STATE OF THE NATION

A Report into Melanoma – A National Health Priority

Final Report

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Insight Economics
Public Policy Corporate Strategy

Melanoma Institute Australia

mpa
MELANOMA PATIENTS AUSTRALIA

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Appendices

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Sunbaker

In 1937 Max Dupain took a photo of a sunbaker, timeless, iconic
But has it sent us down the path of a chronic
Illness that we continue to ignore in our suntanned haze
Sitting blissfully in the sun's midday blaze

This country of ours promotes outdoor living
But we just aren't prepared for how unforgiving
The sun is being on our community
Our Governments are ignoring the reality
Where's the ad campaign that helps educate
Why is a skin check register such a debate
Where is the council planning regulations
That require more shade structures across this nation
More people die from Melanoma than die on our roads
The sun it's a time bomb watch it explode

I see your body shimmering in the heat
Lie back, get burned, rollover and repeat
At beaches and pools around this wide land
Lying near naked in the pursuit of a tan
Lie back, get burned, rollover and repeat
Roasting on a rotisserie like a piece of meat

You are my sisters, my daughters, my teenage niece
What do I need to say to give you release
From this narrative that says a tan is good health
I can't say it more plainly, the sun kills by stealth

You think it's for old people and yes whilst that's true
If you're aged 20 to 40 it could come for you
It's the cancer that kills the most people your age
Just one sunburn could put you on that page
So as well as checking your breasts and having Pap smears
Ask your Doctor for skin checks to avoid future tears

Stage IV Melanoma, I've survived it, for now
With science, good luck and God knows how
See the vitiligo on my skin let it be your reminder
That protecting yourself is ultimately kinder
Than the pain and the fear of Melanoma in your life
Stop seeking a tan so there's no need for the knife
Don't you be the one to leave your family bereft
Don't wait to be told you've got 2 years left.

- *Anne Gately, Stage IV Melanoma Survivor*

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Melanoma is Australia's most fatal skin cancer

Australia has the **highest incidence rates** in the world, with a crude incidence rate **8.7x** the global average

3rd Melanoma is the **3rd** most commonly diagnosed cancer (excl other skin) in Australia

Approximately **17,000** Australians are diagnosed with melanoma each year

2 in 3 will be diagnosed with skin cancer; melanoma represents only **3%** of incidence but **65%** of deaths

Approximately **1,400** Australians lose their lives to melanoma each year

Looking forward, between today and 2030, **205,000** Australians are set to be diagnosed

Without action, between today and 2030, more than **14,000** Australians will lose their lives to melanoma

Absent action, the cost (NPV) of melanoma between now and 2030 is estimated to exceed **$8.7 billion**

$8.7b = **$4.4b** in economic loss of life with **over 136,000 years of life lost** + **>$3.1b** in direct health system costs of treatment + **$1.2b** in out of pocket costs

Vision – 2030 and beyond

With urgent and continued action, **zero deaths** is considered **possible** within our lifetime; but this requires **urgent** & sustained action

Zero mortality is targeted for **road safety**

Melanoma deaths **exceed** road toll **1,384 > 1,113**

Yet, road safety funding **dramatically** exceeds melanoma awareness and prevention funding

Continuing Australia's history of gold standard prevention and awareness

- **Modern prevention and awareness strategy, campaign**
- **Shade in all high risk spaces by 2025**
- **Explicit sun-safe sport policies**
- **Explicit training for outdoor trades**
- **Nationally consistent school policies**

Prevention and awareness strategy to reduce incidence by: **45%**

Leveraging Australia's world leading research to eliminate mortality from melanoma

- **Nationally collaborative research mission**
- **Cancer data assets with full implementation by 2025**
- **Accelerate clinical trials reform implementation**

ROI of research: **>$3.90** per dollar invested

Enhancing early detection

- **Skin check awareness strategy & campaign**
- **Roadmap to National Targeted Screening Program**
- **National melanoma training program for GPs**
- **Increase supply of quality skin checks**
- **Minimum standards for skin checks, diagnosis**

Improve **equitable access to skin checks** and **reduce variation in outcomes**

Improving diagnosis, treatment and care

- **Clinical guidelines and standard of care**
- **Patient navigation services**
- **Fund National Melanoma Nurse Service**
- **Accelerate access to clinical trials**
- **Reform travel and accommodation assistance**

Clinical care standard to save >4,000 lives, reducing mortality by: **32%**

Revolutionising supportive care and survivorship

- **Require written survivorship care plans**
- **Patient Navigation Services**
- **Fund National Melanoma Nurse Service**
- **Patient Reported Outcomes**
- **Increase supply of skin checks**
- **Research technologies & models of care**

Improve **equitable access to services** and **quality of life for survivors**

Executive Summary

Roughly two in three Australians will be diagnosed with some form of skin cancer in their lifetimes. Within this, more than 17,000 Australians are diagnosed with invasive melanoma and 28,000 with *in situ* melanoma each year. This makes melanoma the most commonly diagnosed invasive cancer in Australia after breast and prostate cancer, and sees Australia with the highest per capita incidence of melanoma in the world today.

While melanoma is estimated to account for only three per cent of all skin cancer diagnoses in Australia, it accounts for 65 per cent – almost two-thirds– of all skin cancer death. Every year, approximately 1,400 Australians lose their lives to melanoma. As a result of the disproportionately high incidence and mortality rates of melanoma (relative to other countries and skin cancers, respectively), melanoma is often referred to as Australia's 'national cancer'.

Australia has led the way in both the prevention of melanoma since the 1980s and in the remarkable research breakthroughs in treatment of the last decade. Combined, substantial improvements in survival and quality of life have been realised. At the same time, there remains much more to be done to end the impact of melanoma for Australian families and communities.

Melanoma incidence is set to rise over the forward decade, with more than 205,000 Australians expected to be diagnosed with melanoma between now and 2030. Sadly, more than 18,000 of these Australians will lose their lives to melanoma within five years of their diagnosis. More than 136,000 years of life will be lost, equating to an economic loss of life of $4.4 billion over the 2021-2030 horizon alone.

Moreover, melanoma presents not only significant health risks, but also potentially challenging financial, social and emotional impacts for patients, their families, and the wider Australian healthcare system. For example, the direct health system cost of treating melanoma is expected to exceed $3.1 billion in $NPV_{2\%}$ terms over the 2021-2030 horizon alone, while patients and their families are expected to experience substantial out-of-pocket costs in the order of a further $1.2 billion on top of potential lost income as patients and their families must scale back employment as a result of their treatment.

Combined, the direct financial costs and financial impacts of loss of life from melanoma in Australian communities are estimated to exceed $8.7 billion between now and 2030.

Moreover, patients and their families are also at risk of adverse side effects from melanoma and its treatment. In a survey of 1,137 patients and carers undertaken for this report, more than one in three patients reported experiencing pain, fatigue, and/or skin rashes and irritation as a result of melanoma and its treatment. Around one in 10 patients on average reported experiencing lymphoedema, depression, social isolation and loss of employment and income. Clinical anxiety and depression are also major risks for patients at all stages of melanoma; nearly 40 per cent of all patients reported experiencing anxiety as a result of their diagnosis. Currently, however, there is no clinical standard for the consistent care of melanoma patients and survivors. The absence of a model of care for survivors is set against a backdrop of an enormous expansion in the number of patients and survivors requiring this support. By 2030, the number of long-term survivors is expected to nearly double, with more than 158,000 additional long-term melanoma survivors expected to be added to an estimated prevalence of over 190,000 people today.

But there is hope: these health and economic costs can be dramatically reduced through targeted action by Australian communities, governments and the health care sector. More than perhaps any other cancer, the potential to achieve zero deaths from melanoma is now

possible through coordinated action in prevention, research, early detection, treatment, and supportive care and survivorship. This is possible because:

- *Melanoma is preventable* — Australia has illustrated that melanoma is preventable, and that preventive actions can be cost effective. While Australia has historically commanded a leadership position in skin cancer prevention, this position is at risk due to recent underinvestment in modern prevention awareness campaigns as well as underinvestment in consistent implementation of proven best practice prevention strategies in a range of settings. Much more can be done to improve adoption of skin protective behaviours: through investment in a comprehensive, modernised public health prevention and awareness strategy and public health campaigns, accelerated investment in shade for high risk public spaces, as well as consistent implementation of sun protection policies across schools, workplace and recreational settings.

- *Early detection is associated with high survival rates* — When detected in its earliest stages, long term survival rates for melanoma can approach 100 per cent. While some advancements in research and technology are emerging, the quality of, and access to, early detection in Australia is inconsistent and oftentimes limited, especially for rural and regional populations. A plan to improve early detection, including through a Roadmap for a National Targeted Melanoma Screening Program, can deliver services that are equitable, trustworthy for patients and clinicians, and cost-effective for the community and the healthcare system.

- *Treatment breakthroughs can eliminate mortality from melanoma* — Remarkable new developments in precision medicine now offer the potential for substantial improvements in long term survival and symptom relief for patients with advanced melanomas. Five-year survival rates for patients with advanced metastatic disease have nearly doubled in the last 10 years, and Australia boasts world leading survival outcomes. Data show that addressing variation in treatment across Australia today could reduce mortality by more than a third, while world-leading research offers the potential to improve the prevention of melanoma and the treatment of patient cohorts for which no effective long-term treatment currently exists.

- *Quality of life can be improved through access to supportive care for patients in active treatment and long-term survivors* — Supportive care and survivorship support can substantially improve the quality of life for patients and their carers, helping them live full, active lives and return to both paid and non-paid roles within the community. Establishing a structured approach to the support of patients from the time of diagnosis, to better manage the long-term symptoms and side effects of melanoma and its treatment, can substantially improve the quality and consistency of care for melanoma patients and their ability to fully reintegrate with their families, jobs and communities as long term survivors.

Through investment in research and prevention, combined with new approaches to early detection and adherence to clinical best practice, the prospect of drastically reducing the impact of melanoma on Australian communities in our lifetimes is a real, attainable goal.

This will not happen without sustained, strategic action by Australian Governments and the wider community. This report presents the case for change and a blueprint for coordinated action across the melanoma community, government and wider health care sector.

An action plan to eliminate mortality from melanoma

Based on Australia's performance to date and evidence of impact from policy and investment opportunities, the State of the Nation in Melanoma proposes the following five-point strategy for improving outcomes for melanoma patients and survivors.

This plan has been developed in partnership with melanoma patients, their families, and the wider melanoma community, and is built upon a comprehensive evidence base including:

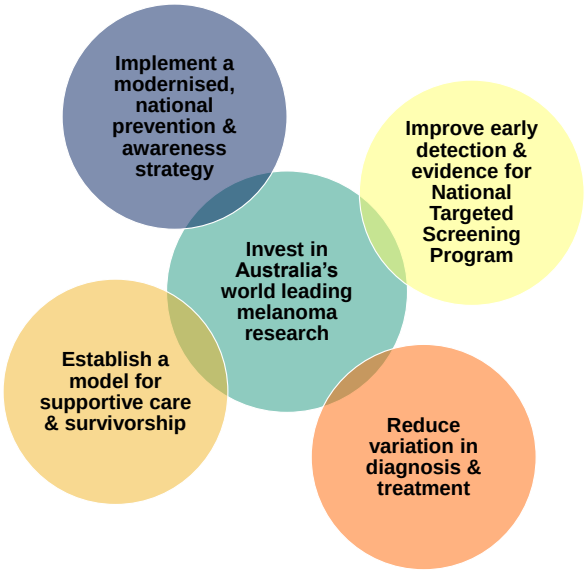
- A statistically significant survey of more than 1,137 patients and carers nationally, providing quantitative data on patient experience and perspectives on policy and investment priorities (See Appendix B)
- Stakeholder consultation and a series of national patient and carer townhall meetings across Australia drawing together insights and ideas from more than 70 patients, carers and melanoma community leaders (See Appendix C)
- A comprehensive literature and data review, including a review of Australian cancer policy settings as well as information around trends in survival, investment and outcomes across each of the major policy domains (See Appendix E).

As shown in Figure 1, the five-point strategy to eliminate melanoma deaths within a generation developed in partnership with the melanoma community consists of the following complementary elements:

1. Implement a modernised, national strategy for melanoma prevention and awareness
2. Invest in Australia's high-impact, world-leading melanoma research
3. Improve early detection and evidence for a National Targeted Screening Program
4. Reduce variation in diagnosis and treatment
5. Establish a model for melanoma supportive care and survivorship.

The rationale and recommendations for each element of the strategy are explored below.

Figure 1: Action Plan for Melanoma: Five-point strategy for ending mortality

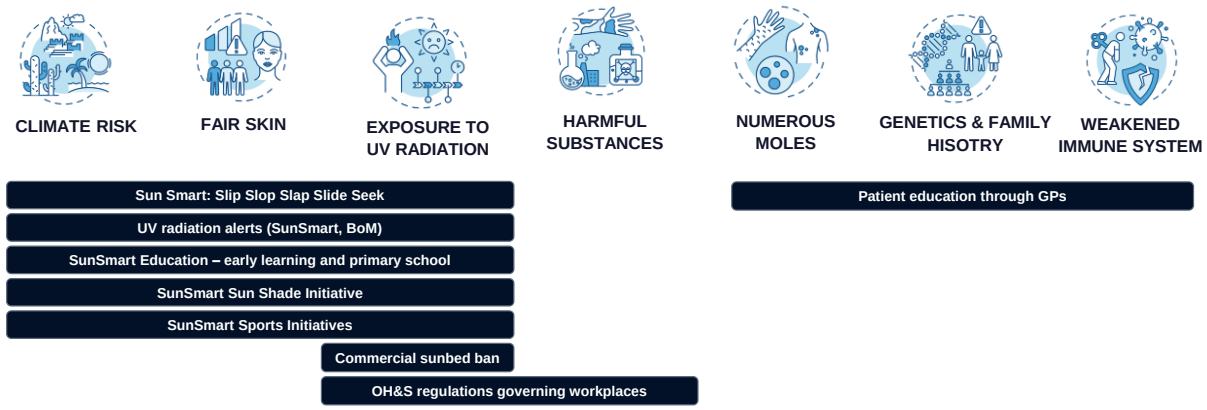


Implement a modernised, national melanoma prevention and awareness strategy: rationale and recommendations

Australia has established itself as a global leader in skin cancer prevention, with its policies recognised by both the US Preventative Services Taskforce and the Centre for Disease Control as the gold standard in melanoma prevention. Sustained investment in skin cancer prevention in aggregate have seen incidence rates in melanoma decline for younger

Australians. Significant successes have included public health awareness campaigns such as the *Slip! Slop! Slap!* campaign, the ban on commercial sunbeds (but not those for personal use), the development of SunSmart policies in primary schools and the establishment of implicit workplace safety requirements, particularly for outdoor workers (Figure 2).

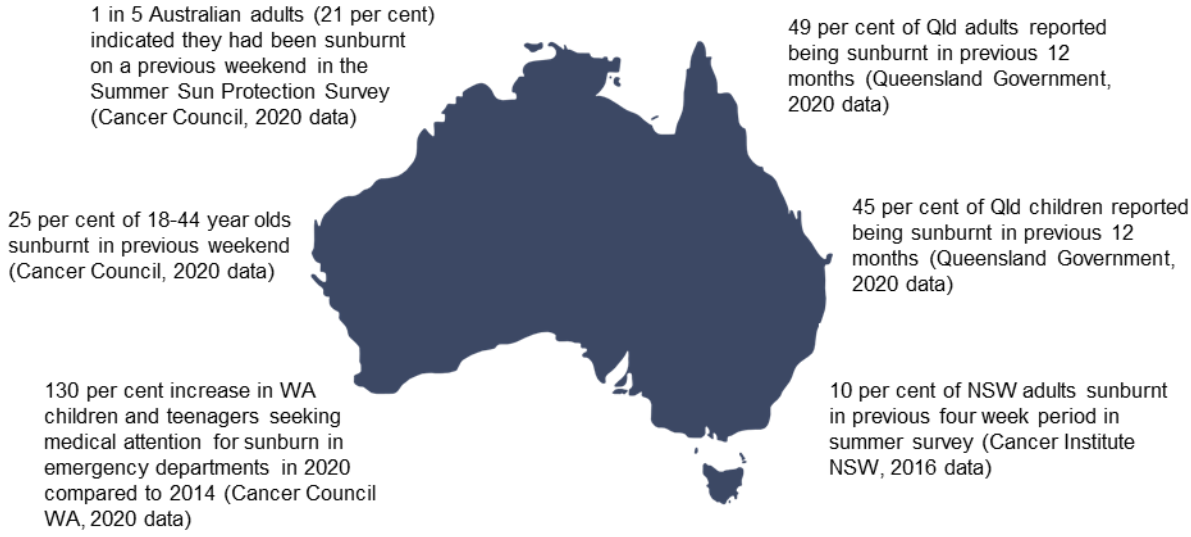
Figure 2: Overview of major prevention efforts in Australia aimed at melanoma risk reduction



Note: Harmful substances include herbicides. Numerous moles are most commonly on the back not the lower arm.

Notwithstanding the significant achievements that have been made, however, the incidence of melanoma in the community remains high and there are indications that the uptake of preventive behaviours remain mixed. Sunburn rates remain high across Australia (Figure 3). Stakeholders attributed inconsistent adherence to sun safe behaviours to a limited understanding of the seriousness of melanoma compared with other skin cancers and significant confusion regarding 'how' to be sun safe and possible risk factors (e.g., UV radiation as distinct from heat). As a result, there continues to be excess exposure to UV radiation and sunburn in the community.

Figure 3: The sunburnt country: sunburn rates remain high across Australia



Source: Queensland Government website, available at https://www.health.qld.gov.au/news-events/news/sun-safety-skin-cancer-children-queensland-protecting; Cancer Institute NSW, 2017, Sun protection behaviours in NSW, p 5; Cancer Council WA, 2021, Number of 10-19 year olds with severe sunburn more than doubles in 2020, available: https://www.cancerwa.asn.au/articles/news-2021/number-of-1019-year-olds-with-severe-sunburn-more-/; Cancer Council, 2020, Media Release: Kids of the 80's and 90's failing the Slip Slop Slap-ometer.

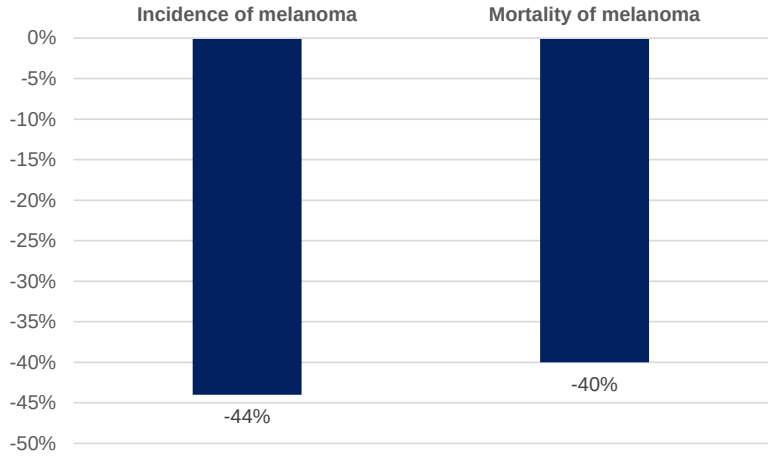
Moreover, while substantial improvements have been made in policy settings in schools, workplaces and among sports and other outdoor clubs, the implementation of policy recommendations remains inconsistent. In particular:

- Sun safety training and compliance are not explicit for all outdoor workers and sports clubs in line with other occupational health and safety guidelines, such as the approach adopted for the prevention of injury or chemical exposure
- There is surprising inconsistency in primary school settings of SunSmart policies reported by stakeholders and virtually no take up of SunSmart policies at a secondary school level
- Sporting clubs are not required to develop sun safe policies in the same way they are required to develop policies for child protection, discrimination or more recently for the prevention of Covid infection
- Shade investments which fall under the purview of local governments are at risk of deprioritisation against a backdrop of significant infrastructure renewal backlogs.

In aggregate, there is also underinvestment in public health messaging for melanoma prevention, which has been largely left to the charitable sector to deliver. Comparing the coordinated approach to road safety to melanoma, for example, indicates disproportionately low investment in melanoma prevention and awareness in spite of similar mortality risks and clear parallels in the potential policy approach for ensuring and coordinating community safety and public health across all states and territories.

Underinvestment in melanoma prevention is likely to be a function of the lag in benefits realisation because Australian experience has consistently shown that prevention can be highly cost effective. For example, skin cancer prevention policies nationally have returned $3.30 for every $1.00 invested, and consistent adoption of sun safe behaviours has the potential to reduce melanoma incidence by 44 per cent (Figure 4). However, the longer horizon for benefits realisation makes these investments easy to defer.

Figure 4: Prevention policy: reduction in incidence from increasing uptake of sunscreen



Source: Gordon, L, Olsen, O, Whiteman, DC, et al., 2020, Prevention versus early detection for long term control of melanoma and keratinocyte carcinomas: a cost effectiveness modelling study, BMJ Open, doi: 10.1136/mbjopen-2019-034388. Note: these incidence reductions are associated with a 100 per cent uptake of sunscreen, arising from undefined policies.

Without action to improve the uptake of prevention, however, high health and economic costs associated with avoidable melanoma incidence will continue to impact Australian communities.

To address gaps in melanoma prevention, the following actions are recommended:

- Invest in a modern, nationally-coordinated prevention and awareness strategy and attendant public health awareness campaigns, pursuing a 'generational change' approach that builds on $20 million commitment to follow a 'road safety' policy approach and sustained investment to improved outcomes
- Accelerate investments in shade with the goal of shading the highest risk public spaces within five-years through a dedicated, collaborative national fund
- Improve adherence to sun safe behaviours in primary schools and uptake in secondary schools through a national collaborative working group
- Treat sun safety in the workplace in a manner consistent with other OH&S issues, including by requiring explicit training in sun safe behaviours for all outdoor workers as is undertaken for other injury and chemical exposure risks
- Treat sun safety in Australian sports and other outdoor clubs in a manner consistent with other sport safety and inclusion issues, including by providing information and resources through the Australian Institute of Sport and through partnership with Play by the Rules.

Importantly, investment in the prevention of melanoma also serve to reduce the incidence of other skin cancers, which combined represent the most prevalent cancer in Australia and place significant pressure on Australia's health care system through surveillance and treatment.

Invest in Australia's high-impact, world-leading melanoma research: rationale and recommendations

The melanoma research community has proven itself to be world-leading, with specialisations in melanoma biology, melanomagenesis, epidemiology, genomics, immunology, advanced therapies, novel detection and diagnostic technologies, and outcomes research.

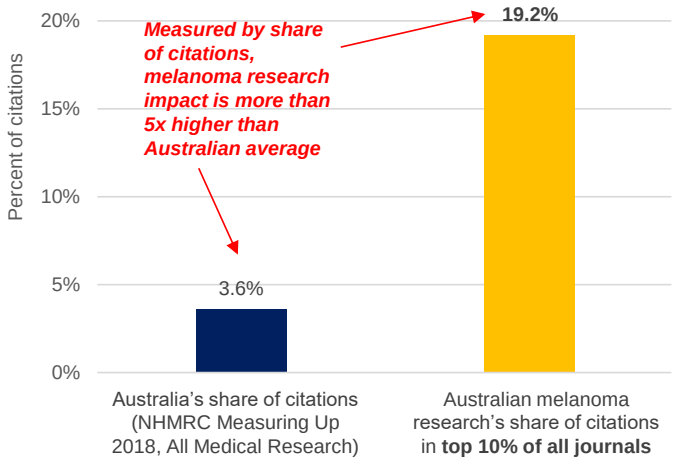
Citation analysis (Figure 5) indicates that Australia's melanoma research community outperforms even Australia's high standards for research excellence; for example, SciVal bibliometric analysis shows that Australian melanoma research accounts for:

- 19.2 per cent of citations in the *Top 10 per cent of journals*
- 2.6 per cent of citations in the *Top 1 per cent of journals*.

This compares favourably to the average citation rate for Australian medical research on average (and not controlling for top-tier journals) of 3.6 per cent.

As a consequence of this high research productivity, the relative citation impact (RCI) performance of Australia's melanoma research community in Top Tier journals (Top 10 per cent of journals) and the most prestigious journals globally (the Top 1 per cent of journals) also exceeds both the national average for medical research and highly competitive National Health and Medical Research Council (NHMRC) funded research benchmarks (Figure 6).

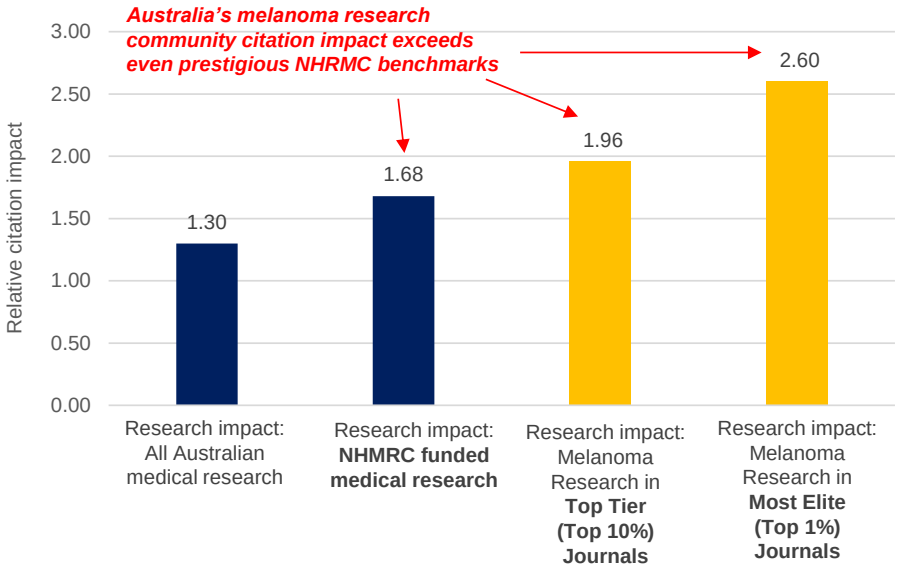
Figure 5: Citation statistic benchmarking: percentage of citations



Source: National Health and Medical Research Council, 2018, Measuring Up, SciVal analysis of melanoma research developed by Melanoma Institute Australia.

These are the measures of the high impact and quality of Australia's melanoma research community. They point to very significant returns on investment from a research productivity perspective of melanoma research in Australia.

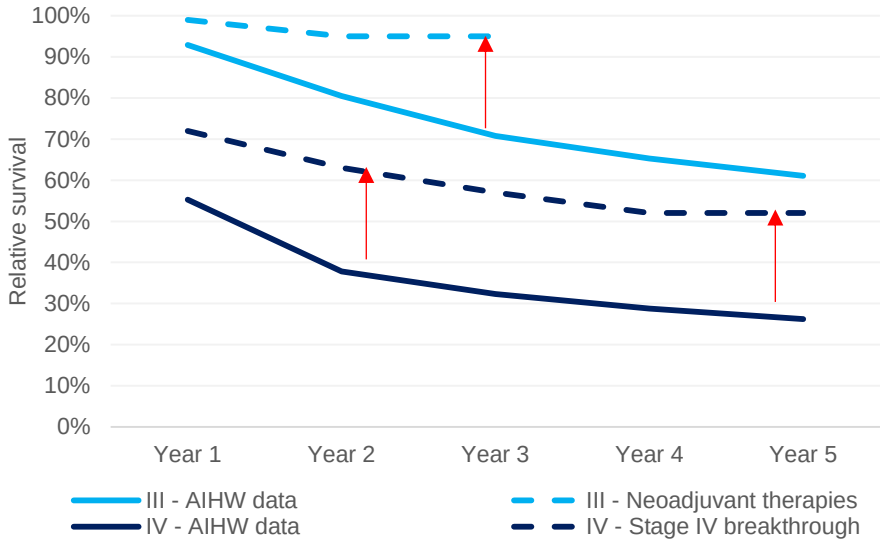
Figure 6: Citation statistic benchmarking – Relative Citation Impact



Source: National Health and Medical Research Council, 2018, Measuring Up, SciVal analysis of melanoma research developed by Melanoma Institute Australia.

Most importantly, Australia's research efforts have translated into improved survival for Australians, through declining incidence in melanoma among younger generations and significant breakthroughs in the treatment of advanced melanoma. For example, breakthroughs in Stage IV treatment have seen five-year relative survival rates nearly double within the last 10 years (Figure 7).

Figure 7: Impact of breakthroughs on mortality in Australia



Note: Depicts a comparison of Australian Institute of Health and Welfare survival rates for Stage III and Stage IV melanoma patients and outcomes published in CheckMate trial and International Neoadjuvant Melanoma Consortium (INMC) study. The most recent staging data made available by the Australian Institute of Health and Welfare is based on patients diagnosed in 2011. Consequently, survival rates are calculated via tracking this cohort across the subsequent five-year period (until 2016).
Source: Australian Institute of Health and Welfare Cancer Data in Australia 2020; Larkin, J, Chiarion-Sileni, V, Gonzalez, R, et al, 2019, Five-Year Survival with Combined Nivolumab and Ipilimumab in Advanced Melanoma New England Journal of Medicine, 381, 1535-1546, doi: 10.1056/NJMoa1910836; Menzies, AM, Amaria, RN, Rozeman, EA, et al, 2021, Pathological response and survival with neoadjuvant therapy in melanoma: a pooled analysis from the International Neoadjuvant Melanoma Consortium (INMC), Nature Medicine, 27, 301-309, doi: 10.1038/s4591-020-01188-3.

Additionally, research breakthroughs in melanoma have also been shown to 'spillover' into other areas of cancer research; for example, recent advances in the treatment of melanoma with novel immunotherapies are being applied to a range of other cancers, including lung, gastric, liver, kidney, Hodgkin lymphoma and urothelial cancers. This further enhances the value of investment in melanoma research, which can generate second round benefits across Australia's medical research landscape.

While these advances in research and survival are to be celebrated, to fully eliminate the incidence of and mortality from melanoma additional investment in new discovery is required; improvements in clinical best practice and full uptake of prevention and awareness policies cannot do it alone.

Australia is uniquely positioned globally to lead the next generation of high impact biology and melanomagenesis research, which could see improved prevention of melanoma and the complete elimination of mortality for all patients diagnosed with melanoma. Australia is also well placed to lead research to optimise the current generation of systemic treatment breakthroughs and to develop advanced technologies and new models of care for the early detection of melanoma.

To that end, it is recommended that the Australian Government invest in a Nationally Collaborative Melanoma Research Mission and Discovery Program. This program would be focused on maximising research output of proven, high impact research teams nationally, with a collaborative approach improving the power and speed of research outcomes. The major components of this program would centre on:

- Understanding melanomagenesis and melanoma biology
- Optimising the use of the current generation of systemic treatments
- Novel imaging and detection technologies

- Evidence development for a National, Targeted Melanoma Screening Program
- Development of Patient Reported Outcomes in Melanoma.

In addition to the development of a Melanoma Research Mission and Discovery Program, core enabling infrastructure challenges should be addressed. These include:

- The development of the national, linked, clinical and population datasets needed to accelerate cancer research as part of a National Cancer Data Ecosystem, consistent with the approach of Australia's developed nation peers, behind which Australia substantially lags.
- Reforms to streamline clinical trials ethics and governance processes to improve Australia's competitiveness as a destination for clinical trials, which persistently remain an unnecessary drag on research productivity, creating cost and overly long timelines, and to reduce barriers to participation in clinical trials by regional patients.

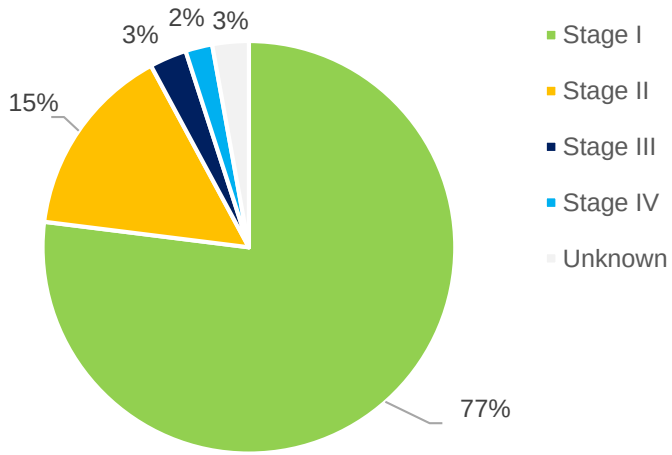
These key enabling infrastructure requirements have long been identified as barriers to research performance and government should set an ambitious target of addressing these challenges by no later than 2025.

Develop a roadmap for improved early detection: rationale and recommendations

When detected in its earliest stages, long term survival rates for melanoma can approach 100 per cent. In Australia, most melanomas are detected in the earliest stages of disease; as illustrated in Figure 9 below, 2011 data (latest data) show that 77 per cent of invasive melanomas are diagnosed at Stage 1. Specifically, 62 per cent of invasive melanomas are diagnosed at Stage IA (less than 1mm of thickness) and 15 per cent are diagnosed at Stage IB (less than 2mm with no ulceration).

This compares favourably to international benchmarks. For example, population data indicates that approximately 64 per cent of melanomas in the UK are detected at Stage I (compared to 77 per cent in Australia) and 80 per cent of melanomas diagnosed in the USA are detected at a 'localised' stage (including Stages I and II, compared to 92 per cent in Australia).

Figure 9: Stage of diagnosis among invasive melanoma diagnoses



Source: Australian Institute of Health and Welfare, 2021, Cancer Data in Australia. Note: this reflects the most recently collected incidence data by stage (diagnosed in 2011). Note: 10-25 per cent of stage II become stage IV melanoma and around 50 per cent of stage III become stage IV (and a proportion of stage I and II become stage III).

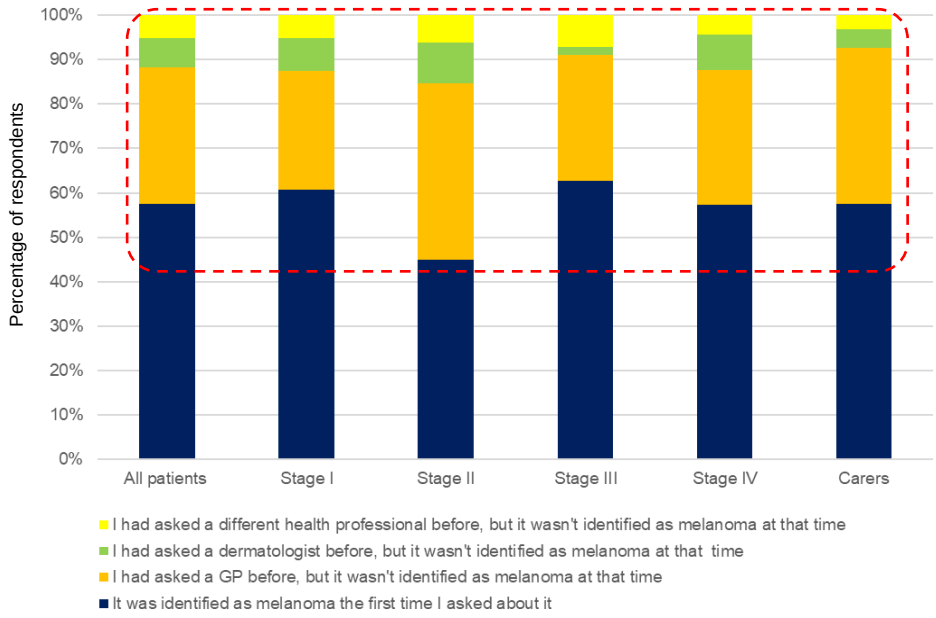
While many melanomas are detected in their earliest stages, there remains substantial room for improvement in the early detection of melanomas. Significant challenges exist with respect to:

- *Lack of patient awareness, empowerment and guidance regarding skin checks* — Stakeholders reported a general lack of awareness within the community regarding individuals' personal risk of melanoma, poor awareness of the need for routine self-skin examination, and inadequate guidance for when to present for a skin check by a health professional. This can lead to a failure to spot a melanoma in its earliest stages, when treatment is most effective, as well as risks of an 'overuse' of the health system by the 'worried well'. The clearer articulation of high-risk groups is essential to improving early detection and health service utilization patterns.
- *Shortage of professionals trained in skin checks* — There is a growing shortage of dermatologists nationally and shortages of trained professionals to perform skin checks in regional areas. These shortages impact waiting times, the ability to access care in regional areas and out-of-pocket costs for patients and carers. Access barriers for regional and socioeconomically disadvantaged patients in particular were identified as a significant problem. Many regional and remote patients are unable to access dermatologist services in regional areas and there can be significant waiting times to access skin checks in primary care settings. In addition, out of pocket costs for skin surveillance among high-risk groups can create barriers to accessing care, particularly for patients from disadvantaged backgrounds.
- *Failure to detect* — Stakeholders expressed concern regarding a lack of minimum standards in skin checks and variation in quality among providers. Survey data indicate a high rate of failure to detect melanoma, with more than 30 per cent of respondents indicating they had asked a GP or dermatologist about a suspicious lesion previously, before it was diagnosed as a melanoma (See Figure 10 below). Survey data indicate that GPs fail to detect lesions at four times the rate of dermatologists, while patients and carers indicated GPs could sometimes be dismissive of patient concerns. It was noted there is relatively limited training in medical school for dermatology and inconsistent uptake of diagnostic aids, such as a the use of a dermatoscope, which have been shown to substantially reduce errors in diagnosis.

These issues point to the need for training and improvements in clinical practice, as well as new models of care for the early detection of melanoma that can improve the effectiveness and efficiency of melanoma surveillance to Australian communities.

Recent research has shown that High Risk Clinics are more effective in the surveillance of melanoma compared to current practice and are cost effective, and importantly can be effectively delivered in a range of care settings. Significant research is also underway to develop more effective approaches to identifying high-risk populations using genetic and environmental factor algorithms through the Australian Centre of Excellence in Melanoma Imaging & Diagnosis and new models of care for delivering skin checks to the community, including in particular to regional and disadvantaged communities. The completion of this research and the rollout of these new models of care should be supported through the development of a Roadmap for a National Targeted Melanoma Screening Program. This can be developed as a major workstream of the Nationally Collaborative Melanoma Research Mission and Discovery Program.

Figure 10: Failure to detect – percentage of patients who had asked health professional about melanoma before it was diagnosed



Source: Melanoma Patient and Carer Survey, see Appendix B.

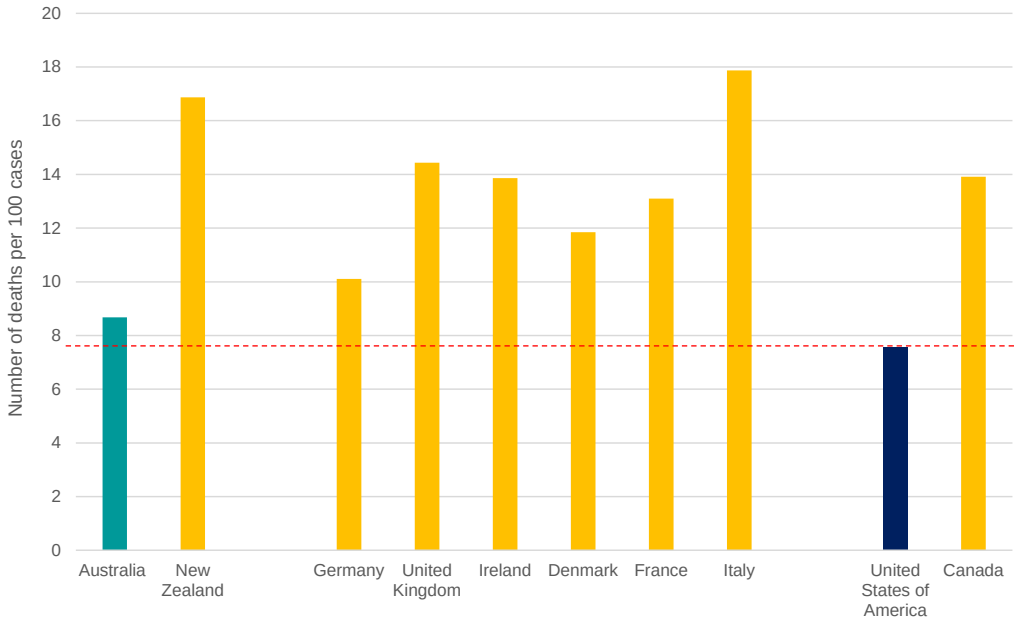
Thus, to improve early detection of melanoma, it is recommended that clinical practice is improved alongside support for a research program focused on evidence development for a National Targeted Melanoma Screening Program. To this end, the key recommendations for action are:

- Increase education and awareness of the risks of melanoma and the need to 'Know the Skin You're In' through routine self-skin checks
- Define minimum standards for skin checks, including the consistent use of whole-body examinations and dermoscopy
- Invest in GP training and dermoscopy program
- Develop a Roadmap for a National Targeted Melanoma Screening Program.

Reduce variation in diagnosis and treatment: rationale and recommendations

Australia enjoys a high standard of care in melanoma nationally, which promotes globally leading survival outcomes. For example, data reported by the International Agency for Research on Cancer show that as of 2020, the rate of deaths from melanoma relative to incidence for Australia was among the world's best, outpaced only by the United States (Figure 11). These outcomes derive from Australia's high quality healthcare system, which is underpinned by universal access to primary care and allied health services, and PBS reimbursement for best evidence-based care in melanoma treatment. Australia also benefits from the availability of clinical guidelines, developed by Cancer Council Australia in partnership with the melanoma community.

Figure 11: Melanoma-specific mortality to incidence rate among selected developed nations (2020)

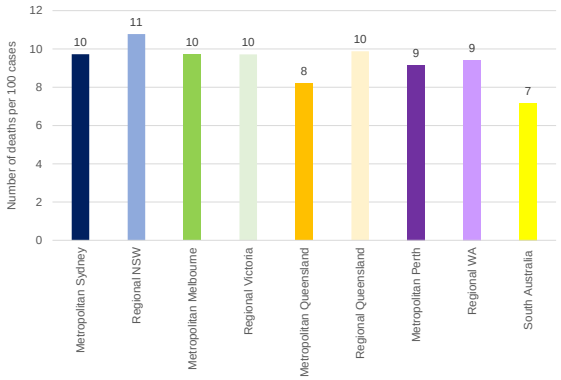


Source: International Agency for Research on Cancer, 2021, Mortality to incidence for selected countries, accessed at: https://gco.iarc.fr/.

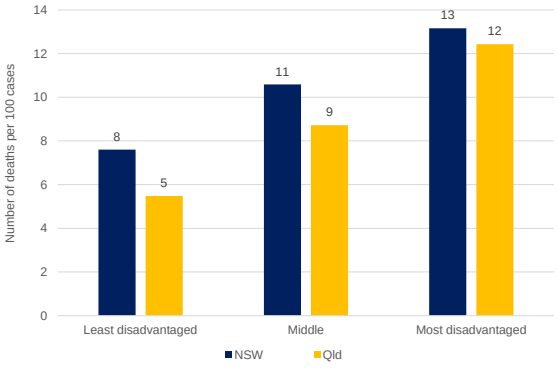
While acknowledging Australia's relative success in survival compared to its international peers, there are several opportunities to improve treatment. In particular, national averages mask variation in care and survival outcomes across the country. For example, regional patients are more likely to experience poor survival outcomes as are persons from socioeconomically disadvantaged backgrounds (Figure 12).

Figure 12: Melanoma specific mortality to incidence rate by geography and socioeconomic disadvantage

Regional variation



Socioeconomic variation



Source: State Cancer Registry data 2013-2017.

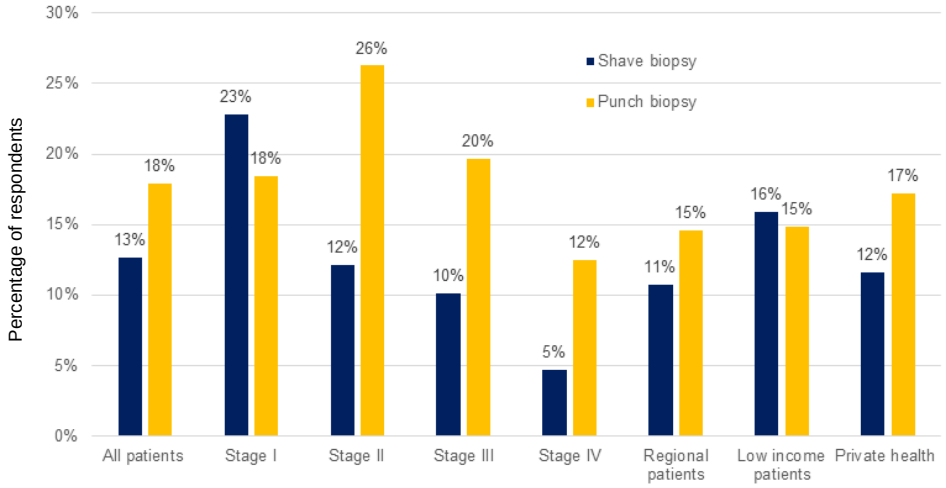
While acknowledging that factors contributing to poorer survival outcomes for some parts of the melanoma patient community compared to others are complex, unwarranted variation in the diagnosis and treatment of melanoma and a lack of patient empowerment were seen as a major contributing factor to poor outcomes for some patients. For example, major challenges identified through the literature and stakeholder consultations included:

- ✓ *High and increasing rates of 'partial' biopsy* — Safe and quality treatment begins with an accurate diagnosis to inform appropriate treatment planning. Data show that the use of partial biopsies, such as shave or punch biopsies, as opposed to excisional

biopsies as recommended by current clinical guidelines, is high and increasing (Figure 13). Critically, partial biopsies are associated with high rates of error and misdiagnosis

- ✓ *Failure to perform Sentinel Lymph Node Biopsies* — As the treatment landscape evolves rapidly for melanoma, the need to accurately stage patients is more important than ever. Stakeholder consultations and a review of literature highlighted that Sentinel Lymph Node Biopsies are not often provided to patients. This practice runs counter to guideline recommendations and potentially prevents patients from being staged in a way that may give them access to life-saving systemic treatments.

Figure 13: Rates of shave and punch biopsies as reported in the Patient and Carer Survey



Source: Melanoma Patient and Carer Survey, see Appendix B.

- ✓ *Variable referral patterns and rates of specialisation in melanoma* — Melanoma is treated in a wide variety of settings nationally, with patients referred to a range of treatment providers that may have varying levels of specialisation in the management of melanoma. This, in turn, can lead to risks of non-adherence to current clinical best practice, failure to access clinical trials and/or inconsistent access to multi-disciplinary teams.
- ✓ *Lack of accreditation for specialised skin services* — GPs are important providers of melanoma care in Australia and in regional areas are often the primary providers of treatment and care to patients. In both metropolitan and regional areas, GPs sometimes provide complex skin services, such as complex biopsies (Sentinel Lymph Node Biopsies) or skin flaps, that go beyond the normal scope of GP practice. While many GPs have invested substantial time and funds into the development of specialist skills, there is also limited and variable regulation of the training requirements and skills associated with advanced skin services, leading to risks in the quality and safety of these provision of these services.
- ✓ *Lack of written treatment and care plans and poor patient empowerment* — Survey data also show the provision of written treatment plans is low: even among patients with advanced metastatic melanoma survey data indicate that only around 40 per cent of patients received a written care plan on average. This potentially contributes to a poor understanding of treatment and diagnosis for some patients. For example, more than one in 10 patients indicated they did not understand their diagnosis and around one in 10 indicated they did not understand their treatment plan.
- ✓ *Regulatory risk for access to novel therapies* — While Australia is currently in line with global best practice for access to novel therapies, stakeholders expressed

concerns that Australia's regulatory and reimbursement system have historically seen delays in publicly subsidised access to medicines, leading to risks of a two-tiered system where the wealthiest parts of the community enjoy access to novel therapies while more disadvantaged groups do not. The need for reform has been underlined by the recommendations of the Inquiry into approval processes for new drugs and novel medical technologies in Australia (the Zimmerman Review) as well as the call for a National Medicines Policy Review and Review of Health Technology Assessment in Australia.

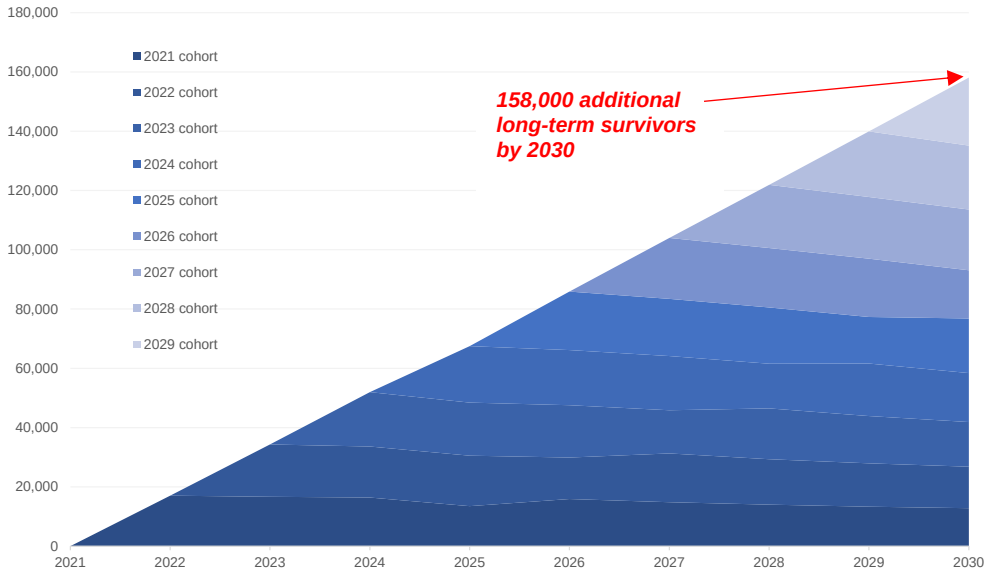
With the potential to reduce melanoma mortality by more than 30 per cent, the following actions to reduce variation in treatment and supportive care are recommended:

- Establish a Patient Navigation Service
- Require written treatment and care plans
- Maintain clinical guidelines for melanoma through a peak national body
- Develop a clinical care standard for melanoma
- Develop a formal process for evidence development to ensure access to clinically important therapies that lack market incentives.

Develop a model of care for melanoma supportive care and survivorship: rationale and recommendations

Demand for survivorship support is set to explode over the forward horizon, as a result of both increasing incidence of melanoma (projected) and research breakthroughs leading to exponential growth in the number of long term survivors. More than 205,000 new patients are expected to be diagnosed with and treated for melanoma over the 2021-2030 horizon, and by 2030 there will be an additional 158,000 new melanoma survivors added to an estimated prevalence of more than 190,000 melanoma survivors today (Figure 14).

Figure 14: Melanoma survivorship growth 2021-2030

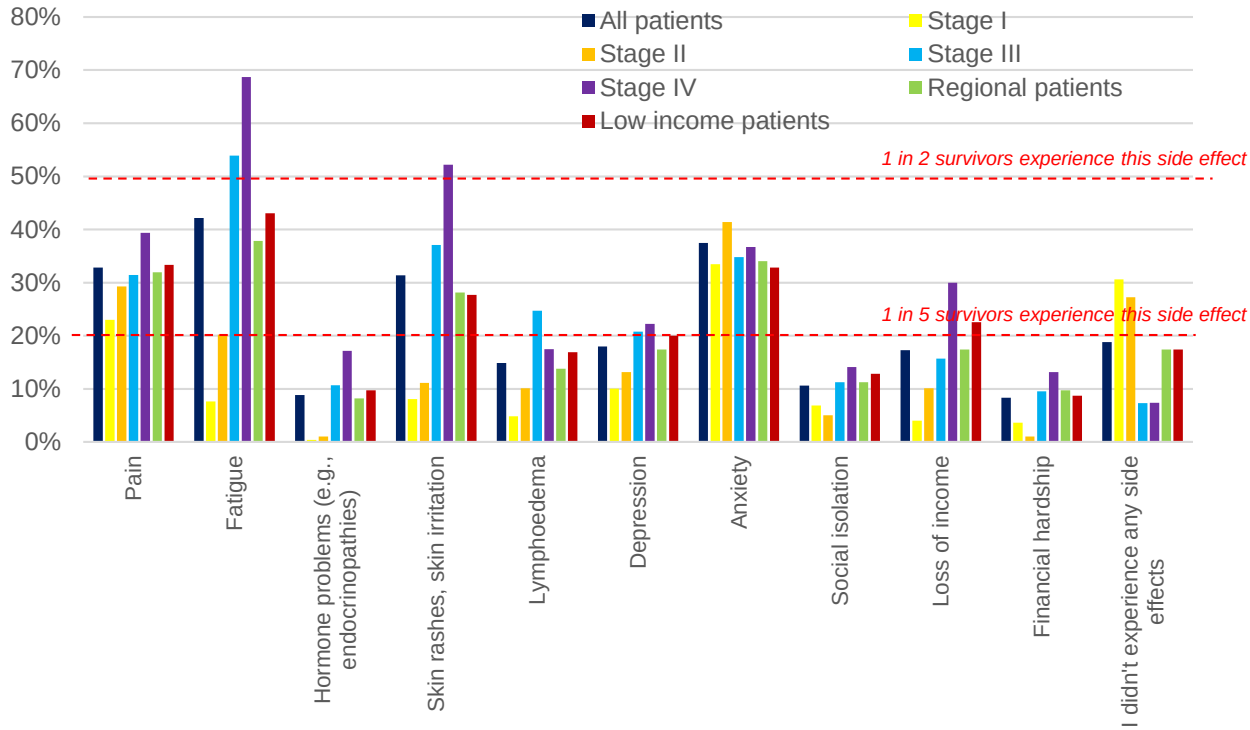


Source: Projections based on Australian Institute of Health and Welfare Australian Cancer Database 2016 and National Mortality Database.

While the advent of targeted and immunotherapies has led to marked increases in long term survival, these therapies can also come with significant side effects. Moreover, even early stage melanoma survivors can require high levels of supportive care, with anxiety and depression a significant risk for melanoma patients at all stages of disease. For example, survey data (Figure 15) indicates that these survivors can have high rates of:

- Pain, with more than one in three patients and survivors reporting the experience of pain, increasing to 40 per cent among Stage IV patients
- Fatigue, with more than one in two Stage III and Stage IV patients and survivors reporting the experience of fatigue
- Anxiety and depression, with nearly 40 per cent of patients and survivors suffering from anxiety and nearly one in five reporting the experience of depression
- Skin rashes and irritation, with one in two Stage IV patients reporting the experience of skin rashes and irritation
- Lymphoedema, with more than 15 per cent of patients with metastatic Stage III and Stage IV melanoma reporting lymphoedema as a side effect of treatment
- Loss of income, with Stage IV and lower income patients most likely to report an adverse effect from the loss of income.

Figure 15: Side effects and off target effects of melanoma and its treatment



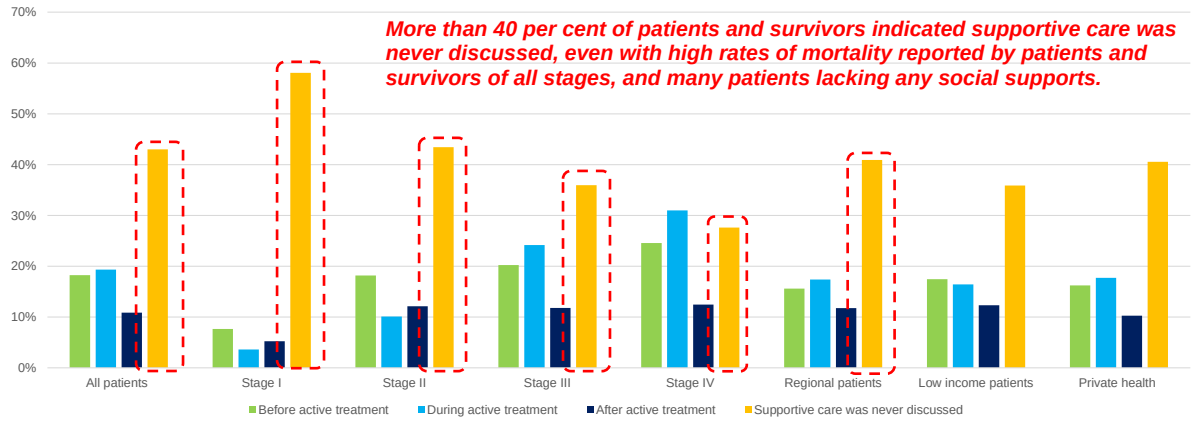
Source: Melanoma Patient and Carer Survey, see Appendix B. "Off target effects" refer to unintended impacts on untargeted genomic sites which present a similar but nonidentical sequence compared to the target site.

Many patients and survivors also lack social supports, making access to supportive care services all the more critical. One in five patients indicated they did not have any carer or family support through their diagnosis and treatment.

One in two respondents (50 per cent) to the Melanoma Patient and Carer Survey indicated survivors did not receive adequate support following the completion of active treatment. In

addition, 40 per cent of patients, including patients with advanced melanoma, indicated supportive care services had never been discussed (Figure 16).

Figure 16: Was supportive care ever discussed?

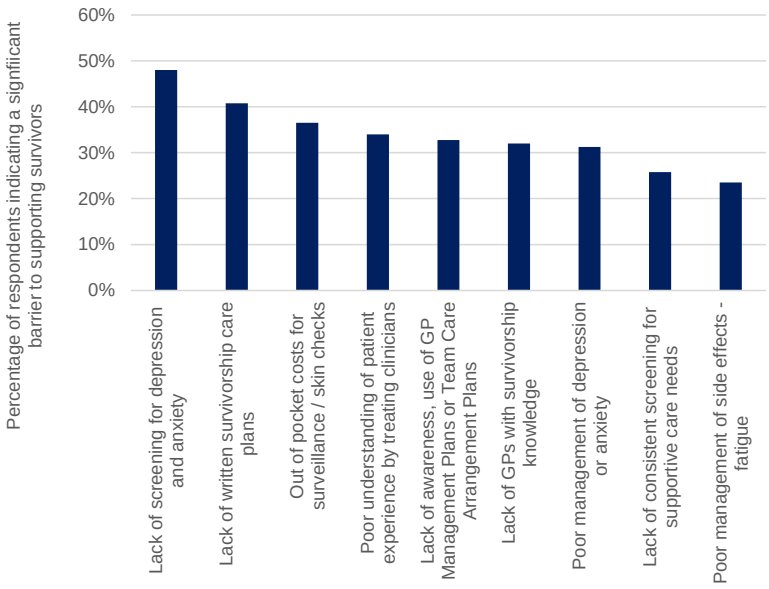


Source: Melanoma Patient and Carer Survey, see Appendix B.

The inadequacy of support was echoed by stakeholders, who highlighted the lack of a structured model for melanoma survivorship. After a lack of screening for anxiety and depression, the most commonly identified barriers to wellbeing for melanoma survivors included (Figure 17):

- Lack of written survivorship care plans, leading to poor awareness of supportive care services; more than 40 per cent of respondents indicated this was a major barrier
- High out of pocket costs; nearly 40 per cent of respondents indicated this was a major barrier for long term survivors
- Poor understanding of patient experience by treating clinicians; more than 30 per cent of respondents indicated this was a major barrier
- Lack of awareness and/or use of GP Management Plans or Team Care Arrangement Plans; more than 30 per cent of respondents indicated this was a major barrier.

Figure 17: What are the major barriers in supporting melanoma survivors?



Source: Melanoma Patient and Carer Survey, see Appendix B.

To improve outcomes for melanoma survivors, the State of the Nation in Melanoma calls for the development of a structured approach to supportive care and survivorship. Specifically, Australian governments and the wider community must:

- Develop a model of care for melanoma survivors
- Mandate the provision of survivorship care plans to all patients
- Fund a National Melanoma Nurse Support Service
- Increase the supply of, and access to, trained professionals in skin checks.

Scorecard summary and implementation considerations

By policy domain, the following table (Table 1) summarises the key findings with respect to the performance of Australia's melanoma policies, the historical success of Australia's policies, and areas for improvement. Furthermore, it describes the recommended action plan for achieving improvement within each domain, as well as how this can be achieved.

By policy domain, the performance of Australia's melanoma policies are rated using a scorecard approach, with the following matrix:

✓✓✓✓✓	Significant, globally-leading contributions to survival and quality of life realised in Australia
✓✓✓✓	Significant, globally-leading contribution to survival and quality of life realised in Australia, but with some inconsistencies in policy implementation observed
✓✓✓	Improvements in survival and quality of life realised, but policy settings not globally-leading and inconsistencies in policy implementation observed nationally
✓✓	Improvements in survival and quality of life realised, but with significant variation in outcomes by jurisdictions or cohort, leading to significant equity concerns and an increase in potentially avoidable mortality
✓	Poor implementation of policies and investments, with little to no contribution to survival and quality of life observed.

Table 1: Scorecard summary of melanoma policy settings in Australia

	Rating	Australian successes	Areas for improvement	Action Plan	How?
Prevention and Awareness	✓✓✓✓	✓ Slip Slop Slap awareness campaign in 1980s ✓ SunSmart programs in primary schools ✓ OHS workplace regulations implemented ✓ Tax incentives for sun safe equipment and clothing ✓ Initial investments in shade by local and state governments ✓ Investment of $20 million in prevention and awareness by Federal Government in December 2021	× Rates of sunburn remain high (>60%), with sun protection behaviour uptake low (only 22% adults, 47% kids) × No sustained modern era awareness and prevention campaign × Consistent adherence to policies in primary schools × Uptake of any prevention in secondary schools × Lack of explicit training and consistent adherence to policies in outdoor workplaces, especially SMEs and outdoor trades × Investment in shade is slow, de-prioritised in context of local government infrastructure backlogs × Significant incidental exposure in weekend sport, sun safety not explicitly required by club sports, AIS × Lack of implementation of supported recommendations from 2017 Inquiry to Skin Cancer	Modern Prevention and Awareness Campaign and Strategy National Shade for High Risk Spaces Program Nationally consistent approach to sun safe policies in schools – primary and secondary Provide sun safe training to all outdoor workers nationally by 2025 Australian Institute of Sport Club Guidance and Best Practice Guidelines in SunSmart programs	Australian Government to lead development of Prevention and Awareness Strategy and campaigns – ensure a generational approach similar to road and safety rather than one off campaign Establish a collaboratively funded national grants fund for accelerating investment in shade Establish national working body led by State Governments focused on consistent implementation of sun prevention policies in all schools Implement training for all trades with employer, union and OH&S regulatory bodies Australian Institute of Sport to incorporate explicit sun smart policies in club development and assessment templates and guidelines

	Rating	Australian successes	Areas for improvement	Action Plan	How?
Research	✓✓✓✓✓	✓ World leading prevention research informing US Prevention Taskforce ✓ Australia citation impact significantly exceeds medical research and NHMRC benchmarks ✓ Significant health gains realised through research, including doubling of survival for melanoma and likely spillover effects ✓ ~50 per cent of advanced melanoma patients enrolled in clinical trials ✓ ACRF funded Australian Centre of Excellence in Melanoma Imaging and Diagnosis ✓ NHRMC Centre of Research Excellence for the Study of Naevi ✓ NHMRC Centre of Research Excellence for Skin Imaging and Precision Diagnosis ✓ Victorian Melanoma and Clinical Trials Service	× Opportunities for deep, nationally collaborative research × Lack of core clinical, population, quality registry data, National Cancer Data ecosystem × Inefficiencies in grants processes × Clinical trial inefficiencies (duplicated and differing governance and ethics requirements leading to long timelines)	Fund Research Program in Melanoma focused on: – Biology and melanomagenesis – Optimising current systemic treatments – Novel Imaging and Detection – Evidence development for program to target high-risk cohorts – Patient Reported Outcomes Fund development core clinical and population data assets as part of an internationally competitive National Cancer Data Ecosystem Implement clinical trials reform by 2025	Nationally Collaborative Melanoma Research Mission and Discovery Program funded through MRFF, NHMRC and Cancer Australia Funding for cancer data assets nationally as part of National Cancer Plan with target of 2025 for full implementation Department of Health Clinical Trials Reference Group to implement clinical trial reforms, State Governments to amend eligibility for Patient Transport Schemes to allow funding for clinical trials

	Rating	Australian successes	Areas for improvement	Action Plan	How?
Early Detection	✓✓✓	✓ Globally leading outcomes in tumour thickness arising from high rates of opportunistic screening	× Increased community awareness of skin changes and uptake of skin checks, especially for high-risk cohorts and low income individuals × No minimum standards specified with regard to skin checks and diagnosis × Need for additional training in melanoma by GPs to reduce failure to detect and risks of potential over-diagnosis × Need to integrate research efforts for early detection into the roll out of new models of care	Awareness strategy and campaign for self skin checks and melanoma risk Develop minimum standards for skin checks and diagnosis (MelCOR) and evaluate GP training and dermoscopy program Increase supply of trained professionals in skin checks Roadmap for a National Targeted Melanoma Screening Program	Commonwealth Government to lead development of Awareness Strategy and Campaign Develop updated clinical guidelines, to be maintained by a peak national body as part of National Cancer Plan Commonwealth to fund national program Australian Governments and melanoma community to address shortage of dermatologists and expand funding for other practitioners trained in skin checks, particularly for regional and disadvantaged communities National Collaborative Melanoma Research Mission and Discovery Program

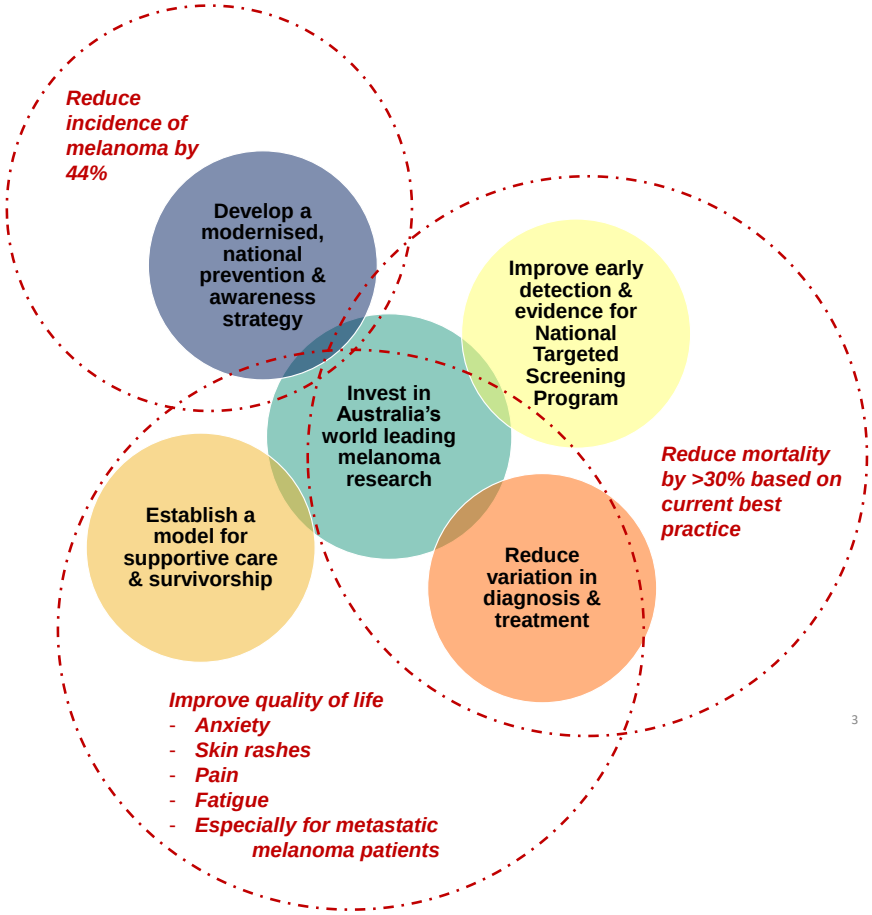
	Rating	Australian successes	Areas for improvement	Action Plan	How?
Diagnosis & Treatment	✓✓✓	✓ High survival rates for early Stage I, Stage II melanomas ✓ Doubling of survival outcomes for advanced melanoma patients through immunotherapy and targeted therapy advancements ✓ PBS funding in line with best-evidence-based care for systemic treatments in melanoma	× Increased use of shave and punch biopsies, associated with high error rates, in contrast to clinical guidelines × Poor adherence to guidelines for Sentinel Lymph Node Biopsy and appropriate referrals × Significant variation in patient outcomes by jurisdiction and income levels × Lack of quality performance benchmarks Patients inconsistently screened for supportive care needs, lack of awareness of supportive care services × Some constraints on treatment planning by clinicians – timing, intensity of systemic therapies × Poor understanding of diagnosis and treatment options × Room for improvement in regional service delivery (including immunotherapies) × Regulatory risk for access to clinically important therapies where there are limited incentives for the registration of new indications and/or reimbursement	Maintain up-to-date clinical guidelines, promoted to all treating clinicians in primary and hospital settings Require written treatment plans Develop quality performance framework for melanoma building on the work of MelCOR Develop Patient Navigation Service Develop formal approach to address access barriers to clinically important therapies where market failures exist	Peak body to be funded, such as Cancer Australia, to maintain up to date clinical guidelines as part of National Cancer Plan in partnership with all Australian Governments State Governments to lead implementation as partners in National Cancer Plan implementation Australian Commission for Safety and Quality in Health Care to develop a clinical care standard and performance indicators for melanoma National Cancer Plan to lead development of Patient Navigation Service, which should be linked to a Melanoma Nurse Service Policy reform through implementation of recommendations of Inquiry into Novel Therapies (Zimmerman Inquiry) for national capped scheme for evidence development for eligible indications, as well as Review of National Medicines Policy, and Review of Health Technology Assessment

	Rating	Australian successes	Areas for improvement	Action Plan	How?
Supportive Care & Survivorship	✓✓	✓ Initial research into Patient Reported Outcomes in Melanoma	× No standard of care for survivorship and supportive care × Survivorship care plans inconsistently provided × Patients inconsistently screened for supportive care needs × Lack of melanoma nursing support × Anxiety and depression often missed × Poor management of fatigue × Lack of awareness of supportive care services	Develop a standard of care for supportive care and long term survivorship Require survivorship care plans Develop Melanoma Nurse Service, linked to Patient Navigation Service Increase supply of trained professionals in skin checks	Peak body to be funded to maintain up to date clinical guidelines with explicit survivorship guidelines State Governments to lead as partners to National Cancer Plan Federal Government funding for melanoma nurses nationally, with National Cancer Plan to lead development of Patient Navigation Funding to address shortage of dermatologists and for other practitioners trained in skin checks, particularly for regional and disadvantaged communities

Payoffs from action

The implementation of these actions would be expected to deliver significant, step change improvements in survival and quality of life (Figure 18).

