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Standards of Service Provision for Melanoma Patients in New Zealand – *Provisional*

National Melanoma Tumour Standards Working Group

New Zealand Government

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Introduction

Background

Melanoma is a major public health issue in New Zealand. New Zealand has the highest incidence of melanoma in the world (a rate of 41.2 per 100,000 population, age standardised to the Segi world population, 2004; by comparison, Australia's rate was 37.2). The latest data available, from 2010, shows that in that year there were 2341 new diagnoses of invasive melanoma, 2265 new diagnoses of melanoma in situ and 324 deaths in New Zealand. In 2010 melanoma was the fourth most commonly registered invasive cancer and the sixth most common cause of death from cancer.

Overall, rates of melanoma incidence and mortality are consistently higher for males compared with females; in 2008 the death rate for males was approximately twice that of females (202 males and 115 females died of melanoma). The 2008 estimated annual public health care cost of melanoma was $24.4 million.

The incidence of melanoma increases with age; the median age at diagnosis was 56 in men and 62 in women in 2008/2009. However, melanoma is one of the more common malignancies in younger age groups. It is the most common malignancy in males between 25 and 40 and females between 15 and 24 years.

Māori, Pacific and Asian peoples in New Zealand develop skin cancer, including melanoma, less frequently than New Zealand Europeans. The Cancer Registry uses self-identification for determining ethnicity. Melanoma in Māori makes up less than 1 percent of all melanoma diagnosed in New Zealand, with an incidence rate of 2.7 per 100,000, age standardised to the Segi world population (2004).

For melanoma, the thickness of the lesion at diagnosis is the strongest predictor of prognosis; in general, the thinner the lesion, the better the outcome. According to an analysis of New Zealand data, advanced age, male sex, non-European ethnicity, and nodular and acral types of melanoma are associated with thick melanomas.

Although Māori and Pacific peoples in New Zealand have a very low melanoma registration rate compared to the New Zealand population as a whole, they generally present with thicker lesions and more extensive disease at diagnosis. There is evidence that poorer prognosis among Māori can be accounted for in part by thickness of melanoma at presentation.

Objective

Tumour standards for all cancers are being developed as a part of the Ministry of Health's 'Faster Cancer Treatment' (FCT) programme's approach to ensuring timely clinical care for patients with cancer. When used as a quality improvement tool, the standards will promote nationally coordinated and consistent standards of service provision across New Zealand. They aim to ensure efficient and sustainable best-practice management of tumours, with a focus on equity.

The standards will be the same for all ethnic groups. However, we expect that in implementing the standards district health boards (DHBs) may need to tailor their efforts to meet the specific needs of populations with comparatively poorer health outcomes, such as Māori and Pacific people.

How the melanoma service standards were developed

These standards were developed by a skilled working group representing key specialities and interests across the melanoma pathway of care. The group was chaired by a lead clinician, and had access to expert advisors in key content areas.

The National Melanoma Tumour Standards Working Group referred to existing evidence-based standards, clinical guidelines and patient pathways when developing the melanoma standards (see Appendix 1). Where no clear evidence was available, expert opinion was obtained through the National Melanoma Tumour Standards Working Group and its advisors.

The path to consensus on key principles of high-quality melanoma management has not been straightforward for the multidisciplinary group assembled to develop these standards. Differing and at times conflicting points of view from a range of experts had to be accommodated. Ultimately, this project has addressed contentious issues through rigorous and respectful debate, along with public consultation.

Tumour-specific national standards were first developed for lung cancer in the *Standards of Service Provision for Lung Cancer Patients in New Zealand* (National Lung Cancer Working Group 2011); these standards have already been used by DHBs to make improvements to service delivery and clinical practice.

Subsequently provisional standards have been developed for an additional ten tumour types: bowel, breast, gynaecological, lymphoma, melanoma, myeloma, head and neck, sarcoma, thyroid and upper gastrointestinal.

The Ministry of Health required all tumour standards working groups to:

> Maintain a focus on achieving equity and whānau ora when developing service standards, patient pathways and service frameworks by ensuring an alignment with the Reducing Inequalities in Health Framework and its principles (Ministry of Health 2002).

Equity and Whānau Ora

Health inequities or health disparities are avoidable, unnecessary and unjust differences in the health of groups of people. In New Zealand, ethnic identity is an important dimension of health disparities. Cancer is a significant health concern for Māori, and has a major and disproportionate impact on Māori communities.

Inequities exist between Māori and non-Māori in exposure to risk and protective factors for cancer, in incidence and outcomes, and in access to cancer services.

Barriers to health care are recognised as multidimensional, and include health system and health care factors (eg, institutional values, workforce composition, service configuration and location), as well as patient factors (eg, socioeconomic position, transportation and patient values). Addressing these factors requires a population health approach that takes account of all the influences on health and how they can be tackled to improve health outcomes.

A Whānau Ora approach to health care recognises the interdependence of people; health and wellbeing are influenced and affected by the 'collective' as well as the individual. It is important to work with people in their social contexts, and not just with their physical symptoms.

The outcome of the Whānau Ora approach in health will be improved health outcomes for family/whānau through quality services that are integrated (across social sectors and within health), responsive and patient/family/whānau-centred.

These standards will address equity and reduce disparities for Māori patients with melanoma in the following ways.

- In terms of prevention and early identification, improving health literacy is recognised as the key to increasing awareness and identification of melanoma at an early stage. Information developed for and provided to patients and their family/whānau will meet Ministry of Health guidelines (Ministry of Health 2012c).
- Health literacy training is recommended for health professionals communicating with patients.
- Timely access will improve access to diagnosis and treatment for all patients, including Māori and Pacific. Ethnicity data will be collected on all access measures, and will be used to identify and address disparities.
- Access to treatment and health outcomes for Māori cancer patients will be measured by the FCT indicators and ethnic specific data recording mortality, morbidity and disability.
- Tools (for example a Whānau Ora assessment tool) will be developed and used to meet the needs of Māori.

Summary of the clinical standards for the management of melanoma services

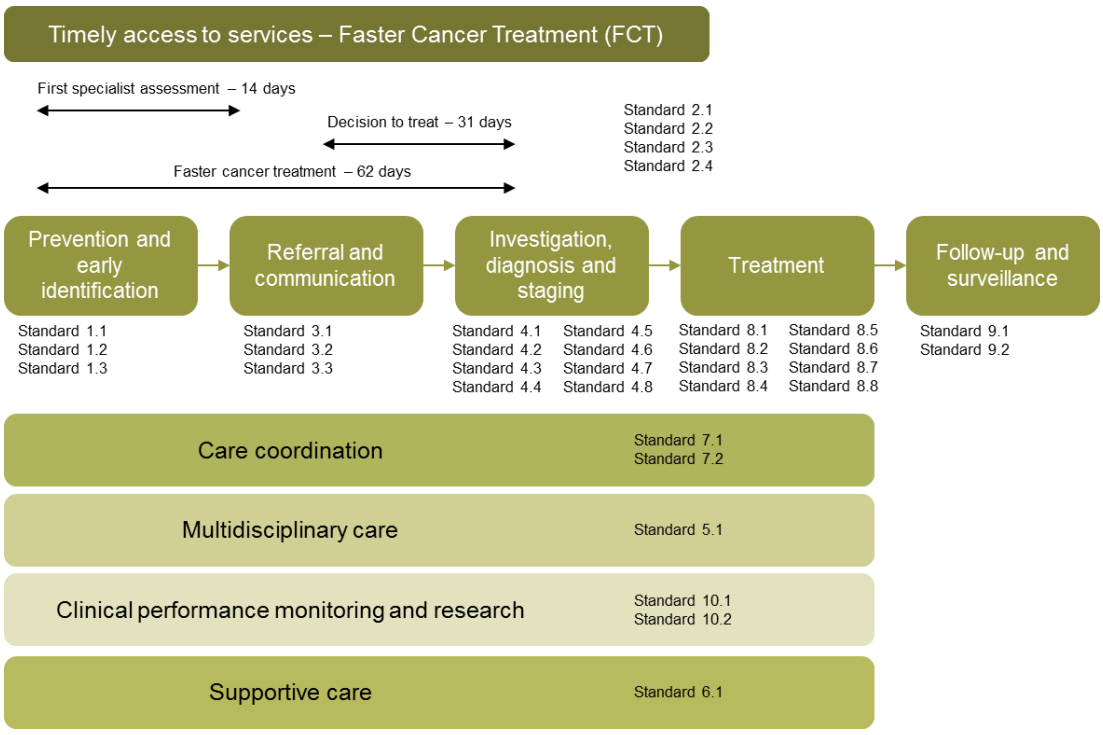
Format of the standards

Each cluster of standards has a title that summarises the step of the patient journey or the area on which the standards are focused. This is followed by the standard itself, which explains the level of performance to be achieved. The rationale section explains why the standard is considered to be important.

Attached to the clusters of standards are good practice points. Good practice points are supported either by the international literature, the opinion of the Melanoma Tumour Standards Working Group or the consensus of feedback from consultation with New Zealand clinicians involved in providing care to patients with melanoma. Also attached to each cluster are the requirements for monitoring the individual standards.

Standards of service provision pathway

The melanoma tumour standards are reflected in the following pathway.



Summary of standards

The standards for the management of melanoma have been divided into 10 clusters:

- prevention and early identification
- timely access to services
- referral and communication
- investigation, diagnosis and staging
- multidisciplinary care
- supportive care
- care coordination
- treatment
- follow-up and surveillance
- clinical performance monitoring and research.

The standards are as follows.

Prevention and early identification

Standard 1.1: Patients are offered evidence-based information on risk factors, prevention and early detection of melanoma.

Standard 1.2: All primary care clinicians are trained to recognise skin lesions suspicious for melanoma.

Standard 1.3: People at increased risk of melanoma are identified and offered management appropriate to their level of risk.

Timely access to services

Standard 2.1: Patients referred with a high suspicion of melanoma receive their first cancer treatment within 62 days of receipt of referral.

Standard 2.2: Patients referred urgently with a biopsy-confirmed or high suspicion of melanoma (including locally recurrent and metastatic melanoma and excluding melanoma in situ) have their first specialist assessment (FSA) within 14 days of receipt of referral.

Standard 2.3: Urgent diagnostic excision for lesions suspicious for melanoma occurs within 14 days of specialist assessment or image-based triage. Image-guided core or fine needle aspiration (FNA) biopsy of suspected tumour occurs within 14 days of the request being received.

Standard 2.4: Patients with a confirmed diagnosis of melanoma (including locally recurrent or metastatic melanoma and excluding melanoma in situ) receive their first cancer treatment within 31 days of the decision to treat.

Referral and communication

Standard 3.1: The formal referral pathway and required information for patients with suspected melanoma is agreed between primary, secondary and tertiary care givers.

Standard 3.2: Patients and their general practitioners (GPs) are provided with verbal and written information about melanoma, diagnostic procedures, treatment options (including effectiveness and risks), final treatment plan and support services.

Standard 3.3: Communications between health care providers include the patient's name, date of birth, National Health Index (NHI) number and contact details, and are ideally electronic.

Investigation, diagnosis and staging

Standard 4.1: Patients have access to a clinician trained in:

- early detection and diagnosis of melanoma, including the use of dermatoscopy
- surgical skills to undertake excision and direct closure of in-situ or thin melanoma
- the triage and referral of patients with lesions of uncertain diagnosis, thicker melanoma and lesions on sites where surgery is difficult.

Standard 4.2: Melanocytic lesions suspected of being melanoma are excised with a 2 mm clinical margin, including a cuff of subcutaneous fat, or referred to a melanoma specialist for assessment. All tissue specimens are sent for formalin-fixed paraffin-embedded histopathology.

Standard 4.3: Melanoma is reported histopathologically and staged histopathologically, clinically and radiologically in accordance with the latest (currently the 7th edition) American Joint Committee on Cancer (AJCC) guidelines. The pathology report for the diagnosis of primary cutaneous melanoma and lymph node metastases is synoptic/structured and includes a minimum data set for Tumour, node, metastasis (TNM) staging and other variables thought to affect clinical behaviour and survival.

