

Report on the Early Detection of Skin Cancer in New Zealand

Early Detection Advisory Group

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Members of the EDAG and the organisations represented below are sincerely thanked for their considerable contribution to this report.

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The EDAG was informed by a number of pieces of work including additional data analysis undertaken by Professor Ann Richardson and Lyn Fletcher from the Department of Public Health and General Practice, Christchurch School of Medicine and Health Sciences, University of Otago and Dr Mary Jane Sneyd, Department of Preventive and Social Medicine, University of Otago.

This report draws strongly on two background documents written by Dr Tony Reeder to inform the SunSmart Partnership strategic framework development in 2001 and 2004. Dr Reeder and the Social and Behavioural Research in Cancer Group of which he is principal investigator are based in the Department of Preventive and Social Medicine, Dunedin School of Medicine, University of Otago, and receive funding support from the Cancer Society of New Zealand and the University of Otago.

The secretariat for EDAG, the stocktake of early detection activities since 1993 and the review of relevant early detection literature since 1993 was undertaken by Quigley and Watts Ltd, with Carolyn Watts as project manager.

EXECUTIVE SUMMARY

Skin cancer, particularly melanoma, is an important health problem in New Zealand. Melanoma incidence and death rates are among the highest in the world. In 2002, melanoma was the third most common type of cancer registration for both males and females.

While melanoma registrations are relatively common (1842 new registrations in 2002), mortality is considerably lower (235 deaths in 2002), indicating that treatment can be effective. In the last 30 years melanoma death rates have been stable, despite a steep increase in incidence during the 1970s and 1980s and a levelling off in the 1990s.

The age-standardised incidence rate for melanoma is approximately 8 times higher in non-Māori than in Māori. However, between 1996 and 2001, the relatively small number of Māori cases had a significantly higher risk of being diagnosed at more advanced stages of disease spread than non-Māori.

In contrast to melanoma, basal cell and squamous cell skin cancer (non-melanoma skin cancers, or NMSC) are very common, especially in the elderly. However, mortality is lower compared to mortality from melanoma, being 111 as compared with 235 deaths respectively in 2002. Nevertheless, NMSC can cause disfigurement and morbidity and, because of the large numbers involved, its treatment is costly to the health system.

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

There are several types of melanoma which differ in their natural history, i.e., they tend to 'behave' differently. The most common types registered in New Zealand are superficial spreading melanoma (with the highest incidence), nodular melanoma and lentigo maligna.

While some thick melanomas arise from thin melanomas, others may arise *de novo*. Therefore, it cannot always be concluded that thick melanomas develop from thin melanomas or that thick melanomas are due to a delay in recognition, presentation and/or diagnosis. For some types, progression is too rapid to enable early detection. Some thin melanomas will never become thick; some may even regress harmlessly.

As it is not yet possible to determine which will progress and which will not, best practice is to completely remove melanocytic lesions with clinical features consistent with melanoma.

Increasing the practice of skin examination either by doctors or laypersons and activities to raise awareness of skin cancer/melanoma are likely to result in an increased detection and recorded incidence of thin melanomas. It has not been shown that the increased detection of thin melanomas corresponds to a reduction in the incidence of thick melanomas and an improvement in survival.

One type of melanoma, nodular melanoma, may arise de novo and is characterised by rapid growth over a period of weeks or months (i.e., it becomes thick fast). Some other types, e.g., superficial spreading and lentigo maligna melanomas, tend to develop more slowly (months, sometimes years). For the slow-growing types, early recognition, presentation and treatment are likely to result in a good outcome.

The most common sites for melanoma are different for men and women, with the leg being the most common site for women, while the trunk is the most common site in men. The difference in mortality between men and women may be related to site in terms of:

- visibility (back vs. leg)
- proximity to the lymphatic system – which could mean greater likelihood of spread.

Therefore it is possible that those most likely to die are those with melanoma on certain parts of the body, as well as those with particular types of melanoma, e.g., nodular melanoma.

In order to better target early detection strategies to reduce mortality from skin cancer, particularly melanoma in New Zealand, additional, more specific information (which is presently lacking) is needed as to:

- who is most likely to develop what type of melanoma (e.g., nodular)
- who is most likely to develop thick melanoma
- who is most likely to die of melanoma
- the extent to which delay in recognition/presentation/diagnosis occurs in New Zealand and reasons for this.

Therefore, more research is needed on the above factors. Until this information becomes available it is difficult to identify strategies that will target those at greatest risk of developing and dying from melanoma.

