



Inquiry into Skin Cancer in Australia

Submission of Melanoma Patients Australia

Background of Melanoma Patients Australia

Melanoma Patients Australia (“MPA”) founded by two young melanoma patients, Brent Grace (now deceased) and Daniel Belcher, and was officially launched on 6 July 2006. Melanoma Patients Australia is the largest patient driven non profit organisation in Australia that offers a national network of support and information to patients, their families, carers, and friends, about melanoma prevention, diagnosis, management and treatment. All of the patient services offered by MPA are offered at no cost and are freely accessible by melanoma patients, their carers, family and friends.

Vision

To reduce the impact of melanoma on all Australians.

Mission

Provide information, support, awareness and advocacy to people affected by melanoma and become the national peak body representing the interests of melanoma patients in Australia.

Relevance to Inquiry

Melanoma Patients Australia deals with members of the community who have been affected by melanoma - either directly or indirectly. We are further positioned to comment given the similarities in cause, treatment and management of melanoma to other skin cancer types (SCC and BCC) . Further, many melanoma patients have a history of other skin cancer diagnoses whether prior to their melanoma diagnosis or in the period following. As such, while Melanoma Patients Australia exists to specifically address melanoma issues in the Australian community, our organisation is well placed to speak on skin cancer more broadly and the topic of this Inquiry is of huge significance and relevance to our members.

Key Drivers

Australia has the highest incidence of melanoma in the world - of the 12,510 Australians diagnosed with melanoma each year, about 1,450 will die from melanoma, and thousands of others experience recurrences or the detection of more primaries that in some cases eventually lead to death. Melanoma is the most common cancer in young Australian adults (20-39 year old)

and is the third most commonly occurring cancer in Australia. The incidence of melanoma in Australia is projected to increase between 2011 and 2020 by over 8 new cases per 100,000 population from 65.5 cases to 74.1 cases in 2020.

Over the years the Prevention message has been modified and expanded to maintain relevance and incorporate measures that reflect growing scientific knowledge of the causes of skin cancer and melanoma. The most obvious example of this is the hugely successful Cancer Council campaign that has grown in messaging (originally “Slip, Slop, Shove” followed by “Slip, Slop, Slap” (launched in 1981)) to the enhanced message of “Slip, Slop, Slap, Seek, Slide” launched in 2007. The Cancer Council has been an integral part in the development of successful sun safe public awareness campaigns, and their role remains as pivotal and relevant now as it did in the 1980s. There is established evidence that the sun safety campaigns introduced in Australia in the 1980s have contributed to the decline in the incidence of skin cancer diagnosis in young Australians. Melanoma Patients Australia fully endorses the continuing work of the various Cancer Councils across Australia, as well as our own Danger Sun Overhead program, in paving the way in sun safety and skin cancer/melanoma prevention messaging within the community.

Yet knowledge of melanoma and skin cancer is not enough. To have an impact, the knowledge must translate into behavioural change (Prevention) and early diagnosis (Early Detection). It is well established that the best patient outcomes in skin cancer and melanoma are achieved through early detection and diagnosis. It is widely accepted that through early detection and prompt treatment, over 90% of skin cancer cases in Australia can be successfully managed.

Active surveillance is integral to the prevention, early detection and diagnosis of skin cancer and melanomas, and can be considered from two important aspects:

The Role of the Individual

It is pivotal that individuals are educated appropriately to understand what skin cancer and melanoma are, and then importantly, how to use that information to properly complete a self skin examination on regular basis. Through ongoing monitoring of the skin for changes and unusual lesions, a person may recognise abnormalities sooner and can be encouraged to seek medical opinion as to whether or not it is a skin cancer or melanoma.

Of equal importance is ensuring that individuals are aware of their personal risk factors for developing skin cancer and melanoma. Where a person is high risk, greater emphasis must be placed on the need for continued personal vigilance and ongoing management/review with a qualified medical practitioner.

The Role of the Medical Practitioner

Medical practitioners play a key role in aiding in the early diagnosis of melanoma and skin cancer.

When a patient reports a suspicious skin spot or lesion it is important that the medical practitioner is adequately equipped to undertake the following:

- Identify the lesion or spot;
- Assess the need for a biopsy;
- Keep accurate records for future monitoring for change/s;
- Where appropriate, conduct the excision using appropriate suture techniques;
- If necessary, recall the patient to ensure full removal of the lesion and the correct surrounding skin margin;
- Where appropriate, refer the patient to a trained specialist for treatment and/or management;
- Provide the patient with accurate information and referral to support services;
- Emphasise the importance to the patient of vigilance in skin examinations given the high risk of recurrence and susceptibility to other skin cancers.
- Ensure regular and ongoing follow up with the patient is undertaken.