Standard 4.4: A diagnosis of melanoma is reported within five working days in 80 percent of cases, and all cases are reported in 10 working days.

Standard 4.5: The European Organisation for Research and Treatment of Cancer (EORTC) protocol is used for the processing and reporting of sentinel node biopsies (SNB).

Standard 4.6: No patient diagnosed with stage I or II melanoma receives further investigation (excluding SNB) unless symptoms suspicious of metastasis are present.

Standard 4.7: Patients with low-volume microscopic nodal disease (N1a and N2a) receive no further investigation unless symptoms suspicious of metastasis are present. Patients with clinically detectable nodal disease (N1b, N2b and N3) or intransits (N2c) are investigated with whole-body positron emission tomography and computed tomography (PET-CT) and FNA or core biopsy.

Standard 4.8: Staging investigations are determined by the planned treatment. Patients are investigated with whole-body PET-CT and contrast magnetic resonance imaging (MRI) of the brain (if neurological symptoms are present) when invasive treatment is planned.

Multidisciplinary care

Standard 5.1: Patients with the following are discussed at a multidisciplinary meeting (MDM):

- stage III and IV cutaneous melanoma
- desmoplastic melanoma
- melanoma under 18 years of age
- non-cutaneous melanoma.

The outcome of the MDM is documented and communicated to the treating clinician, GP and patient within one week.

Supportive care

Standard 6.1: Patients with melanoma and their family/whānau have equitable and coordinated access to appropriate medical, allied health and supportive care services, in accordance with *Guidance for Improving Supportive Care for Adults with Cancer in New Zealand* (Ministry of Health 2010).

Care coordination

Standard 7.1: Patients managed by a melanoma multidisciplinary team (MDT) have access to a clinical nurse specialist or other health professional who is a member of the MDM to help coordinate all aspects of their care.

Standard 7.2: Each treatment centre has a melanoma clinical lead to provide necessary leadership, guidance and provision of melanoma care.

Treatment

Standard 8.1: Histologically confirmed melanomas are re-excised, with additional clinical margins determined by Breslow thickness. Lesions meeting histological staging AJCC T1b or higher are referred to a surgical specialist for consideration of SNB at the time of the re-excision.

Standard 8.2: The MDM discusses the role of radiation treatment to improve local control in the case of patients with desmoplastic melanoma.

Standard 8.3: Sentinel node biopsy is offered to patients with T1b or thicker melanoma who could benefit from the procedure, and is performed by surgeons trained and experienced in the technique. Sentinel node biopsy in melanoma is carried out using triple localisation with preoperative lymphoscintigraphy, intra-operative localisation with blue dye and a gamma probe.

Standard 8.4: An oncological therapeutic lymphadenectomy is offered to all patients with evidence of metastatic nodal disease after appropriate staging and discussion at an MDM. Lymphadenectomy nodal harvest results meet accepted criteria.

Standard 8.5: Patients with loco-regional recurrent, locally advanced and stage IV melanoma are seen or discussed by melanoma specialists experienced in the care of melanoma patients and part of an MDM, including:

- surgical oncologists
- radiation oncologists
- medical oncologists.

Standard 8.6: Patients with non-cutaneous melanoma are discussed in a melanoma MDM as well as the relevant site-specific MDM, with the treating clinician represented.

Standard 8.7: Patients diagnosed with melanoma are assessed by appropriately qualified personnel to identify supportive care needs, including psychological distress, at key points of their cancer journey, ideally using a validated tool and a clear referral process.

Standard 8.8: Patients are offered early access to palliative care services when there are complex symptom control issues, when curative treatment cannot be offered or if curative treatment is declined.

Follow-up and surveillance

Standard 9.1: Follow-up plans are carried out by clinicians experienced in melanoma diagnosis and management, working in conjunction with the patient, their family/whānau and their GP.

Standard 9.2: Patients are taught self-examination.

Clinical performance monitoring and research

Standard 10.1: New and recurrent cases of melanoma, including melanoma in situ, are reported to the New Zealand Cancer Registry.

Standard 10.2: Patients with melanoma are offered the opportunity to participate in research projects and clinical trials where these are available.

1 Prevention and Early Identification

Standard 1.1	Patients are offered evidence-based information on risk factors, prevention and early detection of melanoma.

Rationale

There is consistent evidence that the best avenues for reducing the burden of melanoma are prevention and early diagnosis.

Prevention

The causal association of cutaneous melanoma and non-melanoma skin cancer and solar exposure is established. Although there is no scientifically validated safe threshold level of ultraviolet exposure that allows for maximal vitamin D synthesis without increasing skin cancer risk, it is established that the brief exposures required for vitamin D synthesis are unlikely to increase the risk.

There is strong evidence that exposure to ultraviolet radiation in artificial tanning devices (such as sunbeds and tanning units) causes DNA damage that can lead to the development of both melanoma and non-melanoma skin cancer. The risk increases with greater use and an earlier age at first use.

Early identification

The prognosis for melanoma less than 1mm thick is very good, but survival decreases with increasing thickness.

Further research is needed to develop strategies to better target the detection of melanoma while thin to reduce mortality from melanoma.

Good practice points

1.1 Those at risk of melanoma in New Zealand are advised as follows.

- Sunburn should be avoided and ultraviolet protection (physical methods complemented by sunscreen) adopted.
- Because brief sun exposures are needed to maintain vitamin D levels, total lack of sun exposure is not advisable without vitamin D supplementation.
- The use of artificial tanning devices is strongly discouraged. *Solaria for cosmetic purposes* (Standards Australia/Standards New Zealand Committee CS-064 2008) specifies that those under the age of 18 and those with skin phototype 1 should not use sunbeds. Those 18 years and over should be informed of the risks and lack of evidence for any health benefits.

1.2 All adults, particularly those aged 50 and over, are advised to:

- regularly examine their skin (including skin not normally exposed to the sun) so that they can be aware of any changes
- get someone else to check areas difficult to see, such as their back
- seek advice from a doctor about suspicious lesions.

1.3 Information aimed at reducing melanoma deaths focuses on:

- all adults; particularly males 50 years and over
- raising awareness of melanoma in Māori and other ethnic minorities, including the specific features of nodular and acral lentiginous melanoma.

1.4 Clinicians responsible for communicating with patients and their family/whānau complete health literacy training.

1.5 Information developed for or provided to patients and their family/whānau meets guidelines set out in *Rauemi Atawhai: A guide to developing health education resources in New Zealand* (Ministry of Health 2012c).

Standard 1.2	All primary care clinicians are trained to recognise skin lesions suspicious for melanoma.

Rationale

Primary care clinicians play an important role in the opportunistic discovery of melanoma and non-melanoma skin cancer as part of their everyday practice. Therefore it is essential that they have the competence to identify lesions suspicious of melanoma.

The United Kingdom Melanoma Taskforce recommends that clear and targeted information on recognising lesions suspicious of melanoma is provided to other professionals who come into contact with people's skin; for example physiotherapists and beauticians.

Good practice points

1.6 All primary care clinicians are knowledgeable about the most precise methods of estimating a patient's risk of melanoma, and about subtypes of melanoma.

1.7 All clinicians are alert for skin lesions with malignant features in the context of physical examinations performed for other reasons.

1.8 All allied professionals who come into contact with people's skin have access to training to recognise skin changes suggestive of melanoma and to advise patients with suspicious lesions to see a doctor.

1.9 As part of diagnosing a skin lesion, clinicians also carry out a full skin check.

1.10 Population-based skin screening is not recommended in the absence of substantive evidence as to its effectiveness in reducing mortality at this time.

Monitoring requirements

MR1A	Ensure that organisations responsible for the training of primary care practitioners include the identification of lesions characteristic of melanoma in their curricula.

Standard 1.3	People at increased risk of melanoma are identified and offered management appropriate to their level of risk.

Rationale

While identification of those at increased risk for melanoma provides the potential to focus early detection and prevention, at present it is not possible to identify the absolute risk of an individual to develop melanoma, and there is no evidence to compare the relative effectiveness of specific surveillance techniques in high-risk patients with those at average risk.

Increased age, skin phototype and sun damage are important risk factors for melanoma. Other factors that should be considered in clinical risk assessment include a personal history of melanoma, familial melanoma, large numbers of naevi, familial atypical mole and melanoma (FAMM) syndrome, previous non-melanoma skin cancer and immunosuppression (eg, in organ transplant recipients).

Large congenital melanocytic naevi (CMN) >20 cm in diameter have an increased risk of developing melanoma and neurocutaneous melanocytosis.

Good practice points

1.11 Individuals with two or more first-degree relatives with a history of melanoma at younger than 40 years are examined carefully, and those found to have melanoma and/or multiple atypical naevi:

- are placed under the long-term care of a physician trained and competent in skin surveillance
- are considered for referral to regional clinical genetics services for further assessment, genetic counselling and discussion about genetic testing (rarely indicated)
- (particularly those with multiple atypical naevi) are considered for baseline total body photography and high-quality sequential digital dermatoscopic imaging at 6–12-month intervals to detect new and changing lesions.

1.12 Clinicians responsible for communicating with patients and their family/whānau complete health literacy training.

1.13 Information developed for or provided to patients and their family/whānau meets guidelines set out in *Rauemi Atawhai: A guide to developing health education resources in New Zealand* (Ministry of Health 2012c).

2 Timely Access to Services

Standard 2.1	Patients referred urgently with a high suspicion of melanoma receive their first cancer treatment within 62 days of receipt of referral.
Standard 2.2	Patients referred urgently with a biopsy-confirmed or high suspicion of melanoma (including locally recurrent and metastatic melanoma and excluding melanoma in situ) have their FSA within 14 days of receipt of referral.
Standard 2.3	Urgent diagnostic excision for lesions suspicious for melanoma occurs within 14 days of specialist assessment or image-based triage. Image-guided core or FNA biopsy of suspected tumour occurs within 14 days of the request being received.
Standard 2.4	Patients with a confirmed diagnosis of melanoma (including locally recurrent or metastatic melanoma and excluding melanoma in situ) receive their first cancer treatment within 31 days of the decision to treat.

Rationale

Timely access to quality cancer management is important to support good health outcomes for New Zealanders and to reduce inequities.

Key components of successful cancer management include early recognition and reporting of symptoms, expertise in identifying patients requiring prompt referral and rapid access to investigations and treatment.

A suspicion of melanoma or melanoma diagnosis is very stressful for patients and their family/whānau. It is important that patients, family/whānau and GPs know how quickly patients can receive treatment. Long waiting times may affect local control and survival benefit for some patients with melanoma, and can result in delayed symptom management for palliative patients.

The standards in this cluster ensure that:

- patients receive quality clinical care
- patients are managed through the pathway, and experience well-coordinated service delivery
- delays are avoided as far as possible.

Shorter waits for cancer treatments is a government health target for all radiation treatment patients and chemotherapy patients. The FCT indicators (Standards 2.1, 2.2 and 2.4) adopt a timed patient pathway approach across surgical and non-surgical cancer treatment, and apply to inpatients, outpatients and day patients.

Timely access to services is especially important to address inequities. It is well demonstrated that Māori tend to wait longer for cancer care. A major goal of these standards is to address this issue.

Good practice points

2.1 The FCT indicators exclude melanoma in situ.

2.2 Referral is ideally electronic, with (high-quality macroscopic and/or dermatoscopic) images of the lesion, including a ruler, attached. Suspicious lesions can then be triaged directly for diagnostic excision.

2.3 Teledermatoscopy reports are received by the referrer within five working days of the examination being performed.

2.4 Reports are distributed electronically.

2.5 'High suspicion of melanoma' refers to skin lesions likely to be invasive tumours; usually >6 mm in diameter and irregular in structure and colour. There is often a reliable history of change over several months of observation, or observed by digital dermatoscopic surveillance.

Monitoring requirements

MR2A	Track FCT indicators.
MR2B	Collect and analyse ethnicity data on all access targets and indicators.

3 Referral and Communication

Standard 3.1	The formal referral pathway and required information for patients with suspected melanoma is agreed between primary, secondary and tertiary caregivers.
Standard 3.2	Patients and their GPs are provided with verbal and written information about melanoma, diagnostic procedures, treatment options (including effectiveness and risks), final treatment plan and support services.
Standard 3.3	Communications between health care providers include the patient's name, date of birth, NHI number and contact details, and are ideally electronic.