Figure 18: Payoffs from Action Plan

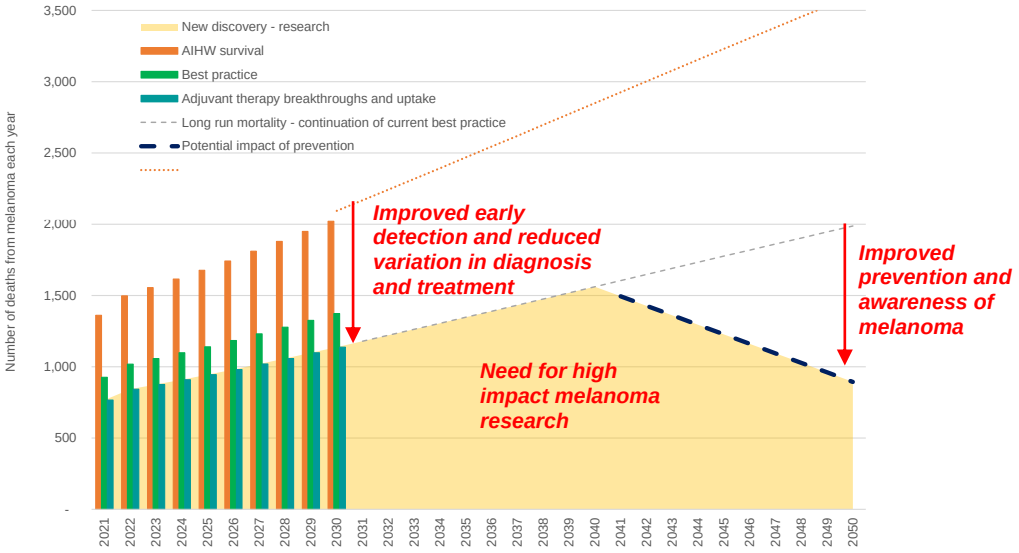


Applying these benefits to future mortality projections shows that a step change in outcomes is possible. As summarised in Figure 19:

- The implementation of current best practice would see mortality reduce by 32 per cent, saving more than 4,000 lives over the next 10 years
- The uptake of expected adjuvant and neoadjuvant therapy breakthroughs could see a further improvement in mortality compared to the status quo depending on the durability of survival improvements observed in early data
- Prevention has the potential to reduce incidence of melanoma by 44 per cent, which is fundamental to putting an end to melanoma deaths within our lifetimes; prevention interventions would also improve non-melanoma skin cancer related outcomes.
- In addition, improved patient support through navigation services and nursing support can substantially improve patient quality of life, through improved management of anxiety, pain, fatigue, rashes, lymphoedema, and other side effects of melanoma and its treatment.

These data show that together, by learning from its past successes and identifying opportunities for improvement, Australia can retain its global leadership position, and put an end to melanoma death within our lifetimes.

Figure 19: Long run mortality expectations – current Australian Institute of Health and Welfare survival rates, best practice survival outcomes, potential impact of additional adjuvant breakthroughs and prevention



Source: Incidence projections to 2030 based on bottom-up cohort method, with current mortality projected to 2050 holding mortality growth constant. Prevention impacts based on Gordon, L, Olsen, C, Whiteman, DC, et al, 2020, Prevention vs early detection for long term control of melanoma and keratinocyte carcinomas: a cost-effectiveness modelling study.

Priorities for implementation

The implementation of these actions would be expected to deliver significant, step change improvements in survival and quality of life. The prioritisation of these actions should promote both short term improvement of outcomes for people presently diagnosed with melanoma and the long run elimination of melanoma incidence and mortality.

To that end, the following actions have been identified as the highest priorities (in order of position in report) for implementation:

- **National Melanoma Prevention and Awareness Strategy** as this has the potential reduce incidence by 44 per cent
- **Nationally Collaborative Melanoma Research Mission and Discovery Program** as new discovery is required to fully eliminate mortality from melanoma and the return on investment in melanoma is expected to exceed $3.90 per dollar invested based on the high impact of Australian melanoma research
- **Roadmap for a National Targeted Melanoma Screening Program** this will deliver an evidence program that is equitable in its reach, trustworthy for patients and clinicians and cost-effective for the community and the healthcare system
- **National Patient Navigation and Melanoma Nurse Service** to ensure equitable access to supportive care services which will improve quality of life for new patients, current patients and long term survivors
- **National Melanoma Training and Dermoscopy program for GPs** as GPs represent the front-line of melanoma detection, and the use of dermoscopy as part of a national minimum standard approach to skin checks increases accuracy of diagnosis and reduces the failure to detect
- **Develop a clinical care standard for melanoma** to reduce unwarranted variation in care as consistent implementation of clinical best practice nationally has the potential to reduce deaths by 32 per cent based on currently funded technologies.

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Chapter 1

Australia's Most Fatal Skin Cancer: Melanoma

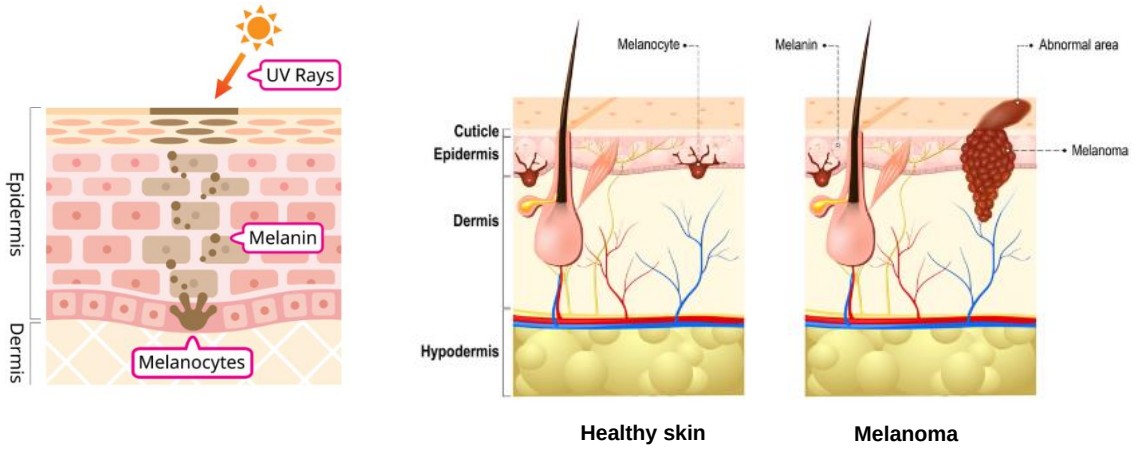
Melanoma is often termed 'Australia's cancer' as a result of the disproportionately high incidence and mortality rates observed in Australian communities compared to other countries.

This chapter provides a brief overview of melanoma: what it is, its causes and symptoms, how is it staged, and how it is treated.

1.1 What is melanoma?

Melanoma is a type of skin cancer that originates in a type of skin cell called melanocytes. Melanocytes are located at the base of the epidermis and produce melanin, which colours the skin. When melanocytes are exposed to UV rays, these cells make more melanin, causing the skin to darken or tan (Figure 1.1).

Figure 1.1 What are melanocytes and what is their role in melanoma?



Melanoma occurs when DNA in the melanocytes becomes damaged, most often due to an over exposure of UV radiation, but sometimes due to inherited genetic risk. As a result of this DNA damage, the melanocytes begin to reproduce uncontrollably to become a malignant lesion known as melanoma (Figure 1.1).

In contrast to other types of skin cancer, such as basal cell carcinoma or squamous cell carcinoma, melanoma is distinguished by its relative invasiveness, which leads to high rates of mortality and years of life lost to cancer. Melanoma is estimated to account for approximately three per cent of all skin cancers (noting that two in three Australians are

expected to be diagnosed with some form of skin cancer before the age of 70),[1] but 65 per cent of all deaths from skin cancer.[2]

Most (95%) melanomas are classified as melanomas of the skin, or cutaneous melanomas. Cutaneous melanomas are distinguished by a high genetic mutational burden and a UV mutation signature.[3]

In addition to cutaneous melanomas, there are rarer sub-types of melanoma, which originate in other tissues:

- *Ocular melanoma* — Ocular melanoma arises in the eye. There are two main sub-types of ocular melanoma: uveal melanoma, which arises in the iris, choroid and ciliary body of the eye, and conjunctival melanoma, which arises on the bulbar conjunctiva. Both forms of ocular melanoma are rare. There is also periocular melanoma, a further form of melanoma which can affect the eyelid and other orbital tissues.
- *Mucosal melanoma* — Mucosal melanomas arise in mucosal surfaces of the body and are very rare tumours. They can be found in the following tissues: the vulva, including the vagina, the anorectal region, the oesophagus, the male genito-urinary tract and the head and neck tissues.
- *Acral melanoma* — Acral lentiginous melanoma is a type of melanoma distinguished by the site of origin: it arises on the palms of the hands, the soles of the feet or beneath the nail (subungual melanoma). It is more commonly found on feet than on hands, and can arise in normal-appearing skin, or it can develop within an existing mole. Acral melanoma is the most common type of melanoma among people with darker skin. Unlike cutaneous melanoma, acral melanoma is not believed to be caused by exposure to the sun or other sources of ultraviolet radiation.

In contrast to cutaneous melanomas, mucosal and acral melanomas have a low mutational burden and rarely display a UV mutation signature.[4]

1.2 Risk factors

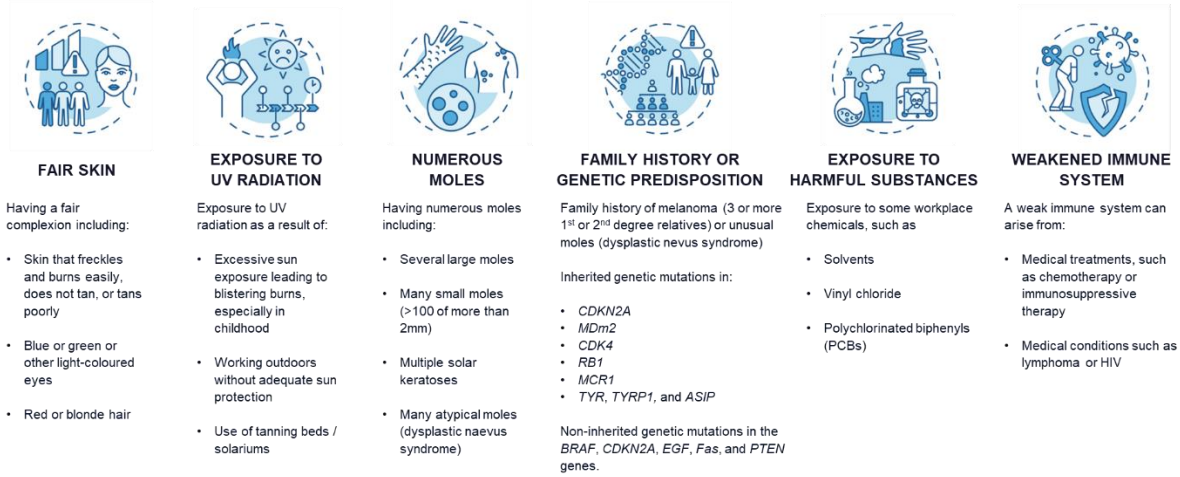
While all Australians must be vigilant against the risks of melanoma, given the country's sunny climate and high UV radiation index compared to other countries, research has found the following factors (Figure 1.2) substantially increase the risk of melanoma:[5]

- Fair complexion
- Exposure to UV radiation
- Numerous moles
- Family history of melanoma.

Other factors can include exposure to harmful substances and a weakened immune system.

[1] 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. Med J Aust, 184(1):6-10.
[2] AIHW 2020 Cancer Data in Australia.
[3] The Cancer Genome Atlas Network, 2015, Genomic Classification of Cutaneous Melanoma, Cell, doi: 10.1016/j.cell.2015.05.044.
[4] The Cancer Genome Atlas Network, 2015, Genomic Classification of Cutaneous Melanoma, Cell, doi: 10.1016/j.cell.2015.05.044, and Atkins, MB, Curiel-Lewandrowski, C, Fisher DE, Swetter, SM, et al., 2021, The State of Melanoma: Emergent Challenges and Opportunities, Clinical Cancer Research, doi: 10.1158/1078-0432.CCR-20-4092.
[5] Berwick, M, Buller, DB, Cust, A, Gallagher, R, Lee, TK, Meyskens, F, Pandey, S, Thomas, NE, Veierød, MB, Ward, S, 2016, Melanoma epidemiology and prevention, Melanoma, 17-49.

Figure 1.2: Risk factors for melanoma



1.3 Signs and symptoms

Melanoma can occur anywhere on the body. In men, melanoma is often found on the trunk of the body, between the shoulders and the hips, or the head and neck. In women, melanoma forms most often on the arms and legs.

Signs of melanoma include changes in a way a mole or pigmented area looks. A mole may:

- Change in size, shape or colour
- Develop irregular edges or borders
- Become more than one colour
- Become asymmetrical
- Become itchy, ooze, bleed and/or become ulcerated.

There may also be a change in the pigment of the skin or satellite moles may appear.

Collectively, these are known as the 'ABCDE' rule of melanoma and are considered a signal to seek medical attention (Figure 1.3).

Figure 1.3: Signs and symptoms of melanoma

However, melanomas do not always conform to the ABCDE rule; some melanomas may present as symmetric nodules. Consequently, Australian Clinical Guidelines for Melanoma recommend any moles that are 'EFG' should be investigated:

- **E**levated
- **F**irm
- **G**rowing.

Similarly, the Skin Cancer College has developed a new method for improving awareness of changes that may be melanoma or other skin cancers called 'SCAN Your Skin', which encourages patients to seek medical attention if a mole is:

- **S**ore
- **C**hanging
- **A**bnormal
- **N**ew.

Risk prediction tools are available online at:

- Melanoma Institute Australia: **www.melanomarisk.org.au**
- SCAN Your Skin: **www.scanyourskin.org/risk-prediction-tool/**
- QIMR Berghofer's Melanoma Risk Predictor: **publications.qimrberghofer.edu.au/Custom/QSkinMelanomaRisk**
- Alfred Health's Melanoma Risk Calculator: **www.alfredhealth.org.au/melanoma-risk-calculator/public**

1.4 Stages of melanoma

Once detected, melanoma is staged (Figure 1.4). The thickness of the tumour, known as the 'Breslow thickness', is the most significant factor in determining the prognosis for the patient, with survival significantly improving for thinner melanomas (<1mm thick):

- *In situ* (Stage 0) means that the melanoma is confined to the cells in the top layer of the skin (epidermis) and is yet to invade the deeper layers (dermis)
- Stage I melanomas can be defined in two ways: 2mm in size, without ulceration or metastasis or lymph node involvement, or up to 1mm in size with ulceration but absent metastasis or lymph node involvement. Stage I melanomas can therefore be classified into two sub-stages, Stage IA and Stage IB, depending on thickness and the presence of ulceration as seen by a pathologist:[6]
  - In Stage IA the tumour is not more than 1mm thick
  - In Stage IB the tumour is greater than 1mm thick, but less than 2mm, or with ulceration.
- Stage II melanomas are thicker and/or display ulceration (bleeding) compared with Stage I melanomas.

  Stage II melanomas are classified into one of three sub-stages: Stage IIA, Stage IIB or Stage IIC:
  - Stage IIA is between 1mm and 2mm thick, but with ulceration (bleeding) or between 2mm and 4mm without ulceration
  - Stage IIB is either between 2mm and 4mm with ulceration, or more than 4mm thick
  - Stage IIC is more than 4mm thick, with ulceration.

[6] Absent further investigation, tumours that are less than 0.8mm with ulceration or between 0.8mm and 1.0mm with or without ulceration are assumed to be Stage IB. If sentinel lymph node biopsy indicates that there is no lymph node metastasis, then these are classified as Stage IA.

- Stage III melanoma is distinguished from previous stages in that the cancer will have been found in one to three lymph nodes and/or has spread to very small areas of nearby skin. The accurate diagnosis of Stage III melanoma therefore requires the use of a sentinel lymph node biopsy (SNLB).

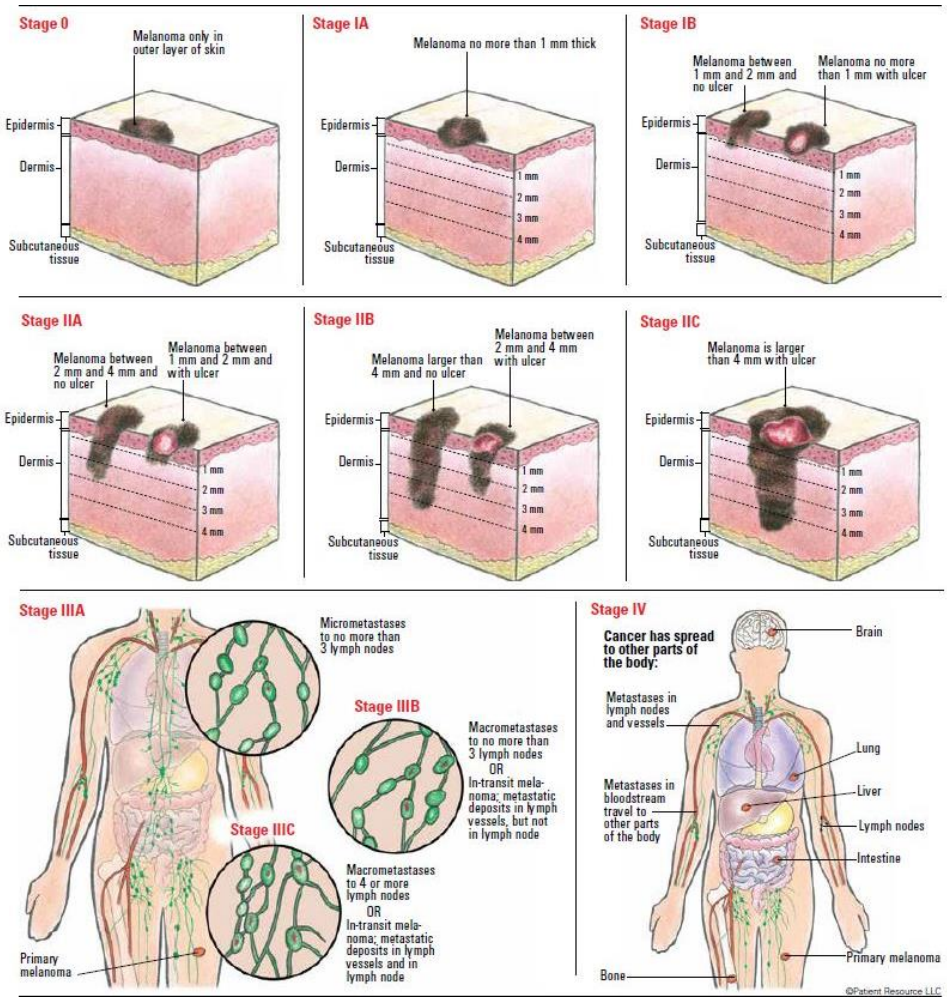
  Stage III melanomas can be classified into one of two subcategories: Stage III resectable or Stage III unresectable:

  - Stage III resectable melanoma is still capable of being removed by surgery (resectable) even though the melanoma has spread to the lymph nodes.
  - Stage III unresectable melanoma cannot be removed through surgery and requires the use of systemic treatments; approximately 35 per cent of Stage III melanomas are unresectable.

- A Stage IV melanoma has spread to distant lymph nodes and organs throughout the body, including the brain, lungs, liver, gastrointestinal (GI) tract, or other distant points in the skin. When detected late, the primary site of the melanoma may never be known.

Stage IV and Stage III unresectable melanoma are termed advanced metastatic melanoma. In the remainder of this report, melanoma rates refer to invasive melanoma (Stage I-IV) unless stated otherwise.

Figure 1.4: Stages of Melanoma



Source: SITC, 2019, Staging Melanoma, accessed at: https://www.sitcancer.org/connectedold/p/patient/resources/melanoma-guide/staging

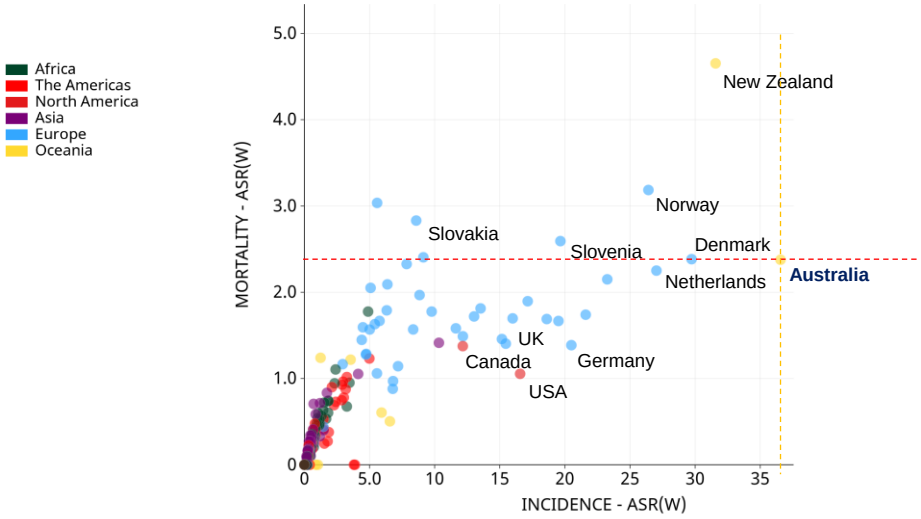
1.5 Incidence and mortality

Skin cancer accounts for the largest number of cancers diagnosed in Australia each year: at least two in three Australians will be diagnosed with some form of skin cancer before the age of 70 and a 2002 survey found that two per cent of the population was being treated for a skin cancer in that year.[7] Moreover, skin cancers account for the highest financial burden of all cancers in Australia.[8]

While less common than other types of skin cancer, melanoma is more dangerous.[9] Melanoma creates a significant health and financial burden to Australian communities, with melanoma accounting for the majority of deaths from skin cancer in Australia.[10]

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 a global average of only 4.2 per 100,000 persons (Figure 1.5).[11]

Figure 1.5: Age-standardised rate (ASR) of incidence and mortality per 100,000 people, invasive melanoma, 2020



Source: 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/.

The Australian Institute of Health and Welfare (later referred to as Australian Institute of Health and Welfare or AIHW) estimates that more than 16,220 Australians were diagnosed with invasive melanoma in 2020 alone, accounting for more than one in 10 cases of cancer diagnosed in Australia today.[12] In addition, the incidence rate of *in situ* melanoma increased by 115 per cent between 2004 and 2019, with more than 23,000 *in situ* or Stage 0 melanomas removed on average each year.[13]

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[7] 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. Med J Aust, 184(1), 6-10.

[8] Sebaratnam, D, Der Sarkissian, S, O'Connor, A, et al., 2020, Out, damned spot! Burden of skin cancer in Australia, Insight Plus, MJA, 16 November; Sanofi, 2020, The burden of Non-Melanoma Skin Cancer (NMSC) in Australia; AIHW, 2017, Burden of Cancer, Burden of Disease in Australia Study, accessed at: https://www.aihw.gov.au/getmedia/a1aec7bd-ddb7-416f-9a7e-f2133cd5d4cb/20965.pdf.aspx?inline=true.

[9] See, for example, the Skin Cancer Foundation website, available: https://www.skincancer.org/skin-cancer-information/melanoma/; AIHW, 2017, Burden of Cancer in Australia, Burden of Disease Study, accessed at: https://www.aihw.gov.au/getmedia/a1aec7bd-ddb7-416f-9a7e-f2133cd5d4cb/20965.pdf.aspx?inline=true.

[10] AIHW, 2020, Cancer Data in Australia, Melanoma incidence and mortality in 2020, Non-melanoma skin cancer mortality 2020; and Staples, M, Elwood, M, Burton, RC, et al., 2006, Non-melanoma skin cancer in Australia: the 2002 national survey and trends since 1985, MJA, 184(1), 6-10.

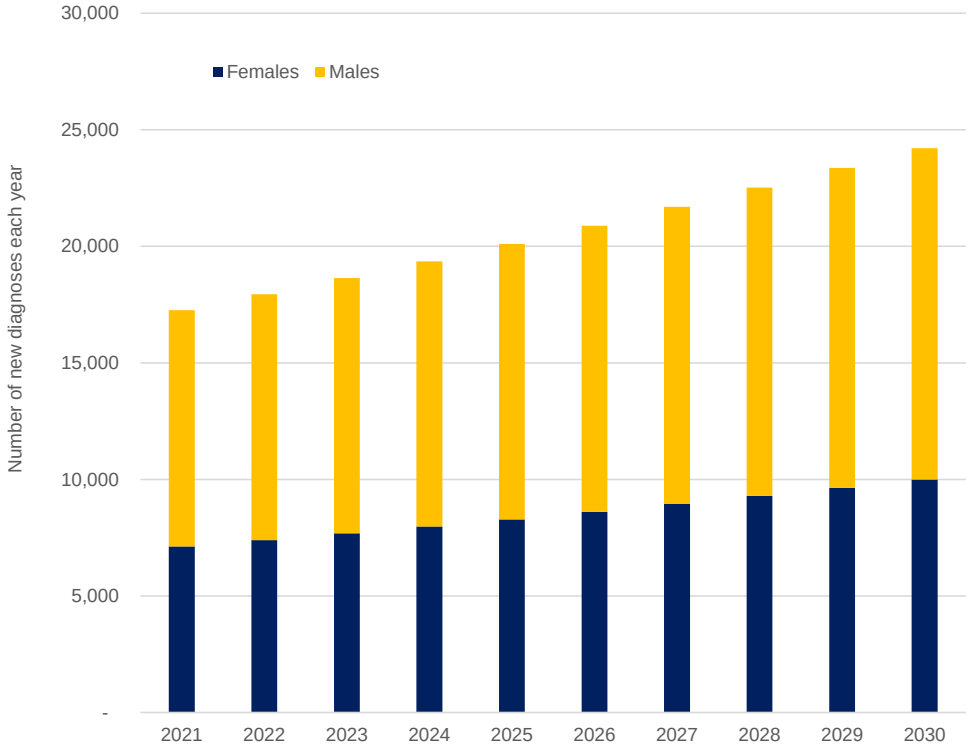
[11] International Agency for Research on Cancer, GLOBOCAN2020, Mortality – ASR (World) vs Incidence – ASR (World), melanoma of skin, in 2020, both sexes, all ages, World Health Organisation, accessed https://gco.iarc.fr/.

[12] AIHW, 2020, Cancer Data in Australia, C43, Melanoma.

[13] Ibid.

Based on current incidence rates for melanoma by sex and age cohort,[14] it is projected that more than 205,000 Australians (205,978 persons) will be diagnosed with melanoma between now and 2030 (Figure 1.6). More than 10,000 of these diagnoses will be for people with advanced melanoma (Stages III and IV).

Figure 1.6: Incidence projections of invasive melanoma in Australia, Males and Females

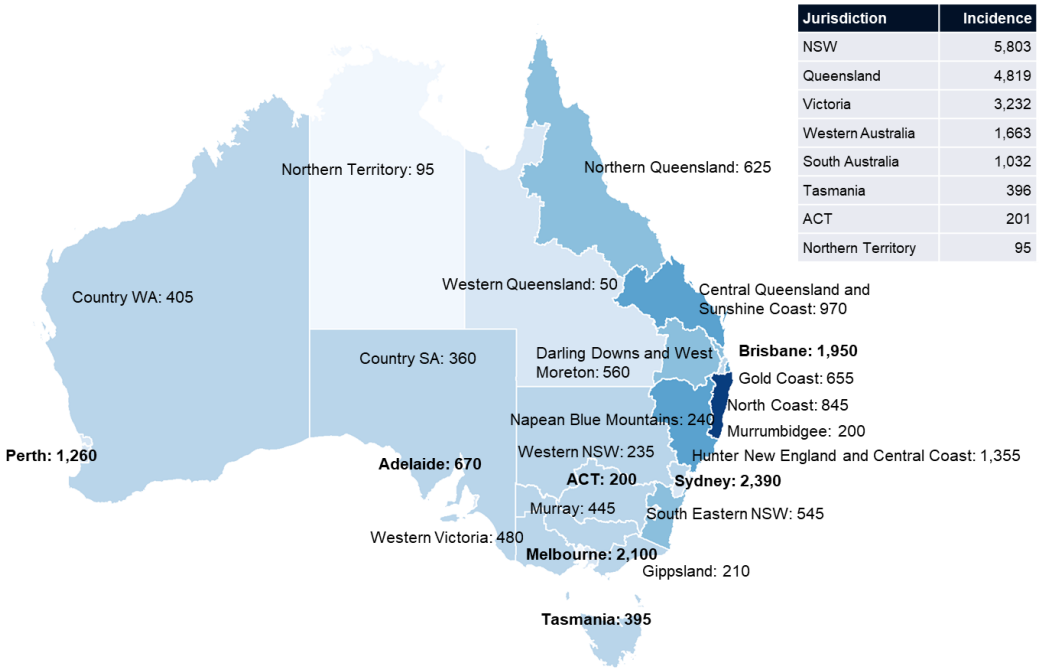


Source: Projections based on Australian Institute of Health and Welfare incidence rates, See Appendix A.

Australian Institute of Health and Welfare reporting of melanoma incidence by small geographic areas over the 2010-2014 period indicates that regional and remote Australians will account for 47 per cent of total incidence (Figure 1.7). Consequently, regional Australia bears a higher proportion of total melanoma incidence.[15] In 2021, it would be expected that roughly 8,040 Australians living in regional areas will be diagnosed. This will be expected to increase to 11,280 Australians by 2030.

[14] See Appendix A.
[15] Regional Australia accounts for 32 per cent of Australia's total population, see ABS, 2021, Regional Population statistics, accessed at: https://www.abs.gov.au/statistics/people/population/regional-population/2019-20#key-statistics.

Figure 1.7: Incidence of invasive melanoma by PHN, 2021



Jurisdiction	Incidence
NSW	5,803
Queensland	4,819
Victoria	3,232
Western Australia	1,663
South Australia	1,032
Tasmania	396
ACT	201
Northern Territory	95

Source: Calculations based on Australian Institute of Health and Welfare, 2019. Cancer statistics for small geographic areas: Primary Health Network (PHN), 2010–2014. Canberra: Table 13 (melanoma). Note figures have been rounded. The Australian Institute of Health and Welfare reported in 2019 that between 2004 and 2015, the number of new cases of melanoma *in situ* of the skin increased by 115 per cent, from 32 per 100,000 persons in 2004 to 68 per 100,000 persons in 2015 (Figure A.5). Large increases were observed both for males and females, with the risk of melanoma in situ increasing with age as with invasive melanoma.

Every year, approximately 1,400 Australians are expected to die from melanoma.[16] Based on current Australian Institute of Health and Welfare survival rates, more than 18,500 Australians diagnosed between 2021 and 2030 will lose their lives to melanoma within five years of diagnosis (Table 1.1).

Table 1.1: Mortality projections in Australia (persons)

Year of diagnosis (cohort)	1 year from diagnosis	2 years from diagnosis	3 years from diagnosis	4 years from diagnosis	5 years from diagnosis	Total – 5 years from diagnosis
2021	340	389	266	275	206	1,476
2022	356	409	280	288	215	1,548
2023	373	429	293	301	225	1,621
2024	391	451	309	314	235	1,700
2025	410	475	325	328	246	1,784
2026	431	500	342	343	257	1,873
2027	454	528	362	360	270	1,974
2028	477	557	381	376	283	2,075
2029	500	585	401	393	295	2,174
2030	524	613	421	410	308	2,275

Source: Projections based on Australian Institute of Health and Welfare incidence rates. This is presented by gender in Appendix A.

[16] AIHW, 2020, Cancer Data in Australia, C43, Melanoma.

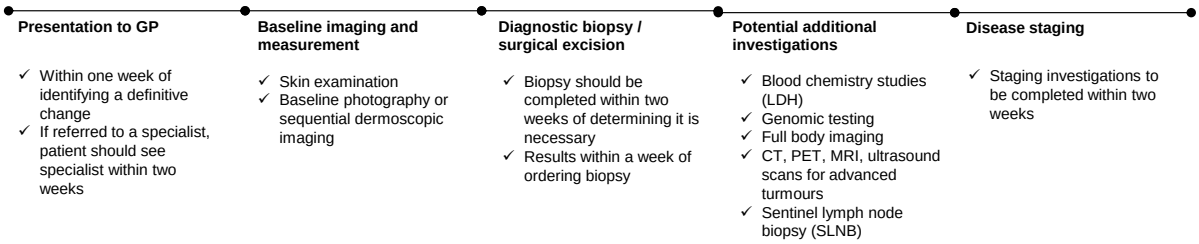
1.6 How is melanoma diagnosed and treated? Australian clinical guideline recommendations

Patients with an unusual skin lesion, or a raised, suspicious lesion, or a person at high risk of melanoma will typically present to a GP. Some patients may also present to a dermatologist or a surgical specialist.

The treating clinician may photograph and measure the lesion and depending on its presentation either immediately remove (excise) the suspected lesion or order a diagnostic partial biopsy which may be followed by a surgical excision (Figure 1.8).

Once the diagnosis of melanoma has been confirmed, the patient may require further local surgery which can be performed by the GP or after referral to a dermatologist or surgeon. Dependent upon the stage of the lesion the patient may be considered for a sentinel node biopsy (identification of the lymph node that drains from the primary melanoma). Specialized blood tests (LDH) and imaging such as ultra sound of lymph nodes, CT scan or PET scan may be considered in the more advanced stages (Stage III and IV) of melanoma.. Genomic testing may be considered where there is a very strong family history of melanoma.

Figure 1.8: Initial investigations, diagnosis and staging

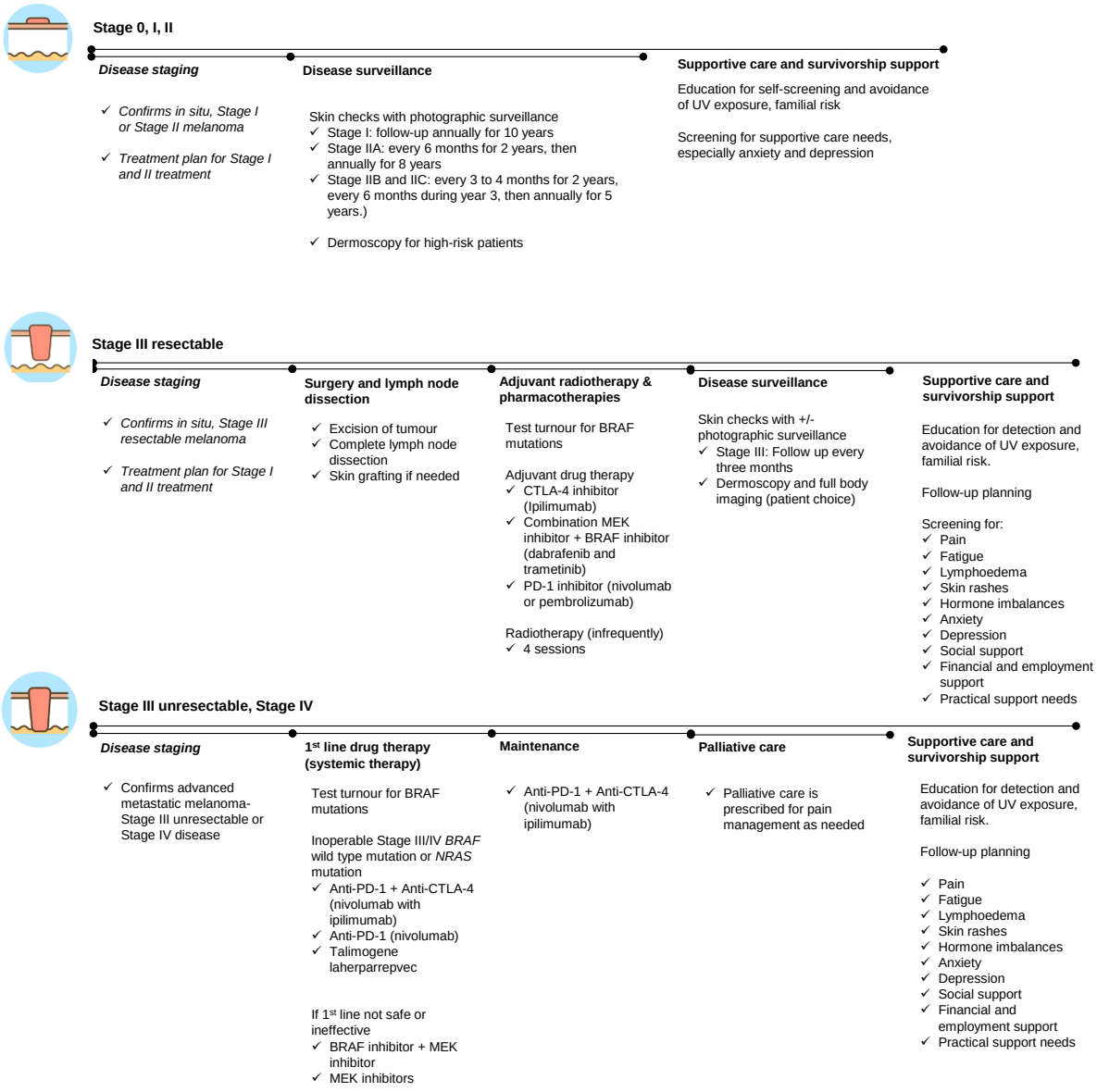


Source: Summary based on Clinical Practice Guidelines for the diagnosis and management of melanoma, available at: https://wiki.cancer.org.au/australia/Guidelines:Melanoma.

Recommended treatment and care based on clinical practice guidelines for the diagnosis and management of melanoma will depend on the staging of the melanoma (Figure 1.9):

- For patients with *in situ*, Stage I or Stage II melanoma, active treatment completes with the surgical removal of the suspected lesion and for stage II, with a sentinel node biopsy if performed. Patients that are high risk may be monitored using sequential digital dermoscopy or full body photography, though this is not currently publicly funded.
- For patients with Stage III resectable melanoma, following the cancer and lymph node excision, adjuvant targeted, or immunotherapy may follow surgery. Frequent follow up including skin checks at least every three months is recommended.
- Patients with advanced melanoma (Stage III unresectable or Stage IV melanoma) are treated with a range of novel systemic therapies, depending on the results of genomic testing (e.g., *BRAF* gene testing), including immunotherapies and targeted therapies. These treatment regimens have substantially improved the survival outlook for patients with metastatic disease compared to what was possible only a decade ago.

Figure 1.9: Recommended treatment and care pathways by Stage after treatment of the primary melanoma and if relevant nodal melanoma



Source: Summary based on Clinical practice guidelines for the diagnosis and management of melanoma, available at: https://wiki.cancer.org.au/australia/Guidelines:Melanoma. Note: Recent success in clinical trials of neoadjuvant therapies (especially for Stage III cancer) indicate possible future inclusion.

Importantly, the above summary represents clinical practice recommendations; in practice, treatment varies by discipline as well as region, depending in the main on the expertise of the clinician and their awareness of clinical best practice guidelines; this is explored further in the report.

Chapter 2

Reducing the impact of melanoma on Australian patients and communities: a call to action

In both health and economic terms, the costs of melanoma faced by the community are high and increasing. At the same time, melanoma is a highly preventable and increasingly curable cancer. Historical evidence and recent research breakthroughs are making the prospect of ending melanoma as we know it possible.

This chapter explains the high health and economic costs of melanoma today, most of which could be avoided through improved implementation of proven prevention and early detection strategies. Taken together, these data show the costs of 'no action' to be incredibly high for Australian communities, both in loss of life and avoidable health expenditure.

2.1 Eliminating deaths from melanoma is within Australia's reach

The last 45 years have seen incredible gains made in the fight against cancer; 5-year survival rates have increased by 35 per cent for all cancers combined in Australia since the late 1980s alone,[17] with many cancers evolving from acute, fatal illnesses to long term chronic conditions.

These gains have been made through a range of improvements in the prevention, early detection, precision of diagnosis, and treatment of a wide range of cancers. Increasingly, communities around the world have seen the potential to end mortality from cancer in our lifetimes as a feasible, achievable goal.

In practice, not all cancers will be able to achieve the ambitious targets that have been set; but for melanoma, the vision is real and attainable within a generation.

It is estimated that nearly 95 per cent of melanomas are preventable through avoiding over exposure to UV radiation, and for many patients, long term cures are possible through early detection and adherence to clinical best practice. Through the consistent adoption of proven policies for prevention and early detection, combined with recent technological advancements in research, the possibility of significantly reducing the impact of melanoma on Australian communities is feasible and realistic particularly if also supported by coordinated policy action and investment.

2.2 The case for change: the costs of the status quo are high

Not only is the prospect of zero deaths from melanoma in our lifetimes attainable, the costs of taking no action to prevent melanoma and the onset of advanced disease are significant. These avoidable health and economic costs are comprised of:

- Health system costs and out of pocket costs to households

[17] AIHW, 2021 Cancer Data in Australia, table S3a.1, available: https://www.aihw.gov.au/reports/cancer/cancer-data-in-australia/.

- Potentially avoidable years of life lost, quality of life impacts and long term side effects of treatment
- Labour market and productivity effects.

These health and economic costs to the community of melanoma over the next 10 years are explored in turn.

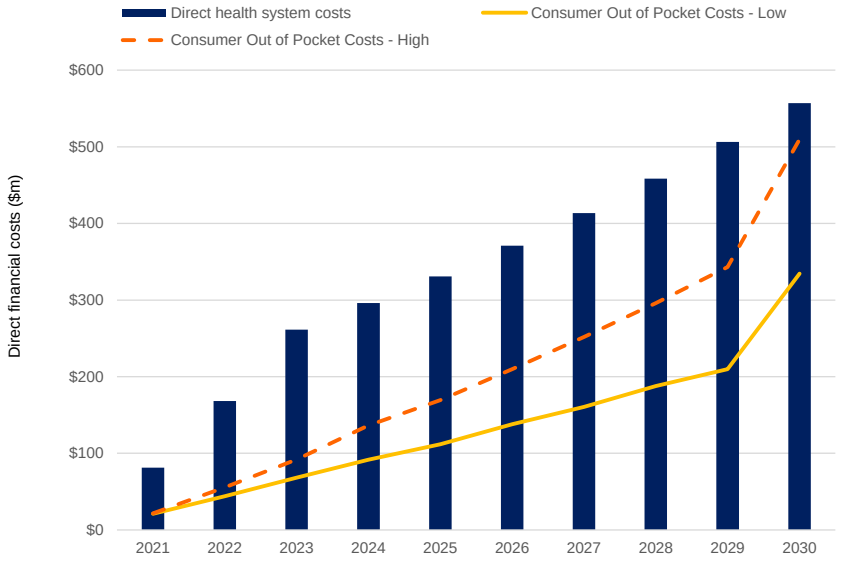
Direct health system and out of pocket costs of melanoma to the community

The direct health system costs of treating melanoma are significant. A micro-costing study of melanoma by stage of diagnosis undertaken in 2017 found over the first three years from diagnosis:

- The mean annual cost per patient for in situ, Stage I and Stage II melanoma patients was $1,681 in $2017 Australian dollars
- The mean annual cost per patient for Stage III resectable melanoma patients was $37,729 in $2017 Australian dollars
- The mean annual cost per patient for Stage III unresectable and Stage IV melanoma patients was $187,720 in $2017 dollars.[18]

Applying these costs to the projected incidence to 2030 indicates that the expected direct health system costs of treating these patients is conservatively estimated to be $3.1 billion over the 2021-2030 period in $NPV_{2\%}$ terms, not factoring in potential treatment costs for recurrence from Year 4 (Figure 2.1) or the potential for a further increase in costs associated with immunotherapies.

Figure 2.1: Direct health system costs and consumer out of pocket costs – Base Case Scenario for all persons diagnosed between 2021 and 2030



Source: Projections based on Australian Institute of Health and Welfare incidence and survival rates for Stage IV reported CheckMate trial (Larkin 2019).

In addition to costs borne by the Australian governments, consumers also face out of pocket costs. 66 per cent of patients surveyed reported incurring out of pocket costs during active

[18] Elliott, TM, Whiteman, DC, Olsen, CM, Gordon, LG, 2017, Estimated Healthcare Costs of Melanoma in Australia Over 3 Years Post Diagnosis, Appl Health Econ Health Policy, 15:805-816, doi: 10.1007/s40258-017-0341-y.

treatment and 38 per cent as long term survivors. In aggregate, consumer out of pocket costs for active treatment and as long term survivors are estimated to be between $1.2 billion and $1.8 billion in $NPV_{2\%}$ terms over the 2021-2030 period, based on the weighted average out of pocket cost estimations from the Melanoma Patient and Carer Survey.

Years of life lost and quality of life impacts

More important than potentially avoidable health care costs are the potentially avoidable loss of life and loss of quality of life.

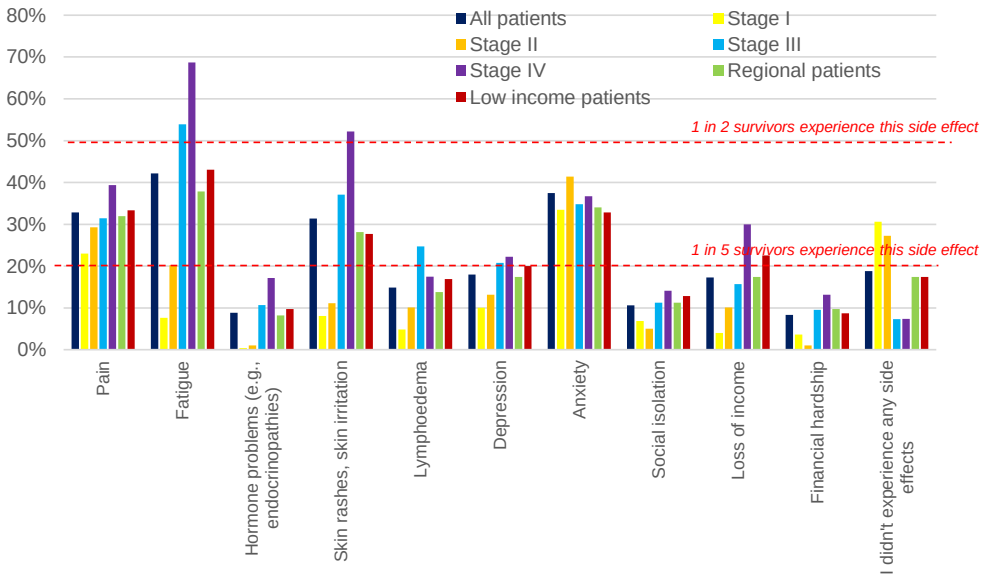
For people diagnosed with melanoma between 2021 and 2030 alone, it is estimated that more than 136,000 potentially avoidable years of life will be lost. Over the 2021-2030 horizon alone, just over 100,000 quality adjusted life years (QALY) will be lost because of melanoma diagnoses.[19] Valued at $50,000 per QALY, this translates into an economic loss of $4.4 billion due to loss of life over the 2021-2030 horizon.

Moreover, for melanoma survivors, their diagnosis and treatment can have significant, long term impacts on their quality of life. Survey data shows these survivors can have high rates of depression and anxiety as well as a high morbidity burden arising from the side effects of treatment, including:

- Pain
- Fatigue
- Skin rashes and irritation
- Lymphoedema.

The incidence of these off target effects increased with advanced stages of disease (Figure 2.2).

Figure 2.2: Quality of life impacts for survivors



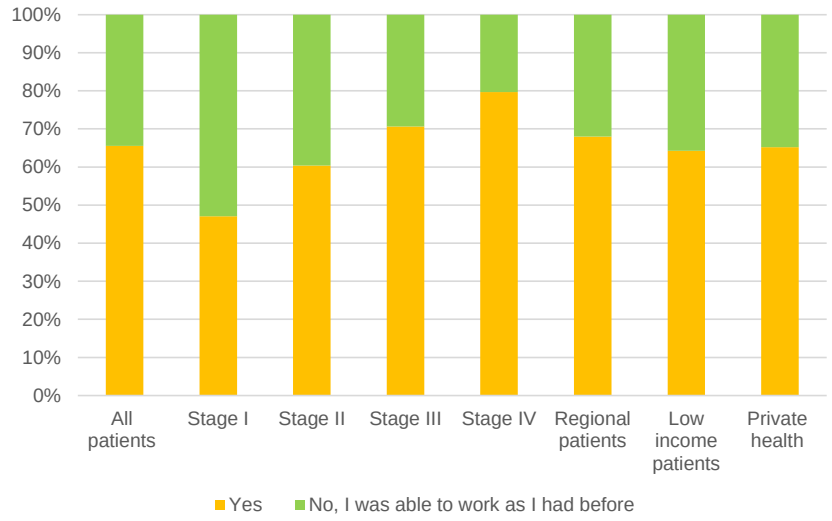
Source: Melanoma Patient and Carer Survey, see Appendix B.

[19] Tran, AD, Fogarty, G, Nowak, AK, et al., 2018, A systematic review and meta-analysis of utility estimates in melanoma, Br J Dermatology, 178:384-393; Elliott, TM, Whiteman, DC, Olsen, CM, Gordon, LG, 2017, Estimated Healthcare Costs of Melanoma in Australia Over 3 Years Post Diagnosis, Appl Health Econ Health Policy, 15:805-816, doi: 10.1007/s40258-017-0341-y.

Labour force effects

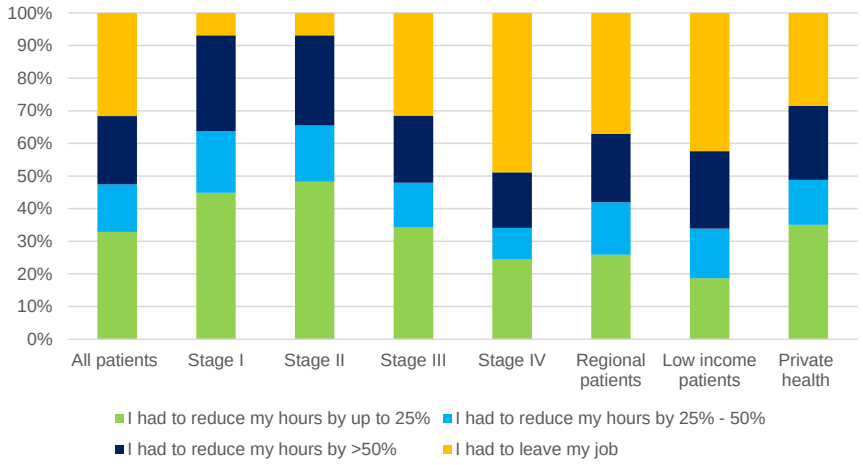
More than 60 per cent of patients indicated their diagnosis and treatment affected their ability to work, including 70 per cent of Stage III patients and 80 per cent of Stage IV patients. Approximately one in two Stage IV patients reported leaving their job as a result of treatment, as did one in three Stage III patients.

Figure 2.3: Impact on patients' ability to work



Source: Melanoma Patient and Carer Survey, see Appendix B.

Figure 2.4: Extent of impact on ability to work



Source: Melanoma Patient and Carer Survey, see Appendix B.

2.3 Drastically reducing the impact of melanoma in our lifetimes: evaluating Australia's performance to date and identifying priorities for Australian communities

Critically, many of the costs to Australian patients, families and communities are avoidable. Melanoma is largely preventable and enjoys durable long term cure rates when detected early. Significant research breakthroughs in the past five years have also changed the survival landscape for patients with advanced melanoma.

Getting to zero deaths from melanoma is more achievable than ever, but requires a renewed, nationally-collaborative strategy to close persistent gaps in policy implementation and accelerate investment in high impact infrastructure and research.

To develop a comprehensive plan for the elimination of melanoma in Australian communities, this report undertakes an evaluation of Australia's performance to date in five key policy domains:

- Prevention and Awareness
- Early Detection
- Diagnosis and Treatment
- Supportive Care and Survivorship
- Research.

Within each of these domains, Australia's efforts and achievements are identified, along with areas where material, step change improvements in survival and quality of life for Australian communities are possible.

The evaluation in each domain (Table 1) is based on evidence developed through:

- A comprehensive literature and data review, including information around trends in survival, investment and outcomes
- A review of Australian cancer policy settings
- Stakeholder consultation and consumer forums (i.e., patients and carers) involving feedback from more than 70 patients, carers and melanoma community leaders
- A national Melanoma Patient and Carer Survey, completed by 1,137 patients and carers from across Australia (See Appendix B).

Australia's performance in each domain is rated using a scorecard approach. Outcomes were scored according to the following matrix:

✓✓✓✓✓	Significant, globally-leading contributions to survival and quality of life realised in Australia
✓✓✓✓	Significant, globally-leading contribution to survival and quality of life realised in Australia, but with some inconsistencies in policy implementation observed
✓✓✓	Improvements in survival and quality of life realised, but policy settings not globally-leading and inconsistencies in policy implementation observed nationally
✓✓	Improvements in survival and quality of life realised, but with significant variation in outcomes by jurisdictions or cohort, leading to significant equity concerns and an increase in potentially avoidable mortality
✓	Poor implementation of policies and investments, with little to no contribution to survival and quality of life observed.

Informed by the evaluation of Australia's performance and opportunities for improvement, the report sets out priority areas for change and a plan for implementation.

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Chapter 3

Prevention and awareness: performance and areas for improvement

Reflecting the real possibility of significantly reducing melanoma incidence through over exposure to UV radiation and mitigation, a national strategy for prevention is needed.

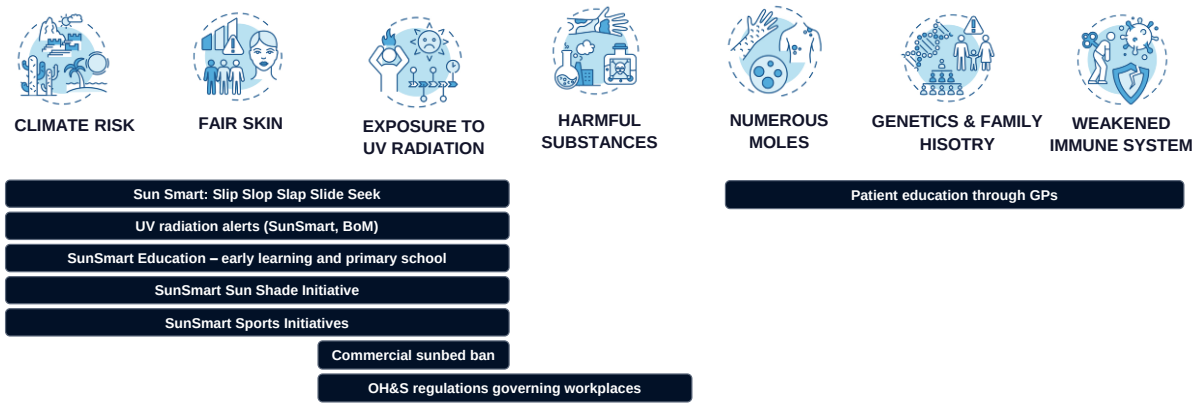
This chapter describes Australia's prior success in melanoma prevention, highlights the gaps in melanoma prevention and awareness, and identifies actions needed to improve the prevention of melanoma in Australian communities.

3.1 Australian successes in melanoma prevention

Melanoma is most often caused by a known and avoidable source – excess exposure to UV radiation; it is estimated that up to 95 per cent of melanomas could be prevented through the avoidance of over exposure to UV radiation.[20]

From as early as 1980, Australia has implemented campaigns and policy settings aimed at improving skin cancer awareness and prevention, targeting a range of risk factors (Figure 3.1). Major policy initiatives have included the *Slip! Slop! Slap!* campaign, a ban on commercial sunbeds (but not those for personal use), and the development of preventative policies and investments in school, workplace (e.g., uniform and controlled use of substances such as herbicides, solvents, and vinyl chloride), recreational and community-based settings.

Figure 3.1: Overview of major prevention efforts in Australia aimed at melanoma risk reduction



As a result of these initiatives, Australia has established itself as the global leader in skin cancer prevention. For example, its policies have been recognised by both the US Preventative Services Taskforce and the Centre for Disease Control as gold standard in melanoma prevention.[21]

[20] Olsen, CM, Wilson, LF, Green, AC, Bain, CJ, Fritschi, L, Neale, RE, Whiteman, DC, 2015, Cancers in Australia attributable to exposure to solar ultraviolet radiation and prevented by regular sunscreen use. Aust N Z J Public Health 2015; 39:471-6.
[21] CDC Community Guide website, available https://www.thecommunityguide.org/content/evidence-shows-community-based-skin-cancer-prevention-works.

A more fulsome description of selected policy and initiatives is provided in Table 3.1 below.

Table 3.1: Overview of selected awareness and prevention initiatives

Initiative	High level description
Awareness campaigns	
Slip! Slop! Slap! campaign (1981)	Launched in 1981, the *Slip! Slop! Slap!* campaign was a television commercial which aimed to encourage Australians to protect their skin. Throughout the 1980s, variants of the advertisement were produced and presented as both paid advertisements and as community service announcements.
'No Tan is Worth Dying for', ban of commercial sunbeds	As of 1 January 2015, commercial solariums units were banned in Australia. This resulted from nearly 10 years of campaigning led by the Cancer Councils across Australia, featuring Clare Oliver's message: 'No Tan is Worth Dying For'.
Preventative policies and regulations	
SunSmart Schools and Early Childhood Membership Program (1994-present)	Since summer 1988-1989, the multi-component, community-wide skin cancer prevention program known as SunSmart has been implemented in Melbourne, Australia. Started in the early 1990s, the SunSmart Schools and Early Childhood Membership Program provides members with assistance in meeting regulatory and duty of care requirements in sun protection, meeting OSH obligations in UV risk reduction for staff, and promotes sun protection policy that is comprehensive and evidence-based (ie, developed, reviewed and approved by SunSmart and Cancer Council Victoria).
Implementation of OH&S workplace regulations	Specific to each state, OH&S legislation has the unified objective of preventing illness, injury and death at (or due to) work. This requires that employers protect workers by providing a safe working environment that is free of (or mitigates) risks to health or safety. Because UV radiation presents a hazard to the health of workers, this requires that employers undertake proper steps to reduce overexposure to UV radiation for outdoor workers. Notwithstanding, employees retain a duty to take reasonable care of their own health and safety and must cooperate with employers' efforts to improve OH&S. The employers' duty of care was first enforced in August 2003 (Eric Reeder v Boral Bricks). Guidelines which assist employers in providing a safe workplace include: • Radiation Protection Series 12 (RPS 12): Radiation Protection Standard for Occupational Exposure to Ultraviolet Radiation (2006) – Australian Radiation Protection and Nuclear Safety Agency (ARPANSA) • Sun protection for outdoor workers / skin cancer and outdoor work – Worksafe Victoria • Guide on Exposure to Solar Ultraviolet Radiation (UVR) – Safe Work Australia.
Investment in shade	Uptake of shade has been promoted by several governments across Australia. For example, as well planned and designed shade can reduce exposure to UV radiation, the Victorian Government has previously invested in shade through its Shade Grants Program. This program, which commenced in 2015, has awarded over $12 million to date. However, funding is highly competitive with one in four applications successful.
Example sport initiatives	Cricket Australia Cricket Australia has a SunSmart policy which applies to players, umpires and other personnel. It makes available on its website, as a resource for cricket clubs, its playing policies and guidelines. Improve your long game Cancer Council NSW's 'Improve your long game' program aims to improve sun protection behaviours of golfers (targeting those aged 40+) by providing free sunscreen at the 1st and 10th tee, as well as information and resources to help reduce skin cancer risk.

Note: This table provides example initiatives. A supplementary list of initiatives implemented in Australia can be found in Iannacone and Green (2014), as well as on the Cancer Council's website. Iannacone, MR, Green, AC, 2014, *Towards skin cancer prevention and early detection: evolution of skin cancer awareness campaigns in Australia*, Melanoma management, 1(1), 75–84.

Historically, these initiatives have been introduced and funded through collaboration between Cancer Councils and State Governments. For example, over the period spanning 1988 to 2011, Cancer Council Victoria and VicHealth jointly funded SunSmart at a cost of

$42 million.[22] However, the Federal Government has previously funded initiatives. For example, in the late-2000s the Federal Government funded the National Skin Cancer Awareness Campaign (NSCAC) which cost $21 million and was themed 'protect yourself in five ways'.[23]

Research has shown these prevention initiatives have generally had a positive impact on community awareness. For example:

- Evaluations of the SunSmart program concluded the program led to increases in sun protection behaviour including increased preference for no tan (12 per cent) and sunscreen use (9 per cent) as well as reduced total sun exposure[24]
- Most Victorian early childhood services (97 per cent) and primary schools (90 per cent) have a written sun protection policy, which is shown to be associated with children and staff more actively protecting themselves from the sun[25]
- An evaluation of the cost effectiveness of Melbourne based advertising campaigns found that, when broadcast with sufficient Target Audience Rating Points (TARPs) during the summer months, sustained youth-focused advertising campaigns continue to provide consistent beneficial impact on sun protection behaviours[26]
- An evaluation of campaigns by the Federal Government found some effectiveness of its 'five ways' initiative.[27]

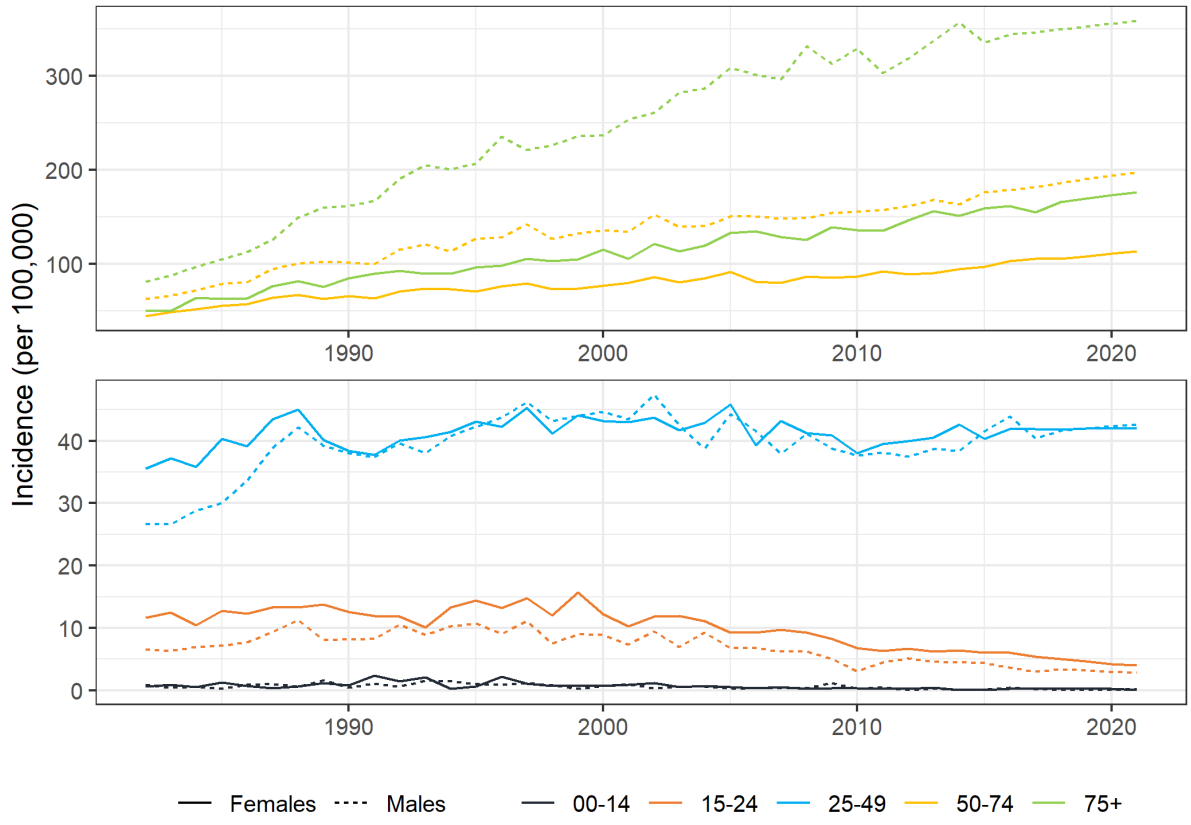
Furthermore, economic evaluations indicate that preventative measures and awareness initiatives have been cost effective and associated with high cost-benefit ratios. For example:

- Skin cancer prevention policies nationally have returned $3.30 for every $1 invested[28]
- The SunSmart Program has returned $2.30 in health care costs for each $1 invested in the program[29]
- Skin cancer prevention policies in NSW have been shown to result in a benefit cost ratio (BCR) of 3.85, suggesting that for every $1 invested a return of $3.85 is generated.[30]

Ultimately, these policies and investments have likely contributed to the decline in the incidence of melanoma in younger cohorts of Australians (Figure 3.2). However, as the risk of skin cancer grows with sun exposure, declining rates of melanoma in younger cohorts do not provide a complete view of the effectiveness of awareness and prevention.

