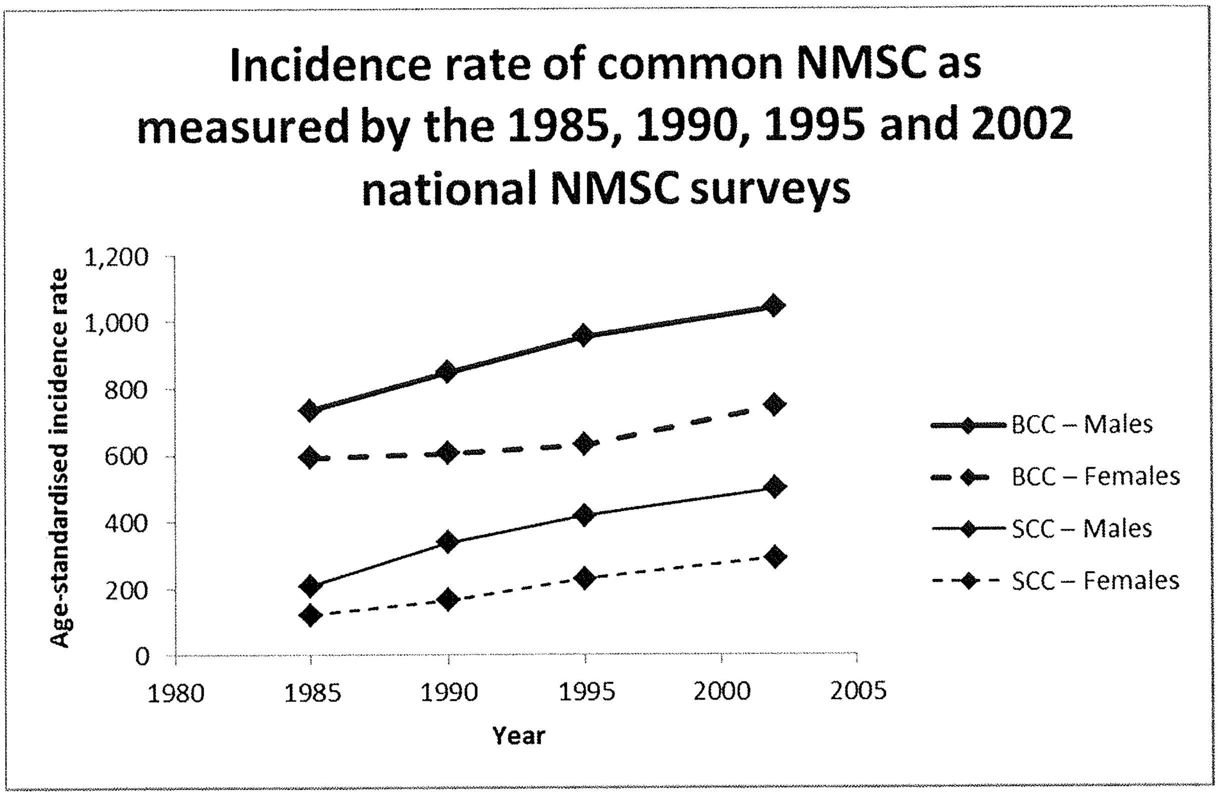
Melanoma: international comparisons

- According the WHO/IARC database GLOBOCAN 2012:
  - Male incidence: Australia has the highest incidence rate of male melanoma in the world (40.5 cases per 100,000), followed very closely by New Zealand (39.2) and then Switzerland (20.2) whose rate is very much less than those of Australia and New Zealand.
  - Female incidence: New Zealand has the highest incidence rate of female melanoma in the world (33.1), followed by Australia (30.0) and then Denmark (22.1).
  - Male mortality: New Zealand has the highest mortality rate of male melanoma in the world (6.9), followed by Australia (5.8) and then Norway (4.7).
  - Female mortality: Slovenia has the highest mortality rate of female melanoma in the world (3.1). New Zealand has the third highest (2.8) and Australia has the sixth highest (2.3).

