



The burden of Non-Melanoma Skin Cancer (NMSC) in Australia

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SANOFI

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A note on naming:

In this report, Non-Melanoma Skin Cancer (NMSC) is described as either 'early stage' or 'advanced'. Early stage NMSC is common, and is characterised by tumours on the skin that have not invaded underlying or surrounding body tissues. Advanced disease is relatively rare, and includes locally advanced cancers (characterised by the movement of tumour cells into underlying or surrounding tissues, a process termed 'invasion'),¹ regional metastatic disease (where cancer cells have moved into lymph nodes) and distant metastatic disease (where cancer cells have moved into parts of the body that are distant from the site of the original tumour). The incidence of each of these stages of disease is discussed further in section 2 of this report. Metastasis is the development of a secondary tumour at a distance from a primary site of cancer.

Acknowledgements

In this report, some patient stories are presented, describing the experience of NMSC patients living with the disease. These are real stories, provided by real NMSC patients, and used with their permission. We thank these patients for their time and candour in sharing their stories. A number of patient photographs, depicting examples of non-melanoma skin cancers, are included in the report. These images are all used with patient consent. We would like to acknowledge the Australian NMSC experts who gave their time to contribute to this report. We also acknowledge the support of PwC Australia to complete the quantitative analysis and findings presented in this report.

¹ Invasive cancer is cancer that has spread beyond the layer of tissue in which it developed and is growing into surrounding, healthy tissues. Definition from National Cancer Institute. Retrieved from: <<https://www.cancer.gov/publications/dictionaries/cancer-terms/def/invasive-cancer>>.

EXECUTIVE SUMMARY

Approximately 587,000 Australians will be diagnosed with skin cancer in 2020; 97 per cent (n=570,100) will be a non-melanoma skin cancer (NMSC). These potentially deadly cancers include cutaneous squamous cell carcinoma (cSCC) and basal cell carcinoma (BCC). Aside from treating clinicians, there is a lack of awareness of the potential morbidity and mortality of advanced NMSC.

This report modelled relative survival data to predict that in 2020, 1,700 adults in Australia will die from advanced NMSC. This translates to up to 4 Australians losing their lives each day due to NMSC. It is estimated that the economic cost of NMSC to Australia will reach \$1.2 billion in 2020.

Melanoma, which accounts for approximately 3 per cent of new skin cancers diagnoses, has seen major advancements in treatments and disease awareness over recent years. By comparison, advanced NMSC has not received the same attention, despite the serious nature of the disease.

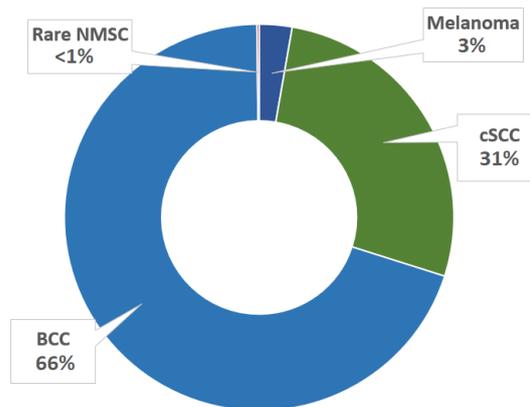
The burden of advanced NMSC for people living in rural and remote areas - particularly farmers - can be more pronounced than for people living in metropolitan centres. This is because they often have limited access to specialists, multi-disciplinary teams and tertiary hospitals. Due to the visible nature of this type of cancer in its advanced stages, there are also serious mental health issues as patients may become isolated and depressed. The patient stories presented in this report demonstrate advanced NMSC may have profound impacts on individuals and their loved ones, yet the patients had little awareness of NMSC prior to diagnosis.

Despite public health efforts to address the risk of skin cancer, NMSC continues to occur frequently in Australia.² The cancer specialists and the patients who were consulted during the preparation of this report agreed that personal vigilance is essential, and that ready access to appropriate clinical care in the community (non-hospital) setting, followed by prompt referral to specialist care where needed, is vital to ensure fast and accurate diagnoses can be made.

Localised NMSC, where the cancer has not spread through the deeper layers of the skin and/or to other parts of the body, can generally be successfully treated. Likewise, BCC patients with advanced disease have benefitted from the introduction of newer generation targeted therapies. For the small percentage of cSCC patients (up to 5 per cent) who are not candidates for curative surgery or curative radiation, there are currently no approved treatments, leading to high morbidity and mortality among this sub-group of NMSC patients, as well as impacts on quality of life.

Comprehensive and up-to-date data regarding incidence and disease-specific mortality are lacking. Beyond clinical trials, there is limited access to effective therapies for advanced cSCC patients who are not candidates for curative surgery or curative radiation. As a result, further research and data collection is needed to better understand incidence, prevalence, cancer staging, mortality and biomarkers for effective treatments for NMSC. Research would also provide the evidence base for broader access to medicines which are effective in treating NMSC, including advanced cSCC for which there are currently few options.

PwC estimated new cases of skin cancer in Australia in 2020:³ 587,000



In 2020, the economic cost of NMSC is estimated to reach:

\$1.2 billion

direct costs, including treatment costs, out-of-hospital costs as well as out-of-pocket expenses

\$10 million

indirect costs, including absenteeism resulting from the additional time off work

7,700 years

of life lost due to premature mortality

² Australian Institute of Health and Welfare. Skin cancer in Australia. Canberra, ACT: AIHW, Department of Health; 2016 Jul 13 [cited 2018 Oct 8]. Report No.: CAN 96. Retrieved from <<https://www.aihw.gov.au/reports/cancer/skin-cancer-in-australia/contents/table-of-contents>>.

³ Australian Institute of Health and Welfare (AIHW) 2018 Cancer Data in Australia; Canberra: AIHW. <https://www.aihw.gov.au/reports/cancer/cancer-data-in-australia/> and Figure 3 of this report.



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1. BURDEN AND CHALLENGES OF NMSC IN AUSTRALIA



1. BURDEN AND CHALLENGES OF NMSC IN AUSTRALIA

1.1 Introduction to NMSC

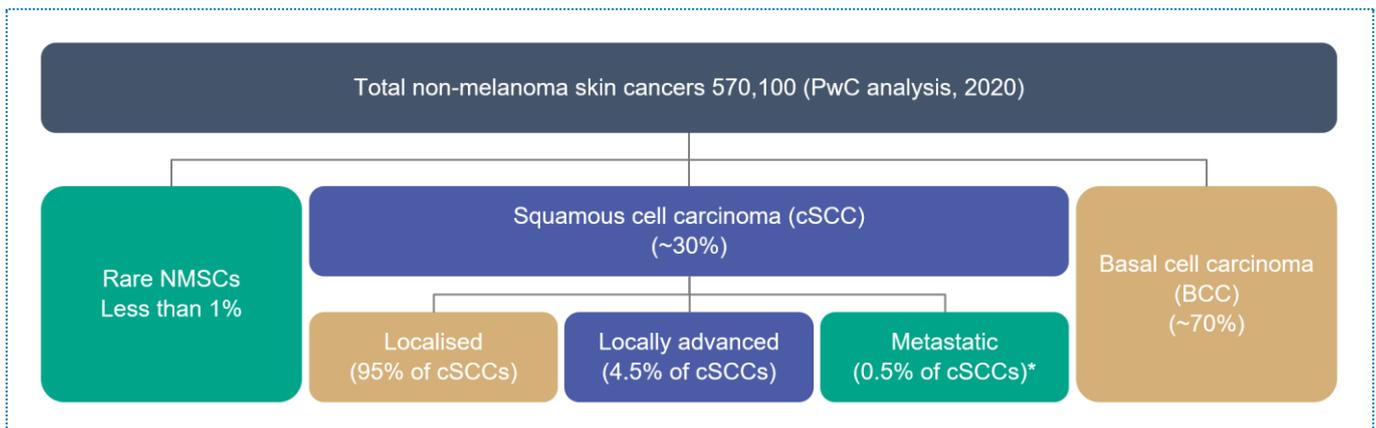
Non-melanoma skin cancers (NMSC) are the most common cancers in Australia and include two main types: cutaneous⁴ squamous cell carcinoma (cSCC) and basal cell carcinoma (BCC), accounting for approximately 30 per cent and 70 per cent of NMSC respectively (Figure 1).⁵ A third group of rare NMSCs, which includes all NMSCs other than cSCCs and BCCs, accounts for less than 1 per cent of total NMSC cases; these diseases are not within the scope of this report.⁶

Section 2 of this report presents data analysis that shows that there are over half a million new cases of cSCC and BCC in Australia annually. Due to the high number of skin cancers, relative to our small population size, Australia and New Zealand have the highest total rate of cancer in the world.⁷ The sheer number of NMSC cases represents a substantial cost to the Australian health system and to individual patients and their families. Moreover, for those

patients whose disease progresses to an advanced state, current treatment options are limited, potentially leading to high morbidity, mortality and impacts on quality of life.^{8,9,10,11}

Rates of NMSC among the Australian population are high and increasing, primarily due to the ageing population and historic migration patterns from largely fair-skinned countries in Western Europe. In addition, our hot climate, historical approach to sun protection, and an outdoor lifestyle, contribute to make Australia the global 'skin cancer capital', and yet for many people, NMSC is a relatively unknown health issue. As will be discussed in Section 2 of this report, cases of cSCC and BCC in Australia number in the hundreds of thousands each year, and therefore these diseases contribute substantially to Australian healthcare system costs, as well as additional costs to patients, their loved ones and the community more broadly.¹²

Figure 1: Estimated breakdown of non-melanoma skin cancers, 2020



* Note: some patients will progress to metastatic disease after their initial diagnosis with localised disease