Rationale

The purpose of the referral pathway is to ensure that all patients with suspected melanoma are referred to the most appropriate melanoma service, and that appropriate standardised information is available in the referral.

Good communication skills are fundamental to the development of an effective relationship between a patient with melanoma and health practitioners.

Good communication is likely to reduce anxiety, and increase patients' trust and confidence in cancer care providers. This will increase the chance that they receive the treatment that is most appropriate for them. Good information may improve compliance with treatment, reduce complaints and enhance health outcomes.

Communications with other health care professionals

There should be rapid and effective two-way information flow between service providers transferring and sharing information on referral, diagnosis, treatment, follow-up and supportive/palliative care.

Good practice points

3.1 Referrals should state either 'suspected melanoma' or 'confirmed melanoma'.

3.2 When a referral contains the words 'suspected melanoma', to help with prioritisation, a macroscopic and dermatoscopic image are provided with an accurate measurement of the lesion using a marker scale or ruler.

3.3 A referral for 'confirmed melanoma' after diagnostic excision includes the synoptic pathological report to aid prioritisation.

3.4 Proforma-based referral is electronic where possible.

3.5 Three-way communication takes place between primary, secondary and tertiary care during a patient's management and care.

3.6 Referrals include relevant medical history, medications and allergies.

3.7 Services develop and implement a did-not-attend (DNA) reduction strategy that particularly focuses on reducing inequalities for Māori.

3.8 All health professionals responsible for engagement with patients and their families/whānau are sufficiently skilled and supported to effectively communicate with all those affected by melanoma, including Māori, Pacific people and those from other ethnic minorities.

Monitoring requirements

MR3A	Provide evidence of a clear and accessible referral pathway.
MR3B	Audit information provided to patients and GPs.

4 Investigation, Diagnosis and Staging

Standard 4.1	Patients have access to a clinician trained in: • early detection and diagnosis of melanoma, including the use of dermatoscopy • surgical skills to undertake excision and direct closure of in-situ or thin melanoma • the triage and referral of patients with lesions of uncertain diagnosis, thicker melanoma and lesions on sites where surgery is difficult.

Rationale

Breslow thickness is generally less in melanomas diagnosed by a clinician compared to melanoma initially recognised by the patient or another layperson.

Early detection of melanoma requires differentiating lesions with minor atypical features and/or documented change from benign lesions.

Where health professionals are trained in the technique, dermatoscopy may improve diagnostic accuracy for melanoma.

Training in dermatoscopy and digital dermatoscopy reduces unnecessary removal of benign lesions that do not have features suspicious of melanoma.

Good practice points

4.1 In larger primary care practices, at least one doctor is designated and trained in the diagnosis and management of melanoma.

4.2 Assessment includes history of change, symptoms and the time course of symptoms.

4.3 For the purposes of detecting melanoma, the whole skin surface is examined under good lighting.

4.4 Clinicians are formally trained in dermatoscopy, to improve diagnostic accuracy.

4.5 High-quality digital macroscopic and dermatoscopic images of lesions suspicious for melanoma are used, to obtain second opinions and for clinicopathological correlation.

4.6 Sequential digital dermatoscopic imaging may be used to detect change in suspicious flat melanocytic lesions lacking dermatoscopic features of melanoma when monitored short-term (ie, over three months).

4.7 Clinicians do not rely on the use of automated instruments alone to diagnose primary melanoma.

Monitoring requirements

MR4A	Review Royal New Zealand College of General Practitioners' oversight of members' compliance with the standard.
MR4B	Ensure that health practitioners participate in skin cancer and dermatoscopy training courses.

Standard 4.2	Melanocytic lesions suspected of being melanoma are excised with a 2 mm clinical margin, including a cuff of subcutaneous fat, or referred to a melanoma specialist for assessment. All tissue specimens are sent for formalin-fixed paraffin-embedded histopathology.

Rationale

Histopathological diagnosis requires evaluation of the architecture and cytology of the entire lesion. Partial biopsies of atypical lesions may miss a small focus of melanoma.

Good practice points

4.8 Partial biopsies are only performed by melanoma specialists.

4.9 Referral to a melanoma specialist may include high-quality digital clinical and dermatoscopic images of the lesion of concern.

4.10 The request form accompanying specimens submitted for biopsy includes a history and written clinical/dermatoscopic description of the lesion. Where possible, especially in borderline lesions, clinical and dermatoscopic images are included, and/or an annotated diagram highlighting specific areas of concern within the lesion.

4.11 Practitioners monitor benign:malignant and naevus:melanoma ratios.

Monitoring requirements

MR4C	Audit percentage of cases in which initial diagnostic excisions are performed with a clear histological margin.
MR4D	Among individual practitioners, audit benign:malignant ratios for lesions suspicious of melanoma.

Standard 4.3	Melanoma is reported histopathologically and staged histopathologically, clinically and radiologically in accordance with the latest (currently the 7th edition) AJCC guidelines. The pathology report for the diagnosis of primary cutaneous melanoma and lymph node metastases is synoptic/structured and includes a minimum data set for TNM staging and other variables thought to affect clinical behaviour and survival.

Rationale

Formal staging of cancer is fundamental in providing clinicians and patients with prognostic information, developing treatment strategies, and directing and analysing

clinical trials. Staging of cutaneous melanoma continues to evolve, through identification and rigorous analysis of potential prognostic factors. The latest multivariate analyses of prognostic factors for melanoma were published in the 7th edition AJCC *Cancer Staging Manual*, published in 2010. This reflects work undertaken by experts from North America, Europe and Australia, who developed the AJCC melanoma staging database, a first-in-kind international integrated compilation of prospectively accumulated melanoma outcome data from several centres and clinical trial cooperative groups. The latest edition represents the outcomes of this collaboration from over 14 cancer centres and involving over 50,000 patients.

Pathologic assessment of a tissue biopsy is a critical aspect in the multidisciplinary management of melanoma patients. Such assessment establishes a definite diagnosis in most cases, and provides information that, to a major extent, influences patient prognosis and directs the next stages of management.

Consistency and speed of reporting is improved by the use of discrete data elements. Synoptic/structured pathology reports are more complete and usable for clinicians' purposes, and improve decision support for melanoma treatment. Such reports can be used for both in-situ and invasive melanoma.

This type of report also allows for easy retrieval of data elements for a variety of uses, including audit and research. Synoptic reports may include a 'comments' or 'microscopic' section, which allows description of an unusual morphology and immunohistochemical stains. In the proforma that appears in Appendix 4, cytogenetic and molecular tests have been included. The proforma may be used for basic microscopic descriptions.

Good practice points

4.12 The AJCC guidelines are adopted.

4.13 The clinical request form is an important starting point for the accurate diagnosis of skin lesions. In addition to the mandatory demographic fields required to be filled in by any International Accreditation New Zealand (IANZ)-accredited laboratory, requesting clinicians should record the specimen site and the type of biopsy. Recording the clinical diagnosis or differential diagnosis is also good practice. In suspicious lesions that have been examined and detected by dermatoscopy, a clinical photograph accompanying the specimen and annotated as to a suspicious area or areas may ensure their representation on the slides.

4.14 The entire lesion is sectioned and examined histologically after formalin-fixation and paraffin embedding.

4.15 For accurate assessment of T1a, T1b and T2 lesions, at least four serial tissue sections are examined. This ensures the most accurate reading of Breslow thickness in lesions in and around the 1mm mark, which is critical for T1 to T2

staging. Four is a reasonable number of sections for the detection of the one mitosis required for T1a–T1b staging.

4.16 Pathologists reporting melanocytic lesions and melanoma have undergone adequate training, participate in regular continuing medical education in this field and have ready access to a second opinion for difficult cases.

4.17 An indication as to whether the case has been reported to the New Zealand Cancer Register is included on the report.

Monitoring requirements

MR4E	Ensure that MDTs use AJCC staging.
MR4F	Through IANZ, review laboratories every year, and audit them comprehensively every three years. Consider reviewing compliance with this standard annually after its introduction.
MR4G	Record the percentage of reports completed in synoptic/structured format.
MR4H	Record the percentage of cases reported to the New Zealand Cancer Registry.
MR4I	Audit correctly filled-out histopathology request forms.

Standard 4.4	A diagnosis of melanoma is reported in five working days in 80 percent of cases, and all cases are reported in 10 working days.

Rationale

A diagnosis of melanoma is an important first step in management, and, as for all malignant diagnoses, a timely report is highly desirable. A target of five working days allows for adequate fixation of the specimen prior to sectioning, as some laboratories fix skin specimens for 24 hours prior to cutting. This also allows for referral to other colleagues in the same department or same city for confirmation/expert opinion of the lesion, if necessary. If the case is being referred for an opinion, an initial report should be issued in the interim, followed by a supplementary report.

Good practice points

4.18 A final report (or provisional report in the case of an expert opinion being sought) is produced within five working days.

Monitoring requirements

MR4J	Monitor compliance through IANZ.

Standard 4.5	The EORTC protocol is used for the processing and reporting of SNB.

Rationale

Sentinel node biopsy is a very strong prognostic and staging technique; its use is supported by the literature, including by the AJCC.

The protocol used to process and report SNB should achieve the best possible detection rate.

In the latest AJCC *Staging Manual* (Edge et al 2010), a positive node is defined as one showing any evidence of metastatic disease, even if detected only with immunohistochemical studies.

Many protocols in widespread use perform multiple levels matched with S100 and melanoma-specific markers such as melan A and HMB-45. These protocols have a positive detection rate of 20–25 percent. The EORTC protocol has a detection rate of up to 33 percent, with a relatively modest increase in technical and pathologist time.

Entry into EORTC clinical trials requires adoption of the EORTC's protocols.

Good practice points

4.19 Using this technique, the node is bisected along the longest axis and six pairs of sections are cut at 50-micron intervals and stained for H and E and S100. Using a melanoma-specific marker such as Melan A/HMB-45 instead of S100 is acceptable in the EORTC protocol provided spares are cut at each level for S100 if necessary.

4.20 Metastatic melanoma is distinguished from nodal naevi and melanophages. SOX 10 is a more recently developed nuclear stain for melanocytes that, in the future, could replace both the S100 and melan A/HMB 45 and aid in differentiating melanocytes from melanophages.

4.21 Reporting of the sentinel node is synoptic/structured, to allow key elements to be easily identified for MDM review. In view of possible changes to the definition of a positive lymph node based on tumour volume, it is highly desirable that this is recorded in the report as <0.1 mm, 0.1–1 mm and >1 mm. See Appendix 5.

Monitoring requirements

MR4K	Ensure that MDMs audit pathology reviews.

Standard 4.6	No patient diagnosed with stage I or II melanoma receives further investigation (excluding SNB) unless symptoms suspicious of metastasis are present.

Rationale

There is no evidence that radiological imaging for stage I and II melanoma has any impact on detecting metastases, or changing patient prognosis and management.

The chance of detecting occult regional or systemic disease in asymptomatic patients with localised stage I or II primary melanoma by extensive imaging studies such as MRI, CT or whole body PET-CT is low, and the process entails high false-positive rates.

Monitoring requirements

MR4L	Audit percentage of patients with primary melanoma who undergo further investigations.

Standard 4.7	Patients with low-volume microscopic nodal disease (N1a and N2a) receive no further investigation unless symptoms suspicious of metastasis are present. Patients with clinically detectable nodal disease (N1b, N2b and N3) or intransits (N2c) are investigated with whole-body PET-CT and FNA or core biopsy.
Standard 4.8	Staging investigations are determined by the planned treatment. Patients are investigated with whole-body PET-CT and contrast MRI of the brain (if neurological symptoms are present) when invasive treatment is planned.

Rationale

Patients with clinical detectable (N1b, N2b, N2c, N3) locoregional melanoma (including recurrences or clinically apparent nodal disease at presentation) require further imaging to detect clinically occult metastatic disease, with a view to providing more accurate prognostic information, changing management and potentially improving survival.

The detection of additional, unsuspected lesions in metastatic melanoma may result in a change of management.