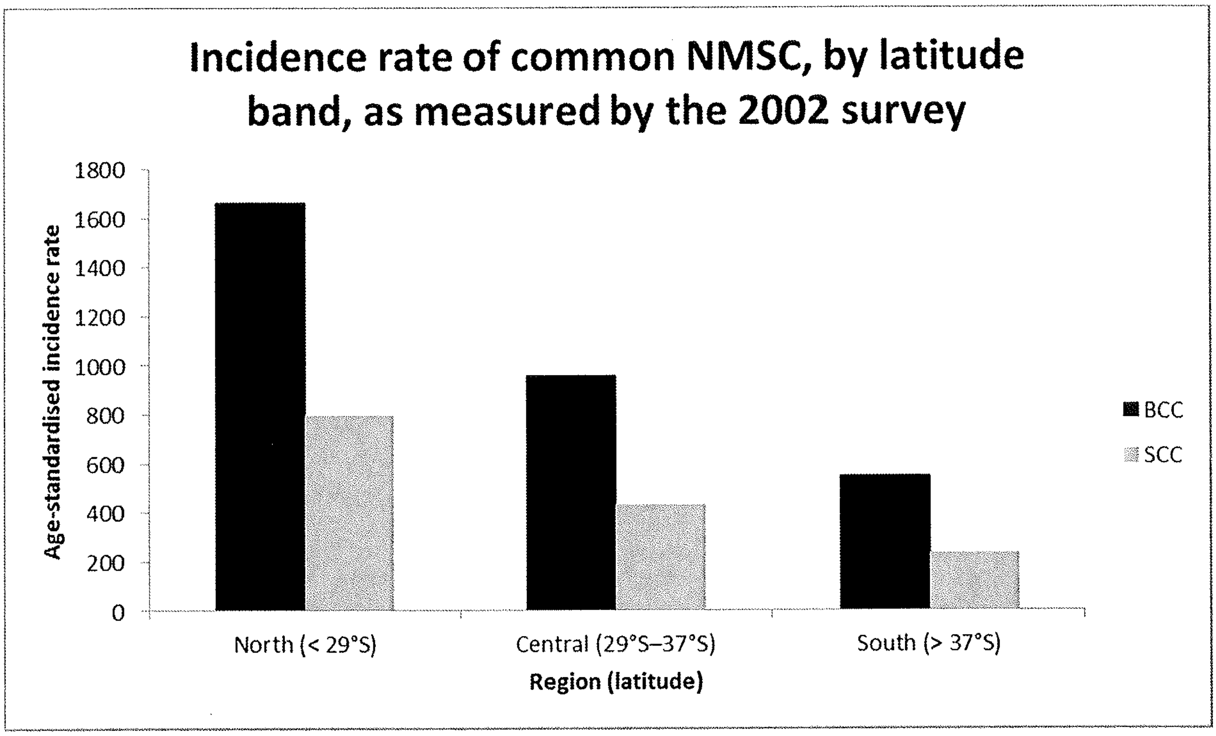
  Note: the age-standardised rates quoted in this section have been standardised using broader age groups and a different standard population than elsewhere in these statistics. These rates cannot be compared to those quoted outside this section.

Non-melanoma skin cancer: incidence

- In 2002, Australia had the highest skin cancer incidence rate in the world. It was estimated that about 2 in 3 Australians would be diagnosed with NMSC by the time they were 70 years old (Staples et al. 2006).
- Common NMSC is by far the most common cancer in Australia. By applying the age-specific incidence rates obtained from the 2002 survey to Australia's 2010 population it is estimated that about 416,000 cases of common NMSC would have been diagnosed in 2010. Based on this estimate NMSC would have outnumbered all other cancers combined by more than 3.5 to 1. Note that this estimate may be conservative because it assumes that the rates in 2010 were the same as in 2002 whereas the four surveys suggest that the rate is in fact rising (see next point).
- The first survey of NMSC incidence was conducted in 1985. Each subsequent survey (1990, 1995 and 2002) found higher rates of BCC and SCC than the previous survey (see following graph).



- The 2002 survey found a very strong association between latitude and the incidence of common NMSC (see following graph). The researchers divided Australia into three broad latitude bands: 'north' was separated from 'central' by the parallel of latitude 29°S, which coincides with the long straight section of the border between Queensland and NSW, and 'central' was separated from 'south' by 37°S, which runs through approximately the middle of Victoria, placing most of Victoria's population in the south region.