⁴ Cutaneous is another word for skin and is used to distinguish cSCC from SCC that occurs in the mouth and throat.
⁵ Cancer Council. (2019). *Non-melanoma cancer*. Retrieved from: <<https://www.cancer.org.au/about-cancer/types-of-cancer/skin-cancer/non-melanoma.html>>.
⁶ Australian Institute of Health and Welfare (AIHW). (2016). *Skin cancer in Australia*. Retrieved from: <<https://www.aihw.gov.au/reports/cancer/skin-cancer-in-australia>>.
⁷ Bray F, Ferlay J, Soerjomataram I, Siegel RL, Torre LA, & Jemal A. Global Cancer Statistics 2018: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries. *CA Cancer J Clin* 2018; 68: 394-424. The online GLOBOCAN 2018 database is accessible at <http://gco.iarc.fr/>, as part of IARC's Global Cancer Observatory.
⁸ Rhee JS, Matthews A, Neuberger M, Logan BR, Murzynski M & Nattinger AB (2006). Validation of a Quality-of-Life instrument for patients with nonmelanoma skin cancer. *Arch Facial Plast Surg*. 8(5):314-318.
⁹ Berens AM, Akkina SR & Patel SA (2017). Complications in facial mohs defect reconstruction. *Curr Opin Otolaryngol Head Neck Surg*. 25(4):258-264.
¹⁰ Harwood CA, Proby CM, Inman GJ & Leigh IM. (2016). The promise of genomics and the development of targeted therapies for cutaneous squamous cell carcinoma. *Acta Derm Venereol*; 96(1):3-16.
¹¹ Kauvar ANB, Arpey CJ, Hruza G, Olbricht SM & Bennett R. (2015). *Dermatol Surg*. 41(11):1214-1240.
¹² AIHW (2019). *Cancer in Australia 2019*. Cancer series no.119. Cat. no. CAN 123. Canberra and Fransen M et al. Non-melanoma skin cancer in Australia. *Med J Aust* 2012; 197 (10): 565-568.

1.2 NMSC incidence and prevalence

1.2.1 Incidence of NMSC

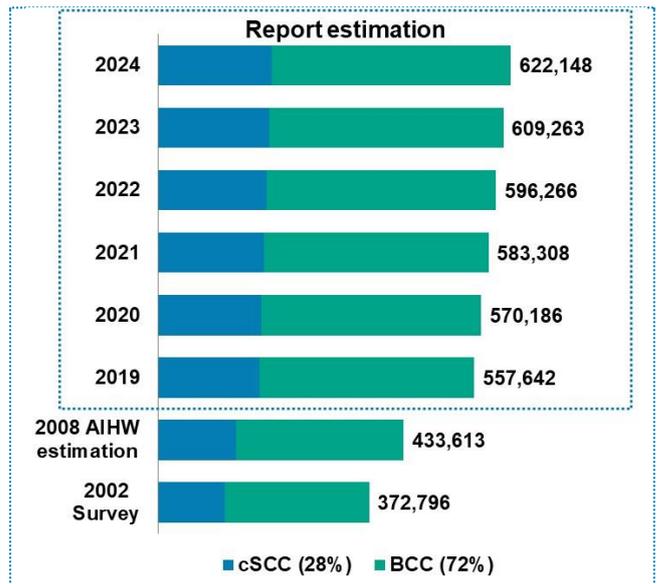
Every year, in Australia, skin cancers account for around 80% of all newly diagnosed cancers (mostly caused by exposure to the sun) and general practitioners have over 1 million patient consultations per year for skin cancer.¹³ Incidence of skin cancer in Australia is one of the highest in the world, two to three times the rates in Canada, the US and the UK.¹³

Figure 2: Estimated age-standardised incidence of non-melanoma skin cancer, all ages in world in 2018¹⁴



The *incidence* of a disease is defined as the rate of new cases diagnosed during a time period (generally one year), providing a measure of risk of being diagnosed with a condition. In Australia, there was an increase in the incidence of cSCC and BCC between 1985 and 2002, which was the most recent year for which national data is available.¹⁵ In 2008, the AIHW¹⁶ used the 2002¹⁷ nationwide data to predict NMSC incidence for that year and estimated that the absolute incidence of BCC across Australia rose from approximately 254,700 in 2002 to 296,000 in 2008, and for cSCC, from approximately 118,100 to 137,700 for the same time period (see Figure 3).

Figure 3: New cases of cSCC and BCC in 2002¹⁸ (survey), 2008 (AIHW estimation)¹⁹ and PwC projections from 2020 to 2024



Locally advanced cSCC (auricular lesion): not a candidate for curative surgery or curative radiation²⁰



¹³ Cancer Council Australia (2019). Skin cancer. Retrieved from: <<https://www.cancer.org.au/about-cancer/types-of-cancer/skin-cancer.html>>.

¹⁴ Khazaei Z, Ghorat F, Jarrahi AM, Adineh HA, Sohrabivafa M, Goodarzi E. (2019). Global Incidence and mortality of skin cancer by histological subtype and its relationship with the human development index (HDI); an ecology study in 2018. *World Cancer Research Journal*, 6:e1265.

¹⁵ Lomas A, Leonardi-Bee J, & Bath-Hextall F. (2012). A systematic review of worldwide incidence of nonmelanoma skin cancer. *British Journal of Dermatology*, 166(5), 1069-1080.

¹⁶ Australian Institute of Health and Welfare & Cancer Australia 2008. Non-melanoma skin cancer: general practice consultations, hospitalisation and mortality. Cancer series no. 43. Cat. no. 39. Canberra: AIHW.

¹⁷ Staples MP, Elwood M, Burton RC, Williams 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, 6-10.

¹⁸ Ibid.

¹⁹ Australian Institute of Health and Welfare & Cancer Australia 2008. Non-melanoma skin cancer: general practice consultations, hospitalisation and mortality. Cancer series no. 43. Cat. no. 39. Canberra: AIHW.

²⁰ Data on File, Sanofi Genzyme.

Projections for the number of new cases of cSCC and BCC estimate that by 2024, there will be over 200,000 cases of cSCC and over 421,000 cases of BCC diagnosed across Australia, totalling over 620,000 with NMSC. Relative to population, this rate is higher than for any other country.²¹ The rate of new NMSC cases in some Australian states, such as Queensland, is even higher than the Australian average.²²

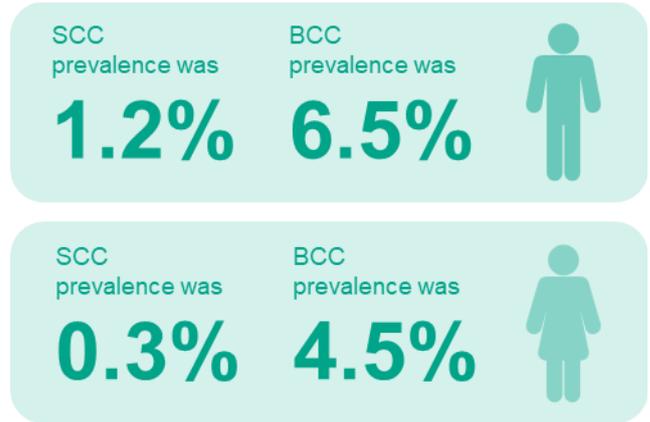
1.2.2 Prevalence of NMSC

Disease prevalence is defined as the actual number of people living with the disease during a period of time or at a point in time. Data on the prevalence of NMSCs in Australia is limited and reports have been variable depending on the patient population investigated. A 2008 study by the National Cancer Control Initiative gathered prevalence data for survey respondents aged 45 and over, finding that 26 per cent of individuals surveyed (over 103,000) reported ever having had NMSC.²³

In 2002, prevalence of NMSC in Australia was estimated to be 2 per cent.²⁴ Studies suggest that prevalence is higher in

Queensland²⁵ at 4.6 per cent, for those aged 20-69 years.²⁶

In 1987, a survey of over 4,200 participants aged between 40-64 in Western Australia found that:²⁷



Metastatic cSCC (clavicular lesions): not a candidate for curative surgery or curative radiation²⁸



²¹ Lomas A, Leonardi-Bee J, & Bath-Hextall F. (2012). A systematic review of worldwide incidence of nonmelanoma skin cancer. *British Journal of Dermatology*, 166(5), 1069-1080.

²² Perera E, Gnaneswaran N, Staines C, Win AK, & Sinclair R. (2015). Incidence and prevalence of non-melanoma skin cancer in Australia: A systematic review. *Australas Journal of Dermatology*, 56(4), 258-267.

²³ Kenny P, Haas M, & Hall J. (2010). *Costs of non-melanoma skin cancer*. Sydney, NSW: CHERE.

²⁴ Staples MP, Elwood M, Burton RC, Williams 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, 6-10.

²⁵ Perera E, Gnaneswaran N, Staines C, Win AK, & Sinclair R. (2015). Incidence and prevalence of non-melanoma skin cancer in Australia: A systematic review. *Australas Journal of Dermatology*, 56(4), 258-267.

²⁶ Green A, Beardmore G, Hart V, Leslie D, Marks R, & Staines D. (1988). Skin cancer in a Queensland population. *Journal of the American Academy of Dermatology*, 19, 1045-1052.

²⁷ Krickler A, English DR, Randell PL, Heenan PJ, Clay CD, Delaney TA, & Armstrong BK. (1990). Skin cancer in Geraldton, Western Australia: a survey of incidence and prevalence. *Medical Journal of Australia*, 152, 399-407.

²⁸ Data on File, Sanofi Genzyme.

