The organisation of melanoma services in NSW

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Executive summary

This report outlines current service arrangements for the detection, diagnosis and management of melanoma in NSW. It encompasses both specialist services for melanoma and services provided by other health-care professionals who encounter patients with concerns about skin lesions, with suspicious lesions, and with diagnosed melanoma in all stages of the disease.

Many different types of practitioners are involved in the detection, diagnosis and management of melanomas. However, the management of melanoma represents a small proportion of the clinical workload of most practitioners. These factors pose major challenges for the education of practitioners and the implementation of guideline recommendations and standards of care.

General practice including community based private skin cancer clinics

Little information is available on general practitioners' activities with regard to the detection of melanoma, excision of suspicious lesions, referral of tissue to histopathologists, referral of patients to dermatologists, surgeons and others, and follow-up. However, it is clear that general practitioners (GPs) are extensively involved in the detection of melanoma and many aspects of the management of patients with melanoma. Although patients commonly present for 'mole checks' and many GPs undertake local excisions of lesions, most GPs manage few patients with diagnosed melanomas. However, it is also likely that a large proportion of incident melanomas are detected or at least suspected by GPs, who subsequently refer patients to dermatologists or surgeons for excision, diagnosis and management.

An understanding of patterns of care for melanoma patients in general practice would be a useful starting point for improving GP education on melanoma management, and for enhancing communication between GPs and specialists and between GPs and patients.

Given the importance of early detection of melanoma, community-based private skin cancer clinics run by GPs have the potential to make a major contribution to melanoma outcomes. However, anecdote suggests that standards of practice in the skin cancer clinics are variable. No accreditation requirements exist for the clinics, and no training or credentialling requirements exist for individual practitioners who work in the clinics. The inclusion of skin cancer clinics in vertically-integrated 'corporate' practices could, on the one hand, improve community access to skin cancer detection and management services, and on the other, promote excessive service delivery or reduce the opportunity for a patient to visit a specialist.

Quality of care in the detection and initial management of melanoma by skin cancer clinics could be assured if the clinics were to adhere to appropriate standards of practice. These standards should ensure that:

- clinic doctors have adequate training and continuing education in the detection and initial management of melanoma,
- histopathologists who examine tissue excised in the clinics have expertise in the diagnosis and grading of melanoma, and

- clinic doctors have referral networks to ensure that patients receive appropriate expert management.

Dermatology

While dermatologists unquestionably make a major contribution to high-quality care at many points in the spectrum of melanoma management, their roles overlap with those of GPs, skin cancer clinic doctors and surgeons. Indeed anecdote suggests that many skin cancer clinic patients perceive that skin cancer clinic doctors are dermatologists. Dermatologists are likely to be able to make their greatest contribution in the following areas:

- Assessing lesions about which GPs are uncertain.
- Excising suspicious lesions, and ensuring that excised tissue is examined by a histopathologist with appropriate expertise.
- Referring patients with newly-diagnosed invasive and/or advanced melanoma to specialist melanoma centres.
- Providing education to GPs and patients about vigilance and follow-up for thin (i.e. non-invasive) lesions that have been successfully excised.
- Providing follow-up for patients with invasive and/or advanced melanoma and sharing care with GPs and oncologists in specialist melanoma centres.

Surgery

The management of melanoma is primarily surgical. Workforce data suggest that there are approximately 500 general surgeons and plastic surgeons in NSW. Any of these surgeons could be involved in excising suspicious lesions and, in some cases, managing invasive and advanced melanomas. With the exception of surgeons working in specialist melanoma centres, most surgeons are likely to manage relatively small numbers of melanoma patients, so individually their experience of melanoma management is likely to be limited. Like GPs, skin clinic doctors and dermatologists, surgeons need to be kept abreast of the latest recommendations for excision techniques, including excision margins, the importance of expert histopathology, and approaches to the diagnosis and management of lymph node involvement.

Pathology

No data currently exist on the quality of melanoma histopathology in NSW, but anecdotes indicate that it is highly variable. High-quality melanoma management depends crucially on high-quality histopathology. Although groups of histopathologists with expertise in melanoma pathology have proposed standards for reporting, no State or national standards have been promulgated. The following steps could lead to improvements in the quality and consistency of melanoma histopathology in NSW:

- Formal endorsement and promotion of standards for reporting on the histopathology of melanoma. It would be desirable for these standards to be accepted nationally.
- Encouragement of pathologists who are not experts in melanoma and do not encounter many suspicious lesions, to refer excision and biopsy material to histopathologists recognised for their expertise.

- Encouragement of large pathology practices to engage at least one histopathologist with expertise in melanoma histopathology.
- Provide information to GPs, dermatologists and surgeons on the elements of good histopathology reporting on melanoma, and on the interpretation of histopathology reports.
- Provide information to GPs, dermatologists and surgeons on how to find histopathologists who are skilled in the diagnosis of suspicious skin lesions.

Medical oncology

Decisions about chemotherapy and/or immunotherapy for patients with metastatic melanoma are made by medical oncologists with expertise in melanoma management. In NSW, medical oncologists with substantial experience in melanoma management are usually available only in specialist melanoma centres. It may be possible for patients with metastatic disease who live far from specialist centres to receive part of their treatment in hospitals closer to home, utilising a local cancer service. This model of 'shared care' is enhanced by effective communication between medical oncologists with melanoma expertise and local medical oncologists or GPs.

Radiation oncology

Radiation therapy has a relatively small but important part in the management of melanoma patients with lymph node involvement and isolated metastases. The decision to use radiotherapy is usually made by a multi-disciplinary team that includes a radiation oncologist. The main problem for service delivery is that a course of radiation therapy takes 6-7 weeks. Consequently, patients mostly seek to be treated in radiation oncology units relatively close to their homes. As for medical oncology, effective communication between the radiation oncologist affiliated with a major melanoma centre and the radiation oncologist in the local unit is critical. However, many patients who live outside Sydney and Newcastle do not have ready access to linear accelerators, as few regional centres in NSW have radiotherapy facilities.

Oncology nursing

Although oncology nursing expertise is available in many NSW hospitals, oncology nurses with expertise in melanoma are mostly to be found in hospitals affiliated with the major melanoma centres (Royal Prince Alfred Hospital, Westmead Hospital, and the Newcastle Mater Hospital). Their responsibilities range from pre- and post-operative care to ensuring that, in all phases, care is coordinated and patient-centred.

Psychosocial aspects of melanoma management

Little information is available on psychosocial services for melanoma patients in NSW. In the major melanoma centres, most of the psychosocial services for patients and their families are provided by oncology nurses and/or members of palliative care teams (described below). GPs also have a substantial role in the provision of psychosocial support for melanoma patients. Psychosocial services for melanoma patients are less developed than those for some other cancers, notably breast cancer. National Health and Medical Research Council guidelines for

the psychological management of breast cancer patients provide a framework for breast cancer services in NSW. The development of psycho-oncology guidelines for melanoma patients in NSW would require a compilation of recommendations relevant to melanoma from guidelines for other cancers, a clear understanding of the psychological needs of melanoma patients, and a patterns-of-care study of the roles and potential roles of the various health professionals who provide care for melanoma patients.

Palliative care

Contemporary palliative care practice in NSW emphasises the value of early involvement of palliative care specialists in the management of all melanoma patients (and indeed all cancer patients) who have an adverse prognosis. This contrasts with the traditional approach, in which patients are referred to palliative care specialists only for the management of the terminal stages of illness. The new approach represents an important shift in thinking about palliative care, both by the many health professionals who are involved in the management of melanoma patients and by patients themselves. However, the widespread lack of palliative care specialists beyond the west of Sydney is a limiting factor.

Like oncologists and other health professionals, there are no palliative care specialists in NSW who exclusively treat melanoma patients. It is generally recognised that much palliative care in NSW – indeed, probably most of the palliative care that is delivered – is provided by non-specialists, including oncologists, oncology nurses, community nurses and GPs. No data are available on the involvement of non-specialists in palliative care. Nor are data available on the extent to which non-specialist practitioners are trained to provide palliative care, or have access to specialists for advice.

Wide variations in the ratio of oncology nurses to cancer cases across NSW suggest substantial variations and deficiencies in access to palliative care in some areas. There is also a particular deficiency in the number of palliative care specialists and oncology nurses funded to carry out home visits for patients in the last stages of their disease.

Multidisciplinary specialist services

Most melanoma patients with complex disease are managed in the specialist centres in metropolitan Sydney (the Sydney Melanoma Unit (SMU) and affiliated services such as Westmead Hospital, the Mater Hospital and the Sydney Adventist Hospital), Newcastle Melanoma Unit (NMU) and in the Northern Rivers area. Patient care in these centres places much emphasis on integrated multi-disciplinary teams that include melanoma surgeons, medical and radiation oncologists with expertise in melanoma management, nuclear medicine physicians, histopathologists with expertise in melanoma pathology, oncology nurses with expertise in melanoma, health professionals with expertise in melanoma psycho-oncology, and palliative care physicians and nurses. The SMU and the NMU represent the nuclei of melanoma services in NSW. They provide outstanding clinical services, provide advice and support for clinicians, produce research on an international scale, and contribute substantially to education and training. They represent foci for the leadership of melanoma services throughout NSW, and indeed more broadly throughout Australia.

A large number of public-sector hospitals in NSW either have oncologists on staff or provide limited oncology services with advice from visiting oncologists. In collaboration with experts from the melanoma centres, these hospitals can provide at least some services for melanoma patients on a local basis, reducing (but mostly not obviating) the need for patients to travel to major centres for all aspects of their treatment. Local services are particularly preferred when a regimen requires repeated treatment sessions, as is the case for radiotherapy.

Clinical trials

The Cancer Institute NSW recommends a target of 10 percent of cancer patients to be enrolled in clinical trials. The proportion of SMU patients involved in trials varies according to the stage of their disease. About 15-20 percent of patients with Stage 3 or Stage 4 melanoma are enrolled in trials, but the overall participation rate across all stages is estimated to be about eight percent. Clinical trials of melanoma treatments are conducted in the NMU as well as the SMU, and patients are enrolled from all hospitals in which SMU and NMU specialists work. Other trials involve the ANZAC Melanoma Trials Group, which is linked with the Trans-Tasman Radiation Oncology Group (TROG).

Given the value of clinical trials in providing information about the efficacy and effectiveness of treatments for melanoma and in improving outcomes for participating patients, it is important that melanoma services throughout NSW are encouraged to enrol as many patients as possible in trials. Any development of melanoma services should make provision for the promotion of participation in clinical trials among patients and clinicians, and for the necessary infrastructure and resources. The establishment of national and State clinical trials registers is likely to increase the expectation of involvement in trials.

Genetic services

Genetic testing is not available as part of routine clinical services in NSW. However, if a melanoma is strongly suspected of having a genetic component, the patient may be referred to one of the State's nine hereditary cancer clinics. He or she will be invited to participate in the Australian Melanoma Family Study, which conducts genetic testing to identify potentially causal gene mutations. All patients who agree to participate are invited to nominate other family members who may also wish to participate in the genetic testing that is conducted within the research framework. The testing generates aggregate family information on potentially causal gene mutations within a family. The patient and the family are referred back to a hereditary cancer clinic if they want individual genetic testing to identify whether they are a carrier of the identified family gene mutation. Outside the research framework, genetic testing is available privately via US-based laboratories.

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1 Introduction

1.1 Objective

This is one of a series of reports on the occurrence and management of melanoma in NSW, commissioned by the Sydney Melanoma Foundation to assist in the development of a Statewide melanoma network.

This report describes:
- components of the health-care system that contribute to the detection and management of melanoma in NSW;
- the interactions of these components with each other; and
- the services that they provide for people affected by melanoma.

A clear understanding of the structure of health-care arrangements can help to identify opportunities to strengthen the delivery and coordination of services. It has been shown that improvements in cancer control can follow from better organisation and linkage of services (Ensuring Quality in Cancer Care, 1999; Goel et al, 1997).

1.2 Melanoma care: overview

In other reports in this series, we have described aspects of the occurrence and nature of melanoma. Salient points for the organisation and delivery of health services are as follows.

- Melanoma is the fourth most common cancer in NSW, after colorectal cancer and cancers of the breast and prostate. About 3,300 new cases are registered each year. The incidence varies across NSW, with the rate on the North Coast being the highest.

- Melanoma affects younger people than most cancers.

- Most melanomas occur on the skin. Suspicious lesions often attract the attention of affected individuals and their health-care attendants, and are therefore potentially amenable to early detection. A large proportion (about 85 percent) of melanomas are superficial, have not spread or metastasised at the time of detection, and can be definitively treated by excision with an adequate margin.

- The occurrence of a melanoma is a risk factor for the occurrence of a subsequent primary melanoma, so affected individuals must be educated to be vigilant and avoid risk factors.

- The 15 percent of melanomas that are invasive, and/or have spread at the time of diagnosis, are associated with a relatively poor prognosis. Management is mainly surgical. Metastatic melanoma is relatively unresponsive to chemotherapy or radiotherapy, although both of these modalities may contribute to the prolongation of survival.

These points have several implications for the health-care system.