[22] Shih, ST, Carter, R, Heward, S, and Sinclair, C, 2017, *Skin cancer has a large impact on our public hospitals but prevention programs continue to demonstrate strong economic credentials*, Australian and New Zealand Journal of Public Health, 41, 371-376.
[23] House of Representatives Standing Committee on Health, 2015, *Skin Cancer in Australia: Our National Cancer Report on the Inquiry into Skin Cancer in Australia*, Commonwealth of Australia, Chapter 2, accessed at: https://www.aph.gov.au/Parliamentary_Business/Committees/House/Health/Skin_Cancer/Report.
[24] Dobbinson, SJ, Volkov, A, Wakefield, MA, 2015, *Continued Impact of SunSmart Advertising on Youth and Adults' Behaviors*, American Journal of Preventive Medicine, 49(1).
[25] Refer to the SunSmart website, available: https://www.sunsmart.com.au/advice-for/schools-early-childhood.
[26] Dobbinson, SJ, Volkov, A, Wakefield, MA, 2015, *Continued Impact of SunSmart Advertising on Youth and Adults' Behaviors*, American Journal of Preventive Medicine, 49(1).
[27] Ipsos-Eureka Social Research Institute, 2010, *Evaluation of national skin cancer awareness*, Final phase (2008-2009).
[28] Shih, STF, Carter, R, Heward, S, Sinclair, C, 2017, *Economic evaluation of future skin cancer prevention in Australia*, Prev Med, 99, 7-12.
[29] Shih, S, Carter, R, Sinclair C, Mihalopoulos C, Vos T, 2009, *Economic evaluation of skin cancer prevention in Australia. Preventive medicine*, 49, 449-53.
[30] Doran, CM, Ling, R, Byrnes, J, Crane, M, Shakeshaft, AP, Searles A, et al., 2016, *Benefit Cost Analysis of Three Skin Cancer Public Education Mass-Media Campaigns Implemented in New South Wales, Australia*. PloS one, 11(1).

Figure 3.2: Decreasing melanoma incidence for younger population



Note: Actual data reported from 1982 to 2017, AHIW forecast to 2021. Source: Australian Institute of Health and Welfare, 2021, Cancer Data in Australia, Book 1a, Melanoma.

3.2 Remaining gaps in prevention and awareness

Notwithstanding the significant achievements that have been made, the incidence of melanoma in the community remains high and there are indications that uptake of preventative behaviours remains mixed.[31]

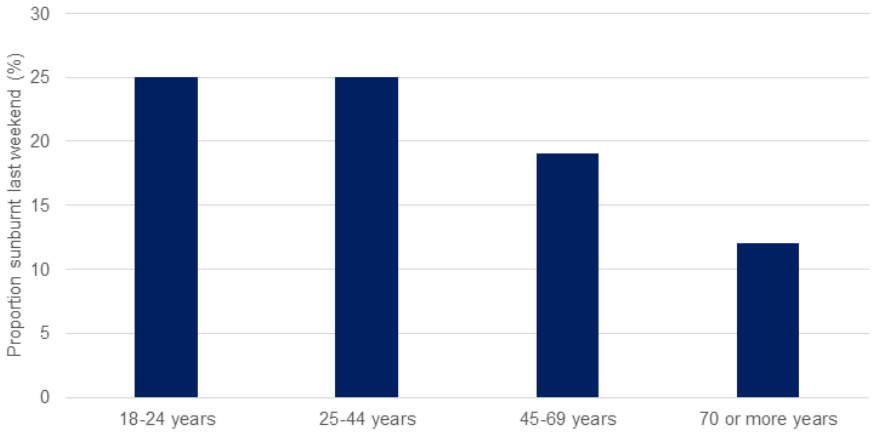
Because high sunburn is associated with failure to successful employ preventative sun safe behaviours, it can be adopted as an indicator of the effectiveness of prevention efforts. Recent survey evidence indicates that sunburn prevalence remains high. For example:

- In 2020, almost half of Queensland's adults (49 per cent) and children (45 per cent) reported being sunburnt in the previous 12 months[32]
- In 2016, 10 per cent of the NSW population aged 18 years and older were sunburnt at least once in the four-week period prior to survey[33]
- In 2020, 102 Western Australian children and teenagers aged between 10 and 19 years sought medical attention for sunburn in emergency departments, compared to 44 in 2014.[34]

[31] One key reason for low uptake is the interrelationship between sun and Vitamin D. Reichrath, J, 2006, The challenge resulting from positive and negative effects of sunlight: how much solar UV exposure is appropriate to balance between risks of vitamin D deficiency and skin cancer? Prog Biophys Mol Biol, 92(1), 9-16, doi: 10.1016/j.pbiomolbio.2006.02.010.
[32] Queensland Government website, available at https://www.health.qld.gov.au/news-events/news/sun-safety-skin-cancer-children-queensland-protecting.
[33] Cancer Institute NSW, 2017, *Sun protection behaviours in NSW*, p 5.
[34] Cancer Council WA, 2021, *Number of 10-19 year olds with severe sunburn more than doubles in 2020*, available: https://www.cancerwa.asn.au/articles/news-2021/number-of-1019-year-olds-with-severe-sunburn-more-/.

This evidence is corroborated by data gathered as part of the Life in Australia™ 2019 Summer Sun Protection Survey, which indicates that over 1 in 5 (21 per cent) survey respondents were sunburnt over the survey weekend (Figure 3.4).

Figure 3.4: Proportion sunburnt higher for younger adults



Source: Cancer Council, 2020, Media Release: Kids of the 80's and 90's failing the Slip Slop Slap-ometer.

To this end, improving policies and increasing investment aimed at prevention of melanoma was the most commonly identified area of need by melanoma patients and carers; more than three in four respondents to the Melanoma Patient and Carer Survey (76 per cent) indicated current policy settings for prevention and awareness are inadequate.

The underlying causes of suboptimal prevention are a complex function of cultural and environmental factors as well as significant gaps in policy settings and investment; these include:

- A pervasive culture of outdoor activities and tanning, leading to high incidental rates of exposure to UV radiation and sunburn
- Poor understanding of melanoma and its seriousness in the community
- Poor understanding of how to 'be sun safe'
- Underinvestment in consistent public health messaging
- Inconsistent implementation of sun safe policies in school settings
- Underinvestment in shade against a backdrop of low sunscreen uptake and UV radiation avoidance
- A lack of explicit sun safe training for outdoor workers
- A lack of explicit sun safety in Australia's sporting clubs.

These challenges are considered in turn.

Outdoor and tanning culture is 'part of Australia's DNA'

Responses to the consumer forums highlighted the view that an outdoor and tanning culture is 'part of Australia's DNA'. Respondents noted that Australians spend time outside playing sport or at the beach, including in the middle of the day (Figure 3.5).

Figure 3.5: Being out in the sun is part of 'Australia's DNA'

It follows that Australia's culture may result in exposure to potentially hazardous UV radiation.

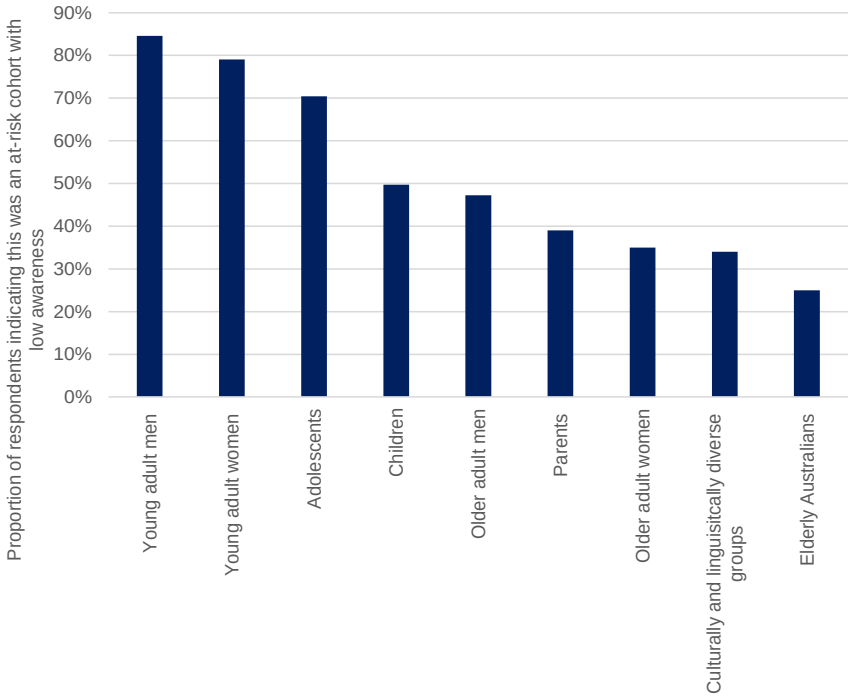
Poor understanding of melanoma and its seriousness

An understanding and awareness of melanoma is necessary for Australians to make well informed decisions regarding exposure to UV radiation. However, Australians tend to be unaware of melanoma and its seriousness. This view was highlighted by a wide range of clinician, researcher, policy, patient and carer stakeholders (Figure 3.6).

Figure 3.6: Seriousness of melanoma not understood

Respondents to the Melanoma Patient and Carer Survey indicated that a lack of awareness and understanding of the seriousness of melanoma was particularly prevalent in younger Australians (Figure 3.7). This corresponds to the rates of sunburn reported in the Summer Sun Protection Survey (Figure 3.4 above).

Figure 3.7: Low awareness among at-risk cohorts – what groups have low awareness of melanoma risk?



Source: Melanoma Patient and Carer Survey, see Appendix B.

The decreasing crude rate of melanoma observed in younger Australians does not contradict perceptions that young people are relatively unaware of risks (or get sunburned relatively frequently). Rather, this is consistent with the view that there have been improvements in skin cancer prevention attitudes over the long term, but there remains much more to be done in terms of raising awareness levels of younger Australians.

This underscores a need to sustain public health messaging and prevention policies aimed at younger generations.

Poor understanding of 'how to be sun safe'

Analysis of survey data conducted through the Social Research Centre indicates that Australians continue to illustrate a lack of awareness of how to 'be sun safe':

- Fewer than one in 10 Australians understand that sun protection is required when UV radiation levels are 3 or above[35]
- Approximately 40 per cent of Australians remain confused about which weather factors cause sunburn.[36]

This was simillarly highlighted through the the consumer forums (Figure 3.8).

[35] Cancer Council ACT, 2018, *9 in 10 Australians don't know when they need sun protection*, https://actcancer.org/news/general/9-in-10-australians-don-t-know-when-they-need-sun-protection/.
[36] Ibid.

Figure 3.8: How to be sun safe is not understood

There is a lot of complexity… what we need is a rule of thumb: "An hour in the sun". Something you think about every day. At the moment, there's too much information, that is causing confusion.

It's hard to craft a public health message. We need simplicity in the messaging to get cut through.

We have the tools available but we're not bringing those to the public. We have those wonderful stickers that change colour when you need to reapply the sunscreen. They used it with children who had to go out and play. They put the sunscreen on, and put their sticker on, and when the sticker changed, they had to go and put more sunscreen on.

And in the week that they did that, they used three times as much sunscreen as they normally would.

How much is enough? How regularly to apply – this is not by any means clearly understood. I looked at the Sun Smart app and it said I needed to apply seven teaspoons of sunscreen. I took a picture and shared [on social media] what seven teaspoons of sunscreen look like, and people were shocked.

It's not just UV it's the amount of sunscreen that needs to be applied and reapplied that isn't understood. I was a cricket umpire, I'm red headed and light skinned. I can see a lot of cricketers and sports people that just don't understand that you've got to reapply. They sweat, they wipe their face. They're always out in the sun.

Barriers to improving the adoption of sun safe behaviour include the feasibility of the recommendations and the credibility of the recommendations. … The current Cancer Council SunSmart recommendations are:

- Use UV skin protection when UV levels are 3 or higher.
- Apply a SPF30 (or higher) broad-spectrum, water-resistant sunscreen.
- Apply to clean, dry skin at least 20 minutes before going outside.
- For a full body application, use 35ml of sunscreen solution.
- Reapply sunscreen every two (2) hours or after swimming or excessive sweating.

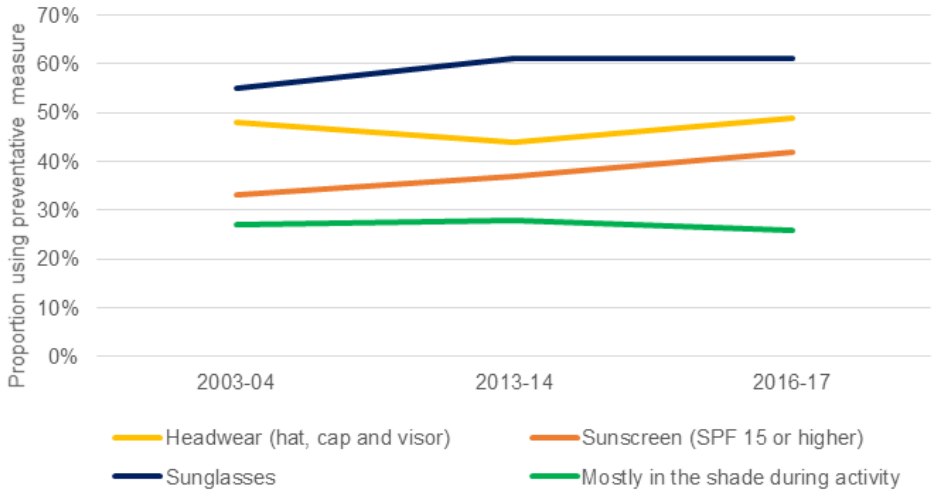
Are people really going to use UV skin protection every time the UV levels outside are 3 or higher? No.

Are people currently organised enough to apply the sunscreen at least 20 minutes before they go out into the sun? No. How much before – 2 hours?

Are people going to put a palm-full (35ml) of sunscreen on every time? No. This is a huge amount of solution to apply.

Cancer Council data provide further evidence around the uptake of preventative measures, showing that across time the use of well accepted preventative measures has not consistently improved since 2004 (Figure 3.9).

Figure 3.9: Mixed uptake of preventative measures



Source: ACT Cancer Council analysis of data from the National Sun Protection Survey, available: https://actcancer.org/news/general/we-are-still-a-sunburnt-country/.

The lack of understanding of how to be 'sun safe' may also reflect a lack of understanding of the risk factors which contribute to melanoma. There was a strong consensus across stakeholders that Australians do not understand the difference between UV radiation and heat, or cumulative risks of ongoing exposure.

Figure 3.10: Australians do not understand risk of melanoma

The consequence of poor understanding of risk is that the community may struggle to undertake preventative measures, or appropriately interpret material made available. This is illustrated by recent attempts to provide Australians with UV radiation related information.

For example, as a key risk factor for skin cancer is excessive exposure to UV radiation, the availability of UV forecasts can enable Australians to mitigate the impact of peak periods. However, for Australians to be able to use this information effectively, they must be able to interpret it. Evidence indicates that they cannot; Nicholson, Murphy, Walker, Tinker & Dobbinson (2019) highlight that: [37]

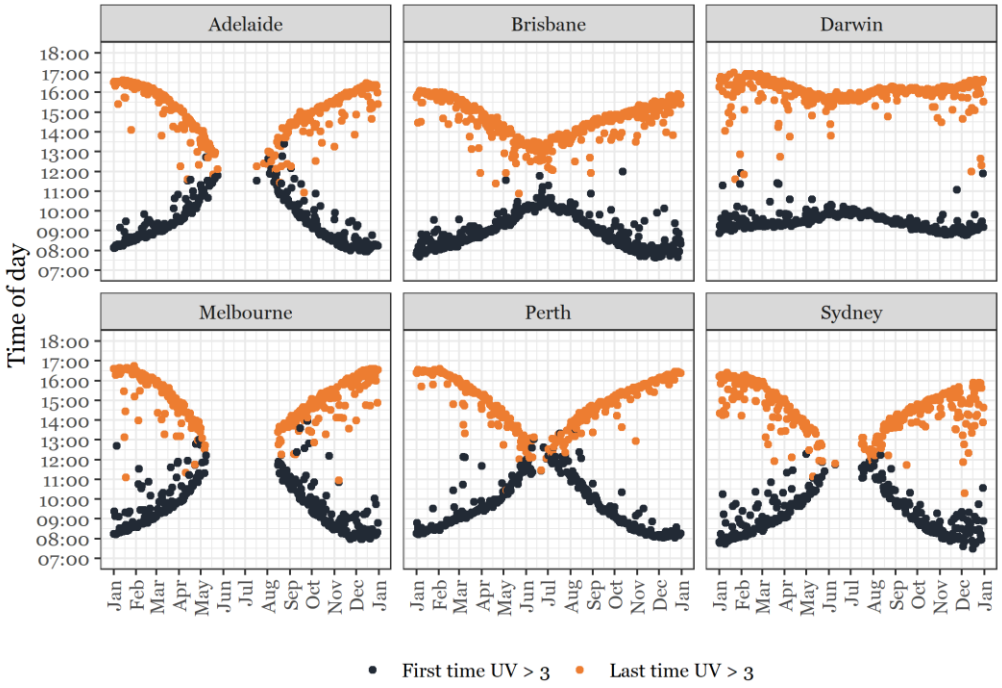
> *No matter how broadly UV forecast information is promoted, it is unlikely to improve sun protection behaviours across the Victorian population due to the low level of basic understanding of UV radiation.*

It follows that a public education and awareness campaign may help promote understanding, and thus help Australians develop more effective sun protection habits.

Another factor influencing how aptly Australians can interpret UV radiation forecasts is the consistency of messaging provided. Although the idea that a UV radiation index equal to or in excess of three is associated with increased risk of melanoma is not particularly complex, perceived rules of thumb and simplifications can contribute to confusion. For example, while suggestions that sun should be avoided between 10am and 4pm may be useful on average, this does not always hold by location and time of year. In Queensland, the UV radiation index can exceed three before 8am and after 4pm (Figure 3.11).

[37] Nicholson, A., Murphy, M, Walker, H, et al., 2019, *Not part of my routine: a qualitative study of use and understanding of UV forecast information and the SunSmart app*. BMC Public Health 19, 1127.

Figure 3.11: First and last time per day that UV radiation index exceeds three in 2019



Source: Insight Economics analysis of UV radiation data, available: https://data.gov.au/data/dataset/ultraviolet-radiation-index-darwin.

Recent approaches avoid this confusion by removing the need to interpret or explain UV radiation. For example, the free SunSmart app notifies users when sun protection is recommended for their location. However, this is only useful to the extent that it is accessible to Australians; that is, that all Australians can use the app and that it is adequately marketed so that Australians are aware that it exists. Similar applications can also promote timely skin checks, provide clear messaging regarding risk factors and provide a means of self-assessment. Mobile applications may allow users to self-identify with a high-risk cohorts and follow subsequent instructions.

Opaque funding arrangements and an underinvestment in public health messaging

Compared to other public health initiatives, funding for the prevention of melanoma has been relatively limited and largely outsourced to the not-for-profit sector, even as federal and state governments incur substantial costs associated with treatment of melanoma.

For example, prior to December 2021, while the Federal Government had committed funding to cancer related initiatives, it had not recently committed funding specifically to melanoma prevention.[38] This trend was broken by the Prime Minister in his 21 December 2021 announcement of a $20 million Australian Government investment over the next two years in skin cancer awareness, including a $10 million national awareness campaign.[39]

At a state level, the Victoria Government is a relative outlier, having committed $15.1 million towards skin cancer prevention over the period spanning 2019 to 2023.

The lack of dedicated funding for melanoma prevention and awareness, despite strong evidence behind the success of preventative measures and awareness campaigns, is indicative of underinvestment. This is further supported by benchmarking of funding for melanoma (and skin cancer more generally) against road safety, which illustrates that road

[38] Based on analysis of recent budget commitments.
[39] Prime Minister of Australia, 2021, Be UV aware and help turn the tide on skin cancer.

safety funding is considerably greater than melanoma awareness and prevention funding, despite similar deaths per annum (Box 3.1).

Box 3.1: Benchmarking expenditure on public health messaging – road safety compared with melanoma

Both road deaths and melanoma are highly preventable; in the event of 'perfect' preventative behavior uptake there would few deaths incurred. Similar to cancer, current road safety initiatives are aiming 'towards zero fatalities and serious injuries' on Australian roads.

At a national level, the number of deaths per annum due to melanoma are of a similar order of magnitude to the number of deaths due to road incidents, with:

- 1,384 deaths expected from melanoma in 2020
- 1,113 deaths expected from road deaths in 2020.

That said, those that die from melanoma are on average much older (median age at death within 75-79) than those that die from road traffic accidents (median age of death of 40-64).

The prevention of road deaths follows a similar public health prevention model to the approach adopted for skin cancer and melanoma. Examples of comparable initiatives are depicted in the table below. It is worth noting that road safety policies are often explicit and enforced by State police forces as well.

Public health policy structure	Road safety examples	Skin cancer and melanoma examples
Infrastructure investment	Speed humps, roundabouts, safety barriers	Shade, sunscreen dispensers
Legislation and regulation	Speed limits, seat belts and blood alcohol limits	SunSmart, no hat no play, OH&S
Awareness campaigns	'Wipe off 5', 'Towards Zero' and "Drink and Drive, You Bloody Idiot'	'Slip! Slop! Slap!', 'There's nothing healthy about a tan'

Despite these similarities, funding for road safety in Australia is much more comprehensive than for melanoma prevention. For example, the Federal Government has substantially committed to funding projects through the National Heavy Vehicle Regulator ($5.5 million in Round 6), the Office of Road Safety's Road Safety Awareness and Enablers Fund ($4 million over four years from 2019-20) and the Office of Road Safety's Road Safety Program ($3 billion). This federal funding is further complemented by State level policies and investments. For example, in 2020, Victoria's Transport Accident Commission (TAC) spent $12.3 million on its nine largest road safety advertising campaigns alone. Similarly, in NSW, the investment in campaigns for road safety for 2019–2020 was $18.6 million.

Due to the complexity and opacity of funding arrangements for skin cancer and road safety across multiple bodies nationally, it is challenging to benchmark like-for-like programs. However, the underinvestment in skin cancer and melanoma prevention compared to road safety can be observed in Victoria as a case study example. Even with the significant increase in funding for shade and GP training in its most recent Cancer Policy statement, increasing total funding to $15 million over the 2019-2023 period and a nation leading position in skin cancer prevention investment, this is vastly outstripped by road safety investments. In 2020 alone the Victorian Transport Accident Commission spent $92 million on education and awareness of road safety. In contrast, $1 million was expended on education and awareness for the Sun Smart program in 2020, translating to a 92 times higher rate of funding for road safety prevention and awareness.

Source: Australian Government Office of Road Safety website, available: https://www.officeofroadsafety.gov.au/programs/infrastructure-programs; Transport Accident Commission 2019/20 Annual report; Victoria State Government, 2020, School shade grants program: round 5 2020 program guidelines. For the purpose of this analysis, the SunSmart Program is classified as an Education initiative and shade investment is classified as an environment/engineering initiative. Expenditure is calculated on a yearly average basis.

Similarly, evidence from stakeholder consultation and consumer forums indicates the view that there is underinvestment in public messaging and preventative infrastructure (Figure 3.12). This underinvestment is problematic, as a failure to undertake long term investment will lead to the erosion of any behavioural improvements gained.[40] Stakeholders indicated there was strong consensus around the need for a modernised prevention and awareness campaign.

[40] Sinclair, C, Foley, P, 2009, *Skin cancer prevention in Australia*, Br J Dermatol, 161, 116-23.

Figure 3.12: Underinvestment in public campaigns, and need for modern prevention and awareness campaign

Of course, developing a suitable strategy for correct sun exposure is a complex task.[41] In Australia, the complexity contributed to limited success of the Federal Government's NSCAC campaign. Indeed, the evaluation of the program found reduced year on year impact and limited uptake of protective behaviours across a range of situations, with significant scope for more changes in sun protection behaviours, attitudes and knowledge.[42]

[41] Stanganelli, I, Naldi, L, Cazzaniga, S, Gandini, S, Magi, S, Quaglino, P, Ribero, S, Simonacci, M, Pizzichetta, M. A., Spagnolo, F, Palmieri, G, Queirolo, P, "Sun Friend project members", 2020. *Sunburn-related variables, secular trends of improved sun protection and short-term impact on sun attitude behavior in Italian primary schoolchildren: Analysis of the educational campaign "Il Sole Amico" ("The sun as a friend")*, Medicine, 99(1).
[42] Ipsos-Eureka Social Research Institute, 2010, *Evaluation of national skin cancer awareness*, Final phase (2008-2009).

A well-executed awareness campaign requires sufficient resources and must leverage the learnings and wealth of Australian expertise available.

Inconsistent implementation in public schools and no policies for secondary schools

Although sun safe policies are encouraged at schools via the SunSmart program, there is no overarching federal approach which is consistently enforced. It follows that different schools have different approaches to prevention, with varying levels of effectiveness.

Evidence from stakeholder consultation and consumer forums indicates that there are a range of concerns regarding the consistency and appropriateness of adopted policy (Figure 3.13). For example:

- Uniform policy is inconsistently implemented and enforced – although the 'no hat no play' policy is enforced at many primary schools, some fail to enforce it
- Planning of and timing of events illustrate a lack of understanding – some administrators continue to organise sports and sport carnivals during peak UV radiation periods.

Figure 3.13: Concerns regarding consistency of policy implementation in schools

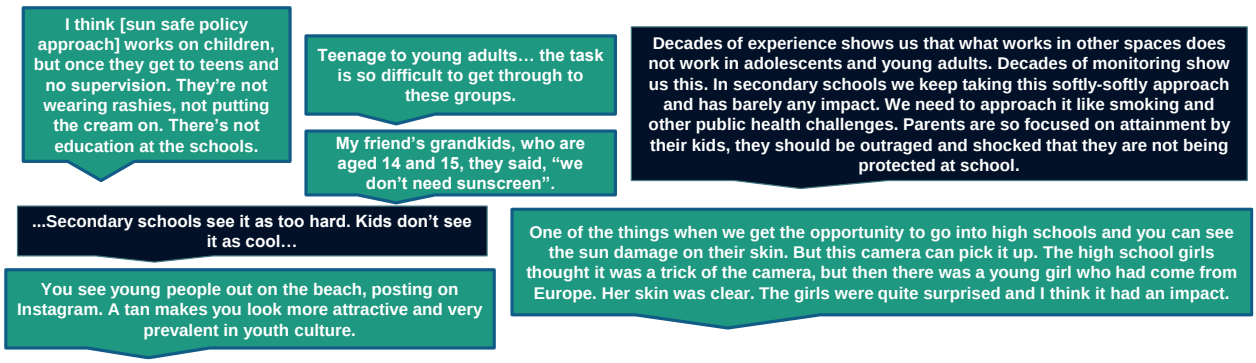
The possible lack of consistency is highlighted in an evaluation of the comprehensiveness of primary school sun-protection policies in tropical North Queensland. Turner, Harrison, Buettner and Nowak (2014) find that:

> *Although policies of Cancer Council accredited 'SunSmart' schools addressed more environmental, curriculum and review-related criteria than those of 'non-SunSmart' schools, the overall median score for both groups was low at 2 from a possible 12….*
>
> *Most policies addressed hat wearing, while criteria related to shade provision at outdoor events, regular policy review and using the policy to plan outdoor events were poorly addressed.*

A frequent concern raised throughout consultation regarded the implementation, or more aptly, lack of implementation of policies in secondary schools. For example, while the 'no hat, no play' initiative is commonly employed in primary schools it is not used in high schools.

Among other things, this reflects the view that reaching secondary school students is difficult given social and cultural barriers. These concerns were raised in the stakeholder consultation and consumer forums (Figure 3.14).

Figure 3.14: Teenage culture contributed to a difficult policy setting



Insufficient implementation of supported recommendations from the Inquiry into Skin Cancer in Australia

Similar issues to those listed above were raised in the Inquiry into Skin Cancer in Australia, which made numerous recommendations to the Federal Government on how to prevent skin cancer. Of these recommendations, the Federal Government supported a subset, however, as indicated in the table below, little has been done in response to these 'supported' recommendations (Table 3.2).

Table 3.2: Progress from prevention policy recommendations supported by government in 2017

Supported recommendation	Progress as of 2021	Source information
Register of sun smart policies with the Australian Sports Commission (ASC)	✓ Link to Sun Smart website on Sporting Schools Website under 'additional resources' × Sun safe policies not listed on ASC website or included in toolkit for establishing a club, with safe and inclusive sport focused on child safety, discrimination and harassment.	Resources | Sport Australia Evidence-based position statements and best practice guidelines | Australian Institute of Sport (ais.gov.au) Integrity Policies and Programs | Sport Australia
Encourage sun smart policies in secondary schools	× No or very limited progress	

Supported recommendation	Progress as of 2021	Source information
Invest in shade for swimming pools	✕ Limited progress	Shade is not listed a strategic priority for Australian Local Government Association 2020-2023 See: https://cdn.alga.asn.au/wp-content/uploads/ALGA-Strategic-Plan.pdf
All sun exposed industries incorporate mandatory sun safety education	– Safe Work Australia includes UV radiation guidance, but UV radiation not included in requirements for training of key trades	For example, sun safe training in Qld: General construction induction | WorkSafe.qld.gov.au

Insufficient uniformity of workplace policy

OH&S regulation requires that employers protect workers by providing a safe working environment that is free from (or mitigates) risks to health or safety, including UV radiation.

Although employers are required to mitigate the risks faced by employees, consistent and deliberate training regarding UV radiation risks is yet to be implemented. For example, in Queensland, a person wanting to work in the construction industry must complete a general construction induction training course with a Registered Training Organisation (RTO). This training provides a range of information in work health and safety laws including common site hazards and how to control the associated risks. Once persons have successfully completed this training, they are issued with a general construction induction training card (previously called a white card), which they must carry whenever they are on site. In Queensland, the training covers *Work Health and Safety Regulation* 2011 (Part 6.5 General construction induction training), which provides significant detail around workplace hazards, but does not at any point canvass risks and protective behaviours from UV radiation.

Concern regarding uniform and workplace policy was raised for all workers who spend large amounts of time outdoors or are outside during peak UV radiation periods (e.g., tradesmen, teachers, military personnel). Furthermore, concern was raised regarding the enforceability of sun safe workplace policy; some stakeholders suggested enforcing sun safety and measuring compliance (e.g., use of sunscreen, hats and sun safe uniforms).

Another concern raised within consultation was regarding the affordability of some of the relevant preventative measures. While the ATO has made workplace personal protective equipment tax deductable, SMEs may struggle to reach the scale that justifies investment in policy development and employee UV radiation safety training.

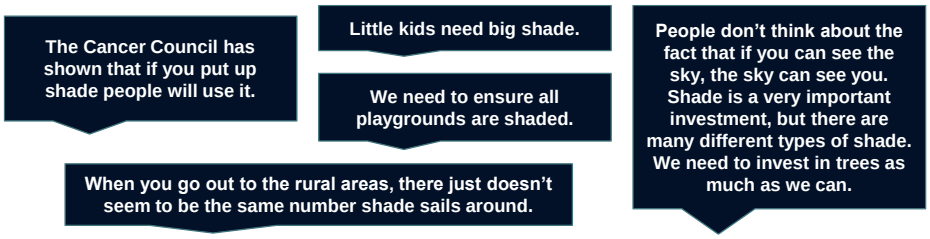
Inconsistent investment in shade

Shade provides a high quality environmental solution to excess UV radiation exposure, and is more passive in the sense that it places less emphasis on individuals being aware of the risks of UV radiation exposure and the costs of melanoma. For example:

- Provided the tree is not deciduous in high UV radiation areas, dense foliage can provide significant sun protection and can overlap with environmental initiatives
- A shade sail that achieves a UVP factor of 15 or greater can provide a 93 per cent reduction in exposure to UV radiation.

Despite its potential as a solution, evidence from stakeholder consultation and the Melanoma Patient and Carer Survey indicates that the current quantum of shade is perceived as insufficient.

Figure 3.15: Stakeholder consultation suggests shade insufficient



Multiple respondents to the stakeholder consultation considered there to be insufficient funding for shade, ie:

> *There are serious structural issues. There's no shade [at sports grounds], they're out there for days on end, for weekends. My view is that this should be treated like road safety. There are structural issues, awareness issues…. It's a very complicated thing and requires a sophisticated response.*
>
> *…We spend a lot on roads, maybe we should be spending more on shade.*

Although across Australia there have been increasing efforts to invest in shade protection, investment has been inconsistent and/or remains inadequate. This is the consequence of variable funding arrangements which follow from shade infrastructure funding responsibility falling to local councils or State governments. To illustrate this variation, while Victoria (through the Victorian 2020-2024 Cancer Plan) has recently committed to more than $10 million investment in new shade sails, other states have made much less progress (Box 3.2). For example:

- NSW is completing an audit of shade requirements
- Queensland has invested between $1.5 million and $2.5 million over the past three years, providing funds for only 309 structures to date (as of the latest performance report).

Box 3.2 – Two case approaches illustrating variable approach to shade

Victoria: The Shade Grants Program

The Shade Grants Program was introduced in the 2020-2024 Cancer Plan and aims to reduce Victorians' exposure to UV radiation. It does this by increasing shade in public places across the state and by promoting uptake of sun protective practices. In the first three rounds of the program, the Victorian Government awarded 1,084 grants worth over $10 million. These grants have made a difference for many Victorian primary and secondary schools, sporting clubs, social groups and early learning centres. Funding has been used to: install permanent shade structures, repair existing shade, purchase portable shade, plant natural shade and purchase sun protective items such as sunscreen, hats and protective clothing.

Queensland: The Sun Smart Shade Creation Initiative

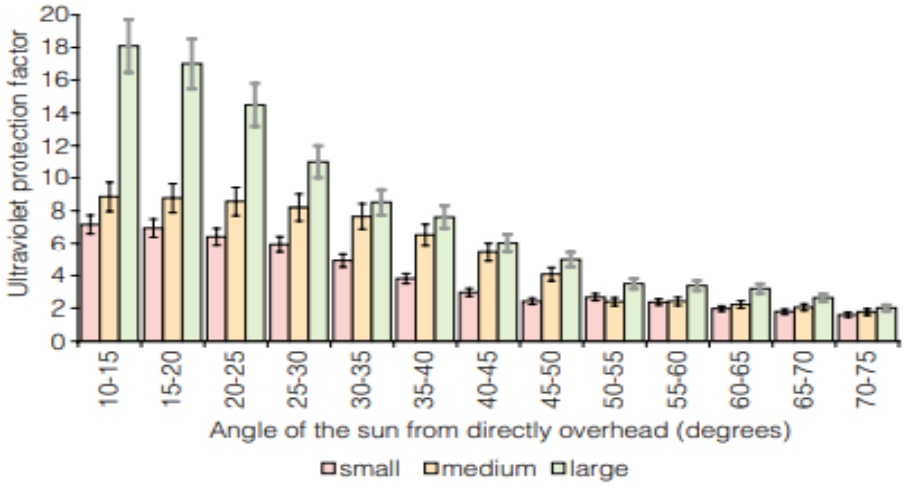
As part of the implementation of the Health and Wellbeing Strategy 2017-2026 Queensland Health's Preventive Health Branch introduced the SunSmart Shade Creation Initiative which provides 50 per cent matched funding of up to $2,000 or $5,000 for portable or permanent shade structures. Since its introduction the program has been reported to have funded 309 organisations, with demand exceeding funded applicants by 100 per cent in each year (319 unsuccessful applicants over the three years). In 2018-19, it was reported that 50 per cent of grants were allocated to the Mackay Hospital and Health Service area as childhood sunburn rates were 16 per cent higher in that area than the state rate. A total of $2.5 million has been allocated across all sun safety policies and, based on the highest rate of funding ($5,000) being allocated to each organisation, this implies $1.5 million in funding for shades. In 2015, nearly 60 (56) per cent of all Queensland children (adults) had been sunburnt in the previous 12 months, and Queensland's mortality rate from melanoma and other skin cancers was 13 per cent higher than the rest of Australia. The target for the program was an increase in the percentage of children practicing sun protection behaviours from 47 per cent to 50 per cent, and for adults to increase from 22 per cent to 24 per cent by 2020.

This inconsistency is also reported at a local level, with stakeholders suggesting that rural communities have reduced access to shade. For example, one stakeholder noted:

> *When you go out to the rural areas, there just doesn't seem to be the same number shade sails around.*

Research has shown that shade requires planning to get it right. For example, Figure 3.16 illustrates that the efficacy of shade size is linked to the angle of the sun – as the sun moves from being directly overhead, the advantage of large shade diminishes. There are many important factors to consider when making shade investments, including: selection of appropriate shade material (and size), consideration of sun angles to maximise protection, and options to maximise broader environmental criteria by maximising tree-planting (subject to UV radiation levels through winter). A well-executed shade initiative could provide very high levels of ultraviolet protection, exceeding 93 per cent above UPF 15.

Figure 3.16: UPF protection from shade



Note: Colours reflect shade size.

Significant exposure in weekend sport

Australians, particularly during childhood and adolescence, spend considerable amounts of time playing outside of school hours sport.[43]

Weekend sport can occur during peak UV radiation periods. As participants in outdoor sports and activities often wear minimal clothing or clothing which is not designed for protection, and as sport continues for prolonged periods, participants, volunteers, officials and spectators become exposed to UV radiation.

Consequently, evidence indicates that sport participants face a higher risk of skin cancer. For example, Snyder, Valdebran, Terrero, Amber, and Kelly note that, in the US:[44]

> *Individuals who practice outdoor sports experience substantially higher ultraviolet radiation exposure, routinely exceed the recommended exposure limits, and are at a higher risk of developing skin cancer.*

[43] For example, in 2017, 63 per cent of children participated in organised physical activity outside of school hours at least once per week, and one in four (20%) children participated in organised physical activity outside of school hours at least three times per week. Australian Sports Commission, 2018, *AusPlay Focus: Children's participation in organized physical activity outside of school hours,* Australian Government, available https://www.sportaus.gov.au/__data/assets/pdf_file/0004/675562/AusPlay_focus_Children_Participation_2.pdf.

[44] Snyder, A, Valdebran, M, Terrero, D, Amber, KT, Kelly, KM, 2020, *Solar Ultraviolet Exposure in Individuals Who Perform Outdoor Sport Activities*, Sports Med Open, 6(1).

Similarly, athletes practicing outdoor sports receive considerable UV radiation doses because of training and competition schedules with high sun exposure.[45] Similarly, reflecting prolonged exposure, golf course workers and, in particular, golfers are an important target for skin cancer prevention campaigns.[46]

Among the issues regarding sport, one participant in the consumer forums noted the lack of shade available at sports grounds:

> *There's no shade [at sports grounds], they're out there for days on end, for weekends. My view is that this should be treated like road safety.*

Furthermore, although various sporting clubs and associations have implemented prevention policies, there is no unified approach. For example, when creating a new sports club with the Australian Institute of Sport, there is no information on sun safety included, however, there is focus on the prevention of child safety and sexual misconduct, discrimination and fair play. This focus pervades the AIS web documentation, and sun safety is not included in best practice guidelines, although there is extensive guidance regarding COVID safe sport.

3.3 Opportunities to improve prevention and awareness

There is strong evidence underpinning best practice prevention recommendations by the CDC's Community Guide, which are based on Australia's experience and involve a multicomponent, community-wide intervention approach focused on increasing the prevalence of sun protection behaviours in childcare centers, primary and middle schools, outdoor recreational and tourism areas, and occupational settings (ACS, 2016).[47] Improving the uptake of sun protection behaviours in Australia will require:

- Generational commitment to and sustained investment in awareness campaigns to improve sun protection, involving strategies directed toward individuals and modern mass media campaigns (i.e., including use of social media)
- Additional environmental and policy changes and investments, including:
  - Consistent implementation of SunSmart policies in primary schools nationally
  - Roll out of SunSmart policies in secondary schools nationally
  - Accelerated investments in shade in public spaces, including playgrounds, pools, sporting clubs and other public areas
  - Increased training to promote personal responsibility and awareness in outdoor trades
  - Increased tools and templates for sporting clubs through the Australian Institute of Sport.

Because these actions reflect evolutions of or improvements on existing policies, the State of the Nation would call on governments to set an ambitious target for the implementation of

[45] Moehrle, M, 2008, *Outdoor sports and skin cancer*, Clin Dermatol, 26(1).
[46] del Boz, J, Fernández-Morano, T, Padilla-España, L, Aguilar-Bernier, M, Rivas-Ruiz, F, de Troya-Martín, M, 2015, *Skin cancer prevention and detection campaign at golf courses on Spain's Costa del Sol. Actas Dermosifiliogr*, 106(1).
[47] Numerous studies have confirmed that this approach and its composites are effective. See, for example: Makin, J, Shaw, K, Winzenberg, T, 2018, *Targeted programs for skin cancer prevention: An Evidence Check rapid review brokered by the Sax Institute (www.saxinstitute.org.au) for the Cancer Institute NSW*, available: https://www.cancer.nsw.gov.au/getattachment/876cc720-2e57-4b1a-8348-58634508224a/targeted-programs-for-skin-cancer-prevention.pdf. The limitations of such research are outlined in Berwick, M, Buller, DB, Cust, A, Gallagher, R, Lee, TK, Meyskens, F, Pandey, S, Thomas, NE, Veierød, MB, Ward, S, 2016, Melanoma epidemiology and prevention, Melanoma, 17-49.

these actions within a five-year horizon. Indeed, it has already set this in motion through its $20 million commitment to raising melanoma awareness.

Policy and investment priorities: Melanoma Patient and Carer perspectives The use of a multicomponent, community-wide intervention approach is supported by responses to the Melanoma Patient and Carer Survey, which indicate that there should be strong focus on 'simple' public health messaging for sun safe requirements. Respondents also indicated this should be accompanied with investment in relevant infrastructure, including signage and sunscreen dispensers aligned with the prevention and awareness campaign to reduce barriers to adoption of sun safe behaviours.

The Melanoma Patient and Carer survey also revealed that, alongside an awareness campaign, investment in infrastructure and the implementation of programs with key partners is viewed as essential to improve uptake of preventative behaviours. Ideas for investment included:

- Increased shade in public spaces, including sporting grounds and swimming pools, and in schools
- Making sunscreen dispensers available alongside hand sanitisers[48]
- Increased warning signage where risk of significant UV radiation exposure is high: at the beach, at the swimming pool, sporting groups, clubs, fields, golf courses, and at schools.

Furthermore, ideas for key partners in the delivery of training and cultural change raised by consumers and stakeholders in the Melanoma Patient and Carer survey and stakeholder consultation and consumer forums included:

- Employer groups, regulatory authorities, vocational education and training providers, and unions and building trades, making sun safe training a component of general construction induction training courses (e.g., blue cards and white cards)
- Sporting clubs
- Primary schools (to increase consistent adherence to SunSmart policies)
- Secondary schools
- Other groups that may be exposed to excess UV radiation, such as groups within the Australian Defence Force.

Stakeholder consultation indicated that collaboration should be sought where possible. For example, planting non-deciduous trees as shade could be undertaken through collaboration between environmental groups and government. However, this must not jeopardise timely shade creation.

The stakeholder consultation and consumer forums revealed the perception that encouraging training may not be enough when implemented in isolation; rather, it was perceived that adherence to standards must be audited (with data to track compliance) and standards must be enforced.

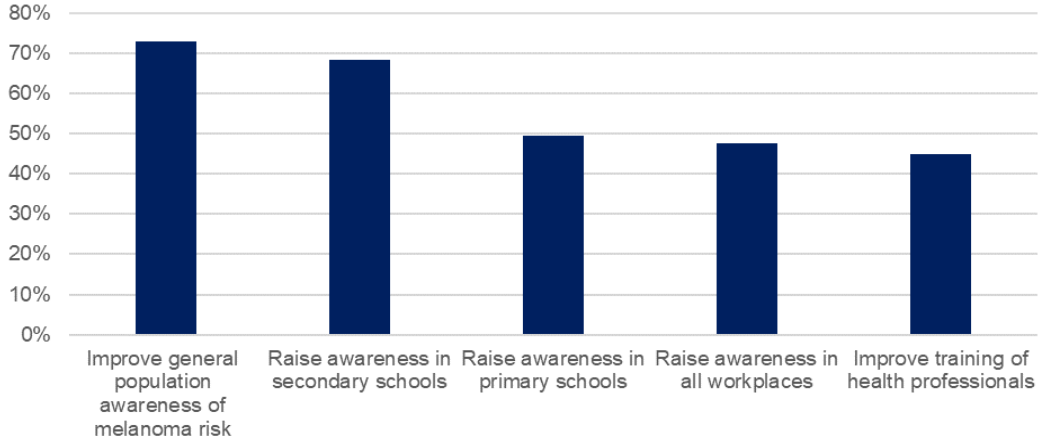
The multicomponent, community-wide intervention approach coincides with patient, carer and stakeholder perspectives regarding the major priorities for the improvement of awareness and understanding of melanoma in the community. For example, respondents to

[48] Standalone sunscreen dispensers have been trialed in numerous local governments including Coffs Harbor. This involves the development of new and for purpose infrastructure. See: ABC, 2019, *Forgot to apply sunscreen? There's a vending machine for that*, available: https://www.abc.net.au/news/2019-12-01/forgot-to-apply-sunscreen-theres-a-vending-machine-for-that/11753460.

the Melanoma Patient and Carer Survey identified the following top five areas of greatest need for improving awareness of melanoma (Figure 3.17):

- Improve general population awareness of melanoma risk
- Raise awareness of melanoma risk in secondary schools
- Raise awareness of melanoma risk in primary schools
- Raise awareness of melanoma risk in workplaces
- Improve training of health professionals to understand melanoma risk.

Figure 3.17 – Five opportunities for improvement in awareness and understanding



Source: Melanoma Patient and Carer Survey, see Appendix B. Note: Y axis measures the proportion of patients who reported the policy as a top 5 priority.

Importantly, some stakeholders emphasised the importance of balancing recommendations regarding prevention of UV radiation related damage with allowing adequate vitamin D.[49]

Other suggestions made by stakeholders include the banning of all sunbeds – not just those for commercial use.

Modern awareness and prevention campaign

The Australian Government has developed a National Preventive Health Strategy, which aims to help Australians improve their health and wellbeing at all stages of life, through:

- Early intervention
- Better information
- Targeting risk factors
- Addressing the broader factors that influence health
- Ensuring our communities, environments and systems reduce risk and enable healthier living.

The evidence described above indicates that skin cancer is a widespread Australian issue, is highly preventable and that there are numerous cost-effective preventative initiatives which can be readily implemented. Consequently, there appears to be ample justification for

[49] Reichrath J, 2006, The challenge resulting from positive and negative effects of sunlight: how much solar UV exposure is appropriate to balance between risks of vitamin D deficiency and skin cancer? Prog Biophys Mol Biol, 92(1), 9-16, doi: 10.1016/j.pbiomolbio.2006.02.010. Aitken JF, Elwood M, Baade PD, et al., 2010, Clinical whole-body skin examination reduces the incidence of thick melanomas. Int J Cancer. 2010 Jan 15;126(2):450-8. doi: 10.1002/ijc.24747. PMID: 19609948.

melanoma prevention and awareness to be include in the strategy. This is especially the case as nationwide initiatives are likely to have larger effects than local initiatives.[50]

Among the policy achievements by 2030 listed in the National Preventative Health Policy is that mass media campaigns are used to influence sun protective behaviour.[51] Indicative of the urgency of this issue, the Federal Government has commitment to invest $10 million in funding a national awareness campaign in 2022. Although the nature of the campaign is not yet clear, stakeholders were unanimous in their support for a modernised revamped Slip Slop Slap approach which takes into account the more fragmented and complex media landscape today.

In addition to leveraging social media, stakeholders emphasised that this approach must not be a 'one size fits all' approach; rather, it necessitates an understanding of the different target audiences and must be appropriately targeted at each. The campaign would be built with input from target audiences and stakeholders, and monitored and assessed over time to ensure continued relevance.

An important theme which emerged through literature review and stakeholder consultations is the importance of sustained and ongoing prevention and awareness; this is recognised in the National Preventive Health Strategy:[52]

> *…sustained and ongoing cancer prevention efforts are critical to embed and reinforce health promoting behaviours*

Therefore, it is important that near term commitments to raising awareness are replicated and supported via generational commitments in the medium and long term.

Shade in all High-risk Public Spaces

The evidence described above indicates that current approaches to developing shade across Australia are not uniform, and may be insufficient in some regions given high UV radiation risk and persistently high reported rates of sunburn.

Stakeholders emphasised that there is an opportunity to leverage learnings from the approaches of Victoria and NSW to improve shade through the adoption of a nationally-coordinated, collaborative approach focused on high-risk spaces.

To address gaps in high-risk shade requirements a national grants program, co-funded by all levels of government, should be established. The aim would be to ensure an equitable and rapid reduction in high UV exposure risk across Australia, ensuring that shade investments are not 'crowded out' by other local government infrastructure backlog demands,[53] and that the least socioeconomically advantaged areas of Australia do not see substantial delays in investment from funding limitations.

The implementation of a national approach would require preparation an inventory of high-risk shade requirements by State, leveraging work already completed to date within each jurisdiction (noting the substantial progress in identifying shade requirements in both Victoria and NSW). High risk sites would be identified through existing audits or by utilising the Cancer Council NSW's criteria for the identification of high-risk sites developed in its Guidelines to Shade (Box 3.3). In addition to UV risk, socioeconomic disadvantage metrics could also be factored in as either a criterion for prioritisation and/or to reflect the total

[50] Masters, R, Anwar, E, Collins, B, et al., 2017, *Return on investment of public health interventions: a systematic review*, J Epidemiol Community Health, 71, 827-834.
[51] Australian Government, 2021, National Preventive Health Strategy, 2021, p 60.
[52] Australian Government, 2021, National Preventive Health Strategy, p 60.
[53] For example, as reported by the NSW Office of Local Government: "Through various programs and initiatives, the Government has assisted local councils in NSW to reduce the infrastructure backlog from $7.5 billion in 2010-11 to $3.8 billion in 2018-19." See Office of Local Government NSW, 2021, Programs and Initiatives: Infrastructure Renewal, accessed at: https://www.olg.nsw.gov.au/.

amount of grant funding support available to reflect that some local councils may have a greater capacity to fund new investments than others.

Box 3.3 – Promoting high value shade

Over 10 years ago, Cancer Council NSW released its Guidelines to Shade (2011). The guidelines, which are targeted at individuals, organisations and local governments, outline a process for identifying shade needs, conducting a shade audit and planning, implementing and evaluating a shade project.

First, an inventory of sites where shade is important must be developed. This is extensive and includes all sites where outdoor activities take place over long periods of time and where the risk of sunburn is high, such as swimming pools, parks, public mall areas, early childhood centres, playgrounds, school grounds and tennis courts.

Once an inventory is developed, sites must be prioritised, with the highest risk sites scoring higher where they meet the following criteria:

1. Time of use:

- Activity at the site is likely to occur between 10am and 3pm
- The site is used over summer
- The site is used over spring and autumn

2. Duration of use:

- Activity at the site occurs for 15 minutes or more at a time

3. Level of use:

- The site is well used on weekends
- The site is well used on weekdays

4. Nature of the site and the activity:

- Users of the site are exposed to high levels of indirect radiation
- Activity at the site is likely to occur in minimal clothing (i.e., swimming pools)

The sites with the highest score should be prioritised.

Source: Cancer Council NSW, 2011, Guidelines to Shade: A practical guide for shade development in New South Wales, accessed at: https://www.cancercouncil.com.au/wp-content/uploads/2011/04/Guidelines_to_shade_WEB2.pdf

It is recommended that a target to complete this work should be established and should be ambitious, so that the current generation of young Australians can benefit. The program could be structured in such a way to fast-track applications and evaluations so that the highest risk sites could be addressed within a five-year horizon; however, the success of such an approach would depend on collaboration among stakeholders across all sectors and the ability to effectively leverage existing resources.

Stakeholders highlighted that environmental objectives, such investment in trees, should be maximised provided the first order objectives for rapidly increasing UV protection in the short term are realised.

Improve training for trades and partnerships with industry groups and regulatory authorities

OH&S legislation requires that employers protect workers by providing a safe working environment that is free of (or mitigates) risks to health or safety, which implicitly includes UV radiation. However, there is no explicit requirement.

Consequently, there is an opportunity to make implicit workplace safety requirements explicit. This change would incorporate sun safety into trainings. This coincides with a stakeholder's suggestion that:

> *We could make sun safe training part of how you get your blue card or your white card [in construction trades].*

Stakeholders also highlighted the opportunity for real people with real melanoma stories to deliver presentations to workplaces, and in doing so highlight the importance of taking appropriate sun safe behaviour. For example, one stakeholder suggested:

> *We need to work with workplaces and schools, taking real people with real stories [to these communities].*

There were mixed views on whether enforcement of sun safe policy and the development of compliance measures (use of sunscreen, hats and sun safe uniforms) should be considered for all workplaces. The emergent middle ground was that sun safety should be brought in line with and treated in a manner consistent with other OH&S issues.

Improve implementation in schools

The evidence described above indicates that there is inconsistent implementation, adherence to and enforcement of policies in primary schools and limited implementation in secondary schools. Consequently, there are numerous opportunities for improvements in the implementation of preventative measures at schools.

Some stakeholders considered an approach which requires schools to implement and enforce policy; for example:

> *Maybe we need to be a bit more authoritarian. You know, how aware are teachers? We need to put in state-wide changes and enforce them.*

> *A major opportunity for prevention is to MAKE SCHOOLS comply. No caps. No sports carnivals and swimming lessons in the middle of the day in summer. Enforce long sleeve rashies. There are policies but the schools don't follow them. These are easy changes to manifest.*

An appropriate policy to improve implementation in schools would build on the success of the SunSmart Program in primary schools to consistently implement best practice in public and secondary schools by 2025:[54]

- Guideline 1: Policy – Establish policies that reduce exposure to UV radiation (this is already achieved through SunSmart).
- Guideline 2: Environmental change – Provide and maintain physical and social environments that support sun safety and that are consistent with the development of other healthful habits (e.g., shade).
- Guideline 3: Education – Provide health education to teach students the knowledge, attitudes, and behavioural skills they need to prevent skin cancer. The education should be age-appropriate and linked to opportunities for practicing sun-safety behaviours.
- Guideline 4: Family Involvement – Involve family members in skin cancer prevention efforts.
- Guideline 5: Professional development – Include skin cancer prevention knowledge and skills in preservice and inservice education for school administrators, teachers, physical education teachers and coaches, school nurses, and others who work with students.
- Guideline 6: Health services – Complement and support skin cancer prevention education and sun-safety environments and policies with school health services.

[54] See: CDC, *Guidelines for School Programs To Prevent Skin Cancer*, available: https://www.cdc.gov/mmwr/preview/mmwrhtml/rr5104a1.htm.

- Guideline 7: Evaluation – Periodically evaluate whether schools are implementing the guidelines on policies, environmental change, education, families, professional development, and health services.

The material utilised as part of, or as an extension of this policy, includes material developed by the Cancer Council and the Cancer Institute of NSW. One supplementary initiative implemented by the Cancer Institute of NSW is summarised in Box 3.3.

Box 3.4 – Sun and UV radiation at School Challenge

In September 2020, the Cancer Institute of NSW launched the Sun and UV at School Challenge for NSW schools. The challenge encouraged K-10 students to demonstrate how to best protect themselves, their friends, and the wider community from the harmful effects of the sun.

The challenge made practical use of classroom resources provided by the Institute.

The program has received positive feedback. For example, sports coordinator and teacher at St Edward's Primary School (which had the highest school participation with 137 entries), Natasha Gippel, commented that:

> *"The Challenge was an invaluable way for my students to learn about sun safety in a very practical way. Some of the students' designs for a sun safe playground were truly incredible. We will be using our prize, 1,500 bottles of sunscreen, to help improve sun protection around the school."*

Improve sun safety in sports

As discussed above, there are numerous gaps in current policy which mean that Australians are exposed to UV radiation while participating in outdoor sport. In response to similar observations, various initiatives have been acknowledged by the literature. For example, literature indicates that:

- Those who are frequently engaged in outdoor leisure activities should be coached about efficient sun protective practices and relevant mobile technologies that may facilitate adherence[55]
- Protective means such as avoiding training and competition with considerable sun exposure, choosing adequate clothing, and applying water-resistant sunscreen need to be propagated in the community of outdoor sportsmen[56]
- Skin protection strategies, such as wearing a wide brimmed hat, long sleeved shirt and the use of sunscreen, may help to reduce the risk of skin cancer in cricketers[57]
- Surfers should regularly adopt sun protection strategies.[58]

Evidence from consultation highlights that working with sports organisations is considered a necessary step in preventing awareness. For example, patients and carers noted that:

> *We need to work with sports people. People that spend time outside, that's the target of Australia. Through sporting organisations, we had an opportunity to work top down through those organisations – that's a huge scope for prevention and awareness.*
>
> *We need to target anyone spending a lot of time outdoors: clubs, sporting, tradies, military.*

One means of promoting sun safety is to incorporate sun safety into the safe and inclusive policies for sport listed on the AIS website. Complemented by Play by the Rules' training and

[55] Snyder, A, Valdebran, M, Terrero, D, Amber, KT, Kelly, KM, 2020, *Solar Ultraviolet Exposure in Individuals Who Perform Outdoor Sport Activities*, Sports Med Open. 6(1).
[56] Moehrle, M, 2008, *Outdoor sports and skin cancer*, Clin Dermatol, 26(1).
[57] Noble-Jerks, J, Weatherby, RP, Meir, R, 2006, *Self-reported skin cancer protection strategies and location of skin cancer in retired cricketers: a case study from membership of the Emu Cricket Club*, J Sci Med Sport, 9(6).
[58] Climstein, M, Furness, J, Hing, W, Walsh, J, 2016, *Lifetime prevalence of non-melanoma and melanoma skin cancer in Australian recreational and competitive surfers*. Photodermatol Photoimmunol Photomed. 32(4), 207-13

support programs, this would likely provide increased tools and templates for sporting clubs. This would be a low cost intervention to increase awareness and take up of sun safe behaviours.

Furthermore, this could leverage work done by sporting clubs and associations such as Cricket Australia and Surf Life Saving Australia. Such an initiative would be pragmatic, which stakeholders considered to be of high importance.

Alternatively, subject to effectiveness, funding to improve and nationalise initiatives may be or merit. Such initiatives include:

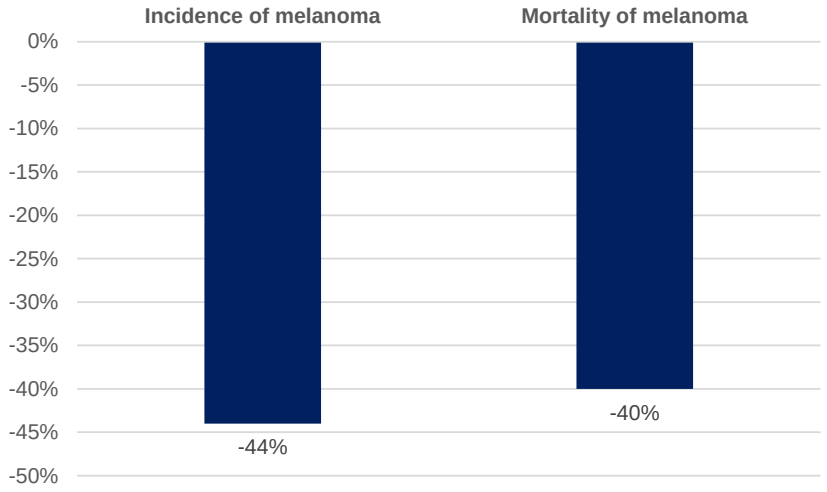
- Cancer Council NSW's 'Improve your long game'
- The provision of free sunscreen during the WACA test.

Other innovative approaches identified in the literature review, which present opportunities for investment, contingent on effectiveness, include UV radiation detection stickers which may improve use of sunscreen in adolescents during sporting events in high UV radiation environments.[59]

3.4 Impact of closing the gaps in prevention

Based on previous Australian experience, it has been estimated that investment in prevention would be expected to result in a 44 per cent reduction in the number of melanomas in people aged 30 years and older and a 39.9 per cent reduction in the number of deaths from melanoma over the next 30 years (Figure 3.18).[60] This order of magnitude reduction in the incidence of melanoma and other skin cancers (45 per cent) was similarly predicted by a European study.[61]

Figure 3.18: Prevention policy: reduction in incidence from increasing uptake of sunscreen



Source: Gordon, L, Olsen, O, Whiteman, DC, et al., 2020, Prevention versus early detection for long term control of melanoma and keratinocyte carcinomas: a cost effectiveness modelling study, BMJ Open, doi: 10.1136/mbjopen-2019-034388. Note: these incidence reductions are associated with a 100 per cent uptake of sunscreen (behavioural change). This behavioural change may arise from a mix of preventative policies.

[59] Horsham, C, Ford, H, Hacker, E, 2020, *Promoting sunscreen use in adolescents playing outdoor sports using UV detection stickers*, Prev Med Rep.
[60] Gordon, L, Olsen, O, Whiteman, DC, et al., 2020, Prevention versus early detection for long term control of melanoma and keratinocyte carcinomas: a cost effectiveness modelling study, BMJ Open, doi: 10.1136/mbjopen-2019-034388.The behavioural change modelled is a 100 per cent uptake of sunscreen use, achieved through undefined means.
[61] de Vries, E, Altsitsiadis, AE, Trakatelli, M, 2012, Potential impact of interventions resulting in reduced exposure to ultraviolet (UV) radiation (UVA and UVB) on skin cancer incidence in four -European Countries, 2010-2050, British Journal of Dermatology, doi: 10.1111/j.1365-2133.2012.11087.x

This estimate of the impact of closing the gaps in prevention is likely conservative.

Melanoma awareness and prevention strategies may also reduce the health and financial burden of other skin cancers, such as basal cell carcinoma and squamous cell carcinoma. These skin cancers are the most common cancers in humans, are associated with the highest financial burden of any cancer in Australia, at an estimated cost of more than $1.2 billion per year in healthcare costs, and result in lower quality of life.[62] Primary prevention is estimated to reduce the number of exercised keratinocyte cancers by 27.2 per cent over a 30 year period.[63]

Other costs that have not been modelled and contribute to the conservative nature of these estimates include possible future litigation costs associated with workplace health and safety deficiencies.

3.5 Conclusions: Scorecard assessment and recommended actions to improve melanoma prevention and awareness

Australia has proven itself to be a leader in skin cancer prevention, but substantial opportunities remain to improve the awareness, understanding and uptake of preventative behaviours nationally. By undertaking an array of improvements, it is possible to almost halve (44 per cent) the incidence of melanoma in our lifetimes.[64]

To that end, the following actions are recommended as part of a national strategy for prevention and awareness:

- Generational commitment to and sustained investment in a modern prevention and awareness strategy and campaign
- Accelerate investment in shade with the goal of shading all high-impact public spaces within five years through a national, dedicated funding scheme
- Improve adherence to sun safe behaviours in primary schools and uptake in secondary schools
- Treat sun safety in a manner consistent with other OH&S issues, including by requiring explicit training in sun safe behaviours for all outdoor workers
- Treat sun safety in Australian sports and other outdoor clubs in a manner consistent with other sport safety and inclusion issues, including by providing information and resources through the AIS and through partnership with Play by the Rules.

Table 3.3: Scorecard assessment and recommendations for action – Prevention and Awareness

	Rating	Australian successes	Areas for improvement	Action Plan
Prevention and Awareness	✓✓✓✓	✓ Slip Slop Slap awareness campaign in 1980s ✓ SunSmart programs in	× Rates of sunburn remain high (>60%), with sun protection behaviour uptake low (only 22% adults, 47% kids)	Modern Prevention and Awareness Campaign and Strategy

[62] Gordon, L, Olsen, O, Whiteman, DC, et al., 2020, Prevention versus early detection for long term control of melanoma and keratinocyte carcinomas: a cost effectiveness modelling study, BMJ Open, doi: 10.1136/mbjopen-2019-034388; 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. Med J Aust, 184(1):6-10

[63] Gordon, L, Olsen, O, Whiteman, DC, et al., 2020, Prevention versus early detection for long term control of melanoma and keratinocyte carcinomas: a cost effectiveness modelling study, BMJ Open, doi: 10.1136/mbjopen-2019-034388..

[64] For example, from complete uptake of sunscreen behaviour.

	Rating	Australian successes	Areas for improvement	Action Plan
		primary schools ✓ OHS workplace regulations implemented ✓ Tax incentives for sun safe equipment and clothing ✓ Initial investments in shade by local and state governments ✓ $20 million investment in prevention through the National Preventative Health Strategy	× No sustained modern era awareness and prevention campaign × Consistent adherence to policies in primary schools × Uptake of any prevention in secondary schools × Lack of explicit training and consistent adherence to policies in outdoor workplaces, especially SMEs and outdoor trades × Investment in shade is slow, de-prioritised in context of local government infrastructure backlogs × Significant incidental exposure in weekend sport, sun safety not explicitly required by club sports, AIS × Lack of implementation of supported recommendations from 2017 Inquiry to Skin Cancer	National Shade for High Risk Spaces Program Nationally consistent approach to sun safe policies in schools – primary and secondary Provide sun safe training to all outdoor workers nationally by 2025 Australian Institute of Sport Club Guidance and Best Practice Guidelines in SunSmart programs

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Chapter 4

Melanoma research in Australia: performance and next horizon opportunities

Australia's melanoma research community are world leaders in melanoma research, delivering an impressive record for research impact. This has translated into significant health gains for Australian melanoma patients, with the potential for durable long-term cures for most melanoma patients expected by 2030.

Important research questions remain, however, and Australia is uniquely positioned to contribute to high impact research breakthroughs in biology, early detection and treatment. Moreover, breakthroughs in melanoma have the potential to spill over into other areas of cancer research, particularly in the improved understanding of the underlying mechanisms of metastasis.

The realisation of high impact outcomes will rely on a nationally collaborative research effort supported by a national cancer data ecosystem and streamlined clinical trials environment, all of which require policy work and investment to fully implement.

This chapter illuminates the major successes of Australia's melanoma research community in the past 15 years, articulates the key questions remaining to be answered, the barriers to Australia seizing the opportunity to lead these areas of research and a program for high impact research in melanoma aimed at the elimination of mortality from melanoma in our lifetimes.

4.1 Australian successes in melanoma research

Australia's melanoma research community conducts high impact, globally leading research. This high impact work is manifest in:

- The melanoma community's outperformance in relative citation impact compared with Australian medical research
- An outsized share of global clinical trials research
- Significant health gains arising from research breakthroughs, translating to improved survival of Australian melanoma patients.

Australia's melanoma community are world leaders in research: citation analysis

Australian medical research is generally assumed to 'punch above its weight' in the evaluation of research impact. For example, the National Health and Medical Research Council (NHMRC) has recently estimated a contribution of 3.6 per cent to all medical journals in 2018 based on bibliometric analysis of medical research reported in its *Measuring Up* reports;[65] thus Australia's share of medical research impact is an order of

[65] National Health and Medical Research Council, 2018, Measuring Up 2018.

magnitude larger than its total population which accounts for only 0.3 per cent of the world population.

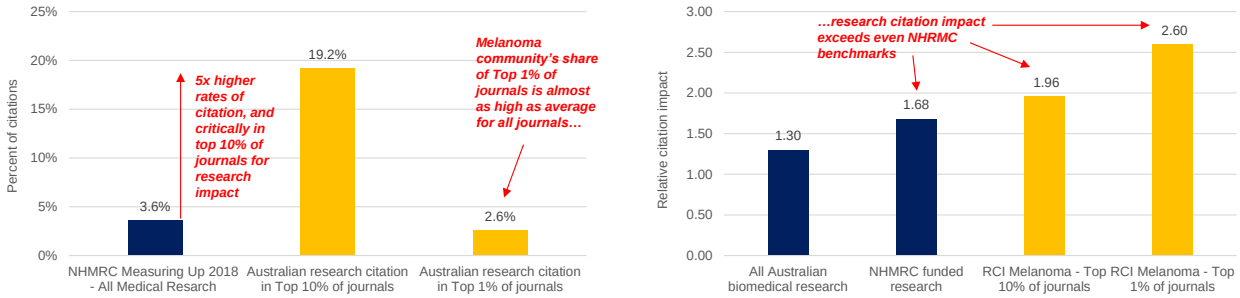
Citation analysis shows that Australia's melanoma research community outperforms even Australia's high standards for research excellence; for example, SciVal bibliometric analysis shows that Australian melanoma research accounts for:

- 19.2 per cent of citations in the *Top 10 per cent of journals*
- 2.6 per cent of citations in the *Top 1 per cent of journals*.