1.3 Risk and protective factors for NMSC

Risk factors

There are various risk factors, both genetic and non-genetic, for the development of NMSC.²⁹

GENETIC RISK FACTORS INCLUDE

- **Skin type and hair colour** – there is a higher risk if a person is fair-skinned, does not tan easily, has freckles, is sunburnt easily and has red or blonde hair
- **Individual history** – those who have had a previous skin cancer have a 36-52 per cent probability of occurrence of a new skin cancer within the next five years
- **Family history** – family history is associated with an increased risk of BCC
- **Ethnic group** – caucasian individuals are at higher risk than other ethnic groups.

NON-GENETIC RISK FACTORS INCLUDE

- **Occupation** – occupational exposure to sunlight is a significant risk factor for NMSC. People who routinely work outdoors are at higher risk for NMSC than indoor workers
- **Age** – older people are at higher risk of developing skin cancer, including NMSC
- **Sex** – there is a higher incidence of NMSC among men than women
- **Geographical location** – risk increases for Caucasian individuals living close to equator
- **Exposure to sunlight** – cumulative exposure is a key risk factor for cSCC, while intermittent sunburn and blistering is a risk factor for BCC.
- **Medical conditions** - certain medical conditions, such as immunosuppression, HPV infections and chronic ulceration are associated with higher risk of skin cancer
- **Exposure to certain chemicals and substances** – smoking, for example, can increase the risk of SCC.

In relation to non-genetic factors, the major risk factor for the development of NMSC is exposure to ultraviolet radiation (UVR), generally as a result of sun exposure.³⁰ Up to 90 per cent of NMSCs are caused by UV exposure.³¹ cSCC risk is associated with cumulative exposure to sun (such as occupational exposure), while for BCC, the risk is more closely associated with intermittent sun exposure (such as through leisure activities).³²

A person's job affects their risk of developing NMSC, mainly in relation to whether the work leads to sun exposure. Occupations that involve outdoor work are associated with increased NMSC risk.³³ A person's attitude towards sun protection also affects the risks of developing NMSC. A survey conducted in Victoria found that Victorian farmers and other rural outdoor workers had poor skin cancer prevention practices, even though they tended to have knowledge about sun protection and many believed that they were at higher risk of developing skin cancer.³⁴ Only 21 per cent of those surveyed always used sunscreen and 20 per cent always wore long-sleeved shirts. Another occupational factor that heightens risk includes chemical exposure; for example, high exposure to pesticides and insecticides have been shown to increase the risk of developing cSCC.³⁵

Protective factors

As shown above, there are hundreds of thousands of new NMSC cases in Australia each year, and most NMSCs are due to sun exposure. The Australian Government House of Representatives Standing Committee on Health conducted an enquiry into skin cancer in Australia (both melanoma and non-melanoma skin cancers) in 2015. The Committee recommended a number of actions, one of which was to consider the effectiveness of public awareness campaigns relating to skin cancers. The Government response accepted the recommendation and noted that there is evidence that such campaigns are cost-effective.³⁶

Australia has a long history of running primary prevention campaigns that aim to educate the public about the dangers of sun exposure and encourage sun-safe behaviours. One example is the Cancer Council's 'Slip, slop, slap, seek and slide' campaign,³⁷ which encourages people to:

- exercise caution during sun exposure, particularly during the middle of the day when the UV intensity is highest
- wear sun protective clothing, covering as much of the body as possible

²⁹ Adapted from: Diepgen T, Fartasch M, Drexler H, & Schmitt, J. (2012). Occupational skin cancer induced by ultraviolet radiation and its prevention. *British Journal of Dermatology*, 167, 76-84.

³⁰ Cancer Council Australia (2017). National Cancer Control Policy – the link between UV and cancer. Retrieved from: <https://wiki.cancer.org.au/policy/UV/Link_between_UV_and_cancer>.

³¹ Diepgen T, Fartasch M, Drexler H, & Schmitt J. (2012). Occupational skin cancer induced by ultraviolet radiation and its prevention. *British Journal of Dermatology*, 167, 76-84.

³² Cancer Council Australia (2017). National Cancer Control Policy – the link between UV and cancer. Retrieved from: <https://wiki.cancer.org.au/policy/UV/Link_between_UV_and_cancer>.

³³ Marebian J, Colt JS, Baris D, Stewart P, Stukel TA, Spencer SK, & Karagas MR. (2007). Occupation and keratinocyte cancer risk: a population-based case-control study. *Cancer Causes & Control*, 18(8), 895-908.

³⁴ Makin JK, Dobbins SJ, & Doyle C. (2009). Victorian farmers' and other rural outdoor workers' skin cancer prevention knowledge and practices. *Journal of Occupational Health and Safety, Australia and New Zealand*, 25(2), 115.

³⁵ Voiculescu V, Calenic B, Ghita M, et al. (2016). From Normal Skin to Squamous Cell Carcinoma: A Quest for Novel Biomarkers. *Dis Markers*. 2016:4517492.

³⁶ Doran C, Ling R, Byrnes J, Crane M, Shakeshaft A, ... Searles A. (2016). Benefit Cost Analysis of Three Skin Cancer Public Education Mass-Media Campaigns Implemented in New South Wales, Australia. *PLoS ONE*, 11(1), e0147665.

³⁷ Cancer Council Australia (2019). *Preventing skin cancer*. Retrieved from <<https://www.cancer.org.au/preventing-cancer/sun-protection/preventing-skin-cancer/>>.

- use a suitable broad-spectrum sunscreen with a strong sun protection factor (SPF) and reapplying regularly
- wear a wide-brimmed hat
- stay in the shade as much as possible when outdoors
- wear sunglasses.³⁸

Another way to prevent skin cancer, or identify the disease while at an early stage, is through secondary prevention; that is, regular skin checks with a medical practitioner.

Despite these public health efforts, NMSC continues to occur frequently in Australia particularly as our population ages.

The cancer specialists and the patients who were consulted during the preparation of this report agreed that personal vigilance is essential, and that ready access to appropriate clinical care in the community (non-hospital) setting, followed by prompt referral to specialist care where needed, is vital to ensure fast and accurate diagnoses can be made.

1.4 Challenges associated with NMSCs

1.4.1 NMSC treatment and diagnosis

The majority of the information in this section has been sourced from: *Cancer Council Australia, the Optimal care pathways for people with basal cell carcinoma and squamous cell carcinoma*,³⁹ and the *Clinical practice guidelines for keratinocyte cancer*.⁴⁰

Treatment for early-stage NMSCs

The type and setting of treatment differs between early-stage and advanced disease. The treatment for early stage

disease is relatively straightforward surgical excision, which has a high cure rate. Treatment is generally carried out in the primary care setting or by a dermatologist in their clinic.

Care pathways for patients with NMSC typically involve presentation to a general practitioner to investigate a lesion. Usually clinical examination and patient history, and possibly a biopsy is sufficient to diagnose a cSCC or BCC. The majority of lesions do not require further investigation to determine a diagnosis, particularly for BCC.

Treatment for locally advanced and metastatic cases of NMSC

While treatment approaches for localised (that is, early stage, non-invasive) cases of NMSC are well established and effective at present, treatment options for patients with locally advanced and metastatic cSCC and BCC are limited. It is estimated that BCC will spread to other parts of the body in less than 0.5 per cent of cases. The risk is higher in cases of cSCC. According to the *Clinical Practice Guidelines for Keratinocyte Cancer*, 4 per cent of cSCC patients will eventually experience metastasis to the lymph nodes.

When the primary NMSC lesion is on the head, face or neck, the anatomy of these regions may constrain the ability to perform surgery that is extensive enough to effect a cure, leading to a higher risk of progression to advanced disease. In some instances, the cancer cells may impact large nerves in the face, which is associated with a poorer prognosis.⁴¹

Locally recurrent BCC (where the tumour comes back at the same site) is usually managed by surgical excision and/or radiation therapy. Patients with locally recurrent cSCC have an increased risk of further local recurrence as well as regional and distant metastases, and require more urgent management.



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³⁸ Cancer Council Australia (2019). *Skin cancer*. Retrieved from: <<https://www.cancer.org.au/about-cancer/types-of-cancer/skin-cancer.html>>.

³⁹ Cancer Council Australia. (2016). *Optimal care pathways for people with basal cell carcinoma or squamous cell carcinoma*. Retrieved from: <<https://www.cancer.org.au/content/ocph/health/optimal-care-pathway-for-people-with-basal-cell-carcinoma-or-squamous-cell-carcinoma-june-2016.pdf>>.

⁴⁰ Cancer Council Australia (2019). *Clinical practice guidelines for keratinocyte cancer*. Retrieved from: <https://wiki.cancer.org.au/australia/Guidelines:Keratinocyte_carcinoma>.

⁴¹ ibid

Ivan's story

Ivan lives in South East Queensland, near his children and four grandchildren. Ivan worked in an office-based job for his whole career, but 12 years ago he found a lump on his temple. A visit to a GP and a CT scan didn't identify anything wrong but over the next six months, the lump grew. Ivan was referred to a surgeon who removed the lump, and it was then diagnosed as a cSCC.

Several years later, the tumour returned on Ivan's temple, and quickly grew to the size of a golf ball. The tumour was surgically removed and this time, Ivan had radiation therapy also.

Some time after this, Ivan experienced double vision. Tests showed that this was because the cSCC had come back. This time, Ivan had only radiation treatment because surgical removal would have resulted in a wound that would be unlikely to heal. Following the radiation therapy, Ivan's vision improved although remained blurry and his eye is still very red, and Ivan has to wear a dressing or sunglasses when he goes out. The tumour seemed to get better, and for another two years, Ivan was well.