- Pigmented skin lesions are extremely common. Because of community awareness of the risk of melanoma, the demand for 'mole checks' is high. Large numbers of patients present for 'mole checks', with or without lesions that they themselves have identified as suspicious. The 3,300 new melanomas diagnosed in NSW each year represent only a small fraction of the diagnostic workload, because the great majority of lesions which cause concern turn out to be benign. Consequently, a large number of clinicians are involved in the detection and diagnosis of melanomas.

- In the clinic setting, the onus is on individual clinicians to identify lesions that have a high risk of malignancy (i.e. to have a high true-positive rate and low false-negative rate), to manage them appropriately, and to avoid a large number of unnecessary excisions of benign lesions (i.e. to have a low false-positive rate). In the histopathology laboratory, the challenge is not only to make the correct diagnosis, but also to report accurately and comprehensively on histological details that determine treatment decisions and prognosis. Given the large numbers of clinicians and pathologists involved, the challenge for the health-care system is to ensure that practitioners have appropriate skills and knowledge and follow contemporary recommendations for detection, diagnosis, referral and follow-up.

- A high level of expertise is required for the assessment and management of patients with invasive melanoma, lymph node involvement and/or metastatic disease. Referral of these patients to specialist centres, or to practitioners affiliated with specialist centres, is strongly recommended.

- Specialist melanoma management is a multi-disciplinary process.

- Secondary prevention, including the early detection of second primary tumours, is an important part of the overall management of melanoma. Services must be available to ensure that patients who have had a melanoma receive appropriate education and follow-up.

- In all but the most highly-specialised units, melanoma patients represent a small proportion of the workload of the health professionals involved. Further, most melanomas are detected by clinicians who encounter relatively few patients with melanoma. This point must be taken into account in any plans to provide clinician education or to disseminate and implement clinical guidelines.

1.3 Pathway for patients with melanoma

Most melanoma patients present in good health with a skin lesion. A small proportion of melanoma patients present with signs of spread (e.g. a lump in the neck, axilla or groin) or with any of the protean manifestations of metastatic disease.

When a patient presents with a skin lesion that the doctor suspects could be melanoma, the doctor has three possible courses of action:

- Monitor the lesion for changes over a brief period of time.
- Excise or biopsy the lesion and send it to a pathologist for histological examination.
- Refer the patient for specialist opinion, usually to a dermatologist or surgeon, who may decide to biopsy and/or excise the lesion.

Once a histological diagnosis of melanoma has been made, treatment options depend to a large extent on the grade and stage of the melanoma. Important features are tumour thickness, the mitotic rate of the tumour, spread to local or regional lymph nodes and manifestations of metastatic disease. These features influence decisions about treatment.

Typically, a patient with a thin melanoma (Breslow thickness <1 mm) and adequate excision margins will not require any further treatment, other than education to be vigilant for new or recurrent lesions and follow-up. However, for a patient with a thin melanoma and inadequate surgical margins around the primary tumour, a wider excision around the primary tumour may be recommended.

Patients with thin lesions have access to follow-up through general practitioners (GPs), doctors working in skin cancer clinics, surgeons or dermatologists. The same clinicians may also undertake wider excision if indicated. However, our impression following interviews with a range of practitioners who treat melanoma is that GPs and dermatologists are less likely than surgeons and skin cancer clinic doctors to undertake wider excision.

Patients who have thicker lesions (Breslow thickness ≥1mm) or more complicated lesions with poor prognostic factors, including signs of metastatic disease, may receive the following treatments depending on the extent to which their disease has progressed.

- Wider excision surgery around the margins of the primary melanoma.
- Sentinel node biopsy to establish the involvement of the lymph nodes.
- Nursing care including patient education, coordination of care, wound management and support.
- Imaging and possibly biopsy to detect and assess metastatic disease.
- Surgery, radiotherapy, chemotherapy or immunotherapy for metastatic disease.
- Regional limb perfusion to treat regional metastases, if appropriate.
- Psychosocial counselling.
- Palliative care.

Wider excision surgery for patients with thicker melanomas is most likely to be undertaken by surgeons on an inpatient basis. In a substantial proportion of cases in NSW, such procedures are performed by surgeons in specialist melanoma units.

Sentinel node biopsy is performed by appropriately-trained surgeons on an inpatient basis, following local lymphatic system mapping by nuclear medicine physicians. Consequently,

sentinel node biopsy tends to be performed in specialist melanoma units with access to a nuclear medicine service.

Palliative care for melanoma patients in NSW is available through specialist providers, generalist providers and support services. Specialist providers include specialist palliative care physicians, specialist palliative care nurses and allied health professionals. Non-specialist palliative care providers include medical, nursing and allied health professionals (e.g. medical, radiation and surgical oncologists, GPs and community nurses) who are not identified as palliative care specialists but have a professional involvement with melanoma patients requiring palliative care. Support services are delivered by professionals who can assist in the processes of daily living, enhancing quality of life, and/or providing emotional and spiritual support (NSW Health, 2001).

Palliative care is provided to melanoma patients in a range of settings including their homes, acute hospital facilities, inpatient palliative care facilities, outpatient clinics at hospitals, and residential aged care facilities. Melanoma patients represent a small fraction of the patient load of palliative care providers.

Psychosocial counselling is typically carried out by nurses and psychologists in a range of settings including clinics, hospitals and patients' homes.

The roles of the various health professions at various stages in the spectrum of melanoma care are summarised in Box 1.1.

Box 1.1: Roles of various health professionals in the spectrum of melanoma care.

Detection
GP, dermatologist, community health/practice nurse

Diagnosis and initial management
GP, dermatologist, surgeon, pathologist, nurse

Subsequent management (including management of recurrence or spread)
GP, dermatologist, surgeon, pathologist, medical oncologist, radiation oncologist, nurse, nuclear medicine physician, palliative care specialist, allied health professionals, community health/practice nurse

Follow up and secondary prevention
GP, dermatologist, surgeon, medical oncologist, community health/practice nurse

1.4 Implications for service development

From the general description of melanoma services in sections 1.2 and 1.3, it is clear that:

- Most patients have a wide range of choices as to the type of service and the type of doctor involved in the detection and early management of lesions that could be melanomas. However, most patients have little information on which to base their choices.

- Many different types of practitioners are involved in the detection, diagnosis and early management of melanomas. The management of melanomas is a small proportion of the clinical workload of most practitioners who care for melanoma patients. This raises difficulties for the delivery of professional education programs and the implementation of guideline recommendations and standards of care.
- It is likely that less than 50% of invasive and/or advanced melanomas are managed in melanoma specialist centres (J Thompson, personal communication, 2005). Service development should aim to ensure that all patients with invasive and/or advanced melanoma are treated in centres with appropriately trained staff and have access to multi-disciplinary expertise.

2 General practice

2.1 General practice and skin cancer clinics

GPs contribute to melanoma management in two types of settings: conventional general practice settings (private practice or institutional practice in an organisation such as an Aboriginal Medical Service); and skin cancer clinics. In both types of settings, GPs are often the first health professionals to see patients with suspicious skin lesions. Patients either present to a GP with concern about a mole, or GPs themselves find a suspicious lesion in the course of a 'mole check' or other physical examination. Skin cancer clinics are described in section 2.3 of this report. GPs working in conventional general practice may be involved in many aspects of melanoma care, from detection to palliation, as shown in Box 1.1.

Between 2002 and 2004, melanoma was the fifth most frequent type of cancer among patients presenting to GPs throughout Australia, following basal and squamous cell carcinoma, prostate cancer and breast cancer. GPs included those working in conventional general practice settings or in skin cancer clinics. Melanoma care was estimated to represent 0.1% of GP patient encounters (AIHW, 2004). However, this figure may not include investigation of suspicious lesions that prove to be benign.

The Cancer Institute NSW has recently funded three rural Divisions of General Practice to investigate local services for melanoma, including the engagement of GPs and nurse practitioners, rates of screening, and community awareness about melanoma. The Institute has also funded a comprehensive patterns-of-care study that will provide considerable insight into the management of all new cases of melanoma in NSW over a one year period.

2.2 Detection and management of melanoma in conventional general practice settings

2.2.1 Training and quality assurance

There is no specific requirement for GPs to be trained in the detection, diagnosis and management of suspicious skin lesions, and great variations exist in GPs' levels of skill and knowledge in this regard. Many GPs voluntarily attend short courses to improve their skills and knowledge about skin conditions and to learn techniques such as dermoscopy, but these courses are not linked to any assessment of competence or credentialling. GPs attending short courses on any topic relevant to general practice are awarded continuing medical education (CME) points which contribute to the maintenance of their vocational registration and eligibility for continuing registration with the NSW Medical Board. However, no data are available on the extent to which GPs undertake education relevant to melanoma management.

Accreditation of general practices is voluntary. Accreditation is a potential mechanism for ensuring that GPs have systems in place to provide appropriate follow-up for patients with or at

high risk of melanoma. Thus, for example, current standards for the accreditation of general practices include the existence (but not the effectiveness) of recall and reminder systems. At present, the existence of such systems is not rigorously applied as a criterion for accreditation, but accrediting agencies could be encouraged to increase their emphasis on recall and reminder systems. A large proportion of general practices use computers for various aspects of patient care, communication and record-keeping. Computerised medical record systems, the most popular of which is Medical Director[R], can prompt GPs to check particular clinical items and flag patients who need to be recalled for review. GPs who wish to do so can thus set up their computers to prompt them to undertake skin checks and recall patients in whom regular skin assessment is indicated. The extent to which this is currently done in NSW general practices is unknown.

GPs who use computers in their practices have access via the internet to a wide range of authoritative information on the prevention, detection, diagnosis and management of melanoma. This includes National Health and Medical Research Council (NHMRC) guidelines on the management of cutaneous melanoma (NHMRC, 1999), which can be downloaded in full. However, anecdote suggests that many GPs are unaware of the existence of guidelines and do not know how to find them on the internet.

Burton et al (1998) found that GPs who had received training in the detection of melanoma were significantly better than untrained GPs at accurately diagnosing suspicious pigmented lesions as melanomas. Girgis and Sanson Fisher (1996) interviewed 97 randomly-selected GPs throughout Australia about skin cancer prevention, early detection and management. The GPs asserted that they were the most appropriate group to screen for and provide education about skin cancer. Factors that discouraged them from screening included lack of time, forgetting, lack of financial incentive and lack of familiarity with patients' screening history. The GPs were least confident about their ability to determine whether skin changes were malignant and their ability to diagnose a melanoma and a dysplastic nevus. The authors concluded that GPs need formal training in skin cancer prevention, detection and management.

Westerhoff, McCarthy and Menzies (2000) reported that GPs in NSW improved their clinical diagnosis of melanoma from 55 percent to 63 percent following training in skin surface microscopy.

2.2.2 Detection, diagnosis and management of melanoma by GPs

A recent survey of a sample of about 200 general practices by The Cancer Council NSW (Copper, 2005, unpublished) revealed that melanomas had been diagnosed in 69 percent of the practices in the preceding 12 months. However, the sample included some GPs from skin cancer clinics, and was largely confined to general practices that had responded to an offer for resources on melanoma from The Cancer Council NSW.

Studies carried out in Queensland have reported a high rate of skin cancer screening by GPs. However, one study found that most skin excisions for benign pigmented lesions were

performed to relieve the concerns of worried patients rather than because of the GPs' concerns about the likelihood of malignancy (Del Mar and Green, 1995).

A recent study in Perth, Western Australia, found that one third of a sample of 468 GPs excised no pigmented lesions within a 14-month index period, and the remaining two-thirds excised a total of 4,741 pigmented lesions within the same 14-month period. Those GPs who had excised at least one lesion excised an average of 15 lesions. Sixty-two of the lesions were diagnosed histopathologically as melanomas *in situ* and 98 as invasive melanomas. The number needed to treat (NNT) was 29 (or 21 if seborrhoeic keratoses were excluded). That is, 29 pigmented lesions were excised for every one that proved to be a melanoma. The NNT ranged from 83 in the youngest patients (aged 10-19 yr) to 11 in the oldest patients (>70 yr) (English, Del Mar and Burton, 2004). In the same study, the authors observed that the GPs surveyed were more reluctant to excise pigmented lesions in patients who were young, female, or from areas of low socioeconomic status. GPs who were recent graduates also were more reluctant to carry out excision procedures.

Lesions excised by GPs are usually sent to a local private pathology group for examination. The pathologist who is allocated to examine a lesion is unlikely to be an expert in the histopathology of melanoma. At present, there are no reporting requirements for pathologists with respect to melanoma, from either the Royal College of Pathologists of Australasia or any other authoritative body.

2.2.3 Referral patterns in conventional general practice settings

No data exist on GPs' referral patterns for patients with suspicious skin lesions or melanomas. An annual survey of a sample of 1,892 GPs from NSW between April 1998 and March 2003 indicated that, for all types of patient encounters, the most frequent specialists to whom GPs referred patients were surgeons, while dermatologists were the fourth most frequent. However, the published results of this survey do not give the reasons for referral (Britt, Miller, Knox et al, 2004), so they are not linked to the occurrence of melanomas.