Non-melanoma skin cancer: mortality

- Compared to the extremely high incidence of NMSC, mortality is quite low, with 543 deaths in 2011 (355 males and 188 females) (AIHW 2014).

Non-melanoma skin cancer: hospitalisations

- Among all hospitalisations in 2011–12 with a principal diagnosis of cancer, NMSC was the most common, with 98,621 hospitalisations (unpublished data from AIHW National Hospital Morbidity Database).

Non-melanoma skin cancer: primary care

- The prevention, management and treatment of NMSC beyond hospital settings cannot be examined in detail because there is very little or no information about the prevention of NMSC either at the population or individual level. With the exception of the data collected through the Bettering the Evaluation and Care of Health (BEACH) Survey of General Practice, there is very little information on primary health care activity (such as public and private allied health services, state-funded community health services, pharmacy, ambulance and tele-health services) or specialist consultations. The BEACH Survey has not been independently evaluated, relies on a paper-based rather than electronic surveying method and has relatively low GP response rates (between 23% and 33% responding to the initial invitation in the 10 years to 2010-11), and results therefore need to be interpreted with caution.

Non-melanoma: expenditure

- In 2008–09, the cost of treatment for NMSC was estimated to be $367.4 million. NMSC ranked second out of all cancers in terms of health system expenditure (AIHW 2013).

References for the above statistics

AIHW 2012a. Cancer incidence projections, Australia 2011 to 2020. Cancer series no. 66. Cat. no. CAN 62. Canberra: AIHW. [p. ix]

AIHW 2012b. Cancer survival and prevalence in Australia: period estimates from 1982 to 2010. Cancer series no. 69. Cat. no. CAN 65. Canberra: AIHW. [p. 87]

AIHW 2013. Health system expenditure on cancer and other neoplasms in Australia: 2008–09. Cancer series no. 81. Cat. no. 78. Canberra: AIHW. [p. 12]

AIHW 2014. Australian Cancer Incidence and Mortality (ACIM) books for 2014. Canberra: AIHW <http://www.aihw.gov.au/acim-books/>.

Armstrong BK 2004. How sun exposure causes skin cancer. In: Hill DJ, Elwood JM & English DR (eds). Prevention of skin cancer. Dordrecht: Kluwer, 89–116.

Staples MP, Elwood M, Burton RC, William JL, Marks R & Giles GG 2006. Non-melanoma skin cancer in Australia: the 2002 national survey and trends since 1985. Medical Journal of Australia 184(1): 6–10.

Recommendation: Consider collecting regular national data on the incidence of non-melanoma skin cancer in Australia

Common NMSC is by far the most common cancer in Australia, outnumbering all other cancers combined by more than 3.5 to 1. Although rarely fatal and usually not complicated to treat, the sheer number of these cancers places significant costs on the Australian health system. As outlined above, NMSC ranked second out of all cancers in terms of health system expenditure in 2008–09. However, currently there is a data gap in relation to the annual incidence of common NMSC because it is not a notifiable disease, and the latest available national estimates based on survey data are now nearly 12 years old.

It is important to measure the incidence of common NMSC at regular intervals because this information is essential both in establishing a baseline and assessing the impact that prevention and public awareness programs are having and whether there are differences by sex, age, state/territory or other characteristics.

There are a number of different models that could be used to collect regular national data on the incidence of common NMSC in Australia. Some potential options for collecting the necessary information are to:

1. include common NMSC as a notifiable cancer in each state and territory and collecting complete data through cancer registries
2. include common NMSC as a notifiable cancer in a set of 'sentinel' regions of Australia and collecting complete data for these regions through cancer registries
3. collect information through regular national surveys approximately every 5 years
4. investigate the utility of other available data for producing NMSC incidence estimates that are fit for purpose.

Further scoping work would need to be undertaken to determine the most appropriate option, however the following are some general considerations for each of these four options.

Option 1: Include common NMSC as a notifiable cancer in each state and territory and collecting complete data through cancer registries

Common NMSC being included as a notifiable cancer would provide highly accurate and ongoing annual information on the incidence of common NMSC in Australia. However, as there are more than 3.5 times as many cases of common NMSC as all other cancer cases combined, state and territory cancer registries would need greater resources and capacity to cope with the increased number of notifications. Also, not all suspected common NMSCs are currently sent to pathology laboratories for verification so more samples of suspected common NMSCs would need to be sent to pathology laboratories, increasing their workload and associated costs. Many common NMSCs are treated by GPs and dermatologists who are currently not legally required to notify any other cancers and hence legislation would need to be changed to make them notifiers of common NMSC.