Then the tumour again came back and grew rapidly. This time surgery was not an option, so Ivan was referred to a medical oncologist at a large hospital. This doctor enrolled Ivan in a clinical trial for a new immunotherapy. Since the trial, the tumour has shrunk and is not detectable.

Ivan's message for anyone who thinks they have an SCC is go to their GP quickly, but to also seek a referral to a cancer specialist to discuss treatment options. He is a bit less outgoing than he used to be, but still sees his family and close friends and neighbours often. Ivan's wife has been by his side throughout his treatment.

For cSCC, the treatment of metastatic disease to lymph nodes is primarily surgical, with or without post-operative radiation therapy. Chemotherapy is also used in metastatic cSCC as part of multimodal therapy or as a stand-alone treatment. However, evidence to support its use is inconsistent⁴² and no chemotherapies or other systemic treatments have been approved for the treatment of advanced cSCC. Outcomes are poorer for cSCC compared to BCC with the use of radiation therapy, and disease recurrence is more likely.⁴³

Clinical trials of targeted therapies and immunotherapies have shown promising results for cSCC patients who are not candidates for curative surgery or curative radiation.⁴⁴

Further, NMSCs, particularly cSCCs, have features that make them likely to respond to treatment with immunotherapy, a type of treatment that harnesses the activity of a patient's immune system so that it can potentially target the cancer more effectively.^{45,46}

Patients from regional, rural and remote locations

While most early stage NMSCs can be easily treated through excision by general practitioners, more advanced cases generally need treatment in hospital. This can pose a greater financial and emotional burden on patients and carers in rural and remote locations, who may need to travel to receive treatment in hospital.⁴⁷ In general, there tend to be fewer specialists in regional and remote areas of Australia compared to major cities. One report found that patients living in rural locations had reasonably frequent skin cancer consultations, but relied on opportunistic reviews, rather than deliberate appointments for NMSC check-ups.⁴⁸ Some literature has also detailed that transport and time may be barriers to accessing care.⁴⁹

State and territory governments provide travel and accommodation subsidies to assist patients with the cost of travel arrangements. Even so, patients generally still must pay out-of-pocket expenses, because the subsidies do not cover the full cost of transport and accommodation. The need for long-distance travel means that working-age patients from regional, rural and remote locations often need to take additional time away from work to cover travel time.⁵⁰

⁴² Burton KA, Ashack KA, & Khachemoune A. (2016). Cutaneous squamous cell carcinoma: a review of high-risk and metastatic disease. *American Journal of Clinical Dermatology*, 17, 491-508.

⁴³ Kwan W, Wilson D, & Moravan V. (2004). Radiotherapy for locally advanced basal cell and squamous cell carcinomas of the skin. *International Journal of Radiation Oncology • Biology • Physics*, 60(2), 406-11.

⁴⁴ Fitzgerald K, & Tsai KK. (2019). Systemic therapy for advanced cutaneous squamous cell carcinoma. *Seminars in Cutaneous Medicine and Surgery*, 38(1), E67-E7.

⁴⁵ Pickering CR, Zhou JH, Lee JJ, Drummond JA, Peng SA, Saade RE, ... & Frederick MJ10. (2014). Mutational landscape of aggressive cutaneous squamous cell carcinoma. *Clinical cancer research*, 20(24), 6582-6592.

⁴⁶ Ascierto PA, Schadendorf D. (2019). Immunotherapy in non-melanoma skin cancer: updates and new perspectives. *Drugs Context*, 8(212583), 1-6.

⁴⁷ Butler SM. (2017). Changes to radiotherapy utilisation in Western NSW after the opening of a local service. *Journal of Medical Radiation Sciences*, 64(4), 251-258.

⁴⁸ Aung ET, Campbell DG, & Mitchell EK. (2019). Post-diagnosis skin cancer follow-up in rural general practice: A mixed-method study. *Australian Journal of General Practice*, 48(4), 222.

⁴⁹ Fennell K, Martin K, Wilson C, Trenergy C, Sharplin G, & Dollman J. (2017). Barriers to seeking help for skin cancer detection in rural Australia. *Journal of Clinical Medicine*, 6(2), 19.

⁵⁰ Cancer Council. The financial cost of healthcare: information for people with cancer and for those caring for someone with cancer. Retrieved from: <https://www.cancer.org.au/content/about_cancer/Support/Patient%20Information%20Flyer_WEB.pdf

Attitudinal factors may also play a role in rural patients' access to care, with individuals often displaying the tendency to minimise the problem and desires to reduce displays of emotions or complaints. Individuals who also display stoicism and machismo, tend to avoid seeking help for their symptoms.⁵¹

1.4.2 Psychosocial impacts

Besides the physical effects of NMSC, there are significant psychological and psychosocial changes that can result from the disease and/or its treatment. Overall, quality of life (QoL) of NMSC patients has not been as comprehensively researched compared to other cancer types, despite the high incidence of NMSC, and the results of studies are quite variable. Moreover, many of the studies involve low patient numbers.

Changes in quality of life

Diagnosis and treatment of the disease can cause shifts in QoL. One study found that 31 per cent of patients with NMSCs experienced moderate to strong impairment of QoL.⁵² The change in QoL primarily stemmed from changes

in emotions, symptoms and function during daily activities, rather than from changes in work or education activities, which reflects the older patient demographic who are more likely to be retired. Studies have also found that QoL values and degree of post-treatment adaptation differ depending on treatment modality. For example, one study found that individuals treated by Mohs' surgery or excision reported higher QoL scores after treatment, compared to patients treated by electrodesiccation and curettage (ED&C).⁵³

QoL effects may also shift depending on age group, although studies are limited. One study, using a skin-specific QoL indicator, found that significantly more patients aged under 60 years reported feeling embarrassed by their disease compared to older patients,⁵⁴ while another study found that younger patients who were single and patients with lesions on exposed areas were more likely to have decreased QoL.⁵⁵ There may be an association with type of NMSC and QoL. In a small study, Caddick reported that individuals diagnosed with BCC had higher pre-treatment QoL compared to their counterparts with cSCC. However, post-treatment, both groups of patients achieved similar QoL scores.⁵⁶

Maria's story

Maria lives in Queensland and has three children and four grandchildren. In 2017, Maria noticed a lump in her left leg. Her GP referred her to hospital, where the lump was surgically removed. In 2018, Maria noticed that the same leg was swollen, but it was a few months before Maria was able to get back to see a doctor. When she went to her GP, she was referred to hospital for tests, which showed that she had cutaneous squamous cell carcinoma (cSCC), which had spread into a lymph gland. Maria had never had any skin cancers before, and hadn't heard of cSCC.

Following her diagnosis, Maria had radiation therapy and chemotherapy through the public health system. Maria felt very tired following each treatment, and took six and a half months' leave from her job during the treatment. In December 2018, Maria's cancer specialist told her that the cancer had spread to her lungs, and that treatment options with conventional therapies (radiation therapy and chemotherapy) were limited. Encouraged by friends and family, Maria asked what other options were available, and found out that she was able to join a clinical trial for a new drug.

Maria started the trial in February 2019 and expects to be on it for at least one year. The latest scans showed that there is no cancer detectable in her lungs. Luckily, Maria's employer has been very supportive, so that Maria has been able to continue working full time throughout the clinical trial period. Also, Maria's daughter has been with her at all of her treatment appointments ever since she was diagnosed. It has been hard for Maria's daughter to see her Mum go through all the treatment, but she knows it's vital.

Maria's message for everyone is, if something is worrying you about your health, it's so important to go to the doctor as quickly as possible; and if you're diagnosed with cancer, it's important to stay positive and focused on keeping as healthy as possible.

- ⁵¹ Fennell K, Martin K, Wilson C, Trenery C, Sharplin G, & Dollman J. (2017). Barriers to seeking help for skin cancer detection in rural Australia. *Journal of clinical medicine*, 6(2), 19.
- ⁵² Steinbauer J, Koller M, Kohl E, Karrer S, Landthaler M, & Szeimies RM. (2011). Quality of life in health care of non-melanoma skin cancer—results of a pilot study. *JDDG: Journal der Deutschen Dermatologischen Gesellschaft*, 9(2), 129-135.
- ⁵³ Chren M, Sahay A, Bertenthal D, Sen S & Landefeld C. (2007). Quality-of-Life Outcomes of Treatments for Cutaneous Basal Cell Carcinoma and Squamous Cell Carcinoma. *Journal of Investigative Dermatology* 127, 1351–1357
- ⁵⁴ Radiotis G, Czajkowska Z, & Manish Khanna MD. (2014). Nonmelanoma skin cancer: disease-specific quality-of-life concerns and distress. In *Oncology nursing forum* (Vol. 41, No. 1, p. 57). Oncology Nursing Society.
- ⁵⁵ Abedini R, Nasimi M, Pour PN, Moghtadaie A, & Tohidinik HR. (2019). Quality of Life in Patients with Non-melanoma Skin Cancer: Implications for Healthcare Education Services and Supports. *Journal of Cancer Education*, 34(4), 755-759.
- ⁵⁶ Caddick J, Green L, Stephenson J, & Spyrou G. (2012). The psycho-social impact of facial skin cancers. *Journal of Plastic, Reconstructive & Aesthetic Surgery*, 65(9), e257-e259.

Robert's story

Robert lives in regional New South Wales, and has chosen to tell his story in his own words, below:

The journey commenced in January of 2015 when my dermatologist excised a cSCC from my right eyebrow and right cheek. The pathology report indicated reasonable clear margins but I was referred to hospital for four weeks of radiotherapy as a precaution.