Anecdote suggests that, with the exception of GPs in skin cancer clinics, some GPs prefer to send patients with suspicious lesions to dermatologists or surgeons for assessment and management. Those GPs who do excise suspicious lesions also tend to refer patients to surgeons when a histopathological diagnosis of melanoma is made.

Anecdote also suggests that some GPs, particularly in rural and remote areas, provide ongoing care for melanoma patients with advanced disease, usually with continuing advice from specialists. Almost all GPs refer patients with more advanced disease to specialist melanoma centres.

In areas with well-established, well-known specialist melanoma services (e.g. Sydney, Newcastle and Lismore), many GPs are likely to refer melanoma patients to these services, which have a strong surgical orientation.

2.2.4 Implications for service development relating to conventional general practice

GPs are extensively involved in the detection of melanoma and many aspects of the management of patients with melanoma. Those who regularly examine skin lesions, i.e. most GPs, should be encouraged to acquire equipment for and undergo training in dermoscopy.

Although patients commonly present for 'mole checks' and many GPs undertake local excisions of lesions, it is likely that most individual GPs manage few patients with diagnosed melanomas. However, it is also likely that a large proportion of incident melanomas are detected, or at least suspected, by GPs who subsequently refer patients to dermatologists or surgeons for excision, diagnosis and management. Because GPs have a major role in the follow-up of patients who have had a melanoma, it is important that specialists give GPs comprehensive advice on recommended follow-up routines.

Few data are available on GPs' activities with regard to the detection of melanoma, excision of suspicious lesions, referral of tissue to histopathologists, referral of patients to dermatologists, surgeons and others, and follow-up. An understanding of patterns of care for melanoma patients in general practice would be a useful starting point for improving GP education on melanoma management, and for enhancing communication between GPs and specialists and between GPs and patients.

2.3 Skin cancer clinics

2.3.1 Origins

The first community-based private skin cancer clinic in NSW was established in Sydney in the early 1990s. Skin cancer clinics have since proliferated, and have acquired a major role in the diagnosis and management of melanoma as well as other skin lesions. Initially, skin cancer clinics were independent private practices. Now the majority are operated by large organisations ('corporate' practices) which also run general practices in multiple sites, pathology services, and other medical and allied-health services.

2.3.2 Staff

Medical staff in skin cancer clinics are mostly GPs, although other medical practitioners with a variety of qualifications have also been employed. GPs who work in the clinics are mostly vocationally registered, as this enables Medicare claims to be maximised. Some of the GPs have postgraduate qualifications that are relevant to their work in the clinics (e.g. a qualification in dermatology at certificate or diploma level), but specific qualifications are not essential. A scan of skin cancer clinic websites indicated that most of the medical staff did not have formal qualifications in the management of skin cancer.

2.3.3 Services and referral pathways in skin cancer clinics

Skin cancer clinics provide a variety of services, ranging from screening for suspicious lesions and the provision of advice on skin cancer prevention to the management of melanomas and non-melanotic skin cancers.

Skin cancer clinics independently perform most of the procedures associated with the detection, diagnosis and initial management of suspicious lesions. Most clinics are equipped with dermatoscopes. Medical staff undertake biopsies and biopsy excisions, and may perform wide excisions for thin melanomas. Some medical staff perform minor plastic-surgery procedures, e.g. rotation flaps. Excised tissue is sent to private pathology groups for assessment. Anecdotes suggest that the quality of histopathology services vary, as does the standard of reporting. In 'corporate' practices, excised tissue is usually sent to the affiliated pathology service, regardless of its expertise in melanoma histopathology.

The majority of patients who attend skin cancer clinics are self-referring or are prompted to attend by friends and family. In a small proportion of cases, GPs recommend that patients go to a skin cancer clinic, and cross-referral is common within 'corporate' practices. Because the clinics are mostly staffed by GPs, patients do not need to be referred by another doctor. Patients are rarely referred to dermatologists by skin cancer clinic doctors.

Patients with more serious skin cancers, including thicker melanomas, are usually referred by skin cancer clinics doctors to surgeons or to tertiary referral centres such as the Sydney Melanoma Unit. Within a 'corporate' practice, they may be referred to a surgeon affiliated with the practice.

2.3.4 Number and distribution of skin cancer clinics in NSW

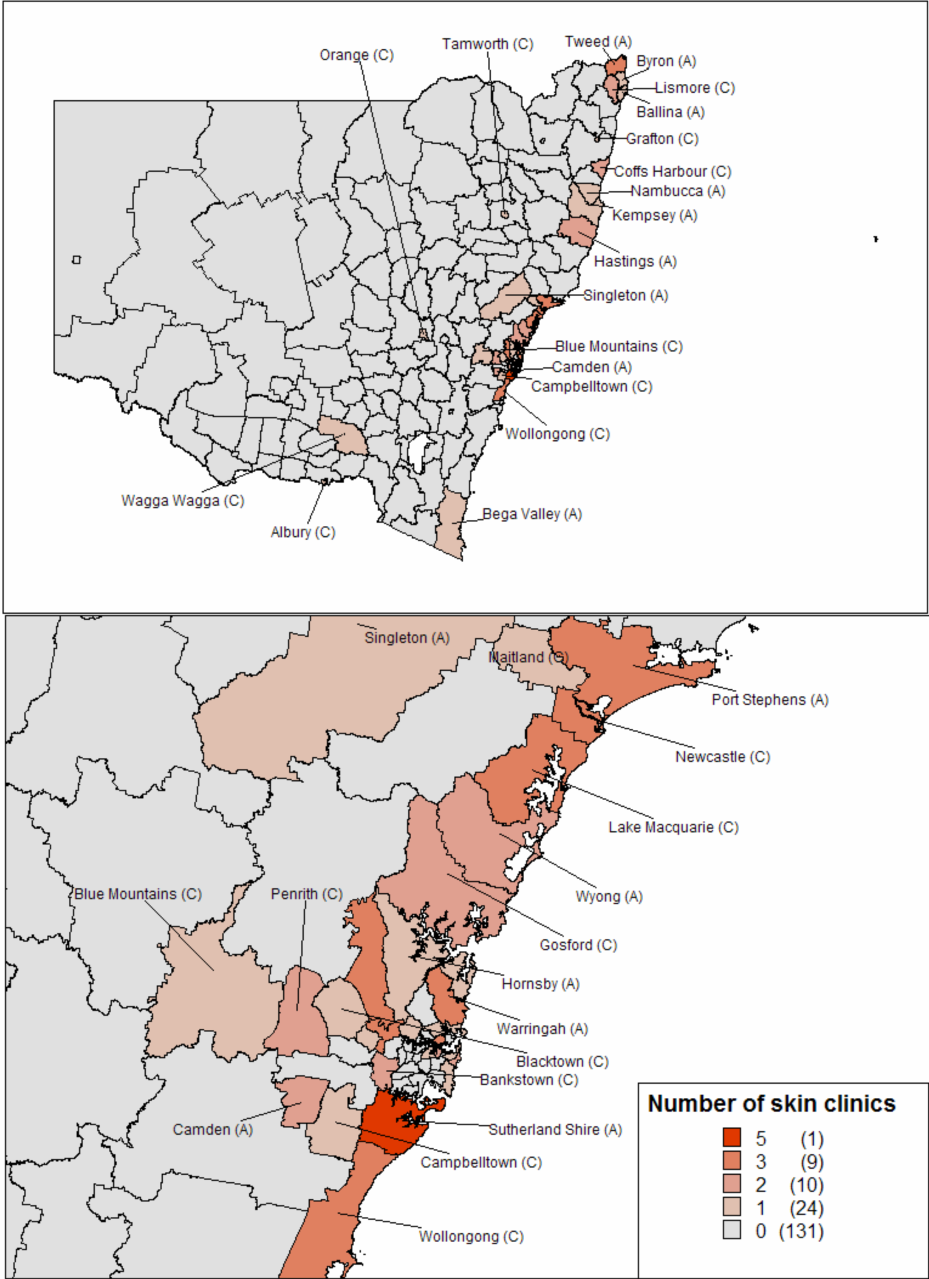
We assessed the distribution of community-based private skin cancer clinics by conducting a search of Telstra electronic White Pages (2005) and Yellow Pages (2005), using terms such as 'skin cancer clinic', 'skin cancer' and 'skin clinic'. We excluded melanoma and skin cancer clinics employing specialists as well as clinics that appeared to focus only on cosmetic therapies. We also excluded medical centres and medical practitioners that provided a range of services which included but were not confined to skin services. Our decision to exclude a clinic was based on the information contained in the telephone-book advertisement and, if necessary, confirmed by directly contacting the clinic. Our search strategy may have missed skin cancer clinics that did not have 'skin cancer' in their business names, as listed in the Telstra White Pages and Yellow Pages. Consequently our search is likely to under-estimate the number of skin cancer clinics in NSW.

All eligible skin cancer clinics were entered into an ACCESS database. Duplicate records were removed. The local government area (LGA) in which each clinic was situated was identified and used to create a map showing the distribution of the clinics throughout NSW (ABS, 1999).

In total, our search identified 76 skin cancer clinics in NSW. The darker the coloured shading in the map (Figure 3.1), the greater the density of skin cancer clinics. The areas with the greatest number of clinics were metropolitan Sydney and its surrounds and the north coast of NSW. Few skin cancer clinics existed in rural NSW (other than the north coast), with the exception of one clinic in each of the following four regional centres: Wagga Wagga, Orange, Tamworth and Albury. The Bega Valley, located on the south coast of NSW is the only locality south of Wollongong with a skin cancer clinic.

The distribution of skin cancer clinics mirrors the incidence of melanoma in NSW particularly in males. Areas with the highest incidence more likely to have skin cancer clinics.

Figure 2.1 Skin cancer clinics in NSW



2.3.5 Billing

Patients treated in skin cancer clinics may be billed privately and submit their own Medicare claims for reimbursement, or may sign a Medicare form for bulk billing by the clinic. The extent of bulk billing is not known. GPs employed in skin cancer clinics may only charge for Medical Benefits Schedule items, including procedure items, that apply to non-specialist medical practitioners.

2.3.6 Quality assurance and accreditation

Currently, skin cancer clinics are not required to undergo any formal accreditation or review process. Consequently, no evaluation of the quality of their services is available. We could not find published or unpublished research reports evaluating the quality of care.

GPs who work in the clinics are, of course, required to earn continuing medical education (CME) points to maintain their vocational registration and registration with the NSW Medical Board. However, the CME may be in fields unrelated to skin cancer. No data are available on the extent to which clinic doctors complete further education or seek continuing education in skin cancer detection and management. Anecdote suggests that the great majority of skin clinic doctors do not have specific training in the detection, diagnosis and management of skin lesions.

The quality of care in skin cancer clinics could be inferred by reviewing patients' complaints about their treatment to the NSW Healthcare Complaints Commission.

2.3.7 Implications for service development relating to skin cancer clinics

Given the importance of early detection of melanoma, the community-based private skin cancer clinics have the potential to make a major contribution to melanoma outcomes. However, the lack of accreditation requirements for the clinics and the lack of credentialling requirements for individual practitioners are likely to lead to variable standards of practice. The inclusion of skin cancer clinics in vertically-integrated 'corporate' practices could, on the one hand, improve community access to skin cancer detection and management services, and on the other, promote excessive service delivery.

It would be highly desirable to encourage skin cancer clinics to adhere to appropriate standards of practice. These standards should ensure that:

- clinic doctors have adequate training in the detection and initial management of melanoma, and
- clinic doctors who excise melanomas refer excised tissue to histopathologists with expertise in the diagnosis and grading of melanoma.

3 Dermatology

3.1 Overview

Dermatologists are specialist medical practitioners with expertise in the prevention, diagnosis and treatment of skin disease, including skin cancers (Australasian College of Dermatologists, 2004a). They represent 1.7 percent of all medical specialists in Australia (AIHW, 2004).

Six conditions account for 92 percent of dermatologists' practice time (AMWAC, 1998):

- solar damage (29 percent),
- skin malignancies (24 percent),
- acne (11 percent),
- dermatitis (10 percent),
- infections (nine percent), and
- psoriasis (nine percent).

Skin malignancies detected, diagnosed and treated by dermatologists include melanoma and non-melanotic skin cancers, such as basal cell carcinoma (BCC) and squamous cell carcinoma (SCC). Most of the 24 percent of dermatologists' time that is spent on skin malignancies is likely to be for the management of BCCs and SCCs, rather than melanoma.

Treatments utilised by dermatologists include drug therapy, laser therapy, cryotherapy, minor surgery and (by referral) selected radiotherapy procedures.

The roles of dermatologists with regard to melanoma are:

- Primary and secondary prevention.
- Detection and diagnosis.
- Initial management, including excision biopsy, which may be definitive for lesions that have favourable pathological features.
- Referral of patients with melanomas that have adverse pathological features and require wide excision and further treatment by surgical, medical or radiation oncologists.
- Counselling and follow-up of patients.

3.2 Dermatology workforce and training in dermatology

In 2003, there were 350 dermatologists across Australia, 7 of whom worked most of their hours as non-clinicians. The mean age of dermatologists in 2002 was 50 years, with females comprising one third of the workforce (AIHW, 2005). Currently 130 dermatologists practice in NSW. Eighty-two percent of the dermatologists listed on the Australasian College of Dermatologists (ACD) website practice in metropolitan Sydney. It appears that only one dermatologist practices in the west of NSW – the remainder are concentrated on the east coast (ACD, 2004b).