Good practice points

4.22 Micrometastases are diagnosed after SNB and completion lymphadenectomy (if performed). ('Micrometastasis' is an operational definition to communicate a level of tumour burden, and is not intended to be used as a more strict definition of microscopic disease that cannot be observed without a microscope.)

4.23 Macroscopic disease is defined as clinically or radiologically detectable nodal metastases confirmed by histology.

4.24 Whole-body PET-CT is preferred where the presence of any systemic disease will alter the management decision.

4.25 Macroscopic nodal, intransit or subcutaneous melanoma is confirmed by FNA or core biopsy. Diagnostic excision is reserved for non-diagnostic investigations.

4.26 Whole-body PET-CT is more sensitive than conventional imaging in detecting distant metastases 4mm or greater at all sites except for the brain. The high background activity in normal brain tissue severely limits detection of metastases.

4.27 In patients with neurological signs and/or symptoms, a contrast-enhanced MRI of the brain is considered.

4.28 Once the diagnosis of metastatic melanoma is established, no further investigations are carried out unless surgery is planned and the detection of additional sites of distant disease would result in a change of management.

4.29 All investigations for metastatic melanoma are completed within two weeks of referral.

Monitoring requirements

MR4M	Audit appropriate investigations, access to PET-CT and timeframes.

5 Multidisciplinary Care

Standard 5.1

Patients with the following are discussed at an MDM:

- stage III and IV cutaneous melanoma
- desmoplastic melanoma
- melanoma under 18 years of age
- non-cutaneous melanoma

The outcome of the MDM is documented and communicated to the treating clinician, GP and patient within one week.

Rationale

International evidence shows that multidisciplinary care is a key part of providing best-practice treatment and care for patients with cancer.

Cancer MDMs are part of the philosophy of multidisciplinary care. Effective MDMs result in positive outcomes for patients receiving the care, for health professionals involved in providing the care and for health services overall. Benefits include improved treatment planning, improved equity of patient outcomes, more patients being offered the opportunity to enter into relevant clinical trials, improved continuity of care and less service duplication, improved coordination of services, improved communication between care providers and more efficient use of time and resources.

Patients with advanced melanoma can be complex to manage due to several factors, including variation in presentation, the potential involvement of any organ and unpredictable course. Recent advances and controversies in melanoma management reinforce a need for carefully considered treatment pathways, to optimise care.

The collection and presentation of accurate patient information at MDMs and comprehensive feedback to patients are fundamental to high-quality care.

Good practice points

5.1 Minimum core membership of a melanoma MDM consists of a general surgeon and/or plastic surgeon, a pathologist, a radiation oncologist, a medical oncologist, a radiologist and a clinical nurse specialist. Other MDT members may be involved, including dermatologists, GPs, adolescent and young adult key workers and palliative care team members.

5.2 The melanoma MDM process within each hospital and region is documented, including: appointment of MDM members, referral pathways, meeting frequency and videoconferencing links between regional and provincial hospitals, where appropriate.

5.3 Details of patients discussed at the MDM are recorded on a standardised MDM template.

5.4 A dedicated clinical nurse specialist or other health professional is appointed to coordinate written and verbal communication (including use of a dedicated melanoma MDM referral proforma).

5.5 Adequate support staff and resources are available to the MDM. Smaller provincial MDTs or treating clinicians present patients to regional MDMs in person or via teleconferencing.

5.6 The MDM records and discusses patients with stage Ib melanoma and above if required.

5.7 The MDM records information in a database that can be collated and analysed locally, regionally and nationally.

5.8 Treating clinicians record reasons for not following treatment plans recommended by the MDM.

5.9 Recommendations from MDM discussions are available as an electronic record and accessible to other members of a patient's health care team.

5.10 All Māori patients and their family/whānau are offered an opportunity to access Whānau Ora assessments and cultural support services.

Monitoring requirements

MR5A	Audit MDM documentation.
MR5B	Collect and monitor ethnicity data on all treatment, timeliness and access targets and indicators.

6 Supportive Care

Standard 6.1	Patients with melanoma and their family/whānau have equitable and coordinated access to appropriate medical, allied health and supportive care services, in accordance with *Guidance for Improving Supportive Care for Adults with Cancer in New Zealand* (Ministry of Health 2010).

Rationale

The psychological, social, physical and spiritual needs of cancer patients are many and varied. These needs can to a large extent be met by allied health care teams in hospitals and in the community. Adults with cancer enjoy improved quality of life following needs assessment and provision of supportive care.

Non-government organisations, including the Cancer Society and the Melanoma Foundation of New Zealand, perform an important role in providing supportive care.

Good practice points

6.1 Patients have their supportive care and psychosocial needs assessed using validated tools (such as the 'Distress Thermometer' or a cancer-related distress self-assessment tool: see Appendix 7) and documented at each stage of their cancer journey, and have access to services appropriate to their needs.

6.2 Information in a language and format appropriate to the patient is offered to each new patient with cancer, and meets the guidelines set out in *Rauemi Atawhai: A guide to developing health education resources in New Zealand* (Ministry of Health 2012c).

6.3 Patients have access to mental health services appropriate to their needs. Those experiencing significant distress or disturbance are referred to appropriate specialist health practitioners.

6.4 Māori patients and their family/whānau are offered access to Whānau Ora assessments and cultural support services.

6.5 Māori patients and those from other cultural groups and their family/whānau are offered access to culturally appropriate cancer support services.

6.6 Individually tailored written information in a plain language format is offered to each new patient with melanoma, and cover:

- general background information about melanoma
- treatment options: specific local arrangements, including information about the MDT and support services, and whom the patient should contact if necessary
- local self-help/support groups and other appropriate organisations.

6.7 Health professionals ensure that patients understand the information provided, or refer them on to suitably qualified service providers/advisors who can interpret information for them.

6.8 Patients are provided with adequate support and information to make decisions about their future health care in consultation with health care providers and family/whānau.

Monitoring requirements

MR6A	Provide evidence of culturally appropriate patient and family/whānau satisfaction surveys, and audit complaints processes.
MR6B	Collect and analyse ethnicity data on all treatment, timeliness and access targets and indicators.

7 Care Coordination

Standard 7.1	Patients managed by a melanoma MDT have access to a clinical nurse specialist or other health professional who is a member of the MDM to help coordinate all aspects of their care.
Standard 7.2	Each treatment centre has a melanoma clinical lead to provide necessary leadership, guidance and provision of melanoma care.

Rationale

The cancer journey is complex, and it is not uncommon for a patient to be seen by many specialists within and across multiple DHBs and across the public and private sectors.

'Care coordination' refers to a system or a role primarily intended to expedite patient access to services and resources, improve communication and the transfer of information between services, address patients' information needs and improve continuity of care throughout the cancer continuum.

Key responsibilities of care coordinators include:

- early identification and assessment of patients at greatest need of support
- care coordination (see above)
- provision of information, support and nursing care
- provision of advice/education to other nurses and health professionals
- ensuring best-practice service provision
- collaboration with other health professionals to improve outcomes for patients.

Given the specialised knowledge required and responsibilities involved, care coordinators should be clinical nurse specialists.

Good practice points

7.1 All patients with melanoma have a nominated single point of contact – ideally a nurse or allied health professional with an in-depth/specialist knowledge of melanoma – to support them to access psychosocial support and information and provide coordination of their cancer journey.

7.2 Services provide all patients with this person's name and contact details, and the care coordinator makes initial contact with the patient within seven days of the initial diagnosis.

7.3 Tools are developed to specifically meet the needs of Māori (such as Whānau Ora assessments); these tools are used to inform patient treatment plans and care coordination.

Monitoring requirements

MR7A	Audit database records and clinical notes on contact points between care coordinators and patients.
MR7B	Provide evidence of culturally appropriate patient and family/whānau satisfaction surveys, and audit complaints processes.
MR7C	Collect and analyse ethnicity data on all treatment, timeliness and access targets and indicators.

8 Treatment

Standard 8.1	Histologically confirmed melanomas are re-excised, with additional clinical margins determined by Breslow thickness. Lesions meeting histological staging AJCC T1b or higher are referred to a surgical specialist for consideration of SNB at the time of the re-excision.

Rationale

Evidence-based clinical margins decrease local recurrence.

Sentinel node biopsy is the best staging and prognostic test for melanoma.

Good practice points

8.1 All doctors who undertake re-excision of melanoma are appropriately trained and experienced.

8.2 Margins may be modified by clinical site or patient co-morbidities.

8.3 Re-excision of melanoma in situ to 5–10 mm clinical margins and AJCC T1a cases of melanoma to 10 mm clinical margins can be performed as a local anaesthetic procedure by either an appropriately trained and experienced primary care doctor or a melanoma specialist.

8.4 Patients are informed about melanoma in general and increased risks for further new melanoma, and advised to undergo regular full-body skin checks.

8.5 Lesions meeting histological staging AJCC T1b or higher are referred to an appropriately trained and experienced surgical specialist for consideration of SNB at the time of the re-excision.

8.6 Excisions have vertical edges and extend to, but do not include, the deep fascia, as clinically appropriate.

8.7 Precise measurement of clinical margins is mapped out from the scar with a ruler before the definitive excision.

8.8 Patients are provided with information about surgical excision risks: wound infection, haematoma, failure of skin graft and flap, numbness, scarring, seroma and lymphoedema and the possibility that further surgery will be required.

8.9 Patients undergoing surgery are offered the choice for their tissue to be disposed of by standard methods, or with appropriate tikanga.

8.10 Appropriate data collection systems are in place to collate, publish and audit data on post-surgery complications.

8.11 Clinicians adhere to guidelines in the following table.

Breslow thickness	Additional clinical margin
Melanoma in situ (Tis)	5–10 mm
<1.0 mm (T1)	10 mm
1–2 mm (T2)	10–20 mm
2–4 mm (T3)	20 mm
>4 mm (T4)	20 mm

Monitoring requirements

MR8A	Audit re-excision rates and referrals for consideration of SNB.
MR8B	Audit post-surgery morbidity rates.

Standard 8.2	The MDM discusses the role of radiation treatment to improve local control in the case of patients with desmoplastic melanoma.

Rationale

Desmoplastic melanoma most commonly occur on the head and neck, and entail an increased risk (36–52 percent) of neurotropism, which is associated with an increased risk of local recurrence.

Good practice points

8.12 Radiation treatment is offered to patients where the melanoma is unresectable, where the clinical margins are <1 cm and where the melanoma has marked neurotropism.

Monitoring requirements

MR8C	Audit treated cases of desmoplastic melanoma to assess: • documentation of MDM discussion • clinical margin status • percentage of patients receiving radiation treatment • recurrence rates.

Standard 8.3	Sentinel node biopsy is offered to patients with T1b or thicker melanoma who could benefit from the procedure, and is performed by surgeons trained and experienced in the technique. Sentinel node biopsy in melanoma is carried out using triple localisation with preoperative lymphoscintigraphy, intra-operative localisation with blue dye and a gamma probe.

Rationale

Studies have shown that the SNB technique is useful for identifying small lymph node metastases in patients with intermediate thickness melanoma (1–4 mm); it detects metastases in the sentinel node in 18–33 percent of these patients. Sentinel node biopsy allows for accurate staging, prognostic information and improved regional control.

Thin melanomas (<1 mm) are the most common form of melanoma, and can usually be cured through surgical removal of the primary tumour. While SNB is not necessary in most cases, it may be considered in select patients with thin melanomas who have poor prognostic factors, such as ulceration or dermal mitoses.

Thick melanomas (>4 mm) are considered more likely to undergo haematogenous metastasis. There are few studies focusing on the use of SNB in patients with thick melanomas. The technique may be considered in select cases, subject to MDM discussion.

Complete removal of the remaining lymph nodes (completion lymphadenectomy) has been shown to prevent or limit further cancer spread in some patients and facilitate better regional control. It is not yet known whether this approach improves survival.

Good practice points

8.13 Sentinel node biopsy is considered for all patients with melanomas of intermediate thickness, and for patients with thin melanoma only where certain criteria are met (such as an ulceration and/or mitotic rate ≥1). Sentinel Node Biopsy is considered for patients with thick melanomas for staging or to facilitate regional control.

