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MELANOMA PATIENTS AUSTRALIA

PRE-BUDGET
SUBMISSION

MELANOMA PATIENTS AUSTRALIA

5 January 2022

The Hon Greg Hunt MP
PO Box 6022
House of Representatives
Parliament House
Canberra ACT 2600

Dear Minister Hunt,

Re: Melanoma Patients Australia 2022-23 Pre-Budget Submission

On behalf of Melanoma Patients Australia (MPA), we welcome the opportunity to provide a submission regarding a critical health priority for Australians, to inform the 2022-23 Federal Budget.

MPA is a not-for-profit organisation dedicated to supporting and representing all Australians affected by melanoma. We provide a range of national support services free of charge for melanoma patients, and their families and carers, including emotional support and information, education, peer to peer connections, and formal support groups. We have been supporting Australians affected by melanoma since 2006 and are uniquely placed as Australia's premier melanoma support and advocacy organisation.

Currently, due to MPA's limited funding and resource capacity, the growing number of Australian patients and families facing a diagnosis of melanoma are not able to access the supportive care and cancer survivorship care services that they need and deserve. In Australia's advanced health care environment, the evolution, accessibility and success of best-practice melanoma treatments, especially immunotherapy, has meant that many more people are living longer with a diagnosis of melanoma. Australians affected by melanoma need support and advocacy to navigate their way through treatment and beyond, through supportive and survivorship care, with the varied that come from surviving advanced melanoma, whether that be treatment side effects, getting back to work or adapting to the life-impacting changes that a serious cancer diagnosis like melanoma brings.

We urgently need investment in enhancing MPA's currently unfunded National Melanoma Support Service and Telehealth Nurse Service, which are stretched beyond capacity, and also need a significant investment towards the establishment of a National Melanoma Nurse Service, to address the grave inequities that exist for patients needing melanoma specific nursing care in Australia.

As such, MPA requests your consideration for inclusion of funding for the following melanoma support services, for delivery by MPA in 2022-23 and beyond, in the 2022-23 Federal Budget:

- 1) \$1.5 million per annum to further develop MPA's National Melanoma Telehealth Patient Support Service; and
- 2) \$55 million investment to develop a National Melanoma Nurse Service

Yours sincerely,

Victoria Beedle
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WHAT IS MELANOMA?

Melanoma is a cancer that originates in skin cells called 'melanocytes'. Melanocytes are the cells that produce melanin which colour the skin. When melanocytes are exposed to ultraviolet (UV) rays, these cells make more melanin, causing the skin to darken or tan. If left untreated, these skin changes can result in melanoma, the most aggressive form of skin cancer. When people are affected with melanoma, the DNA in the melanocytes becomes damaged, and they begin to reproduce uncontrollably, leading to a malignant lesion known as melanoma. Melanoma is most often caused by overexposure to UV and sometimes due to inherited genetic risk.