Medical graduates with appropriate basic postgraduate experience are eligible to apply for entry into a five-year training program in dermatology through the ACD (ACD, 2004a). As at January 2005, 60 accredited training posts were available for first-year dermatology trainees across Australia (ACD, 2005). Twenty training posts are offered in NSW, 17 in Victoria, 12 in Queensland, five in South Australia and four in Western Australia. Fourteen trainees were expected to complete their specialist training in 2005. A further 12 were expected to finish after 2005.

Dermatologists work a 46.3 hour week on average, with 40.4 hours in direct contact with patients (AHWAC, 1998). Ninety-six percent of dermatologists work in private practice, just over one percent work mainly in acute public-sector hospitals and the remainder work in other settings. Data from 1995-96 showed that dermatologists practising outside the metropolitan areas provided twice as many services as their metropolitan colleagues, and saw three times the number of patients (AHWAC, 1998).

A 1998 review of the dermatology workforce in Australia recommended that graduate output be increased to 16 per year to meet future demands (AHWAC, 1998). There is a continuing shortage of dermatologists in Australia. Rural and some non-capital city urban areas, in particular, are most affected. Many dermatologists provide services to these areas on a regular basis through a variety of arrangements (e.g. fortnightly clinics on a visiting basis). GPs have tried to meet the demand for dermatological services by increasing their knowledge and skills in dermatology through observation of practising dermatologists and further training.
The ACD does not provide diploma-level or other courses in dermatology for non-specialists. However, individual dermatologists do provide continuing education sessions for clinicians in other fields, including updates on the detection and treatment of melanoma.

3.3 Referral to a dermatologist

Most patients are referred to a dermatologist by their GPs. The major reasons for GP referrals to a dermatologist include (AHWAC, 1998):

- ‘the severity of the condition, the condition is unresponsive to treatment, the rarity of the diagnosis,
- a lack of experience within the practice regarding the condition and its treatment
- at the request of the patients to be referred’.

With respect to melanoma, it is increasingly likely that a major reason for referral to a dermatologist is fear of litigation (Lee, 2005). This arises because many GPs are not confident of their ability to rule out the diagnosis of melanoma on the one hand, but are reluctant to excise lesions unnecessarily on the other.

If a GP chooses to refer a patient to a dermatologist with a suspicious lesion or diagnosed melanoma, the dermatologist will decide on subsequent action according to the severity of the lesion. If the lesion is judged not to be so advanced as to require immediate surgical attention, the dermatologist carries out what may be either initial management or definitive management, depending on the histopathology. There is substantial overlap between the role of

dermatologists and the role of surgeons in the initial assessment and management of melanoma. The overlap occurs especially in the following clinical situations:

- Clinical diagnosis of a pigmented lesion as a likely melanoma.
- Initial management, including excision biopsy.
- Definitive management of thin lesions that do not warrant further surgery and/or other treatments.
- Counselling and follow-up of patients, including follow-up for secondary prevention and early detection of second lesions among patients who have previously had a melanoma.

A GP's referral choice between a dermatologist, a surgeon and a specialist melanoma unit is likely to be determined by the GP's perception of the severity of the lesion, the relative ease of referral access for the patient, and the GP's knowledge of melanoma detection and management. The Sydney Melanoma Unit (see section 13.2 of this report), the largest melanoma unit in Australia, conducts multi-disciplinary clinics that include dermatologists.

In 1995, NSW GPs referred patients to dermatologists at the rate of 0.91 per 100 patient encounters (AHWAC, 1998). Following referral, the average waiting time to see a dermatologist in NSW is 17 days for patients consulting a dermatologist in private practice and 35 days for public outpatient departments (AMWAC, 1998).

The relationship between GPs and dermatologists is mostly positive. However, the proliferation of GP-run skin cancer clinics has caused concern to the dermatology profession. Dermatologists have raised questions about the extent and quality of GPs' training for their role in skin cancer clinics, over-servicing through unnecessary excisions and inappropriate surgical procedures. They have pointed to instances of GPs either representing themselves to the public as specialists or being perceived as specialists in skin cancer detection and management. Dermatologists have also expressed concerns about the use of computerised equipment for the diagnosis of pigmented skin lesions, and especially about misleading the public with regard to the diagnostic accuracy of the equipment. The use of such equipment by practitioners who have inadequate clinical skills in the diagnosis of melanoma is considered to have the potential to put patients at risk (ACD, 2004c).

3.4 Implications for service development

There is a need to clarify the roles of dermatologists in the detection, diagnosis and management of melanoma, including follow-up of patients who have received treatment for melanoma. While dermatologists unquestionably make a major contribution to high-quality care at many points in the spectrum of melanoma management, their roles overlap with those of GPs, skin cancer clinics and surgeons. It would be desirable for the ACD to consider the roles of dermatologists in an optimal system for the detection and management of melanoma, and to promote these roles to others involved in melanoma multi-disciplinary management.

Dermatologists are likely to be able to make their greatest contribution in the following areas:

- Assessing lesions about which GPs are uncertain.
- Excising suspicious lesions, and ensuring that excised tissue is examined by a histopathologist with appropriate expertise.
- Referring patients with newly-diagnosed invasive and/or advanced melanoma to specialist melanoma centres.
- Providing education to GPs and patients about vigilance and follow-up for thin (i.e. non-invasive) lesions that have been successfully excised.
- Providing follow-up for patients with invasive and/or advanced melanoma, sharing care with GPs and oncologists in specialist melanoma centres.

4 Surgery

4.1 Role of surgeons in melanoma management

The management of melanoma is primarily surgical, and every patient with a melanoma can be expected to undergo at least one surgical procedure. Procedures range from simple excision of a localised lesion to complex procedures such as sentinel lymph node biopsy, excision of affected nodes, surgical management of other metastases, and regional perfusion for disease affecting a limb.

As described in Chapters 2 and 3, the initial surgical management of melanomas, i.e. excision of suspicious lesions, is often undertaken by GPs, skin clinic doctors and dermatologists. However, many patients are referred to general surgeons for excision of suspicious lesions, or to plastic surgeons if excision poses a cosmetic threat (e.g. facial lesions). Other specialist surgeons may be involved for melanomas in particular sites, particularly mucosal lesions and melanoma of the eye.

As of 2005, 1,165 surgeons were in active practice in NSW. Of these, 425 (36 percent) were general surgeons, and 82 (seven percent) were plastic surgeons (RACS Interim Activities Report, 2005).

Patients with invasive melanoma usually come to the attention of general surgeons or plastic surgeons. Those with complex melanomas that involve locoregional spread and/or metastases should be treated by oncological surgeons with expertise in melanoma surgery, working in specialist melanoma centres.

Melanoma patients represent a very small proportion of the caseload of most surgeons. Only the small number of melanoma surgeons who work in specialist melanoma units manage significant numbers of melanoma patients, including patients with lymph node involvement and more extensive disease.

No data are available on the roles and performance of surgeons in melanoma management. The Sydney Melanoma Unit, in collaboration with the School of Public Health, University of Sydney and the Northern Rivers Department of Rural Health, has embarked on a study of patterns of care for melanoma, funded by the Cancer Institute NSW. This study will, *inter alia*, investigate surgical management of melanoma in detail across the State.

4.2 Implications for service development

Many melanomas are excised by GPs, skin clinic doctors and dermatologists, i.e. practitioners who are not surgeons. It is important that these practitioners are kept abreast of the latest recommendations for excision techniques, including excision margins. They should also understand the need for expert histopathology, and they should send excised tissue only to histopathologists whom they can trust to provide accurate, comprehensive reports.

It is likely a few hundred general surgeons and plastic surgeons are also involved in excising suspicious lesions and, in some cases, managing invasive and advanced melanomas. With the exception of surgeons working in specialist melanoma centres, most surgeons are likely to manage relatively small numbers of melanoma patients, so individually their experience of melanoma management is likely to be limited. Like GPs, skin clinic doctors and dermatologists, these surgeons should keep abreast of the latest recommendations for excision techniques, including excision margins and approaches to the diagnosis and management of lymph node involvement. They too should understand the need for expert histopathology, and they too should send excised tissue only to histopathologists whom they can trust to provide accurate, comprehensive reports.

5 Pathology

5.1 Importance of expert histopathology

Expert examination of excised tissue or biopsy material and accurate reporting of its main histopathological features are crucial components of the management of melanoma. High-quality histopathology not only produces a definitive diagnosis but also provides information that helps to establish the patient's prognosis and determine treatment. Scolyer et al (2005) wrote:

> 'For the pathological report to be as accurate as possible, it is important that the clinician provides the pathologist with an adequate tissue sample and appropriate clinical details. If circumstances permit, an excision biopsy with narrow clearance margins is the most appropriate biopsy of a melanocytic tumour. This will enable an accurate assessment and allow definitive treatment to be planned appropriately if a diagnosis of melanoma is confirmed. Incomplete biopsies (such as shave, punch or curetting biopsies) may impair the accuracy of pathological diagnosis and the assessment of some important parameters and should be avoided if possible. Clinical factors that influence pathological assessment of melanocytic tumours include patient age and sex, the site of the lesion and others factors (such as prior biopsy, other trauma, surface irritation, pregnancy, topical treatment and recent strong sunlight exposure) should be communicated to the pathologist. The latter features may induce atypical pathological features and lead to a misdiagnosis of melanoma. The prognosis for patients with localised primary cutaneous melanoma depends principally on tumour thickness, but other factors such as the presence or absence of ulceration, mitotic rate, Clark level, anatomical site, age and sex are also important. The distance of the tumour from the excision margins and the presence of desmoplasia, neurotropism, regression, satellites or vessel involvement are other features that may affect prognosis and management. It is therefore important that the pathology report details all these factors. The use of a synoptic format pathology report can facilitate this.'

5.2 Pathology workforce and training in pathology

Approximately 400 pathologists practise in NSW. Of these, 41 percent (i.e. 164 individuals) are anatomical pathologists. Melanoma represents a very small proportion of the tissue assessment carried out by anatomical pathologists.

The majority of Australia's 72 accredited pathology laboratories in Australia are located in New South Wales and Victoria. These laboratories are run by a relatively small number of corporate pathology practices. Because of this, it is feasible for each practice to engage at least one pathologist with expertise in melanoma histopathology, and to promote and disseminate guidelines for the reporting of melanoma histopathology.

5.3 Reporting standards for melanoma

The Royal College of Pathologists Australia provides its members with a fact file on melanoma. This gives an overview of features that may be found in range of melanomas, including features

that point to prognosis. However, it does not provide guidance on reporting of the pathological findings. Although groups of histopathologists with expertise in melanoma pathology have proposed standards for reporting, no national standards have been promulgated.

No data currently exist on the quality of melanoma histopathology in NSW, but anecdotes indicate that it is highly variable. Some centres, such as those affiliated with the SMU, are recognised as providing definitive histopathology reporting, and are often asked to review tissue samples that have been examined by other histopathologists.

5.4 Implications for service development

High-quality melanoma management depends crucially on high-quality histopathology. The following steps could lead to improvements in the quality and consistency of melanoma histopathology in NSW:

- Formal endorsement and promotion of standards for reporting on the histopathology of melanoma. It would be desirable for these standards to be accepted nationally.
- Encouragement of pathologists who are not experts in melanoma and do not encounter many suspicious lesions to refer excision and biopsy material to histopathologists recognised for their expertise.
- Encouragement of large pathology practices to engage at least one histopathologist with expertise in melanoma histopathology.
- Provide information to GPs, dermatologists and surgeons on the elements of good histopathology reporting on melanoma, and on the interpretation of histopathology reports.
- Provide information to GPs, dermatologists and surgeons on how to find histopathologists who are skilled in the diagnosis of suspicious skin lesions.

6 Medical oncology

6.1 Role of medical oncologists in melanoma management

As we emphasised in Chapter 4, the management of melanoma is primarily surgical. The main role of medical oncology is the treatment of patients with metastatic disease, using chemotherapy and immunotherapy. Medical oncologists also contribute to palliative care.

Little information is available on the number of medical oncologists in NSW and their practice locations, and no data are available on the number or proportion of medical oncologists who participate in the treatment of melanoma patients. Data on membership of the Medical Oncology Group of Australia suggest that, in 2004, 63 registered specialist physicians were practising as oncologists in NSW, and there were 11 medical oncology trainees in the State. These figures refer to individuals, not full-time equivalents, and some medical oncologists may practise at more than one site (Barton, Frommer and sam Gabriel, 2004). Our impression is that medical oncologists with expertise in melanoma are typically based at the specialist melanoma centres, although the same individuals may also treat patients in other sites.

We interviewed medical oncologists with melanoma expertise in three hospitals in the Sydney and Newcastle metropolitan areas. All had a field of cancer expertise in addition to melanoma, e.g. breast cancer, gynaecological cancers, and cancer immunology and immunotherapy. That is, no individual medical oncologist had a full-time caseload of melanoma patients. Typically their melanoma caseload represented 20-50 percent of their total caseload. The spectrum of the medical oncologists' activities included pain management and other aspects of palliative care for their melanoma patients, in collaboration with palliative care teams.