8.14 In order that they may make an informed choice about SNB, patients are provided with information about the likelihood of the SNB being positive based on the histological features of their melanoma. Validated online nomograms (such as the Memorial Sloan-Kettering Cancer Center melanoma nomogram: www.mskcc.org/cancer-care/adult/melanoma/prediction-tools) provide this information as a percentage. Clinicians inform patients of the role of SNB, the technique itself, its limitations, potential complications and alternative management if it is declined. This discussion is instigated by both the primary clinician and the surgeon who performs SNB.

8.15 Preoperative lymphoscintigraphy is carried out to identify which draining lymph node fields contain the sentinel node(s). Technetium99 nanocolloid is injected intradermally around the scar, and dynamic and static lymphoscintograms obtained.

8.16 Lymphoscintograms are reported by radiologists and nuclear medicine specialists trained and experienced in the technique.

8.17 Sentinel node biopsy is performed by surgeons trained and experienced in the technique. (The accepted learning curve is 30 successfully completed cases.)

8.18 Sentinel node biopsy is performed within 18 hours of lymphoscintigraphy.

8.19 Incisions are marked out with consideration to therapeutic lymphadenectomy access, should nodes be positive.

8.20 All patients with a positive SNB receive completion lymphadenectomy at this time.

8.21 Appropriate data collection systems are in place to collate, report and audit post-surgery complications.

Monitoring requirements

MR8D	Audit regional MDM T1b melanoma records, including reasons for omission when SNB was not carried out.

Standard 8.4	An oncological therapeutic lymphadenectomy is offered to all patients with evidence of metastatic nodal disease after appropriate staging and discussion at an MDM. Lymphadenectomy nodal harvest results meet accepted criteria.

Rationale

Effective management of stage III melanoma results in better regional control, potential survival benefits and recruitment into clinical trials. Surgeons and units experienced in lymphadenectomy improve outcomes for patients.

Good practice points

8.22 All stage IIIb patients receive imaging with whole-body PET-CT prior to surgery.

8.23 Lymphadenectomy is performed by trained and experienced surgeons.

8.24 Operation notes fully describe the anatomical boundaries of the lymphadenectomy and lymph node levels removed.

8.25 A therapeutic axillary lymphadenectomy includes levels I–III.

8.26 Therapeutic neck lymphadenectomies are tailored to individual patients' metastatic disease, and may include radical, modified radical or selective neck lymphadenectomy with or without a parotidectomy.

8.27 A therapeutic inguinal lymphadenectomy involves skeletonisation of the femoral vessels and removal of pudendal nodes, nodes anterior to the external oblique and 'Cloquet's' nodes in the femoral canal.

8.28 Patients with palpable inguinal node metastases or more than three positive nodes below the inguinal ligament are considered for clearance of iliac and obturator nodes in the pelvis.

8.29 Patients with staging evidence of pathological intrapelvic nodes undergo an iliac and obturator lymphadenectomy with or without an inguinal lymphadenectomy.

8.30 All patients with stage III melanoma are discussed at an MDM and considered for adjuvant radiotherapy or enrolment in clinical trials. Radiation treatment is discussed after the resection of nodal disease in the following situations:

- palpable (macroscopic) metastatic nodal involvement of one or more parotid node, two or more neck or axillary nodes, or three or more groin nodes
- extranodal spread (of tumour)
- a maximum metastatic node diameter of ≥3 cm in the neck or ≥4 cm in the axilla or groin (TROG (Trans Tasman Radiation Oncology Group).

8.31 Patients have access to a lymphoedema specialist (physiotherapist) to fit compression garments and provide education about post-operative lymphoedema management.

8.32 Appropriate data collection systems are in place to collate, report and audit data on post-surgery complications.

Monitoring requirements

MR8E	Audit nodal harvest numbers.
MR8F	Audit post-surgery morbidity rates.

Standard 8.5	Patients with loco-regional recurrent, locally advanced and stage IV melanoma are seen or discussed by melanoma specialists experienced in the care of melanoma patients and part of an MDM, including: • surgical oncologists • radiation oncologists • medical oncologists.

Rationale

Surgery has been shown to be effective in palliating symptoms and, in carefully selected patients, may improve overall survival.

Radiation treatment has been shown to be effective in palliating symptoms and decreasing recurrence of melanoma after surgery.

Systemic therapy has been shown to be effective in palliating symptoms and improving survival.

Good practice points

Surgery

8.33 Clinical recurrence in a previously resected nodal basin is resected after appropriate staging investigations.

8.34 Where there is a local recurrence with no clinical nodal involvement, SNB is considered.

8.35 Where there are multiple dermal recurrences, surgical excision and/or BRAF testing and treatment is considered. If on the limbs, referral for consideration of isolated limb infusion is considered.

8.36 Isolated limb infusion is provided by trained and experienced clinicians at centres that have the resources to carry out this complex procedure; preferably, a national isolated limb infusion centre is established.

8.37 For patients with limited brain metastasis and no or minimal extracranial disease resection of the brain metastasis is considered.

8.38 For patients with single-level spinal cord compression and minimal or no other metastatic disease, surgical treatment is considered.

8.39 For patients with symptomatic or limited visceral disease, surgical resection is considered.

Radiation oncology

8.40 If it has not been previously given, radiation treatment is considered after the resection of nodal disease in the following situations:

- palpable (macroscopic) metastatic nodal involvement of one or more parotid nodes, two or more neck or axillary nodes, or three or more groin nodes
- extranodal spread (of tumour)
- a maximum metastatic node diameter of ≥3 cm in the neck or ≥4 cm in the axilla or groin (Trans Tasman Radiation Oncology Group criteria).

8.41 Radiation treatment after surgical resection of locally recurrent melanoma is considered.

8.42 Stereotactic radiation treatment of the brain metastasis is considered for patients with one–three limited brain metastases and no or controlled extracranial disease.

8.43 Whole brain radiation treatment could be considered after a surgical resection or stereotactic radiation treatment of a brain metastasis, to improve the chance of progression-free survival.

8.44 Patients with localised symptoms from melanoma metastases are considered for referral for radiation treatment to these sites.

Medical oncology

8.45 Patients with advanced melanoma have their tumour assessed for the presence of the BRAF V600 mutation.

8.46 BRAF mutation inhibitor therapy is available for BRAF-mutation-positive patients (expected to be approximately 50 percent).

8.47 For BRAF wild-type patients and for BRAF-mutation-positive patients who have progressed or could not receive BRAF inhibitor therapy, immunotherapy (such as anti-CTLA-4 or anti-PD-1/PDL-1 antibodies) is available.

8.48 Palliative systemic therapy with single-agent dacarbazine or temozolamide is considered for patients who are not candidates for treatment with BRAF-inhibitor therapy or immunotherapy and those whose cancer has progressed after optimal treatment with other options.

Monitoring requirements

MR8G	Audit details of patients discussed at the MDM.
MR8H	Record the percentage of patients tested for BRAF mutation.
MR8I	Audit availability of stereotactic radiation for the treatment of brain metastasis and other metastatic disease.

Standard 8.6	Patients with non-cutaneous melanoma are discussed in a melanoma MDM as well as the relevant site-specific MDM, with the treating clinician represented.

Rationale

Non-cutaneous melanomas are rare entities, often presenting late with advanced disease. To date there are no well-established protocols for staging and treatment of these types of melanoma. Patients with non-cutaneous melanoma should all be referred to a tertiary MDT with experience in the specific region as well as a melanoma MDT, to allow for potential trial enrolment and melanoma-specific adjuvant therapy. International advice may be sought in more complex cases.

Ocular melanoma is complex, and has special anatomical considerations. Further information can be found in the supplementary document on oncular and periocular melanoma accompanying the *Clinical Practice Guidelines for the Management of Melanoma in Australia and New Zealand* (Australian Cancer Network and NZGG Melanoma Guidelines Revision Working Party 2008).

No survival benefit has been shown with aggressive surgery (abdominoperineal resection, complete vulvectomy and hysterectomy) compared to wide local excision in anorectal or vulvovaginal melanoma. Publication of surgical margins is lacking from the literature, but there is evidence in melanoma of the vulva that AJCC staging prognostic indicators in cutaneous melanoma (Breslow depth, ulceration and mitosis) are relevant.

There is a lack of evidence for SNB in non-cutaneous melanoma. Disease progression via haemotological rather than lymphatic spread may negate any prognostic benefit, but in melanoma of the anus or vulva, where SNB can be performed relatively easily, it may play a role in staging and prognosis.

Good practice points

8.49 Suspicious non-cutaneous lesions are referred to a melanoma specialist or site-specific specialist with experience in melanoma for diagnosis and treatment.

8.50 All patients with ocular melanoma are treated by or discussed with specialised units where eye-conserving therapies are available, along with the melanoma MDT.

8.51 Perioperative evaluation of non-cutaneous melanoma includes staging with whole-body PET-CT. Ultrasound or MRI to assess depth of penetration of non-cutaneous melanoma is used to identify patients suitable for a limited procedure.

8.52 Relevant melanoma specialists as well as a site-specific specialist with experience in melanoma undertake treatment and follow-up of patients with non-cutaneous melanoma.

8.53 For ocular melanoma, periodic observation, transpupillary thermotherapy, charged particle irradiation, stereotactic radiotherapy, local tumour resection, enucleation and exenteration are considered.

8.54 For uveal melanoma, eye-conserving plaque radiotherapy, which results in local control comparable to surgery in most tumours, is considered.

8.55 For conjunctival melanoma, local resection is considered (the role for topical chemotherapy and radiotherapy is as yet undefined).

8.56 Primary melanoma of the vulva or vagina is treated with wide local excision with clinical margins in keeping with cutaneous melanoma, if complete resection can be obtained. Consideration is given to SNB at time of wide excision.

8.57 Primary melanoma of the anorectum is treated with sphincter-sparing surgery if complete resection can be obtained.

8.58 If a complete resection cannot be obtained with wide local excision, more aggressive surgery or radiotherapy is considered to gain local control, in discussion with the patient and considering quality-of-life issues.

8.59 In non-cutaneous melanoma with clear clinical margins, adjuvant radiotherapy to assist with local control is discussed at the MDM.

8.60 In patients for whom surgical clearance is unobtainable due to patient or disease factors, palliative radiotherapy for symptom control is discussed.

8.61 For melanoma of the anus or vulva, SNB is offered to patients who could benefit from the procedure, and is performed by trained and experienced surgeons.

8.62 Patients with established nodal metastases at presentation undergo therapeutic lymphadenectomy at the time of the definitive procedure for local control. (There is no role for elective lymphadenectomy.)

8.63 Foci of metastatic disease are treated according to general principles for the treatment of metastatic cutaneous melanoma in the absence of any data to suggest otherwise.

Monitoring requirements

MR8J	Audit complete data collection, including pathology (incorporating all AJCC staging criteria for cutaneous melanoma and surgical margins), staging, management (including adjuvant therapy), local and distant recurrence and survival.

Standard 8.7	Patients diagnosed with melanoma are assessed by appropriately qualified personnel to identify supportive care needs, including psychological distress, at key points of their cancer journey, ideally using a validated tool and a clear referral process.

Rationale

The diagnosis and treatment of cancer disrupts people's lives. People affected by cancer have many needs beyond their medical treatment, and may be reluctant to ask for help. Some may find it difficult to articulate their concerns, or lack knowledge about the support services available or the skill to access them. Others may not recognise their needs at all. Consequently health professionals need to thoughtfully assess social support needs and ensure patients and their family/whānau get the support and guidance they require.

While many health professionals think they are good at identifying distress, research shows that they often do not recognise distress in their patients. Patients do not always voice that they are distressed. For most health professionals, distress is not a core aspect of their training or their job, and so it is not their focus or they may not feel confident broaching this area. There is also the danger with distress that the 'bystander effect' operates – everybody thinks that somebody else is monitoring it. While the emotional aspect of cancer can be considered to be the responsibility of all health professionals involved, it is helpful to have planned pathways to assess distress, and it makes sense that these focus on key times throughout the cancer journey.

Key points of the cancer journey include at diagnosis; at the start, during and at the end of treatment; at relapse; and when death is approaching.