The effective prevention and early diagnosis of melanoma and skin cancer requires that the treating medical practitioner undertake all of the above in a timely and efficient manner. Failure to diagnose and/or correctly remove skin cancers and/or melanomas can have significant implications to the patient's prognosis and treatment options. Melanoma Patients Australia therefore recommends and encourages the continued training of medical practitioners in current skin cancer and melanoma detection techniques as well as best practice treatment options and ongoing patient management plans.

There has been a rapid advancement in the treatment options for advanced melanoma in the past five years and current treatments now include immunotherapies and personalised treatments. It is important that doctors understand how these treatments relate to their patients and develop the skills to participate as an active member of the patient's treatment team moving forward. Further, not every melanoma patient will be able to access the treatments and/or clinical trials due to factors such as tumour type, prognosis and extent of their disease - these are obviously matters for each patient to review with their specialist. As such, doctors need to be able to support the patient in making an informed decision regarding all of the available treatment options and clinical trials, while also ensuring the patient is supported through the process by organisations such as Melanoma Patients Australia.

Yet despite improved survival outcomes offered to some patients by these new and emerging therapies, there is still no cure for advanced melanoma. Patients are (and will most likely continue to) articulate feelings of anxiety, stress and confusion in dealing with their disease. As melanoma gradually shifts to being a chronic disease in the long term, for now, melanoma must still be recognised as a serious condition and patient's referred to support and advocacy services as an integral component of their care.

Terms of Reference

1. Options to improve implementation of evidence-based best practice treatment and management.
2. Strategies to enhance early diagnosis.
3. Effective Strategies for Prevention.
4. The need to increase levels of awareness in the community and among health professionals.

Recommendations

Given the nature of the Terms of Reference, each of the following Recommendations presented by Melanoma Patients Australia address a number of the Terms of Reference (that is to say, many of the strategies that can be adopted for one Term of Reference will provide impact and benefit to another Term of Reference).

There are many aspects that need to be incorporated into any strategic approach to reducing the impact of melanoma and skin cancer in the Australian community. Many of these will be highlighted in through the submissions already presented to the Commission which we have been able to read and now endorse.

Melanoma Patients Australia considers it is important for the Inquiry to consider the following recommendations:

- ***Continuation of studies into skin cancer and melanoma - from an epidemiological perspective - and ongoing investment in research into skin cancer and melanoma treatments and patient management systems.***
- ***Support of ongoing training programs for doctors in the primary setting on issues such as skin cancer diagnosis; correct use of tools to aid diagnosis; excision techniques and wound/suture care to minimise patient scarring; and the importance of clear patient communication.***
- ***Consultation and involvement of the patient community in the development, delivery and review of skin cancer and melanoma research projects.***
- ***Clinical trials are an integral part of the development of new and improved therapies for skin cancer and melanoma. While efforts have been made to centralise information on current clinical trials available to patients, there is still a great deal of work to be done in ensuring accuracy, currency and accessibility of the information in a patient friendly format.***

- ***Improved equality of access for all Australians to potentially life saving treatments through the prompt listing on the Pharmaceutical Benefits Scheme.***
- ***Continuation and expansion of prevention programs and services, such as the the Danger Sun Overhead Program (run exclusively through Melanoma Patients Australia) and Cancer Council initiatives - these programs may require further government investment and funding.***
- ***Endorsement and investment in collaborative prevention strategies that bring together the patient community, cancer organisations (particularly the Cancer Councils) and research institutions, to facilitate greater and more effective prevention outcomes.***
- ***Continuation of public education programs such as the MPA Community Melanoma Forums and Symposiums which have proven effective in educating the general public; supporting and informing melanoma patients; and providing a platform for doctors, specialists and service organisations to come together to offer assistance to patients.***
- ***Public outreach and awareness programs incorporating melanoma risk assessment tools such as the newly formulated evidenced based Scan Your Skin campaign developed by Queensland Institute of Medical Research, Skin and Cancer Foundation of Australasia and MPA Danger Sun Overhead Program.***
- ***Government campaign to encourage the translation of skin cancer awareness attitudes and knowledge of what skin cancer and melanoma are, into behavioural change encouraging sun protection measures in conjunction with the importance of early detection.***

The daunting reality is that melanoma is referred to as being “Australia’s Cancer” and Australia as being the “Melanoma Capital of the World”. These are not terms that Australia should willingly accept and we have the power to make a positive change to this reality. It is encouraging that this Inquiry is seeking to ignite the discussion into skin cancer and melanoma in Australia and we are grateful for the opportunity to provide a patient voice in relation to the Terms of Reference.

Written and prepared on behalf of Melanoma Patients Australia by Ms Tilly Ryan, CEO.