This compared favourably to the average across all medical research in all journals (not controlling for top-tier journals) of 3.6 per cent.

Similarly, the research community's relative citation impact (RCI) benchmarks for the Top 10 per cent and Top 1 per cent also exceed the national average for medical research, as well as highly competitive NHMRC funded research (Figure 4.1).

Figure 4.1: Citation statistic benchmarking: percentage of citations and relative citation impact metrics



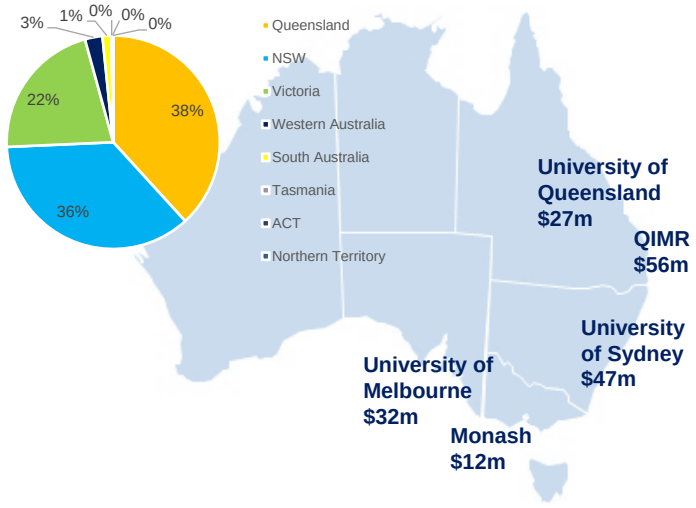
Source: National Health and Medical Research Council, 2018, *Measuring Up*, SciVal analysis of melanoma research developed by Melanoma Institute Australia.

Australia's melanoma research community is predominantly located in Australia's major population centres, with 38 per cent of NHMRC, Medical Research Future Fund (MRFF), Cancer Australia and Cancer Council research funding[66] being allocated to leading research institutes in Queensland. Within Queensland, the University of Queensland and QIMR Berghofer Medical Research Institute (QIMR Berghofer) are key research centres in melanoma research (Figure 4.2).

After Queensland, NSW accounts for a further 36 per cent of funding, with the University of Sydney being a major research node within NSW, followed by 22 per cent allocated to universities and research institutes in Victoria, with major research centres being the University of Melbourne and Monash University.

[66] Since 1999, the National Health and Medical Research Council has contributed $231 million in funding for melanoma research nationally. A further $8.2 million in research projects has been funded through the MRFF and $2.2 million through Cancer Australia to date. The Cancer Councils also provide funding; for example, Cancer Council Victoria reports expenditure of $3.2 million on melanoma research.

Figure 4.2: Funding by state and top five research institutes and universities

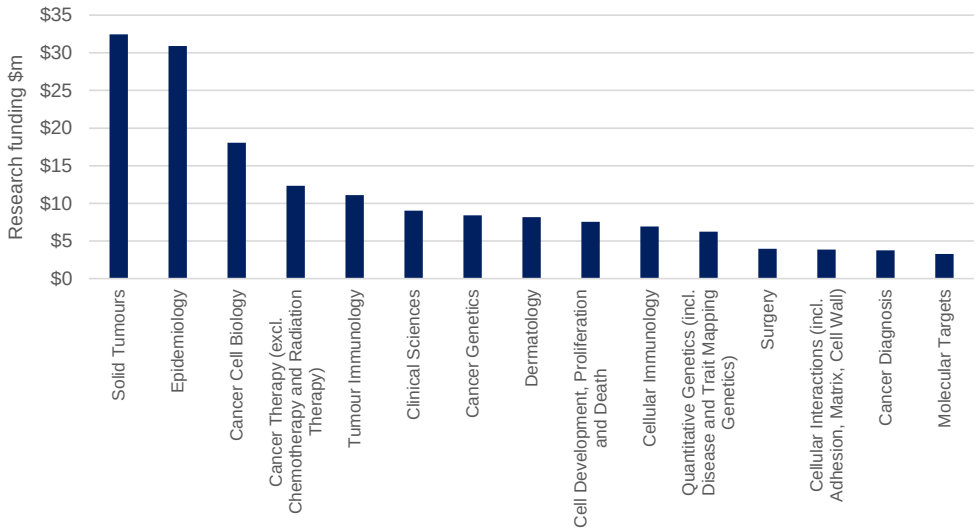


Source: National Health and Medical Research Council and Medical Research Future Fund, melanoma research 1999-2021.

Australian research excellence in melanoma has been developed across a range of fields (Figure 4.3), including in particular:

- Epidemiology
- Cancer cell biology
- Cancer therapies
- Immunology.

Figure 4.3: Funding by field of research (1999-2020)

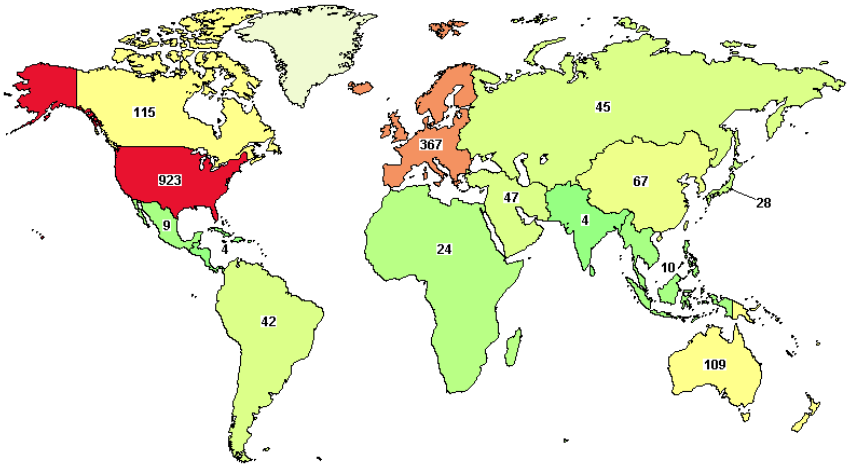


Source: National Health and Medical Research Council funding melanoma research 1999-2021.

Research excellence in clinical trials

Over the 2001-2021 period, Australia has also attracted an outsized share of global clinical trials, reflecting the quality of the research community and significant incidence of melanoma in Australia relative to other countries (Figure 4.4). This is relatively unusual given Australia's small share of the global population (0.3 per cent).

Figure 4.4: Clinical trials in melanoma (all phases of research) – 2001-2021 period



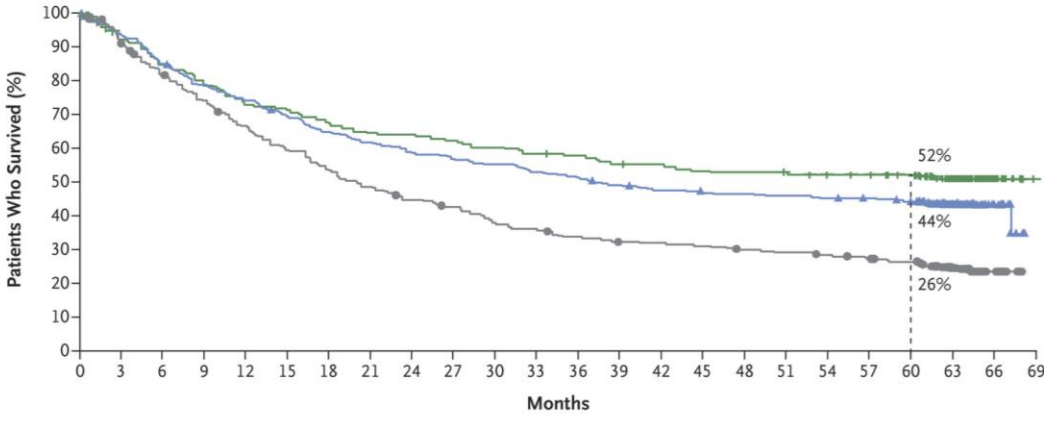
Source: Clinicaltrials.gov

Significant health gains from research

Importantly, Australia's research efforts have translated into improved survival for Australians. As outlined in Chapter 3, Australian epidemiological research and prevention programs have seen a declining incidence in melanoma among younger generations of Australians.

There have also been significant breakthroughs in the treatment of advanced melanoma, to which Australian researchers have been leading contributors.[67] For example, in 2019, five-year outcomes data from the CheckMate 067 clinical trial (CheckMate trial) showed that the use of combination immunotherapies for Stage IV patients doubled expected survival from 26 per cent to 52 per cent on average (Figure 4.5).

Figure 4.5: Impact of immunotherapy breakthroughs: CheckMate trial



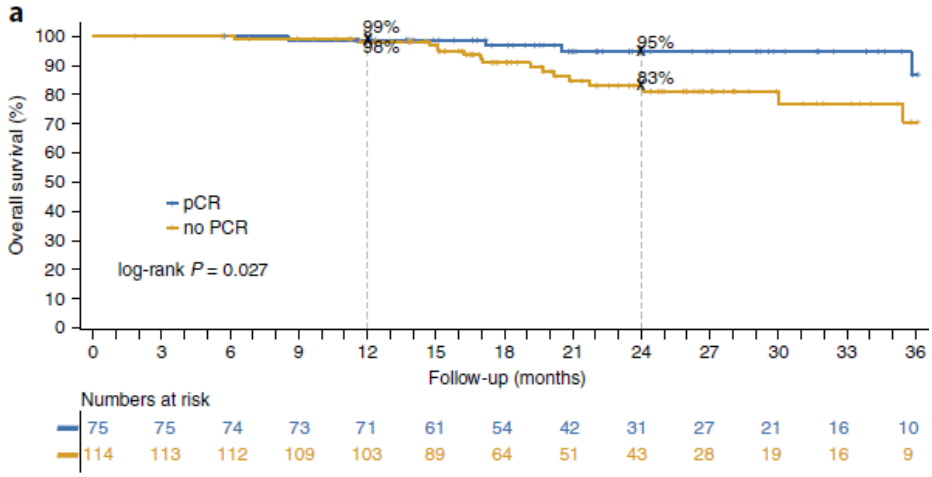
No. at Risk																							
Nivolumab plus ipilimumab	314	292	265	248	227	222	210	201	199	193	187	181	179	172	169	164	163	159	157	155	150	92	14	0
Nivolumab	316	292	266	245	231	214	201	191	181	175	171	164	158	150	145	142	141	139	137	135	130	78	14	0
Ipilimumab	315	285	253	227	203	181	163	148	135	128	113	107	100	95	94	91	87	84	81	77	73	36	12	0

Source: Larkin, J, Chiarion-Sileni, V, Gonzalez, R, et al, 2019, Five-Year Survival with Combined Nivolumab and Ipilimumab in Advanced Melanoma New England Journal of Medicine, 381, 1535-1546, doi: 10.1056/NJMoa1910836.

[67] See citations below, and, for example: Robert, C, Long, GV, Brady, B, Dutriaux, C, Maio, M, Mortier, L, Hassel, JC, Rutkowski, P, McNeil, C, Kalinka-Warzocha, E, Savage, KJ, 2015, Nivolumab in previously untreated melanoma without BRAF mutation, New England journal of medicine, 372(4), 320-330.

Other recent research breakthroughs in development include the use of systemic therapies in neoadjuvant settings for Stage III patients; early data indicates patients could see similar step change improvements in survival as realised through the use of combination therapies in Stage IV settings (Figure 4.6).

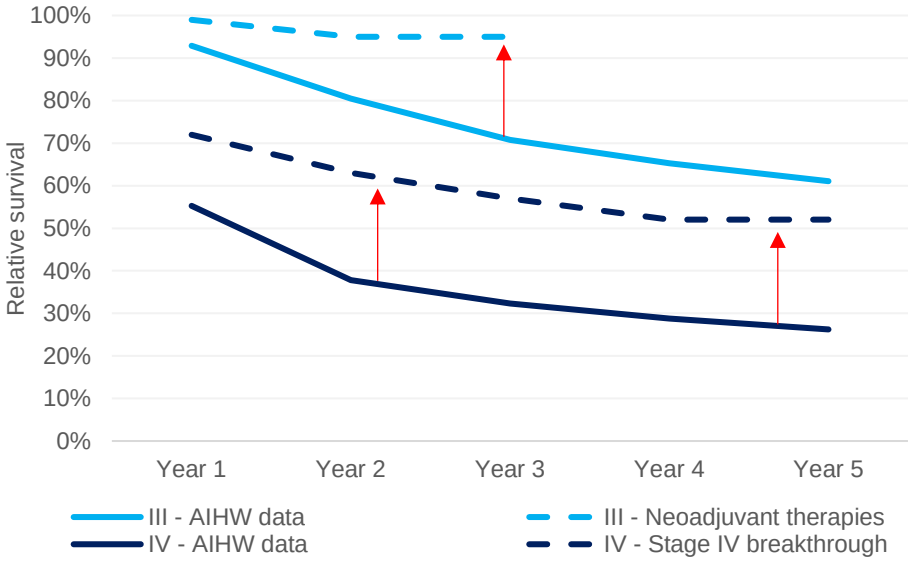
Figure 4.6: Impact of neoadjuvant therapies in Stage III



Source: Menzies, AM, Amaria, RN, Rozeman, EA, et al, 2021, Pathological response and survival with neoadjuvant therapy in melanoma: a pooled analysis from the International Neoadjuvant Melanoma Consortium (INMC), Nature Medicine, 27: 301-309, doi: 10.1038/s4591-020-01188-3.

Measured in comparison with the Australian Institute of Health and Welfare's most recent estimates of relative survival rates by stage,[68] these breakthroughs are delivering significant step changes in survival outcomes (Figure 4.7).

Figure 4.7: Impact on mortality in Australia – comparing Australian Institute of Health and Welfare survival rates for Stage III and Stage IV melanoma patients and outcomes published in CheckMate trial and International Neoadjuvant Melanoma Consortium (INMC) study



Source: Australian Institute of Health and Welfare Cancer Data in Australia 2020; Larkin, J, Chiarion-Sileni, V, Gonzalez, R, et al, 2019, Five-Year Survival with Combined Nivolumab and Ipilimumab in Advanced Melanoma New England Journal of Medicine, 381, 1535-1546, doi: 10.1056/NJMoa1910836; Menzies, AM, Amaria, RN, Rozeman, EA, et al, 2021, Pathological

[68] These data were collected for patients diagnosed in 2011; the Australian Institute of Health and Welfare estimates survival rates for the subsequent five years (until 2016). This is the only survival rate or incidence by stage data collected.

response and survival with neoadjuvant therapy in melanoma: a pooled analysis from the International Neoadjuvant Melanoma Consortium (INMC), Nature Medicine, 27, 301-309, doi: 10.1038/s4591-020-01188-3.

Similarly, success has been had in the development and support of combinational therapies in a range of settings, including for patients with metastatic melanoma with BRAF V600E or V600EK mutations,[69] adjuvant settings for Stage III patients,[70] and in instances of melanoma brain metastases.[71]

The field of melanoma research presents a paradigm for understanding cancer signaling, tumor immunology and their clinical application (Merlino, et al, 2016). Leveraging these research advancements, melanoma research is increasingly productively applied to other forms of cancers. Consequently, realised gains from research extend beyond those associated with improving the outcomes of melanoma patients.

4.2 Major research questions in melanoma and Australia's role

Looking forward, the major research questions in melanoma are focused on an improved understanding of:

- *Biology* — The biology of melanoma, including identification of biomarkers and enhanced understanding of metastasis, cell dormancy, and cell plasticity and pluripotency
- *Early detection and diagnosis* — Advanced technologies for high resolution detection of malignant versus benign melanomas, including advanced imaging (3D and 2D), artificial intelligence, opportunities to develop distributed imaging solutions to support improved detection and diagnosis, and the development of cost-effective population screening programs, focused on risk prediction algorithms based on genetic, environmental and skin type risk factors
- *Treatment and resistance* — Optimising current systemic treatment breakthroughs, understanding treatment resistance in primary melanoma, and managing toxicity following systemic treatment
- *Patient outcomes* — Developing validated Patient Reported Outcomes (PROs) for melanoma.

With a disproportionately large and diverse population of melanoma, and a reputation for high impact research built through consecutive years of success, Australia is well placed to lead the global research field in answering some of these major questions.

Melanoma biology: understanding melanomagenesis, dormancy, metastasis, plasticity and pluripotency

The last 10 to 15 years have seen significant advances in the understanding of melanoma biology.

For example, several large-scale, massive parallel sequencing studies have provided valuable insights into the genetics of melanoma. Initial whole-exome sequencing studies demonstrated that *NF1*, *ARID2*, *PPP6C*, *RAC1*, *SNX31*, *TACC1*, and *STK19* are significantly

[69] Long, GV, Stroyakovskiy, D, Gogas, H, Levchenko, E, de Braud, F, Larkin, J, Garbe, C, Jouary, T, Hauschild, A, Grob, JJ, Chiarion Sileni, V, 2014, Combined BRAF and MEK inhibition versus BRAF inhibition alone in melanoma, New England Journal of Medicine, 371(20), 1877-88.
[70] Long, GV, Hauschild, A, Santinami, M, Atkinson, V, Mandalà, M, Chiarion-Sileni, V, Larkin, J, Nyakas, M, Dutriaux, C, Haydon, A, Robert, C, 2017, Adjuvant dabrafenib plus trametinib in stage III BRAF-mutated melanoma, New England Journal of Medicine, 377(19), 1813-23.
[71] Long, GV, Atkinson, V, Lo, S, Sandhu, S, Guminski, AD, Brown, MP, Wilmott, JS, Edwards, J, Gonzalez, M, Scolyer, RA, Menzies, AM, 2018, Combination nivolumab and ipilimumab or nivolumab alone in melanoma brain metastases: a multicentre randomised phase 2 study, The Lancet Oncology, 19(5), 672-81.

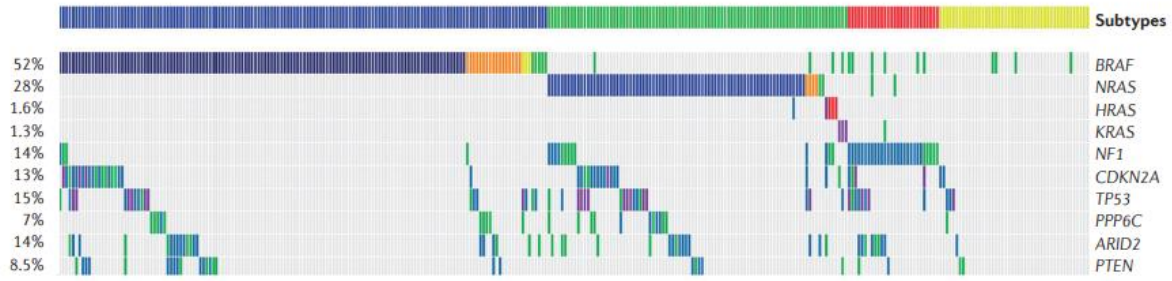
mutated genes in melanoma.[72] Subsequent to this, through work undertaken as part of The Cancer Genome Atlas, four major sub-types of cutaneous were established:

- *BRAF* mutant
- *RAS* mutant
- *NF1* mutant
- Triple Wild-Type.

Mutations in each of the identified driver genes, *BRAF*, *RAS*, and *NF1*, contribute to deregulation of the MAPK/ERK pathway, leading to uncontrolled cell growth. These three sub-types are more often associated with cutaneous melanomas, arising on sun-exposed surfaces of the body, and are distinguished by a high mutational burden, a UV mutation signature and infrequent structural rearrangements.[73] By contrast, the Triple Wild Type melanomas lack UV mutations.[74]

The most common subtype found was the *BRAF* sub-type, with 52 per cent of tumors harbouring *BRAF* somatic mutations (Figure 4.8). This was followed by the *RAS* sub-type, with a further 31 per cent of melanomas.

Figure 4.8: Frequency of genetic mutations in melanoma – four major sub-types identified



Source: The Cancer Genome Atlas Network, 2015, Genomic Classification of Cutaneous Melanoma, Cell, doi: 10.1016/j.cell.2015.05.044

Genomic sequencing of uveal melanomas was also developed in the Cancer Genome Atlas work, which revealed the number of coding mutations to be low (17 per tumour) compared with cutaneous melanoma, where hundreds of mutations are detected.[75] Moreover, no UV-induced mutational signature was identified. Recurrent coding mutations were found, which could be associated with metastatic transformation.[76] In addition to involvement in the development of the Cancer Genome Atlas, Australian researchers have been involved in subsequent studies enhancing understanding of the genomic sequencing of additional melanomas, from cutaneous, acral and mucosal sites.[77]

Studies have also identified various susceptibility loci for melanoma. For example, a meta-analysis found that of the 20 loci that reach genome wide significance for cutaneous

[72] Atkins, MB, Curiel-Lewandrowski, C, Fisher DE., Swetter, SM, et al., 2021, The State of Melanoma: Emergent Challenges and Opportunities, Clinical Cancer Research, doi: 10.1158/1078-0432.CCR-20-4092.
[73] For example, see: Akbani, R, Akdemir, KC, Aksoy, BA, Albert, M, Ally, A, Amin, SB, Arachchi, H, Arora, A, Auman, JT, Ayala, B, Baboud, J, 2015, Genomic classification of cutaneous melanoma, Cell, 161(7), 1681-96.AIHW, 2020, Cancer Data in Australia, C43, Melanoma.
[74] Atkins, MB, Curiel-Lewandrowski, C, Fisher DE., Swetter, SM, et al., 2021, The State of Melanoma: Emergent Challenges and Opportunities, Clinical Cancer Research, doi: 10.1158/1078-0432.CCR-20-4092.
[75] Royer-Bertrand, B, Torsello, M, Rimoldi., D, et al., 2016, Comprehensive Genetic Landscape of Uveal Melanoma by Whole-Genome Sequencing, American Society of Human Genetics, doi: 10.1016/j.ajhg.2016.09.008.
[76] Ibid.
[77] Hayward, NK, Wilmott, JS, Waddell, N, Johansson, PA, Field, MA, Nones, K, Patch, AM, Kakavand, H, Alexandrov, LB, Burke, H, Jakrot, V, 2017, Whole-genome landscapes of major melanoma subtypes, Nature, 545(7653), 175-180; Newell, F, Kong, Y, Wilmott, JS, Johansson, PA, Ferguson, PM, Cui, C, Li, Z, Kazakoff, SH, Burke, H, Dodds, TJ, Patch, AM, 2019, Whole-genome landscape of mucosal melanoma reveals diverse drivers and therapeutic targets, Nature communications, 10(1), 1-15.Aitken JF, Elwood M, Baade PD, et al., 2010, Clinical whole-body skin examination reduces the incidence of thick melanomas. Int J Cancer. 2010 Jan 15;126(2):450-8. doi: 10.1002/ijc.24747. PMID: 19609948.

malignant melanoma risk, five are in regions related to pigmentation, three in naevus related regions and four in regions related to telomere maintenance.[78]

Research has also shown clinical variation in presentation of melanoma can vary with geography and ethnicity.[79]

The improved understanding of distinct molecular profiles of melanoma has enabled the improved diagnosis and treatment of patients.[80] For example, the integration of major immunogenic methods across cancers analysed by the Cancer Genome Atlas and associated research has led to potential therapeutic and prognostic implications for cancer management.[81]

As researchers' understanding of melanoma biology has deepened, so too has understanding of the complexity of the cellular and molecular heterogeneity in melanoma. It is now understood that there is significant variation in melanoma cells not only between different patients, but also between lesions within the same patient, and even within the same tumour.[82]

This improved understanding of melanoma's complexity has given rise to new questions with respect to understanding the mechanisms and progression of melanoma and implications for its prevention; the complexity of cell populations of non-responders; the role of cell dormancy and the microenvironment; and the mechanisms of metastasis:[83]

- *Melanomagenesis* — Formal biological and molecular research into how melanomas actually begin is one of the most important foundations for the prevention of melanoma. It is largely accepted that for melanomagenesis, a founder mutation is required to spur uncontrolled proliferation of melanocytes; intriguingly, however, these driver mutations are also detected in normal, healthy skin.[84] This raises the question of why some cells, upon acquiring an oncogenic driver mutation, have the capacity to form melanomas, whereas others remain largely dormant.[85] Significant questions remain regarding the roles of different forms of UV light (e.g., UVB compared with UVA), gene expression, melanin (eumelanin and pheomelanin), cell signaling, DNA damage response, autophagy, and inflammation, and the effects of nutrition.[86] Resolving these questions can enable the more effective prevention of melanoma, which is currently limited compared to other cancers.

- *Cell dormancy* — In melanoma, there are many cases where patients see their disease recur after a disease-free interval, which could last a decade or more following the removal of the primary lesion. As noted by Atkins (2021), it has never been determined whether the underlying mechanisms for prolonged disease-free interval reflects the existence of dormant cells or the slow, but steady growth of a very small number of residual tumour cells. Because dormant cells may retain a degree of sensitivity to the treatment, understanding these processes is important to designing

[78] Law, MH, Bishop, DT, Lee, JE, Brossard, M, Martin, NG, Moses, EK, Song, F, Barrett, JH, Kumar, R, Easton, DF, Pharoah, PD, 2015, Genome-wide meta-analysis identifies five new susceptibility loci for cutaneous malignant melanoma, Nature genetics, 47(9), 987-95.
[79] Lee, HY, Chay, WY, Tang, MB, Chio, MT, Tan, SH, 2012, Melanoma: differences between Asian and Caucasian patients, Ann Acad Med Singap, 41(1), 17-20.
[80] The Cancer Genome Atlas Network, 2015, Genomic Classification of Cutaneous Melanoma, Cell, doi: 10.1016/j.cell.2015.05.044.
[81] Gide, TN, Quek, C, Menzies, AM, Tasker, AT, Shang, P, Holst, J, Madore, J, Lim, SY, Velickovic, R, Wongchenko, M, Yan, Y, 2019, Distinct immune cell populations define response to anti-PD-1 monotherapy and anti-PD-1/anti-CTLA-4 combined therapy, Cancer cell, 35(2), 238-55; Thorsson, V, Gibbs, DL, Brown, SD, Wolf, D, Bortone, DS, Yang, TH, Porta-Pardo, E, Gao, GF, Plaisier, CL, Eddy, JA, Ziv, E, 2019, The immune landscape of cancer, Immunity, 51(2), 411-2.
[82] Atkins, MB, Curiel-Lewandrowski, C, Fisher DE, Swetter, SM, et al., 2021, The State of Melanoma: Emergent Challenges and Opportunities, Clinical Cancer Research, doi: 10.1158/1078-0432.CCR-20-4092.
[83] The following three paragraph summaries are drawn from Atkins, MB, Curiel-Lewandrowski, C, Fisher DE, Swetter, SM, et al., 2021, The State of Melanoma: Emergent Challenges and Opportunities, Clinical Cancer Research, doi: 10.1158/1078-0432.CCR-20-4092 unless otherwise noted.
[84] Vredevoogd, DW, Peeper, DS, 2021, Enabling oncogenes, Science, 373(6559): 1088-1089, doi: 10.1126/science.abl4510.
[85] Ibid.
[86] Sample, A Yu-Ying, H, 2017, Mechanisms and prevention of UV induced melanoma, Photodermatology, Photoimmunology, and Photomedicine, doi: 10.1111/phpp.12329.

adjuvant therapy regimens and potential salvage spurs the 'awakening' of these dormant cells. The extent to which 'persister' cells may evolve with time and the role of the immune system are other important, active areas of research.

- *Metastasis* — Like many other cancers, the metastatic spread of melanoma is a major determinant of patient outcomes and the primary cause of death. In contrast to other cancers, however, melanoma metastasis frequently occurs from primary tumors that are measured in millimeters. The cellular and molecular mechanisms responsible for this phenotype are not completely understood. Because mortality among melanoma cancer victims is directly associated with the metastatic properties of the tumor, early detection and accurate diagnosis of malignant melanoma would significantly improve patient treatment and disease outcome. In particular, researchers are focused on the discovery of molecular markers associated with metastatic disease, and an improved understanding of the tumour microenvironment in tumourigenic processes.

- *Cell plasticity and pluripotency* — Melanocytes derive from a highly invasive, multi-potent embryonic cell population termed the neural crest. Neural crest cells give rise to many cell types, and the embryonic neural crest program utilises several cellular processes commonly associated with cancer metastasis, including epithelial-to-mesenchymal transition (EMT) and cell invasion. It has been found that highly plastic melanoma cell populations can switch between different cell states. Researchers are now exploring whether the high degree of plasticity and the aggressive nature of malignant melanoma may derive from the aberrant re-activation of the embryonic neural crest program, typically silenced through the process of normal melanocyte differentiation.[87] Advancing understanding of these melanoma cell populations will rely on further single cell RNA sequencing, spatial profiling, and other advanced phenotypic and functional characterisation.

There is a strong consensus within the research community that Australia is uniquely positioned to lead high impact melanomagenesis and biology research (Figure 4.9). As evident in NHMRC funding patterns, there exist Australian centres of research excellence in melanoma biology and Australia has a disproportionately large and diverse population of melanoma patients. Australia's world leading patient database, biobank, and multidisciplinary teams provide a strong (in absolute and comparative terms) foundation for the continuation of successful research.

Moreover, improving the understanding of metastasis in melanoma is likely to have significant spillover benefits to other cancers, just as checkpoint inhibitor therapy breakthroughs in melanoma are being translated into other cancers today. In particular, melanoma is an excellent model to investigate the mechanistic bases of metastasis. Roughly 90 per cent of cancer deaths are attributable to metastasis[88] and uncovering the mechanisms responsible for metastatic spread may reveal previously unappreciated vulnerabilities of cancer cells more generally. Melanoma has the advantage of being able to be detected earlier than many other solid tumours and is comparatively accessible, which supports improved understanding of tumourigenesis.

Accelerating research in melanomagenesis and biology will require investments in:[89]

- Clinical biopsies at the time of surgery to inform pre-metastatic niches, including bone marrow in addition to sentinel lymph nodes

- Development of more sensitive tools for detection of micrometastases in tissues and disseminated cells in liquid biopsies

[87] Hanniford, D, Ulloa-Morales, A, Karz, A, et al., 2020, Cancer Cell, 37, 55-70, doi: 10.1016/j.ccell.2019.12.007.
[88] Lambert, AW, Pattabiraman, DR, Weinberg, RA, 2017, Emerging Biological Principles of Metastasis, Cell, 168(4): 670-691, doi: 10.1016/j.cell.2016.11.037; Hanniford, D, Ulloa-Morales, A, Karz, A, et al., 2020, Cancer Cell, 37, 55-70, doi: 10.1016/j.ccell.2019.12.007.
[89] Based on research stakeholder feedback and Atkins, et al 2020.

- Longitudinal tissue and data collection from early melanoma survivors, including liquid biopsies that follow tumour associated material
- Development of animal models to recapitulate complex human melanoma cell development and microenvironment, including immune system effects
- Increased focus on non-cutaneous forms of melanoma.

Figure 4.9: Researcher perspectives on major research questions in biology, and Australia's opportunity to lead research globally in this area

Optimising current generation of systemic treatment breakthroughs, and understanding treatment resistance and minimisation of toxicity

The past decade has seen unprecedented breakthroughs through the development of targeted therapies and immunotherapies, the combination of regimens in the metastatic setting, and the introduction of adjuvant and neoadjuvant systemic therapies.

There was a consensus view that further clinical research is required to define the optimal usage of these therapies, as well as understand non-responders and treatment resistance (Figure 4.10). In particular: [90]

- *Systemic treatment selection* — Level 1 evidence to support optimal first line therapy for patients is needed. There are no pre-treatment biomarkers available to guide the selection of immunotherapy or targeted therapy for specific patients. Similarly, there is an unmet need for biomarkers to guide adjuvant therapy treatment selection, treatment duration and dosage/intensity.
- *Duration of systemic treatment* — Data indicate that 40 to 50 per cent of patients that discontinue systemic treatment with targeted therapies will experience disease progression within six to nine months. More information is needed to determine which and when patients can safely stop therapy.
- *Treatment resistance* — A majority of patients with *BRAF* mutations will require additional therapy due to treatment resistance. Additional research to improve the underlying mechanisms of resistance, informed by serial specimen collection, are required to inform future therapy development.
- *Therapies for other melanoma sub-types* — The second most common driver of mutation in melanoma is *NRAS*, which currently lacks a specific inhibitor therapy. While patients with an *NRAS* mutation can achieve some clinical benefits through the use of MEK and ERK inhibitors, these patients require the development of a novel inhibitor focused on the *NRAS* pathways. Similarly, while *NF1* mutant melanomas share similar pathway activations to other sub-types, there is limited evidence that MEK inhibitors are effective against the *NF1* sub-type.
- *Novel therapies* — An increasing understanding of the significant heterogeneity and high plasticity of resistant tumour cell subpopulations has revealed the development of a complete cure for some patient cohorts will depend on the development of a new class of therapies, which target yet to be discovered pathways, but could be focused on pigment cell differentiation and neural crest de-differentiation.

Delivering breakthroughs in regards to these remaining research questions will require further investment in both industry-led and investigator-led clinical trials.

[90] Atkins, MB, Curiel-Lewandrowski, C, Fisher, DE, Swetter, SM, et al., 2021, The State of Melanoma: Emergent Challenges and Opportunities, Clinical Cancer Research, doi: 10.1158/1078-0432.CCR-20-4092.

Figure 4.10: Researcher perspectives on major research questions in melanoma treatment

Develop Patient Reported Outcomes for Melanoma

Related to the concept of optimising therapies to minimise toxicity and side effects, Patient Reported Outcomes (PROs) are now recognised as an important opportunity to improve patient outcomes particularly in the context of long-term side effects from systemic treatments, but in very early stages of melanoma development.

Patient Reported Outcomes can support symptom and adverse event monitoring to enable better patient care, as well as tools to guide investment in research and regulatory decision-making. Patient Reported Outcomes are particularly important because while symptoms are common among patients receiving treatment for advanced cancers, research has found they are undetected by clinicians up to half the time.[91]

The goal would be to develop a Patient Reported Outcome model for melanoma that enables real time screening of patients and improved referrals to support services, such as referral to peer support or psychosocial support services.

As the potential benefits of Patient Reported Outcomes are becoming better understood, there has been increasing investment in systems for the collection, reporting and use of Patient Reported Outcomes, including by the NIH,[92] NCI,[93] FDA,[94] the EMEA,[95] French

[91] Pakhomov, SV, Jacobsen, SJ, Chute, CG, Roger, VL, Agreement between patient-reported symptoms and their documentation in the medical record, *Am J Manag Care*, 14(8), 530-539.
[92] Licqurish, SM, Cook, OY, Pattuage, LP, Saunders, C, Jefford, M, Koczwara, B, Johnson, CE, and Emery, JD, 2019, Tools to facilitate communication during physician‐patient consultations in cancer care: An overview of systematic reviews, *American Cancer Society*, https://doi.org/10.3322/caac.21573.
[93] National Cancer Institute, 2008, *The Nation's Investment in Cancer Research: A plan and Budget Proposal for Fiscal Year 2008*.
[94] US Food and Drug Administration, 2009, *Guidance for industry: patient reported outcome measures: use in medical product development to support labelling claims*.
[95] European Medicine Agency, 2016, *The use of patient reported outcome measures in oncology studies*.

National Cancer Institute,[96] PCORI,[97] and NORD[98] across a range of conditions. For example, the US National Institutes of Health developed the Patient-Reported Outcomes Measurement Information System (PROMIS) as a centralised electronic repository and data collection facility to support the collection of Patient Reported Outcomes across domain-specific measures of physical, mental, and social health across diseases.

Through these investments and trials to date, the benefits of Patient Reported Outcomes have been progressively demonstrated and valuable lessons in systems design have been learned. Electronic collection of Patient Reported Outcomes has been shown to be reliable, valid, and accepted by patients, including among older patient cohorts. Systematic reviews of studies have found that Patient Reported Outcomes can improve patient-clinician communication and can also increase patient satisfaction,[99] improve symptom management,[100] improve pain management, physician-patient communication, and symptom detection and control,[101] increase utilisation of supportive care,[102] and increase patient involvement in care.[103] In addition, a recent study (See Box 4.1) found the use of Patient Reported Outcomes improved survival.

Box 4.1: Understanding the clinical benefit of Patient Reported Outcomes – An ASCO study

A recent study by ASCO randomly assigned patients receiving routine outpatient chemotherapy for advanced solid tumors at Memorial Sloan Kettering Cancer Center to report 12 common symptoms via tablet computers or to receive usual care consisting of symptom monitoring at the discretion of clinicians. Those with home computers received weekly e-mail prompts to report between visits. Treating physicians received symptom print outs at visits, and nurses received e-mail alerts when participants reported severe or worsening symptoms.

The study found that among 766 patients evaluated, health related quality of life improved among more participants in the intervention group than usual care (34% v 18%) and worsened among fewer (38% v 53). Moreover, patients receiving intervention were:

- Less frequently admitted to the ER (34% v 41%; P = .02)
- Less frequently hospitalised (45% v 49%; P = .08)
- Reported a higher quality of life (34% vs 18%)
- Remained on chemotherapy longer (mean, 8.2 v 6.3 months; P=.002).

It was also found that 75 per cent of the intervention group was alive at 1 year, compared to 69 per cent of patients with usual care (P=.05).

Overall survival was assessed in a follow-up study which found that median overall survival was 31.2 months in the Patient Reported Outcome group and 26.0 months in the usual care group.

Source: Basch, E, Deal, AM, Kris, MG, Scher, HI, Hudis, CA, Sabbatini, P, Rogak, L, Bennett, AV, Dueck, AC, Atkinson, TM, Chou, JF, Dulko, D, Sit, L, Barz, A, Novotny, P, Fruscione, M, Sloan, JF, and Schrag, D, 2016, Symptom Monitoring With Patient-Reported Outcomes During Routine Cancer Treatment: A Randomized Controlled Trial', *J Clin Oncol* 34, 557-565, American Society of Clinical Oncology; Basch E, Deal AM, Dueck, AC, et al. 2017, Overall Survival Results of a Trial Assessing Patient-Reported Outcomes for Symptom Monitoring During Routine Cancer Treatment. JAMA, 318(2), 197–198. doi:10.1001/jama.2017.7156.

Taken together, evidence suggests the potential benefits from Patient Reported Outcomes can be significant, with the potential to reduce hospitalisations and ED presentations and improve adherence to therapy, as well as the development of data to inform research and

[96] The French National Cancer Institute, 2016, *Driving progress in cancer control*
[97] Patient Centred Outcomes Research Institute, funded as part of the US Patient Protection and Affordable Care Act of 2010.
[98] National Organisation for Rare Disorders, 2018, *IAMRARE Registry Program*, Summary by NORD Chairman Marshall L Summar, MD, on the need for registries in rare diseases, accessed at https://rarediseases.org/iamrare-registry-program/.
[99] Dewan, E, Hoque, AE, Rasa R, Lorgelly, P, Sampurno, F, Evans, M, Evans SM, 2019, A randomised controlled trial comparing completeness of responses of three methods of collecting patient-reported outcome measures in men diagnosed with prostate cancer, *Quality of Life Research*, 28, 687–694 https://doi.org/10.1007/s11136-018-2061-7.
[100] Basch, E, Deal, AM, Dueck, AC, et al., 2017, Overall Survival Results of a Trial Assessing Patient-Reported Outcomes for Symptom Monitoring During Routine Cancer Treatment, *JAMA,* 318(2), 197–198, doi:10.1001/jama.2017.7156.
[101] Licqurish, SM, Cook, OY, Pattuage, LP, Saunders, C, Jefford, M, Koczwara, B, Johnson, CE, and Emery, JD, 2019, Tools to facilitate communication during physician‐patient consultations in cancer care: An overview of systematic reviews, American Cancer Society, https://doi.org/10.3322/caac.21573.
[102] *Ibid.*
[103] *Ibid; Consumers Health Forum of Australia, 2020, Media release: Healthy trio performs best when together.*

regulatory decision-making. At the same time, evidence also shows outcomes are highly dependent on system design and implementation.

While initial work has been completed to support the development of Patient Reported Outcomes in melanoma,[104] further work needs to be done as part of an equitable, national approach to the development of Patient Reported Outcomes to improve cancer care (Figure 4.11). This should be supported through a research program (to develop and validate melanoma specific Patient Reported Outcomes) and implemented as part of a national Patient Reported Outcome strategy by the National Cancer Plan.

Figure 4.11: Stakeholder perspectives on Patient Reported Outcomes progress and opportunities

Research on the use of real time Patient Reported Outcomes for Australian melanoma patients will provide learnings that can be leveraged across other cancer and disease areas.

Advanced technologies and models of care for detection of melanoma

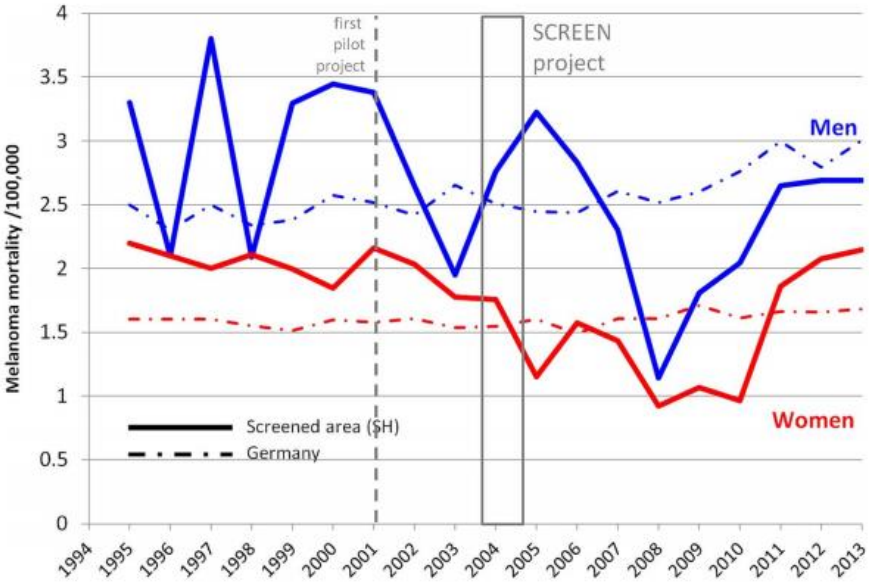
Improved long run survival and complete cure rates in melanoma are associated with the detection of melanoma in its earliest stages.

With the exception of Germany, which has implemented a bi-annual skin cancer screening program for persons aged 35 and older, no national or international authorities currently recommend population-based screening for melanoma.[105]

The background for Germany's current research and policy landscape is that, over the 2003-2004 period, it funded a trial to investigate the potential benefits of a population screening approach for skin cancer called the Skin Cancer Research to Provide Evidence for Effectiveness of Screening in Northern Germany (SCREEN) study. The original study reported a relative 48 per cent reduction in melanoma mortality resulting from a program of a one-time clinical visual skin cancer screening combined with a disease awareness campaign. As shown in Figure 4.12, a significant reduction in mortality was observed over the 2005-2008 period for both men and women, in sharp contrast to mortality rates across wider Germany.

[104] Blood, Z, Tran, A, Caleo, L, et al., 2021, Implementation of patient reported outcomes measures and patient reported experience measures in melanoma clinical quality registries: a systematic review, BMJ Open, doi: 10.1136/bmjopen-2020-040751.
[105] International Agency for Research on Cancer, World Health Organisation, 2020, World Cancer Report

Figure 4.12: Mortality outcomes following population screening trials and national population screening programs across Germany



Source: Boniol, M, Autier, P, Gandini S, 2015, Melanoma mortality following skin cancer screening in Germany, BMJ Open, 5:e008158, doi: 10.1136/bmjopen-2015-008158.

As a result of these initial findings, a national population screening program was introduced across Germany in 2008. Simulation studies foresaw that biennial screening of the German population aged 35-85 years assuming a 20 per cent participation rate would reduce melanoma mortality by 45 per cent over 20 years.[106] Mortality results across Germany were followed up through 2013, however, it was found that the observed declines in melanoma mortality rates for men and women in the region that had participated in the SCREEN study were transient and had not persisted with time (Figure 4.12).[107]

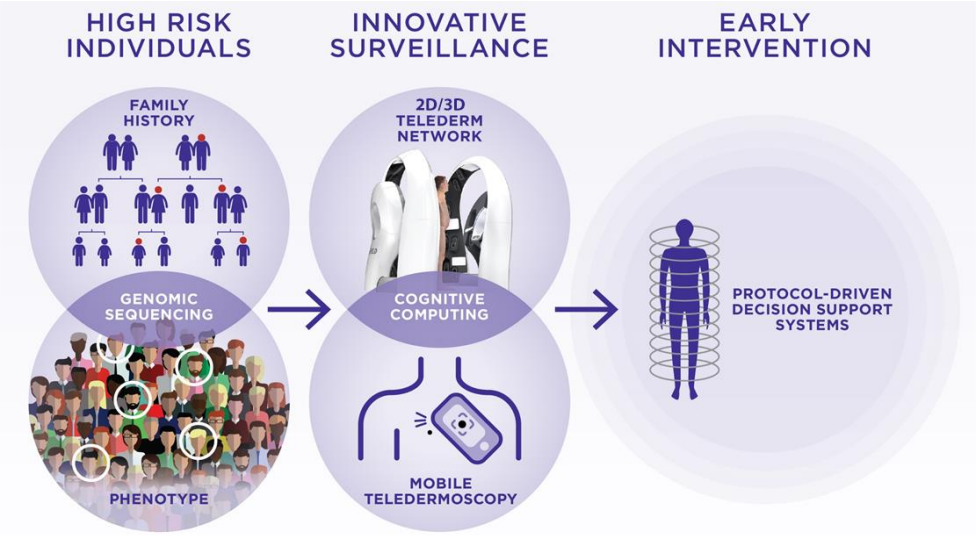
On balance it has been assessed that further research is required to determine the most effective approach to screening for melanoma. In the United States, for example, the US Preventive Services Task Force determined that there was 'insufficient' evidence that population screening reduces melanoma mortality.[108] These findings have been echoed by research here in Australia[109] and are reflected in Australia's Clinical Practice Guidelines for Melanoma.

Importantly, these recommendations do not say that some form of screening program would not be beneficial – rather, they say that there is insufficient evidence. The challenge is to best identify the cohorts that would benefit from a screening program.

Against this background the research focus within the field of early detection has shifted towards opportunities to utilize risk prediction algorithms coupled with novel approaches to surveillance technologies to support early detection (Figure 4.13).

[106] Boniol, M, Autier, P, Gandini, S, 2015, Melanoma mortality following skin cancer screening in Germany. BMJ Open, 5:e008158; and Eisemann, N, Waldmann, A, Garbe, C, et al., 2015, Development of a microsimulation of melanoma mortality for evaluating the effectiveness of population-based skin cancer screening. Med Decis Making, 35:243–54.
[107] Boniol, M, Autier, P, Gandini, S, 2015, Melanoma mortality following skin cancer screening in Germany, BMJ Open, 5:e008158
[108] US Preventative Services Taskforce, 2016, Screening for Skin Cancer US Preventive Services Task Force Recommendation Statement, JAMA, 316(4), 429-435, doi: 10.1001/jama.2016.8465.
[109] Janda, M, Cust, A, Neale, RE, et al., 2020, Early detection of melanoma: a consensus report from the Australian Skin and Skin Cancer Research Centre Melanoma Screening Summit, Early detection of melanoma: a consensus report, Australian and New Zealand Journal of Public Health, 44(2), 111-115.

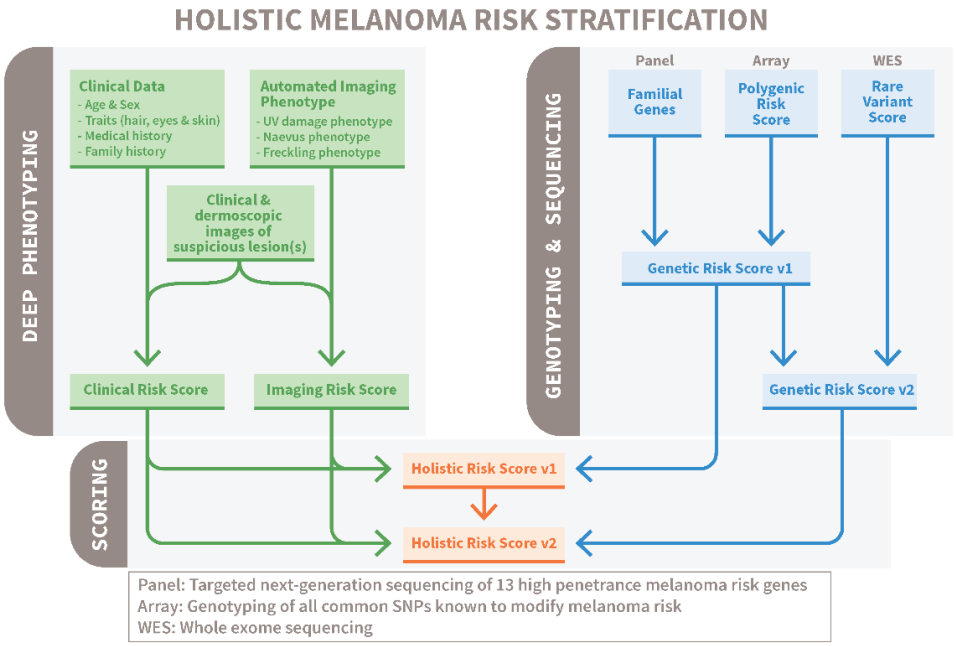
Figure 4.13: Research to support novel approaches to early detection



Source: Soyer, HP, 2021, Precision Prevention of Melanoma, University of Queensland.

Risk algorithms are in development to more precisely determine risk cohorts, based on a range of demographic, phenotypic, and clinical factors (Figure 4.14).

Figure 4.14: Research to support novel approaches to early detection



Source: Soyer, HP, 2021, Precision Prevention of Melanoma, University of Queensland.

In addition to improved risk algorithms, new technologies, such as full body imaging and Artificial Intelligence (AI) or augmented intelligence are also expanding potential health system capabilities for early detection and diagnosis.[110] Image-based surveillance has the potential to improve visual diagnostic accuracy and the improved early detection of melanoma and digital follow-up with serial imaging has been shown to be effective in the advanced surveillance of high risk populations.

[110] See, for example: Mar, VJ, Soyer, HP, 2018, Artificial intelligence for melanoma diagnosis: how can we deliver on the promise? Annals of Oncology, 29(8), 1625-1628.

Research is focused on the most effective models, such as the use of 2D or 3D advanced imaging systems coupled with advanced computing capabilities, but as stakeholders noted, further work is needed to fully develop recommendations for increased use of advanced imaging and AI technologies (Figure 4.15).

Figure 4.15: Stakeholder perspectives on opportunities in imaging and AI

Acknowledged as leading this research effort globally,[111] the Australian Cancer Research Foundation (ACRF) funded Australian Centre of Excellence in Melanoma Imaging & Diagnosis has just commenced a major clinical study to compare routine clinical care with an intensive skin surveillance program consisting of 3D total body photography, sequential digital dermoscopy, and melanoma risk stratification (Box 4.2).

Box 4.2: Australian Centres of Excellence focused on early detection and diagnosis

Australian Centre of Excellence in Melanoma Imaging & Diagnosis (ACEMID) Cohort Study

ACEMID aims to develop more efficient and effective screening for the early detection of melanoma through the provision of an innovative 3D total body photography system.

Participants will be asked to participate in 3D total body photography every six, 12 or 24 months for the three year study duration based on their melanoma risk. To be eligible to participate participants must be 18 years of age or older and have a regular medical practitioner. There will be 15 ACEMID sites located in Queensland, New South Wales and Victoria.

IMAGE: Melanoma Surveillance Photography to improve early detection of melanoma in very high-risk (or high-risk) patients

The IMAGE trial aims to assess whether using melanoma surveillance with baseline total body photography (with tagged dermoscopic images), results in improved diagnostic accuracy and earlier detection of melanoma compared to clinical surveillance without baseline photography as an aid. It will also investigate whether using Melanoma Surveillance Photography significantly reduces the number of unnecessary biopsies in high-risk individuals.

Study participants are randomised to either a control or intervention arm. Participants randomised to the intervention arm will attend a research clinic and receive baseline total body imaging with dermoscopy. These images will then be used as a baseline to compare future routine surveillance visits. Participant image files will be uploaded on to a secure USB, for participants to then review their images with their regular treating doctor or Dermatologist, where they will conduct a skin check using the images on file.

[111] Atkins, MB, Curiel-Lewandrowski, C, Fisher DE, Swetter, SM, et al., 2021, The State of Melanoma: Emergent Challenges and Opportunities, Clinical Cancer Research, doi: 10.1158/1078-0432.CCR-20-4092.

Source: Australian Centre of Excellence in Melanoma Imaging & Diagnosis. Both of these trials can be found at: https://acemid.centre.uq.edu.au/research/clinical-trials.

Research is also focused on emerging opportunities to explore distributed imaging technology approaches to improve the frequency and thereby resolution of imaging lesions. These distributed technologies, using smartphones and apps, are in very preliminary stages of development.

Figure 4.16: Stakeholder perspectives on the potential and challenges of distributed imaging technologies

Alongside the development of advanced risk algorithms and innovative surveillance technologies, research is also required to develop new models of care for the delivery of cost-effective screening programs. High Risk Clinics has been shown to be cost-effective for at-risk cohorts (Box 4.3), but stakeholders also noted that new models of care are needed to target cohorts that may face a range of health literacy, income and other barriers to accessing services, leading to significant variation in mortality (Figure 4.17).

Box 4.3: High Risk Clinics for Skin Surveillance

A prospective cohort study by Melanoma Institute Australia and University of Sydney has demonstrated that it is feasible for a structured surveillance program for high risk patients to be implemented on a large scale in numerous settings, including dermatology clinics and primary care skin cancer clinics.

The study recruited 593 patients across 2012 to 2018 with a high-risk of melanoma across four sites: the Sydney Diagnostic Centre at the Royal Prince Alfred Hospital, the Newcastle Skin Check, Melanoma Institute Australia and Westmead Hospital.

Patients were offered whole-body examinations every six months using dermoscopy, total body photography and sequential digital dermoscopy imaging. The researchers found that two-thirds of new melanomas were detected with the help of total body photography and digital dermoscopy monitoring.

The study demonstrated that the protocol devised by the researchers can be undertaken beyond a melanoma specialist centre. It also indicated that the protocol can be effectively rolled out in dermatology clinics and primary care skin cancer clinics as diagnostic tools, and that structured surveillance protocols were more important than clinical specialty.

Previous analysis of the High Risk Clinic model at these four sites has also shown that the model is cost-effective compared with routine care and has the potential to deliver cost savings of between $20 million and $34 million over a five-year period.

The mean saving was A$6,828 (95% CI, $5,564 to $8,092) per patient, and the mean quality-adjusted life-year gain was 0.31 (95% CI, 0.27 to 0.35).

Taken together, this provides the basis for the wider roll out of High Risk Clinic models of care nationally in both dermatology clinics and in primary care settings.

Source: Melanoma Institute Australia, Guitera, P, Menzies, SW, Coates, E, Azzi, A, Fernandez-Penas, P, Lilleyman, A, Badcock, C, Schmid, H, Watts, CG, Collgros, H, Liu, R, van Kemenade, C, Mann, GJ, Cust, AE, 2021, Efficiency of Detecting New Primary Melanoma Among Individuals Treated in a High Risk Clinic for Skin Surveillance, JAMA Dermatol; Watts, CG, Wortley, S, Norris, S, et al., 2018, A National Budget Impact Analysis of a Specialised Surveillance Program for Individuals at Very High-risk of Melanoma in Australia, Applied Health Economic Health Policy, 16, 235-242, doi: 10.1007/s40258-017-0368-0.

Figure 4.17: Need to develop new models of care that target disadvantaged, regional areas

Stakeholders were optimistic about the role of developing technologies (e.g., AI) in enabling improved models of care and a targeted screening program to identify high-risk cohorts. Emphasis was placed on finding the right context for the use of new technologies, identifying areas where they are complementary and do not pose potential hazards. For example, a context in which distributed imaging technology may be beneficial is to enable patient-led surveillance in between appointments. In addition, mobile applications may allow timely reminders for self-checks for high-risk cohorts, as well as risk cohort stratification.

Given Australia's position and the remaining research questions to be answered, future research opportunities in early detection include:

- Randomised controlled trial (RCT) for the expansion of High Risk Clinics, building on the outcomes of the NSW High Risk Clinic approach
- RCT for a screening program of high-risk cohorts, building on the work of initial ACEMID trials
- Research to develop new models of care for screening and service delivery to high-risk cohorts based on genetic and socioeconomic factors that may impede timely access to health services
- Expanding investment in the development of teledermoscopy models of care.

This would be supported by the development of a roadmap for a National Targeted Melanoma Screening Program, with the goal of establishing a program that is *equitable in its reach, trustworthy for patients and clinicians and cost-effective for the community and the healthcare system*.

The development of a screening and surveillance program for high-risk cohorts is consistent with recommendations made by the Standing Committee on Screenings (Box 4.4).

Box 4.4: Recommendation for GP surveillance programs

The Standing Committee on Screening recommended that general practitioners:

- develop surveillance programs for patients at high-risk
- assess patients who are concerned and develop appropriate management programs depending on their level of risk and
- who identify risk factors for skin cancer in patients presenting for other reasons to educate patients about sun protection measures and offer them an opportunity for a full body examination and an appropriate management plan.

Subsequently, in an article published in the Australian Journal of General Practice, Arasu et al (2019) stratified people into high-risk (Fitzpatrick skin type I–II, red hair, family history of melanoma, personal history of skin cancer, genetic syndromes; immunosuppression [renal transplant], >100 naevi, >20 solar keratoses), increased risk, and average-to-low risk cohorts. High-risk cohorts are encouraged to undertake 3-4 month self-checks, with 6-12 monthly skin checks with a doctor.

This reflects a development of the risk cohorts described in the most recent edition of RACGP's guidelines for preventative activities in general practice (9th edition).

Source: Standing Committee on Screening, 2019, Screening and early detection of skin cancer: Statement; Arasu, A, Meah, N, Sinclair, R, 2019, Skin checks in primary care, Australian Journal of General Practice, 48(9), doi: 10.31128/AJGP-03-19-4887; RACGP, 2016 (updated 2019), Guidelines for preventative activities in general practice, 9th edition.

4.3 Barriers to realising research impact

Looking forward, the major barriers to realising melanoma research impact include:

- Lack of funding mechanisms to foster high impact, nationally collaborative research approaches
- Lack of core population and clinical datasets to inform research
- Persistent inefficiencies and costs in ethics and governance processes governing clinical trials research leading to long time delays and cost.

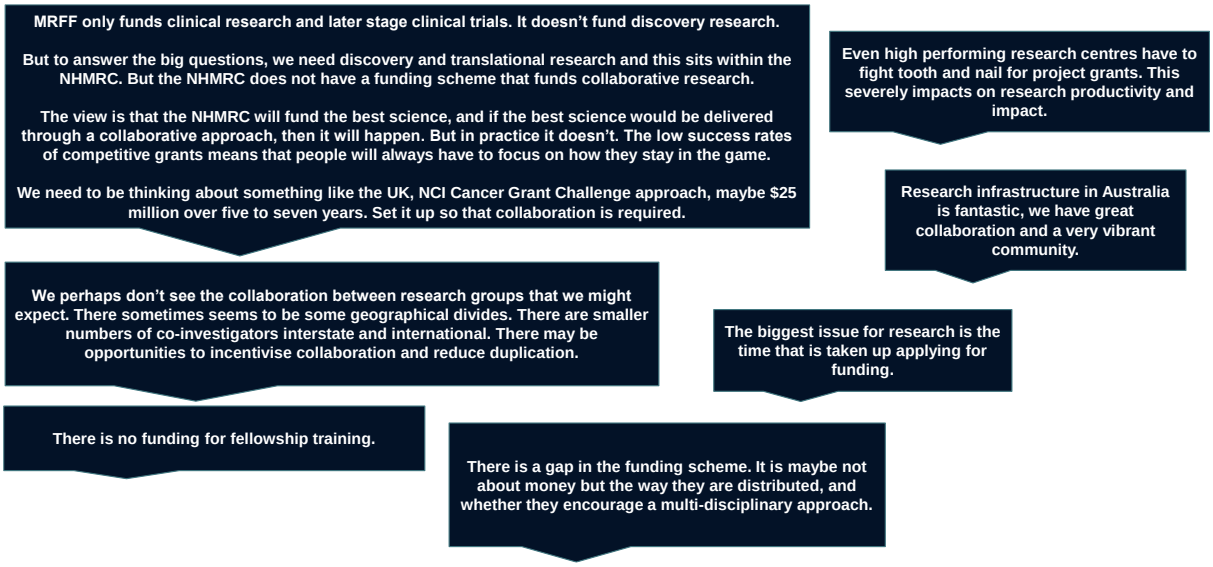
Lack of funding mechanisms to foster high impact, nationally collaborative research approaches

Notwithstanding significant goodwill and research collaboration across the sector, stakeholders consistently indicated funding structures do not incentivise the nationally-collaborative approach needed to deliver breakthroughs in the biology domain in particular (Figure 4.14).

While MRFF Research Missions can provide significant, multi-year programs of high impact research, MRFF is aimed at late-stage clinical research; the needed discovery research is funded in the main by the NHMRC and current competitive grant processes do not in practice foster the large-scale collaboration identified by multiple stakeholders. To support the large-scale program that would deliver the significant step change in impact, a Cancer Grant Challenge approach, similar to the approach adopted by the NCI and the UK, could be funded by either the NHMRC or by Cancer Australia, to the extent that either expands its current research remit as part of a National Cancer Plan, or through an expansion in the remit of the MRFF Research Missions.

Researchers also noted funding structures diverted high impact teams away from research towards continual grants processes; a multi-year program supporting proven teams was seen as important enabling infrastructure for maximising research output.

Figure 4.18: Researcher and policy stakeholder perspectives on funding challenges



Fragmented cancer data sets impede research impact

The availability of data and complex analytical tools to support accelerated research is necessary to realise breakthroughs in cancer research. This has been true since the advent of the modern cancer research era in the 1970s, but has become even more urgent in the era of precision medicine, with ever larger datasets enabling improved understanding of patient and tumour heterogeneity, which in turn enables breakthroughs in therapies.

The accelerated research of cure for melanoma, and other cancers, depends fundamentally on the ability of researchers, clinicians, and patients to collaborate in sharing their collective data and knowledge.

While there have been some efforts to support the development of improved cancer datasets in Australia, Australia continues to lack the clinical and population data sets necessary to improve research outcomes. In particular:

- State Cancer registries are at staggeringly varied states of maturity
- Natural history and clinical data are captured but siloed in a fragmented health care system
- Public healthcare providers are limited in their capacity to innovate by international software vendors that decline to modify clinical software except in only very select circumstances and at often exorbitant prices

- Clinical quality registries are few and far between, oftentimes with limited scope due to funding limitations.

While work on linking cancer datasets has been purported to be in development by Federal Agencies, and Cancer Australia supported the development of a cancer data strategy in 2008, relatively little progress has been made towards the development of national infrastructure capability.

Figure 4.19: Researcher perspectives on cancer data barriers

This stands in stark contrast to the US, where the National Cancer Institute has committed to the development of a National Cancer Data Ecosystem as part of the Cancer Moonshot Initiative (Box 4.3).

Box 4.5: The National Cancer Institute National Cancer Data Ecosystem

NCI is developing a National Cancer Data Ecosystem to enable and encourage all participants across the cancer research and care continuum to share, access, combine, and analyse diverse data, increasing the potential for new discoveries and reducing burden of cancer.

The Cancer Data Ecosystem will be supported by a cloud-based infrastructure and will feature interactive portals that give users access to these data and allow for in-depth data analysis. This infrastructure will enable researchers, patients, and clinicians to incorporate their own data, fostering collaboration and advancing discoveries that improve our understanding of the mechanisms driving cancer – ultimately leading to more informed treatment choices and better patient outcomes.

The National Cancer Data Ecosystem is underpinned by the NCI Cancer Research Data Commons, which is a virtual data science infrastructure that connects cancer research data collections with analytical tools and can be used to store, analyse, share, and visualise cancer research data. The Cancer Research Data Commons includes:

- The NCI Genomic Data Commons, which is a resource for sharing genomic and clinical data to create a more complete understanding of genetic drivers of cancer
- The Proteomic Data Commons, which is a resource for sharing and analysing proteomic data. The PDC is populated with data from the Clinical Proteomic Tumor Analysis Consortium program and will grow to include other data sources over time
- The Imaging Data Commons, which will be a resource for sharing and analysing multi-modal imaging data from clinical and basic cancer research studies. The IDC will build on Google-provided tools such as BigQuery and the Google Healthcare API.

NCI Cloud Resources infrastructure capabilities will allow researchers to access and analyse large-scale genomic, proteomic, and imaging data in the cloud using a variety of analytic tools and pipelines, without the need to download data to their local computer. The Cloud Resources provide researchers with secure workspaces, where they can store the results of their analyses, and optionally share them with other scientists, to foster greater collaboration and new discoveries.

Ultimately, NCI's CRDC infrastructure and related resources will allow researchers, clinicians, and patients to share important data and resources to advance cancer research.

The Enhanced Data Sharing Working Group has recommended the development of this ecosystem within 1-5 years.

Source: Cancer Australia website, available: https://www.cancer.gov/research/key-initiatives/moonshot-cancer-initiative/implementation/data-ecosystem; https://datascience.cancer.gov/data-commons/cloud-resources; and Enhanced Data Sharing Working Group Recommendation: The Cancer Data Ecosystem, pp 6674.

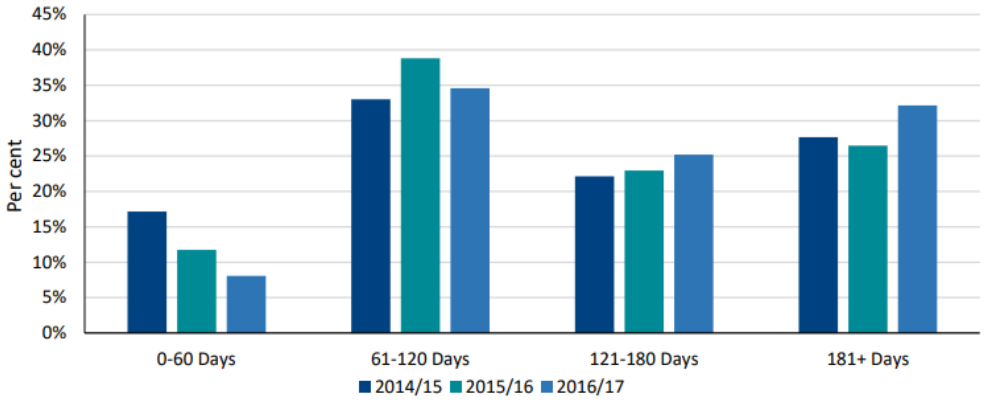
Regulatory inefficiencies in clinical trials ethics and governance processes and other access barriers

Clinical trials benefit patients, advance medical knowledge and are estimated to be worth around $1 billion to the Australian economy each year. However, the regulatory environment for the conduct of clinical trials in Australia is complex, with state and local health networks having duplicated and differing governance, and ethics requirements occurring across multiple jurisdictions.[112]

Clinical trial reforms in Australia have been identified as an impediment to Australia's competitiveness as a destination for clinical trials for the better part of 20 years. While efforts have been made to strengthen clinical trials in Australia, including the development of a National Clinical Trials Governance Framework, the development of a framework for collection of national aggregate statistics on clinical trials, and the harmonisation of ethics approvals processes, timelines for clinical trials start times remain stubbornly long.