Good practice points

8.64 Assessment takes into account the psychological, social, spiritual and financial needs of the patient and their family/whānau.

8.65 Information is gathered from a variety of sources, including through a validated tool (for example the NCCN 'Distress Thermometer') and a consideration of the risk factors for distress.

8.66 Criteria and pathways for a graduated intervention approach are developed to ensure patients are appropriately and efficiently referred to relevant social or specialist psychological support services.

8.67 Supportive care assessments and interventions are undertaken in suitable facilities and locations, which take into consideration patients' needs for privacy and comfort, and their mobility.

Monitoring requirements

MR8K	Audit plans of care, assessment tools and the referral process as documented in patient records.

Standard 8.8	Patients are offered early access to palliative care services when there are complex symptom control issues, when curative treatment cannot be offered or if curative treatment is declined.

Rationale

Currently, patients with stage IV melanoma will likely die from their disease. Many will experience a high symptom burden; this may be related to the disease or the treatment, and emphasises the importance of palliative care.

A diagnosis of cancer and its subsequent treatment can have a devastating impact on the quality of a person's life, as well as on the lives of families/whānau and other carers. Patients may face new fears and uncertainties, and may have to undergo unpleasant and debilitating treatments. Patients should expect to be offered optimal symptom control and psychological, cultural, social and spiritual support. They may want to be assured that their families/whānau and carers will receive support during illness and, if they die, following bereavement.

Palliative care is the care of people who are dying from active, progressive diseases or other conditions that are not responsive to curative treatment. Palliative care embraces the physical, social, emotional and spiritual elements of wellbeing – tinana, whānau, hinengaro and wairua – and enhances a person's quality of life while they are dying. Palliative care also supports the bereaved family/whānau (Ministry of Health 2001).

The objective of palliative care is to alleviate suffering and provide compassionate care for the patient and their family/ whānau. Competence in palliative medicine and sensitivity to people's beliefs and values are two key prerequisites for a provider of palliative care. Clinicians should form a care plan for palliative patients with a view to ensuring that pain and other potentially distressing symptoms are relieved, dignity is preserved and there is engagement with family/whānau (Ministry of Health 2001).

Good practice points

8.68 A clinical nurse specialist is included in the MDT to provide assistance with symptom control, support patients and their family//whānau, coordinate care of patients between settings when necessary, and assist in clarifying goals of care.

8.69 Patients are screened for palliative care needs at their initial visit, at appropriate intervals and as clinically indicated.

8.70 Patients and families/whānau with complex physical, psychosocial and spiritual needs are referred to a specialist palliative care team when necessary at any stage during the illness.

8.71 Cultural and spiritual support is made available if required.

8.72 Screening for palliative care needs, comprehensive assessment and care planning are undertaken at appropriate intervals.

8.73 Access to palliative care, decision-making and care planning is based on a respect for the uniqueness of the patient and their family/whānau, independent of their current health status, diagnosis, age, gender, cultural background or geography. Their needs and wishes guide decision-making and care planning.

8.74 Provider organisations ensure that patients and their family/whānau have easy access to a range of free, culturally and educationally appropriate and high-quality information materials in a variety of formats about cancer and palliative care services.

8.75 Systems are in place to ensure the views of patients and their family/whānau are taken into account when developing and evaluating cancer and palliative care services. All such services support patients and family/whānau to participate in their own care by offering a range of informal opportunities, such as self-help activities and peer support schemes in community settings.

8.76 Formal mechanisms are in place to ensure that patients, their carers and family/whānau have access to bereavement care, information and support services.

8.77 Patients and their families/whānau are offered palliative care options and information in plain language that is targeted to their particular needs, and this is incorporated into their care plans.

8.78 Practitioners assess dying patients in a timely manner, and discuss advance care planning and end-of-life goals of care with patients and family/whānau, using a end-of-life care pathway.

Monitoring requirements

MR8L	Audit proposed plans of care, onward referrals and follow-up responsibilities recorded at MDM reviews and in patients' notes.

9 Follow-up and Surveillance

Standard 9.1	Follow-up plans are carried out by clinicians experienced in melanoma diagnosis and management, working in conjunction with the patient, their family/whānau and their GP.
Standard 9.2	Patients are taught self-examination.

Rationale

The purpose of follow-up is to detect recurrence early, detect new primary melanoma and provide ongoing patient education and psychosocial support.

No completed randomised trials have compared various follow-up schedules, so these recommendations are based on expert opinion. Schedules vary dramatically between countries. A reduction in both follow-up frequency and follow-up duration is being increasingly adopted as national guidelines are reviewed.

A follow-up schedule based on retrospective data from the Sydney Melanoma Unit/Melanoma Institute of Australia is currently the most evidence-based schedule; it offers a reduced follow-up frequency compared to the current Australia/New Zealand guidelines.

Recent modelling has demonstrated that only a small number of patient diagnoses would have been delayed by more than two months with reduced follow-up.

Australian data show that 18–23 percent of patients developed a recurrence within 10 years, and 80 percent of recurrences develop in the first three years. Recurrence occurring more than 10 years after diagnosis is extremely low – less than 1 percent annually.

Patient education in self-examination is an integral component of the follow-up schedule, and facilitates earlier diagnosis of recurrence.

Follow-up frequency may vary depending on patients' needs.

Good practice points

9.1 A written follow-up plan is made with the patient and given to the patient and their GP.

9.2 Recommended follow-up protocol is as follows.

- AJCC stage I melanoma is assessed annually until the 10th anniversary.
- Stage IIa melanoma is assessed six-monthly for two years and then annually until the 10th anniversary.
- Stage IIb–IIc melanoma is assessed four-monthly for two years, six-monthly in the third year and annually thereafter until the 10th anniversary.
- Stage III melanoma is assessed three-monthly in the first year, four-monthly in the second year, six-monthly until the fifth year and annually thereafter until the 10th anniversary.
- Stage IV melanoma is assessed as for stage III, with additional visits as per clinical requirements.

9.3 A lead clinician in charge of follow-up is nominated and made known to the patient and their GP. (A primary-care clinician may take over this role from a hospital-based clinician once hospital-level care has been completed.)

9.4 The GP's involvement in follow-up is encouraged, and appropriate training and support is provided to GPs for this purpose.

9.5 Follow-up visits involve a thorough history focusing on symptoms that can indicate recurrent disease (eg, new skin lesions, palpable tumours in lymph node basins and unexplained systemic complaints such as fatigue, shortness of breath, headache, weight loss and gastrointestinal symptoms).

9.6 Follow-up visits also include a complete skin check, including the scalp, and a physical examination for lymphadenopathy. Particular attention is given to the intransit pathway – such as skin between the site of the melanoma and the draining lymph node basin(s).

9.7 Patients who develop lymphoedema have access to assessment and therapy services, including complex physical therapy and fitting and provision of compression garments where indicated.

9.8 Patients with melanoma in situ are mainly followed up to screen for new melanomas. Follow-up protocol for these patients is as for those with stage Ia melanoma.

9.9 The risk of multiple primary melanomas is higher in patients with atypical mole syndrome (also known as FAMM), multiple naevi (especially >100) and/or atypical naevi. These patients should undergo lifelong skin checks, along with total body photography and high-quality sequential digital dermatoscopy.

Monitoring requirements

MR9A	Audit information provided to patients and their family/whānau.
MR9B	Audit organisational compliance with follow-up plans.

10 Clinical Performance Monitoring and Research

Standard 10.1	New and recurrent cases of melanoma, including melanoma in situ, are reported to the New Zealand Cancer Registry.

Rationale

Substantial melanoma data, including treatment-related data, are being collected in New Zealand not only by the New Zealand Cancer Registry but also by DHBs and others. Cancer data-related projects are being undertaken or planned by the Ministry of Health, Cancer Control New Zealand and regional cancer networks.

These include:

- development of the National Cancer Core Data Definitions Interim Standard (IT Health Board 2011) to ensure that minimum agreed cancer data are collected and stored in a consistent manner
- piloting of that Interim Standard by the Southern Cancer Network, with a view towards the other three networks developing comparable regional clinical data repositories for cancer
- Cancer Registry collection of TNM stage data
- the introduction of structured (synoptic) reporting
- improved access to an online Cancer Registry for medical practitioners and researchers
- the Ministry of Health's 'National Patient Flow Project'.

The collection of data on melanoma management in the primary care setting has not yet been addressed.

Initially the group developing the *Clinical Practice Guidelines for the Management of Melanoma in Australia and New Zealand* (Australian Cancer Network and NZGG Melanoma Guidelines Revision Working Party 2008) focused on the development of a national melanoma database. However, in light of the above developments, the group ultimately recommended strengthening and linking existing data repositories and improving access to such data for clinicians and researchers.

Reports to the New Zealand Cancer Registry are based upon histopathological assessment. Histopathology reports convey information to clinicians, and determine subsequent management, prognostication and information-sharing with the patient. They also convey information essential to health planners and researchers.

The Cancer Registry Act 1993 and Cancer Registry Regulations 1994 require that all new cases of malignant disease, including in-situ cancers, be reported to the New Zealand Cancer Registry.

Good practice points

10.1 Melanoma data beyond those required by the New Zealand Cancer Registry, including treatment data, are reported to existing and planned national repositories.

10.2 Regional cancer networks ensure information on any existing or planned regional clinical data repositories that include melanoma is available to clinicians and researchers.

10.3 Cancer Control New Zealand ensures information on developments in collecting TNM staging for melanoma is available to clinicians and researchers.

10.4 The Ministry of Health ensures information on implementation of the *National Cancer Core Data Definition Interim Standard* (IT Health Board 2011) is available to clinicians.

10.5 Clinicians consult the agencies mentioned above before establishing a new data repository for melanoma.

10.6 Histopathological data on melanoma are submitted to the Cancer Registry in a structured (synoptic) format.

10.7 Data submitted to the Cancer Registry are complete, accurate, timely and sustainable.

10.8 Cancer Registry data are accessible to health planners, clinicians and researchers (having regard to ethical standards for their use).

Monitoring requirements

MR10A	Audit the completeness of Cancer Registry data.
MR10B	Audit the accuracy of Cancer Registry data.
MR10C	Audit the timeline for Cancer Registry notifications and data publication.

Standard 10.2	Patients with melanoma are offered the opportunity to participate in research projects and clinical trials where these are available.

Rationale

Research into melanoma can ultimately result in survival benefits for patients through an improved understanding of melanoma pathogenesis, genetics, incidence or outcomes, thereby leading to more effective early diagnosis and treatment and improved coordination of post-intervention treatment.

Services should contribute towards improving the availability of data for research by implementing robust audit procedures, maintaining relevant database(s) and recruiting people into research projects and clinical trials.

Good practice points

10.9 Recruitment for research and clinical trials takes place as part of the treatment-planning process.

10.10 Data is efficiently captured for research purposes, and where possible research data are translated into clinical practice to improve patient outcomes. Research data should include details of pre- and post-intervention treatment and management.

10.11 Core data relating to referrals to MDMs are captured to enable linking with the New Zealand Cancer Registry and other cancer data collections.

10.12 Research into Māori patients with melanoma and their family/whānau and communities is facilitated, to address the question as to why these patients often present with thicker melanomas.

10.13 Employing organisations value and facilitate the participation of clinicians in research, and demonstrate this through the dedicated allocation of time, administrative support and quality review.

10.14 Melanoma treatment centres continually recruit to and engage in at least one current registered national melanoma study.

10.15 Melanoma treatment centres maintain a listing of clinical trials to which patients are being recruited, and make this available for collation on a national basis.

10.16 Melanoma treatment centres participate in national melanoma audit processes, the results of which are made publicly available.

Monitoring requirements

MR10D	Audit melanoma treatment centres' entry of patients into clinical trials.