The majority of patients with metastatic melanoma can receive most of their treatment in a specialist melanoma centre. Patients who live far from a specialist melanoma centre may receive some of their treatment in a hospital closer to home if medical oncologists in the centre can refer them to local medical oncologists for follow-up care. Table 6.2 shows the distribution of medical oncology capacity in NSW hospitals. Many larger hospitals in NSW have their own oncology staff. Table 6.1 defines the service classifications used in Table 6.2.

Table 6.1 Hospitals providing Level 4-6 medical oncology services and other arrangements for visiting medical oncology in NSW (Barton, Frommer, Sam Gabriel, 2004)

Service Level	Medical oncology
Level 6	Full range of medical oncology, including autologous bone-marrow transplantation.
Level 5	Chemotherapy services. One or more specialist oncologists.
Level 4	Consultative services only – no oncologists on staff.

Source: Barton, Frommer and sam Gabriel, 2004

Table 6.2 Hospitals providing medical and radiation oncology services, by service level (as defined in Table 6.1), NSW, 2004

Area Health Service	**Level 6**	**Level 5**	**Level 4**
	Medical oncology	**Medical oncology**	**Medical Oncology**
Central Sydney	Royal Prince Alfred	Concord	
Northern Sydney	Royal North Shore	Sydney Adventist Mater Hornsby	Manly
South Eastern Sydney	Prince of Wales St Vincent's St George		Sutherland
South Western Sydney	Liverpool	Campbelltown Bankstown	Bowral
Western Sydney	Westmead		Blacktown
Central Coast		Gosford	
Hunter	Mater		Muswellbrook
Illawarra	Wollongong		Nowra
Wentworth		Nepean	Mt Druitt Katoomba
Far West			Broken Hill
Greater Murray		Wagga Wodonga (Vic)	Griffith Finley
Macquarie			Dubbo
Mid-North Coast		Port Macquarie	Taree
Mid-Western			Bathurst Orange
New England			Armidale Tamworth
Northern Rivers		Lismore	Grafton Tweed Heads
Southern			Goulburn Bega Moruya

*Area Health Services as they existed to 31 December 2004
** Private hospitals
RPAH=Royal Prince Alfred Hospital. RNSH=Royal North Shore Hospital. POWH=Prince of Wales Hospital

In some regions, oncologists conduct clinics on a 'fly in, fly out' basis, managing patients in conjunction with local general physicians and GPs. Arrangements for the provision of oncology services on a visiting basis are listed in Box 6.1.

Box 6.1 Visiting oncology services, NSW

The following supply specialist clinical oncology services on a visiting basis:
Central Sydney AHS – to Concord and Dubbo
Northern Sydney AHS – to Port Macquarie and Manly
Western Sydney AHS – to Bankstown, Blacktown
South Eastern Sydney AHS – to Bathurst, Orange, Tamworth, Sutherland, Inverell
Hunter AHS – to Muswellbrook, Taree
Wentworth AHS – to Katoomba
South Western Sydney AHS – to Bowral
Illawarra AHS – to Nowra
Northern Rivers AHS – to Grafton, Tweed Heads
Greater Murray AHS – to Finley, Griffith.

Interstate health departments supply clinical oncology services on a visiting basis as follows:
ACT – to Goulburn, Moruya, Bega
Queensland – to Armidale
South Australia – to Broken Hill
Victoria – to Albury

6.2 Implications for service development

Decisions about chemotherapy or immunotherapy for patients with metastatic melanoma are made by medical oncologists with expertise in melanoma management, who are mostly available only in specialist melanoma centres. It may be possible for patients with metastatic disease who live far from specialist centres to receive part of their treatment in hospitals closer to home, utilising a local cancer service. In general, good communication already exists between medical oncologists with melanoma expertise and local medical oncologists, enabling shared care to occur. The total number of medical oncologists in the State is relatively small, so many know each other personally; this facilitates communication.

7 Radiation oncology

7.1 Role of radiation oncologists in melanoma management

Radiation oncology has a relatively small role in the management of melanoma. Radiotherapy is typically employed in patients with advanced melanoma. In combination with surgery, radiotherapy can improve control of the cancer either at the primary site or in the regional lymph nodes. Radiotherapy is also used to improve quality of life in patients receiving palliative care. Patients with a primary melanoma that is not amenable to surgery may also be offered radiotherapy (Stevens, 2005).

Patients are usually referred to a radiation oncologist by a surgeon or a medical oncologist. Increasingly, the decision to use radiotherapy is made in a multi-disciplinary case review meeting, in the presence of the surgeon, medical oncologist, pathologist, oncology nurses and allied health staff, as well as the radiation oncologist.

A typical course of radiotherapy involves five daily attendances each week at a radiation oncology unit over six weeks, plus time at the start for detailed treatment planning. Therefore, if a patient lives far from a specialist melanoma centre that is affiliated with a radiation oncology unit, he or she will have to be away from home for at least six weeks. This is obviously disruptive and is likely to be distressing for a patient undergoing cancer treatment.

Consequently, wherever possible, the radiation oncologist affiliated with the specialist melanoma centre refers the patient to a radiation oncology unit close to the patient's home, and communicates actively with the local radiation oncologist about treatment decisions made to date. Any trained radiation oncologist can be expected to have the knowledge to deliver radiotherapy to a melanoma patient, following an expert decision that radiotherapy is indicated. However, relatively few patients living outside the Sydney or Newcastle metropolitan areas and related conurbations have ready access to radiotherapy facilities. The only linear accelerators in NSW outside the metropolitan areas are in Lismore, Port Macquarie, Wagga Wagga and Wodonga (Wodonga is in Victoria but provides services for NSW patients living close to the Victorian border, e.g. in Albury, the twin city of Wodonga). Linear accelerators are also located in Penrith and Campbelltown, on the periphery of the Sydney metropolitan area, and in Gosford, midway between Sydney and Newcastle.

The availability of public- and private-sector radiotherapy services in NSW is outlined in Table 7.2. Table 7.1 defines the service classifications used in Table 7.2.

Table 7.1 Classification of radiation oncology services in NSW hospitals

Service Level	Radiation oncology
Level 6	Full range of radiation oncology services, including brachytherapy.
Level 5	Linear accelerators. No brachytherapy.
Level 4	Consultative (visiting) services only – no oncologists on staff.

Source: Barton, Frommer and sam Gabriel, 2004

Table 7.2 Hospitals providing radiation oncology services, by service level (as defined in Table 7.1), NSW, 2004

Area Health Service*	Level 6	Level 5	Level 4
	Radiation Oncology	Radiation Oncology	Radiation Oncology
Central Sydney	RPAH		Concord
Northern Sydney	RNSH	Sydney Adventist** Mater**	
South Eastern Sydney	POWH St Vincent's St George		Sutherland
South Western Sydney	Liverpool	Campbell-town	Bankstown Bowral
Western Sydney	Westmead		Blacktown
Central Coast		Gosford	
Hunter	Mater		
Illawarra	Wollongong		Nowra
Went-worth		Nepean	
Far West			Broken Hill
Greater Murray		Wagga Wagga Wodonga (Vic)	Griffith Finley
Macquarie			Dubbo
Mid-North Coast			Port Macquarie
Mid-Western			Bathurst Orange
New England			Armidale Tamworth Inverell
Northern Rivers			Grafton
Southern			Goulburn Bega

*Area Health Services as they existed to 31 December 2004
** Private hospitals
RPAH=Royal Prince Alfred Hospital. RNSH=Royal North Shore Hospital. POWH=Prince of Wales Hospital

As described in Chapter 6, in some regions, oncologists conduct clinics on a 'fly in, fly out' basis, managing patients in conjunction with local general physicians and GPs. Arrangements for the provision of oncology services on a visiting basis are listed in Box 6.1.

7.2 Implications for service development

Radiation therapy has a relatively small but important part in the management of melanoma patients with lymph node involvement and isolated metastases. The decision to use radiotherapy should be made by a multi-disciplinary team that includes a radiation oncologist. The main problem for service delivery is that a course of radiation therapy takes 6-7 weeks. Consequently, patients mostly seek to be treated in radiation oncology units relatively close to their homes. Effective communication between the radiation oncologist affiliated with a major

melanoma centre and the radiation oncologist in the local unit is critical. However, many patients who live outside Sydney and Newcastle do not have ready access to linear accelerators. Improved access depends on an increased number of radiation oncology units, especially outside the metropolitan areas. Any increase in the number of linear accelerators must be accompanied by an increase in the number of radiation oncologists, physicists and technicians.

8 Nuclear medicine

8.1 Role of nuclear medicine physicians in melanoma management

The main role of nuclear medicine physicians in melanoma management is their contribution to the diagnosis of the spread of disease to lymph nodes. Nuclear medicine physicians perform lymphoscintigraphy, which provides anatomical information on melanoma spread. This in turn guides surgeons in making therapeutic decisions about locoregional control of melanoma, particularly decisions about lymph node dissection.

Lymphoscintigraphy – and hence nuclear medicine physicians – are most likely to be involved in the management of patients whose melanomas are ≥0.75 mm thick. Surgery is carried out within 24 hours of lymphoscintigraphy so that isotopes injected into the lymphatics can be detected, thereby enabling the identification of sentinel nodes. The contribution of sentinel node biopsy to melanoma outcomes remains controversial.

Nuclear medicine facilities exist throughout NSW. They have numerous clinical roles unassociated with melanoma. Few nuclear medicine physicians specialise in melanoma. Lymphoscintigraphy is also performed on patients with breast cancer.

Nuclear medicine physicians are trained through the Royal Australasian College of Physicians. Many of these physicians are also members of the Australian and New Zealand Society of Nuclear Medicine, which is a multi-profession association of physicians, physicists, chemists, radiopharmacists, technologists, nurses and others interested in the practice of nuclear medicine.

8.2 Implications for service development

Centres that assess and perform surgery on patients with invasive melanoma need to have timely access to high-quality nuclear medicine services with expertise in lymphoscintigraphy.

9 Oncology nursing

9.1 Roles of oncology nurses in the management of melanoma

Nurses have a range of roles in the care of melanoma patients. Community nurses are well placed to detect suspicious skin lesions. Nurses in hospitals, specialist centres and general practice have leading roles in the coordination of care, patient education, pre-operative assessment, post-operative care including wound management, psychosocial support, monitoring patients' condition, and palliative care.

Oncology nursing resources vary greatly among Area Health Services in NSW. Over the calendar year 2002, the potential number of new cancer patients per oncology nurse varied from 23 in the (former) South Eastern Sydney AHS to 281 in the (former) New England AHS. These figures refer to all registrable cancers, not just melanoma.

Data from the NSW Nursing Survey on nurses' self-reported involvement in oncology is given in Table 9.1. The counts refer to individual nurses, not full-time equivalents. The public and private sectors are included. The data in Table 9.1 could indicate that oncology nurses have greatly varying workloads or that patients may have varying access to cancer nurses. Distance and terrain may also affect workload, especially in rural AHSs.

Data on the oncology nursing workforce only provide clues as to the extent of specialist nursing resources for melanoma. No consolidated data are available on specialist nursing resources specifically dedicated to melanoma. However, anecdotes suggest the workload of oncology nurses associated with the main specialist centres is such that the nurses have to be extremely selective in their counselling and follow-up roles.

Table 9.1 Nursing workforce by Area Health Service, NSW, 2002, in relation to total number of new cancer cases, 2001

Area Health Service	Oncology nursing workforce					Total number of new cancer cases	Average number of cancer cases per nurse
	Surgery	General	Haema-tology	Radio-therapy	Total		
Central Coast	1	8	19	1	29	1,756	61
Central Sydney	8	25	38	0	71	1,986	28
Far West	1	1	0	0	2	196	98
Greater Murray	0	7	1	1	9	1,282	142
Hunter	9	35	22	1	67	2,733	41
Illawarra	2	13	12	1	28	1,814	65
Macquarie	0	2	1	0	3	476	159
Mid North Coast	2	12	7	0	21	1,573	75
Mid Western	1	5	1	1	8	848	106
New England	0	2	1	0	3	842	281
Northern Rivers	0	4	7	1	12	1,628	136
Northern Sydney	7	44	55	7	113	3,757	33
South Eastern Sydney	23	41	78	21	163	3,724	23
Southern	2	5	0	0	7	2,708	387
South Western Sydney	1	9	9	1	20	923	46
Wentworth	1	8	12	1	22	1,134	52
Western Sydney	9	44	35	6	94	2,487	26
Unknown	2	14	18	3	37	–	–
NSW (total)	69	279	316	45	709	29,964	42

Source: NSW Nurses' Registration Survey, 2002; reported in Barton, Frommer and sam Gabriel, 2004

9.2 Implications for service development

Specialist oncology nurses have critical roles in many aspects of the management of melanoma patients. Their responsibilities range from specific nursing care (e.g. post-operative wound management) to ensuring that, in all phases, care is coordinated and patient-centred. Any service development initiatives for melanoma management in NSW must examine the apparently very variable availability of oncology nurses across the State, and include steps to redress workforce shortages where they occur.