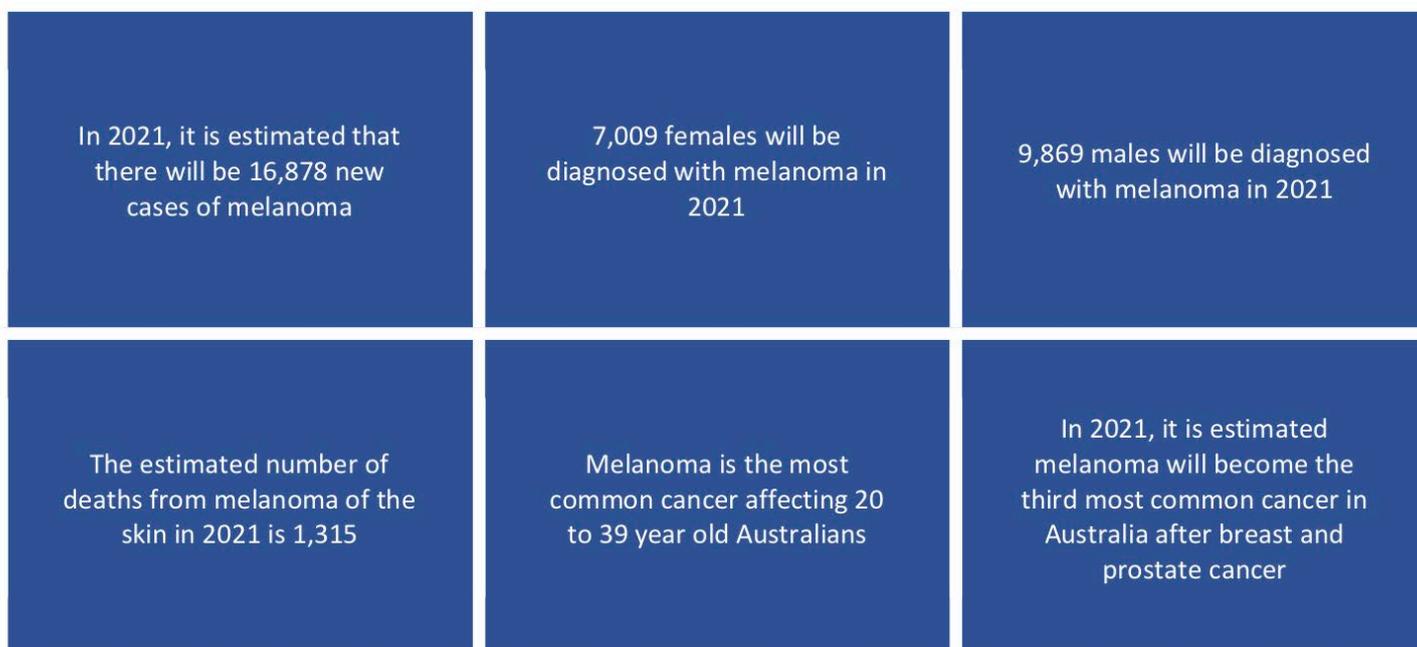
Melanoma in Australia

Melanoma has been coined as 'Australia's cancer' because of the disproportionately high incidence and mortality rates observed in Australian communities compared to other countries. For example, the incidence rate of melanoma in Australia is the highest in the world, with the World Health Organisation (WHO) reporting an age standardised incidence rate of invasive melanoma at 36.6 per 100,000 Australians in 2020, compared to the global average of 4.2 per 100,000 persons.¹

In 2021, it was estimated that melanoma will be the third most common cancer in Australia after breast and prostate cancer and cause 1,315 deaths. Concerningly, melanoma is the most common cancer affecting 20–39-year-old Australians.

Australia's report card on melanoma can be seen below:

Figure 1: Australia's Melanoma Report Card 2021²



¹ International Agency for Research on Cancer, GLOBOCAN2020, Mortality – ASR (World) vs Incidence – ASR (World), melanoma of skin, in 2020, both sexes, all ages, World Health Organisation, accessed <https://gco.iarc.fr/>.

² Australian Government – Cancer Australia, 'Melanoma of The Skin' (Web Page, 2021) <https://www.canceraustralia.gov.au/cancer-types/melanoma/statistics>

MELANOMA PATIENTS AUSTRALIA

Founded by two young Australian melanoma patients, Melanoma Patients Australia (MPA) was officially launched on 6 July 2006.

MPA is an independent, not-for-profit organisation dedicated to supporting and representing people affected by melanoma.

Nationally, MPA provides a range of free support services for melanoma patients, and their families and carers, including emotional support and information, education, peer to peer connections, formal support groups. MPA's novel Melanoma Telehealth Nurse Service, which has been in place for 18 months.

Currently, MPA receives no government funding and provides our services free of charge.

Figure 2: Support Options Currently Offered by MPA

| MPA Support | |
|--|--|
| Melanoma Telehealth Nurse Service | <ul style="list-style-type: none"> National Melanoma Telehealth Nurse Service provided by an oncology specialist nurse 0.6 FTE Patient Navigation and referral services for specialist services |
| Telephone Support Services | <ul style="list-style-type: none"> National Melanoma Support Line which provides Emotional Support, Information and Connections Telephone Support Group Sessions provided for metastatic melanoma patients across Australia in collaboration with Cancer Council NSW |
| Online Support Groups | <ul style="list-style-type: none"> MPA Closed Support Groups on Facebook. Providing support to over 2,500 patients and families across Australia. |
| Support Groups (Face to Face and via Zoom) | <ul style="list-style-type: none"> Face-to-Face support groups in QLD – Brisbane, Gold Coast, Sunshine Coast, Toowoomba, Mackay, Townsville; NSW – Sydney, Hunter Region; ACT – Canberra; VIC – Melbourne; SA – Adelaide; NT - Darwin. Face-to-face groups are currently suspended due to the COVID-19 pandemic and delivered digitally via Zoom. |
| Peer to Peer Support Program | <ul style="list-style-type: none"> Connecting people who have similar experiences with melanoma |
| Evidence-Based Health Information and Education | <ul style="list-style-type: none"> Public Information Forums providing evidence-based information and education from leading experts across Australia Digital and printed health resources explicitly designed to provide patients, families and carers with evidence-based information and education |
| Health Professionals Portal | <ul style="list-style-type: none"> MPA is currently developing a dedicated health professionals' web portal to provide healthcare professionals with best-practice information to support their patients and families impacted by melanoma |