For example, while 'time to first patient recruited' is the global benchmark for clinical trial approval times, these data are still not available in Australia even with the introduction of National Aggregate Statistics in 2015.[113] Instead, the closest metric available six years into the data collection process is 'overall study start up' time, and the latest data for this metric indicated that more than one in three trials had an overall study start up time of more than 181 days (Figure 4.16).

Figure 4.20: Overall study start times for clinical trials in Australia (latest data)



Source: Clinical Trials Project Reference Group, 2018, Clinical Trials in Australian Public Health Institutions 2016-17 (NAS 3 report) A comparison over 3 years from 2014 to 2017 Framework for National Aggregate Statistics (NAS) - Third Activity Report, (CTPRG), p 17

As other neighbouring jurisdictions see the quality of their research infrastructure and healthcare systems improve, Australia's historical advantages may be progressively eroded. Australia's clinical trial industry is facing competition from more populous regions in

[112] Clinical Trials Project Reference Group, 2018, Clinical Trials in Australian Public Health Institutions 2016-17 (NAS 3 report) A comparison over 3 years from 2014 to 2017 Framework for National Aggregate Statistics (NAS) - Third Activity Report, (CTPRG).
[113] Ibid.

Europe, South America and Asia that are looking to expand their clinical trials footprint, offering access to large patient populations.[114]

In addition, reform to enable eligibility for clinical trials for patients requiring government assistance with travel, through Patient Transport Schemes/Patient Transport and Accommodation Schemes are an important aspect of ensuring equitable access to clinical trials regardless of means. Some stakeholders also suggested potential bias against including regional / remote participants in clinical trials.

Figure 4.21: Stakeholder perspectives on clinical trial challenges

On balance, notwithstanding the efforts of Australian governments and agencies in recent years, there is broad consensus that objectives of reform work have not been met and reduce Australia's ability to attract clinical trials.[115]

In addition to inefficiencies in ethics and governance, geographic and financial barriers often disadvantage regional and remote patients and patients from socio-disadvantaged backgrounds. For example, in Australia today, each state and territory operates its own patient assisted transport scheme which provides limited and variable funding for regional patients to access treatment, but critically it must be the current 'standard of care'. Consequently, patients participating in clinical trials may become ineligible for this funding if the trial is not assessed to be the standard of care.

Addressing inequities and limitations in these schemes, particularly in relation to clinical trials, was recommended by the Senate Standing Committee on Community Affairs' 2007 *Highway to health: better access for rural, regional and remote patients* inquiry. In particular Recommendations 11 and 12 were squarely focused on expanding access to clinical trials; these reforms have not been implemented.

Addressing these inequities in the short term is an important priority alongside reforms to streamline ethics and governance processes to bring Australia in line with international best practice.

[114] MTP Connect, 2020, Medical Technology, Biotechnology & Pharmaceutical Sector Competitiveness Plan.
[115] *Ibid.*

4.4 Return on investment in melanoma research

Extensive academic research has shown that medical research generally, and cancer research specifically, delivers significant improvements in both health and economic prosperity. Investment in cancer research directly produces:

- *Health gains*, in the form of improved survival and improvements in quality of life
- *Investment effects*, in the form of leveraging investment and activity into an economy that would not have otherwise occurred
- *Jobs creation*, including in particular highly skilled jobs
- *Productivity spillovers,* arising from the spillover of knowledge from disease area into the treatment of other cancers and chronic health conditions through open, networked research communities.

These direct effects then have wider multiplier effects throughout the economy, often leading to a significant return on investment.

For example, a 2012 RAND study commissioned by Cancer Research UK found that public and charitable investments in cancer research generated a 40 per cent per annum return for every dollar invested in perpetuity,[116] while a 2008 study by the Cancer Institute of NSW of the returns on cancer research in Australia similarly found a return of $2.34 in health gains alone (ignoring other investment or spillover effects) for every dollar expended on cancer research.[117]

Wider studies of the benefits of medical research have similarly identified significant returns on investment from medical research, including a recent 2017 study by the Australian Commission on Safety and Quality in Health Care found that Australian investigator-led clinical trials delivered a return of $5.80 for every dollar invested[118] and a study for the Association of Australian Medical Research Institute (AAMRI) in 2018 that estimated a return of $3.90 for every dollar invested in medical research,[119] of which $2.60 is estimated to be derived on average from heath gains and $1.30 is estimated to be derived from productivity spillovers.

Given the significant improvements in survival delivered by melanoma research globally, and the Australian melanoma community's outsized contribution to this impact, with SciVal bibliometric analysis showing Australian melanoma research accounts for five times as many citations in the top 10 per cent of journals than the Australian average for all medical research, it would be expected that the returns on investment would be at the upper range of return on investment in research. The benefits from melanoma research would increase further due to spillover effects on other solid tumour research. For example, recent advances in the treatment of melanoma with novel immunotherapies are now being applied to a range of other cancers, including lung, gastric, liver, kidney, Hodgkin lymphoma and urothelial cancers. This further enhances the value of investment in melanoma research, which can generate second round benefits across Australia's medical research landscape.[120]

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[116] RAND, Medical Research: What's It Worth?, BMC Medicine, 2012
[117] CINSW, 2008, Health Returns on Cancer Research Investments
[118] Australian Clinical Trials Alliance, 2017, Economic evaluation of investigator-initiated clinical trials conducted by networks
[119] KPMG, 2018, Economic Impact of Medical Research in Australia, accessed at: https://aamri.org.au/wp-content/uploads/2018/10/Economic-Impact-of-Medical-Research-exec-summary.pdf
[120] Khoja, L, Butler, MO, Kang, SP, et al., 2015, Pembrolizumab, J. immunotherapy cancer, 3(36), https://doi.org/10.1186/s40425-015-0078-9; Kulangara, K, Zhang, N, Corigliano, E, Guerrero, L, Waldroup, S, Jaiswal, D, Jansson, MS, Shah, S, Hanks, D, Wang, J, Lunceford, J, Savage, MJ, Juco, J, Emancipator, K, 2019, Clinical Utility of the Combined Positive Score for Programmed Death Ligand-1 Expression and the Approval of Pembrolizumab for Treatment of Gastric Cancer. *Arch Pathol Lab Med*; 143 (3), 330–337, doi:https://doi.org/10.5858/arpa.2018-0043-OA; Kudo, M, 2019, Combination Cancer Immunotherapy with Molecular Targeted Agents/Anti-CTLA-4 Antibody for Hepatocellular Carcinoma. *Liver cancer*, *8*(1), 1–11. https://doi.org/10.1159/000496277

4.5 Conclusions: Scorecard assessment and recommended actions to accelerate melanoma research

This analysis shows that Australia's melanoma research community is world-leading, and well positioned to lead high impact melanoma research across a number of domains. Major areas of investment opportunity to maximise research impact and improvements for survival include:

- Fund a Nationally Collaborative Research Mission and Discovery Program
  - Discovery research in melanomagenesis and melanoma biology
  - Clinical trials program focused on optimisation of current generation of immunotherapies and targeted therapies
  - Advanced imaging and AI technologies
  - Research to support the development of a high-risk screening program and model of care for high-risk melanoma, including genetic and environmental risk and socioeconomic disadvantage
- Invest in core data infrastructure to support development of a National Cancer Data Ecosystem by 2025 and health services implementation science
- Implement clinical trial reforms by 2025, including harmonisation of ethics and governance, and patient and transport funding for clinical trials.

Table 4.1: Scorecard assessment and recommendations for action – Melanoma Research

	Rating	Australian successes	Areas for improvement	Action Plan
Research	✓✓✓✓✓	✓ World leading prevention research informing US Prevention Taskforce ✓ Australia citation impact significantly exceeds medical research and NHMRC benchmarks ✓ Significant health gains realised through research, including doubling of survival for melanoma ✓ ~50 per cent of advanced melanoma patients enrolled in clinical trials ✓ ACRF funded Australian Centre of Excellence in Melanoma Imaging and Diagnosis (ACEMID) ✓ NHRMC Centre of Research Excellence for the Study of Naevi ✓ NHMRC Centre of Research Excellence for Skin Imaging and Precision Diagnosis Victorian Melanoma and Clinical Trials Service	× Opportunities for deep, nationally collaborative research effort × Lack of core clinical, population, quality registry data, National Cancer Data ecosystem × Inefficiencies in grants processes × Clinical trial inefficiencies (duplicated and differing governance and ethics requirements leading to long timelines)	Fund Research Program in Melanoma focused on: – Melanomageneisis and Biology – Optimising current systemic treatments – Novel Imaging and Detection – Evidence development for program to target high-risk cohorts – Patient Reported Outcomes Fund development of core clinical and population data assets as part of an internationally competitive National Cancer Data Ecosystem Implement clinical trials reform by 2025

Chapter 5

Early detection of melanoma: performance and areas for improvement

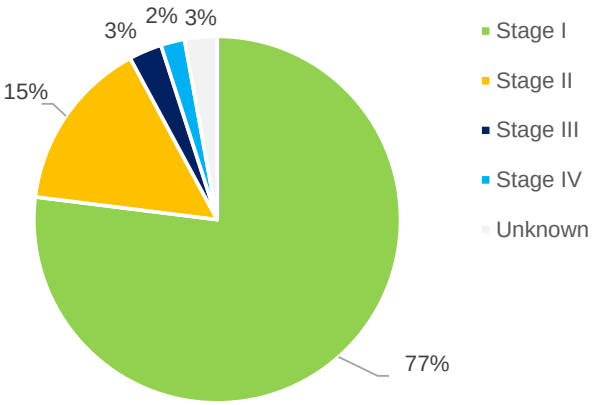
Five-year survival rates for melanomas detected in Stages I and II are relatively high; for example, Australian Institute of Health and Welfare data report 5-year survival estimates of 99.2 per cent and 73.6 per cent, for Stages I and II, respectively (2011 data, most recent data). Improving early detection of melanoma is therefore important in reducing mortality from melanoma, as well as the costs and quality of life effects associated with treatment and care of advanced melanoma.

This chapter presents the current approach to early detection of melanoma, identifies areas for improvement and sets out an action plan to increase the early detection of melanoma in Australian communities.

5.1 Australian successes in early detection of melanoma

Tumour thickness is negatively associated with melanoma survival.[121] In Australia, most melanomas are detected in the earliest stages of disease; 62 per cent of invasive melanomas diagnosed at Stage IA (less than 1mm of thickness) and further 15 per cent are diagnosed at Stage IB (less than 2mm with no ulceration).[122] In total, 77 per cent of melanomas are diagnosed at Stage I (Figure 5.1).

Figure 5.1: Stage of diagnosis



Source: Australian Institute of Health and Welfare, 2021, Cancer Data in Australia. Note: this reflects the most recently collected incidence data by stage (diagnosed in 2011). Note: 10-25 per cent of stage II become stage IV melanoma and around 50 per cent of stage III become stage IV (and a proportion of stage I and II become stage III).

[121] Azzola, MF, Shaw, HM, Thompson, JF, Soong, SJ, Scolyer, RA, et al., 2003, Tumor mitotic rate is a more powerful prognostic indicator than ulceration in patients with primary cutaneous melanoma. Analysis of 3661 patients from a single center, Cancer, 97(6), 1488–1498.
[122] Cramb, SM, Duncan, EW, Aitkens, J, et al., 2020, Geographical patterns in melanoma incidence across Australia: can thickness differentials reveal the key drivers?, Annals of Cancer Epidemiology, 4(11), doi: 10.21037/ace-20-13.

This compares favourably to international benchmarks. For example, population data indicates that approximately 64 per cent of melanomas in the UK are detected at Stage I (compared to 77 per cent in Australia)[123] and 80 per cent of melanomas diagnosed in the USA are detected at a 'localised' stage (including Stages I and II, compared to 92 per cent in Australia).[124]

Moreover, as noted in Chapter 4, Australia has championed research in the development of new strategies for early detection. In particular, a number of High Risk Clinics for Melanoma have been in operation which have demonstrated a cost effective service for the surveillance of high-risk melanoma patients that is feasible to be expanded into dermatology and primary care settings. Australia has also funded Centres of Excellence focused on the development of novel detection and diagnosis techniques, including the Australian Centre of Excellence in Melanoma Imaging and Diagnosis as well as the Centre of Research Excellence for the Study of Naevi.

5.2 Areas for improvement in early detection of melanoma

While further research and evidence development is needed to define high risk cohorts and develop a cost effective approach to the screening of high risk individuals, opportunities exist to improve early detection within current practice settings today. Key challenges to early detection of melanoma in Australia today include:

- Lack of patient empowerment
  - Poor awareness of the risks and signs of melanoma, and the need to 'Know the Skin You're In' through routine skin checks
  - No formalised approach for identifying high-risk individuals
  - Skin checks de-prioritised relative to other health checks in primary care settings
  - Perceptions of dismissiveness of patient concerns at times by some GPs
- Lack of minimum standards in skin checks, including inconsistent use of best practice whole-body examination and dermoscopy
- Need for additional GP training in melanoma
- Access barriers for regional and disadvantaged patients arising from skills shortages and out of pocket costs
  - Out of pocket costs can be significant, particularly for low-income households and people who develop multiple skin cancers
  - Long waiting times and high costs to see dermatologists across Australia, particularly for regional Australians with the ability to see dermatologists in regional areas near impossible for many
  - Long waiting times to see GPs in regional areas.

These concerns were echoed in the Melanoma Patient and Carer Survey. Three in four patients and carers indicated not enough was being done for early detection of melanoma, making it an equal priority with prevention in terms of perceptions of inadequate policy

[123] Herbert, A, Koo, MM; Barclay, ME, Greenberg, DC, Abel, GA, Levell, NJ, Lyratzopoulos, G, 2020, Stage-specific incidence trends of melanoma in an English region, 1996–2015: longitudinal analyses of population-based data, Melanoma Research, 30(3), 279-285, doi: 10.1097/CMR.0000000000000489

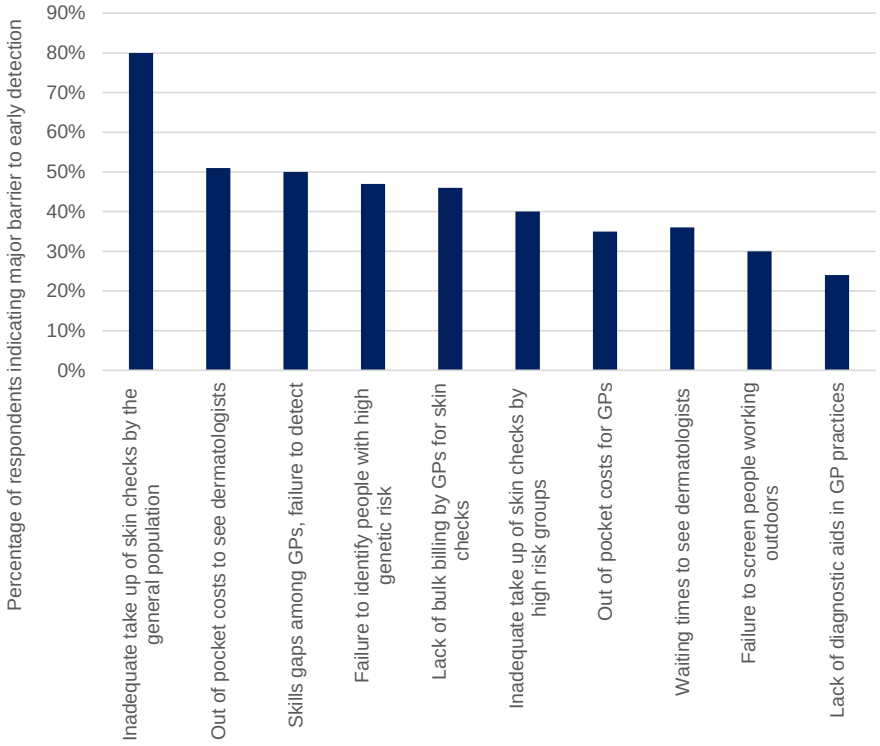
[124] National Cancer Institute data, note not reported by Stage see: https://seer.cancer.gov/explorer/application.html?site=53&data_type=1&graph_type=4&compareBy=sex&chk_sex_1=1&race=1&age_range=1&advopt_precision=1&advopt_display=2

settings and investment. The major barriers to early detection identified most frequently as significant gaps included:

- Inadequate take up of skin checks by the general population (as opposed to screening), by a considerable margin with 80 per cent of respondents indicating this to be a 'Top 5' barrier to early detection
- Out of pocket costs to see dermatologists, with 50 per cent of respondents indicating this was a Top 5 barrier to early detection
- Skills gaps among some GPs, leading to a failure to detect, identified by 48 per cent of respondents.

Other challenges raised include a failure to identify people with high genetic risk, costs of seeing GPs for skin checks, inadequate take up of skin checks by high risk cohorts and waiting times to see dermatologists (Figure 5.2).

Figure 5.2: What are the barriers to early detection and diagnosis?



Source: Melanoma Patient and Carer Survey, see Appendix B.

These issues are considered in turn.

Lack of awareness of own risk and appropriate circumstances for skin checks across Australian communities, and lack of skin check uptake

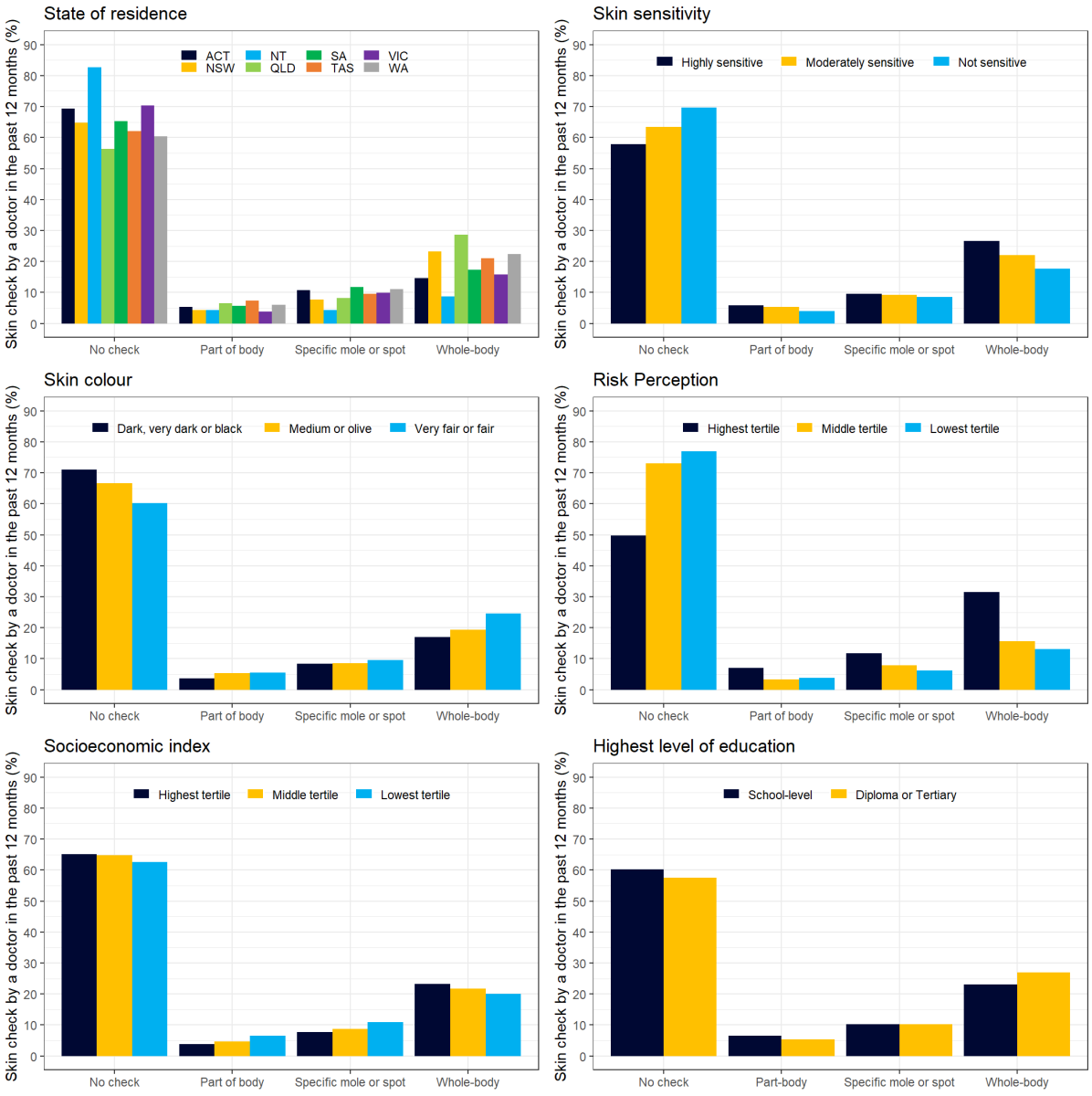
An Australian study showed that the overall proportion reporting whole-body skin checks in the past 12 months was on average around only 20 per cent over the 2006-07 to 2010-11 period (Figure 5.3).[125] It also found:

- Skin check rates were higher in Queensland, which was also associated with one of the best survival outcomes over the 2013-2017 period (State Cancer Registry data).

[125] Reyes-Marcelino, G, Tabbakh, T, Espinoza, D, et al., 2021, Prevalence of skin examination behaviours among Australians over tie, Cancer Epidemiology, doi: 10.1016/j.canep.2020.101874.

- More disadvantaged people were less likely to receive a whole-body skin check. Lower rates of presentation for skin checks among low-income households may be a contributing factor to the poorer survival outcomes for this cohort.

Figure 5.3: Uptake of skin checks by geography, risk, socioeconomic factors



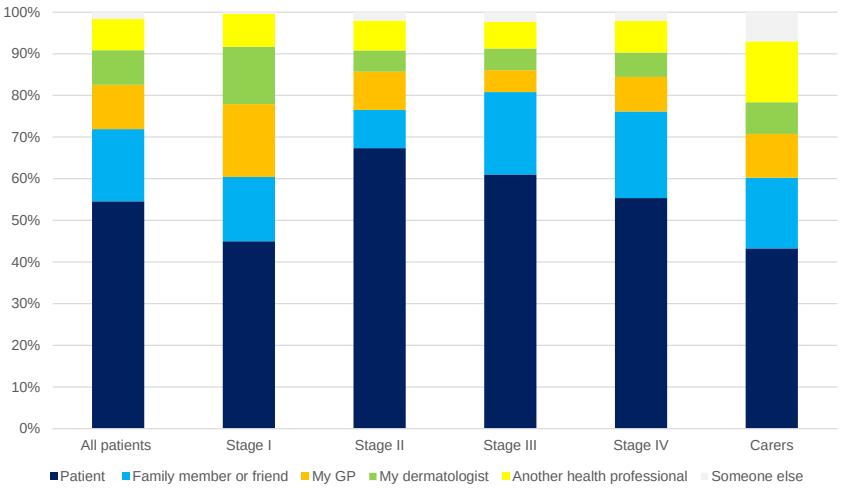
Source: Reyes-Marcelino, G, Tabbakh, T, Espinoza, D, et al., 2021, Prevalence of skin examination behaviours among Australians over time, Cancer Epidemiology, doi: 10.1016/j.canep.2020.101874.

Relatively low uptake of whole-body examinations coincides with views raised in the stakeholder consultation and consumer forums regarding poor awareness of own risks and appropriate circumstances for skin checks in the community (Figure 5.4).

Figure 5.4: Lack of awareness of skin checks

Awareness of the importance of skin checks and skin changes in the context of an opportunistic screening approach becomes very important, noting that clinician-led examinations are crucial to the effective identification of melanoma lesions. Data from the Melanoma Patient and Carer Survey showed that either the patient themselves or a family member were often the first to notice a suspicious lesion (Figure 5.5).

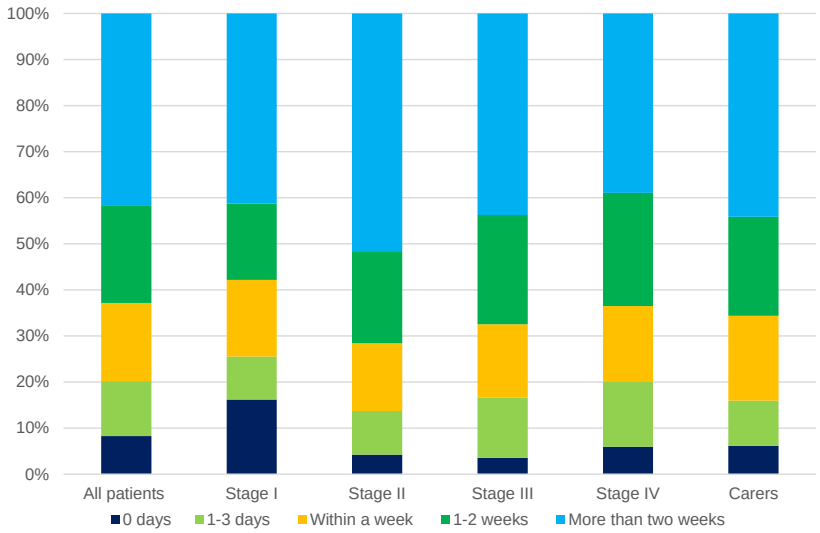
Figure 5.5: Who first noticed the lesion? Responses by stage



Source: Melanoma Patient and Carer Survey, see Appendix B.

In addition, the time to present for a skin examination by a health professional was reported to be longer than recommended guidelines.[126] More than 40 per cent (42 per cent) of patients and carers reported that it took more than two weeks to present to a GP or dermatologist after spotting a suspicious lesion. There was no significant variation by regional status, income status or insurance status, although regional patients were marginally more likely to wait more than two weeks (44 per cent).

Figure 5.6: How much time elapsed between noticing the lesion and presenting to a health professional?



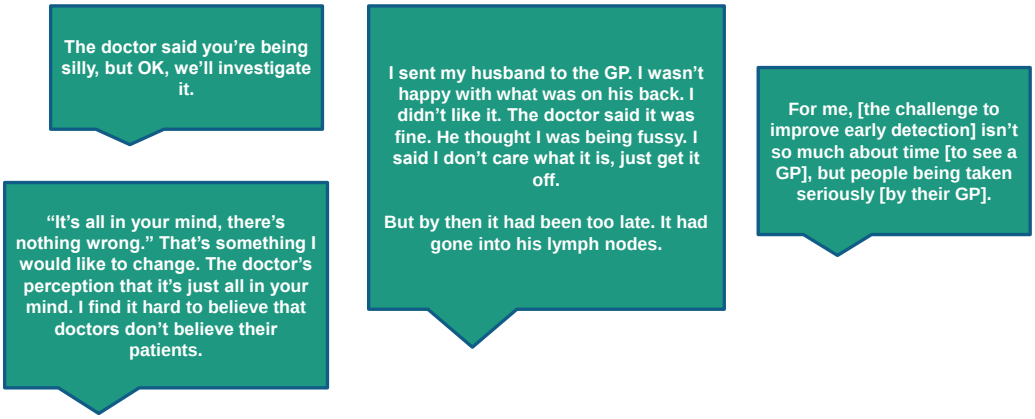
Source: Melanoma Patient and Carer Survey, see Appendix B. Note: responses by stage.

[126] See the Optimal timeframes in the Optimal Care Pathway for Melanoma at: https://www.cancer.org.au/assets/pdf/melanoma-optimal-cancer-care-pathway, p 18.

Lack of patient empowerment: dismissiveness of patient concerns

Stakeholders also highlighted concerns related to poor awareness of the risks and signs of melanoma in the community and dismissiveness by some GPs of patient concerns. Both in response to the survey and at the consumer forums, patients and carers expressed frustration and sometimes anger towards situations where they felt they were not listened to and/or not taken seriously or believed by their GPs (Figure 5.7).

Figure 5.7: Examples of perceptions of dismissiveness of patient concerns



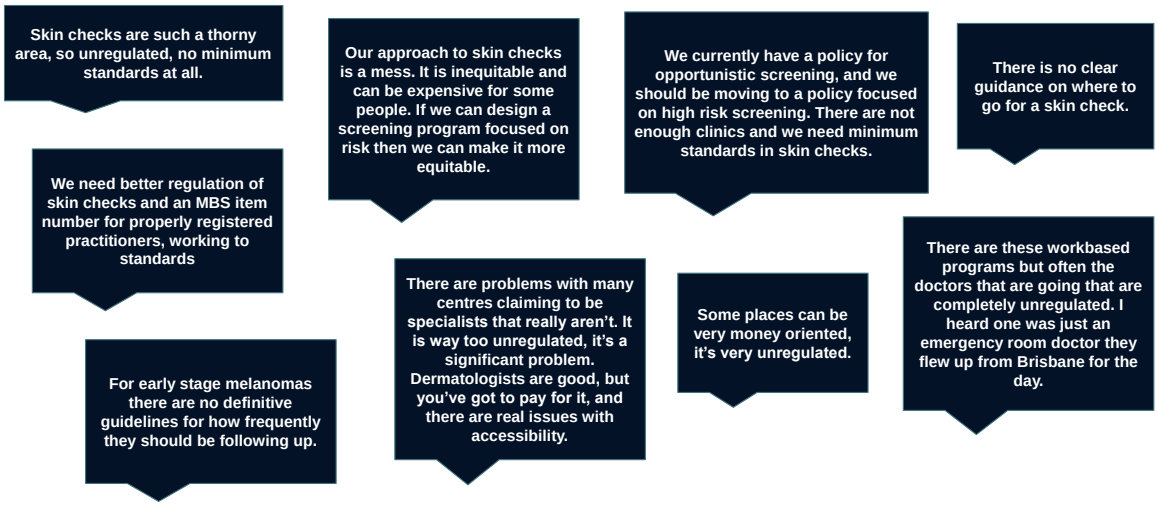
Lack of minimum standards in skin checks

Stakeholders, patients and carers expressed significant concern over the lack of regulation with regard to skin checks. Variation in approach is evident in the Cancer Council data, which shows significant rates of part body or specific spot examination compared with whole-body examination. While Australian Clinical Guidelines for Melanoma provide information about the use of diagnostic aids, stakeholders consistently expressed concern that more explicit minimum standards could be established to improve the quality of skin checks.

The guidelines note that meta-analyses performed on studies in a variety of clinical and experimental settings have shown that using dermoscopy improves diagnostic accuracy for melanoma; diagnostic accuracy using a dermatoscope is 15.6 times higher than with naked eye (clinical) examination.

New technologies are currently being research and offer the potential to improve quality and consistency of skin checks (see Chapter 4).

Figure 5.8: Stakeholder perspectives on lack of minimum standard approach to skin checks



Need for additional GP training in melanoma

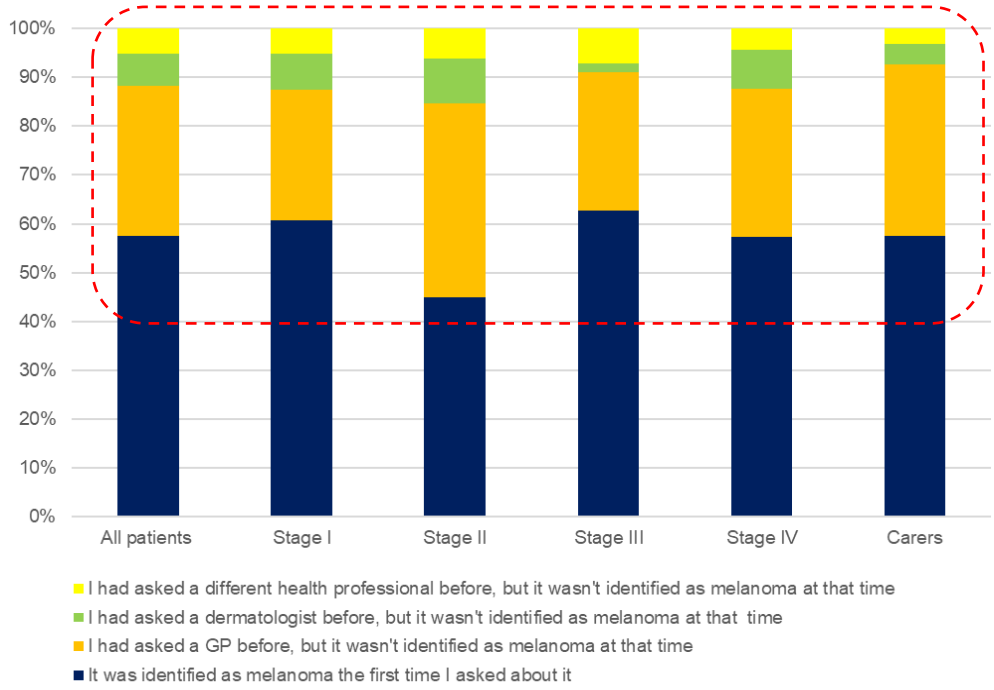
GPs are on the front-line of melanoma detection and diagnosis, and in regional areas are the primary providers for patients. For example, in 2020, it was reported that in general practice, dermatological presentations represent approximately 16 per cent of patient encounters, with skin cancers being a significant portion of these encounters.[127] Despite this, there is very limited training in dermatology generally and melanoma specifically:[128]

> *Despite the significant burden of dermatological disease, structured training for general practice registrars and medical students remains poor, in our opinion.*
>
> *A study including 17 of the 18 medical schools within Australia revealed on average just five lectures are dedicated to dermatology during each program and only 35 per cent of medical schools required dermatological learning targets to be met for exam purposes.*

There is evidence to suggest that additional training for GPs in the diagnosis and management of skin cancer, including pigmented lesions and melanoma, would improve outcomes for patients and the wider health system. For example, a recent international meta-analysis on the number of skin biopsies necessary to detect one melanoma concluded that specially-trained pigmented lesion specialists have the lowest number (5.9), followed by dermatologists (9.6), and primary care doctors (22.6).[129]

Results from the Melanoma Patient and Carer Survey also indicated a higher rate of failure to detect among GPs compared with dermatologists. Just over 40 per cent of patients (43 per cent) and carers (42 per cent) reported they or their family member had asked about a lesion before a diagnosis of melanoma was made.

Figure 5.9: Failure to detect rates



Source: Melanoma Patient and Carer Survey, see Appendix B.

[127] Sebaratnam, D, Der Sarkissian, S, O'Connor, A, and Gupta, M, 2020, Out, damned spot! Burden of skin cancer in Australia, Insight+, MJA, https://insightplus.mja.com.au/2020/45/out-damned-spot-burden-of-skin-cancer-in-australia/, and RACGP, DE16 - Dermatology contextual unit, https://www.racgp.org.au/education/education-providers/curriculum/2016-curriculum/contextual-units/presentations/de16-dermatology.
[128] Sebaratnam, D, Der Sarkissian, S, O'Connor, A, and Gupta, M, 2020, Out, damned spot! Burden of skin cancer in Australia, Insight+, MJA, https://insightplus.mja.com.au/2020/45/out-damned-spot-burden-of-skin-cancer-in-australia/
[129] Petty, AJ, Ackerson, B, Garza R, et al., 2019, Meta-analysis of number needed to treat for diagnosis of melanoma by clinical setting, J Am Acad Dermatol, 82(5), 1158-1165.

As the data show, GPs failed to detect lesions at four times the rate of dermatologists. While the impact of a delay in detection is variable across melanoma sub-types, it can be risky for some sub-types, such as nodular melanomas, which account for approximately 21 per cent of all cutaneous melanomas. For nodular melanomas, the thickness of the lesion increases by three per cent per month, leading to increased risks of adverse outcomes where there are delays in diagnosis.[130]

This underscores the need for minimum standards in skin checks, including whole-body examination and the regular use of dermatoscopes, as well as the need for additional investment in training of GPs and other practitioners to support melanoma detection, diagnosis and appropriate referrals.

Figure 5.10: Stakeholder perspectives on the need for additional GP education and training in melanoma

[130] Baade, PD, English, DR, Youl, PH, 2006, The Relationship Between Melanoma Thickness and Time to Diagnosis in a Large Population-Based Study, JAMA, 1422:1427.

Access barriers to skin checks

The ability to access skin checks was reported to be highly variable nationally. Significant barriers include:

- *Lack of access to dermatologists* — National Department of Health data indicate there is an existing shortage of 22 dermatologists nationally, and this is expected to increase over the 2030 period to a shortage of 90 dermatologists by 2030.[131]

  The existing and increasing shortage of dermatologists in Australia has resulted in very significant wait times, even in capital cities, and almost impossible ability to access dermatologists in regional areas, with 92 per cent of practicing dermatologists working in major metropolitan areas. One stakeholder noted that on average it took six months to see a dermatologist nationally, while patients in regional Queensland noted there could be a wait time of six to eight weeks just to have a suspicious lesion excised.[132]

  Addressing the shortage of dermatologists appears to be challenging, with diffuse accountability across funders and regulatory organisations: the Australian College of Dermatologists determines the number of accepted candidates, but seeks funding for training from State governments ($150,000 per registrar), even as 93 per cent of dermatologist work occurs in the private sector.[133]

- *Limited time with GPs in regional areas* — It was noted by many stakeholders that in some regional areas GPs were often similarly stretched leading to fewer rates of skin checks, although this was not uniform for all areas.[134] Compared to major cities the number of medical practitioners is low. The Australian Government has recently tried to tackle GP shortages in regional and rural areas with MBS funding incentives in the 2021-22 Federal Budget.

- *Out of pocket costs* — Out of pocket costs were reported to be high, particularly for households on low or no income, and where patients needed to travel. Average out of pocket costs for a GP are $22.16 per consult, while dermatologist out of pocket costs were reported to be $70.92 on average.[135] Out of pocket costs for pathology range from $12.95 to $41.10 depending on the test ordered,[136] and genomic tests can exceed $450. Sequential digital dermoscopy imaging for 1-3 lesions incurs out of pocket costs of $77.92, and Sequential digital dermoscopy imaging for more than 1-3 lesions involves an out of pocket cost of $89.76.[137] Out of pocket costs for excision range from $43.60 to $55.20 depending on the type of excision.[138] The cumulative impact of these costs can present a significant challenge for some patients and families, particularly where long term survivors require routine skin surveillance to detect potential second melanomas early.

[131] Department of Health, 2017, Australia's Future Health Workforce – Dermatology, May 2017, p 27.
[132] Department of Health, 2017, Australia's Future Health Workforce – Dermatology, May 2017.
[133] The Australasian College of Dermatologists, 2019, Submission to The Office of the NSW Productivity Commissioner in response to NSW Productivity Discussion Paper: Kickstarting the productivity conversation November 2019. The Australasian College of Dermatologists, 2019, 2020-21 Pre-Budget Submission to the Australian Government Treasury, December 2019.
[134] National Health Workforce Dataset.
[135] $2021 dollars. See MBS Online, AIHW, 50th percentile, National costs, Out-of-pocket cost per specialist attendance and per obstetric attendance, by Primary Health Network (PHN) area, 2016–17
[136] Ibid.
[137] $2021. Watts, CG, Cust, AE, Menzies, SW, et al., 2014, Specialised Surveillance for Individuals at High-risk for Melanoma, JAMA Dermatol, doi: 10.1001/jamadermatol.2014.1952.
[138] See MBS Online

Figure 5.11: Barriers to accessing skin checks

5.3 Opportunities to improve early detection

Significant opportunities to improve early detection exist through better adherence to, and knowledge of clinical best practice and expanding access to skin checks in high-risk populations.

Australian communities need to "know their own skin", so that they can notice suspect skin change and subsequently present to clinicians. This can be achieved through a campaign to promote increased awareness of own risk and appropriate circumstances for skin checks in the general community and specifically in high-risk cohorts, potentially leveraging the wider mass media campaign for prevention.

At the same time, self-checks are limited in accuracy and clinicians retain an important role in detection and diagnosis. Clinicians must be accessible and provide high quality services. This can be achieved through improved adherence to clinical best practice and expanding access to skin checks, particularly for high-risk populations:

- Define minimum standards for skin checks in clinical guidelines
- Invest in education and training for GPs in melanoma
- Increase supply of trained professional in skin checks, particularly focused on regional, remote and disadvantaged communities, including via:
  - Training GPs
  - Funding development of other craft groups in skin check competencies: nurse practitioners, technicians

– Addressing shortage of dermatologists.

Finally, while some advancements in research and technology appear promising, evidence development is necessary. To this end, a roadmap to a National Targeted Melanoma Screening Program is needed to deliver an evidence-based program that is equitable in its reach, trustworthy for patients and clinicians and cost-effective for the community and the healthcare system.

Improve awareness of own risk and appropriate circumstances for skin checks

In the absence of a population screening approach, where policy settings are focused on opportunistic screening of suspicious lesions, investment in patient education and awareness with respect to signs of melanoma become critical to early detection and diagnosis.

In addition to skin checks by clinicians, thorough and systematic skin examinations by patients and their family members on a monthly basis is also recommended.[139] A United States population-based, case-control study of 1,199 Connecticut residents reported a 63 per cent reduction in fatal or advanced melanoma associated with self-skin examination with the mean thickness of melanomas being significantly lower in those who performed self-skin examination (1.09 mm) compared with those who did not (1.65 mm).

Studies have also shown patient awareness and education initiatives can be effective in inducing awareness of skin changes and an increase in skin examinations. For example, a Queensland trial of patient education in skin examinations found that, among older men at risk of melanoma, the use of video based behavioral interventions increased presentation for a skin examination by 12 per cent and increased the number of whole-body skin examinations by 21 per cent.[140]

Patients and carers were strongly in support of a campaign to increase awareness of the need for skin checks (Figure 5.12).

Figure 5.12: Patient and Carer perspectives regarding the opportunity to increase awareness

Applying the impact of increased early detection among men and women[141] could result in a 3.7 per cent reduction in the number of advanced melanomas. In addition, it leads to direct

[139] Tripp, MK, Watson, M, Balk, SJ, et al., 2016, State of the Science on Prevention and Screening to Reduce Melanoma Incidence and Mortality: The Time Is Now, CA Cancer Journal, 66(6), 461-480, doi: 10.3322/caac.21352.
[140] Janda, M, Youl, P, Neale, R, Aitken, J, Whiteman, D, Gordon, L, Baade, P, 2014, Clinical skin examination outcomes after a video-based behavioral intervention: analysis from a randomized clinical trial, JAMA Dermatol, 150(4), 372-9.
[141] Gordon, L, Olsen, C, Whiteman, DC, et al., 2020, Prevention versus early detection for long term control of melanoma and keratinocyte carcinomas: a cost effectiveness modelling study, BMJ Open, doi: 10.1136/bmjopen-2019-034388,

health cost savings to government through the avoidance of late stage melanoma in the order of $59.6 million in $NPV_{2\%}$ terms.

Fund GP training and national dermoscopy program

Early detection is best accomplished through whole-body skin examination by a clinician trained in best practice skin check methods, supported by use of diagnostic aids such as a dermatoscope. A major opportunity to improve early detection is to increase GP training, similar to the training rolled out in Victoria (Box 5.1).

Box 5.1: Improving diagnosis: Dermoscopy for Victorian General Practice Program

The Dermoscopy for Victorian General Practice Program aims to improve skin cancer detection among Victorian GPs. The program is delivered by Cancer Council Victoria's SunSmart program and is supported by the Australasian College of Dermatologists. It aims to create more accurate diagnoses of skin cancer through providing dermoscopy equipment and training.

With appropriate training, dermoscopy in primary care is more accurate than naked eye examination, with improvements in sensitivity and specificity. Moreover, the use of dermoscopy leads to fewer unnecessary referrals and excisions. Early skin cancer detection in rural and regional areas relies heavily on GPs. In 2018 and 2019 combined, the program reached 209 GPs. Of these, 146 (70 per cent) were located in rural and regional Victoria.

Victorian GPs commented on the impact this program has on skin cancer detection:

'The program has made an immediate difference to my practice with tangible results. While I was examining a patient with a chest infection, I noticed a lesion on his back that looked suspicious. I used my recently acquired dermatoscope to confirm my diagnosis. An immediate biopsy came back as a level 2 melanoma.' - GP from Bright

'I'd like to thank you and the team again for a thoroughly enjoyable and educational course. I'm happy to report that the first opportunistic skin check I completed identified a stage 2 melanoma thanks to the dermatoscope.' - GP from Ballarat

Source: DHHS, 2020, Victorian Cancer Plan 2020-2024, Improving cancer outcomes for all Victorians, p 43

If the rate of melanomas missed by GPs (31 per cent across all patients) was reduced to equal the rate of melanomas missed by dermatologists (seven per cent across all patients), this could reduce the proportion of thick melanomas with risk of adverse impacts (nodular melanomas).[142] Assuming a 20 per cent reduction in failure to detect through improved standards and training, and thereby a reduction in the missed detection of melanomas that progress rapidly (21 per cent of melanomas), would see mortality over the 2021-2030 horizon reduced by 115 deaths. The direct health cost savings to government of avoiding late-stage melanoma would be $67.6 million in $NPV_{2\%}$ terms.

In addition, enhancing capabilities of GPs helps address skill shortages affecting rural areas, and therefore may help mitigate out of pocket costs incurred by patients, i.e., through fewer unnecessary referrals and excisions. This would be complemented by improved models of care, including increased use of technology (such as those researched by ACEMID).

Define minimum standards for skin checks

Studies have shown that increased awareness of changes in lesions and whole-body skin examinations reduce the risk of being diagnosed with a thick melanoma, which is associated with improved survival outcomes. For example:

[142] Aitken, JF, Elwood M, Baade, PD, et al., 2010, Clinical whole-body skin examination reduces the incidence of thick melanomas. Int J Cancer, 126(2), 450-8.

- The conduct of a whole-body clinical skin examination in the three years before diagnosis was associated with a 14 per cent lower risk of being diagnosed with a thick melanoma.[143]
- QIMR Berghofer estimated that an increase in the uptake of annual skin examinations by clinicians using a dermatoscope could reduce the number of thick melanomas (>1mm) by 3.7 per cent compared to the status quo, translating into a 1.9 per cent reduction in deaths from melanoma compared to the base case.[144]

Increase the supply of professionals trained in skin checks

GPs will remain key providers in the provision of early detection and diagnosis of melanoma, but research shows that other health professionals from a range of craft groups can be trained to successfully perform skin checks with the use of diagnostic aids, including nurse practitioners and technicians. This could provide an important new model of care for people living in regional, remote and disadvantaged communities.

The shortage of dermatologists should also be urgently addressed to reduce waiting times and limit the growth of out of pocket costs for dermatologist services. This would appear to require compromise among stakeholders or new funding models for training places but should be completed with some urgency given the length of time required to train a dermatologist.

Develop a Roadmap for a National Targeted Melanoma Screening Program

As outlined in Chapter 4, multiple research streams are focused on the development of improved risk algorithms, innovative surveillance approaches and models of care to enable the introduction of a program aimed at high risk cohorts. NSW research of four High Risk Clinics over a 10 year period demonstrated the feasibility and cost effectiveness of an intensive surveillance model of care for people at very high-risk of melanoma. Where required, randomised controlled trials should be funded to develop the necessary evidence building on this work for implementation (see also, Chapter 4).

Stakeholders, patients and carers alike were strongly in favour of research to develop new cost effective models of care that reduce barriers to access, particularly among regional and disadvantaged cohorts.

Complementary tools which could promote increased accessibility include self assessment applications, and mobile imaging units. Evidence regarding the cost effectiveness of these tools is developing.

[143] Aitken, JF, Elwood M, Baade, PD, et al., 2010, Clinical whole-body skin examination reduces the incidence of thick melanomas. Int J Cancer, 126(2), 450-8.
[144] Gordon, L, Olsen, C, Whiteman, DC, et al., 2020, Prevention versus early detection for long term control of melanoma and keratinocyte carcinomas: a cost effectiveness modelling study, BMJ Open, doi: 10.1136/bmjopen-2019-034388.

Figure 5.13: Stakeholder, patient and carer perspectives of the opportunity to increase awareness

5.4 Impacts from improving early detection

Improving early detection would be expected to reduce the incidence and cost of treating advanced melanomas by more than five per cent per annum:

- Increased presentation for skin checks could see a 3.7 per cent reduction in the number of advanced melanomas and direct health cost savings in the order of $59.6 million in $NPV_{2\%}$ terms to government through the avoidance of late stage melanoma
- If the rate of melanomas missed by GPs (31 per cent across all patients) was reduced to equal the rate of melanomas missed by dermatologists (seven per cent across all patients), this could reduce the proportion of thick melanomas with risk of adverse impact (assumed to be 21 per cent of all advanced melanomas). Consequently, in addition the incidence of advanced melanoma could be reduced by approximately four per cent.

In total more than 200 deaths from melanoma over the 2021-2030 horizon could be prevented along with direct healthcare costs of more than $127 million in $NPV_{2\%}$ terms.

In time, with additional research breakthroughs in algorithms to better identify at-risk Australians and models of care, the improvements in melanoma mortality would be expected to further increase.

5.5 Conclusions: Scorecard assessment and recommended actions to improve early detection of melanoma

Evidence from data and the community shows that, while Australia tends to detect the majority of melanomas at early stages, improvements in early detection are a major priority area for government and the wider community.

Research must continue to develop evidence to support the cost-effective identification of high-risk cohorts using advanced algorithms (see Chapter 4) and new models of care for long term skin surveillance. There should be particular focus on disadvantaged cohorts and the barriers they face in timely access to skin checks (e.g., costs). To this end, a Roadmap for a National, Targeted Melanoma Screening Program bringing together the key research efforts should be a major priority of the Nationally Collaborative Melanoma Research Mission and Discovery Program.

In parallel, significant action can be taken today to improve early detection:

- Increase awareness of the need for skin checks in the general community and high-risk cohorts in particular, potentially leveraging the wider mass media campaign for prevention
- Define minimum standards for skin checks in clinical guidelines, including in particular the use of dermoscopy
- Invest in education and training for GPs in melanoma
- Increase supply of trained professional in skin checks, particularly focused on regional, remote and disadvantaged communities, including via:
  - Training GPs
  - Funding development of other craft groups in skin check competencies: nurse practitioners, technicians
  - Addressing shortage of dermatologists.

Table 5.1: Scorecard assessment and recommendations for action – Early Detection

	Rating	Australian successes	Areas for improvement	Action Plan
Early Detection	✓✓✓	Globally leading outcomes in tumour thickness arising from high rates of opportunistic screening	Increased community awareness of skin changes and uptake of skin checks, especially for high-risk cohorts and low income individuals No minimum standards specified with regard to skin checks and diagnosis Need for additional training in melanoma by GPs to reduce failure to detect and risks of potential over-diagnosis Need to integrate research efforts for early detection into the roll out of new models of care	Awareness strategy and campaign for self skin checks and melanoma risk Develop minimum standards for skin checks and diagnosis (MelCOR) and evaluate GP training and dermoscopy program Increase supply of trained professionals in skin checks

	Rating	Australian successes	Areas for improvement	Action Plan
				Roadmap for a National Targeted Melanoma Screening Program

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Chapter 6

Diagnosis and treatment: performance and areas for improvement

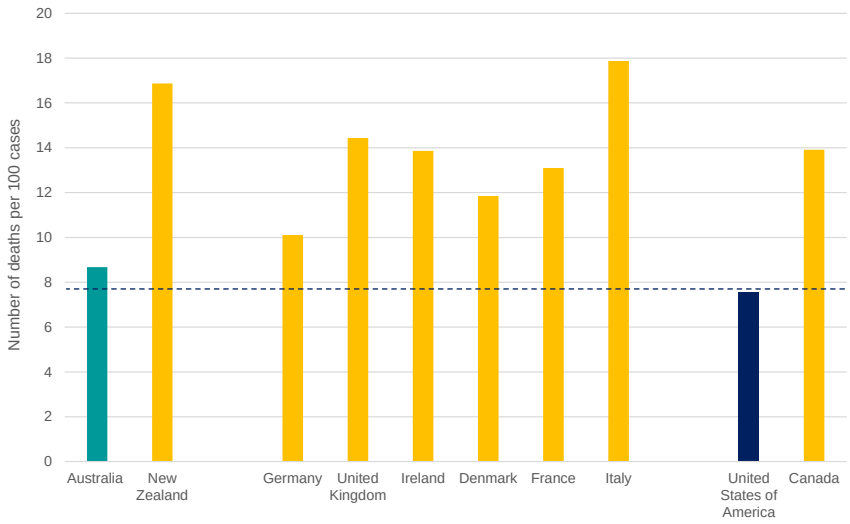
As the treatment landscape for melanoma rapidly evolves against a backdrop of continued research breakthroughs, ensuring equitable access to treatment and care is fundamental to reducing mortality and improving the quality of life of survivors. Providing appropriate treatment depends on receiving an accurate and timely diagnosis. This chapter provides an overview of Australia's performance in treatment and diagnosis.

Supportive care, which is integral to the health and wellbeing of patients and should be discussed with both patients and their families at all stages of treatment and survivorship, is discussed in the following chapter.

6.1 Australian successes in diagnosis and treatment

Australia enjoys a high standard of care in melanoma nationally, which contributes to globally leading survival outcomes. For example, data reported by the International Agency for Research on Cancer show that as of 2020, Australia's mortality to incidence rate, which measures the number of deaths relative to the number of cases, was among the world's best, outpaced only by outcomes in the United States (Figure 6.1).

Figure 6.1: Mortality to incidence rate among selected developed nations (2020 data, number of deaths per 100 cases)



Source: International Agency for Research on Cancer, 2021, Mortality to incidence for selected countries, accessed at: https://gco.iarc.fr/.

These outcomes derive from Australia's high quality health care system, which is underpinned by universal access to primary and allied health care services and PBS funding

support for best evidence-based care in melanoma treatment (Table 6.1), which is currently in line with global best practice.

Table 6.1: Benchmarking systemic therapy funding through PBS against other jurisdictions

Drug therapy	Australia Cancer Council Guidelines for Melanoma / EviQ	Europe ESMO Guidelines for Cutaneous Melanoma (2020)	US (NCCN)	UK (NICE)
Nivolumab + ipilimumab (Combination PD-1 inhibitor + CTLA-4 inhibitor)	✓ PBS funded, 1st line, anti-PD1 or 2nd line for BRAF/MEK alterations, Unresectable Stage III + Stage IV	✓ 1st line, advanced or metastatic melanoma	✓	✓- 1st line, Stage III, IV
Nivolumab (PD-1 inhibitor monotherapy)	✓ PBS funded, 1st line, anti-PD1 or 2nd line for BRAF/MEK alterations, Unresectable Stage III + Stage IV ✓ PBS-funded, 1st line anti-PD1, Resected Stage III B/C/D + Stage IV adjuvant	✓ 1st line, advanced or metastatic melanoma ✓ 1st line, unresectable or metastatic BRAF-V600-WT ✓ Adult patients with complete resection of stage IIIB/C or IV melanoma	✓	✓- 1st line, Stage III, IV ✓- 1st line, Stage III adjuvant after complete resection
Talimogene laherparepvec (T-VEC) (Oncoloytic virus therapy)	-	✓ 1st line, Stage IV	✓	✓- Stage III, IV
Cobimetinib and vemurafenib (MEK inhibitor + BRAF inhibitor)	✓ PBS funded, 1st line, Stage III unresectable or Stage IV with BRAF mutation	✓ 1st line unresectable or metastatic melanoma with the BRAF V600E mutation	✓	-
Ipilimumab (CTLA-4 inhibitor)	✓ PBS funded, any line, Unresectable Stage III + Stage IV malignant melanoma, either as monotherapy or in combination with nivolumab *Not PBS listed or TGA registered indication as adjuvant therapy	✓ Adjuvant Stage III ✓ 2nd line metastatic melanoma	✓	✓- 1st line Unresectable Stage III and Stage IV ✓- 2nd line Unresectable Stage III and Stage IV
Binimetinib + encorafenib (Combination MEK inhibitor + BRAF inhibitor)	✓ PBS funded, 1st line, Unresectable Stage III + Stage IV with BRAF mutation	✓ Advanced unresectable or metastatic melanoma with a BRAF V600E or V600K mutation	✓	✓- 1st line, Stage III, IV with BRAF V600 mutation
Dabrafenib + trametinib (Combination MEK inhibitor + BRAF inhibitor)	✓ PBS funded, 1st line, adjuvant treatment for resected Stage IIIB/C/D melanoma	✓ 1st line, Stage III unresectable or Stage IV with the BRAFV600 mutation following complete resection ✓ Adjuvant Stage III	✓	✓ Stage III, IV
Trametinib (BRAF inhibitor)	✓ PBS funded, 1st line, Unresectable Stage III + Stage IV melanoma, positive BRAF V600 mutation	✓ Stage III unresectable or Stage IV with the BRAFV600 mutation following complete resection	ü	✓ Stage III, IV

Drug therapy	Australia Cancer Council Guidelines for Melanoma / EviQ	Europe ESMO Guidelines for Cutaneous Melanoma (2020)	US (NCCN)	UK (NICE)
Pembrolizumab (PD-1 inhibitor)	✓ PBS-funded 1st line Unresectable Stage III + Stage IV ✓ PBS funded, adjuvant Stage IIIB/C/D	✓ Stage IV, Adjuvant Stage III ✓ 2nd line metastatic after failure of ipilimumab BRAF or MEK inhibitor ✓ Adjuvant treatment of adults with stage III melanoma and lymph node involvement after complete resection	✓	✓- 1st line Unresectable Stage III and Stage IV ✓- 2nd line Unresectable Stage III and Stage IV, after ipilimumab and BRAF V600 mutation positive treated with BRAF or MEK inhibitor
Dabrafenib (MEK inhibitor)	✓ PBS-listed for unresectable Stage III/Stage IV BRAF V600 mutation positive melanoma as monotherapy, otherwise in combination with trametinib as above	✓1st line unresectable or metastatic melanoma with the BRAF V600E mutation		✓
Vemurafenib (BRAF inhibitor)	✓ PBS-listed for unresectable Stage III/Stage IV BRAF V600 mutation positive melanoma as monotherapy, otherwise in combination with trametinib as above	✓1st line or 2nd line after interleukin-2 metastatic melanoma with BRAF V600E and V600K mutations		✓
Dacarzabine (Chemotherapy)	✕ Superseded	-	✓	✓ - 2nd line
Interferon alfa-2b	✕ Discontinued	✓ Recommended use confined to ulcerated Stage IIC primary where no other options are available	-	-

Source: EviQ, Cancer Council Guidelines for Melanoma (current), ESMO Guidelines for Cutaneous Melanoma, NCCN guidelines for melanoma, NICE guidelines for Cutaneous Melanoma. EViQ, is an Australian web-based protocol system; ESMO refers to the European Society for Medical Oncology; the National Comprehensive Cancer Network (NCCN) is an alliance of US cancer centres; and the National Institute for Health and Care Excellence (NICE) is UK based.

In addition, Australian Governments have engaged the charitable sector, led by Cancer Council Victoria, to develop an updated Optimal Care Plan for melanoma is available through the Cancer Council Australia website.[145] Optimal Care Plans seek to empower patients and clinicians with regard to the holistic treatment and care of the patient from

[145] Cancer Council Australia, 2021, Optimal Care Pathway for Melanoma, Second Edition, available at: https://www.cancer.org.au/assets/pdf/melanoma-optimal-cancer-care-pathway.

prevention through to diagnosis, treatment and care. They include key information support requirements by stage of treatment as well as a high-level summary of treatment and care.

Australia's melanoma charity sector and clinical community, led by Melanoma Institute Australia, have also developed clinical guidelines for safe and quality treatment of cutaneous melanoma, as well as some high-level guidance available for rarer sub-types of melanoma. These guidelines are hosted by the Cancer Council Australia.[146] Clinical guidelines establish evidence based standards for the accurate diagnosis and treatment of melanoma in Australia, which are intended to guide clinical best practice and reduce unwarranted variation in treatment.

Related to the establishment of evidence based best practice, another significant contribution of Australia's melanoma community has been the improved diagnosis of melanoma through more accurate staging. Australian researchers have contributed to the development of the 8th edition of the American Joint Committee on Cancer (AJCC) staging system for melanoma, which adopts the Tumour-Node-Metastasis (TNM) classifications. The AJCC is recognised as the authoritative guide for cancer staging,[147] with the accurate diagnosis of melanoma foundational to providing appropriate treatment.

6.2 Areas for improvement in diagnosis and treatment

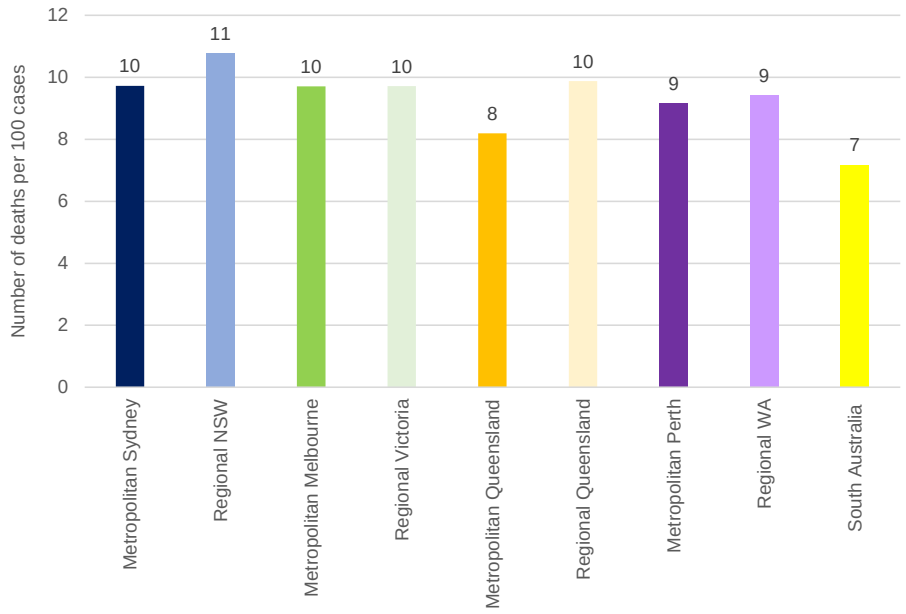
While acknowledging Australia's success in the treatment and care of melanoma compared to its international peers (Figure 6.1), there are a number of opportunities to improve treatment nationally. Viewing Australia's performance in aggregate can mask significant variation in outcomes for some parts of the community.

For example, Figure 6.2 highlights the variable outcomes observed by geographic area, with regional NSW and regional Queensland patients seeing poorer outcomes than their metropolitan counterparts.

Survival outcomes are even more pronounced when viewed through the lens of economic disadvantage. Socioeconomic data was not reported in all jurisdictions; Figure 6.3 shows only the jurisdictions that reported socioeconomic disadvantage data. As shown in Figure 6.3, affluent persons (the least disadvantaged parts of the community) are significantly more likely to survive their melanoma diagnosis than a person from the most disadvantaged economic quintile. The weighted average mortality to case rate for disadvantaged communities in these two states (which account for just over 60 per cent of all cases of invasive melanoma) is nearly double that of the rate for the least disadvantaged communities.

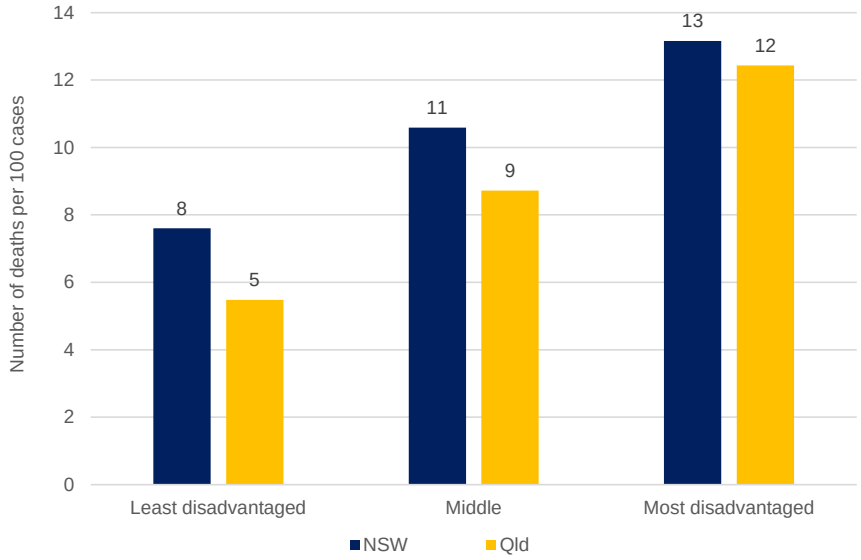
[146] Clinical practice guidelines for the diagnosis and management of melanoma, available at: https://wiki.cancer.org.au/australia/Guidelines:Melanoma
[147] American College of Surgeons website, available: https://www.facs.org/quality-programs/cancer/ajcc.

Figure 6.2: Mortality to incidence rate by geography: State Cancer Registry data 2013-2017 (Number of deaths per 100 cases)



Source: State Cancer Registry data

Figure 6.3: Mortality to incidence rate by disadvantage: State Cancer Registry data 2013-2017



Source: State Cancer Registry data

The factors contributing to poorer survival outcomes for some parts of the melanoma patient community compared to others are complex, and will include timing of detection in these communities (Chapter 5) as well as the accuracy of diagnosis and quality of treatment and care. Within the diagnosis and treatment domain, however, stakeholders and the literature point to a number of challenges within current clinical practice that, if addressed, would see improvements in the diagnosis and treatment of melanoma in Australian communities. These issues include:

- ✓ High rates of partial biopsy, which are associated with high rates of error

- ✓ Failure to perform Sentinel Lymph Node Biopsies, without which patients may be inappropriately staged and miss out on access to novel therapies that may enable long term survival
- ✓ Variable rates of specialisation in melanoma and inconsistent access to multi-disciplinary teams
- ✓ Lack of accreditation for specialised skin services in primary care settings
- ✓ Lack of written treatment and care plans
- ✓ Regulatory risk for access to novel therapies
- ✓ Variable access to clinical trials, particular for regional and remote communities.

High rates of partial biopsy

The recommended biopsy technique for suspected melanoma is excision with narrow margins. [148]

Partial biopsy techniques, such as a 'punch' or a 'shave' biopsy, may lead to misdiagnosis as a result of base transection or unrepresentative sampling of a large lesion. Where this occurs, there may be an underestimate of tumour thickness or an inability to assess overall tumour architecture, leading to misdiagnosis and inappropriate treatment of a patient. Research highlights the significant risks associated with the use of partial biopsies:

- A 2019 study found that in the context of shave biopsies (with or without base transection), thickness was underestimated to a greater extent for thick melanomas (2.15 mm on average) than for thin melanomas (0.06mm). [149]
- Similarly, punch biopsies *underestimate thick melanomas by 5.86 mm on average*.[150]
- Shave biopsies and punch biopsies are associated with false-negative misdiagnosis rates with adverse outcomes that are *2.4 and 16.8 times the rate of misdiagnosis in excisional biopsies*.[151]

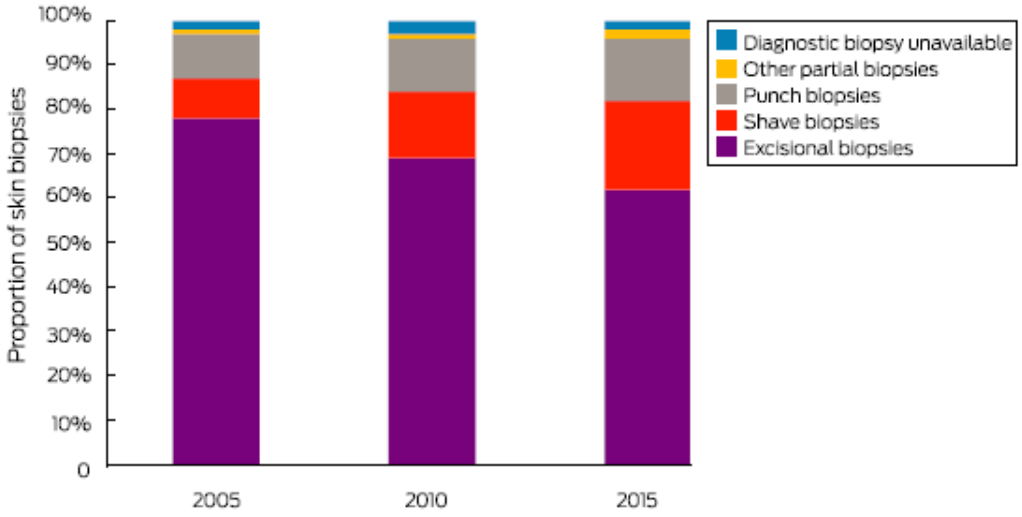
Moreover, base transection is a particular problem when the tumour thickness is close to the 1 mm threshold which would dictate the need for a Sentinel Lymph Node Biopsy, with errors potentially impeding the accuracy of further staging and enabling access to adjuvant therapies for Stage III melanoma.