10 Palliative care

10.1 Scope of palliative care

Palliative care has, in the past, been synonymous with providing relief for patients in the terminal stages of disease. However, the scope of palliative care has expanded to include active intervention early in and throughout the course of incurable illness. The World Health Organization (WHO, 2005) defines palliative care as:

> 'an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.'

10.2 Palliative care for melanoma

Palliative care for melanoma patients in NSW is available through specialist providers, generalist providers and support services. Specialist providers include specialist palliative care physicians, palliative care nurses and allied health professionals. Generalist providers include medical, nursing and allied health professionals who have a professional involvement with patients requiring palliative care (e.g. medical, radiation and surgical oncologists, community nurses, GPs), but whose practice is not confined to palliative care. Support services include professionals who can assist in the processes of daily living, enhancing quality of life, and/or providing emotional support. They range from various health professionals through organised volunteer services to ministers of religion (NSW Health, 2001).

Palliative care is provided to melanoma patients in a range of settings including their homes, acute hospital facilities, inpatient palliative care facilities, outpatient clinics at hospitals, and residential aged care facilities.

Melanoma patients represent a very small fraction of the work performed by palliative care providers. Most palliative care activity is concerned with cancer patients, but palliative care services are becoming increasingly involved with patients who have other life-threatening illnesses, e.g. chronic heart failure.

10.3 Referral pathways

Referrals of melanoma patients to palliative care typically come from surgeons, specialist nurses, radiation oncologists and medical oncologists. Patients are usually referred 9-12 months before death. Palliative care specialists recommend that patients are referred as early as possible so that the palliative care team becomes integrated into their overall management. If referral to palliative care specialists is delayed until late in the disease, patients may regard the referral as a sign of impending death. They can feel abandoned by their oncology team,

and have difficulty accepting that palliative care specialists understand the history of their disease. (K Clarke, personal communication, 2005).

10.4 Palliative care workforce

10.4.1 Medical

As of 2004, 54 palliative care physicians were listed on the register of the Royal Australasian College of Physicians as practising in NSW. Workforce estimates suggest a need for 99 palliative care physicians in the State. Data on the distribution of palliative care specialists across NSW are not available. It is likely that substantial variations exist in the availability of palliative care physicians; Area Health Services with tertiary referral centres which treat large numbers of patients requiring palliative care (e.g. cancer patients) are likely to have more palliative care staff than other AHSs (Barton, Frommer and sam Gabriel, 2004).

Most palliative care specialists practice in metropolitan Sydney, and some practice along the east coast of NSW to the north and south of Sydney. No palliative care specialists are located beyond the west of Sydney. However, some of the palliative care specialists who work in metropolitan Sydney conduct regular outreach clinics in rural regions. For example, palliative care physicians in Sydney South West Area Health Service (SSWAHS) run a fortnightly clinic in Dubbo.

10.4.2 Nursing

The NSW Department of Health conducts surveys of the nursing workforce, obtaining nurses' self reports about their major areas of activity (Barton, Frommer and sam Gabriel, 2004). This survey covers the public and private sectors combined. In the most recent survey, which was conducted in 2002, the total number of nurses working in palliative care in NSW was 431. Of these, 84 were clinical nurse consultants, 275 were registered nurses and 72 were other nursing personnel.

Palliative care nurse workloads appear to have varied markedly among AHSs. Area Health Services with the highest numbers of palliative care nurses in relation to population were the (former) New England, Southern, and the Mid-North Coast AHSs coast. Areas with the lowest numbers relative to population rates included the (former) Wentworth, Mid-Western and Central Sydney Area AHSs. Areas with the highest number of cancer deaths per palliative care nurse included Wentworth, Southern, Mid-Western and Central Sydney AHSs.

In NSW there is a particular shortage of nurses to carry out home visits for patients who prefer to go through the terminal stages of illness and death in their own homes.

Like palliative care medical specialists, palliative care nursing specialists from Sydney South West AHS provide ongoing advice to palliative or community nurses in Dubbo, and they occasionally undertake outreach visits.

10.5 Implications for service development

Melanoma patients account for only a small proportion of the patients who are treated by specialists in palliative care. However, their needs are substantial, and it is important that the specialist palliative care workforce is large enough to provide for all melanoma patients who need palliative services.

Key issues in palliative care are:

- the timing of referral to the palliative care team, and
- the opportunity for palliative care teams to provide 'parallel services', wherein the oncology team shares patient care with the palliative care team, rather than the transferring care to the palliative care team.

All melanoma patients with an adverse prognosis should have early access to palliative care specialists. Where feasible, the provision of 'parallel' palliative care services is likely to enhance patients' quality of life.

Much palliative care is provided by non-specialists. It is important not only that those who deliver palliative care services receive training in the aspects of palliative care that they undertake, but also that they understand the special problems and needs of melanoma patients with advanced disease.

11 Psychosocial care for melanoma patients: research perspective

11.1 The scope of psychosocial research

Much of the internationally published research on psychosocial aspects of melanoma has been carried out in NSW. In this chapter we provide a summary of the psychosocial literature for melanoma in NSW in order for the reader to gain a better understanding of the types of psychosocial services which can be provided for melanoma patients.

Psychosocial research on melanoma can be divided into four broad areas:

- Psychosocial responses to melanoma
- Psychosocial needs of melanoma patients
- Psychosocial predictors of survival, relapse and other outcomes
- Psychosocial therapies for patients with melanoma.

11.2 Psychosocial responses to melanoma

Milton (1997) described the fears experienced by patients who are given a diagnosis of melanoma. These include:

- the mysterious nature of their illness
- the cause of their illness
- mutilation or disfigurement by surgery
- pain following surgery or other treatment
- complications of treatment
- cost of the treatment
- dying
- being dead
- leaving relatives or friends
- being an object of pity
- being treated as an object rather than a person
- showing cowardice
- having to trust strangers
- loneliness
- people lying to them
- relapse

Brown et al (2000a) described melanoma patients' quality of life (QOL), coping and psychological adjustment. Patients with metastatic melanoma attending the SMU between 1991 and 1996 were asked to complete a series of questionnaires every three months for up to two years after their diagnosis. The authors reported marked variations over time and among

patients on three QOL questionnaires. A relationship was established between QOL scores and individual coping and psychological adjustment, suggesting a psychological basis to differences between patients' QOL. There was little systematic variation over time in patients "effort to cope" or in their mood.

Brown et al (2000b) investigated how patients with melanoma coped in their last year of lives. Questionnaires were sent to a cohort of SMU patients with Stage IV melanoma. The authors found that:

> "In the last year of life, patients' cognitive appraisal of their disease remained relatively stable, whereas their use of active coping strategies increased."

Patients experienced increasing levels of tiredness, and their mood and ability to function in their daily lives deteriorated.

11.3 Psychosocial needs of melanoma patients

Bonevski et al (1999) assessed the perceived needs of a sample of patients attending the Newcastle Melanoma Unit. The sample included patients with any stage of melanoma. The patients were administered the Cancer Needs questionnaire (Foot, 1996; Foot and Sanson-Fischer, 1995) which assessed five main categories of need:

- Psychological (anxiety, anger, confusion, fear and depression).
- Health information (needs for information about the disease, treatment, prognosis).
- Physical and daily living (coping with side effects, physical symptoms and loss of independence in daily living).
- Patient care and support (staff sensitivity to physical and emotional needs, privacy and choice of specialists).
- Interpersonal communication (difficulties in talking and relating to others).

The questionnaire also included 12 melanoma-specific items.

The melanoma patients were found to have most unmet needs in relation to health information, psychological issues and melanoma-specific items. The authors recommended that patient needs should be monitored routinely in oncology care so that groups of patients with specific needs could be identified. Methods for responding to these needs require further research and development.

Schofield et al (2001) sampled newly-diagnosed melanoma patients at the SMU to record patients' recollections of the experience of hearing the news that they had cancer, and to investigate their preferences with regard to hearing about the diagnosis. Schofield et al also assessed disparities between the patients' preferences and recommendations given in recently-developed consensus guidelines for the delivery of bad news. Patients were included in the study if their primary melanoma had a Breslow thickness of >1.5mm.

For the most part, the consensus guidelines were consistent with patients' preferences. However, the results indicated that some changes could be made to improve the guidelines. For example, the patients did not feel that the doctor needed to tell them about cancer support services or help them tell others about their diagnosis. Very few patients wanted another health professional present when they received their diagnosis. Patients also wished to be confident that they were getting the best treatment – a point not included in the consensus guidelines. With respect to patients' recent experiences in receiving their diagnosis, patients perceived that there were delays in getting their diagnosis. They did not feel that they had been given enough opportunity to ask questions.

Schofield et al (2003) reported a relationship between communication practices and psychosocial status in patients attending the SMU with a melanoma that had a Breslow thickness >1.5mm.

Communication practices linked to lower anxiety scores included:

- Preparing the patient for a possible diagnosis of cancer.
- Ensuring that people whom the patient wanted to hear the diagnosis were present when the diagnosis was given.
- Giving the patient as much information about the diagnosis as he or she wished.
- Providing written information.
- Presenting the information clearly.
- Answering patients' questions on the same day that they were asked.
- Talking about the patient's feelings.
- Being reassuring.

Communication practices linked to lower depression scores (i.e. less depression) included:

- Using the word 'cancer'.
- Discussing the severity of the situation.
- Discussing life expectancy.
- Discussing how the cancer might affect other aspects of the patient's life.
- Encouraging the patient to be involved in treatment decisions.

Davey, Armstrong and Butow (2005) interviewed 26 melanoma patients about their views on information provided by their doctor and separate written information from The Cancer Council NSW. The patients were recruited through the private rooms of two medical oncologists and a cancer clinic in Sydney. Most patients considered that information from the two sources would be equally accurate. Just over a third of patients felt that information from their doctor was more accurate than that from the Cancer Council. Patients were keen to discuss information that they had received from the Cancer Council with their doctor. Patients wanted their doctor's opinion on the accuracy and relevance of this material. However, patients were concerned that, in asking about the written material, they may take up too much of the doctor's time, may undermine the doctor's authority, affect ongoing care, or be perceived as not trusting their doctor. The authors recommended 'that

- doctors should be willing to discuss information patients obtain from other sources

- doctors should initiate discussion of information from sources obtained by their patients to encourage patients to discuss such information with them and to allay their fears about doing so, and
- independent information should contain an acknowledgement that the information may be different to that provided by the doctor and that the patients should discuss the information with the doctor.'

Butow at al (1998) interviewed a group of melanoma and breast cancer patients. Patients' preferences for communication about the diagnosis were not always consistent with published guidelines. Psychological adjustment was related to patients' ratings of the quality of the doctor's discussion of treatment options, but not about the diagnosis of cancer and its implications. Patients who wanted more emotional support at the time of diagnosis subsequently experienced poor psychological adjustment.

The differences in patients' preferences show that it is simplistic to issue a prescriptive list of methods for telling patients about a diagnosis of cancer. Guidelines for clinicians should be derived from patient-based data rather than limited to clinical opinion. Guidelines about communication at the time of diagnosis should also cover the implications of the diagnosis and treatment decisions.

11.4 Psychosocial predictors of survival, relapse and other outcomes

There is considerable international interest in psychosocial predictors of the onset and course of cancer (Butow, Coates and Dunn, 1999). Butow et al (1999) conducted a prospective study of the psychosocial predictors of outcomes in patients with melanoma. All new patients with metastatic melanoma attending the SMU between 1991 and 1995 were given a series of questionnaires. Follow-up status was determined through a search of medical records or by contacting the patients' GPs. Five psychological variables measured at study entry were found to correlate positively with patients' 'time to death'. Melanoma patients were more likely to survive if they:

- were married,
- had a positive outlook on their prognosis,
- did not think that their melanoma greatly affected their daily life,
- exhibited higher levels of anger about their situation, or
- had a higher quality of life.

Brown et al (2000c) studied patients with early-stage melanoma at the SMU. They investigated psychosocial predictors of time to relapse and survival. Patients who experienced longer periods without relapse included those who aimed to be cured, those who did not use avoidance strategies and those who were concerned about their disease. Shorter survival duration was associated with a positive mood (i.e. denial), the use of avoidance as a strategy,

not being concerned about their disease and being concerned about the impact of the disease on the family.

While there is some evidence to suggest that psychosocial factors predict certain patient outcomes, it is not clear to what extent modification of psychosocial factors will improve outcomes in patients.

11.5 Psychosocial therapies for patients with melanoma.

Newell, Sanson-Fischer and Savolainen (2002) conducted a systematic review of psychological therapies for cancer patients. To be included in the review, studies had to provide the "results of a randomised controlled trial that evaluated the effectiveness of a psychological intervention in improving cancer patients' psychosocial, side-effect immune or survival outcomes." The authors noted the general poor quality of the studies and found it difficult to conclude with any certainty that psychological therapies are indeed effective. However, the therapies which provided the most promise for the medium to long-term psychological outcomes included group therapy, education, structured and unstructured counselling and cognitive behaviour therapy.

Butow and her colleagues are currently evaluating the impact of a psychosocial intervention designed to increase optimism and minimisation of the effects of cancer in metastatic cancer patients (Brown, et al 2000b).