Current Challenges for MPA

- 1) Escalating demand for MPA support services, with melanoma's increasing incidence and declining mortality rates
- 2) MPA is providing extended support and intervention services across the continuum of care from diagnosis to end of life, due to melanoma treatment success and increasing survivorship care needs
- 3) Patients and families are presenting to MPA with more complex support needs

MPA faces several significant challenges in managing the ever-increasing demand for our highly valued support services. This is due to the incredible breakthroughs in treatment options available for Australian melanoma patients, especially over the last six years.

Through our experiences and engagement with patients, it is evident that survival outcomes for melanoma patients have improved significantly due to advances in treatment access and success. MPA is now finding the supportive care services that we offer are in higher demand, with more patients and caregivers needing ongoing support from MPA over a more extended period across the continuum of care, from diagnosis to end of life. Key factors contributing to this escalating demand for MPA's support services include the improved clinical and survival outcomes for many patients on treatments such as immunotherapy, but also the support needs for the many patients facing relapse after successful initial and/or prior treatments.

Additionally, MPA has identified that many patients, once discharged from their cancer treatment team or a clinical trial, are still in need of ongoing supportive care services and are facing a large number of cancer survivorship issues that require melanoma specifically tailored solutions, which MPA is best placed to deliver.

In addition, with the impact of the COVID-19 pandemic, MPA has seen a significant increase in the distress and anxiety levels of patients and families, which means that they require more support to a higher degree of acuity and complexity.

MPA PRE-BUDGET SUBMISSION

Through establishing a partnership with the Australian Government, MPA has identified two programs outlined below to better support Australian melanoma patients across the complex cancer care continuum from diagnosis to end of life and optimise patient outcomes for 'Australia's cancer' – melanoma. MPA's ownership of these programs will alleviate the burden on the Australian Healthcare System – the necessity for advancement in supportive melanoma care – which has emerged as the by-product of the welcome treatment success and improved survival outcomes for Australian melanoma patients.

Federal Government Investment in Melanoma Support – Program 1

1) Further Develop MPA's National Melanoma Telehealth Patient Support Service

The initial shock of a diagnosis of melanoma is often overwhelming. As Australia's premier melanoma support and advocacy organisation, MPA provides a range of critical support service free of charge to melanoma patients and their families.

MPA currently provides a novel and unique Melanoma Telehealth Nurse Service, and Telephone Support Services through the National Melanoma Support Line.

MPA's National Melanoma Support Service has been operational for over 14 years and offers emotional support, information, connections and external referrals via telephone and a range of digital means to people affected by melanoma. It connects patients, and their families and carers, to MPA's wide range of support groups, peer mentoring program, and information and education forums and resources. MPA's support services are currently delivered by a mix of paid employees and trained volunteers from a range of backgrounds, and cover a wide range of relevant disciplines such as nursing, social work, counselling and lived experience of melanoma.

MPA's Melanoma Telehealth Nurse Service has been operational for 18 months and supports patients in navigating the healthcare system, accessing available services, and making decisions regarding their health. This personalised support service is available to all melanoma patients, and their families and carers, and is particularly valuable to melanoma patients in regional, rural and remote areas who are not proximal to or under the care of a major treatment centre. The service is delivered by a melanoma oncology nurse (0.6 FTE), and provides the following critical support:

- Liaising with a patient's GP, melanoma coordinator nurse, clinical trials nurse and oncologist as requested
- Providing connections to multidisciplinary allied health services such as dietitians, exercise physiologists, psychologists and more
- Providing connections to MPA's wide range of support services, and other continuum of care services as required
- Encouraging patients to proactively manage their melanoma diagnosis and treatment, including practical tips to manage symptoms and side effects

- Providing information on how to talk to family and friends about a melanoma diagnosis and the melanoma journey
- Helping patients consider the right questions to ask their oncologist, surgeon and wider health team
- Providing evidence-based information and educational resources
- Palliative care and pain management support
- Advanced care planning

Currently MPA receives no government funding for the provision of these critical services that support over 5,000 melanoma patients and families each year.

In the current environment of escalating demand for MPA’s support services, due to melanoma’s increasing incidence and declining mortality rates, advances in treatment access and outcomes, and ever-expanding and increasingly complex supportive care and survivorship care needs, and in the context of MPA’s current funding and resource constraints, there is an evident imperative for funding investment by the Australian Government, to enable MPA to continue to support Australian melanoma patients adequately and equitably.

