

New Australian melanoma management guidelines: the patient perspective

The involvement of patient advocates should ensure that guidelines are rigorously patient-focused

The fundamental objective of clinical management guidelines for any disease entity is to ensure that the information required to provide evidence-based management recommendations to patients is readily available to their treating clinicians. It is well established that familiarity with guidelines by clinicians and adherence to them increases the number of patients receiving best-practice care and improves outcomes.¹ However, although management guidelines are intended primarily for clinicians, they must also reflect the patient perspective.²

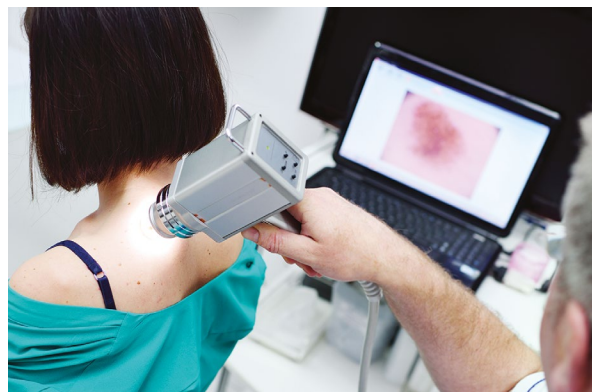
Patient representation on the Melanoma Guidelines Working Party

After identifying the need to produce new Australian guidelines on the management of melanoma, a multidisciplinary working party — under the auspices of Cancer Council Australia and the Melanoma Institute Australia — was established in 2014 to critically assess new evidence and update the previous national guidelines. In addition to clinicians and researchers, two patient advocates (consumer representatives), representing patients with melanoma from around Australia through their affiliations with patient advocacy and support networks, were invited to join the working party. These patient advocates had personal experience of melanoma diagnosis and treatment and extensive prior involvement in melanoma advocacy. This meant that they were able to make important contributions based on their experience as well as providing feedback from the patient networks they represented.

Electronic publication

Whereas the two previous editions of Australian melanoma guidelines, published in 1999 and 2008 respectively, were printed documents, each taking more than 4 years to compile,^{3,4} the new guidelines were electronic and were made available on Cancer Council Australia's Wiki platform.⁵ This publication format allowed individual sections to be published as they were completed and permitted selective updating as new evidence became available.

Electronic publication has also meant that the guidelines are more readily accessible to both doctors and patients. They can simply search on their computer, tablet or smartphone for "Australian melanoma guidelines" or go directly to the guidelines website (<https://wiki.cancer.org.au/australia/Guidelines:Melanoma>).⁵ The level of evidence supporting each guideline recommendation is clearly



documented, informing doctors and assisting patients in their decision-making process.

Patients' expectations from their treating clinician

When patients who are concerned about the possibility of having a primary melanoma consult a general practitioner, dermatologist or surgeon, they are entitled to expect that evidence-based guidelines will be followed and therefore that the steps below will take place:

- if there are any suspicious skin lesions, they will be carefully examined;
- if the doctor suspects that a lesion may be a melanoma, the recommended form of biopsy will be carried out (usually complete excision biopsy with a 2–3 mm margin);
- if melanoma is diagnosed, the recommended treatment and likely outcome will be clearly explained;
- the melanoma will be staged correctly, appropriately wide surgical excision will be recommended, and the option of sentinel node biopsy will be discussed for melanomas 1 mm or greater in Breslow thickness or 0.8–1.0 mm in thickness with higher risk pathological features, so that prognosis can be estimated accurately and the eligibility for adjuvant post-operative systemic therapy can be determined;^{6,7} and
- the potential benefits and possible side effects of adjuvant therapy will be discussed.

When patients are given a diagnosis of metastatic melanoma in regional lymph nodes, or at a systemic site and are referred to a surgeon, medical oncologist or radiation oncologist, again, they should be able to expect that the following will happen:

- appropriate surgery will be recommended, and surgery that may be unnecessary (eg, completion lymph node dissection for sentinel node positivity^{8,9}) will

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not be undertaken without a full discussion of the advantages and disadvantages; and

- if surgery is not considered appropriate, therapeutic systemic therapy options will be discussed, again with a realistic description of the likely benefits and possible side effects.¹⁰

Use of the guidelines

While different stakeholders will use guidelines in different ways, they are intended to be useful to both clinicians and patients:

- to GPs, particularly those who work in skin cancer clinics;
- to dermatologists, who see many patients when they first present with a primary melanoma but who rarely manage patients with metastatic melanoma;
- to surgeons who treat patients with both primary and metastatic melanoma;
- to medical and radiation oncologists who are involved in the care of patients with metastatic disease; and importantly,
- to patients by providing a reliable source of information.

It is hoped that by having access to guidelines based on the best available evidence, both treating clinicians and patients will be better informed, treatment options will be better understood, and patients will receive the most appropriate care. The ongoing involvement of patient advocates in the process of developing and updating the Australian melanoma guidelines should ensure that they are useful and relevant to patients and that the health care outcomes most valued by them are considered, resulting in guidelines that are rigorously patient-focused, as they should be.

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