Appendix 1:
National Melanoma Tumour Standards Working Group Membership

Chair

Mr Richard Martin, Consultant Surgical Oncologist, Waitemata DHB

Members

Dr Mark Barnett, Consultant Radiologist, Waitemata DHB

Dr Catherine Barrow, Consultant Medical Oncologist, Capital & Coast DHB

Dr Vanessa Blair, General Surgeon, Northland DHB

Dr Chris Boberg, General Practitioner, MelNet/Royal New Zealand College of General Practitioners

Mr Isaac Cranshaw, Surgeon, Auckland DHB/Skin Institute

Mr Gary Duncan, Plastic Surgeon/Chair, MelNet, Hutt Valley DHB

Dr Michael Eccles, Chair in Cancer Pathology, New Zealand Institute for Cancer Research Trust, University of Otago

Dr Patrick Emanuel, Consultant Histopathologist and Dermatopathologist, Diagnostic Medlab

Linda Flay, Chief Executive Officer, Melanoma Foundation of New Zealand

Dr Mark Foley, General Practitioner, The Skin Clinic Marlborough

Dr Jacqui Gardner, Consultant Anatomical Pathologist, Canterbury DHB

Barbara Hegan, Health Promotion Advisor, Skin Cancer Control, Cancer Society of New Zealand

Juliet Ireland, Health Psychologist, Auckland DHB

Dr Melissa James, Radiation Oncologist, Canterbury DHB

Mr John Kenealy, Consultant Plastic Surgeon/Head of Department, Counties Manukau DHB

Trish Leathem, Clinical Nurse Specialist, Skin Cancer, Counties Manukau DHB

Mr Will McMillan, Consultant Plastic Surgeon, Southern DHB

Betsy Marshall, Coordinator, MelNet

Jacqueline Mathieson, Inpatient Unit Coordinator, Te Omanga Hospice

Dr Amanda Oakley, Clinical Associate Professor/President, New Zealand Dermatological Society, Waikato DHB/New Zealand Dermatological Society

Susan Perry, Consumer Representative, Melanoma Foundation of New Zealand

Dr Susan Seifried, General Surgeon, Tasman Bay Surgical

Ex officio members

Emma Maddren, Project Manager, Northern Cancer Network

Deirdre Maxwell, Network Manager, Northern Cancer Network

Dr Richard Sullivan, Network Clinical Director, Northern Cancer Network

Advisors

Mr John Chaplin, Head and Neck Surgeon, Melanoma Unit/Auckland DHB

Dr Peter Hadden, Consultant Opthalmologist/Clinical Senior Lecturer in Opthalmology, Auckland DHB/University of Auckland

Mr Richard Harman, Surgical Oncologist, Melanoma Unit/Waitemata DHB

Helen Kinchley, Melanoma Clinical Nurse Specialist, Waitemata DHB

Lyn Mourant, Registered Nurse, Melanoma Foundation of New Zealand

Associate Prof Peter Sykes, Clinical Head of Department, Obstetrics and Gynaecology, University of Otago

Appendix 2: Glossary

Adjuvant therapy	Additional treatment to increase the effectiveness of the main treatment (often surgery), such as chemotherapy, systemic therapy or radiotherapy
Advance care planning	A process of discussion and shared planning for future health care
AJCC	American Joint Committee on Cancer
Allied health professional	One of the following groups of health care workers: physiotherapists, occupational therapists, dietitians, orthoptists, paramedics, prosthetists/orthotists and speech and language therapists
Anti CTLA-4 and anti-PD1/PDL-1 antibodies	New Stage IV melanoma management in the form of immunotherapy
Benign	Not cancerous; not malignant
Best practice	A method or approach that is accepted by consensus to be the most effective way of doing something, in the circumstances; may or may not be based on evidence
Biopsy	Removal of a sample of tissue or cells from the body to assist in the diagnosis of a disease
BRAF	A member of the Raf kinase family of growth signal transduction protein kinases. This protein plays a role in regulating the MAP kinase/ERKs signalling pathway, which affects cell division, differentiation, and secretion. BRAF inhibitor drugs block this pathway
Breslow thickness	A measure of thickness for malignant melanoma, measured from the top layer of skin to the bottom of the tumour. The deeper the melanoma has grown, the more likely it is that some cells may have spread through the blood stream or lymphatic system
Cancer journey	The individual and personal experience of a person with cancer throughout the course of their illness
Cancer Networks	Cancer Networks were formed in response to national policy to drive change and improve cancer services for the population in specific areas. There are four regional networks: Northern, Midland, Central and Southern
Cancer service pathway	The cumulative cancer-specific services that a person with cancer uses during the course of their experience with cancer
Care coordination	Entails the organising and planning of cancer care, who patients and family/whānau see, when they see them and how this can be made as easy as possible. It may also include identifying who patients and family/whānau need to help them on the cancer pathway

Chemotherapy	The use of drugs that kill cancer cells, or prevent or slow their growth (also see systemic therapy)
Clinical margin	The clinically estimated margin around the lesion or scar
Clinical trial	An experiment for a new treatment
Computed tomography (CT)	A medical imaging technique using X-rays to create cross-sectional slices through the body part being examined
Confirmed diagnosis (used in FCT indicators)	The preferred basis of a confirmed cancer diagnosis is pathological, noting that for a small number of patients cancer diagnosis will be based on diagnostic imaging findings
Curative	Aiming to cure a disease
Cutaneous	Pertaining to skin
Decision to treat (used in FCT indicators)	A decision to begin a patient's treatment plan or other management plan, following discussion between the patient and treating clinician
Dermatologist	A vocationally registered doctor who specialises in the diagnosis and treatment of skin disorders
Dermatoscopy (dermoscopy)	A diagnostic technique to examine skin lesions, using magnification, a bright light and some means to reduce reflection from the skin. Digital dermatoscopy refers to digital dermatoscopic images
DHB	District Health Board
EORTC	European Organisation for Research and Treatment of Cancer
Excision	The removal of tissue by surgery
Familial atypical mole and melanoma syndrome (FAMM)	Also referred to as atypical mole syndrome
Faster Cancer Treatment (FCT)	A Ministry of Health programme that will improve services by standardising care pathways and timeliness of services for cancer patients throughout New Zealand
Faster Cancer Treatment indicators	Measures of cancer care collected through DHB reporting of timeframes within which patients with a high suspicion of cancer access services. The indicators are internationally established and provide goals for DHBs to achieve over time
Fine needle aspiration (FNA) cytology	The use of a fine needle to biopsy a tumour or lymph node to obtain cells for cytological confirmation of diagnosis
First specialist assessment (FSA)	Face-to-face contact (including telemedicine) between a patient and a registered medical practitioner or nurse practitioner for the purposes of first assessment for their condition for that specialty
First treatment (used in FCT indicators)	The treatment or other management that attempts to begin the patient's treatment, including palliative care
GP	General practitioner

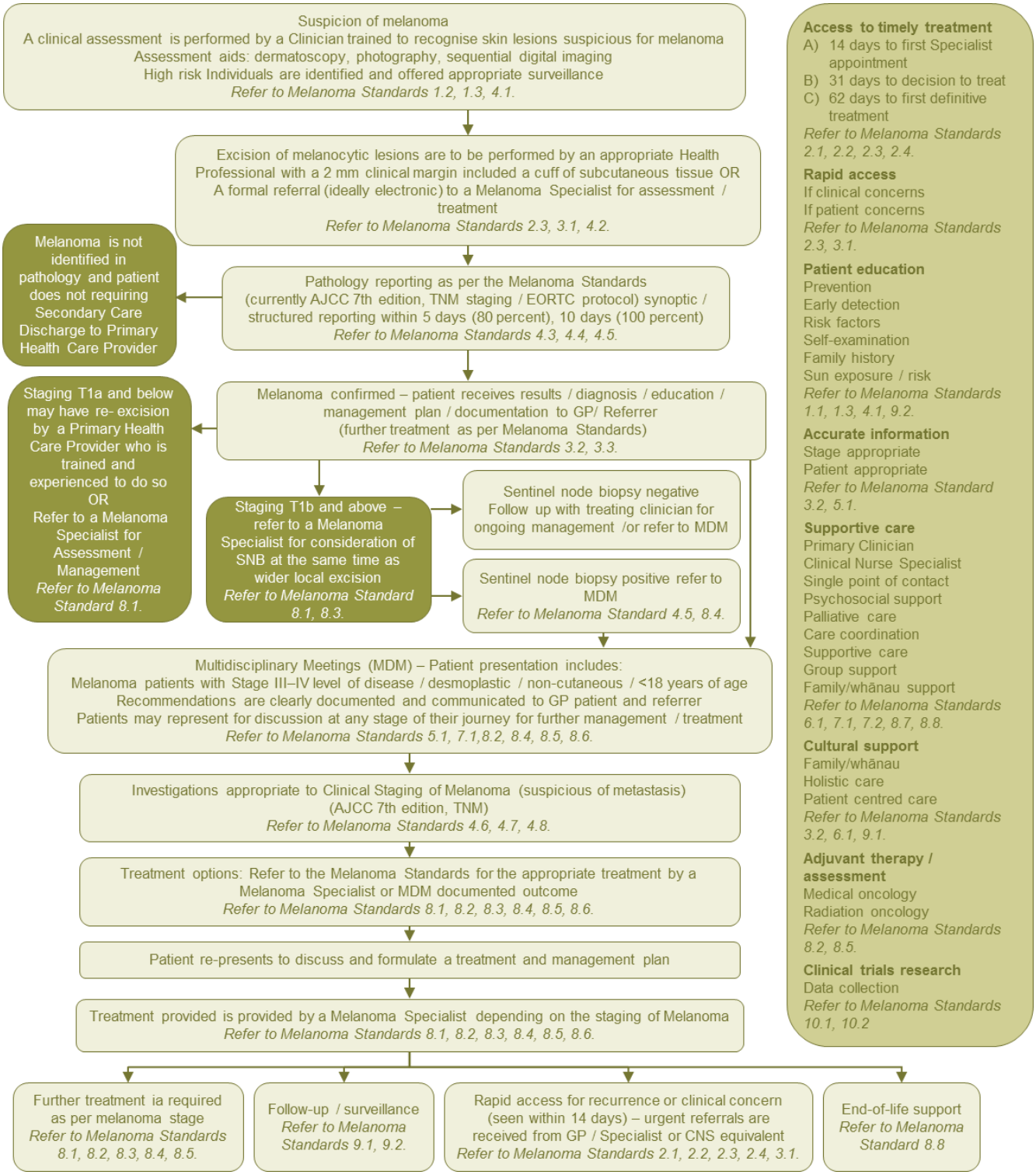
Health equality/equity	Absence of unnecessary, avoidable and unjust differences in health (Ministry of Health 2002)
Health inequality/inequity	Differences in health that are unnecessary, avoidable or unjust (Ministry of Health 2002)
High suspicion of cancer (used in FCT indicators)	Where a patient presents with clinical features typical of cancer, or has less typical signs and symptoms but the clinician suspects that there is a high probability of cancer
Histological	Relating to the study of cells and tissue on the microscopic level
Histopathologist	A vocationally registered doctor who specialises in examining tissue samples microscopically in order to make a diagnosis and ensure tumour excision is complete
Isolated limb infusion	A technique that may be used to deliver anticancer drugs directly to an arm or leg, and allows a patient to receive a high dose of drugs in the area where cancer has recurred
Lesion	An area of abnormal tissue
Local recurrence	Local persistence of a primary tumour due to incomplete excision; melanoma appearing at the site of previous excision of a primary tumour
Lymphadenopathy	Disease or swelling of the lymph nodes
Lymphoedema	A condition in which excess fluid collects in tissue and causes swelling. It may occur in the arm or leg after lymph vessels or lymph nodes in the underarm or groin are removed or treated with radiation
Magnetic resonance imaging (MRI)	A non-invasive method of imaging, which allows the form and metabolism of tissues and organs to be visualised (also known as nuclear magnetic resonance)
Malignant	Cancerous. Malignant tumours can invade and destroy nearby tissue and spread to other parts of the body
Medical oncologist	A doctor who treats cancer patients through the use of chemotherapy, and, for some tumours, immunotherapy
Medical oncology	The specialist treatment of cancer patients through the use of chemotherapy and, for some tumours, immunotherapy
Melanoma	A form of skin cancer that arises in melanocytes, the cells that produce pigment
Melanoma in situ	Melanoma confined to the most superficial layer of the skin; by definition it has no ability to metastasise
Melanoma specialist	A physician trained and competent in melanoma management
Metastases	Cancerous tumours in any part of the body that have spread from the original (primary) origin. Also known as ‘secondaries’
Metastatic disease	A disease that has spread from the organ or tissue of origin to another part of the body
Morbidity	The state of being diseased