11.6 Psychosocial monitoring and care in melanoma patients in NSW.

Currently, no research exists on the monitoring and provision of psychosocial care in NSW. Based on our interviews with a wide variety of staff involved in the care of melanoma patients, provision of standardised information, attention to psychosocial needs and provision of psychological care appears highly variable across specialist melanoma centres, hospitals, skin cancer clinics, general practitioners, dermatologists, surgeons and nurses. For example, the NMU places great emphasis on the psychosocial care of its patients. It has standardised protocols for the provision of melanoma specific-information, and employs a nurse to monitor and respond to their patient's needs during (and often beyond) the time of their involvement with the NMU. Other centres and practitioners do not appear to have set protocols for the provision of information, and do not necessarily provide ongoing attention to their patients' other psychosocial needs.

11.7 Implications for service development

Based on the NSW literature on psychosocial aspects of melanoma care, we propose that the NSW Melanoma Network could encourage or support the following initiatives.

- Assess patterns of psychosocial care for melanoma patients in various clinical settings (specialist melanoma services, skin cancer clinics individual surgeons' and dermatologists' practices and in general practice). The patterns-of-care study should establish processes for psychosocial monitoring of patients and their needs, provision of information and provision of psychological therapies. The study should establish which health professionals are involved in these aspects of the monitoring and provision of psychosocial care.
- Identify all the potential guidelines which are available to assist clinicians in providing information to their patients about their diagnosis, prognosis and treatment options.
- Review the various guidelines for the provision of information to cancer patients, and modify these to include recommendations from studies that have specifically assessed the needs of melanoma patients.
- Summarise the key points from these guidelines in a checklist for doctors, nurses and other clinicians. This should include guidance on referral pathways and on how clinicians can provide for patients with special needs.
- Distribute the guidelines and checklists to relevant health professionals in NSW.
- Routinely monitor the psychosocial needs of patients with this checklist/questionnaire.

12 Inpatient services

12.1 Types and distribution of melanoma services

Melanoma patients receive care from a wide range of health professionals in public-sector hospitals within NSW Area Health Services (AHSs), both as inpatients and outpatients. The level of coordination of the care of melanoma patients varies considerably from hospital to hospital.

In the financial year 2001-2002, a total of 6,864 procedures were carried out in NSW public and private hospitals for 3,260 unique admitted patients with a diagnosis of invasive melanoma. The 6,864 procedures included those undertaken in same-day admissions, but did not include procedures done on an outpatient basis. Table 12.1 lists the major ICD-10 groupings (WHO, 2005) for these procedures, assuming that they were carried out for reasons relating to melanoma management.

Table 12.1 Major ICD-10 groupings of the 6,864 procedures carried out in NSW in 2001-02 for patients with a diagnosis of melanoma

Major ICD grouping	Number of procedures N=6,864	Proportion (percent)
Dermatological and plastic	3,396	49
Invasive, cognitive and interventions not classified elsewhere	1,757	26
Blood and blood-forming organs	527	8
Chemotherapy and radiation oncology	198	3

Source: Barton et al, in press

Sixty-eight percent of melanoma procedures were carried out in private hospitals.
The most common dermatological and plastic procedures are listed in Table 12.2

Table 12.2 Major dermatological and plastic procedures for patients with a diagnosis of melanoma, NSW, 2001-02

Procedure	Number of procedures	Proportion (percent) N=3,396
Excision of skin and subcutaneous tissue	2,721	80
Local skin flap, simple	190	6
Local skin flap, large	106	3
Other split skin graft, small	99	3
Other full-thickness skin graft	86	3

Thirty percent of all procedures were performed in public and private facilities in the former Central Sydney AHS, 15 percent in Northern Sydney AHS, 14 percent in the Hunter AHS, and 10 percent in South Eastern Sydney AHS. These four AHSs accounted for 68 percent of the melanoma procedures in NSW in 2001-02, but only 39 percent of the State's population and 40 percent of new cases of melanoma in that year.

12.2 The hospitals

A recent report for the Cancer Institute NSW included an overview of hospitals in NSW that provide cancer services, either on site or on a consultative basis (Barton, Frommer and sam Gabriel, 2004) Cancer services were categorised into six levels. Those involving specialist oncology were in levels 4-6, defined in Table 12.3.

Table 12.3 Classification of medical and radiation oncology services in NSW hospitals

Service Level	Medical oncology	Radiation oncology
Level 6	Full range of medical oncology, including autologous bone-marrow transplantation.	Full range of radiation oncology services, including brachytherapy.
Level 5	Chemotherapy services. One or more specialist oncologists.	Linear accelerators. No brachytherapy.
Level 4	Consultative (visiting) services only – no oncologists on staff.	

Source: Barton, Frommer and sam Gabriel, 2004

NSW hospitals were categorised according to these three levels. Hospitals with medical and radiation oncology services are listed in Table 12.4. Of course, not all of the hospitals with cancer services have expertise in melanoma management. However, hospitals with cancer services have a capacity to provide some services for melanoma patients, with advice from specialist melanoma centres. This can enable patients who live far from a specialist melanoma centre to receive at least some components of their treatment (e.g. radiotherapy, chemotherapy and palliative care) at hospitals closer to their homes.

Table 12.4 Hospitals providing medical and radiation oncology services, by service level (as defined in Table 12.3), NSW, 2004

Area Health Service*	Level 6		Level 5		Level 4	
	Medical Oncology	Radiation Oncology	Medical oncology	Radiation oncology	Medical Oncology	Radiation Oncology
Central Sydney	RPAH	RPAH	Concord			Concord
Northern Sydney	RNSH	RNSH	Sydney Adventist** Mater** Hornsby	Sydney Adventist** Mater**	Manly	
South Eastern Sydney	POWH St Vincent's St George	POWH St Vincent's St George			Sutherland	Sutherland
South Western Sydney	Liverpool	Liverpool	Campbell-town Bankstown	Campbell-town	Bowral	Bankstown Bowral
Western Sydney	Westmead	Westmead			Blacktown	Blacktown
Central Coast			Gosford	Gosford		
Hunter	Mater	Mater			Muswellbrook	
Illawarra	Wollongong	Wollongong			Nowra	Nowra
Went-worth			Nepean	Nepean	Mt Druitt Katoomba	
Far West					Broken Hill	Broken Hill
Greater Murray			Wagga Wodonga (Vic)	Wagga Wodonga (Vic)	Griffith Finley	Griffith Finley
Mac-Quarie					Dubbo	Dubbo
Mid-North Coast			Port Macquarie		Taree	Port Macquarie
Mid-Western					Bathurst Orange	Bathurst Orange
New England					Armidale Tamworth	Armidale Tamworth Inverell
Northern Rivers			Lismore		Grafton Tweed Heads	Grafton
Southern					Goulburn Bega Moruya	Goulburn Bega

*Area Health Services as they existed until 31 December 2004

** Private hospitals

RPAH=Royal Prince Alfred Hospital. RNSH=Royal North Shore Hospital. POWH=Prince of Wales Hospital

12.3 Implications for service development

Specialist melanoma services in NSW are concentrated in a few sites in metropolitan Sydney and Newcastle and in the Northern Rivers area. Most melanoma patients with complex disease are managed in the specialist centres. A large number of public-sector hospitals in NSW either have oncologists on staff or provide limited oncology services with advice from visiting oncologists. In collaboration with melanoma specialists, these hospitals can provide at least some services for melanoma patients on a local basis, reducing (but mostly not obviating) the need for patients to travel to major centres for all aspects of their treatment. Local services are particularly preferred when a regimen requires repeated treated sessions, as occurs in radiotherapy.

13 Multi-disciplinary specialist melanoma services

13.1 Distribution of specialist melanoma services

While multi-disciplinary cancer care is increasingly available in many cancer treatment services throughout NSW, there are only two dedicated, named multi-disciplinary specialist melanoma units in NSW: the Sydney Melanoma Unit (SMU) and the Newcastle Melanoma Unit (NMU). A large number of specialists in melanoma also practice at Westmead Hospital (in western Sydney), and at Lismore and Tweed Heads (in northern NSW), and many of them are affiliated with the SMU or NMU. In addition, specialists affiliated with the SMU undertake melanoma surgery in several private hospitals throughout the Sydney metropolitan area, of which the largest are the Mater Hospital, Crows Nest, and the Sydney Adventist Hospital, Wahroonga. As well as their clinical workload, the SMU and NMU have substantial research programs and provide basic and advanced training to doctors and other health professionals.

13.2 Sydney Melanoma Unit

The SMU was established in the early 1960s and is now the largest melanoma unit in the world. It is the major referral centre for melanoma patients in NSW and patients from other Australian States and overseas are also assessed and treated. The SMU has approximately 1,200 new patients per annum, and provides 8,000 follow-up consultations each year. It has an international reputation for the quality of most aspects of melanoma management. Areas of particular repute include histopathology, isolated limb perfusion and infusion, lymphatic mapping and sentinel lymph node biopsy, medical oncology (including immunology and immunotherapy), radiation oncology, and palliative care (Thompson et al, 2003).

The SMU's clinical service represents a leading model of integrated multi-disciplinary care. Melanoma patients in the SMU have access to a wide range of healthcare professionals with particular expertise and experience in the diagnosis and treatment of melanoma. They include surgeons, medical oncologists, radiation oncologists, nuclear medicine physicians, histopathologists, radiologists, palliative care specialists, oncology nurses and allied health professionals. Specialists associated with the SMU attend a weekly multi-disciplinary meeting to review cases, discuss options for patient management, and provide updates on the latest clinical research. Trainee and visiting health professionals are encouraged to attend these meetings.

A clinical and research service specialising in the detection of melanoma – the Sydney Melanoma Diagnostic Centre – is affiliated with the SMU. It has developed and evaluated techniques for whole-body photography and digital imaging of skin lesions, enabling detailed monitoring of patients at high risk of melanoma. The unit's director also provides training for other clinicians in dermoscopy.

The SMU is well known internationally for its involvement in research into the management of melanoma. It runs several clinical trials, some in association with other melanoma specialist

units in the State, and participates in national and international clinical trials led by other centres. The SMU manages a comprehensive clinical database that is used in clinical care and for clinical research. The database has been made available for many collaborative international research projects.

Alongside its clinical and research functions, the SMU is extensively involved in clinical education and training at all levels. It provides for medical and nursing students, interns, resident medical officers, registrars and fellows. It also provides research training for several doctoral research students.

The SMU's current main base is at Royal Prince Alfred Hospital, Sydney. Following a recent generous donation, its base is expected to move to the Mater Hospital, Crows Nest. Operations of the SMU are supported financially by the Sydney Melanoma Foundation, which is dedicated to raising funds from community donations, bequests and corporate sponsorship. The Foundation is managed under the auspices of the University of Sydney, and SMU senior staff have academic posts in the University.

13.3 Newcastle Melanoma Unit

The NMU, which was modelled on the SMU, was opened in 1981. Like the SMU, it has placed great emphasis on an integrated multi-disciplinary team to care for melanoma patients. It has also created a clinical and research database similar to that of the SMU. Over the last 25 years, the NMU has established a reputation for excellence in all aspects of care, including efforts toward improving the psychosocial aspects of patient care.

The NMU's main base is at the Mater Misericordiae Hospital in the Newcastle suburb of Waratah. Patients of the NMU are also treated at the John Hunter Hospital, and some research activities have been located at Royal Newcastle Hospital. The NMU has academic links with the University of Newcastle.

The NMU and the SMU collaborate closely. Clinicians from the NMU regularly attend SMU multi-disciplinary meetings and contribute to clinics conducted by the SMU.

13.4 Implications for service development

The SMU and the NMU represent the nuclei of melanoma services in NSW. They provide outstanding multi-disciplinary clinical services, provide advice and support for clinicians, produce research on an international scale, and contribute substantially to education and training. The SMU in particular will retain a leadership position in the development of melanoma services throughout NSW, and indeed throughout Australia.

14 Genetic services for melanoma in NSW

14.1 Overview of the genetics of melanoma

The rationale and organisation of the genetic services available for melanoma in NSW can only be described in the context of the genetics of melanoma and strategies for genetic testing.

The term 'familial' refers to a condition that is more common in relatives of an affected individual than in the general population (Trent, 2005). Familial melanoma is defined as a condition where (a) two-first degree relatives in a family are diagnosed with melanoma, or (b) three relatives in a family are diagnosed with melanoma, irrespective of degree of relationship. Between six and 18 percent of patients with cutaneous melanoma have at least one first-degree relative with melanoma.

A melanoma is suspected of having a genetic component if (a) three or more first-degree relatives of the patient have had a melanoma; or (b) the patient is aged <40 years at diagnosis; or (c) the patient has had multiple primary melanomas, often combined with a family history. Melanoma has a genetic component in eight to 12 percent of cases. However, of the 3,300 new melanomas diagnosed each year in NSW, only one to two percent (30-60 cases) have a genetic predisposition that can be *detected* with existing knowledge and technology.

Two susceptibility genes for melanoma have been identified: CDKN2A and CDK4. CDKN2A encodes two distinct tumour-suppressor proteins: INK4A (p16) and ARF (p14). Mutations in CDKN2A can result in unregulated cell growth and neoplastic progression.