By October of 2015 I was getting blurred vision in my right eye and heat build up in my right cheek. I was referred to the Chris O'Brien Lifehouse, where further scans confirmed the extent of the recurrent SCC and surgery was scheduled for February 2016. In medical terms, the diagnosis was recurrent SCC to the right mid-face with extensive invasion. The operation was to remove the recurrent mid-face tumor, along with a selective neck dissection. There was also perineural invasion of my right infra-orbital nerve, one of the important nerves of the face. As a result, removal of my right eye, free flap resection and a graft from my left leg were also needed. I was discharged on the 4th March 2016 to commence wound management followed by a seven week radiation therapy course as a hospital outpatient, with constant follow up and scans to monitor results. Two further procedures at Chris O'Brien Lifehouse were required to adjust the mid-face suspension and lip. Fortunately I have family in Sydney which made the follow up visits and ongoing procedures less inconvenient and costly. Whilst I have private health cover, whose contribution was enormous, the out of pocket expenses exceeded \$25,000, and are ongoing. In April and July 2019 further skin tumors in the head and neck area were excised in hospital, on referral from my dermatologist who checks my skin regularly, at a minimum every six months.

My lifestyle, which included a lot of active outdoor activities such as surfing and fishing, has been impacted noticeably. Fortunately my remaining eye is healthy and has good peripheral vision so I can continue to drive for which I am extremely grateful.

cSCC and BCC are generally considered non-life threatening, with melanoma being given all attention and health warning. I can testify that SCC, particularly in the area of head and neck, can be extremely debilitating and an ongoing threat to a person's health and lifestyle.

"There was also perineural invasion of my right infra-orbital nerve, one of the important nerves of the face. As a result, removal of my right eye, free flap resection and a graft from my left leg were also needed"

Psychological impact of NMSCs and its treatments

A major component of the shift in QoL is psychological distress. Psychological distress can stem from anxiety about recurrence of disease, and side effects from treatment. For example, surgical treatment of NMSC can result in scarring, physical disability and facial disfigurements.

Recurrence of cSCC and BCC can occur, with the three year cumulative risk for the same skin cancer being 18 per cent and 44 per cent for cSCC and BCC respectively.⁵⁷ One study found that 77 per cent of patients faced anxiety surrounding skin cancer recurrence,⁵⁸ while another reported that 45 per cent of participants had minimal to moderate concerns about recurrence of NMSC, while 29 per cent worried 'quite a bit' or 'very much' about new occurrences.⁵⁹

Appearance is also a significant issue for some patients.^{60 61} Patients with the disease on conspicuous areas such as the face, head and neck, may face challenges in physical functioning, such as incomplete eyelid closure, nasal obstruction and impaired oral function as well as an increased chance of developing anxiety relating to their

condition.⁶² Issues with physical disfigurement may extend to cause psychosocial and relational issues.⁶³

Radiotis *et al* found a gender effect whereby female patients expressed a greater level of concern about QoL indicators relating to appearance compared to male patients.⁶⁴ Furthermore, individuals with more than one skin cancer were more likely to be concerned about their appearance.⁶⁵

Metastatic cSCC (supraclavicular lesion): not a candidate for curative surgery or curative radiation⁶⁶



⁵⁷ Marcel I, & Stem R. (2000). Risk of Developing a Subsequent Nonmelanoma Skin Cancer in Patients With a History of Nonmelanoma Skin Cancer: A Critical Review of the Literature and Meta-analysis. *Archives of Dermatology*, 136(12), 1524-1530

⁵⁸ Radiotis G, Czajkowska Z, & Marish Kharna MD. (2014). Nonmelanoma skin cancer: disease-specific quality-of-life concerns and distress. In *Oncology nursing forum*. 41(1):. 57-65. Oncology Nursing Society.

⁵⁹ Kömer A, Garland R, Czajkowska Z, Coroiu A, & Khanna M. (2016). Supportive care needs and distress in patients with non-melanoma skin cancer: Nothing to worry about?. *European Journal of Oncology Nursing*, 20, 150-155.

⁶⁰ Radiotis G, Czajkowska Z, & Marish Kharna MD. (2014). Nonmelanoma skin cancer: disease-specific quality-of-life concerns and distress. In *Oncology nursing forum*. 41(1):. 57-65. Oncology Nursing Society.

⁶¹ Burdon-Jones D, Thomas P, & Baker R. (2010). Quality of life issues in nonmetastatic skin cancer. *British Journal of Dermatology*. 162(1), 147-151

⁶² Rhee J, Matthews B, Neuburg M, Buzynski M, & Nattinger A. (2005). Creation of a quality of life instrument for nonmelanoma skin cancer patients. *Laryngoscope*. 115(7), 1178-1185

⁶³ *ibid*

⁶⁴ Radiotis G, Czajkowska Z, & Marish Kharna MD. (2014). Nonmelanoma skin cancer: disease-specific quality-of-life concerns and distress. In *Oncology nursing forum*. 41(1):. 57-65. Oncology Nursing Society.

⁶⁵ Arts LPJ, Waalboer-Spuij R, de Roos KP, Thissen MR, Scheimans LJ, Aarts MJ, ... & Louwman MW. (2019). Health-Related Quality of Life, Satisfaction with Care, and Cosmetic Results in Relation to Treatment among Patients with Keratinocyte Cancer in the Head and Neck Area: Results from the PROFILES Registry. *Dermatology*, 1-10.

⁶⁶ Data on File, Sandi Genzyme.



2. ECONOMIC COSTS OF NMSC IN AUSTRALIA

2. ECONOMIC COSTS OF NMSC IN AUSTRALIA

NMSCs are the most expensive cancers in Australia, mainly due to high incidence (approximately 570,100 new cases estimated for 2020).⁶⁷ The economic burden of disease extends beyond its contribution to health system expenditure, to productivity and social burden of disease.

NMSC can also affect multiple different stakeholders including the Commonwealth, state and territory governments; patients, employers, carers and family members. The framework used to define costs is articulated in Figure 4.

The direct costs of NMSC are experienced across the health sector, including in general practitioner, hospital and other out of hospital settings. Costs of treatment for one year following diagnosis were estimated. Patient lifetime costs were not included in this analysis. The patient pathway is distinct between cSCC and BCC as depicted in Figure 5 and Figure 6. BCC patients are able to access targeted therapies subsidised through the PBS.

Figure 4: Economic cost framework for analysis of NMSC in Australia

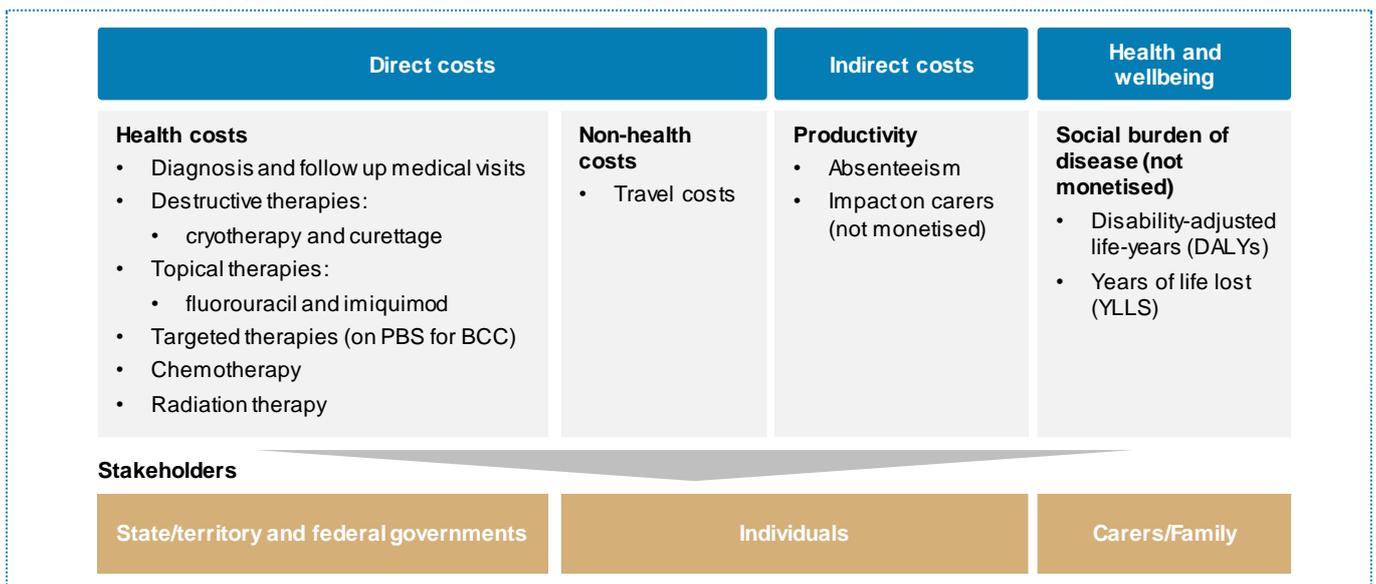
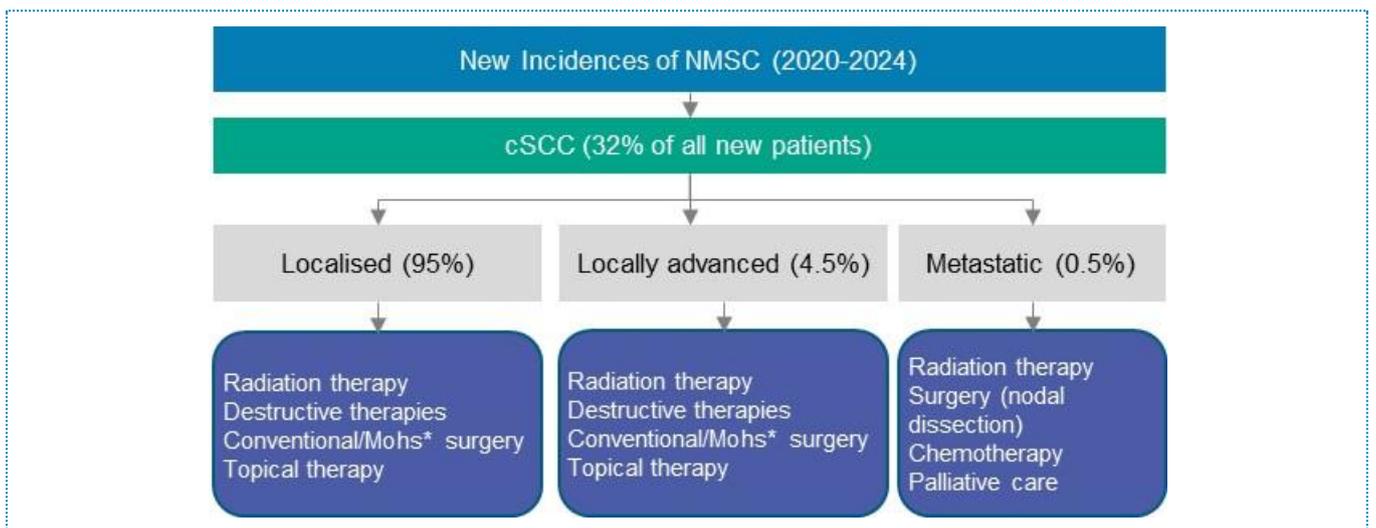