Yet the use of punch and shave biopsies not only remains high, it has been increasing.

For example, a Victorian study reported proportion of shave biopsies increased from nine per cent of all skin biopsies in 2005 to 20 per cent in 2015, despite guideline recommendations (Figure 6.4).[152] Medicare data also shows skin biopsy rates have increased by 66 per cent over the past decade.

[148] See: Clinical practice guidelines for the diagnosis and management of melanoma, available at: https://wiki.cancer.org.au/australia/Guidelines:Melanoma
[149] de Menezes, SL, Kelly, JW, Wolfe, R, et al., 2019, The increasing use of shave biopsy for diagnosing invasive melanoma in Australia, MJA, 211(5), 213-218.
[150] Ibid
[151] Ng, J, Swain, S, Dowling, JP, 2010, The Impact of Partial Biopsy on Histopathologic Diagnosis of Cutaneous Melanoma, JAMA, Arch Dermatol, 146(3), 234-239.
[152] de Menezes, SL, Kelly, JW, Wolfe, R, et al., 2019, The increasing use of shave biopsy for diagnosing invasive melanoma in Australia, MJA, 211(5), 213-218.

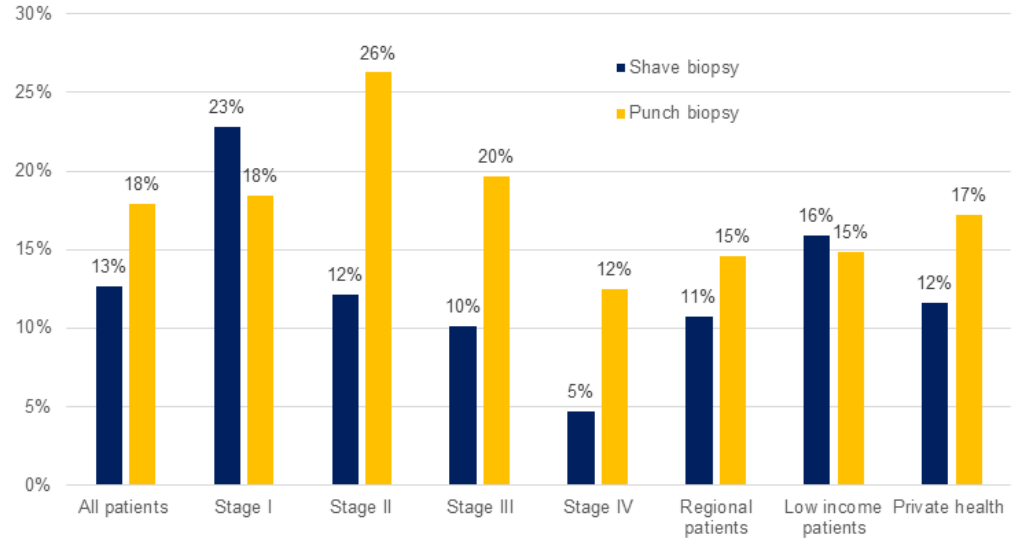
Figure 6.4: Rates of partial biopsy: Victoria Melanoma Service



Source: de Menezes, SL, Kelly, JW, Wolfe, R, et al., 2019, The increasing use of shave biopsy for diagnosing invasive melanoma in Australia, MJA, 211(5), 213-218.

Rates of shave and punch biopsies reported in the Melanoma Patient and Carer Survey were consistent with the Victorian study (Figure 6.5) and similarly high.

Figure 6.5: Rates of shave and punch biopsies as reported in the Patient and Carer Survey



Source: Melanoma Patient and Carer Survey, see Appendix B.

Failure to undertake Sentinel Lymph Node Biopsy required for accurate staging

In the 8th edition of the AJCC staging system, Sentinel Lymph Node Biopsy is required for pathological staging of all patients whose primary melanomas are greater than 1 mm thick.[153] Many clinical practice guidelines also recommend Sentinel Lymph Node Biopsy for patients with tumors 0.8 - 1 mm thickness when other high-risk features are present, such as the

[153] Gershenwald, JE, Scolyer, RA, Hess, KR, Sondak, VK, Long, GV, Ross, MI, Lazar, AJ, Faries, MB, Kirkwood, JM, McArthur, GA, Haydu, LE, 2017, Melanoma staging: evidence-based changes in the American Joint Committee on Cancer eighth edition cancer staging manual, CA: a cancer journal for clinicians, 67(6), 472-492.

presence of ulceration, a high mitotic rate, young patient age (<40), or lymphovascular invasion.[154]

The literature review and stakeholder consultations significant and widespread non-adherence to clinical guidelines with respect to the performance of Sentinel Lymph Node Biopsies, which may prevent the appropriate staging of patients and access to immunotherapies; for example:[155]

- A population-based study in Queensland between 2010 and 2014 reported rates of Sentinel Lymph Node Biopsy of only 33 per cent for Stage 1b and Stage 2 melanoma patients.
- The 2006 New South Wales Melanoma Patterns of Care Study reported that Sentinel Lymph Node Biopsy was performed on only 45 per cent of patients diagnosed with a melanoma >0.75 mm thick.[156]

Clinician attitudes and 'disbelief' of the data on Sentinel Lymph Node Biopsies are reported to be contributing factors to lower rates of SNLB than would be expected:

- A 2020 study found 18 per cent of dermatologists thought Sentinel Lymph Node Biopsies were unimportant, and 26 per cent were unsure if Sentinel Lymph Node Biopsies played an important role in melanoma management. Eight per cent of dermatologists would not discuss Sentinel Lymph Node Biopsies with their patients.[157]
- A similar study in 2021 focused on GPs found less than two-thirds of GPs thought that Sentinel Lymph Node Biopsies had an important role in the management of patients with melanoma. Of GPs who would discuss SLNB with eligible patients, less than 40 per cent correctly identified that SLNB is recommended for patients with an invasive melanoma >1 mm thick. The report concluded that while GPs were generally supportive of Sentinel Lymph Node Biopsies, familiarity with the guidelines was low, particularly regarding which patients should be considered for SLNB.[158]

The literature was echoed with strong concerns among stakeholders (Figure 6.6).

[154] Scolyer, RA, Rawson, RV, Gershenwald, JE, et al., 2020, Melanoma pathology reporting and staging. Mod Pathol, 33, 15–24, https://doi.org/10.1038/s41379-019-0402-x.
[155] The benefits of biopsy-based staging and management are well defined; for example, by providing prognostic information and allowing identification of patients with nodal metastases who may benefit from immediate complete lymphadenectomy. Morton, DL, Thompson, JF, Cochran, AJ, Mozzillo, N, Nieweg, OE, Roses, DF, Hoekstra, HJ, Karakousis, CP, Puleo, CA, Coventry, BJ, Kashani-Sabet, M, 2014, Final trial report of sentinel-node biopsy versus nodal observation in melanoma, New England Journal of Medicine, 370(7), 599-609.
[156] Rapport, F, Smith, AL, Cust, AE, et al., Identifying challenges to implementation of clinical practice guidelines for sentinel lymph node biopsy in patients with melanoma in Australia: protocol paper for a mixed methods study, BMJ Open, 10.
[157] Smith, AL, Watts, CG, Robinson, S, Schmid, H, Goumas, C, Mar, VJ, Thompson, JF, Rapport, F; Australian Melanoma Centre of Research Excellence Study Group, Cust, AE, Knowledge and attitudes of Australian dermatologists towards sentinel lymph node biopsy for melanoma: a mixed methods study, Australas J Dermatol, 62(2), 168-176.
[158] Watts, CG, Smith, AL, Robinson, S, Chang, CS, Goumas, C, Schmid, H, Kelly, JW, Hong, AM, Scolyer, RA, Long, GV, Spillane, AJ, Henderson, M, Gyorki, DE, Mar, VJ, Morton, RL, Saw, RP, Varey, AH, Mann, GJ, Thompson, JF, Cust, AE, 2020, Australian general practitioners' attitudes and knowledge of sentinel lymph node biopsy in melanoma management, Aust J Gen Pract, 49(6), 355-362.

Figure 6.6: Stakeholder perspectives on risks with respect to Sentinel Lymph Node Biopsies

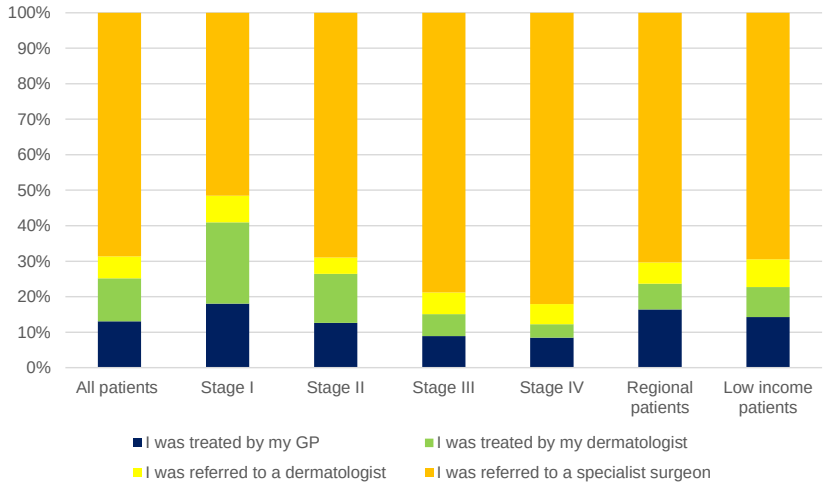
Variable rates of specialisation in melanoma and inconsistent access to multi-disciplinary teams

Variation in patient outcomes is also a function of the huge variety of settings in which melanoma patients (at all stages of disease) are managed.

Data show melanoma is treated in a wide variety of settings across capital city and metropolitan regions, with potentially varying levels of specialisation in melanoma and variable access to multi-disciplinary team (MDT) care.

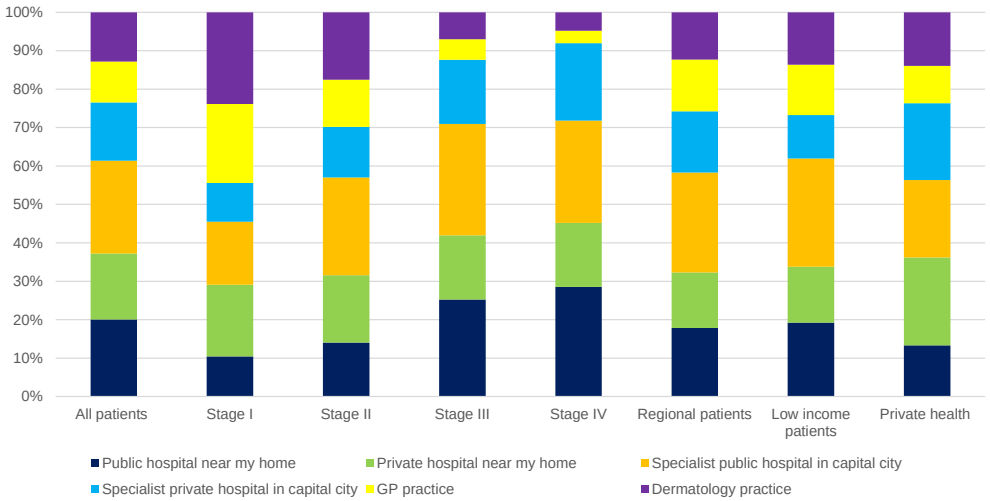
For example, results from the Melanoma Patient and Carer Survey indicate that most patients are referred to a specialist surgeon, with around 70 per cent (60 per cent) of patients reporting receipt of treatment by a specialist surgeon on average. Even among patients with advanced Stage IV disease, however, a proportion reported being treated by their GP. Patients across all stages are also treated in both specialist centres and regional areas.

Figure 6.7: Treatment and referral patterns



Source: Melanoma Patient and Carer Survey, see Appendix B.

Figure 6.8: Treatment settings



Source: Melanoma Patient and Carer Survey, see Appendix B.

These data are consistent with stakeholder concerns regarding referral patterns and in particularly, potentially unequal access to multi-disciplinary teams for patients with metastatic melanoma. For example, as shown in Figure 6.9, concerns were raised that some general oncologists or surgeons may not have experience in the treatment of melanoma or be current with best practice guidelines and research, which may increase the risk of poorer outcomes for the patient.

Ultimately, variation in clinical practice and access to services nationally culminates in variation in survival outcomes, with regional patients and patients from low socioeconomic status areas shown to be most at risk.

Figure 6.9: Variation in clinical practice and referral patterns

Need for accreditation of the provision of specialised skin services by GPs

GPs are critically important service providers for people diagnosed with melanoma and have an important role to play in meeting demand for complex skin services, particularly in regional areas and against a backdrop of persistent skills shortages in dermatology. In regional areas, they are often the primary providers for patients; Figure 6.1 above shows regional patients are more likely to be treated by their GP on average.

In both metropolitan and regional areas, however, GPs with a skin interest may perform a range of specialised skin services that go beyond the normal scope of GP practice; major examples include more complex biopsies and skin flaps.

Many GPs have undertaken specialist training as part of developing a special interest in skin, but stakeholders reported wide variation in the quality and scope of this training. Stakeholders raised concerns for a lack of regulation for what constitutes appropriate training for more advanced services as well as a lack of recognition for GPs that have invested in their practice and skills. There was a consistent concern among stakeholders regarding the need for a clear articulation of training and accreditation requirements for more advanced skin services to ensure the safety and quality of these services.

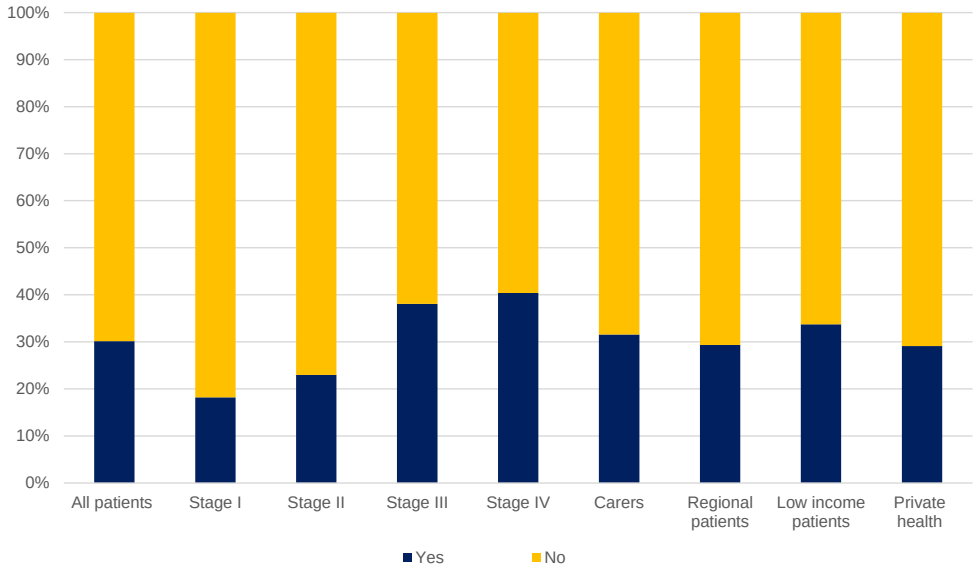
Figure 6.10: Lack of regulation for the provision of highly specialised skin services in primary care settings

The Royal Australian College of General Practitioners (RACGP) has reported that it is planning to review and expand the curriculum for medical school graduates, as well as better define the normal scope of practice for GPs in relation to skin services and provide some formal recognition of GPs with skills that go beyond the normal scope of practice. Once the normal scope of practice has been established, this would allow for accreditation of training or of the services to ensure minimum standards for quality and safety are met.

Lack of written treatment plans and patient understanding of diagnosis, treatment plans and options

Notwithstanding OCP guidance for the provision of written treatment plans for melanoma patients and their families, Melanoma Patient and Carer Survey data show the provision of written treatment plans is low, with only 30 per cent of patients reporting having received a written treatment plan. Rates are low even among patients with advanced metastatic melanoma; survey data indicate that only around 40 per cent of patients with advanced melanoma receive a written care plan on average (Figure 6.6).

Figure 6.11: Did you receive a written treatment plan?

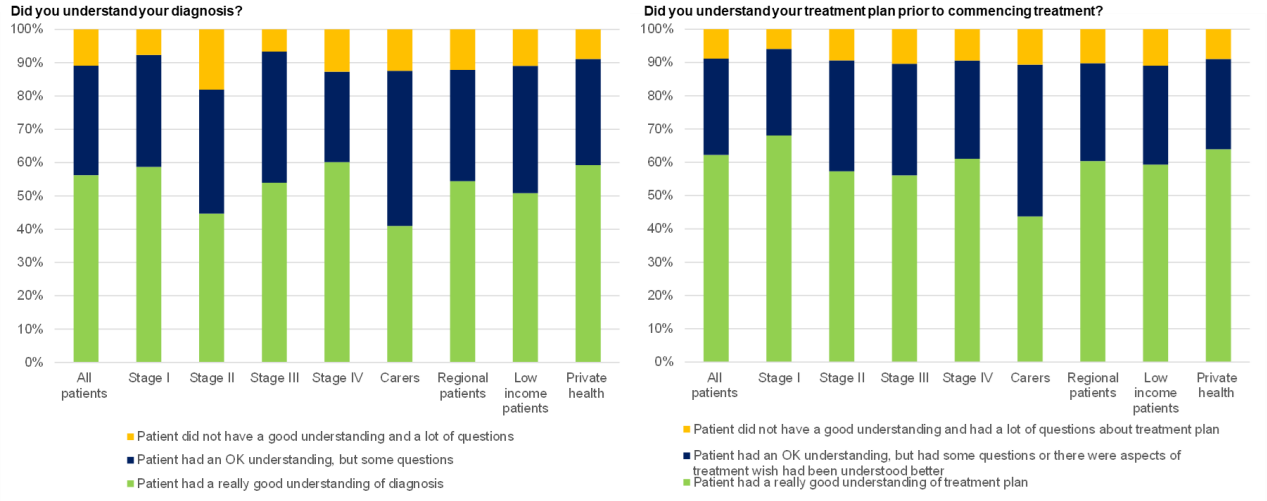


Source: Melanoma Patient and Carer Survey, see Appendix B.

This, alongside risks of low health literacy among some groups, likely contributed to a poor understanding of their diagnosis and treatment plan (Figure 6.12), with:

- Just over one in ten patients indicating they did not understand their diagnosis and around one in 10 indicating they did not understand their treatment plan
- 30 per cent of patients reporting significant questions or that they wished they had understood aspects of their diagnosis or treatment
- 30 per cent of patients noting that they had questions or wished they had better understood aspects of their diagnosis or treatment
- More than half of carers noting that they had questions or wished they had better understood aspects of their diagnosis or treatment.

Figure 6.12: Understanding of diagnosis and treatment by patients and carers



Source: Melanoma Patient and Carer Survey, see Appendix B.

One in three patients and carers indicated patients were not sufficiently empowered with information to access treatment and care once they had been diagnosed. Among respondents who felt patients were not empowered, the three most frequently identified barriers included:

- Lack of awareness of treatment options (64 per cent of respondents)
- Lack of awareness of supportive care, with 64 per cent of respondents indicating this was an issue for patients (See also Chapter 7)
- Lack of information about melanoma generally (47 per cent of respondents), which would enable patients to engage more effectively with the health system.

A lack of information and understanding about treatment and supportive care options was also a major theme of the consumer forums (Figure 6.13).

Figure 6.13: Stakeholder perspectives on lack of information and the impacts on patients

Note: continued on the next page

Regulatory risks for access to novel therapies

Currently Australia is broadly in sync with best evidence-based care in melanoma treatment today, but stakeholders indicated there remain constraints in treatment planning exerted by the PBS as well as long run risks to access to novel therapies, particularly for rare indications. While Australia is in line with global best practice today, it has often lagged its international peers in gaining access to novel systemic therapies (Figure 6.14).

Figure 6.14: Stakeholder perspectives on access to novel therapies, treatment planning constraints and regulatory risk

Reflecting an increasing understanding of these risks, the Australian Government has launched a number of inquiries into medicines access, including the Inquiry into Approval Processes for New Drugs and Novel Medical Technologies in Australia,[159] the Review of National Medicines Policy[160] and a Review of Health Technology Assessment in Australia to be completed as part of the execution of a Strategic Agreement between the Australian Government and Medicines Australia.[161] Through these reviews, there are opportunities to more consistently improve access to novel therapies, particularly where:

- There may not be private incentive to develop evidence to support the registration of a new indication for a systemic therapy and/or reimbursement through the PBS, which is often the case for rarer cancers, or
- Hospitals may decline to fund the medicine due to attendant, high in-patient costs associated with the administration of the systemic therapy.

Where a medication lacks an indication for use in melanoma, it may be prescribed off-label, the outcomes of which may not be well documented, further frustrating the development of evidence needed to support additional indications and reimbursement. Where a medication is not PBS listed or not available in public hospital settings, patients may receive medications by privately funding

[159] See: Inquiry into approval processes for new drugs and novel medical technologies in Australia, available at: https://www.aph.gov.au/Parliamentary_Business/Committees/House/Health_Aged_Care_and_Sport/Newdrugs
[160] See Review of the National Medicines Policy available at: https://consultations.health.gov.au/technology-assessment-access-division/national-medicines-policy-review/
[161] Strategic Agreement 2022-2027, see https://www.medicinesaustralia.com.au/policy/strategic-agreement-2022-2027//

access to these medications or through compassionate access programs, the access to which has been historically opaque. This gives rise to the risk of a two-tiered system, where more affluent patients can self-fund and close access gaps arising from delays in regulatory processes, while less affluent patients are unable to access cutting edge therapies, leading to sub-optimal and inequitable survival outcomes across socioeconomic groups.

The development of a formalised process for identifying therapies where there is inadequate evidence to support listing and limited market incentives, such as for a very small patient population with, say, a rare sub-type of melanoma, would be a welcome improvement to provide enhanced regulatory certainty for patients, their families and treating clinicians. This has been formally recommended by the Inquiry into approval processes for new drugs and novel medical technologies in Australia (the Zimmerman Review) and should be implemented by Government as a next step.

6.3 Opportunities to improve outcomes in diagnosis and treatment

To improve outcomes for patients and their families, there should be improved adherence to clinical best practice and improved information support for patients to better engage with their providers. This aligns to patient perspectives regarding the priorities for improved treatment; as shown in Figure 6.15, patients identified the 'Top 5' priorities to better empower patients to access treatment and care to be to:

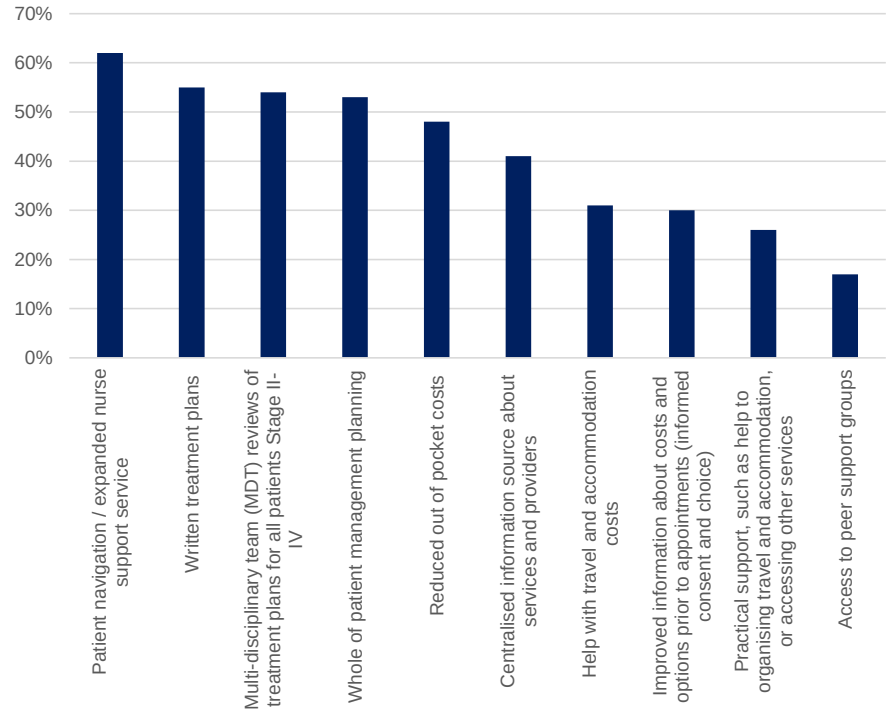
- Develop a patient navigation service and/or expand access to nurse support services (62 per cent of respondents)
- Provide written treatment plans to all patients (55 per cent of respondents)
- Require multi-disciplinary team (MDT) reviews of treatment plans for all patients Stage II-IV (54 per cent of respondents)
- Ensure whole-of-patient management planning (53 per cent of respondents), including planning for supportive care alongside other treatment
- Reduce out of pocket costs (48 per cent of respondents).

Other significant priorities included creating a centralised information source about services and providers, providing more help with travel and accommodation costs, improving information about costs and options prior to appointments (informed consent and choice), introducing practical support services, such as help to organise travel and accommodation or accessing other services, and improved access to peer support groups.

Taken together, the following actions are recommended to improve the consistency and quality of diagnosis and treatment of melanoma and information support for patients and their families:

- Establish a Patient Navigation Service
- Require written treatment and care plans
- Maintain clinical guidelines for melanoma through a peak national body
- Develop a clinical care standard for melanoma
- Develop a formal process for evidence development to ensure access to clinically important therapies that lack market incentives.

Figure 6.15: How can we better empower patients to access treatment and supportive care?



Source: Melanoma Patient and Carer Survey, see Appendix B.

Develop a Patient Navigation Service

Against a backdrop of patients having a poor understanding of their diagnosis and treatment, feeling unsupported in navigating to supportive care and survivorship services, the development of a Patient Navigation Service, integrated with specialist melanoma nurse support (see Chapter 7) was most frequently identified as the top priority to improve outcomes for patients and survivors in the Melanoma Patient and Carer Survey, with more than 60 per cent of respondents listing the development of a navigation and nurse service as a Top 5 priority.

Empirical studies have found that patient navigation can improve the timeliness of diagnostic resolution and care,[162] and is increasingly becoming the standard of care.[163] Patient navigation services can also improve health care service effectiveness and efficiency, with a pilot program in the US leading to fewer hospitalisations, ED visits and intensive care admissions; this case study is shown in Box 6.1.

Box 6.1 Case study – The Patient Care Connect Program

In the Patient Care Connect Program, lay patient navigators (as distinct from nurse patient navigators) support patients with cancer from diagnosis through survivorship to end of life. They empowered patients to engage in their health care and navigated them through a complex health care system. The setting was the University of Alabama at Birmingham Health System Cancer Community Network, which includes two academic and 10 community cancer centres across Alabama, Georgia, Florida, Mississippi, and Tennessee. Participants were Medicare beneficiaries with cancer who received care at participating institutions from 2012 through 2015. The observational study used propensity score–matched regression analysis to compare quarterly changes in the mean total Medicare costs and resource use between 'navigated patients' and 'non-navigated' matched comparison patients.

[162] Wells, KJ, Battaglia, TA, Dudley, DJ, et al., 2008, Patient navigation: state of the art or is it science?, *Cancer*, 113(8), 1999–2010; Robinson-White, S, Conroy B, Slavish, KH, Rosenzweig, M, 2010, Patient navigation in breast cancer: a systematic review. *Cancer Nurs*, 33(2f), 127–140.

[163] National Comprehensive Cancer Network, 2014, *The case manager or patient navigator: providing support for cancer patients during treatment and beyond*, National Comprehensive Cancer Network. http://www.nccn.com/living-with-cancer/understanding-treatment/152-case-managers-for-cancer-patients.html, accessed December 2019.

In total, 12,428 patients (mean age at cancer diagnosis, 75 years; 52.0% female) were propensity score matched, including 6,214 patients in the navigated group and 6,214 patients in the matched non-navigated comparison group. Compared with the matched comparison group, the mean total costs per navigated patient declined by an additional $781.29 per quarter (β = −781.29, SE = 45.77, P < .001), for an estimated $19 million decline per year across the network. Inpatient and outpatient costs had the largest between-group quarterly declines, at $294 and $275, respectively, per patient. Moreover, the study found that among navigated patients, compared with matched comparison patients (P < .001):

- Emergency department visits decreased by 6.0 per cent
- Hospitalisations decreased by 7.9 per cent
- Intensive care unit admissions decreased by 10.6 per cent.

As a result, costs to Medicare and health care use from 2012 through 2015 declined significantly for navigated patients compared with matched comparison patients.

Source: Rocque, GB, Pisu, M, Bradford, JE, et al., 2017, Resource Use and Medicare Costs During Lay Navigation for Geriatric Patients with Cancer, *JAMA Oncol*., 3(6), 817-825, doi:10.1001/jamaoncol.2016.6307.

Patient navigation services can be particularly important for patients with high unmet needs and low health literacy. For example, the National Cancer Institute in the US established a Patient Navigation Research Program, which was evaluated by multiple studies to determine the impact of the program on service outcomes, patient satisfaction and care for priority groups. Studies found that cancer patients experiencing unemployment, unstable housing and lack of social supports experienced longer times to diagnostic resolution and treatment without patient navigation support but there was no difference along any of these variables in the patient navigation services arm.[164] The potential for patient navigation to support disadvantaged and/or priority groups has been confirmed by other studies, which have found that patient navigation services improve adherence to follow-up diagnostic procedures and treatment, particularly for those who are medically underserved.[165] Patient navigators can also help patients gain access to financial support.[166]

Figure 6.16: Patient and carer perspectives on patient navigation services and information support

[164] Rodday, AM, Parsons, SK, Snyder, F, Simon MA, et al., 2015, Impact of patient navigation in eliminating economic disparities in cancer care, *Obstetrics and Gynecology Cancer,* 121, 4025-4034, doi: 10.1002/cncr.29612.
[165] Fouad, M, Wynn, T, Martin, M, Partridge, E, 2010, Patient navigation pilot project: results from the Community Health Advisors in Action Program (CHAAP), *Ethn Dis*., 20(2), 155-61.
[166] Natale-Pereira, A, Enard, KR, Nevarez, L, and Jones, LA, 2011, The Role of Patient Navigators in Eliminating Health Disparities, *Cancer*, 117(15 suppl), 3543-52, doi: 10,1002/cncr.26264.

Taken together, these data demonstrate that patient navigation services have the potential to deliver significant value, and will become increasingly important in the context of increasing numbers of melanoma patients and survivors.

Require written treatment and care plans

There are strong guidelines for the provision of written treatment plans and survivorship care plans at the commencement of active treatment and the completion of active treatment as clinical best practice in cancer treatment and care. Recommendations for the provision of written care plans at the start of active treatment and the completion of treatment have been published by the NHS in the UK,[167] ASCO in the US,[168] and in Australia, with the recent development of OCPs for a range of tumours, which have been endorsed by the National Cancer Expert Reference Group.

The provision of a written care plan, particularly for patients with advanced melanoma, is a foundational element for empowering patients to understand their diagnosis and treatment plan. Written treatment and care plans can also encourage systematic discussion and referral to supportive care services at key treatment intervals.

Maintain clinical guidelines for melanoma through a peak national body

Melanoma is one of the few cancers for which clinical guidelines have been developed nationally.

This has been championed not by Australian governments, however, but by the charitable sector. This dilutes the potential awareness, use and impact of these clinical guidelines nationally, and increases the risk that they are not kept current. Moreover, they are not consistently referenced by key providers. For example, the current guidelines can be found indirectly through the RACGP depending on how one navigates the website, but the current melanoma clinical guidelines are not available under the RACGP's full list of guidelines, nor are the most current guidelines returned if one searches 'melanoma' in the search function. The complexity, inconsistency and fragmented approach of current clinical guideline development could be significantly streamlined and improve the uptake of guidelines through a national approach.

Australia should identify a peak national body to develop, maintain and promote the use of clinical guidelines nationally to reduce unwarranted variation and improve the consistent delivery of quality treatment and care.

Historically, the National Cancer Expert Reference Group was the organisation charged with improving quality and safety in cancer care. The National Cancer Expert Reference Group was a panel of experts and jurisdictional and consumer representatives established by the Council of Australian Governments in 2010 to develop a national cancer work plan to improve cancer care in Australia. The National Cancer Expert Reference Group identified the value of a national approach to delivering consistent and optimal cancer care; its primary initiative under this banner was the development of the Optimal Care Plans. In 2020, the Australian Government disbanded the Council of Australian Governments and with it, the National Cancer Expert Reference Group.

In the intervening time, Cancer Australia has been charged with the responsibility of the development of a National Cancer Plan. Cancer Australia was established by the Australian Government in 2006 to benefit all Australians affected by cancer, and their families and carers. Cancer Australia aims to reduce the impact of cancer, address disparities and improve outcomes for people affected by cancer by leading and coordinating national, evidence-based interventions

[167] Natale-Pereira, A, Enard, KR, Nevarez, L, and Jones, LA, 2011, The Role of Patient Navigators in Eliminating Health Disparities, *Cancer*, 117(15 suppl), 3543-52, doi: 10,1002/cncr.26264.
[168] American Society of Clinical Oncology, 2020, *Cancer Treatment and Survivorship Care Plans*, https://www.cancer.net/survivorship/follow-care-after-cancer-treatment/asco-cancer-treatment-and-survivorship-care-plans.

across the continuum of care.[169] Cancer Australia will partner and engage across sectors to encourage transferability and adoption of best practices. This will help to address unwarranted variations and improve quality of care and cancer outcomes for all patients, irrespective of their socio-demographics or where they enter the health system.[170]

Cancer Australia is not currently funded to develop, maintain and promote clinical guidelines for all cancers but this could be supported as part of the development of Australia's Cancer Plan to improve equity, quality and predictability in melanoma (and other) cancer care.

Establish a quality framework for melanoma to ensure adherence to clinical best practice

Clinical care standards go beyond clinical guidelines to promote adherence to best practice care.

Clinical care standards are the mechanism by which quality frameworks for care are established in Australia and play an important role in reducing unwarranted variation in clinical practice. Clinical care standards define the minimum care people should expect to be offered or receive, regardless of where they are treated in Australia.[171] Clinical Care Standards are evidence-based and incorporate performance indicators to drive quality and safety improvements across healthcare settings.

At present, there are a range of clinical care standards that have been developed in Australia and are in use; these include:

- Acute Coronary Syndromes
- Acute Stroke
- Antimicrobial Stewardship
- Colonoscopy
- Delirium
- Heavy Menstrual Bleeding
- Hip Fracture
- Osteoarthritis of the Knee
- Management of Peripheral Intravenous Catheters Clinical Care Standard
- Third and Fourth Degree Perineal Tears
- Venous Thromboembolism Prevention.

In addition, clinical care standards are in development for acute anaphylaxis, cataracts, low back pain and sepsis.

No clinical care standard has been developed for any cancer to date, despite cancer accounting for the greatest disease burden of all health conditions in Australian communities today based on the Australian Institute of Health and Welfare's most recent Burden of Disease study.[172]

In light of the variation in clinical practice and survival outcomes observed for Australian melanoma cancer patients, it is critical that a clinical care standard and quality framework is developed for melanoma. This clinical standard could build on the work of MelCOR and ideally incorporate indicators for quality, including:

[169] See Cancer Australia: https://www.canceraustralia.gov.au/about-us.
[170] *Ibid.*
[171] Australian Commission for Safety and Quality in Health Care, 2021, Clinical Care Standards, available at: https://www.safetyandquality.gov.au/standards/clinical-care-standards.
[172] AIHW, 2020, Burden of Disease, Australia's Health 2020, accessed at: https://www.aihw.gov.au/reports/australias-health/burden-of-disease.

- The provision of written treatment plans as a standard of care
- Requirements for MDT reviews for selected patients as a standard of care
- Discussion of supportive care as a standard of care
- Discussion of clinical trials as a standard of care
- Minimum standards for palliative care.

Develop a formal process for evidence development for clinically important indications that lack market incentives for registration and reimbursement

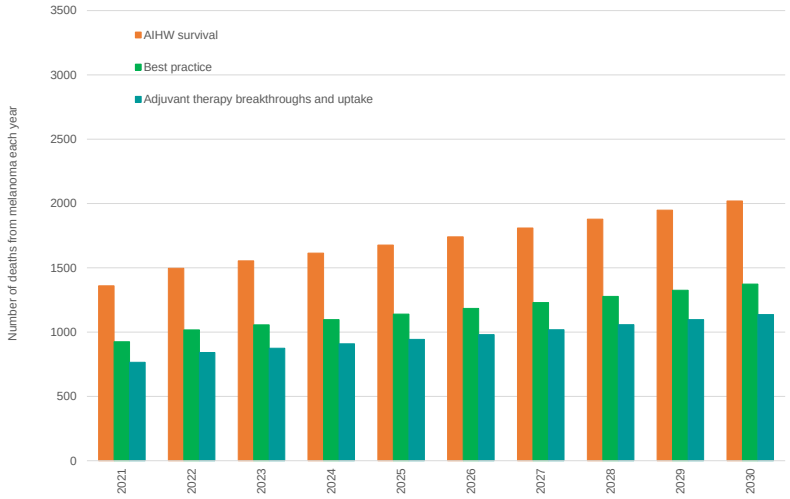
To reduce the risks of unnecessary delays in access to novel therapies arising from market failures or barriers to evidence development, it is recommended that government develop a formal process for the identification of clinically important therapies where there are insufficient market incentives for evidence development to support the registration of new indications and/or PBS reimbursement, or substantial inconsistencies in access across Australian jurisdictions or hospital settings.

Government should develop formal criteria for the identification of clinically important therapies where there are access challenges, and provide a formalised pathway for evidence development and funding depending on the nature of the specific product and patient context. Pathways for evidence development could include a registry or trials approach where there are inadequate incentives for evidence development.

6.4 Impacts from improvements in the diagnosis and treatment of melanoma

Based on current mortality to incidence outcome data reported by State Cancer Registries, if current clinical (regional) best practice were achieved nationally, there would be a 14.5 per cent reduction in the number of deaths from melanoma each year, achieving best practice outcomes based on average survival for the least disadvantaged quintile would see mortality reduce by 32 per cent. Over the 2021-2030 horizon, if clinical best practice was realised nationally, this would prevent the death of between approximately 2,000 and 4,400 people.

Figure 6.17: Benefits of reducing unwarranted variation and achieving clinical best practice in melanoma



Source: Projections based on Australian Institute of Health and Welfare Cancer Data in Australia 2020; State Cancer Registry data for clinical best practice; Menzies, AM, Amaria, RN, Rozeman, EA, et al, 2021, Pathological response and survival with neoadjuvant

therapy in melanoma: a pooled analysis from the International Neoadjuvant Melanoma Consortium (INMC), Nature Medicine, 27, 301-309, doi: 10.1038/s4591-020-01188-3.

6.5 Conclusions: Scorecard assessment and recommended actions to improve diagnosis and treatment of melanoma

The data show that Australia enjoys a high standard of care in melanoma nationally, which promotes globally leading survival outcomes.

While acknowledging Australia's relative success in survival compared to its international peers, there are a number of opportunities to improve treatment nationally. In particular, variation in care and survival outcomes across the country are evident in the data, and supported by stakeholder views, which highlight the variable management of melanoma across different settings at all stages of disease, as well as inconsistent and potentially inappropriate referral patterns and/or poor access to MDTs. Patients require more support along the journey to understand their diagnosis, treatment and supportive care options.

With the potential to reduce melanoma mortality by more than 30 per cent, the following actions to reduce variation in treatment and supportive care are recommended:

- Establish a Patient Navigation Service
- Require written treatment and care plans
- Maintain clinical guidelines for melanoma through a peak national body
- Develop a clinical care standard for melanoma
- Develop a formal process for evidence development to ensure access to clinically important therapies that lack market incentives.

Table 6.1: Scorecard assessment and recommendations for action – Diagnosis and Treatment

	Rating	Australian successes	Areas for improvement	Action Plan
Diagnosis & Treatment	✓✓✓	✓ High survival rates for early Stage I, Stage II melanomas ✓ Doubling of survival outcomes for advanced melanoma patients through immunotherapy and targeted therapy advancements ✓ PBS funding in line with best-evidence-based care for systemic treatments in melanoma	× Increased use of shave and punch biopsies, associated with high error rates, in contrast to clinical guidelines × Poor adherence to guidelines for Sentinel Lymph Node Biopsy and appropriate referrals × Significant variation in patient outcomes by jurisdiction and income levels × Lack of quality performance benchmarks Patients inconsistently screened for supportive care needs, lack of awareness of supportive care services × Some constraints on treatment planning by clinicians – timing,	Maintain up-to-date clinical guidelines, promoted to all treating clinicians in primary and hospital settings Require written treatment plans Develop quality performance framework for melanoma building on the work of MelCOR Develop Patient Navigation Service Develop formal approach to address access barriers to clinically important therapies where market failures exist

	Rating	Australian successes	Areas for improvement	Action Plan
			intensity of systemic therapies × Poor understanding of diagnosis and treatment options × Room for improvement in regional service delivery (including immunotherapies) × Regulatory risk for access to clinically important therapies where there are limited incentives for the registration of new indications and/or reimbursement	

Chapter 7

Supportive care and survivorship: performance and areas for improvement

As the incidence of melanoma increases and mortality rates fall, over the next decade the number of melanoma survivors in Australia is expected to continue to increase exponentially. The needs of melanoma patients and survivors can remain high, arising from numerous factors, including potential financial stress, psychosocial impacts and the management of long-term treatment side effects. Simultaneously, stakeholders and survey respondents indicated there can be significant gaps in available information and support for survivors.

This chapter outlines the major trends in survivorship and work completed to date to support survivors, as well as future opportunities to improve outcomes for patients and carers.

7.1 What are supportive care and survivorship, and why are they so important?

Supportive care is a term that can mean different things to different people. Clinicians, for example, may sometimes think about supportive care in relatively narrow clinical terms, such as interventions to manage infection or pain, and in some cases may not consider supportive care to be a core component of treatment.

Increasingly, however, supportive care is being defined more broadly and recognised as a core component of cancer treatment and care. For example, the National Cancer Institute defines supportive care to be:

> *Supportive care is care given to improve the quality of life of patients who have a serious or life-threatening disease. The goal of supportive care is to prevent or treat as early as possible the symptoms of a disease, side effects caused by treatment of a disease, and psychological, social, and spiritual problems related to a disease or its treatment. Supportive care is also sometimes called comfort care, palliative care, and symptom management.*[173]

Within Australia, the definition of supportive care is most comprehensively described by the Optimal Care Pathways, which have been recently updated by the Cancer Council Victoria and endorsed by Cancer Australia.[174] The Optimal Care Pathways call for the provision of supportive care screening across physical, psychological, social, information and spiritual domains from diagnosis to ensure appropriate treatment and care planning at all stages of care.

[173] National Cancer Institute, 2020, NCI Dictionary of Cancer Terms, supportive care, https://www.cancer.gov/publications/dictionaries/cancer-terms/def/supportive-care.
[174] See: Optimal Care Pathway for Melanoma, 2021, Second Edition, available at: https://www.cancer.org.au/assets/pdf/melanoma-optimal-cancer-care-pathway

Survivorship care is closely related to supportive care. For example, the NCI defines survivorship to be:

> *Survivorship focuses on the health and well-being of a person with cancer from the time of diagnosis until the end of life. This includes the physical, mental, emotional, social, and financial effects of cancer that begin at diagnosis and continue through treatment and beyond. The survivorship experience also includes issues related to follow-up care (including regular health and wellness checkups), late effects of treatment, cancer recurrence, second cancers, and quality of life. Family members, friends, and caregivers are also considered part of the survivorship experience.*[175]

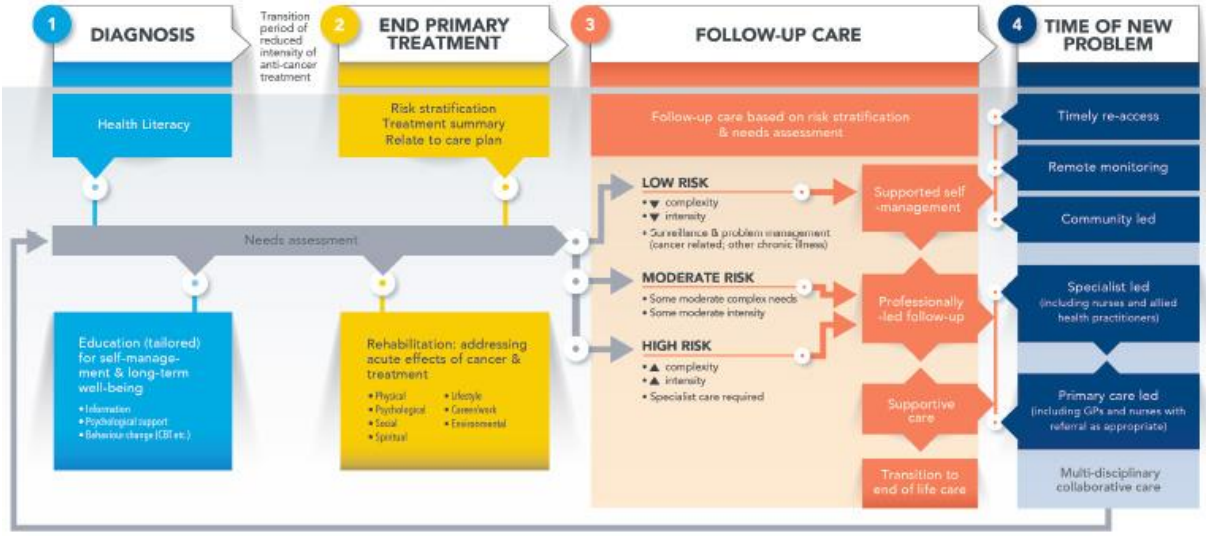
> *A survivorship care plan is a detailed plan given to a patient after treatment ends, that contains a summary of the patient's treatment, along with recommendations for follow-up care. In cancer, the plan is based on the type of cancer and the treatment the patient received. A survivorship care plan may include schedules for physical exams and medical tests to see if the cancer has come back or spread to other parts of the body. Getting follow-up care also helps check for health problems that may occur months or years after treatment ends, including other types of cancer. A survivorship care plan may also include information to help meet the emotional, social, legal, and financial needs of the patient. It may include referrals to specialists and recommendations for a healthy lifestyle, such as changes in diet and exercise and quitting smoking. Also called follow-up care plan.* [176]

While in its broadest definition a person is a cancer survivor from diagnosis for the remainder of their life,[177] in practice the use of the term 'survivorship' tends to be applied from when a person transitions from active anti-cancer treatment to post-treatment care and disease surveillance. Thus, a survivorship care plan (also called a follow-up care plan or post-treatment care plan) is typically provided at the conclusion of active treatment.

The Clinical Oncology Society of Australia (COSA), like the Optimal Care Pathway for Melanoma, recommends a model for supportive care and survivorship care that begins at diagnosis, through the provision of information for self-management and supportive care for long term wellbeing (Figure 7.1). The COSA Model highlights that supportive care needs should be identified from diagnosis to ensure the patient and their family are screened for, and referred to, supportive care from diagnosis through active treatment and as long-term survivors.

[175] National Cancer Institute, 2020, NCI Dictionary of Cancer Terms, survivorship care, https://www.cancer.gov/publications/dictionaries/cancer-terms/search?contains=false&q=survivorship
[176] National Cancer Institute, 2020, NCI Dictionary of Cancer Terms, survivorship care, https://www.cancer.gov/publications/dictionaries/cancer-terms/search?contains=false&q=survivorship
[177] Hewitt, ME., Ganz PA, 2006, From cancer patient to cancer survivor: lost in translation, An American Society of Clinical Oncology and Institute of Medicine Symposium, Washington, National Academies Press.

Figure 7.1: Clinical Oncology Society of Australia Model of Supportive and Survivorship Care



Source: Vardy, JL, Chan, RJ, Koczwara, B, Lisy, K, et al, 2019, Clinical Oncology Society of Australia position statement on cancer survivorship care, Royal Australian College of General Practitioners, 48(12).

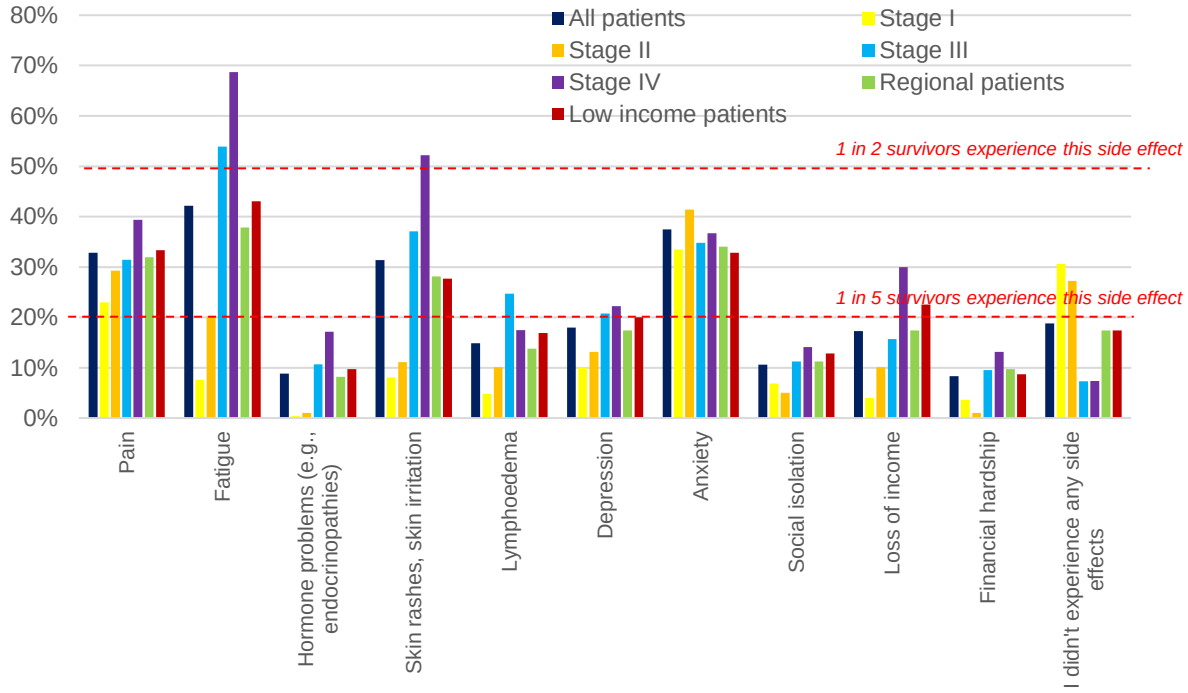
Access to supportive care services both during active treatment and as a survivor are critical to the long-term wellbeing of melanoma patients and survivors.

Patients and survivors can experience severe side effects from treatment, such as lymphoedema, skin rashes and irritation, endocrinopathies, scarring, loss of sight, as well as depression and anxiety. These side effects deteriorate patient and survivors' long-term quality of life and potentially impact treatment adherence and survival. Symptoms often do not present alone, with patients experiencing 'symptom clusters', such as pain, fatigue, and emotional distress. For example, survey data indicates that these survivors can have high rates of:

- Pain, with more than *one in three patients and survivors reporting the experience of pain*, increasing to 40 per cent among Stage IV patients
- Fatigue, with more than *one in two Stage III and Stage IV patients and survivors reporting the experience of fatigue*
- Anxiety and depression, with *nearly 40 per cent of patients and survivors suffering from anxiety* and nearly one in five reporting the experience of depression
- Skin rashes and irritation, with *one in two Stage IV patients reporting the experience of skin rashes and irritation*
- Lymphoedema, with more than 15 per cent of patients with metastatic Stage III and Stage IV melanoma reporting lymphoedema as a side effect of treatment
- Loss of income, with Stage IV and lower income patients most likely to report an adverse effect from the loss of income.

Figure 7.2 highlights the significant adverse effects that many patients and survivors must manage as a result of their diagnosis and treatment, which often increase with severity.

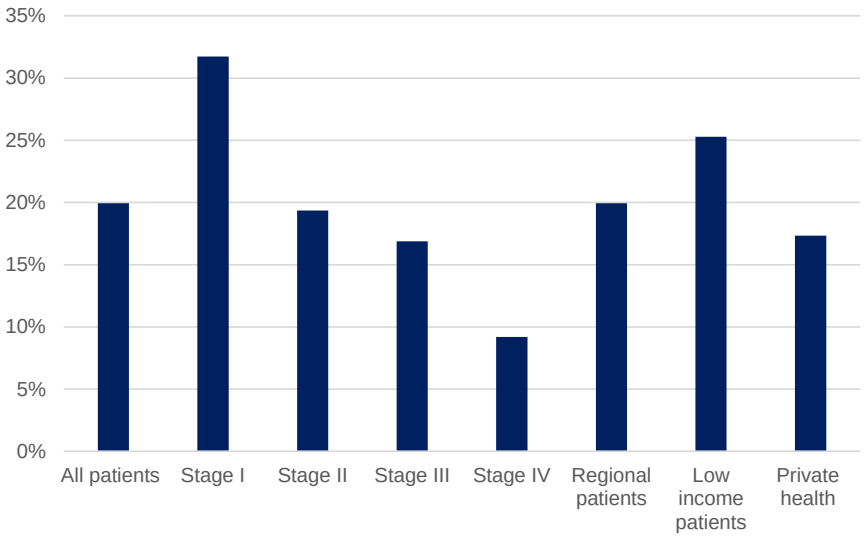
Figure 7.2: Side effects and off target effects of melanoma and its treatment



Source: Melanoma Patient and Carer Survey, see Appendix B.

The provision of supportive care services to patients and survivors can help to better manage these side effects and improve quality of life across these domains. Moreover, many patients and survivors lack social supports, making access to supportive care services for patients and long-term survivors all the more critical. For example, one in five patients indicated they did not have carer support through their diagnosis (Figure 7.3).

Figure 7.3: Percentage of patients and survivors that indicated they did not have any carer support



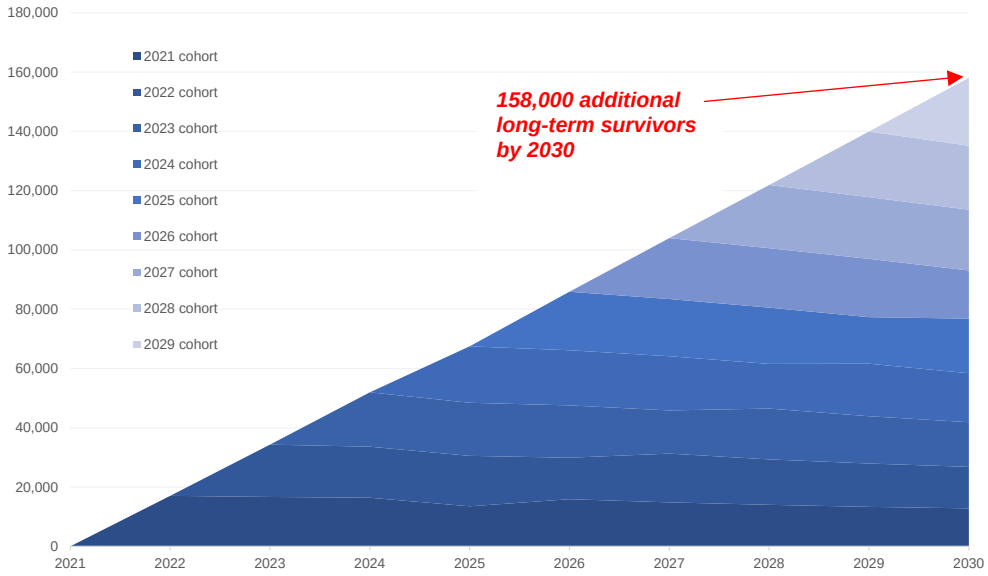
Source: Melanoma Patient and Carer Survey, see Appendix B.

Concerningly, low-income patients were more likely to report no carer support (one in four), increasing the risk of multiple unmet needs for patients. Furthermore, nearly one in 10 metastatic melanoma patients reported no carer support.

7.2 Increasing incidence and survival is leading to exponential growth in melanoma patients and survivors needing support

Demand for supportive care services is set to explode over the forward horizon, as a result of both increasing incidence of melanoma and research breakthroughs leading to exponential growth in the number of long-term survivors. More than 205,000 new patients expected to be diagnosed with and treated for melanoma over the 2021-2030 horizon, and by 2030 there will be an additional 158,000 new melanoma survivors added to an estimated prevalence of more than 190,000 melanoma survivors today (Figure 7.4).

Figure 7.4: Melanoma survivorship growth 2021-2030



Source: Projections based on Australian Institute of Health and Welfare Australian Cancer Database 2016 and National Mortality Database.

7.3 Australian progress in supportive care and survivorship

Australian governments and researchers have been increasingly invested in improving supportive care arrangements for cancer patients and survivors, both generally and for melanoma survivors specifically. In particular, there have been efforts to improve policy settings and supportive care arrangements through:

- The development of the Optimal Care Pathway for melanoma, developed by the Cancer Council and endorsed by Cancer Australia, which:
  - Calls for screening for supportive care needs from diagnosis and throughout treatment and long-term survivorship
  - Provides a checklist for patients and treating clinicians at each stage of treatment to ensure key questions are answered at critical phases of treatment planning
  - Provides increased information to clinicians, patients and carers about potential side effects and provides a list of organisations to which patients may be referred.

- MBS funding General Practitioner Management Plan (GPMP) or Team Care Arrangements (TCA). The aim of GPMPs and TCAs is to help practitioners coordinate the care of people with chronic conditions.
- MBS funding for the GP Mental Health Treatment Plan, where patients can be eligible to access Medicare rebates for up to 10 individual and 10 group services from a clinical psychologist or other allied mental health professional in a calendar year.
- The establishment of a High Risk Clinic at Melanoma Institute Australia to improve the ongoing surveillance of survivors
- Foundational research into the development of Patient Reported Outcomes for Melanoma, to improve the understanding of long-term effects of melanoma treatment.

In addition, Melanoma Patients Australia and other patient support organisations provide support to patients, survivors and their families. For example, Melanoma Patients Australia provides patients and carers with information and emotional support through a range of services including:

- National Melanoma Support Line
- A range of patient and carer support groups, including face-to-face, closed Facebook, and telephone support groups
- Peer-to-Peer Linkage programs
- A Melanoma Nurse Telehealth Service
- Referral services support to Cancer Councils, Centrelink, disability, aged care and palliative care services
- Legal and financial assistance.

7.4 Areas for improvement in supportive care and survivorship

Notwithstanding efforts to improve supportive care provided to melanoma patients and survivors to date, there is a consensus among the melanoma community that systems for supportive and survivorship care for melanoma are inadequate in Australia, and there is much to be done.

The major challenges for patients and long-term survivors included:

- Lack of screening for supportive care generally, with a lack of screening for anxiety and depression specifically identified to be an acute problem for patients
- Lack of nurses for melanoma patients
- No structured model for survivorship, including a lack of written survivorship care plans for patients and their families
- High out of pocket costs for long-term survivors.

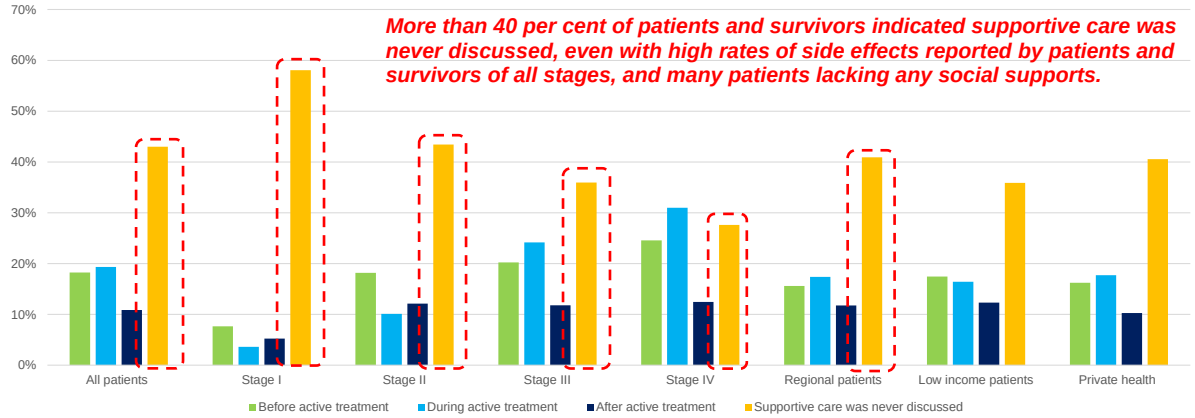
Inconsistent screening for supportive care

Stakeholder consultation, consumer forums and the Melanoma Patient and Carer Survey revealed significant concerns that patients are not consistently screened for supportive care, both during active treatment and as long-term survivors, and more generally, there is

inadequate provision of information to support patient engagement in their treatment and care planning.

For example, the Melanoma Patient and Carer Survey indicated that just over 40 per cent of patients and survivors considered that supportive care had never been discussed with them (Figure 7.5).

Figure 7.5: Was supportive care ever discussed?



Source: Melanoma Patient and Carer Survey, see Appendix B.

Inconsistent screening for supportive care was even reported at later stages of melanoma:

- More than one in three Stage III patients and survivors indicated that supportive care had never been discussed (36 per cent)
- Nearly one in three Stage IV patients and survivors indicated that supportive care had never been discussed (28 per cent).

This is concerning because as shown in Figure 7.2 above, a significant proportion of patients across all stages reported significant adverse effects arising from melanoma and treatment, including pain, fatigue, skin rashes and irritation, lymphoedema, depression and anxiety, and financial hardship.

Anxiety in particular was reported at roughly the same rate across all patients, *regardless of stage of diagnosis*, while most other side effects increased with the stage of melanoma. The Melanoma Patient and Carer Survey revealed high rates of anxiety and depression among melanoma patients and survivors, with nearly 40 per cent of respondents reportedly suffering from anxiety as a survivor and nearly one in five reporting the experience of depression, which is consistent with the findings of other literature reviews.[178] The lack of screening for anxiety and depression was the most frequently identified barrier to melanoma survivor wellbeing, with nearly one in two patients and survivors reporting the lack of screening for anxiety and depression as a major barrier.

Consumer forums also highlighted this as a significant gap in treatment and care nationally (Figure 7.6).

[178] A systematic review in 2018 found the prevalence of severe depression, minor depression and anxiety to be significantly higher in people living with cancer than the general population; for example 15 per cent of cancer patients are estimated to experience severe depression and 20 per cent are estimated to experience minor depression, compared to only five per cent of the general population; and 10 cent of patients with cancer are treated for anxiety, with two thirds of these patients experiencing clinically significant anxiety, compared with only seven per cent of the general population. See: Pitman, A, Suleman, S, Hyde, N, et al., 2018, Depression and anxiety in patients with cancer, BMJ, doi: 10.1136/bmj.k1415.
[178] >7 unmet needs for patients and >6 unmet needs for carers.

Figure 7.6: Stakeholder, patient and carer perspectives on supportive care: challenges with depression and anxiety

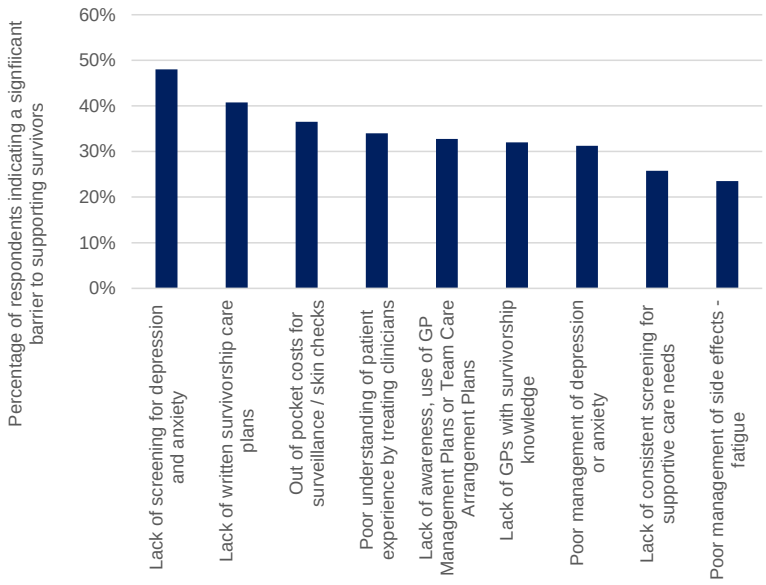
Lack of a structured model for melanoma survivorship

There is currently no model of care for melanoma survivorship.

One in two respondents (50 per cent) to the Melanoma Patient and Carer Survey indicated survivors did not receive adequate support following the completion of active treatment, which was further echoed by patient and carer views, which consistently called out the lack of a structured model for melanoma survivorship. After a lack of screening for anxiety and depression, the most commonly identified barriers to wellbeing for melanoma survivors included:

- Lack of written survivorship care plans, leading to poor awareness of supportive care services, with more than 40 per cent of respondents indicating this was a major barrier
- High out of pocket costs, with nearly 40 per cent of respondents indicating this was a major barrier for long term survivors
- Poor understanding of patient experience by treating clinicians, with more than 30 per cent of respondents indicating this was a major barrier
- Lack of awareness and/or use of GP Management Plans or Team Care Arrangement Plans, with more than 30 per cent of respondents indicating this was a major barrier.

Figure 7.7: What are the major barriers in supporting melanoma survivors?



Source: Melanoma Patient and Carer Survey, see Appendix B.

These data echoed clinician, patient and carer stakeholder perspectives that an explicit, structured model of care for long-term melanoma survivors is required.

Figure 7.8: Survivor specific challenges

Moreover, screening for psychosocial support needs is critical to supporting survivors. Research has shown that psychological distress is potentially modifiable through intervention, with guidelines recommending several evidence-based strategies in helping to manage cancer survivors' psychological symptoms. There is strong evidence that:[179]

- Access to emotional support services improves the well-being of people with cancer
- The opportunity to discuss feelings with a member of the treatment team or counsellor decreases psychosocial distress
- Participation in peer support programs is beneficial for patients with poor perceived social support, and can help patients in a variety of ways, including the transfer of information, practical assistance and emotional empathy and comfort
- Psycho-educational programs decrease anxiety and depression.

Increased screening for supportive care services at key stages of diagnosis and treatment should be developed as a quality indicator as part of a clinical care standard and quality framework for melanoma.

Lack of melanoma nurses nationally

Oncology nurses look after people who are diagnosed with cancer. These nurses will administer medication, provide care, and offer information and support throughout treatment.

As the treatment options for melanoma have evolved, however, new treatment-related side effects have also emerged, which can be challenging to diagnose, complex to manage, and potentially persistent throughout a patient's life.[180] The severity of side effects from oral targeted therapies was reported to create risks for non-adherence to treatment. Moreover, due to the rapid shift in treatments nurses and other treatment clinicians are likely to have limited experience with the management of these side effects.

To better support patients from diagnosis through treatment and long-term survivorship, programs have been developed with the goal of providing information to melanoma specialist nurses (Box 7.1).[181]

Box 7.1: The Melanoma Foundation's Melanoma Nursing Initiative and Melanoma Institute Australia's Melanoma Nurse training modules

Melanoma Institute Australia Nurse Training Modules

Melanoma Institute Australia is an accredited provider for the Royal Australian College of General Practitioners (RACGP), and provides accredited content from Australian College of Remote and Rural Medicine (ACRRM), Australian College of Nursing (ACN), Australian Practice Nurses Association (APNA) and the Australasian College of Dermatologists.