While including common NMSC as a notifiable cancer would provide the highest quality data possible, there would be costs and issues which may outweigh the benefits. If additional resourcing were available, the collection of NMSC incidence data through cancer registries would need to be prioritised against other data needs such as the collection of stage of cancer at diagnosis.

Note that Tasmania collected all NMSCs diagnosed from when their cancer register was established in 1982 through until 2005 when it became clear that they could not continue to register common NMSCs with the resources they had.

The AIHW does not consider this a preferred option due to the significant costs and issues identified, although it would provide the highest quality data possible on the incidence of common NMSC.

Option 2: Include common NMSC as a notifiable cancer in a set of 'sentinel' regions of Australia and collecting complete data for these regions through cancer registries

While this option would involve lower overall costs than option 1, all the same issues would need to be considered only on a smaller scale. The quality of data provided through this model would not be as high as that from option 1 because it would only be a sample of data, but a careful selection of the sentinel regions would mean that the results could be representative of the whole of Australia. An additional cost under this option is that periodic monitoring of the demographics and characteristics of the sentinel regions may be needed to ensure the selected 'sentinel' regions remained representative of the whole country.

While including common NMSC as a notifiable cancer in sentinel regions would provide high quality data, there would be costs and issues which may outweigh the benefits. If additional resourcing were available, the collection of NMSC incidence data through cancer registries for sentinel regions would need to be prioritised against other data needs such as the collection of stage of cancer at diagnosis.

Due to the costs and issues identified, the AIHW does not consider this a preferred option, although it may be worth including this option in any further scoping work that is undertaken.

Option 3: Collect information through regular national surveys approximately every 5 years

Collecting information on the incidence of common NMSC through regular national surveys would update information on incidence, allow for the monitoring of trends in incidence rates in different sectors of the community (e.g. males versus females, different age groups, different regions) and allow better incidence estimates to be made for the years in between surveys. Potentially a national survey could also help to assess, and increase, the level of awareness of skin cancer in the Australian community and identify effective strategies for prevention and increasing public awareness.

The cost of collecting information on common NMSC through regular national surveys, while not insignificant, is likely to be less than option 2 and substantially less than option 1. While the quality of data on the incidence of common NMSC collected through a national survey would be high, the incidence estimates would be subject to sampling error and this may limit the extent to which results can be generalised to the Australian population, particularly for smaller population groups. One major benefit of collecting information through a national survey is that as well as collecting data on the incidence of common NMSC, a survey could also be used to collect other high-priority information in relation to skin cancer (such as information on public awareness and prevention) and conducting a survey would also provide opportunities to increase public awareness of skin cancer.

The AIHW considers it would be worthwhile undertaking some further scoping work to explore the feasibility, costs and potential benefits of this option.

Option 4: Investigate the utility of other available data for producing NMSC incidence estimates that are fit for purpose

Other data that are currently available may be able to be used to produce regular estimates of the incidence of common NMSC in Australia. For example, it may be possible to use Medicare Australia data to produce regular estimates of the incidence and prevalence of skin cancer. Further investigations may reveal that the use of data linkage to bring together two or more existing data sources could be beneficial in estimating common NMSC incidence. If so, the AIHW would be well-placed to do such work, as an accredited Commonwealth Integrating Authority.

The first step may be a feasibility study. If it is found to be feasible to use existing data sources to produce regular estimates of common NMSC incidence, this option is likely to involve the lowest overall cost, however, the resulting data may have some limitations. As these data sources are not specifically designed for the purpose of measuring the incidence of common NMSC there could be certain limitations in what it is possible to estimate and the accuracy of estimates produced.

The AIHW considers it would be worthwhile undertaking some further scoping work to explore the feasibility, costs and potential benefits of this option.

We would be pleased to discuss our understanding of skin cancer in Australia and our recommendation to consider collecting regular national data on the incidence of non-melanoma skin cancer in Australia further at your request.

Yours sincerely

Mr David Kalisch
Director (CEO)
27 March 2014