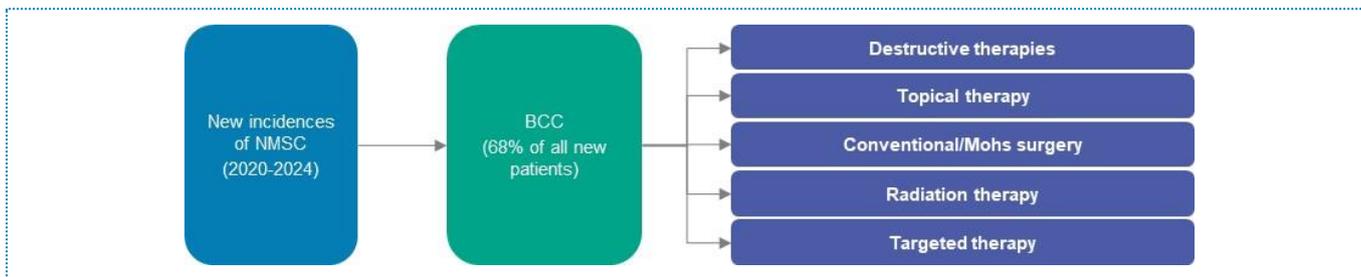
Figure 5: cSCC patient pathway to guide assessment of direct costs



* Only a small percentage of Australian cSCC patients are treated using Mohs surgery

⁶⁷ Fransen M et al (2012). *Medical Journal of Australia*, 197(10), 565-568.

Figure 6: BCC patient pathway to guide assessment of direct costs



2.1 Cost of NMSC

The economic burden of NMSC in 2020 is estimated to be approximately \$1.2 billion (AUD dollars) in direct and indirect costs (Table 1). This economic burden includes costs of new patients diagnosed in 2020, including those who progressed to metastatic disease. Although cSCC represents around 32 per cent of all patients with NMSC, almost 40 per cent of the cost of NMSC is associated with cSCC.

With the projected population growth and the growth in NMSC incidence due to Australia’s ageing population, the economic burden of NMSC is estimated to be \$6.1 billion in direct costs and \$69.7 million in indirect costs (absenteeism) over the next five years (2020 – 2024).

Table 1: Direct and indirect costs of NMSC in 2020

Cost category	2020 estimated cost (\$m)	Proportion of total cost (number of patients) ¹
Direct health costs (healthcare system)		
Diagnosis & follow-up	172.8	15% (570,100 all patients)
Out of hospital treatment	58.9	5% (381,700)
In hospital treatment	719.1	61% (195,700)
Sub-total (\$m)	950.8	-
Direct health costs (out-of-pocket)		
Out of hospital costs	161.7	14% (381,700)
In hospital costs	11.8	1% (195,700)
Sub-total (\$m)	173.5	-
Direct non-health costs (travel)		
Patient costs	20.0	2% (74,000)
Government costs	23.0	2% (74,000)
Sub-total (\$m)	43.0	-
Indirect costs		
Absenteeism ²	13.3	1% (4,500)
Total direct and indirect costs	1,180	-

1. Numbers of patients are not mutually exclusive 2. Indirect costs were estimated only for locally advanced and metastatic cSCC. *Percentages may not total 100 due to rounding



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General practitioners provide the majority of care for early stage patients with cSCC and BCC. However, the majority of the economic burden of NMSC is associated with treatments in hospital (65 per cent of direct health costs for NMSC) for the patients with advanced NMSC or early-stage disease when a more complex procedure is needed (see Table 2).

The average annual direct health cost per new patient in 2020 with NMSC is estimated to be \$1,970, which includes diagnosis, follow-up consultations and treatments in and out of hospital (see Table 3). The average cost per patient for cSCC is higher than BCC because cSCC has a greater likelihood of progressing to advanced disease, which requires more complex treatment, such as excision and repair procedures in hospital settings, chemotherapy and radiation therapy.

Table 2: Total direct health costs (governments and patients) for NMSC in 2020

	Total NMSC	cSCC	BCC
Total direct health cost (\$m)	1,124	419	705
Portion of cost for diagnosis and follow-up	23%	20%	25%
Portion of cost for treatment out of hospital	12%	10%	13%
Portion of cost for treatment In hospital	65%	70%	62%

Table 3: Direct and indirect costs of NMSC in 2020

	Total NMSC	cSCC	BCC
Incidence	570,100	183,500	386,600
Cost per patient (\$)	1,970	2,280	1,820

2.1.1 Comparison to previous NMSC direct health costs

In 2008-09, the total healthcare expenditure⁶⁸ nationwide for NMSC was estimated to be \$367m. Specifically, the costs for hospital admitted patients, out-of-hospital and prescription pharmaceuticals were \$224m, \$133m and \$10m respectively.⁶⁹ Another study calculated that the total cost of NMSC in Australia which includes diagnosis, treatment and pathology in 2010 was \$511 million, and was predicted to rise to \$703m in 2015.⁷⁰

In 2020, the annual cost of NMSC to the healthcare system with new patients is estimated to be around \$951m, \$173m with diagnosis and follow-up consultations, \$59m with out of hospital treatment and \$719m with treatment of admitted patient (see Table 4). The annual direct health cost of new

cases of NMSC is high by comparison to the annual direct cost of new cases of melanoma. New cases of melanoma (including both localised and locally advanced) cost the health system between \$187 million to \$216 million in 2017. Inclusion of treatments for presumptive melanoma later identified as benign lesions increased the cost to \$272 million annually.⁷¹

Table 4: NMSC health system expenditure in Australia

Year	Total health system expenditure (\$m)
2010 ⁷²	511*
2015 ⁷³	703*
2020 (current estimate)	951

* It was not clear whether these studies have included out of pocket costs

⁶⁸ Expenditure was sourced using the Disease Expenditure Database which contains estimates of expenditure for admitted patient hospital services, out-of-hospital medical services, prescription pharmaceuticals, optometrical and dental services, community mental health services and public health cancer screening.

⁶⁹ Australian Institute of Health and Welfare (2013). Health system expenditure on cancer and other neoplasms in Australia, 2008-09. Retrieved from: <<https://www.aihw.gov.au/getmedia/296395cc-f241-4c2f-a1a2-9e0b7c6a4d79/16199.pdf.aspx?inline=true>>.

⁷⁰ Fransen M, Karahalios A, Sharma N, English D R, Giles GG, & Sinclair RD. (2012). Non-melanoma skin cancer in Australia. *Medical Journal of Australia*, 197(10), 565-568.

⁷¹ Elliott T M, Whiteman DC, Olsen CM, & Gordon LG. (2017). Estimated healthcare costs of melanoma in Australia over 3 years post-diagnosis. *Applied health economics and health policy*, 15(6), 805-816.

⁷² Fransen, M., Karahalios, A., Sharma, N., English, D. R., Giles, G. G., & Sinclair, R. D. (2012). Non-melanoma skin cancer in Australia. *Medical Journal of Australia*, 197(10), 565-568.

⁷³ *ibid*

2.2 cSCC direct costs

It is estimated that the annual direct health and non-health costs of new patients with cutaneous SCC in Australia (inclusive of diagnosis, follow-up, patient out-of-pocket expenses, in/out of hospital costs, and travel) amounts to \$431 million in 2020 (see Table 5). Treatment options for cSCC include conventional treatments such as destructive therapies, surgical excision and repair, radiation therapy and in some cases, chemotherapy. At present in Australia

there are no newer generation treatments (such as targeted therapies or immunotherapies) that have been subsidised for mainstream use in cSCC. Currently, access to some newer generation therapies is restricted to clinical trials for some suitable patients.