Melanoma Institute Australia has developed a series of education programs and freely available content to contribute to ensuring best practice and equity of care in melanoma on a national and international level.

To support nurse education and development, Melanoma Institute Australia hosts conferences and provides a series of free, online educational content including:

- Overview of how targeted therapies and immunotherapies are being used in the treatment of advanced melanoma and the importance of the nursing role in assessment and management of side effects from these treatments, developed and delivered in partnership with the Cancer Nurses Society of Australia

[179] NHRMC, National Breast Cancer Centre, the National Cancer Control Initiative, 2003, Clinical practice guidelines for the psychosocial care of adults with cancer; Dieng, M, Butow, PN, Costa, DS, Morton, RL, Menzies, SW, Mireskandari, S, Tesson, S, Mann, GJ, Cust, AE, Kasparian, NA, 2016, Psychoeducational intervention to reduce fear of cancer recurrence in people at high-risk of developing another primary melanoma: results of a randomized controlled trial, Journal of Clinical Oncology, 34(36), 4405-4414; Zabalegui, A, et al., 2005, Nursing and cancer support groups, JAN, doi: 10.1111/j.1365-2648.2005.03508.x.
[180] Melanoma Nursing Initiative, 2021, About the Melanoma Nurse Initiative, accessed at: https://themelanomanurse.org/about/
[181] Allcan, 2017, Spotlight on cancer nurses: the heart of high-quality cancer care.

- Access to clinical trials in melanoma
- Diagnosis and management of clinical anxiety
- Clinical assessments of lesions and diagnosis of melanoma
- Role of pathology
- Surgery and post-operative care.

In addition to training nurses, Melanoma Institute Australia has funded a Melanoma Nurse Telehealth Service, which is delivered by Melanoma Patients Australia. The Melanoma Nurse Telehealth Service supports patients in navigating the health system, accessing available services, and making decisions regarding their health.

The Melanoma Nursing Initiative

The Melanoma Nursing Initiative (MNI) was established by the Melanoma Foundation in the United States to address a range of nursing challenges associated with advancements in melanoma treatment. The MNI is a nurse-centric effort, designed to educate and engage healthcare providers to address adverse events associated with melanoma therapies, adherence issues, and patient education, thereby improving therapeutic outcomes for patients with melanoma.

The MNI has brought together a range of materials to improve the treatment and care of melanoma patients and survivors, including videos on key aspects of melanoma care, descriptions of possible side effects, care step pathways, and a range of toolkits.

The Melanoma & Skin Cancer Advocacy Network (MSCAN) has recently adapted the MNI's Stage III Decision support tools to Australian clinical settings.

Source: Melanoma Institute Australia, 2021, Melanoma Education Portal, Nurse Modules, accessed at: https://melanomaeducation.org.au/nursemodules/ and Melanoma Nurse Initiative, accessed at: https://themelanomanurse.org; Melanoma Foundation, 2021, The Melanoma Nursing Initiative, accessed at: https://themelanomanurse.org/.

While there is limited research regarding the precise quantum of benefit derived from specialist melanoma nurse services, a concerted effort to support nurses in their central adverse event management role is likely to yield life-saving results.[182] Moreover, studies[183] have found access to oncology nurses deliver significant benefits to patients and the wider health care system:

- Specialised oncology nursing led to significant improvements in patient-reported outcomes in key supportive care domains: unmet needs, quality of life, and continuity of care, as well as a shift in patterns of health resource utilisation from acute care settings to the community over the course of the intervention[184]
- Nursing interventions had a positive impact on patients' self-management of cancer pain[185]
- One-to-one support approach (combining specialist nurses and support workers) could lead to an annual net saving of £19 million to the National Health Service[186]
- The introduction of a specialist nurse into the cancer care pathway could release about 10 per cent of cancer expenditure (based on economic modelling from one city)[187]

[182] Rubin, KM, 2017, Advances in Melanoma: The Rationale for the Melanoma Nursing Initiative, Clinical Journal of Oncology Nursing, 21(4) Supplement, doi: 10.1188/17.CJON.S4.7-10.
[183] Allcan, 2017, Spotlight on cancer nurses: the heart of high-quality cancer care; Sussman, J, Bainbridge, D, Whelan, TJ, Brazil, K, Parpia, S, Wiernikowski, J, Schiff, S, Rodin, G, Sergeant, M, Howell, D, 2017, Evaluation of a specialized oncology nursing supportive care intervention in newly diagnosed breast and colorectal cancer patients following surgery: a cluster randomized trial, Supportive Care in Cancer, https://doi.org/10.1007/s00520-017-3981-4.
[184] Sussman, J, Howell, D, Bainbridge, D, Brazil, K, Pyette, N, Abbas,i S, Whelan, T, 2011, The impact of specialized oncology nursing on patient supportive care outcomes, J Psychosoc Oncol, 29(3), 286-307.
[185] Jahn, P, Kuss, O, Schmidt, H, Bauer, A, Kitzmantel, M, Jordan, K, Krasemann, S, Landenberger, M, 2014, Improvement of pain-related self-management for cancer patients through a modular transitional nursing intervention: a cluster-randomized multicenter trial, Pain, 155(4):, 46-754, doi: 10.1016/j.pain.2014.01.006.
[186] Frontier Economics, 2010, One to one support for cancer patients.
[187] Macmillan Cancer Support, 2010, Demonstrating the economic value of co-ordinated cancer services. An examination of resource utilisation in Manchester.

- Clinical nurse specialist roles can prevent emergency admissions and speed-up care pathways, allowing time for up to 13 new patients per week to be seen.[188]

In Australia, however, nursing support for melanoma patients is limited, with stakeholders estimating less than 10 specialist melanoma nurses are funded nationally.[189] This compares to nearly 100 breast cancer nurses and more than 35 prostate cancer nurses funded nationally (Box 6.3). While Melanoma Institute Australia and Melanoma Patients Australia collaborated in 2019 to establish a Melanoma Telehealth Nurse Service to better support patients and bridge this gap, the availability of nursing support for melanoma patients nationally remains substantially underfunded.

This creates serious concerns for equity of access to nursing services and poor outcomes for patients with melanoma, especially advanced metastatic melanoma. Patients with advanced metastatic melanoma are similarly complex to patients with metastatic breast cancer: melanoma metastasises to the brain more frequently than any other cancer. But melanoma patients do not receive the same nursing support as other cancers, which receive Australian Government funding to support a national nursing workforce.

Box 7.2: Case study comparison in Australian Government funding for breast and prostate cancer nurses

Breast cancer, prostate cancer and melanoma are high incidence cancers which enjoy similarly high rates of survival if detected early and similarly poor prognosis if detected in advanced stages. In spite of the similar challenges faced by patients with these cancers, there is substantial inequity in nursing support for these patients nationally.

Breast cancer nurses

In 2019, the Australian Government announced the injection of $27 million in funding to increase the number of breast cancer nurses to nearly 100 nurses nationally. This doubling of funding will ensure 98 specialist Breast Care Nurses by 2022-23, building on $20.5 million already invested by the Australian Government in this initiative. As part of the 41 additional nurses, the additional funding supports an increase of more than 30 specialist nurses to be dedicated to supporting metastatic breast cancer patients and their loved ones. The announcement noted that metastatic breast cancer requires complex care, and with this additional funding nurses will now be able to spend more time supporting patients and families with advanced breast cancer.

Prostate cancer nurses

In 2020 the Australian Government announced funding of $23 million over three years for the prostate cancer nursing program through the Prostate Cancer Foundation of Australia. This additional funding has been made in addition to existing prostate cancer nurses, placing funded specialist nurses at more than 29 locations across Australia since 2013.

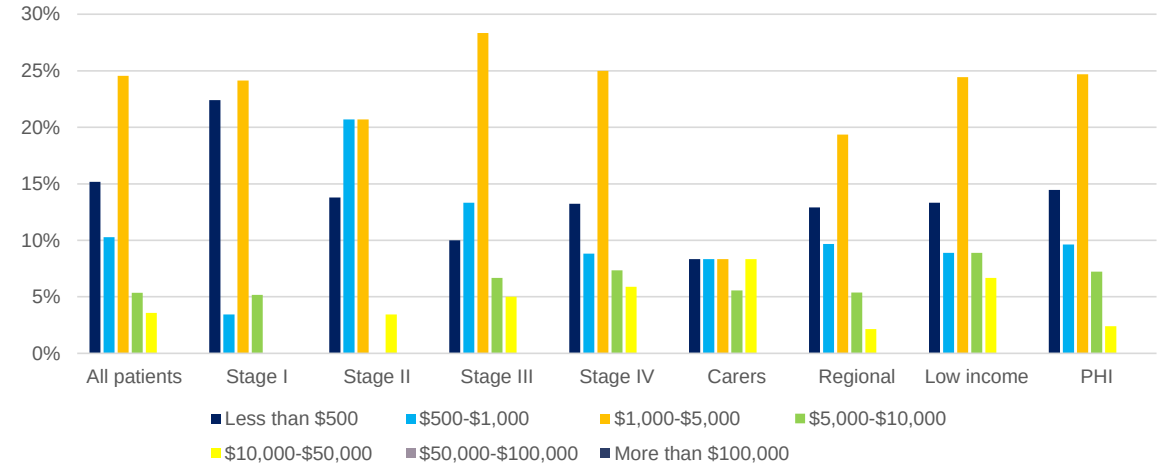
Source: Prime Minister of Australia, 2019, Vital funding boost to support Australian women with breast cancer; Australian Institute of Health and Welfare, 2021, Cancer Incidence data, accessed at: https://www.aihw.gov.au/reports/cancer/cancer-data-in-australia/contents/cancer-incidence-by-age-visualisation; Australian Institute of Health and Welfare, 2021, Cancer Data in Australia, table S8.1; Cancer Australia, 2020, Breast Cancer, Metastatic breast cancer: What are the symptoms of metastatic breast cancer?, accessed https://www.canceraustralia.gov.au/affected-cancer/cancer-types/breast-cancer/metastatic-breast-cancer; Minister for the Department of Health, 2020, $23 million investment for prostate cancer nurse program; https://www.health.gov.au/ministers/the-hon-greg-hunt-mp/media/23-million-investment-for-prostate-cancer-nurse-program.

High out of pocket costs for survivors

Just under 40 per cent of patients (38 per cent) experienced out of pocket costs as a survivor compared to 66 per cent of patients during active treatment. Although long-term survivorship costs were estimated to be lower than costs during active treatment, one in four patients estimated their out-of-pocket costs to be in the order of $1,000 to $5,000 per annum as a long-term survivor.

[188] Royal College of Nursing, 2010, Specialist nurses. Changing lives, saving money.
[189] Based on participation in training programs and other hospital engagement. Stakeholders estimated total number was likely between five and 10 nurses.

Figure 7.9: Estimated per annum out of pocket costs for long-term survivors



Source: Melanoma Patient and Carer Survey, see Appendix B.

These additional costs can put stress on households. In 2017–18, the average equivalised disposable household income was $1,062 per week (which compares to $1,046 per week in 2015–16 and $1,018 per week in 2007–08), which is income available after tax used to pay for housing, food and other household needs. This drops to $462 per week for low-income households. Furthermore, just over 70 per cent of households have debt.

7.5 Opportunities to improve supportive care and survivorship

To improve outcomes for melanoma patients and survivors, the State of the Nation in Melanoma calls for the development of a structured approach to supportive care and survivorship. The development of a Patient Navigation and Melanoma Nurse Support Service (see Chapter 6) are important actions to improving awareness of supportive care and survivorship services for patients and survivors; as part of implementing these actions, Australian governments and the wider community must also explicitly:

- Develop a model of care for melanoma survivors
- Mandate the provision of survivorship care plans to all patients
- Fund a National Melanoma Nurse Support Service
- Increase the supply of, and access to, trained professionals in skin checks particularly for regional and low income patients.

Develop an explicit, structured model of care for melanoma survivors

Access to supportive care is critical to reducing the morbidity associated with melanoma and its treatment, particularly in the context of novel targeted therapies and immunotherapies which present new and potentially severe side effects.

To enable the implementation of a more structured approach to supporting melanoma survivors, a new model of care should be defined in the clinical guidelines, attendant clinical quality framework and clinical care standard for melanoma.

The survivorship model of care should also be incorporated into the education and training of GPs in melanoma and a core component of the services provided by the Patient Navigation and Melanoma Nurse Services.

The model of care should articulate consistent screening for side effects of melanoma and its treatment, including in particular anxiety and depression, which can be easily overlooked. The guidelines should provider clear referral pathways for patients to services.

Over time, a nationally consistent approach to Patient Reported Outcomes for melanoma should be incorporated into the model of care, digitally enabled where possible.

Require survivorship care plans

As noted in Chapter 6, there are strong guidelines for the provision of written treatment plans and survivorship care plans at the commencement of active treatment and the completion of active treatment as clinical best practice in cancer treatment and care.

Increasingly, studies have explored the benefits of survivorship care plans, which in the literature are defined as treatment summaries and follow-up care instructions. Like written care plans, existing research regarding the potential for survivorship care plans to improve health outcomes is limited,[190] although recent research in the US found that survivorship care plans can improve compliance with follow-up care recommendations (Box 7.3).

Box 7.3: Benefits of Treatment Summaries and Follow-up Care Instructions for Cancer Survivors

Cancer survivors require follow-up care to ensure early detection of recurrence, management of late/long term effects, preventive screening for early detection of second primary malignancies, as well as other forms of preventive care. But not all survivors receive necessary follow-up care. Combining survivorship care plans and patient navigation may be a successful strategy to improve survivor's receipt of necessary follow-up care.

Using data from the 2010 LIVESTRONG online survey of cancer survivors (N = 3,854), one study tested associations between receipt of follow-up care instructions (FCI) and treatment summaries (TS) paired with patient navigation (PN), and survivor's receipt of cancer surveillance, preventive cancer screening, and attendance at regular medical appointments. The study found:

- Survivors who received FCI, TS, and patient navigation were the most likely to report attendance at all medical appointments (aOR 4.17, 95% CI 2.30, 7.57, $p \leq .001$) and receipt of preventive cancer screening (aOR 3.56, 95% CI 2.28, 5.55, $p \leq .001$).
- Receipt of FCI was associated with greater likelihood of attendance at all regular medical appointments (aOR 2.28, 95% CI 1.60-3.23), receipt of cancer surveillance (aOR 1.64, 95% CI 1.28-2.09), being up to date on preventive cancer screening (aOR 2.63, 95% CI 2.00-3.47), and with fewer late/long-term effects (IRR 0.77, 95% CI 0.69-0.85).
- Receipt of TS was associated with greater likelihood of attendance at all regular medical appointments (aOR 1.79, 95% CI 1.31-2.44) and being up to date on preventive cancer screening (aOR 1.43, 95% CI 1.14-1.78), but not cancer surveillance or late/long-term effects.

Another study leveraging the LIVESTRONG survey, which evaluated 3,682 post-treatment cancer survivors over a nine-month period, found that survivors who received a TS experienced significantly fewer post-treatment emotional concerns ($P < .05$). Survivors who received a TS more often reported that their needs had been met, including receiving information about possible late effects, care they received during treatment, and care they received after treatment.

Sources: Jabson, JM, 2015, Treatment summaries, follow-up care instructions, and patient navigation: could they be combined to improve cancer survivor's receipt of follow-up care?, *J Cancer Surviv*., 9(4), 692-8, doi: 10.1007/s11764-015-0444-0; Jabson, JM, 2015, Follow-up care instructions, treatment summaries, and cancer survivors' receipt of follow-up health care and late/long term effects. *Support Care Cancer,* 23, 1851-1856. https://doi.org/10.1007/s00520-014-2532-5; Rechis, R, Beckjord, EB, Nutt, S, Potential benefits of treatment summaries for survivors' health and information needs: results from a LIVESTRONG survey, *Journal of Oncology Practice,* 10(1), 75-78, doi: 10.1200/JOP.2013.000973.

Written survivorship care plans, particularly against a backdrop of low health literacy, are important tools to close information gaps for patients and their families, and will encourage systematic discussion of supportive care services and effective referral to those services.

[190] Jacobsen, PB, DeRosa, AP, Henderson, TO, Mayer, DK, et al., 2018, Systematic Review of the Impact of Cancer Survivorship Care Plans on Health Outcomes and Health Care Delivery, *Journal of Clinical Oncology*, 36(20), doi: 10.1200/JCO.2018.77.7482.

Expand the supply of and access to professionals trained in skin checks

In addition to upskilling GPs in melanoma and dermoscopy, government should also increase the supply of and access to trained professional in skin checks, particularly focused on regional and remote and disadvantaged communities. This could be through an expansion in the number of High Risk Clinics for melanoma survivors in the short term, which have been shown to be more effective and efficient than standard surveillance approaches,[191] and the development of new models of care for skin checks for patients as part of the Roadmap to a National Targeted Melanoma Screening Program.

Establish a National Melanoma Nurse Service

Advanced melanoma patients experience similarly complex care and support to advanced breast and prostate cancer patients, and it is unclear why there is not an equitable approach to nursing support per incidence case nationally. Indeed, melanoma has the highest rate of brain metastasis of any solid tumour.

Adopting an equitable approach to oncology nursing would see the Australian Government support an additional 84 melanoma nurses nationally.[192] This would require an injection of approximately $55 million in new funding for melanoma nurses and could be rolled out using the models piloted and proven for breast and prostate cancer nurses. Importantly, such a service should also be integrated into the National Patient Navigation Service.

7.6 Impacts of improved access to supportive care and survivorship

Improving patient and survivor access to supportive care services is expected to:

- Reduce the severity of clinical anxiety and depression[193]
- Improve the management of side effects, reduce presentations to emergency departments, and support adherence to therapy[194]
- Improve attendance at follow-up appointments.[195]

Improving access to professionals trained in skin checks as part of a long-term surveillance strategy may contribute to reductions in survival disparity for disadvantaged and regional cohorts (See Chapter 6, Figures 6.4 and 6.5).

7.7 Conclusions: scorecard assessment and action plan for supportive care and survivorship

Demand for supportive care services to support patients and survivors is set to increase rapidly by 2030. More than 205,000 new patients are expected to be diagnosed with and treated for melanoma over the 2021-2030 horizon, and by 2030 there will be an additional

[191] Watts, CG, Cust, AE, Menzies, SW, Mann, GJ, and Morton RL, 2017, Cost-Effectiveness of Skin Surveillance Through a Specialized Clinic for Patients at High Risk of Melanoma, Journal of Clinical Oncology 2017 35:1, 63-71, doi: 10.1200/JCO.2016.68.4308.
[192] 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.
[193] Ibid.
[194] Rocque, GB, Pisu, M, Bradford, JE, et al., 2017, Resource Use and Medicare Costs During Lay Navigation for Geriatric Patients with Cancer, *JAMA Oncol*., 3(6), 817-825, doi:10.1001/jamaoncol.2016.6307.
[195] Jabson, JM, 2015, Treatment summaries, follow-up care instructions, and patient navigation: could they be combined to improve cancer survivor's receipt of follow-up care?, *J Cancer Surviv*., 9(4), 692-8, doi: 10.1007/s11764-015-0444-0; Jabson, JM, 2015, Follow-up care instructions, treatment summaries, and cancer survivors' receipt of follow-up health care and late/long term effects. *Support Care Cancer,* 23, 1851-1856. https://doi.org/10.1007/s00520-014-2532-5; Rechis, R, Beckjord, EB, Nutt, S, 2013, Potential benefits of treatment summaries for survivors' health and information needs: results from a LIVESTRONG survey, *Journal of Oncology Practice,* 10(1), 75-78, doi: 10.1200/JOP.2013.000973.

158,000 new melanoma survivors added to an estimated prevalence of more than 190,000 melanoma survivors today.

This creates new challenges for the healthcare system and requires new models of care to be developed. One in two respondents (50 per cent) to the Melanoma Patient and Carer Survey indicated survivors did not receive adequate support following the completion of active treatment. This was echoed by responses to the consumer forums, which consistently highlighted the absence of a structured model for melanoma survivorship.

To improve outcomes for melanoma survivors, the State of the Nation in Melanoma calls for the development of a structured approach to supportive care and survivorship:

- Develop a model of care for melanoma survivors
- Mandate the provision of survivorship care plans to all patients
- Fund a National Melanoma Nurse Support Service, to be linked to the Patient Navigation Service
- Increase the supply of, and access to, trained professionals in skin checks.

These actions should be closely integrated with the research stream, including the development of Patient Reported Outcomes and a National Targeted Melanoma Screening Program as part of the Nationally Collaborative Melanoma Research Mission and Discovery Program.

Table 7.1: Scorecard assessment and recommendations for action – Supportive care and Survivorship

	Rating	Australian successes	Areas for improvement	Action Plan recommendations
Supportive Care & Survivorship	✓✓	✓ Initial research into Patient Reported Outcomes in Melanoma	× No standard of care for survivorship and supportive care × Survivorship care plans inconsistently provided × Patients inconsistently screened for supportive care needs × Lack of melanoma nursing support × Anxiety and depression often missed × Poor management of fatigue × Lack of awareness of supportive care services	Develop a standard of care for supportive care and long-term survivorship Require survivorship care plans Develop Melanoma Nurse Service, linked to Patient Navigation Service Increase supply of trained professionals in skin checks

Chapter 8

A Plan of Action to end mortality from melanoma: performance, priorities, payoffs and pathways

The previous chapters outlined Australia's successes and areas for improvement across five major domains of work: prevention and awareness, research, early detection and diagnosis, treatment, and survivorship and supportive care.

This chapter consolidates the evidence from previous chapters into an overall summary of Australia's performance and provides a roadmap for change. Actions are identified in each domain, along with an assessment of the expected benefits from realisation and recommendations for implementation.

8.1 Summary of Australia's performance and opportunities for improvement

On balance, Australia has achieved much in the prevention, research, treatment and care of melanoma patients and carers. Its greatest successes have been in the domains of prevention and research, where Australia has established itself as a world leader, and has delivered significant improvements in survival.

At the same time, there is much to be done. There are still significant variations in awareness of the seriousness and invasiveness of melanoma and uptake of prevention, with high rates of sunburn still reported in Australian communities and high incidental UV radiation exposure as a consequence of Australia's outdoor culture. Awareness of the importance of self-skin checks and understanding of high risk groups are highly variable across Australian communities, and likely contribute to significant variation in outcomes observed across regions and among income groups.

Australia's GPs are critical front-line workers in the detection and diagnosis of melanoma. Additional training and equipment to undertake best practice skin checks as part of the normal scope of practice, and accreditation to enable delivery of specialised skills in skin, are important steps to improving outcomes for patients and supporting GPs.

Adherence to clinical best practice remains an elusive goal in spite of melanoma being distinguished as one of the few cancers with national clinical guidelines. Clinical guidelines recommend against partial biopsy, and yet these practices are not only persisting, but increasing in clinical use. The consistent use of Sentinel Lymph Node Biopsy and improved understanding of referral pathways require urgent correction to ensure patients are able to access best practice care nationally.

A more structured approach to supportive care and survivorship is needed, to ensure patients and survivors receive written treatment and survivorship plans, are screened for supportive care needs and receive timely information about services that can improve their wellbeing and quality of life.

Table 8.1 summarises performance across the various domains.

Table 8.1: Australia's performance in the control of melanoma – scorecard assessment

	Rating	Australian successes	Areas for improvement
Prevention and Awareness	✓✓✓✓	✓ Slip Slop Slap awareness campaign in 1980s ✓ SunSmart programs in primary schools ✓ OHS workplace regulations implemented ✓ Tax incentives for sun safe equipment and clothing ✓ Initial investments in shade by local governments and State governments	× Rates of sunburn remain high (>60%), with sun protection behaviour uptake low by many (only 22% adults, 47% kids) × No sustained modern era awareness and prevention campaign × Consistent adherence to policies in primary schools × Uptake of any prevention in secondary schools × Lack of explicit training and consistent adherence to policies in outdoor workplaces, especially SMEs and outdoor trades × Investment in shade is slow, de-prioritised in context of local government infrastructure backlogs × Significant incidental exposure in weekend sport, sun safety is not explicitly required by club sports, AIS × Lack of implementation of supported recommendations from the House of Representative Skin Cancer in Australia Report (2017)
Research	✓✓✓✓✓	✓ World leading prevention research informing US Prevention Taskforce ✓ Australia citation impact significantly exceeds medical research and NHMRC benchmarks ✓ Significant health gains realised through research, including doubling of survival for melanoma and likely spillover effects ✓ ~50 per cent of advanced melanoma patients enrolled in clinical trials ✓ ACRF funded Australian Centre of Excellence in Melanoma Imaging and Diagnosis ✓ NHRMC Centre of Research Excellence for the Study of Naevi ✓ NHMRC Centre of Research Excellence for Skin Imaging and Precision Diagnosis ✓ Victorian Melanoma and Clinical Trials Service	× Opportunities for deep, nationally collaborative research × Lack of core clinical, population, quality registry data, National Cancer Data ecosystem × Inefficiencies in grants processes × Clinical trial inefficiencies (duplicated and differing governance and ethics requirements leading to long timelines)

	Rating	Australian successes	Areas for improvement
Early Detection and Diagnosis	✓✓✓	✓ Globally leading outcomes in tumour thickness arising from high rates of opportunistic screening	× Increased community awareness of skin changes and uptake of skin checks, especially for high-risk cohorts and low income individuals × No minimum standards specified with regard to skin checks and diagnosis × Need for additional training in melanoma by GPs to reduce failure to detect and risks of potential over-diagnosis × Need to integrate research efforts for early detection into the roll out of new models of care
Diagnosis & Treatment	✓✓✓	✓ High survival rates for early Stage I, Stage II melanomas ✓ Doubling of survival outcomes for advanced melanoma patients through immunotherapy and targeted therapy advancements ✓ PBS funding in line with best-evidence-based care for systemic treatments in melanoma	× Increased use of shave and punch biopsies, associated with high error rates, in contrast to clinical guidelines × Poor adherence to guidelines for Sentinel Lymph Node Biopsy and appropriate referrals × Significant variation in patient outcomes by jurisdiction and income levels × Lack of quality performance benchmarks × Patients inconsistently screened for supportive care needs: lack of awareness of supportive care services × Some constraints on treatment planning by clinicians – timing, intensity of systemic therapies × Poor understanding of diagnosis and treatment options × Room for improvement in regional service delivery (including immunotherapies) × Regulatory risk for access to clinically important therapies where there are limited incentives for the registration of new indications and/or reimbursement
Supportive Care & Survivorship	✓✓	✓ Initial research into Patient Reported Outcomes in Melanoma	× No standard of care for survivorship and supportive care × Survivorship care plans inconsistently provided × Patients inconsistently screened for supportive care needs × Lack of melanoma nursing support × Anxiety and depression often missed × Poor management of fatigue × Lack of awareness of supportive care services

Notes: Per Chapter 2, scorecard assessment based on: ✓✓✓✓✓ = Significant, globally-leading contributions to survival and quality of life realised in Australia; ✓✓✓✓ = Significant, globally-leading contribution to survival and quality of life realised in Australia, but with some inconsistencies in policy implementation observed; ✓✓✓ = Improvements in survival and quality of life realised, but policy settings not globally-leading and inconsistencies in policy implementation observed nationally; ✓✓ = Improvements in survival and quality of life realised, but with significant variation in outcomes by jurisdictions or cohort, leading to significant equity concerns and an increase in potentially avoidable mortality; and ✓ =Poor implementation of policies and investments, with little to no contribution to survival and quality of life observed.

8.2 Action plan to eliminate melanoma as we know it

Based on Australia's performance to date and evidence of impact from policy and investment opportunities, the State of the Nation in Melanoma proposes the following 5-point strategy for improving outcomes for melanoma patients and survivors (Figure 8.1):

1. Implement a modernised, national strategy for melanoma prevention and awareness
2. Invest in Australia's high-impact, world-leading melanoma research
3. Improve early detection and evidence for a National Targeted Screening Program
4. Reduce variation in diagnosis and treatment
5. Establish a model for melanoma supportive care and survivorship.

Figure 8.1: Action Plan for Melanoma: Five-point strategy for ending mortality in our lifetimes

The key actions within each strategy element are outlined below.

Implement a modern, national strategy for prevention and awareness

A national strategy for melanoma prevention and awareness would include:

- Invest in modernised, national prevention and awareness campaigns that reflect the new ways Australians consume public health messages in light of an evolving media landscape
- Accelerate investments in shade for the highest risk public spaces within five years
- Improve adherence to sun safe behaviours in primary schools and uptake in secondary schools
- Treat sun safety in the workplace in a manner consistent with other OH&S issues, such as the prevention of injury or chemical exposure, including by requiring explicit training in sun safe behaviours for all outdoor workers
- Make sun safety explicit in child safe sport.

These actions are detailed in turn. Actions must leverage previously developed resources and networks, such as those developed by MPA's Consumer Advisory Group. Underpinning the effectiveness of this campaign is ensuring that consumers are engaged at all stages of development (especially those in target demographics).

Prevention and awareness **Action 1.1: Generational investment in modern era national prevention and awareness campaigns**	
What	Continue to invest in modern prevention and awareness public health campaigns that reflect the new ways Australians consume information and public health messages.
Why	The Federal Government has released its National Preventative Health Strategy which calls for a campaign to improve awareness and prevention of skin cancer, including melanoma. Subsequently, the Federal Government committed $20 million over the next two years to raising skin cancer awareness, including $10 million in a national awareness campaign. This is a welcome investment, especially given the relatively long horizons between uptake of preventative policies and reduction in skin cancer incidence. The national awareness campaign should build on lessons of previous campaigns and concerns regarding current fragmentation of the modern media landscape (social media, etc.). Furthermore, there must be a generational commitment via sustained investment, with the road safety governance, policy and investment approach providing a useful model for delivering sustained improvements and outcomes for the next generation of Australians.
Key partners	Federal Government, State Governments, Not-For-Profit Sector, Australian families and communities
Lead partner	Federal Government

Prevention and awareness **Action 1.2: Accelerate investments in shade with the goal of shading the highest risk public spaces within five years**	
What	Fund shade for the highest risk public spaces across Australia within five years building on the models and work developed in Victoria and NSW.
Why	Compared to the challenges of inducing behavioural change and wide uptake of sun safe behaviours, investment in the built environment is comparatively easy. This is not to say it does not require planning: adequate planning for sun angles, appropriate materials and the potential to maximise broader environmental goals through investment in trees are all important aspects of delivering effective shade in public spaces. With childhood sunburn and incidental UV radiation exposure being the two primary drivers of cutaneous melanoma, persistent poor uptake of sun safe behaviours and the high potential for UV radiation avoidance through investment in shade (UV reduction of 93 per cent for shades with an Ultraviolet Protection Factor of 15 or greater), the need to address extant gaps in shade by 2025 is an urgent priority for Australian communities.
Key partners	Federal Government, State Governments, Not-For-Profit Sector, Australian families and communities
Lead Partner	Federal Government

Prevention and awareness **Action 1.3: Improve adherence to sun safe behaviours in primary schools and uptake in secondary schools**	
What	Consistent uptake and enforcement of sun safe policies across all schools in Australia by 2025. Departments of Education and teacher training institutes (accreditation, institutes of teaching) should increase expectations and training for teachers to improve the consistent adoption of sun safe policies. The increase in expectations may require the systematic introduction of standards that can be maintained and audited for quality assurance purposes. There should be an immediate focus on the supply of sun safe uniform and preventative measures.

Why	The Cancer Council has developed world-class sun smart policies for implementation in primary and secondary schools, but there is inconsistent uptake of these policies in primary schools and a near zero uptake in secondary schools. Interviews with multiple stakeholders indicated the challenge is a 'lack of will' to see improved adherence rather than a 'lack of funding'.
Key partners	State Governments, Teacher training institutes, Cancer Councils, Australian families
Lead partner	State Governments, Teacher training institutes

Prevention and awareness **Action 1.4: Treat sun safety in a manner consistent with other OH&S issues, including by requiring explicit training in sun safe behaviours for all outdoor workers**	
What	Treat sun safety in a manner that is consistent with other OH&S issues. An initial step is to require explicit sun safe training for outdoor workers, complemented by partnerships with employer groups, unions and regulatory bodies. In line with other OH&S issues there should be clear accountability for organisations and auditing of compliance, e.g., via a 'positive-duty' on companies and employers to implement sun safe practices.
Why	Sun safe policies are now implicit in all OHS regulations nationally, however, there is evidence of inconsistent adherence to these policies, with the risk expected to increase for outdoor workers employed by SMEs. Explicit training continues to be focused on traditional workplace hazards, including for example the avoidance of falls, safe use of equipment, and exposure to chemicals. The introduction of explicit training requirements and increased awareness raising in workplaces offers an important and relatively low-cost opportunity to foster the continued culture change required to make sun safe behaviour the cultural norm in outdoor work.
Key partners	Federal and State Governments, Employer Groups, Unions, Registered Training Organisations, Melanoma Patients, Melanoma Charities. For example, MPA's Consumer Advisory Group has developed a network in this area that is readily mobilised.
Lead partner	State Governments

Prevention and awareness **Action 1.5: Make sun safety explicit in child safe sport**	
What	Make sun safety policies explicit through Australian Institute of Sport sports clubs training and assessment documentation improvement and partnerships with sporting clubs.
Why	Childhood sunburn and incidental exposure are the two major determinants of melanoma incidence. While sun safe policies are made available on the Australian Institute of Sport school clubs website, it is not explicitly identified as a 'child safe' requirement for sports clubs, which focuses on the prevention of child sexual abuse and discrimination. There are more guidelines for COVID safe sport than sun safe sport. Making sun safety an explicit criteria for club management is again a low cost opportunity to foster cultural change in high-risk sports settings.
Key partners	Federal Government, State Departments of Sport, Australian Institute of Sport, Play by the Rules, Sports associations and clubs, Australian families and communities, Not-For-Profit Sector. For example, MPA's Consumer Advisory Group has developed a network in this area that is readily mobilised.
Lead partner	Australian Institute of Sport

Invest in High Impact Melanoma Research

The actions to improve research outcomes include:

- Fund a Nationally Collaborative Melanoma Research Mission and Discovery Program
- Develop clinical and population datasets as part of a National Cancer Data Ecosystem strategy

- Implement clinical trials reforms to reduce ethics and governance administrative burden.

These actions are detailed in turn.

Invest in High Impact Melanoma Research **Action 2.1: Fund a Nationally Collaborative Melanoma Research Mission and Discovery Program**	
What	Fund a National Melanoma Research Mission and Discovery Program incorporating the following research streams over a 5 to7 year period: – Melanomagenesis and biology – Optimising current systemic treatments – Novel Imaging and Detection – Evidence development for program to target high-risk cohorts – Patient Reported Outcomes
Why	As a leader in melanoma research globally and with a disproportionate number of melanoma patients, Australia is uniquely positioned to deliver high impact research across a range of domains including basic biology and molecular research, treatment advances, Patient Reported Outcomes (to inform clinical practice and therapy development, and improve patient outcomes), and advanced imaging and surveillance approaches. A National Melanoma Research Mission and Discovery Program would maximise the impact of Australia's proven research centres of excellence and could see significant advances in survival and quality of life over the next 15 years. Further, this also translates into improved treatment and outcomes in other cancers.
Key partners	Federal Government Research Agencies (MRFF, NHMRC, Cancer Australia), State Government, Research Institutes, Clinicians and Not-For-Profit Sector
Lead Partner	Federal Government

Invest in High Impact Melanoma Research **Action 2.2: Develop clinical and population datasets as part of a National Cancer Data Ecosystem strategy**	
What	Develop national clinical and population datasets through the National Cancer Plan by 2025.
Why	Australia should leverage new cloud-based technologies and computing capabilities to catch up with its international peers in the development of national clinical and population data sets which are the foundations of advanced research capabilities.
Key partners	Federal Government, State Governments, Research Institutes, Clinicians and Not-For-Profit Sector
Lead Partner	Federal Government

Invest in High Impact Melanoma Research **Action 2.3: Implement clinical trials reforms to reduce ethics and governance administrative burden.**	
What	Implement ethics and governance reforms in clinical trials by 2025.
Why	Clinical trials benefit patients, advance medical knowledge and are estimated to be worth around $1 billion to the Australian economy each year. However, the regulatory environment for the conduct of clinical trials in Australia is complex, with state and local health networks having duplicated and differing governance, and ethics requirements occurring across multiple jurisdictions. Timelines for trial establishment remain persistently long. The Clinical Trials Reference Group is currently exploring options for a 'one stop shop' for clinical trials; Government should set a target of implementing these policies by no later than 2025.
Key partners	Federal Government, industry, research institutes, clinical trials groups
Lead partner	Federal Government Clinical Trial Reference Group

Improve early detection

The actions to early detection outcomes include:

- Increase education and awareness of the risks of melanoma and the need to 'Know the Skin You're In' through routine self-skin checks
- Define minimum standards for skin checks, including the consistent use of whole-body examinations and dermoscopy
- Invest in GP training and dermoscopy program
- Develop a Roadmap for a National Targeted Melanoma Screening Program.

These actions are detailed in turn.

Improve early detection **Action 3.1: Increase education and awareness of the need for routine self-skin checks in the general community – 'Know the Skin You're In' – with focus on high risk cohorts in particular**	
What	Leverage the National Preventative Health Strategy's draft plan for a mass media campaign on prevention of skin cancers and melanoma to focus on improved awareness of moles that may be risky or suspicious.
Why	Against the current backdrop of opportunistic screening policy settings and low levels of health literacy in parts of the country, patient education and awareness of the need to seek health advice for changing lesions presents an important opportunity to improve early detection and survival. Evidence shows significant variation in the uptake of skin examinations, with high-risk cohorts reporting lower rates of skin examination compared with the wider community, and beneficial reductions in the numbers of thick melanomas from skin checks. Consistently defined warning signs should be communicated, addressing historical variations in communicated signs of risk and subsequent confusion.
Key partners	Federal Government, State Governments, Melanoma Patients, Melanoma Charities, Australian families and communities
Lead partner	Federal Government

Improve early detection **Action 3.2: Define minimum standards for skin checks**	
What	As part of an update to melanoma clinical guidelines, include explicit guidance with regard to whole-body examination procedures, imaging requirements and use of diagnostic aids such as dermatoscope should be included to reduce risks of failure to detect. These minimum standards should be rolled out as part of a GP training program nationally (e.g., though continuing medical education).
Why	Stakeholders, patients and carers expressed significant concern over the lack of regulation with regard to skin checks. Variation in approach is evident in the Cancer Council data, which shows significant rates of part body or specific spot examination compared with whole-body examination. While Australian Clinical Guidelines for Melanoma provide information about the use of diagnostic aids, stakeholders consistently expressed concern that more explicit minimum standards could be established to improve the quality of skin checks.
Key partners	Federal Government, Royal Australian College of General Practitioners, Australasian College of Dermatologists, Melanoma patients, Melanoma charities
Lead partner	Federal Government

Improve early detection **Action 3.3: Invest in GP training and dermoscopy program**	
What	Fund training program and provision of each GP practice with a dermatoscope, alongside a review of the curriculum for melanoma planned by the RACGP.
Why	GPs are on the frontline of melanoma detection and diagnosis nationally. Given this critical role in Australia's health system and evidence of relatively limited training and variable approaches to skin checks in the community, additional funding is needed to upskill GPs nationally as part of their normal scope of practice. Participation in a national training program could be incentivised through the provision of a dermatoscope for each GP practice.
Key partners	Federal Government, Royal Australian College of General Practitioners, Melanoma Patients and Melanoma Charities
Lead partner	Federal Government

Improve early detection and diagnosis **Action 3.4: Increase supply of trained professional skin checks and new models of care, particularly focused on regional, remote and disadvantaged communities**	
What	Increase supply of trained professional skin checks and new models of care, particularly focused on regional and remote and disadvantaged communities.
Why	The shortage in dermatologists should be addressed by Australian Governments and the Australian College of Dermatologists. Additional funding for the development of other craft group expertise in skin check competencies, such as nurse practitioners and technicians, should be invested in to address access and cost gaps which will likely remain for regional patients and low-income households. These access barriers likely contribute to the significant variation in outcomes observed for these groups, and research to develop a new model of care for these cohorts (as part of the development of a High-risk Screening Program) is needed.
Key partners	Federal and State Governments, and Royal Australian College of General Practitioners, Australasian College of Dermatologists, Cancer Nurses Society of Australia, Melanoma Charities
Lead partner	Federal Government

Reduce variation in diagnosis and treatment

The actions to improve treatment and care outcomes include:

- Establish a Patient Navigation Service
- Require written treatment and care plans
- Maintain clinical guidelines for melanoma through a peak national body
- Develop a clinical care standard for melanoma
- Develop a formal process for evidence development to ensure access to clinically important therapies that lack market incentives.

These actions are detailed in turn.

Reduce variation in treatment and care **Action 4.1: Fund a Patient Navigation Service**	
What	Establish a Patient Navigation Service for melanoma to support patients to navigate a federated healthcare system.
Why	The development of a Patient Navigation Services integrated with a National Melanoma Nurse Service was most frequently identified as the top priority to empower patients and survivors in the Melanoma Patient and Carer Survey. Patient navigation services have the potential to deliver significant value to melanoma patients and the wider Australian community. Empirical studies have found that patient navigation can improve the timeliness of diagnostic resolution and timeliness of care, reduce hospitalisations, reduce emergency department visits, and is increasingly becoming the standard of care. Patient navigation services can be particularly important for patients with high unmet needs and low health literacy. As validated Patient Reported Outcomes are developed for melanoma, these can be integrated into the service, enabling more effective and efficient supportive care services over time.
Key partners	Federal and State Governments, Royal Australian College of General Practitioners, Australasian College of Dermatologists, Cancer Nurses Society of Australia, Melanoma Patients, Melanoma Charities
Lead partner	Cancer Australia through the National Cancer Plan

Reduce variation in treatment and care **Action 4.2: Require written treatment and care plans**	
What	Require written treatment and care plans
Why	Less than 40 per cent of patients with advanced melanoma reported receiving a written care plan and a subset of patients reported poor understanding of their diagnosis and treatment. The provision of written care plans is increasingly seen as a marker of quality and recommended in cancer reform programs to better inform and empower patients.
Key partners	Federal and State Governments, Royal Australian College of General Practitioners, Australasian College of Dermatologists, Royal Australian College of Surgeons, Cancer Nurses Society of Australia, Melanoma Patients, Melanoma Charities
Lead partner	State Governments

Reduce variation in treatment and care **Action 4.3: Maintain clinical guidelines for melanoma through a peak national body**	
What	Maintain clinical guidelines through a national approach, as part of a national strategy for reducing unwarranted variation across all cancers, including melanoma
Why	Melanoma is distinguished as one of the few cancers with clinical guidelines. The lack of a consistent and national approach to the development of evidence-based recommendations for clinical best practice dilutes the potential awareness, use and impact of these clinical guidelines nationally, and increases the risk that they are not kept current. Moreover, they are not consistently referenced by key providers. The complexity, inconsistency and fragmented approach of current clinical guideline development could be significantly streamlined and by doing so, Australia could improve the uptake of guidelines through a national approach. Australia should identify a peak national body to develop, maintain and promote the use of clinical guidelines nationally to reduce unwarranted variation and improve the consistent delivery of quality treatment and care.
Key partners	Federal and State Governments, Royal Australian College of General Practitioners, Australasian College of Dermatologists, Cancer Nurses Society of Australia, Melanoma Patients, Melanoma Charities
Lead partner	Cancer Australia through the National Cancer Plan to identify appropriate national body to adopt leadership role over longer term

Reduce variation in treatment and care **Action 4.4: Create a quality performance framework and audit compliance with clinical best practice through clinical quality registries, including requirements for written treatment plans and other quality indicator**	
What	Create quality performance framework and clinical care standard for melanoma building on the work of MelCOR through the Australian Commission for Safety and Quality in Health Care
Why	Data show inconsistent adherence to clinical best practice in a range of services including: • Failure to use of diagnostic aids that improve accuracy such as a dermatocope • Inappropriate use of partial biopsies including shave biopsies and punch biopsies • Failure to undertake Sentinel Lymph Node Biopsy needed to appropriately stage patients and potentially gain access to systemic therapies • Unclear scope of practice for GPs leading to advanced skin services potentially provided by clinicians with limited training • Variable knowledge in systemic treatments and low case volumes in melanoma leading to unwarranted variation in treatment of advanced metastatic melanoma • Lack of screening for supportive care • Inconsistent referrals to supportive care services. The development of quality performance framework and clinical care standard by the Australian Commission for Safety and Quality in Health Care, with arrangements for auditing of performance against these indicators is an important policy reform to reduce unwarranted variation in clinical practice and achieve best practice outcomes nationally.
Key partners	Federal and State Governments, Royal Australian College of General Practitioners, Australasian College of Dermatologists, Cancer Nurses Society of Australia, Melanoma Patients, Melanoma Charities
Lead partner	Australian Commission for Safety and Quality in Health Care

Reduce variation in treatment and care **Action 4.5: Develop a formal process for addressing access gaps for clinically important therapies**	
What	As part of the Inquiry into Approval Processes for New Drugs and Novel Medical Technologies in Australia and the Review of the National Medicines Policy, Government should establish a formal mechanism for the consistent identification of clinically important therapies where there are persistent market barriers to the registration of new indications and/or reimbursement applications or inconsistencies in access across Australian jurisdictions.
Why	Where a medication lacks an indication for use in melanoma, it may be prescribed off-label, the outcomes of which may not be well documented, further frustrating the development of evidence needed to support additional indications and reimbursement. Where a medication is not PBS listed or not available in public hospital settings, patients may receive medications by privately funding access to these medications or through compassionate access programs, the access to which has been historically opaque. This gives rise to the risk of a two-tiered system, where more affluent patients can self-fund and close access gaps arising from delays in regulatory processes, while less affluent patients are unable to access cutting edge therapies, leading to sub-optimal and inequitable survival outcomes across socioeconomic groups. Government should develop formal criteria for the identification of clinically important therapies where there are access challenges, and provide a formalised pathway for evidence development and funding depending on the nature of the specific product and patient context. Pathways for evidence development could include a registry or trials approach where there are inadequate incentives for evidence development.
Key partners	Federal and State Governments, Industry, Melanoma Patients, Melanoma Charities
Lead partner	Federal Government

Develop a new model of care for survivorship

The actions to improve survivorship include:

- Develop a model of care for melanoma survivors
- Mandate the provision of survivorship care plans to all patients
- Establish a National Melanoma Nurse Service
- Increase the supply of and access to trained professionals in skin checks, particularly focused on regional and remote and disadvantaged communities.

Develop a new model of care for melanoma survivorship **Action 5.1: Develop a model of care for melanoma survivors**	
What	Update clinical guidelines to provide for explicit model for long term care of melanoma survivors
Why	As melanoma survivorship has increased, so too has the need for explicit guidance on the management of side effects from treatment, as well as clinical levels of anxiety and depression which are poorly screened for today. As validated Patient Reported Outcomes are developed for melanoma, these can be integrated into the service, enabling more effective and efficient supportive care services over time.
Key partners	Federal and State Governments, Royal Australian College of General Practitioners, Australasian College of Dermatologists, Cancer Nurses Society of Australia, Melanoma Patients, Melanoma Charities
Lead partner	Federal Government

Develop a new model of care for melanoma survivorship **Action 5.2: Mandate the provision of survivorship care plans**	
What	Require the provision of survivorship care plans
Why	Survivorship care plans provide the basis for informational support to patients and their empowerment with the healthcare and allied health system. Research has shown survivorship care plans can improve the uptake of follow up care and quality of life.
Key partners	Federal and State Governments, Royal Australian College of General Practitioners, Australasian College of Dermatologists, Royal Australian College of Surgeons, Cancer Nurses Society of Australia, Melanoma Patients, Melanoma Charities
Lead partner	State Governments

Reduce variation in treatment and care **Action 5.3: Fund a National Melanoma Nurse Service**	
What	Government fund melanoma nurses workforce, including specialist nurses, nationally to enable equal access to nurses across all cancer patients.
Why	To address gaps in patient understanding around their diagnosis and treatment, and a lack of information and support in navigating to supportive care and survivorship services, the development of a National Melanoma Nurse Service, integrated with a Patient Navigation Service, was most frequently identified as the top priority to improve outcomes for patients and survivors in the Melanoma Patient and Carer Survey. Adopting an equitable approach to oncology nursing based on prior nursing initiatives would see the Australian Government support an additional 84 melanoma nurses nationally, including at most 12 specialist nurses. As validated Patient Reported Outcomes are developed for melanoma, these can be integrated into the service, enabling more effective and efficient supportive care services over time.

Key partners	Federal and State Governments, Royal Australian College of General Practitioners, Australasian College of Dermatologists, Cancer Nurses Society of Australia, Melanoma Patients, Melanoma Charities
Lead partner	Federal Government

Develop a new model of care for melanoma survivorship **Action 5.4: Increase the supply of professionals trained in skin checks**	
What	Increase the supply of health professionals trained in skin checks
Why	Current wait times to see GPs in regional areas and dermatologists nationally are excessively long; the average waiting time for a GP in a regional area was reported to be 6-8 weeks and nationally the average waiting time for a dermatologist was reported to be 6 months. The Department of Health estimates there is a shortage of 22 dermatologists nationally which is projected to expand to 90 by 2030. At the same time, high out of pocket costs to see dermatologists in particular create cost barriers to care for some patients, particularly among disadvantaged groups. Research in High Risk Clinics in NSW showed that quality in skin surveillance could be delivered by a range of practitioners; Government should fund an expansion in the supply of professionals trained in skin checks targeted at regions and cohorts with high access barriers alongside the development of a Roadmap for a National Targeted Melanoma Screening Program.
Key partners	Federal and State Governments, Royal Australian College of General Practitioners, Australasian College of Dermatologists, Cancer Nurses Society of Australia, Melanoma Patients, Melanoma Charities
Lead partner	Federal Government

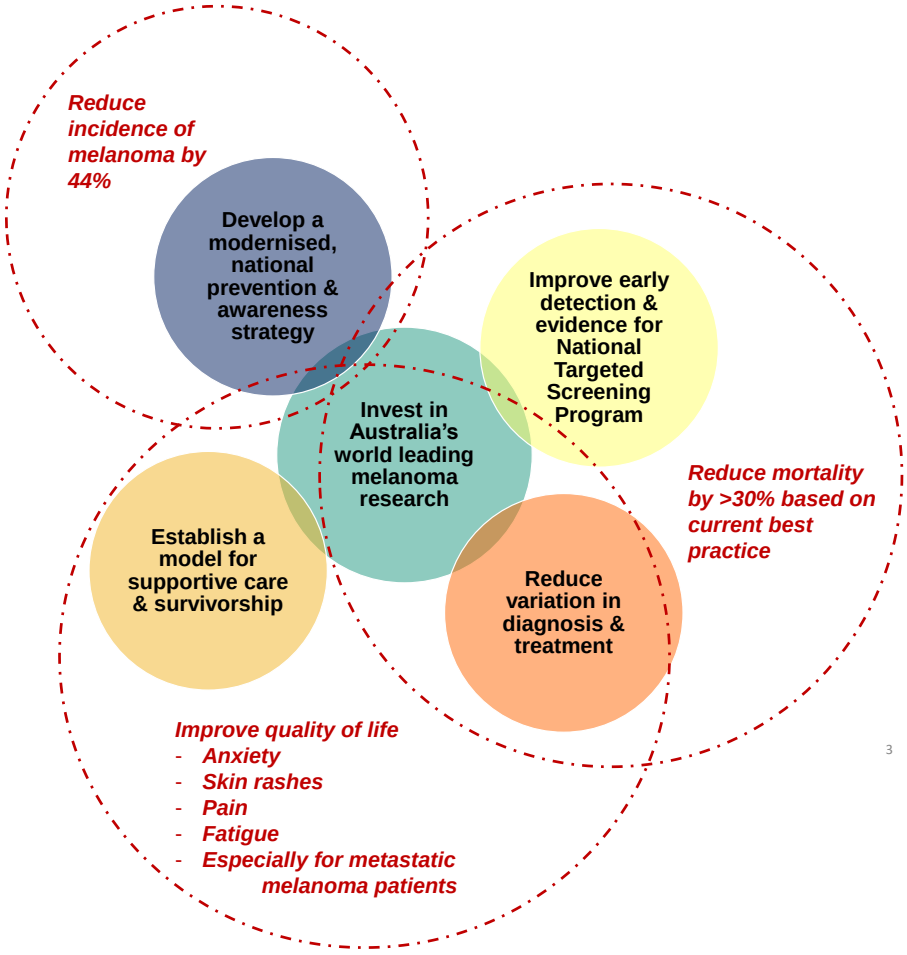
8.3 Impacts of action

COVID-19 has proven that economic and political success is founded on the health of the country's population.[196]

As demonstrated in the previous chapters, the implementation of these actions would be expected to deliver significant, step change improvements in survival and quality of life (Figure 8.2), both in the long term (prevention and research) and the short term (detection and diagnosis, treatment and care, and survivorship).

[196] The Lancet, 2021, Health as a foundation for society, 397(10268), 1, doi: 10.1016/S0140-6736(20)32751-3.

Figure 8.2: Payoffs from Action Plan

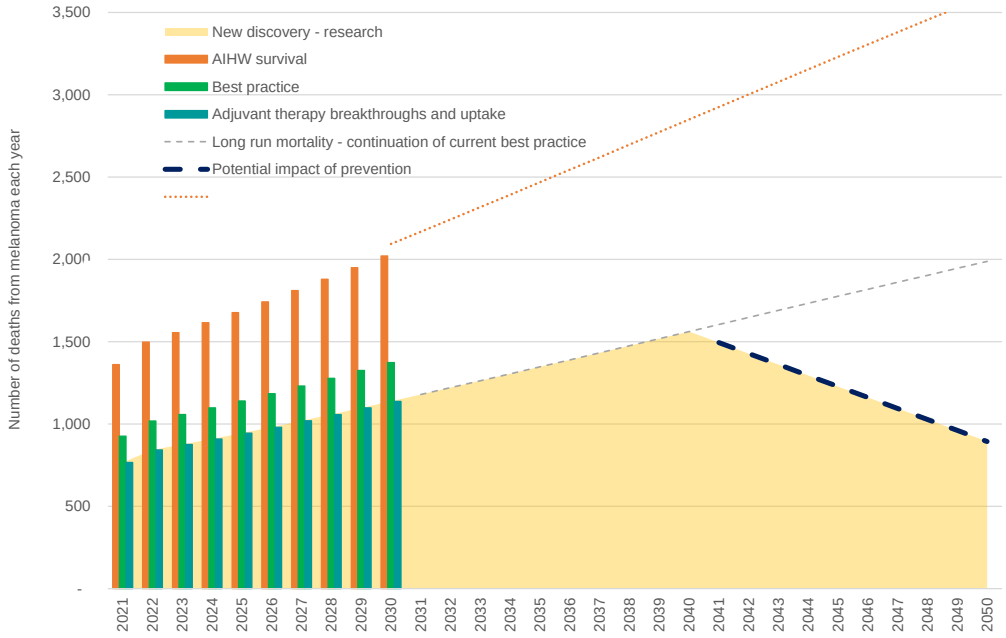


Modelling shows significant (Figure 8.3), step change outcomes are possible through the implementation of the proposed plan. In particular:

- The implementation of current best practice would see mortality reduce by 32 per cent nationally, saving more than 4,000 lives over the next 10 years alone
- The uptake of expected adjuvant therapy breakthroughs could see a further improvement in mortality compared to the status quo depending on the durability of survival improvements observed in early data
- Prevention has the potential to reduce incidence by 45 per cent, which is fundamental to seeing zero deaths from melanoma within our lifetimes. Importantly, prevention interventions would improve outcomes for melanoma and non-melanoma skin cancer patients.

In addition, improved patient support through navigation services and nursing support can substantially improve patient quality of life, through improved management of anxiety, pain, fatigue, rashes, lymphoedema, and other side effects of melanoma and its treatment.

Figure 8.3: Long run mortality expectations – current Australian Institute of Health and Welfare survival rates, best practice survival outcomes, potential impact of additional adjuvant breakthroughs and prevention



Source: Incidence projections to 2030 based on bottom-up cohort method, with current mortality projected to 2050 holding mortality growth fixed. Prevention impacts based on Gordon, L, Olsen, C, Whiteman, DC, et al., 2020, Prevention vs early detection for long term control of melanoma and keratinocyte carcinomas: a cost-effectiveness modelling study, BMJ Open.

8.4 Pathways for implementation

Australia is at a unique juncture with a National Preventative Health Strategy and National Cancer Plan in development.

Australia's health system is defined by a federated model of government supported by a complex and sophisticated not-for-profit charity sector which has been taking on an increasing services delivery role as survival rates from cancer have improved. The National Preventative Health Strategy (Draft) and National Cancer Plan (in development) present Australian communities with the opportunity to work more collaboratively across the federated model of health care to achieve more equitable services and outcomes.

Several of the recommendations in this report are not 'melanoma-specific', and indeed, would benefit from a 'pan-cancer', national approach with the goal of reducing inefficiencies and maximising the outcomes of the policy reforms and investment.

Some of these recommendations, however, are melanoma-specific and will require implementation by the melanoma community in partnership with Australian governments.

What actions recommended by this plan cut across all cancers, and can be implemented through the National Cancer Plan?

While the development of a National Cancer Plan is in its infancy and not expected to be delivered until 2023, there are a number of major recommendations contained in this report which would benefit from a nationally consistent approach and investment in key infrastructure; these include:

- Establish a national approach to maintain up-to-date clinical guidelines, OCPs and quality frameworks for all cancers, including melanoma

- Establish up-to-date information directories of services and supportive care for all cancers, including melanoma, to be available at Cancer Australia's website as well as via other organisations
- Establish a national approach to genomic testing to support early detection across all cancers
- Developing formalised approach to clinically important therapies that lack market incentives for registration and/or listing, or where there are inconsistencies in access nationally
- Develop a National Cancer Data Ecosystem in line with Australia's international peers, bringing together clinical, population and quality registry data assets to support research and continual improvement in clinical care for all cancers, including melanoma
- Develop a nationally consistent and equitable model of care for patient navigation and nurse support services
- Develop a nationally coordinated approach to Patient Reported Outcomes, with specific metrics for each cancer but underpinned by a common infrastructure and standards approach
- Develop a nationally consistent approach to palliative care services.

What actions are melanoma specific, which will need to be implemented outside of the National Cancer Plan?

Other actions are melanoma specific, and depending on the governance arrangements proposed by the National Cancer Plan for the collaborative implementation of reforms aimed at improving the quality and safety in cancer care, could be implemented through a National Melanoma Sub-Working Group to the National Cancer Plan's implementation.

Melanoma Prevention and Awareness Strategy

- Accelerate investments in shade, targeting the highest risk public spaces within a five-year horizon
- Improved adherence to sun safe policies in schools, targeting full implementation in primary schools by 2025
- Prevention and awareness strategy and campaigns for melanoma (and other skin cancers) as part of the National Preventative Health Strategy
- Explicit Australian Institute of Sport sports clubs training and assessment documentation improvement and partnerships with sporting and other outdoor clubs, such as the Scouts
- Explicit sun safe training for outdoor trades and partnerships with unions

Invest in High Impact Melanoma Research

- Establish a Nationally Collaborative Melanoma Research Mission and Discovery Program

Early detection

- Establish minimum standards for skin checks
- 'Know the Skin You're In' awareness strategies and campaigns

- National GP training and education in melanoma and dermoscopy
- Increasing the supply of trained professionals for skin checks

Reduce variation in diagnosis, treatment, supportive care and survivorship

- Create a quality framework and clinical care standard for melanoma
- Establish a National Melanoma Nurse Service
- Develop a model of care for melanoma survivorship and update clinical guidelines to provide explicit guidance for survivorship care.

Partnerships in delivery

To support the effective implementation of the proposed actions alongside the development of a National Cancer Plan by Cancer Australia, it is recommended that a National Melanoma Sub-Working Group to be established, as part of the National Cancer Plan's development and implementation, to provide for the ongoing engagement and collaboration of Australian governments and the melanoma community in melanoma policy actions, with the goal of minimising duplication and maximising benefits realisation.

8.5 Priorities for action

A primary challenge in prioritising action in melanoma is that some actions have a long lag between investment and benefits realisation. The full realisation of prevention efforts will only be seen in the next generation and investment in research also vests with a 15-year lag; but without these investments, the very significant benefits of reduced incidence and mortality will never be realised.

At the same time, to only focus on these long-term goals would neglect the significant needs facing melanoma patients today, who need better support to navigate to the right treatment and care, and greater support to manage the significant side effects that they may be experiencing, be they physical, emotional, financial or social.

The prioritisation of the proposed actions must balance short-term benefits improvement of outcomes for people diagnosed with melanoma today with the long run elimination of melanoma incidence and mortality.

To that end, the following actions have been identified as the highest priorities for implementation:

- **National Melanoma Prevention and Awareness Strategy** as this has the potential reduce incidence by 44 per cent if implemented in a sustained way to deliver generational change
- **Nationally Collaborative Melanoma Research Mission and Discovery Program** as new discovery is required to fully eliminate mortality from melanoma and the return on investment in melanoma is expected to exceed $3.90 per dollar invested based on the high impact of Australian melanoma research
- **Roadmap for a National Targeted Melanoma Screening Program** this will deliver an evidence-based program that is equitable in its reach, trustworthy for patients and clinicians and cost-effective for the community and the healthcare system

- **National Patient Navigation and Melanoma Nurse Service** to ensure equitable access to supportive care services which will improve quality of life for current patients and long term survivors
- **National Melanoma Training and Dermoscopy program for GPs** as GPs represent the front-line of melanoma detection. The use of dermoscopy as part of a national minimum standard approach to skin checks increases accuracy of diagnosis and reduces the failure to detect
- **Develop a clinical care standard for melanoma to reduce unwarranted variation** in treatment and care as consistent implementation of clinical best practice nationally has the potential to reduce deaths by 32 per cent based on currently funded technologies.

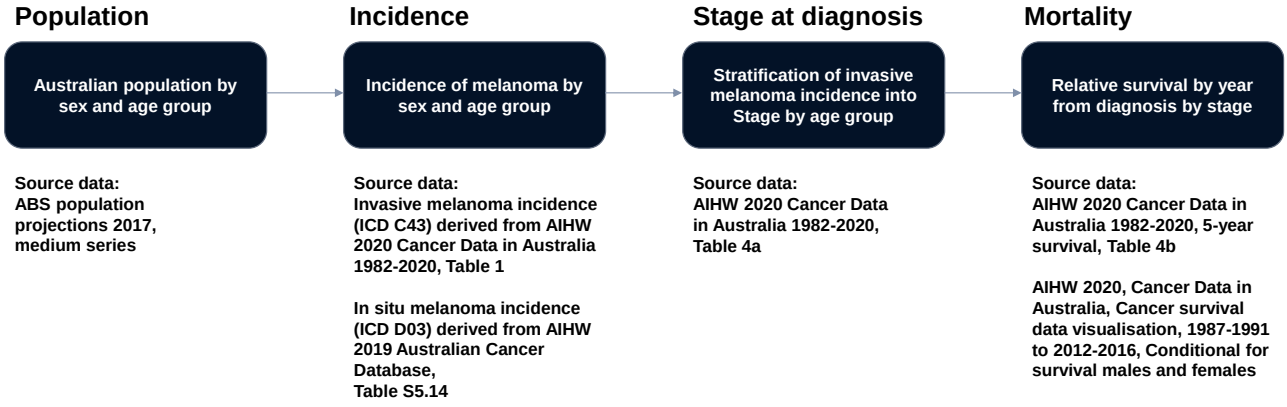
Appendix A

Incidence, mortality, survivorship and cost projections

A.1 Data sources

The following data sets were used to project incidence and mortality of invasive melanoma based on projection of the population by sex and age, with long term (15 year) incidence rates by sex and age cohorts applied to these population groups (Figure A.1). Expected diagnosis and mortality by stage were based on Australian Institute of Health and Welfare data.

Figure A.1: Key data sets



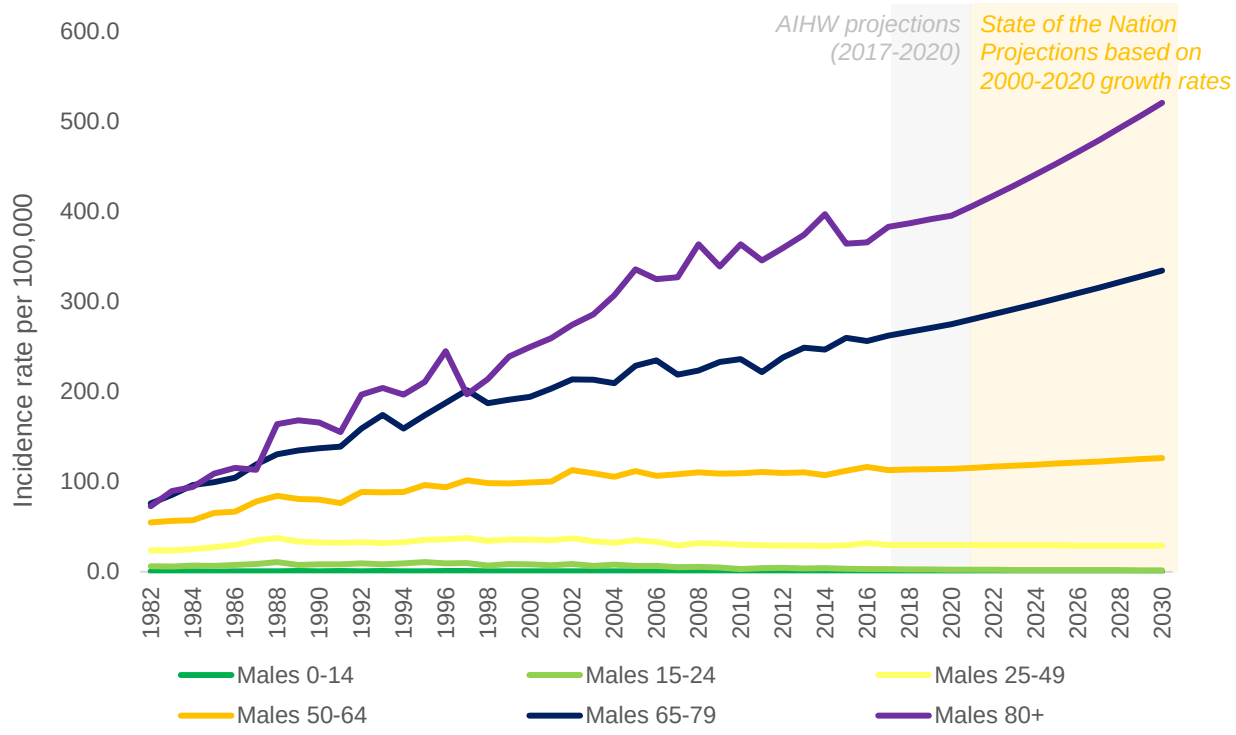
Australian population projections by sex and age were obtained from the ABS, based on Medium Series growth assumptions. This allowed for varying incidence rates to be applied to different age groups. One-year ABS age projections were grouped into key cancer life stages: children (0-14 years old), adolescent and young adult (AYA) (15-24 years old), adults with young families (25-49), older adults (50-64), retired adults (65-79) and elderly adults (80 years+).

Long run trends in incidence rates per 100,000 by sex and 5-year age cohort were evaluated and aggregated into key life stage groupings. Projections for incidence rates per 100,000 were based on the average annual growth observed over 2000-2020 to account for the impact of modern cancer control prevention strategies on incidence rates, particularly on younger Australian cohorts.