Mortality	Either (a) the condition of being subject to death or (b) the death rate, which reflects the number of deaths per unit of population in any specific region, age group, disease or other classification, usually expressed as deaths per 1000, 10,000 or 100,000
Multidisciplinary meeting (MDM)	A deliberate, regular, face-to-face meeting (which may be held through videoconference) to facilitate prospective multidisciplinary discussion of options for patients' treatment and care by a range of health professionals who are experts in different specialties. 'Prospective' treatment and care planning makes recommendations in real time, with an initial focus on the patient's primary treatment. Multidisciplinary meetings entail a holistic approach to the treatment and care of patients
Multidisciplinary team (MDT)	A group of specialists in a given disease area. The MDT meets regularly to plan aspects of patient treatment. Individual patient cases might be discussed at an MDM, to best plan approach to treatments
National Health Index (NHI) number	A unique identifier for New Zealand health care users
Ocular melanoma	Eye melanoma
Oncology	The study of the biological, physical and chemical features of cancers, and of the causes and treatment of cancers
Palliative	Anything that serves to alleviate symptoms due to an underlying cancer but is not expected to cure it
Palliative care	Active, holistic care of patients with advanced, progressive illness that may no longer be curable. The aim is to achieve the best quality of life for patients and their families/whānau. Many aspects of palliative care are also applicable in earlier stages of the cancer journey in association with other treatments
Pathologist	A doctor who examines cells and identifies them. The pathologist can tell where a cell comes from in the body and whether it is normal or a cancer cell. If it is a cancer cell, the pathologist can often tell what type of body cell the cancer developed from. In a hospital practically all the diagnostic tests performed with material removed from the body are evaluated or performed by a pathologist
Pathology	A branch of medicine concerned with disease; especially its structure and its functional effects on the body
Patient pathway	The individual and personal experience of a person with cancer throughout the course of their illness; the patient journey
Positron emission tomography (PET)	A highly specialised imaging technique using a radioactive tracer to produce a computerised image of body tissues to find any abnormalities. PET scans are sometimes used to help diagnose cancer and investigate a tumour's response to treatment

Positron emission tomography and computed tomography (PET-CT)	An advanced imaging technique combining an injected material (18 Fluorine) which is taken up by cancer cells and a CT scan
Primary care	Primary-level health services provided by a range of health workers, including GPs and nurses
Prognosis	A prediction of the likely outcome or course of disease; the chance of recovery or recurrence
Psychological support	Professional support that helps people with a wide range of psychological problems, such as anxiety and depression, and provides emotional assistance during times of distress
Radiation oncologist	A person who is registered as a medical practitioner by the relevant medical board, is a fellow of the Royal Australian and New Zealand College of Radiologists or equivalent and is licensed to prescribe radiation therapy
Radiologist	A doctor who specialises in creating and interpreting pictures of areas inside the body using X-rays and other specialised imaging techniques. An interventional radiologist specialises in the use of imaging techniques for treatment; for example catheter insertion for abscess drainage
Radiology	The use of radiation (such as X-rays, ultrasound and magnetic resonance) to create images of the body for diagnosis
Radiotherapy (radiation treatment)	The use of ionising radiation, usually X-rays or gamma rays, to kill cancer cells and treat tumours
Randomised controlled trial	A study in which people are allocated by chance alone to receive one of several interventions, one of which is the standard of comparison
Recurrence	The return, reappearance or metastasis of cancer (of the same histology) after a disease-free period
Referred urgently (used in FCT indicators)	Describes urgent referral of a patient to a specialist because he or she presents with clinical features indicating high suspicion of cancer
Resection	Removal of tissue from the body by surgery
Sentinel node biopsy (SNB)	A surgical procedure to determine whether certain types of cancer have spread to nearby lymph nodes
Stage	The extent of a cancer, especially whether the disease has spread from the original site to other parts of the body
Staging	Usually refers to the TNM system for grading tumours by the AJCC
Supportive care	Supportive care helps a patient and their family/whānau to cope with their condition and treatment – from pre-diagnosis through the process of diagnosis and treatment to cure, continuing illness or death, and into bereavement. It helps the patient to maximise the benefits of treatment and to live as well as possible with the effects of their disease

Surgical oncologist	A vocationally registered doctor who specialises in using surgery to treat cancer
Synoptic report	A standardised proforma for the reporting of cancer
Systemic therapy	Treatment using substances that travel through the bloodstream, reaching and affecting cells all over the body
Tertiary	Third level. Relating to medical treatment provided at a specialist institution
Tumour, node, metastasis (TNM)	A staging system that describes the extent of cancer
Ultrasound	A non-invasive technique using ultrasound waves (high-frequency vibrations beyond the range of audible sound) to form an image
Unresectable	Not able to be removed by surgery
Whānau	Māori term for a person's immediate family or extended family group. In the modern context, sometimes used to include people without kinship ties
Whānau Ora	An inclusive interagency approach to providing health and social services to build the capacity of New Zealand families. It empowers family/whānau as a whole, rather than focusing separately on individual family members
X-ray	A photographic or digital image of the internal organs or bones produced by the use of ionising radiation

Appendix 3:
The Melanoma Patient Pathway



Appendix 4:
Proposed Reporting Proforma for Primary Cutaneous Malignant Melanoma

Surname	.....	Given names	.....
Date of birth	.....	NHI	.....
Sex	.....	Hospital/practice	.....
Date of collection	.....	Date of receipt	.....
Date of reporting	.....	Report no	.....
Pathologist	.....	Surgeon	.....

Clinical data

* Clinical site .....

* Specimen type .....

Excisional biopsy ☐ Incisional (diagnostic) biopsy ☐ Punch biopsy ☐
Shave ☐ Curettings ☐

Any relevant clinical information (eg, evolution of lesion over time or history of trauma)

.....

Clinical photograph provided No ☐ Yes ☐

Macroscopic description

Size of specimen Length .....mm Width .....mm Depth ..... mm

* Maximum diameter of lesion .....mm

Maximum height of lesion .....mm

Atypical features No ☐ Yes ☐ Uncertain ☐

Description of lesion .....

Histological data .....

Microscopic description (if appropriate) .....

Histopathological subtype

Lentigo maligna ☐ Superficial spreading ☐ Nodular ☐
Acral lentiginous ☐ Desmoplastic ☐
Not otherwise classified ☐

* Invasion No (ie, in-situ melanoma) ☐ Yes ☐

If invasion is identified

** Breslow thickness	0..... mm							
** Ulceration	No	☐		Yes	☐			
** Mitotic index	.....mm^2							
* Lymphovascular invasion	No	☐		Yes	☐			
** Microsatellite/intransit metastasis	No	☐		Yes	☐			
* Neurotropic/perineural invasion	No	☐		Yes	☐			
Growth phase	Radial	☐		Vertical	☐			
* Tumour infiltrating lymphocytes	Absent	☐		Non-brisk	☐	Brisk	☐	
	Focal	☐		Diffuse	☐			
* Regression	No	☐		Yes	☐			
Clark level	1 ☐	2 ☐		3 ☐	4 ☐	5 ☐		
Pre-existing naevus	No	☐		Yes	☐			
Molecular/cytogenetic tests	No	☐		Yes	☐	Result	☐	

** Margins

In-situ component

Peripheral	Involved	☐	Clear but <1 mm	☐
	Clear ≥1 mm	☐	.....mm (to nearest 1 mm)	

Invasive component

Peripheral	Involved	☐	Clear but <1 mm	☐
	Clear ≥1 mm	☐	.....mm (to nearest 1 mm)	
Deep	Involved	☐	Clear but <1 mm	☐
	Clear ≥1 mm	☐	.....mm (to nearest 1 mm)	

** TNM pathological (p) stage	(AJCC) T			
* SNOMED code	.....			
** NZ Cancer Register	No	☐	Yes	☐
Comments	.....			
Diagnosis	.....			

Pathologist..... Date .....

* = Further prognostic variables.
** = Mandatory fields for AJCC staging.

Appendix 5:
Proposed Reporting Proforma for Sentinel Node Biopsy

Clinical data

Site: Axillary ☐ Inguinal ☐ Cervical ☐ Other ☐

Side: Right ☐ Left ☐

Macroscopic description

Three-dimensional measurement: .....

Macroscopic abnormality: No ☐ Yes ☐

Dye seen in tissue: No ☐ Yes ☐

Histological data

Number of sentinel nodes identified: .....

Number of nodes involved: .....

For each positive node:

Location of deposit(s)

Subcapsular No ☐ Yes ☐

Parenchymal No ☐ Yes ☐

Extracapsular invasion No ☐ Yes ☐

Maximum size of deposit <0.1 mm ☐ 0.1–1.0 mm ☐ >1.0 mm ☐

Size of metastasis ..... mm

Appendix 6:
Proposed Reporting Proforma for Completion Lymphadenectomy

Clinical data

Clinical site:

Axillary ☐ Inguinal ☐ Cervical levels 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ Other ☐

Localisation: Right ☐ Left ☐

Histological data

Number of nodes identified: .....

Number of nodes involved: .....

Highest/most apical node involved No ☐ Yes ☐ Not identified clinically ☐

Extracapsular invasion No ☐ Yes ☐

Size of largest nodal deposit .....

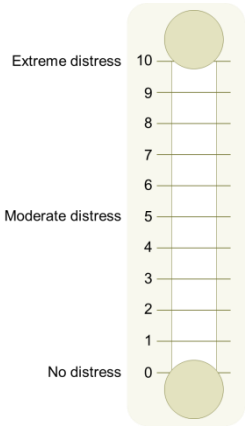
Margin of specimen clear No ☐ Yes ☐

Summary (AJCC staging)

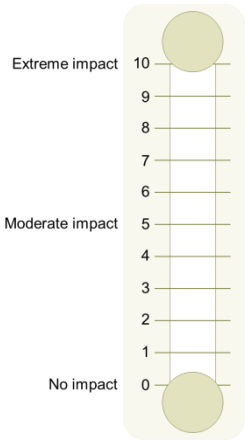
Appendix 7:
Cancer-related Distress Self-assessment Tool

Attach Bradma	**Cancer-related distress self-assessment**	Date:

Please circle the number (0–10) that best describes how much distress (mamae) you have been experiencing in **the past week** including today



Please circle the number (0–10) that best describes how much impact this distress (mamae) has had on your life



Please indicate if any of the following has been a problem for you in the past week including today. Be sure to check Yes or No for each.

Yes	No	**Spiritual (wairua) concerns**
		Practical problems
☐	☐	Childcare
☐	☐	Housing
☐	☐	Financial
☐	☐	Transportation
☐	☐	Work / school
☐	☐	Cultural obligations
☐	☐	Hospital processes
		Family (whānau) problems
☐	☐	Dealing with children
☐	☐	Dealing with partner
☐	☐	Other family members
☐	☐	Family/whānau dealing with the situation
		Emotional (hinengaro) problems
☐	☐	Depression
☐	☐	Fears
☐	☐	Anxiety
☐	☐	Sadness
☐	☐	Worry
☐	☐	Loss of interest in usual activities

Yes	No	**Physical (tinana) problems**
☐	☐	Appearance
☐	☐	Bathing / dressing
☐	☐	Breathing
☐	☐	Changes in urination
☐	☐	Constipation
☐	☐	Diarrhoea
☐	☐	Eating
☐	☐	Fatigue
☐	☐	Feeling swollen
☐	☐	Fevers
☐	☐	Getting around
☐	☐	Indigestion
☐	☐	Memory / concentration
☐	☐	Mouth sores
☐	☐	Nausea
☐	☐	Nose cry / congested
☐	☐	Pain
☐	☐	Sexual
☐	☐	Skin dry / itchy
☐	☐	Sleep
☐	☐	Tingling in hands / feet

Other problems

.....
.....
.....

Appendix 8: References

Development of the melanoma standards was informed by key national and international documents. Those documents that most directly influenced the development of the standards are listed below.

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