Table 5: Direct and indirect costs of new cSCC patients in Australia in 2020

Cost Item	2020 estimated cost (\$m)	Proportion of total cost (number of patients) ¹
Direct health costs: diagnosis and follow up		
Diagnosis	33.8	8% (183,500; all cSCC patients)
Follow-up consultations	23.1	5% (183,500; all cSCC patients)
Sub-total (\$m)	56.9	-
Direct health costs: cSCC treatments – out of hospital		
Destructive therapy	1.8	>1% (32,100)
Topical therapy	0.3	>1% (4,800)
Surgical excision & repair	15.1	3% (81,100)
Sub-total (\$m)	17.2	-
Direct health costs: cSCC treatments – in hospital		
Palliative care	0.6	>1% (79)
Surgical excision & repair	260.5	61% (66,300)
Radiation therapy	24.2	6% (3,600)
Chemotherapy	1.2	>1% (770)
Sub-total (\$m)	286.6	-
Direct health costs: out of pocket (patients)		
Out of hospital	53.4	12%
In hospital	4.7	1% (70,800)
Sub-total (\$m)	58.1	-
Direct non-health costs (travel)		
Travel related government costs	6.3	1% (26,400)
Travel related patient costs	5.5	1% (26,400)
Sub-total (\$m)	11.8	-
Total (\$m)	430.6	-

1. Numbers of patients are not mutually exclusive. *Totals may not sum due to rounding.

Treatment options for cSCC vary with the clinical stage at diagnosis. The majority of patients (95 per cent) are diagnosed at an early stage and the treatment options are similar to BCC. For a small group of cSCC patients, around 5 per cent, cancer is diagnosed at a locally advanced or metastatic stage.

The annual direct health cost per new cSCC patient diagnosed at an early stage is similar to BCC, estimated at \$1,798 in 2020 (see Table 6). For locally advanced cSCC patients, where surgical excisions are more often performed in hospital settings, the cost per new patient is estimated to be \$3,979. Metastatic patients, those in whom the disease has spread to local lymph nodes (regional metastasis), contribute the highest direct cost to the health system, around \$17,255 per patient. This is mainly due to complex surgical procedures, repair surgeries and additional radiation therapy and chemotherapy for some patients. For patients with distant metastasis, where the disease has spread to other parts of the body, there are few treatment options and the cost per patient is lower than regional metastasis, around \$7,234, which includes palliative care costs.

Table 6: Average direct health cost per new patient and total treatment costs for new cSCC cases, by clinical stage in 2020

Clinical stage	Estimated average treatment cost per patient, 2020	Estimated total treatment cost, 2020 (\$m)
cSCC (% of patients in stage at diagnosis)		
Localised (95%)	1,798	313.5
Locally advanced (4.5%)	3,979	32.9
Metastatic (regional) (0.4%)	17,255	13.5
Metastatic (distant) (0.1%)	7,234	1.0
cSCC (% of early stage patients who progress)		
Metastatic (regional) (1.7%)	17,344	53.8
Metastatic (distant) (0.3%)	7,514	4.1

2.3 Indirect costs for advanced cSCC

Most patients diagnosed with NMSC will undergo treatments that have limited impact on their daily activities, for example: small excisions and destructive therapies (cryotherapy or curettage). However, there are a small percentage of patients diagnosed with locally advanced or metastatic cSCC who will experience serious impacts on their daily life due to more complex surgeries, chemotherapy and radiation therapy. A percentage of these individuals need to take time off work to attend appointments, manage treatment and sometimes even decide to retire early.

Based on average employment rates, time off needed and average salaries, it is estimated that the time in productivity loss will be **\$13.3 million** in 2020, and reach **\$69.7 million** by 2024 (see Table 7).

Table 7: Indirect cost summary for new locally advanced and metastatic cSCC cases, 2020 and 5-year projection

Cost item	2020 (New incidences – 12,800)	5 year projection (All patients – 67,200)
Absenteeism	\$13.3 million	\$69.7 million

2.4 Impact on health and wellbeing in advanced cSCC

The burden of disease for NMSC can be expressed in DALYs (disability-adjusted life years); measured in years of healthy life lost, either through premature death defined as dying before the ideal life span (years of life lost, YLL) or, equivalently, through living with disability due to illness or injury (years lived with disability, YLD). Due to its high incidence, it was estimated that NMSC was the ninth highest cancer in terms of non-fatal burden, with almost 3 per cent of all non-fatal cancer burden in 2011. In this same year, DALY was estimated to be 9,369, with 86 per cent of these years being attributed to YLL.⁷⁴

2.4.1 Premature mortality in metastatic cSCC

Early stage NMSC is generally not life threatening.⁷⁵ Advanced disease is harder to treat successfully and is more likely to cause death.

Australians diagnosed with NMSC have lower relative survival - that is, higher likelihood of dying within a given time period - than the general Australian population

Five-year relative survival:⁷⁶



The total number of deaths due to cSCC is estimated at 1,714 in 2020.

2.4.2 Impact on carers

As well as impacts to the individuals diagnosed, NMSC also affects the quality of life of carers, including impacts on their employment levels, social participation, mental health and primary healthcare use.

⁷⁴ Australian Institute of Health and Welfare. (2017). *Burden of cancer in Australia*. Retrieved from: <https://www.aihw.gov.au/getmedia/a1aec7bd-ddb7-416f-9a7e-f213cd5d4cb/20965.pdf.aspx?inline=true>.

⁷⁵ Canadian Cancer Society. (2019). *Survival statistics for non-melanoma skin cancer*. Retrieved from: <http://www.cancer.ca/en/cancer-information/cancer-type/skin-non-melanoma/prognosis-and-survival/survival-statistics/?region=ab>.

⁷⁶ Australian Institute of Health and Welfare (AIHW) 2018 Cancer Data in Australia; Canberra: AIHW. Retrieved from: <https://www.aihw.gov.au/reports/cancer/cancer-data-in-australia/>.

Important characteristics about carers and the impacts of this role on wellbeing include:⁷⁶

- Most carers are female. Female carers are more likely to have intensive caring roles, experience higher rates of depression and, as a result of challenges to balancing work and caring, are more likely to rely on government pensions/allowances as their main income source
- Male carers are likely to be older than their female counterparts and are more likely to go unrecognised, reducing their access to social and emotional support. Male carers are also more likely to have a disability
- Young carers often need to balance education with caring which may result in lower levels of educational attainment and workforce participation compared to peers
- Many people in caring roles do not identify as carers, and as such, are often not linked to services and supports that can assist them. These individuals are often referred to as 'hidden carers'.

2.5 BCC direct costs

BCC has a low propensity to progress to more advanced disease. Because of this, the frequency of treatments and cost analysis were conducted on the BCC group as a whole, without disaggregating this population into different disease stages.

The direct health and non-health costs of new BCC cases in Australia (inclusive of diagnosis, follow-up consultations, patient out-of-pocket expenses, in/out of hospital costs, and travel) is estimated at \$725 million in 2020 (see Table 8). The largest cost item within this total estimate is in-hospital treatment, including surgery and repair, estimated at \$433 million in 2020.

For BCC, in addition to the conventional treatments available, such as destructive therapies, surgical and Mohs excision, patients with locally advanced or metastatic disease can be treated with targeted therapies which are subsidised through the Pharmaceutical Benefits Scheme. To qualify for subsidised targeted therapy, a patient's disease must not be treatable with surgery and curative radiation therapy.

Table 8: Direct health and non-health costs of new BCC patients in Australia in 2020

Cost Item	2020 estimated cost (\$m)	Proportion of total cost (number of new patients) ¹
Diagnosis and follow up		
Diagnosis	68.5	10% (387,000; all BCC patients)
Follow-up consultations	47.4	7% (387,000; all BCC patients)
Sub-total (\$m)	115.9	-
BCC treatments – out of hospital		
Destructive therapy	3.8	1% (67,800)
Topical therapy	1.4	>1% (15,800)
Surgical excision & repair	33.4	5% (179,808)
Targeted therapy	3.1	>1% (n.a.)
Sub-total (\$m)	41.7	-
BCC treatments – in hospital		
Surgical excision & repair	426.5	59% (124,800)
Radiation therapy	6.1	1% (967)
Sub-total (\$m)	432.6	-
Direct health out of pocket costs to patients		
Out of hospital	108.3	15% (all patients)
In hospital	7.0	1% (124,800)
Sub-total (\$m)	115.3	-
Direct non-health costs		
Travel related government costs	10.3	1% (47,500)
Travel related patient costs	9.1	1% (47,500)
Sub-total (\$m)	19.4	-
Total (\$m)	724.8	

1. Numbers of patients are not mutually exclusive. *Totals may not sum due to rounding.

⁷⁶ Carers NSW Australia. *Strategic Plan 2018-2021*. Retrieved from: <<https://www.carersnsw.org.au/publications/strategic-directions>>.

2.6 Limitations

There are a range of limitations that affect the estimation of the cost of NMSC to the Australian health system and economy more broadly:

- Incidence and prevalence statistics are not routinely available as, unlike other cancers, cSCC and BCC are not reportable to cancer registries. For the economic analysis, data gaps were addressed through the use of projections and conservative assumptions.
- Data gaps also exist in relation to clinical activity associated with NMSC, since there is no requirement by general practitioners to report the incidence of NMSCs to cancer registries. Often, cases of NMSCs are resolved in general practitioner clinics, with general practitioners treating approximately 50 per cent of cases,⁷⁷ and hospitals, skin cancer clinics and specialists generally treating the remainder. Consequently, it is likely that the disease is under-reported, and that the publicly available data underestimates the true incidence, particularly in relation to early stage disease.
- NMSC incidence data have largely been generated as a result of academic research. Major nation-wide studies were conducted by a team of researchers at the University of Melbourne in 1985, 1990, 1995 and 2002, with data collected through surveys. There have also been surveys conducted regionally, but given that those samples are not representative of the whole population, and that the prevalence and incidence of NMSC varies across regions, such data are not suitable for nation-wide extrapolation.