A.2 Incidence projections

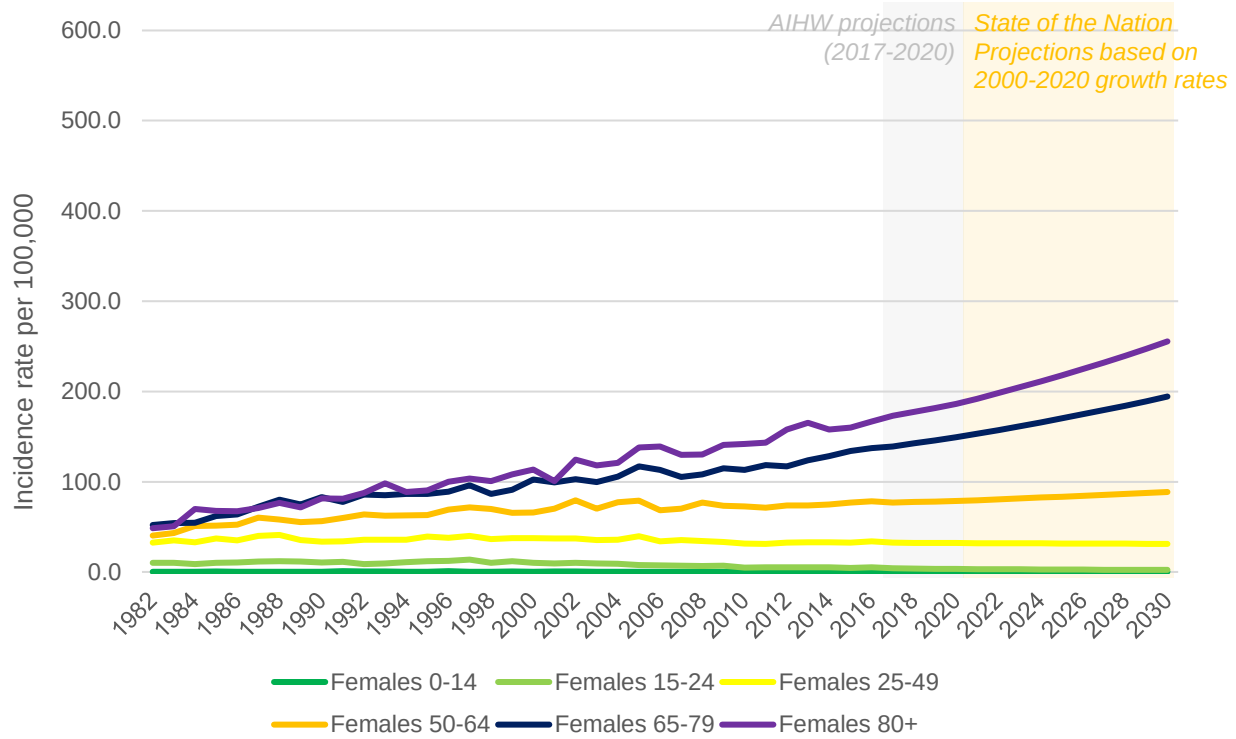
In 2020, the Australian Institute of Health and Welfare estimated 16,221 persons would be diagnosed with melanoma, up from an estimate of 15,726 persons diagnosed in 2019. Based on long run incidence rate projections by sex and age cohort, and expected Australian population growth, 17,260 persons are expected to be diagnosed in 2021, growing to more than 24,000 by 2030 (Figures A.2 and A.3).

Figure A.2: Incidence of invasive melanoma by age group, males



Source: Australian Institute of Health and Welfare, 2020, Cancer Data in Australia, Melanoma, Table 1

Figure A.3: Incidence of invasive melanoma by age group, females

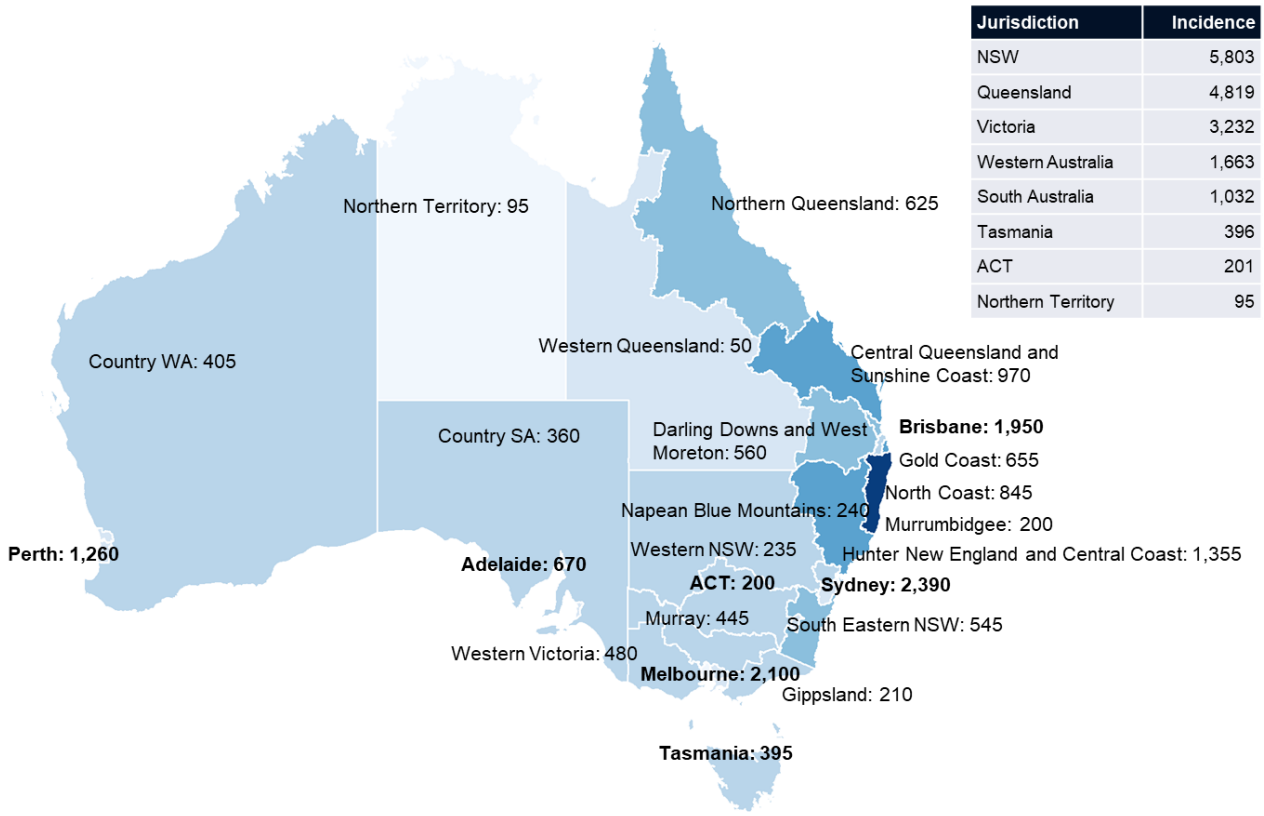


Source: Australian Institute of Health and Welfare, 2020, Cancer Data in Australia, Melanoma, Table 1

Incidence by region was estimated by stratifying total incidence into PHN using reported melanoma incidence by small geographic areas over the 2010-2014 period (Australian

Institute of Health and Welfare). These data show that regional and remote Australia accounts for 47 per cent of total incidence (Figure A.4). In 2021, it would be expected that roughly 8,040 Australians living in regional areas will be diagnosed in 2021. This will be expected to increase to 11,280 Australians by 2030.

Figure A.4: Incidence of invasive melanoma by PHN, 2021



Jurisdiction	Incidence
NSW	5,803
Queensland	4,819
Victoria	3,232
Western Australia	1,663
South Australia	1,032
Tasmania	396
ACT	201
Northern Territory	95

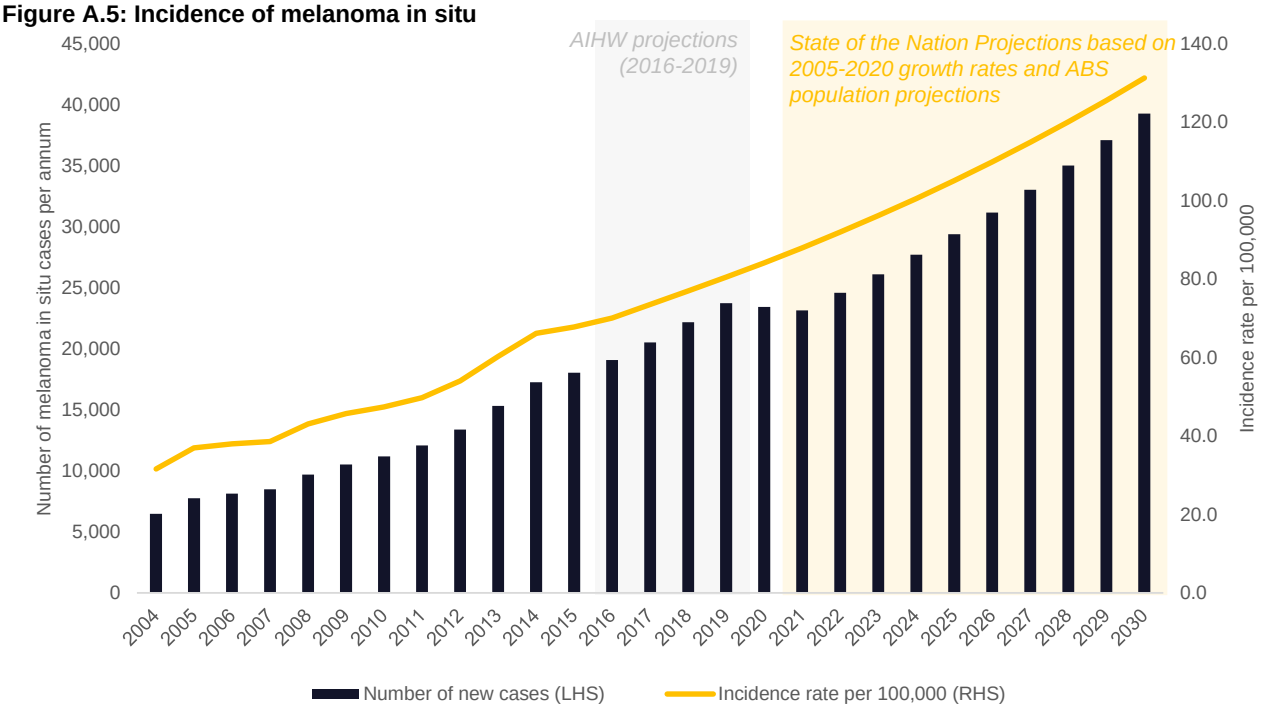
Source: Calculations based on Australian Institute of Health and Welfare, 2019. Cancer statistics for small geographic areas: Primary Health Network (PHN), 2010–2014. Canberra: Table 13 (melanoma). Note figures have been rounded.

The Australian Institute of Health and Welfare reported in 2019 that between 2004 and 2015, the number of new cases of melanoma *in situ* of the skin increased by 115 per cent, from 32 per 100,000 persons in 2004 to 68 per 100,000 persons in 2015 (Figure A.5). Large increases were observed for both males and females, with the risk of melanoma in situ increasing with age as with invasive melanoma.

The Australian Institute of Health and Welfare expect the rate of melanoma in situ was expected by the Australian Institute of Health and Welfare to reach 81 per 100,000 persons in 2019, or more than 23,700 cases in that year, which was 51 per cent higher than the number of invasive melanoma diagnoses in that year (15,726).

Holding the growth rate in incidence observed in last three years (5 per cent per annum growth) constant over the 2021-2030 period and applying this incidence rate to ABS projections implies that in situ melanoma will grow from approximately 23,000 cases in 2021 to more than approximately 39,000 cases by 2030. Based on these assumptions the in situ melanoma rate would increase to 131 per 100,000 by 2030.

Figure A.5: Incidence of melanoma in situ



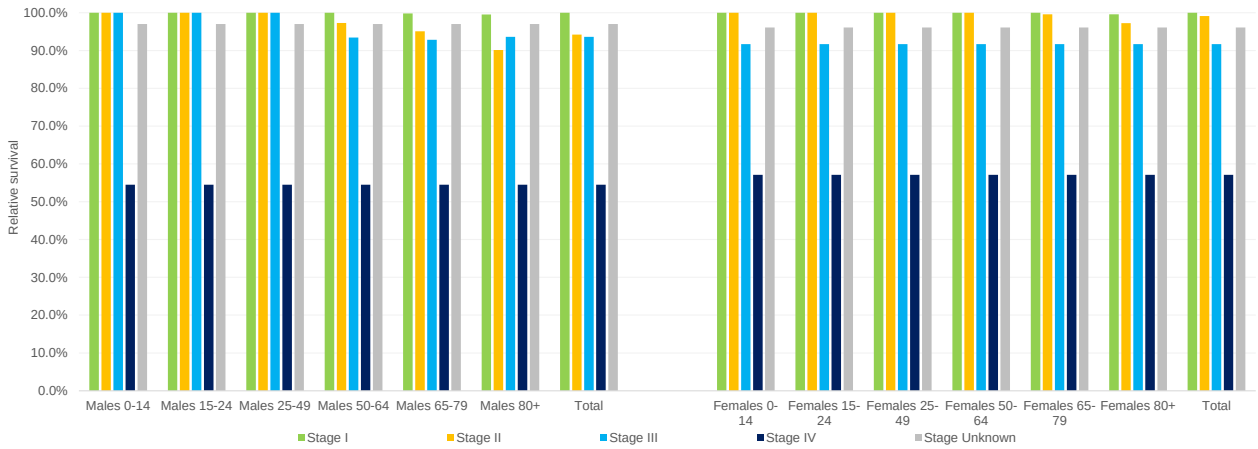
Source: Australian Institute of Health and Welfare, 2019, Cancer Data in Australia, based on Australian Cancer Database, Table S5.14. Note actual AIHW data 2004-2015, projected Australian Institute of Health and Welfare data 2015-2019, projected data from 2020-2030 based on average annual growth rates

A.3 Survival and mortality projections

Australian Institute of Health and Welfare provides data of survival by year for invasive melanoma based on sex and age.

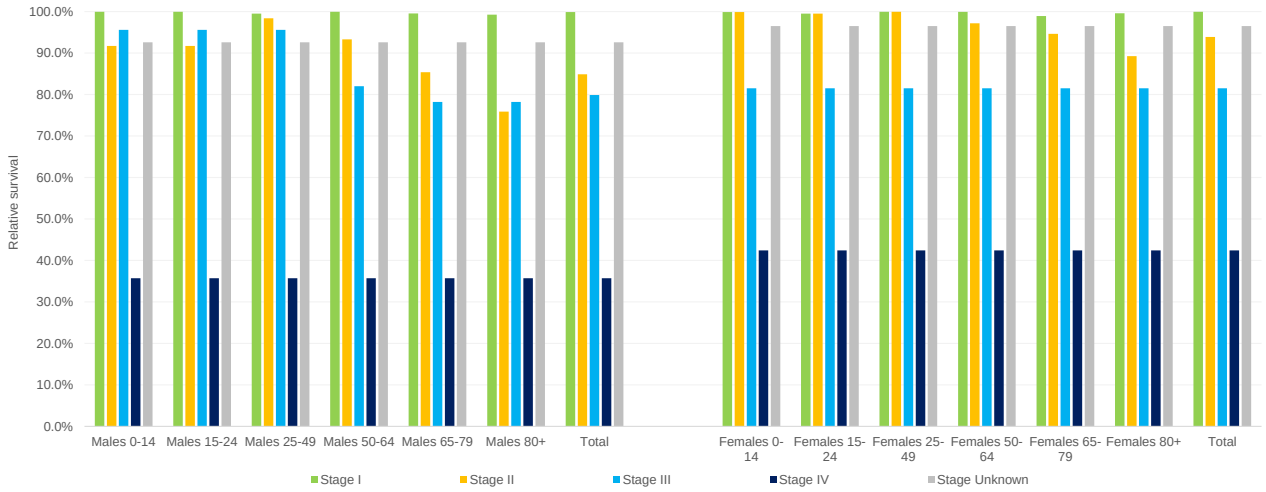
It is noted that the most recent staging data prepared by the Australian Institute of Health and Welfare is based on an analysis of patients diagnosed in 2011. Consequently, survival rates are calculated via tracking this cohort across the subsequent five-year period (until 2016). There is little difference between the all-stage one, three and five-year relative survival rates implied by this data and the most recent all-stage survival rate estimated provided by the Australian Institute of Health and Welfare (2013-2017).

Figure A.6: Survival by sex and stage, 1 Year from diagnosis



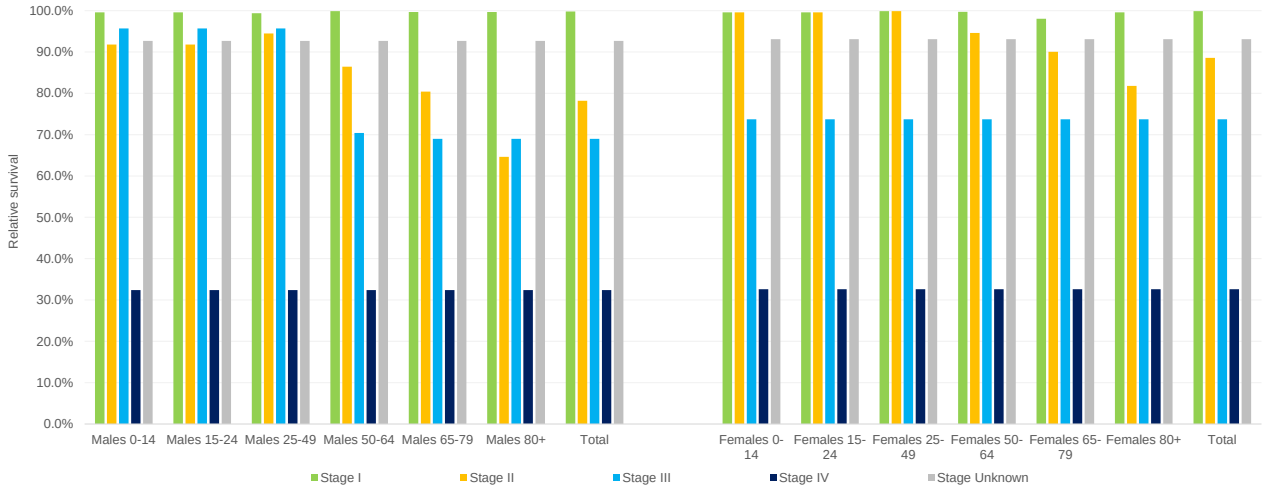
Source: Australian Institute of Health and Welfare, 2020, Cancer Data in Australia, Melanoma, Table 4b

Figure A.7: Survival by sex and stage, 2 Years from diagnosis



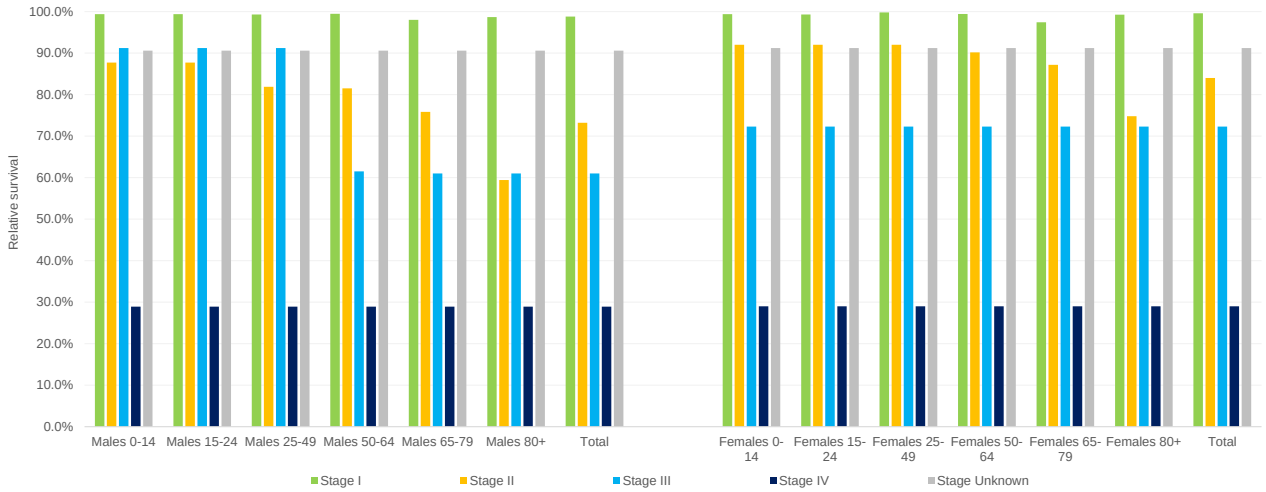
Source: Australian Institute of Health and Welfare, 2020, Cancer Data in Australia, Melanoma, Table 4b

Figure A.8: Survival by sex and stage, 3 Years from diagnosis



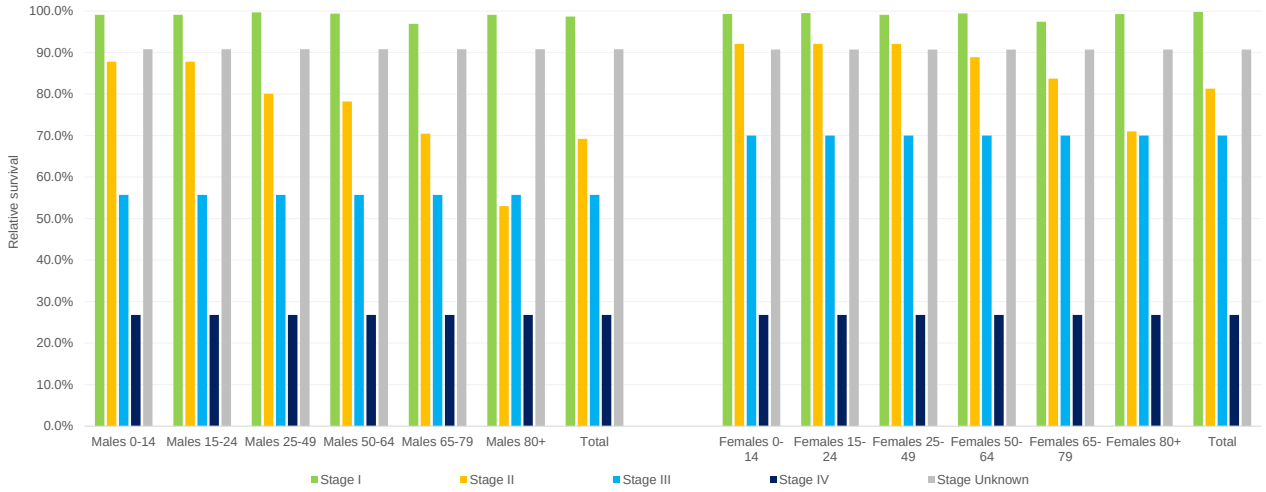
Source: Australian Institute of Health and Welfare, 2020, Cancer Data in Australia, Melanoma, Table 4b

Figure A.9: Survival by sex and stage, 4 Years from diagnosis



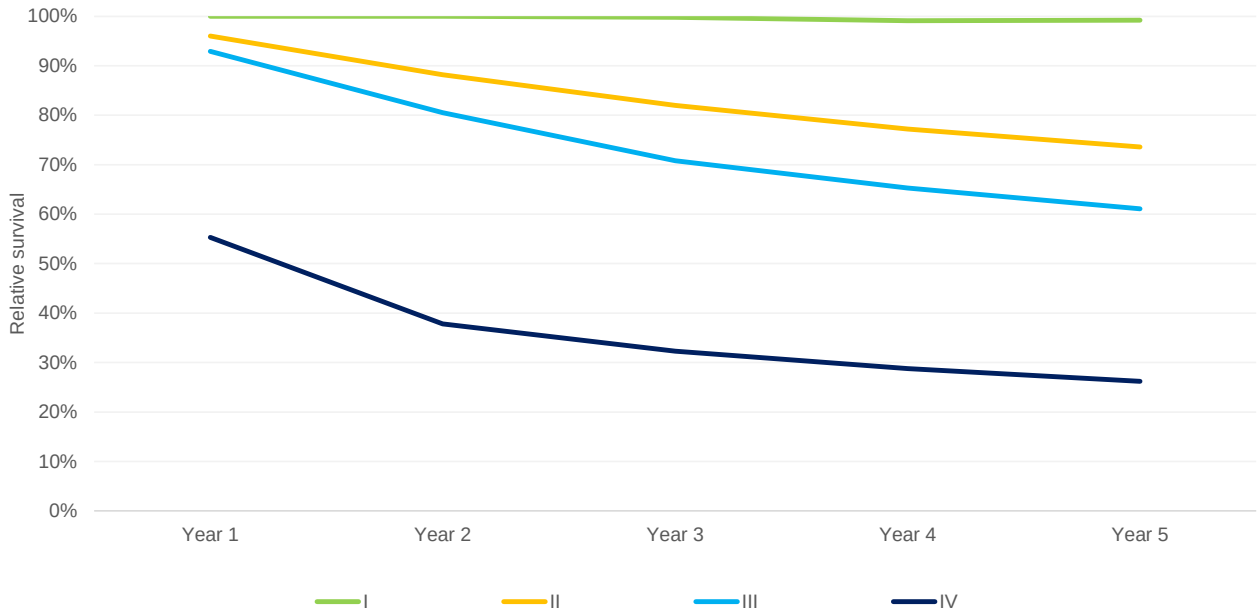
Source: Australian Institute of Health and Welfare, 2020, Cancer Data in Australia, Melanoma, Table 4b

Figure A.10: Survival by sex and stage, 5 Years from diagnosis



Source: Australian Institute of Health and Welfare, 2020, Cancer Data in Australia, Melanoma, Table 4b

Figure A.11: Survival by stage, all persons, 1-5 Years since diagnosis – Australian Institute of Health and Welfare (2011 data)



Source: Australian Institute of Health and Welfare, 2020 (staged data based on cohort diagnosed in 2011), Cancer Data in Australia, Melanoma, Table 4b

Based on most recent survival rates by stage for each sex as reported by the Australian Institute of Health and Welfare in 2020, more than 18,500 Australians (18,501) diagnosed over the next 10 years will lose their lives to melanoma within five years of their diagnosis (Table A.1).

Table A.1: Expected 5-year mortality from year of diagnosis for people diagnosed between 2021 and 2030 – Australian Institute of Health and Welfare projections

	Males							Females							Persons
	Year 1	Year 2	Year 3	Year 4	Year 5	Total		Year 1	Year 2	Year 3	Year 4	Year 5	Total		Total
2021	256	281	163	196	160	1,055		84	108	103	79	45	421		1,476
2022	269	295	171	205	167	1,107		88	114	109	83	48	441		1,548
2023	282	310	179	214	175	1,159		91	120	114	87	50	462		1,621
2024	296	326	189	223	183	1,216		95	126	120	91	52	484		1,700
2025	311	342	199	233	191	1,276		100	132	126	96	54	508		1,784
2026	326	361	210	243	200	1,340		104	139	132	101	57	533		1,873
2027	345	381	222	254	210	1,413		110	147	139	106	60	562		1,974
2028	362	402	235	265	220	1,484		115	155	147	112	63	591		2,075
2029	380	422	247	276	229	1,555		120	163	154	117	66	620		2,174
2030	398	442	260	287	239	1,625		126	171	161	123	69	650		2,275

Source: Calculations based on Australian Institute of Health and Welfare survival projections

Based on current survival rates by stage for each sex as based on the Checkmate trial, however, the number of people expected to lose their lives from melanoma will decline from more than 18,500 Australians (18,501) to 17,393 Australians (Table A.2). This will see 1,108 additional Australians alive as a result of the research breakthroughs in Stage IV treatments alone, and more than 8,000 years of life gained on average. The use of systemic therapies in neoadjuvant therapies for Stage III patients would increase this further.

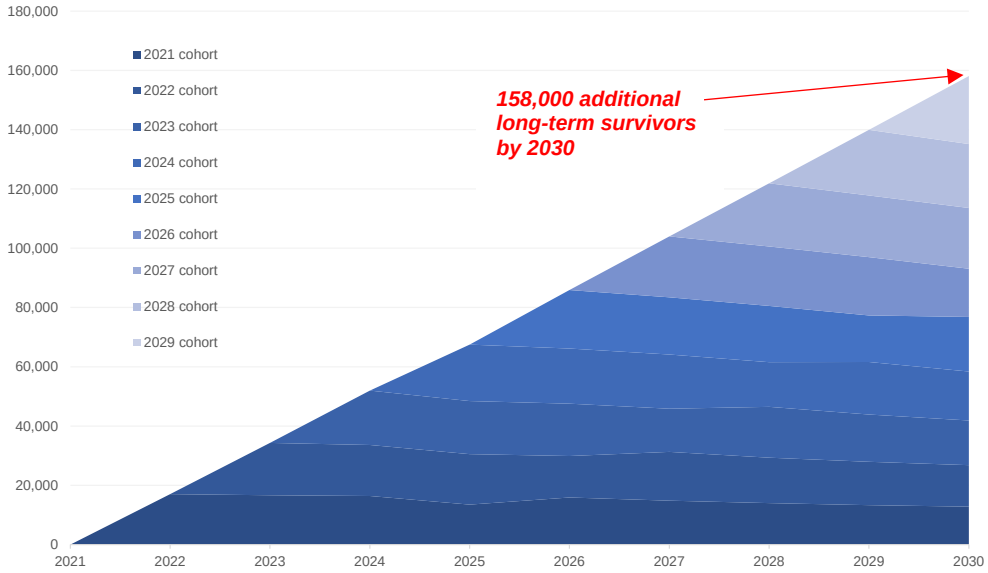
Table A.2: Expected 5-year mortality from year of diagnosis for people diagnosed between 2021 and 2030 – Stage IV advances

	Males							Females							Persons
	Year 1	Year 2	Year 3	Year 4	Year 5	Total		Year 1	Year 2	Year 3	Year 4	Year 5	Total		Total
2021	211	256	170	200	155	990		68	102	99	81	43	394		1,384
2022	222	269	178	209	162	1,039		71	108	104	85	45	413		1,452
2023	233	282	187	218	169	1,089		74	113	110	89	47	433		1,521
2024	245	297	197	227	177	1,143		78	119	115	93	49	454		1,597
2025	257	313	207	237	185	1,199		81	125	121	98	52	477		1,676
2026	271	329	218	248	194	1,260		85	132	127	102	54	501		1,761
2027	287	349	231	259	203	1,329		90	139	134	108	57	528		1,857
2028	302	368	244	270	213	1,397		94	147	141	114	60	555		1,953
2029	317	387	257	281	222	1,464		98	154	148	119	63	583		2,048
2030	333	406	270	292	231	1,531		103	162	156	125	66	612		2,143

Source: Calculations based on Australian Institute of Health and Welfare survival projections and survival data from Checkmate Trial

Based on continued high rates of incidence, the number of survivors is expected to substantially increase. The Australian Institute of Health and Welfare reported that there were more than 190,000 melanoma survivors in Australia as of 2015. Based on projections of incidence and mortality, by 2030 there will be an additional 158,000 melanoma survivors in Australian communities (Figure A.12), added to an existing prevalence of around 190,000.

Figure A.12: Additional survivorship projections to 2030



Source: Projections based on Australian Institute of Health and Welfare Australian Cancer Database 2016 and National Mortality Database.

Table A.3: Prevalence of melanoma survivors as at 1 year since diagnosis, 5 years since diagnosis and 34-years since diagnosis, as at the end of 2015

Years since diagnosis	Prevalence
1	13,456
5	57,395
34	191,270

Source: Australian Institute of Health and Welfare Cancer in Australia Statistics

A.4 Costs of melanoma

Modelling has been developed to estimate the direct health system costs, out of pocket consumer costs and impacts on QALY gained. Disease recurrence has been factored into first three years of data, but not explicitly modelled over the longer term to be conservative. Further, while rates of recurrence and timing of recurrence data are available, it is less clear what assumptions should be made regarding later stage treatments. Specifically:

- Direct health system impacts in Years 1-3 are based on Elliott, TM, et al (2017).
- Direct health system impacts Years 4+ are based on market data, assumes consultations fees and imaging and photography costs are incurred three times per year, plus excision fees every two years and 15 per cent take up of psychosocial care plans (10 sessions per year funded by MBS) based on Melanoma Patient and Carer Survey data.
- Out of Pocket consumer costs are based on Melanoma Patient and Carer Survey data, which reported that 66 per cent of consumers and 38 per cent of consumers incurred out of pocket costs during active treatment and survivorship phase, respectively. Based on the low range of cost estimate available in each answer, the weighted average out of pocket cost during active treatment was estimated to range from $5,600 per patient in Stage I to $7,682 per patient in Stage IV. For long run

survivorship, the weighted average out of pocket cost was estimated to be $2,900 on average per annum across all stages.

- All costs were assumed to increase at a rate of 3.1 per cent per annum.[197]
- QALY estimates were 0.97 for Stages I and II, and 0.77 for Stages III and IV, based on Gordon et al (2020).
- Cost per QALY assumed to be $50,000/QALY gained.

A.5 Sensitivity analysis

Alternate discount rates

Future cash flows are discounted at a social discount rate to reflect the time value of money, that is, it is generally better to have a dollar today than a dollar tomorrow. The 'risk-free' rate is generally assumed to be the current rate for 20-year Commonwealth bonds, which at the time of the report preparation was just over 2.0 per cent.[198] Ten-year Treasury bonds were valued at 1.5 per cent.

Historically, Treasury bond rates have been higher, such that a historic social or 'risk free' discount rate would have been valued at 5.0 per cent; Pharmaceutical Benefits Advisory Committee Guidelines last updated in 2016 recommend the adoption of a base rate of 5.0 per cent, with a first sensitivity discount rate of 3.5 per cent. [199]

Sensitivity analyses of 5.0 per cent and 3.5 per cent were undertaken in line with historical economic impact standards.

	Total healthcare costs	Direct healthcare costs	Out of pocket costs
Social discount rate 2.0%	$4.2b	$3.1b	$1.2b
Social discount rate 3.5%	$3.8b	$2.8b	$1.1b
Social discount rate 5.0%	$3.4b	$2.6b	$1.0b

[197] AIHW, 2020, Health expenditure Australia 2018-19https://www.aihw.gov.au/reports/health-welfare-expenditure/health-expenditure-australia-2018-19/contents/summary
[198] ASX, 2021, Government Bonds, Treasury Yield Curve, accessed at: https://www2.asx.com.au/markets/trade-our-cash-market/equity-market-prices/bonds.
[199] Available at: https://pbac.pbs.gov.au/section-3a/3a-1-overview-and-rationale-of-economic-evaluation.html.

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Appendix B

Survey of Melanoma Patients and Carers

B.1 Approach

Over April and May 2021, a Patient and Carer Survey was distributed by Melanoma Patients Australia and Melanoma Institute Australia with the support of the Australian melanoma community.

The survey was multiple-choice and designed using a page-logic format so that respondents only answered questions based on their experience. Drafts of the survey were piloted with consumers and researchers and revised according to pilot results feedback. The survey took approximately 10-15 minutes to complete. Responses were confidential and analysed by Insight Economics.

B.2 Response Statistics

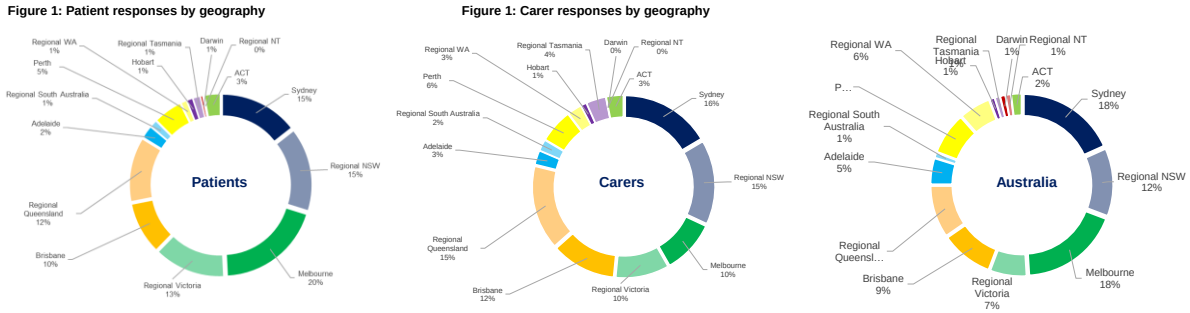
In total, 1,137 patients and carers responded to the Melanoma Patient and Carer Survey; within this, 920 patients responded and 217 carers responded. The sample is statistically valid, with 95 per cent confidence the true value would be within +/-2.8 per cent margin of error.

There was also an excellent response from both patients and carers by region, age, income, stage of treatment, and insurance status.

Geographic distribution of respondents

Response rates by geography aligned to Australia's population distribution, with a good response from each state and territory as well as capital cities and regional areas compared with ABS data for the wider population.

Figure B.1: Who responded? Survey response statistics by region



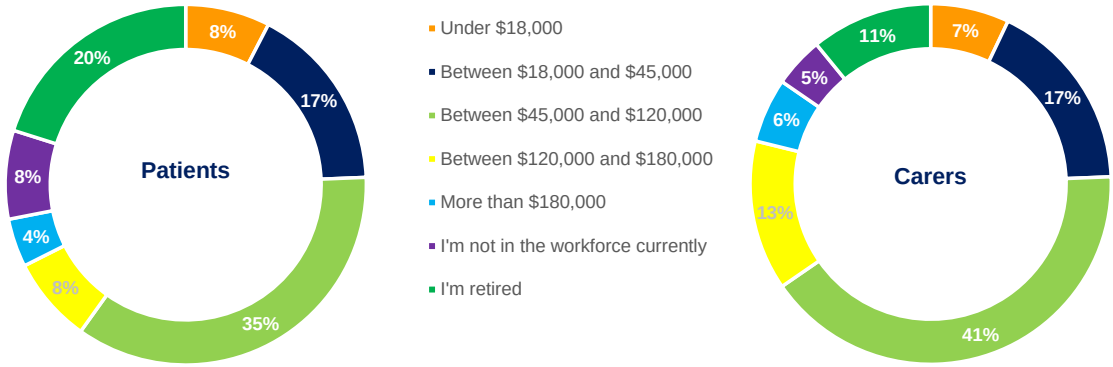
Source: Melanoma Patient and Carer Survey, ABS data

Income distribution of respondents

There was also a good distribution of respondents by income level, retired status and workforce participation status. Persons in the workforce were relatively over-represented. Excluding retired persons and persons not in the workforce, persons earning less than $18,000 accounted for 11 per cent of respondents that were also in the workforce (compared to 19 per cent in the wider population participating in the workforce); persons earning

between $18,000 and $45,000 accounted for 23 per cent of respondents that were also in the workforce (compared to roughly 22 per cent of the wider population); 60 per cent earned between $45,000 and $180,000 (compared to 56 per cent in the wider population); and six per cent earned over $180,000 per year (compared to three per cent in the wider population). The proportion of retired persons responding (20 per cent) strongly correlated to the wider population (15 per cent) while persons not participating in the workforce were relatively under-represented (eight per cent compared to 24 per cent).

Figure B.2: Who responded? Survey response statistics by income



Source: Melanoma Patient and Carer Survey

Table B.1: Distribution of Australians by income bracket, labour force participation status

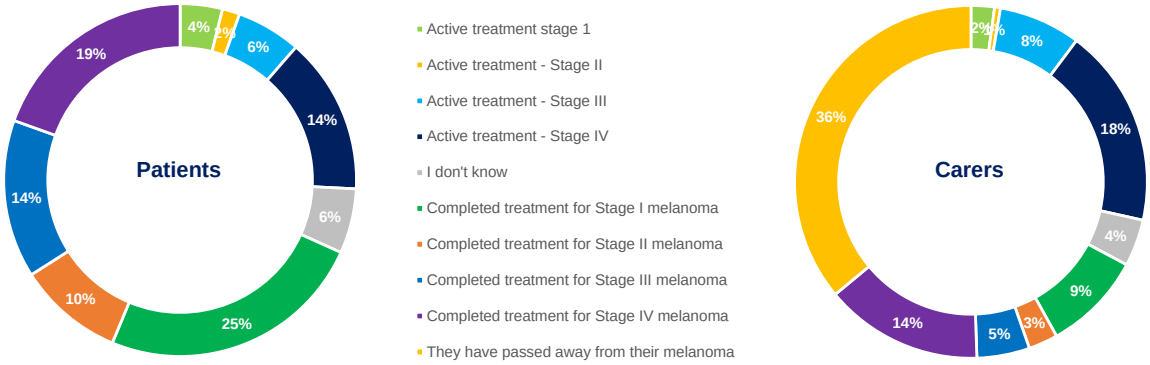
Individuals by tax bracket (ATO and ABS data)	
Less than 18,000	19%
$18,000-$37,000	22%
$37,000-$80,000	40%
$80,000-$180,000	16%
More than 180,000	3%
Proportion of population that is retired	15%
Proportion of persons not in the labour force	24%

Source: ATO and ABS data

Income distribution of respondents

Patients and carers from all stages of treatment responded, although the sample was over-represented by patients with advanced melanoma. Patients in either active treatment or a survivor of Stage III melanoma accounted for 21 per cent of respondents compared to three per cent of incidence. Patients in either active treatment or a survivor of Stage IV melanoma accounted for 36 per cent of respondents compared to two per cent of incidence. A similar pattern was observed among carers, with 22 per cent and 55 per cent of respondents indicating their loved one had been diagnosed with Stage III or Stage IV, respectively. Approximately 30 per cent and 12 per cent of patient respondents indicated they were in active treatment or a survivor of Stage I or Stage II melanoma, respectively, which compares to incidence of 77 per cent and 15 per cent in Australian Institute of Health and Welfare data for melanoma incidence. This indicates a very high level of confidence in the data for Stages II through IV while the margin for error among Stage I survivors is somewhat wider (+/- six per cent).

Figure B.3: Who responded? Survey response statistics by stage of melanoma



Source: Melanoma Patient and Carer Survey, ATO data

Other variables

- *Subtype* — Three per cent of patient respondents reported diagnosis of a rare subtype of melaoma, including ocular (1.6 per cent) or mucosal (1.3 per cent) subtype. A few respondents also indicated a diagnosis of acral melanoma as well. A similar response pattern was observed in the carer survey, with 2.6 per cent indicating a family member had been diagnosed with ocular melanoma and one per cent with a mucosal melanoma.
- *Gender* — Women accounted for a higher proportion of respondents in the patient survey (66 per cent) than is observed in the incidence of melanoma (41 per cent). Women also accounted for most carer responses (86 per cent).
- *Insurance status* — Persons with PHI were over-represented in the patient survey (69 per cent) and carer survey (70 per cent) compared to the wider population (44 per cent, APRA 2020).
- *Country of birth* — Just over 95 per cent of patient respondents were born in Australia (84 per cent), New Zealand (5 per cent), England (4 per cent), Scotland (2 per cent) or Ireland (1 per cent). This accords with the risk profile for melanoma patients.
- *Language* — Nearly 98 per cent of patient respondents spoke only English, with the balance (two per cent) speaking both English and another language well at home.

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Appendix C

Stakeholder Consultation and Consumer Forums

Combined with consumer forum consultations, more than 67 stakeholders were engaged on the challenges and opportunities to improving outcomes in melanoma. In this Appendix, an overview of the Stakeholder Consultation and Consumer Forum is provided.

C.1 Overview of Consumer Forums

Melanoma Patients Australia convened a series of three consumer forums with patients and carers around Australia over the course of April and May 2021.

The objective of the consumer forums was to hear in patients' own words about what they see as the major challenges and opportunities for change in three key policy domains:

- Improving awareness, understanding and prevention
- Improving early detection
- Improving access to treatment and care for patients and survivors.

The consumer forums were developed with the goal of enabling all participants a chance to have a say. To that end, three workshops were held:

- The Queensland, Northern Territory and Western Australia Consumer Forum was held on 29 April 2021. The forum was co-chaired by Victoria Beedle, CEO of Melanoma Patients Australia, and Penny Tovey, from the Melanoma Patients Australia Consumer Advisory Group.
- The New South Wales, Australian Capital Territory and South Australia Consumer Forum was held on 4 May 2021. The forum was co-chaired by Victoria Beedle, CEO of Melanoma Patients Australia, and Karen van Gorp, Co-Chair of the Melanoma Patients Australia Consumer Advisory Group.
- The Victorian and Tasmanian Consumer Forum was held on 14 May 2021. The forum was co-chaired by Victoria Beedle, CEO of Melanoma Patients Australia, and Peter Gourlay, Co-Chair of the Melanoma Patients Australia Consumer Advisory Group.

C.2 Overview of Stakeholder Consultation

Thirty-eight stakeholders were consulted through the national stakeholder engagement process, bringing a diverse range of perspectives on the challenges and opportunities for melanoma patients (listed in Acknowledgments section).

The consultation brief provided to the stakeholders is presented in Appendix C.3 below.

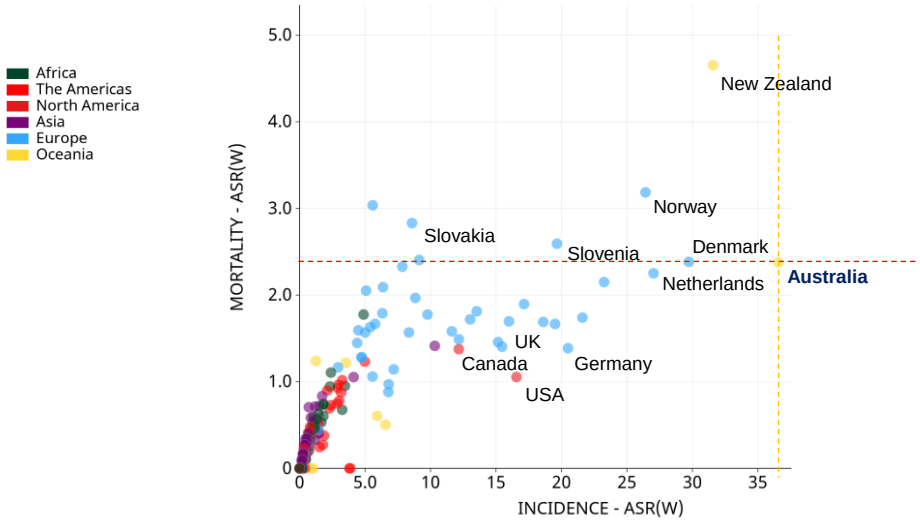
C.3 Consultation brief

Project Background

Melanoma is often termed 'Australia's cancer' as a result of the high incidence and mortality rates observed in Australian communities compared to other countries.

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 a global average of only 4.2 per 100,000 persons (Figure 1).[200]

Figure 1: Age-standardised rate (ASR) of incidence and mortality per 100,000 people, invasive melanoma, 2020



Source: 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/

The Australian Institute of Health and Welfare (AIHW) estimates that more than 16,220 Australians were diagnosed with invasive melanoma in 2020 alone, accounting for more than one out of every ten cases of cancer diagnosed in Australia today.[201] In addition to this, the incidence rate of in situ melanoma increased by 115 per cent between 2004 and 2019, with more than 23,000 in situ melanomas removed each year.[202]

As a result of this high incidence rate, AIHW data show that the lifetime melanoma mortality risk in 2020 has increased by 42 per cent (mortality risk of 1 in 140 persons) compared to the mortality risk observed in 1982 (mortality risk of 1 in 240).[203] Every year, approximately 1,400 Australians are expected to die from melanoma.[204]

Melanoma presents not only significant health risks, but potentially also challenging financial, social and emotional impacts for patients, their families, and the wider Australian healthcare system. Patients and their families can experience substantial out-of-pocket costs associated with surveillance, informal care and treatment, as well as adverse impacts on employment.[205] Patients and carers are also at risk for depression or anxiety, which often

[200] 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/
[201] AIHW, 2020, Cancer Data in Australia, C43, Melanoma
[202] AIHW, Cancer in Australia, 2019
[203] AIHW, Cancer Data in Australia, Cancer data commentary 2, Risk of melanoma of the skin by age and over time, 2020
[204] AIHW, 2020, Cancer Data in Australia, C43, Melanoma
[205] See for example KPMG, 2014, Advanced Melanoma: The real cost of Australia's National Cancer, report to Melanoma Patients Australia; Watts, CG, Cust, AE, Menzies, SW, et al., 2014, Specialised Surveillance for Individuals at High-risk for Melanoma, JAMA Dermatol., doi: 10.1001/jamadermatol.2014.1952; Doran, CM, Ling, R, Byrnes, JJ, Crane, M, et al., 2015,

intensifies with advanced stages of disease.[206] Moreover, while many novel therapies offer substantial improvements in survival, they can also come with very significant long-term side effects. Thus, as survival rates from melanoma have increased, so too, has the need for more effective survivorship support to patients and their families.

At the same time, very significant advances in research and technology are emerging, enabling new approaches to the treatment of advanced disease, as well as more effective and efficient tools for early detection and diagnosis. New developments in precision medicine treatment approaches to metastatic melanoma offer the potential for substantial improvements in long-term survival and symptom relief, while emerging use of full body imaging and new machine learning algorithms have been shown to improve early detection and diagnosis.[207]

Taken together, these data indicate that while much has been achieved in Australia, there is much more to be done, and improving outcomes in melanoma remains a critical policy priority for Australian communities.

Melanoma Institute Australia and Melanoma Patients Australia have engaged Insight Economics to take stock of the current landscape for melanoma in order to identify opportunities for policy change and investment to improve outcomes for patients and carers as well as the wider Australian community. It is intended that the State of the Nation in Melanoma strategy will make recommendations from how Australia can best improve outcomes for patients: from accelerating high impact research in melanoma through to enhanced approaches to early detection, diagnosis and treatment, as well as improvements in policy settings for survivorship and end of life care.

Key questions for discussion

- ***Research*** — Australia's research community are leaders in melanoma research globally, which has seen significant advances in the understanding of melanoma biology as well as novel diagnostic and treatment technologies. In particular recent advances in novel and combination immunotherapies and targeted therapies have shown enormous promise in treating metastatic melanoma, with the potential to increase 5-year survival by a factor of ten over the standard of care available in 2010 alone.
    - How would you characterise the major research questions and opportunities in melanoma research today? For example, are there significant challenges or opportunities in:
        - Biology and aetiology
        - Prevention
        - Early detection, diagnosis, and/or prognosis
        - Treatment and resistance
        - Survivorship and outcomes evaluation
    - Are there major technology disruptions on the horizon that have the potential to further significantly improve survival, quality of life or deliver cost

Estimating the economic cost of skin cancer in New South Wales; and Watts, CG, Wortley, S, Norris, S, Menzies, SW, et al., 2018, A National Budget Impact Analysis of a Specialised Surveillance Program for Individuals at Very High-risk of Melanoma in Australia

[206] See Pitman, A, Suleman, S, Hyde, N, et al., 2018, Depression and anxiety in patients with cancer, BMJ, doi: 10.1136/bmj.k1415 and KPMG, 2014, The Economic Cost of Advanced Melanoma, report to MPA, page 8.

[207] ESMO, 2019, Cutaneous melanoma: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up, Annals of Oncology 30: 1884-1901, doi: 10.1093/annonc/mdz411.

effectiveness in health service delivery? Do you have an expectation of the time horizon for these technologies to become available?

  - How can Australia's research impact in global melanoma research be maximised? Do you see any major impediments (infrastructure, skills, regulatory) to the conduct of research in Australia that should be addressed? What should be done to accelerate research in Australia or Australia's participation in global research efforts?

  - How does the impact of research in melanoma spillover into other areas of research? Have current research pathways and treatments for immunotherapies positively impacted other areas of cancer research or treatments, such as lung, breast and kidney disease? In what ways has this occurred?

- ***Prevention and awareness*** — While not all melanoma cancers are preventable,[208] the risk of many melanomas can be reduced through the avoidance of ultraviolet (UV) exposure. Australia has historically led the way globally in the prevention of melanoma and other skin cancers through the *Slip-Slop-Slap* campaign of the 1980s and the *SunSmart* program initiated in 1998 in Australian primary schools. In addition, state and territory occupational health and safety standards provide a regulatory framework to guide safety UV radiation exposure, while the Australian Taxation Office (ATO) has allowed for tax deductions on necessary personal protective equipment for people working outdoors. These policies aimed at prevention have seen the incidence and mortality risk for younger Australians decrease substantially compared with older Australian cohorts.[209] At the same time, incidence rates remain persistently high among males and in socioeconomically disadvantaged cohorts, and there may be opportunities to improve the effectiveness of prevention policy settings.

  - What do you see as the major successes and learnings from Australia's efforts to reduce UV exposure?

  - Do you think there is sufficient awareness of the seriousness of melanoma? Should more be done to improve understanding and awareness of melanoma? What do you think could be done to improve understanding and awareness, to support broader prevention efforts?

  - What do you see as the major opportunities to improve preventative policy settings? Are there at-risk groups that require a new or modified approach?

  - Are there new approaches to prevention being implemented in parts of Australia or internationally that could usefully inform Australia's policy approach to melanoma prevention?

- ***Early detection and diagnosis*** — Five-year survival rates for melanomas detected in Stages I and II are relatively high, with AIHW estimates reporting 5-year survival of 99.2 per cent and 73.6 per cent in 2020, for Stages I and II, respectively. The outlook remains more challenging for Australians with melanoma detected at more advanced stages, however, notwithstanding significant advances in the past 10 years. In 2020, AIHW estimated the 5-year survival rate for a melanoma detected in Stage IV to be 26.2 per cent,[210] although recent breakthroughs in novel

[208] Please note the scope of the report is inclusive of ocular and mucosal melanomas as well as cutaneous melanoma.
[209] AIHW, Cancer Data in Australia, Cancer data commentary 2, Risk of melanoma of the skin by age and over time, 2020
[210] AIHW, 2020, Cancer Data in Australia, Table 4b: 1 to 5-year relative survival for selected cancers for those diagnosed in 2011, by sex, age group and RD-stage.

immunotherapies and combination therapies have been shown to increase 5-year survival rates to up to 52 per cent.[211] While these advances in treatment are significant, early detection remains an important pillar of melanoma policy settings.

With the exception of Germany, which has implemented a bi-annual skin cancer screening program for persons aged 35 and older, no national or international authorities currently recommend population-based screening for melanoma.[212] Increasingly, however, opportunities to utilise prediction algorithms based on a range of demographic, phenotypic, and clinical factors are being explored to support early detection. Moreover, new technologies, such as full body imaging and AI are also expanding potential health system capabilities for early detection and diagnosis.

  - What are the major barriers or opportunities to improving the early detection and diagnosis of melanoma in Australia?

  - Are there any workforce, infrastructure or regulatory impediments that slow rapid detection and diagnosis?

  - Are there particular at-risk cohorts that are consistently missed in current policy settings?

  - Are there any domestic or international jurisdictions that have pursued a particularly effective approach to early detection and diagnosis that could inform improved policy settings in Australia?

- ***Treatment*** — While Australians face significant risks from melanoma, Australians also enjoy the benefits of an advanced, high quality health care system that achieves world-leading outcomes in survival.

  - Do Australians have timely and equitable access to current global standards of diagnosis, treatment and/or care in melanoma? Are there any major gaps in your view?

  - Are GPs and skin specialists sufficiently aware of the evolving new treatments becoming available for Stage III and Stage IV, including immunotherapies, targeted therapies, neo-adjuvant versus adjuvant treatment?

  - Are there opportunities to improve the effectiveness and/or efficiency of health service delivery for patients diagnosed with melanoma in Australia today? Are there any issues with variation in care nationally that should be addressed?

  - Is access to treatment and care equitably available across geographies and/or settings? Are there any barriers to treatment for regional patients or carers to treatment and care?

  - Are patients sufficiently empowered to navigate the healthcare system? Do melanoma patients have access to nurses and care co-ordinators? Do you have ideas for how patients could be better supported to access treatment and supportive care?

[211] See Larkin, J, Chiarion-Sileni, V, Gonzalez, R, Grob, J-J, et al., 2019, Five Year Survival with Combined Nivolumab and Ipilimumab in Advanced Melanoma, New England Journal of Medicine, DOI: 10.1056/NEJMoa1910836

[212] International Agency for Research on Cancer, World Health Organisation, 2020, World Cancer Report.

  - Are patients aware of and able to access clinical trials in your view? Are there particular cohorts that miss out on clinical trials? What do you see as the major barriers and enablers to supporting participation in clinical trials? Should more be done to support people to participate in clinical trials?

  - Do out of pocket costs present major barriers to treatment and care for patients and their families? Should more need be done to support patients and carers through new payment models, insurance, regulatory systems or other funding mechanisms?

- ***Supportive care and end of life care*** — Melanoma and its treatment can lead to deterioration in a patient's quality of life along a number of different dimensions, including physical, psychological, social, sexual and cognitive domains. Patients can experience severe side effects from treatment, such as endocrinopathies, scarring, loss of sight, lymphodema, as well as depression and anxiety among other issues. A range of supportive care services can be provided to better manage these side effects and improve a patient's quality of life across these domains. Optimal care plans recommend active screening patients and their carers for supportive care needs throughout their treatment and care journey to prevent or treat as early as possible the symptoms and side effects of melanoma and its treatment. In addition, where treatment options are exhausted, it is also essential that patients and their families require access to end-of-life care and palliation.

  - What do you see as the main psychosocial and physical issues facing patients during active treatment? How are these being addressed by the supportive care system currently? Are there any areas of supportive care that require further development?

  - Do patients have a good understanding of supportive care options? Are patients and their carers empowered to find and access these services?

  - Are patients able to equitably access end-of-life care in a timely way? Are there any barriers or challenges to accessing quality end-of-life and palliative care? Are there ways this could be improved for patients and their families?

- ***Survivorship*** — As the incidence of melanoma increases and mortality rates fall, the number of melanoma survivors in Australia is expected to continue its exponential increase over the coming decade. While active treatment has ended, the needs of melanoma survivors can remain high, arising from a wide range of factors including potential financial stress, psychosocial impacts and the management of long-term treatment side effects.

  - Are melanoma survivors and their families able to navigate to survivorship services effectively? What are the major barriers and enablers to accessing survivorship support?

  - Does more need to be done to support survivors and their families with the psychosocial and physical impacts of melanoma and its treatment?

  - Does more need to be done to support wellbeing among melanoma survivors, such as improved access to exercise, nutrition, mental health, allied health, or other practical support services?

  - Does more need to be done to support the financial impact of melanoma on survivors and their families? Are there particular groups at risk of financial hardship? What should be done to help these groups in your view?

Appendix D

Glossary

Term	Definition
Acral melanoma	Acral lentiginous melanoma is a type of melanoma distinguished by the site of origin: it arises on the palms of the hands, the soles of the feet or beneath the nail (subungual melanoma).
Adjuvant	Literally means helper or helping. Adjuvant therapy refers to additional cancer treatment given after primary treatment to reduce the risk that the cancer will return. Includes chemotherapy, radiation therapy, hormone therapy, targeted therapy, or biological therapy.
Biobank	Biobanks are created to store biological samples for use in research. Tissue samples, such as blood or tumour tissue, are collected from the patient with their consent, annotated with clinical information, and preserved for later evaluation by scientific and medical researchers seeking to understand the causes, development, diagnosis and treatment of melanoma.
Biomarker	A biomarker, or tumour marker, is a biological molecule found in blood, other body fluids or tissues that is a sign of a normal or abnormal process, or of a condition or disease. For example, elevated levels of CA125, a protein, biomarker for ovarian cancer (although levels can be elevated as the result of other conditions as well). HE4, inhibin, β-hCG, Alpha-fetoprotein, LDH, CEA, and CA19-9 are other examples of biomarkers for ovarian cancer that have been evaluated in ovarian cancer research and/or may be used in current clinical practice.
Biopsy and partial biopsy	A skin biopsy involves removing cells or skin samples from the body for laboratory examination. A partial biopsy occurs aims to extract and test part of the lesion. A shave biopsy involves using a tool (similar to a razor) to remove a small section of the top layers of the skin. A punch biopsy involves removing a small core of skin including deeper layers. An excisional biopsy involves removing (with a scalpel) the entire lesion.
BRAF	A human gene that encodes a protein called B-Raf, helping transmit chemical signals from outside the cell to the cell's nucleus.
Common Scientific Outline	Common Scientific Outline, or CSO, is a classification system organised into six broad areas of scientific interest in cancer research: biology; aetiology; prevention; early detection, diagnosis, and prognosis; treatment; cancer control, survivorship, and outcomes research. The CSO is complemented by a standard cancer type coding scheme.
CT scan	A CT scan, or computed tomography scan (formerly computerised axial tomography scan, or CAT scan) is a medical imaging procedure that uses computer-processed combinations of many X-ray measurements taken from different angles to produce cross-sectional (tomographic) images (virtual "slices") of specific areas of a scanned object, allowing the user to see inside the object without cutting.
Cutaneous	Having to do with the skin.
Data ecosystem	Refers to the infrastructure, analytics, and applications used to capture and analyse data.
Dermoscopy	Non-invasive method allowing the in vivo evaluation of colours and microstructures of the epidermis, the dermoepidermal junction, and the papillary dermis, which are not visible to the naked eye.
Diagnostic resolution	Reaching a “final” verdict on whether the lesion is cancer.
Disease recurrence	Return of a disease after remission.

Term	Definition
Embryonic	In a rudimentary stage with potential for development.
Endocrinopathies	Diseases of an endocrine gland, ie, a hormone problem.
Epidermis	Outermost of the three layers that make up the skin, the inner layers being the dermis and hypodermis.
Epithelial-to-mesenchymal transition	Process by which epithelial cells (which constitute thin tissue forming the outer layer of a body's surface) lose their cell polarity (intrinsic asymmetry) and cell–cell adhesion (ability to interact and attach properly with neighbouring cells), and gain migratory and invasive properties to become mesenchymal stem cells (cells that develop into connective tissue, blood vessels, and lymphatic tissue).
Exome	The part of the genome composed of exons, which are sequences that contribute to the final protein product encoded by that gene (after removing introns).
ICD-10	ICD-10 stands for International Classification of Disease version 10. ICD-10 is the 10th revision of the International Statistical Classification of Diseases and Related Health Problems (ICD), a medical classification list by the World Health Organization (WHO). It contains codes for diseases, signs and symptoms, abnormal findings, complaints, social circumstances, and external causes of injury or diseases. Work on ICD-10 began in 1983, became endorsed by the Forty-third World Health Assembly in 1990, and was first used by member states in 1994. It remains current until January 1, 2022, when it will be replaced by ICD-11. Melanoma is coded as C43 in ICD-10.
Immunotherapy	Immunotherapy is a type of cancer treatment that helps your immune system fight cancer. The immune system helps your body fight infections and other diseases. It is made up of white blood cells and organs and tissues of the lymph system. Immunotherapy is a type of biological therapy. Biological therapy is a type of treatment that uses substances made from living organisms to treat cancer.
In situ melanoma (melanoma in situ)	Sometimes called pre cancer. It refers to cancer cells in the top layer of skin (the epidermis) which have not grown into deeper layers of the skin.
Incidence	The number of newly diagnosed cases of melanoma cancer each year.
Invasive melanoma	The melanoma cells cross from the epidermis and malignant cells enter the dermis.
Lesion	A region in a tissue or organ which has suffered damage through injury or disease.
Lymphoedema	Swelling of part of the body, usually a limb. Is a possible side effect of cancer treatment, when lymph nodes have been removed or damaged causing lymph fluid to build up..
Lymphovascular invasion	The invasion of a cancer to the blood vessels and/or lymphatics (organ system responsible for draining fluid and returning it to the bloodstream).
Melanin	A dark pigment primarily responsible for skin colour.
Melanocytes	Melanin-producing neural crest-derived cells (migratory cell population that generate a wide variety of cell and tissue types) located in the bottom layer of the skin's epidermis, the uvea, the inner ear, vaginal epithelium, meninges, bones, and heart. Melanin is a dark pigment primarily responsible for skin colour.
Metastatic cancer	Occurs when cancer cells break off from the original tumor, spread through the bloodstream or lymph vessels to another part of the body.
Mortality	A measure of the number of people deceased from melanoma cancer, typically expressed on a per annum basis.
MRI scan	Magnetic resonance imaging, or MRI, scan is a procedure in which radio waves and a powerful magnet linked to a computer are used to create detailed pictures of areas inside the body. These pictures can show the difference between normal tissue and cancer.
Mucosal melanoma	Arise in mucosal surfaces of the body and are very rare tumours. They can be found in the following tissues: the vulva, including the vagina, the anorectal region, the oesophagus, the male genito-urinary tract and the head and neck tissues.

Term	Definition
Neoadjuvant	Treatment given as a first step to shrink a tumour prior to the main treatment. Neoadjuvant therapy includes systemic therapy, radiation therapy, and hormone therapy.
Non-governmental organisation	A non-governmental organisation, or NGO, refers to organisations that are operated independently of any government, typically on a not-for-profit basis and one whose purpose is to address a social or political issue.
Net present value	Net present value is the value of a future stream of cash flows in today's dollar terms, hence the 'present value' of a sum of money. Generally speaking, money is worth more today than it is tomorrow, because it is possible to invest and grow money over time. Present value calculations allow for a like-for-like comparison between two alternative investments that may have payoffs or benefits realisation at different time horizons. For this report a social discount rate of 2 per cent is applied, which is the risk free rate based on current 20 year Australian bond rates.
Ocular melanoma	Ocular melanoma arises in the eye. There are two main sub-types of ocular melanoma: uveal melanoma, which arises in the iris, choroid and ciliary body of the eye, and conjunctival melanoma. Both forms of ocular melanoma are rare. There is also periocular melanoma, a further form of melanoma which can affect the eyelid and other orbital tissues.
Off label	Off-label use is the use of pharmaceutical drugs for an unapproved indication or in an unapproved age group, dosage, or route of administration.
Oncolytic virus therapies	A form of immunotherapy that uses viruses to infect and destroy cancer cells.
Opportunistic screening	Occurs when a health professional offers an additional examination or test as part of a routine medical check-up.
Pan-cancer	Across all cancers.
PET scan	Positron Emission Tomography (PET) is a nuclear medicine technology that uses short-lived radioisotopes to enable the non-invasive imaging of metabolic functions within the body. A small amount of radioactive glucose (sugar) is injected into the patient's vein, and a scanner is used to make detailed, computerised pictures of areas inside the body where the glucose is taken up. Because cancer cells often take up more glucose than normal cells, the pictures can be used to find cancer cells in the body. While computed tomography (CT) and magnetic resonance imaging (MRI) primarily provide information about anatomical structure, PET can image and quantify biochemical and/or physiological function. This is important because functional changes caused by disease, such as cancer, are often detectable before any structural abnormalities become evident.
Phenotypic	The set of observable characteristics or traits of an organism.
Plasticity	The quality of being easily shaped or moulded.
Pluripotency	Describes the ability of certain substances to produce several distinct biological responses.
Prevalence	The number of people diagnosed and living with melanoma; includes newly diagnosed cases plus other survivors.
PROs	Patient Reported Outcomes (PROs) are assessments based on a report that comes directly from a patient about the status of their health without amendment or interpretation of their response by a clinician or anyone else.
Randomised controlled trial	A trial (experiment) in which subjects are randomly assigned to one of two groups: the experimental group, which receives the intervention, and the control group, which receives an alternative treatment. The process is considered to provide reliable evidence as it controls for confounding factors through randomness.
Real world data	Real world data or real world evidence is information related to the health status and health care delivered to patients routinely collected through a variety of sources such as clinical registries, electronic medical records (EMRs), patient reported outcome (PRO) platforms, pharmaceutical Benefits Scheme (PBS) and Medical Benefits Scheme (MBS) data.
Resectable	Able to be removed by surgery.

Term	Definition
Sentinel lymph node	The first lymph node to which cancer cells are most likely to spread from a primary tumour.
Survivorship	Consistent with the NCI dictionary, survivorship refers to the health and well-being of a person with cancer from the time of diagnosis until the end of life.
Systemic therapies	Any type of cancer treatment that targets the entire body.
Targeted therapy	Targeted therapy is the foundation of precision medicine. It is a type of cancer treatment that targets proteins that control how cancer cells grow, divide, and spread.
Teledermoscopy	Provision of dermatology services at a distance, using technology.
Tumourigenesis	The process of tumour development.
Ulceration	Formation of open wound that develops on the skin.
Wild type	Term to describe a gene when found in its natural, non-mutated (unchanged) form.

Appendix E

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