The incidence of CDKN2A mutations among melanoma-prone families ranges from 25-40 percent, while CDKN2A mutations are only found in 0.2 to two percent of sporadic melanoma patients ('sporadic' means scattered, isolated cases, not occurring in family clusters). Mutations in p16 may account for up to 25 percent of familial melanomas worldwide. The p16 gene appears to be a rare, highly penetrant gene that is transmitted in most families in an autosomal dominant fashion. The estimated frequency of the mutated p16 gene in the general population is 0.01%.

An international study by the Melanoma Genetics Consortium of 80 families from Europe, Australia and the USA found that the penetrance of CDKN2A mutations (the probability that a person carrying a specific mutation will develop melanoma) reached 30 percent by age 50, and 67 percent by age 80 (National Cancer Institute, 2005). However, geographic location influenced penetrance: penetrance was greater in areas that had higher population incidence of melanoma. Thus, the lifetime penetrance of CDKN2A mutations was 58 percent in Europe and 91 percent in Australia. Differences in penetrance among geographic locations were proportionate to differences in the incidence of sporadic melanoma: penetrance was 3.74 times higher in Australia, the USA and Sweden than Western Europe. These findings suggest that the same factors that affect geographic incidence rates of melanoma also affect the expression of melanoma among CDKN2A mutation carriers.

A pigmentation-associated predisposition to cancer is indicated by the melanoma risk of melanocortin-1-receptor (MC1R) polymorphic variants with the 'red hair colour' or RHC phenotype: red hair, fair skin, sun sensitivity and freckling. An Australian study of 15 familial melanomas found that the presence of a single MC1R variant significantly increased the penetrance of CDKN2A mutation from 50 percent to 84 percent, and decreased the mean age of onset of melanoma from 58 yr to 37 yr (Box et al, 2001 cited in Carli and Salvini, 2004). A Dutch study found that CDKN2A mutation penetrance increased from 18 percent to 35 percent with one MC1R variant allele, and to 55 percent with two MC1R variant alleles. Both studies showed the effect of MC1R on penetrance of CDKN2A mutation is primarily determined by the common RHC variants (van der Velden et al, 2001).

14.2 Genetic testing

Clinical genetic testing is possible for the CDKN2A mutation. When the mutation is detected in a patient, there is potential to offer predictive DNA testing for other family members. Pre-symptomatic DNA testing is a predictive test for future melanoma risk, and tells family members whether they are a carrier of the mutation that runs in the family, irrespective of the occurrence of melanoma.

An advantage of genetic testing is that it can identify individuals at highest risk of melanoma. This may ultimately lead to improved prevention and earlier detection. It may also offer some degree of reassurance to those found to be non-carriers, and may lessen their concern about transmitting an increased risk of melanoma to their offspring.

A disadvantage of genetic testing is that it can cause psychological burden for those found to be carriers. A DNA test result also has implications for close family members of those tested. First-degree relatives of a carrier have a 50 percent risk of also being a carrier of the same mutation.

In familial melanoma, the interpretation of the test result is not yet clear, particularly for non-carriers; melanoma incidence is increased even in non-carriers of the mutation because of the effects of other (as yet unidentified) modifying genes. An increased risk of other cancers is also suspected, especially pancreatic cancer, which is not consistently but frequently reported. However, this risk cannot as yet be estimated.

The Melanoma Genetics Consortium has concluded that predictive DNA testing for familial melanoma is not yet recommended, except in clearly defined research programs. This is primarily because (a) it has poor predictive value for lifetime risk of melanoma; (b) there is possible involvement of yet undiscovered melanoma genes; and (c) mutation status does not affect clinical care and follow up strategies.

For example, a 'good' test result for non-carriers of a mutation cannot provide complete reassurance, because non-carriers still have an increased (but not yet specified) risk of melanoma. Thus all first- and second-degree relatives of a patient diagnosed with familial melanoma are recommended to have yearly skin examinations from the age of 10 yrs onwards.

An important component of care is education about sun protection and self-examination of the skin. All those affected should also be advised to undergo examination by a doctor with appropriate expertise if a pigmented growth occurs on the skin or if changes of any type occur within pigmented skin conditions.

Although the International Melanoma Genetics Consortium recommend genetic testing only as part of a research protocol – the test is clinically available through several laboratories in the US, where the question of whether it leads to improvement in assessment and management of patients has been left to the judgement of individual physicians.

14.3 Genetic services in NSW

14.3.1 Genetics education and counselling

The NSW Centre for Genetics Education, based at Royal North Shore Hospital, is a Statewide resource for genetics education and counselling. It is funded by the NSW Department of Health to provide information to individuals and family members affected by genetic conditions, as well as to health professionals. Local genetic counselling services are also available across NSW.

14.3.2 Hereditary cancer clinics

Nine hereditary cancer clinics have been established in NSW. A small proportion of melanoma patients suspected of having a genetic component are assessed in these clinics. Patients are mainly referred to the clinics by their GPs or medical or radiation oncologists. Interestingly, few patients are referred to the hereditary cancer clinics by dermatologists, skin cancer clinics or surgeons.

Assessment of a melanoma patient in a hereditary cancer clinic begins with a detailed family history to confirm the grounds for suspecting that the melanoma has a genetic component. It has been estimated that 20 percent of patients with melanoma report having at least one relative with the disease, but for up to 44 percent of these patients, the family history of melanoma turns out to be incorrect – the relative who was described as having melanoma actually had some other condition. As described in section 14.1, between six and 18 percent of patients with cutaneous melanoma have at least one first-degree relative with melanoma – the likely figure is around 10 percent.

14.3.3 Genetic testing

Genetic testing is not offered as part of routine clinical service in the hereditary cancer clinics. Thus, in contrast to breast or colorectal cancer management, it is not standard practice to take blood samples from melanoma patients and their families with the purpose of identifying a

gene mutation. However, if a melanoma is strongly suspected of having a genetic component, the patient is invited to participate in the Australian Melanoma Family Study (AMFS), which conducts genetic testing to identify potentially causal gene mutations.

All patients who agree to participate are invited to nominate other family members who may also wish to participate in the genetic testing that is conducted within the research framework. The testing generates aggregate family information on potentially causal gene mutations within a family. Individual results are not available to the patient or the family through the AMFS. The patient and the family are informed whether or not a genetic mutation or variation has been identified within the family. The patient and the family are referred back to a hereditary cancer clinic if they want individual genetic testing to identify whether they are a carrier of the identified family gene mutation. If follow-up individual predictive genetic testing is required, the hereditary cancer clinic takes further blood samples for analysis in an accredited laboratory.

In summary, the process is as follows:
1) The GP or other medical practitioner involved in the melanoma patient's care suspects a genetic component and refers the patient to a hereditary cancer clinic.
2) The hereditary cancer clinic takes a detailed family history, and provides education, counselling and referral to the AMFS.
3) The AMFS identifies that a gene mutation has been identified within the family, and refers those family members who wish to pursue individualised genetic testing and follow-up back to the hereditary cancer clinic.
4) The hereditary cancer clinic may undertake individual predictive genetic testing for those patients who want it. New samples are required and testing is done for the gene mutation that has already been identified in the family.

There is significant uncertainty regarding the interpretation of the results of genetic predictive testing. Not all genetic mutations or variations affecting the causative gene have been identified as yet, and there is uncertainty about the penetrance of some gene variations that have been identified. Consequently, even if a melanoma patient or family member is found to have a gene mutation or variation, the implications are often uncertain.

For those patients who have a family history but are found not to carry a genetic mutation, the implications are also uncertain, because they still have a higher risk of melanoma than the general population. Therefore even a negative result cannot be used to reassure family members.

Thus, irrespective of the individual results of genetic testing, all patients and their families are advised to have regular checks for skin changes and to avoid sun exposure. Patients may return to their GPs for regular screening.

The initial search for a disease-causing mutation of the p16 gene in a family is a complex and expensive process. At present in NSW, this is undertaken within the research framework of the AMFS. Follow-up testing to confirm the mutation in the patient and/or find the same mutation in other family members costs around $150 per sample.

Hereditary cancer clinics are not specifically funded to conduct genetic screening for melanoma. Such screening is not covered by Medicare, and if it is, done the clinics must absorb the costs into their existing operating budget.

Should patients and relatives with a strong family history of melanoma and/or multiple primary melanomas have direct access to genetic testing for p16 mutations if they wish to pay for it? Although some patients may participate in the AMFS in order to obtain genetic testing, the AMFS does not use a NATA accredited laboratory, and it may take up to 12 months for samples to be examined. Some patients may elect to pay for genetic testing in US based laboratories. The cost is in the range US$2,000-3,000 to find the initial mutation, and then US$300-400 for each subsequent test to find the same mutation in other family members.

14.4 Implications for service development

Pending further discoveries about the genetics of melanoma, the key question is whether predictive genetic testing should continue to be only available within the research framework of the AMFS or be made available via hereditary cancer clinics.

The fact that genetic testing is available privately via US-based laboratories creates an inequity. In addition, patients who opt for the US-based service do not necessarily receive appropriate education and counselling about the result. It is important that all patients understand the implications and limitations of a positive and negative test result, and this requires that they have access to specialist genetic counselling services. A compromise may be for clinical genetic testing that is done privately to be organised via a hereditary cancer clinic, so that patients can receive the required counselling before the test and after they receive the results.

If local testing continues to be done via the AMFS, it would also be desirable for the AMFS to seek NATA accreditation, and to be given the resources that are needed to maintain accreditation.

15 Clinical trials in melanoma

15.1 Arrangements for clinical trials

Involvement in clinical trials is an important part of high-quality cancer care. There is evidence that cancer patients who are enrolled in clinical trials have better outcomes, regardless of the arm of the trial to which they are randomly allocated, and that the patients of institutions involved in clinical trials have better outcomes overall.

Melanoma specialists in and affiliated with the SMU and NMU are extensively involved in both leading and participating in clinical trials. Trials are conducted at Royal Prince Alfred Hospital, Westmead Hospital and in Newcastle, and patients are enrolled from all hospitals in which SMU and NMU specialists work. Other trials involve the ANZAC Melanoma Trials Group, which is linked with the Trans-Tasman Radiation Oncology Group (TROG). The Sydney Cancer Centre, in Royal Prince Alfred Hospital, conducts clinical trials which include melanoma patients. They include trials of radiotherapy and interferon use. Melanoma patients treated at the Royal Canberra Hospital are also involved in trials. Coordination of trials occurs at the institution where the trial is based.

Most clinical trials are funded by pharmaceutical companies, but a few are research-driven and supported by research-funding agencies and other forms of fund-raising. Pharmaceutical companies typically fund universities for staff costs relating to their trials. Funding for the trial employees also comes from other sources, including the National Health and Medical Research Council (NHMRC), Australia Post, the Melanoma and Skin Cancer Research Institute at Royal Prince Alfred Hospital, from bequests and donations, and from overseas funding agencies such as the US National Institutes of Health. In Australia, about three quarters of trials relating to melanoma management are Phase 3 trials, which assess the safety and efficacy of interventions in patients.

Recently, national and State initiatives have been taken to create a register of all clinical trials. In NSW, this will be coordinated by the Cancer Institute NSW, and will be covered in the Institute's legislation.

The SMU is the only melanoma institution in NSW that has substantial infrastructure for the conduct of clinical trials. Clinical trials staff in the SMU are employed by the University of Sydney. The SMU database is used to establish feasibility of conducting a trial in the SMU population, and it includes a capacity to link the clinical trials information to the SMU data.

Several organisations provide support for trials, training for staff, and annual conferences, all designed to share experience and improve the quality of the conduct of trials. These include:

- NHMRC Clinical Trials Centre, located adjacent to Royal Prince Alfred Hospital.
- Data managers' group of the Clinical Oncological Society of Australia, which provides workshops, education and an annual conference.
- NHMRC Australian Health Research Data Managers Association Group, which runs courses.

- The Australian Research Council, which runs courses for pharmaceutical and commercial scientists and regulatory affairs managers.

However, once a trial is approved by an ethics committee, there is no systematic monitoring of its conduct.

15.2 Participation of melanoma patients in clinical trials

The Cancer Institute NSW recommends a target of 10 percent of cancer patients be enrolled in clinical trials. The proportion of SMU involved in trials varies according to the stage of their disease. Patients with Stage 1 melanoma are not usually involved in trials, and only a small percentage of Stage 2 patients are involved. About 15-20 percent of patients with Stage 3 or 4 melanoma are enrolled in trials. The overall participation rate across all stages is estimated to be about eight percent.

The Sydney Melanoma Diagnostic Centre conducts prevention trials enrolling some of the Stage 1 patients who are assessed or treated in the SMU.

15.3 Implications for service development

Given the value of clinical trials in providing information about the efficacy and effectiveness of treatments for melanoma and in improving outcomes for participating patients, it is important that melanoma services throughout NSW are encouraged to enrol as many patients as possible in trials. Any development of melanoma services should make provision for the promotion of participation in clinical trials among patients and clinicians, and for the necessary infrastructure and resources. The establishment of national and State clinical trials registers is likely to increase the expectation of involvement in trials.

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