Costs were estimated for the first course of treatment, diagnostic process and consultations with general practitioners and/or specialists of new NMSC patients within the first year of diagnosis. Possible costs to treat progressive disease was considered only in relation to cSCC patients progressing to metastatic disease and it was assumed to take place within the first year of diagnosis.

The World Health Organization (WHO) describes palliative care as *'an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual'*.⁷⁸ It is unclear to what extent NMSC patients access palliative care. During treatment for advanced disease radiation therapy may be used to ease tumour burden, rather than with curative intent. However, the extent to which such therapies are applied with curative intent or palliative intent is not clear from the available information. As such, the analysis performed has separated out radiation therapy and chemotherapy for patients with advanced disease, from purely palliative care (eg pain relief) and a conservative estimate of 5 per cent of patients with metastatic disease has been used, based on consultation with cancer specialists.



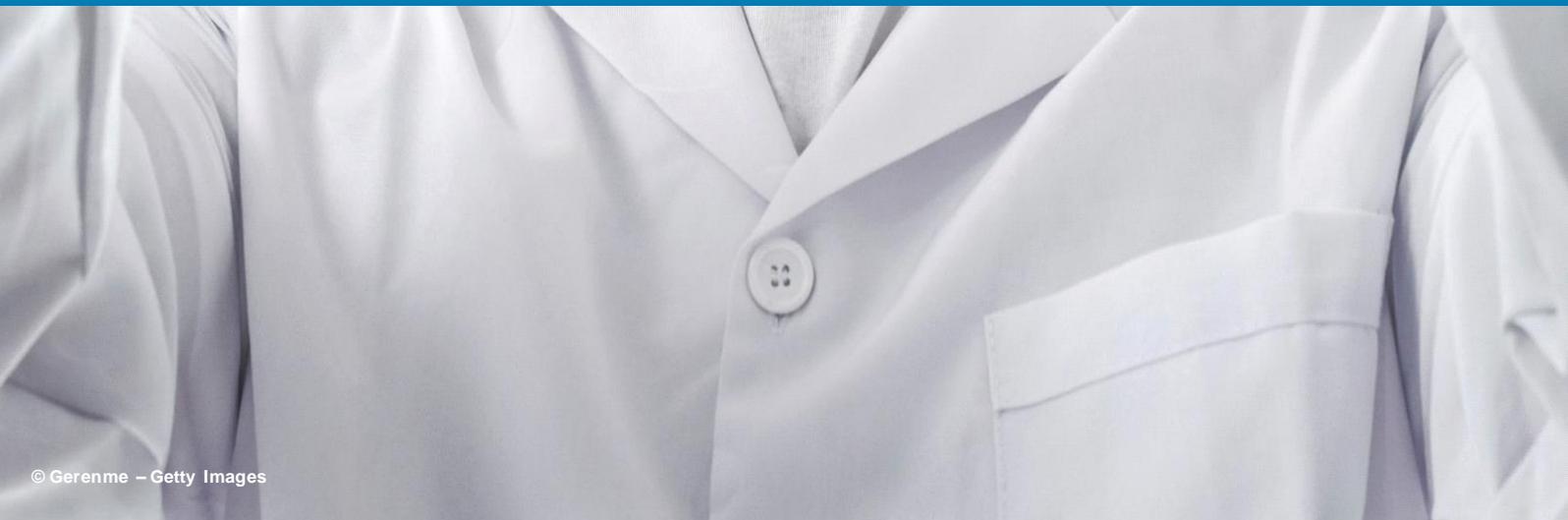
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⁷⁷ Sinclair R. (2012) Skin checks. *Australian Family Physician*, 41(7), 464-469.

⁷⁸ WHO (World Health Organization) 2014. *Global Atlas of Palliative Care at the End of Life*. Geneva: WHO.



3. FUTURE IMPACT AND CONCLUSIONS



3. FUTURE IMPACT AND CONCLUSIONS

3.1 Impact of maintaining the status quo

There will be an estimated 570,100 new NMSC cases diagnosed across Australia by the end of 2020. This is significant compared to the 16,000 expected new cases of melanoma by the end of 2020.⁷⁹ Over five years from 2020, nearly 3 million new NMSC cases are expected. These new cases will contribute a substantial cost to the Australian health system and create additional costs to patients. Some of the factors leading to growth in the number of NMSC cases over the next five years cannot be altered. For example, our ageing population, and historic sun exposure which may lead eventually to cancer.

Conventional treatment (surgery and radiation therapy) is often ineffective for advanced NMSC. Recently, BCC patients with advanced disease have benefitted from the introduction of newer generation targeted therapies. But sadly, as things stand, patients who are diagnosed with advanced cSCC, who are not candidates for curative surgery or curative radiation therapy, have few treatment options.

- The modelling of relative survival data predicts that in **2020** nearly **1,700 people** will lose their fight with NMSC

3.2 Conclusion

The analysis presented here demonstrates the substantial cost involved in diagnosing and treating new NMSC cases in Australia. In preparing this report, it was apparent from reviewing the skin cancer literature, accessing data, and talking to patients and cancer specialists, that NMSC is relatively poorly understood. Comprehensive and up to date data regarding incidence and disease-specific mortality are lacking, and beyond clinical trials, there is limited access to effective therapies for cSCC for patients with advanced disease who are not candidates for surgery or radiation therapy. Patients report little awareness of NMSC as a potentially serious disease prior to diagnosis.

There are continued misperceptions of NMSC as being non-life threatening, whereas the data and patient stories presented in this report demonstrate that NMSC can have profound impacts on patients and their loved ones, including disfigurement (due to both the disease itself, and surgical treatment), a reduced ability to participate in work and leisure pursuits, and in some cases many years of disease recurrence and treatment. Patients also spoke of being told that there were no options for treatment other than clinical trials, because their cancer was inoperable.

People living in rural and remote locations face additional challenges. There is an overall lower rate of cancer survival among rural and remote populations of Australia, compared to urban areas.⁸⁰ Specialist care may be harder to access for patients that live in regional, rural or remote areas. This means that they are likely to face greater challenges than their counterparts living in metropolitan areas to get the diagnosis and care they need close to home.

Given how common NMSC is in Australia, these findings are surprising. There is a role for further research and data collection to better understand incidence, prevalence, cancer staging, mortality and biomarkers for effective treatments for NMSC. Research would also provide the evidence base for broader access to medicines which are effective in treating NMSC, including advanced cSCC for which there are currently few options.



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⁷⁹ Australian Institute of Health and Welfare (AIHW) 2018 *Cancer Data in Australia*; Canberra: AIHW. Retrieved from: <<https://www.aihw.gov.au/reports/cancer/cancer-data-in-australia/>>.

⁸⁰ Australian Institute of Health and Welfare (2019). *Cancer in Australia 2019*. Retrieved from: <<https://www.aihw.gov.au/reports/cancer/cancer-in-australia-2019/contents/summary>>.

APPENDIX: GLOSSARY OF TERMS

Term	Definition
Basal cell carcinoma (BCC)	The most common type of non-melanoma skin cancer
Biopsy	The examination of tissue removed from a living person's body to discover the presence, cause, or extent of a disease
Chemotherapy	The use of anti-cancer drugs to destroy cancer cells
Cutaneous	Relating to, or affecting the skin
Electrodesiccation and curettage (ED&C)	Electrodesiccation and curettage (ED&C) is a surgical procedure used to remove skin lesions including SCCs and BCCs. Following injection of local anesthetic, the surgeon then uses a curette to remove the abnormal cells by scraping down to a layer of uninvolved tissue. Finally, desiccation (electrosurgery) is performed with a small, metal instrument used to widen the margin and cauterize the wound to minimize bleeding. The wound is left to heal without sutures and typically heals over several weeks.
Excision	Removal of a SCC or BCC by cutting it out; ie, surgical removal
Immunotherapy	A type of cancer treatment that boosts the body's natural defenses to fight cancer
Incidence	The rate of new cases diagnosed during a time period (generally one year), providing a measure of risk of being diagnosed with a condition
Localised	Cancer that is contained to its original site in the body and has not spread to any surrounding parts of the body
Locally advanced/ invasion	The movement of cancer cells into tissues underlying or directly surrounding the original tumour site
Keratinocyte cancer	Another name for non-melanoma skin cancer
Lesion	A region in an organ or tissue in the body which has suffered damage through injury or disease, including a tumour.
Lymph nodes	Small lumps of tissue that contain white blood cells, which fight infection. They filter lymph fluid, which is composed of fluid and waste products from your body tissues. Lymph nodes also help activate your immune system if you have an infection. Cancers can spread to lymph nodes (termed nodal metastasis or locally advanced cancer).
Metastasis/metastatic	Metastasis is the process of cancer cells moving away from the original site in the body and spreading to other sites. In this report NMSC is described as either regional metastatic disease (where cancer cells have moved into lymph nodes) or distant metastatic disease (where cancer cells have moved into parts of the body that are distant from the site of the original tumour).
Mohs surgery	A surgical technique used to treat skin cancer. Thin layers of skin containing cancer cells are gradually removed and examined until only cancer-free tissue remains.
Nodes/nodal	Lymph nodes
Prevalence	The actual number of people living with the disease during a period of time or at a point in time
Radiotherapy/radiation therapy	The use of precisely targeted x-rays to destroy cancer cells
Squamous cell carcinoma (SCC)	The second most common type of non-melanoma skin cancer. 'Cutaneous SCC or cSCC' is used to distinguish SCC of the skin from SCC that occurs in the mouth and throat
Ultraviolet radiation (UVR)	Invisible energy produced by the sun, made up of three wavelengths, UVA, UVB and UVC. Both UVA and UVB are known to cause cancer.



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