It is estimated that this would require an investment of \$1.5 million per annum in 2022 and 2023, to enhance MPA’s National Melanoma Telehealth Patient Support Service, through the creation of a multidisciplinary team of eight full time equivalent (FTE) melanoma healthcare professionals.

| Estimated Program Cost: \$1,500,000 per annum | |
|--|--|
| Deliverables | Outcomes |
| <u>Enhancing the MPA National Melanoma Support Service and Telehealth Nurse Service by creating a multidisciplinary telehealth team of 8 FTE melanoma healthcare professionals from various disciplines such as; Nursing, Social Work, Counselling and Allied Health.</u> | Equitable and greater access to healthcare professionals with melanoma expertise for patients and caregivers, including those in regional, rural and remote Australia. |

Federal Government Investment in Melanoma Support – Program 2

2) Establish a National Melanoma Nurse Service

Cancer (oncology) nurses are integral members of multidisciplinary healthcare teams that care for people who are diagnosed with cancer. These nurses administer medication, provide care, and offer information and support throughout treatment, helping patients navigate their complex cancer journey and overcome barriers to optimal cancer care.

Melanoma patients do not receive the same specialist nursing support as other cancers, such as breast and prostate cancer, which receive Australian Government funding to support a national nursing workforce; this is despite melanoma being the third most common cancer in Australia.³

³ Australian Government – Cancer Australia, ‘Melanoma Of The Skin’ (Web Page, 2021) <<https://www.canceraustralia.gov.au/cancer-types/melanoma/statistics>>

Advanced melanoma patients experience similarly complex care and support to advanced breast and prostate cancer patients. Melanoma has the highest rate of brain metastasis of any solid tumour, yet there is no equitable approach to nursing support per incidence case nationally.

Through MPA’s critical role in providing support services for melanoma patients and their families, MPA has identified that many people affected by melanoma are unaware of the services they can access. Once connected to MPA, many communicated that they felt unsupported and were unsure where to seek help during their cancer care. One core issue identified through patient contact with MPA is the lack of understanding regarding how and where melanoma patients can access and receive support throughout their cancer journey.

Thus, nursing support for melanoma patients through the establishment of a National Melanoma Nurse Service by MPA, to provide optimal care from diagnosis to end of life, is essential to ensure ongoing continuity and best-practice supportive care for people affected by melanoma.

There are currently only eight dedicated melanoma-specific nurses based within Australia's major melanoma treatment centres. It is time to adopt an equitable approach to cancer nursing across Australia, with Australian Government funded specialist melanoma nurses per the breast and prostate cancer nursing workforce precedent.

Adopting an equitable approach to oncology nursing through establishing a specialist National Melanoma Nurse Service network would see the Australian Government support an additional 84 melanoma nurses nationally, including 16 specialist nurses.⁴

It is estimated that this would require an injection of \$55 million in new funding for melanoma nurses nationally, and could be rolled out by MPA using the models piloted and proven for breast and prostate cancer nurses.

| Estimated Program Cost: \$55,000,000 | |
|--|--|
| Deliverables | Outcomes |
| Adopting an equitable approach to oncology nursing would see the Australian Government support an additional 84 melanoma nurses nationally, of which 16 would be dedicated to supporting advanced melanoma patients and their families. | Equitable and greater access to health care especially for those with for advanced melanoma. |

Importantly, both of the above-proposed MPA services could be linked and piloted alongside any Cancer Care Navigation Service that the Australian Government may be considering. This investment would ensure that the 16,878 people diagnosed with melanoma each year and the 158,000 people currently living and struggling with melanoma in Australia get the care and support they need and deserve.

⁴ Calculated by applying an equivalent nurses to patients ratio to melanoma incidence, based on the number of breast cancer nurses to breast cancer incidence, noting a similar rate was also evidence for prostate cancer nurses to prostate cancer incidence.

Melanoma has long-lasting impacts on the physical, mental health and wellbeing of patients and their families

If the gaps in supportive care and cancer survivorship care for Australians affected by melanoma are left unaddressed, the consequences of melanoma will be far-reaching with damaging health implications.

It is critical to urgently address the need to enhance MPA's currently unfunded National Melanoma Telehealth Patient Support Service, which is stretched beyond capacity, and make a significant investment in a National Melanoma Nurse Service to enable MPA to address the grave inequities that exist for patients needing melanoma specific nursing care in Australia.

For further information or any additional queries relating to this Submission, please contact:



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