In the last ten years mortality has remained stable, despite an increase in incidence. It is likely that action undertaken by the Cancer Society and a range of other providers has contributed to this trend.

New Zealand research shows a high level of awareness that melanoma is a serious disease (and also that death from melanoma is thought to be more common relative to other cancers than it actually is). While doing further research to identify targeted strategies to reduce mortality, it is important to ensure health professionals and the public retain a high level of knowledge.

Although there is consistent evidence that public education campaigns lead to a greater number and proportion of thin melanomas being detected, it has not been shown that these result in a corresponding reduction in thick melanomas. Furthermore, such campaigns can result in increased anxiety and unnecessary action, e.g., an increase in the proportion of inappropriate doctor visits. Therefore, until we know whom we should target to reduce the incidence of thick melanomas (knowing also that targeted campaigns improve specificity and cost effectiveness), a 'general' approach to a broad population group is needed.

This approach should enable the public to retain a high level of awareness that melanoma is a serious disease by providing good quality information, while at the same time acknowledging that knowledge doesn't necessarily translate into action.

Because there remains uncertainty about the natural history of melanoma, the most at risk groups and the different outcomes for different types, the early detection of skin cancer, particularly melanoma, does not lend itself to a media campaign. EDAG therefore recommends strategies that will provide high-quality information on skin cancer, particularly melanoma, such as the information programmes developed by the Cancer Society for prostate and breast cancers.

Knowing what we know (and don't know), age is likely to be the best predictor of mortality, as mortality from melanoma and NMSC increases with age. An information programme aimed at reducing melanoma deaths should therefore focus on people 50 years of age and over.

A recent large population-based study in Australia found that melanomas detected by physicians were more likely to be thin at diagnosis than those detected by laypersons. Therefore, the information programme should begin with information for health professionals to ensure they have a good understanding of risks, diagnosis and the management of skin cancer, particularly melanoma. It would be unethical to promote public education without first ensuring that primary care providers (including GPs) are well equipped to manage skin cancer, particularly melanoma.

The overall objectives of the programme would be to:

- provide information to assist health professionals in their understanding of risks, diagnosis and the management of skin cancer, particularly melanoma

- increase knowledge about skin cancer, particularly melanoma, among other relevant health workers (e.g., physiotherapists)
- maintain a high level of knowledge about skin cancer, particularly melanoma, in people aged 50 years and over
- improve the quality of information currently available to people 50 years and over, including what to look for and specific information on nodular melanoma, as nearly half (46.7%) of thick (>3 mm) melanomas are nodular
- encourage people to consult a doctor about suspicious lesions.

Target audiences would be:

- intervention groups
 - health professionals and health workers
 - professional and public media
- population segment
 - people 50 years and older.

In addition to strategies to maintain a high level of awareness among both the public and health professionals, EDAG considered other early detection policies and strategies. With regard to these, and for the reasons outlined in its report, EDAG made a number of additional recommendations.

EDAG does not recommend the practice of skin check (sometimes referred to as spot check) programmes/clinics outside of established medical practice. This is because they have not been evaluated and because of concerns about the possibility of:

- inadequate follow up and referral
- inadequate lighting (which could result in a lesion being missed)
- lack of privacy
- examination of single lesions without a full body examination
- the risk of creating a false sense of security among consumers.

EDAG also recommends monitoring and evaluation of existing skin check programmes/clinics, which would provide useful information about their effectiveness.

Although cancers of the skin, particularly melanoma, are an important health problem, screening does not meet the Cancer Society criteria for endorsement. Of particular significance is that:

- there is no high quality evidence from a randomised controlled trial that screening is effective in reducing mortality, therefore its value is unknown
- it is not possible to conclude whether or not screening for skin cancer does more good than harm (possible harms including unnecessary biopsies and treatment).

As a result EDAG recommends that:

- population screening for melanoma, basal cell cancer or squamous cell skin cancer should not be endorsed or promoted in New Zealand
- opportunistic screening by health professionals should not be encouraged as routine practice. In situations where screening is undertaken, it should be done on the basis of informed choice. Individuals should be informed about the potential benefits and risks of screening and the likely implications of a positive or negative result.

Clinicians should remain alert for skin lesions with malignant features in the context of physical examinations performed for other reasons.

People, particularly those 50 years of age and over, should regularly examine their skin (including skin not normally exposed to the sun) so that they will be aware of any changes; they should ask for help from someone else to check difficult to see areas, such as their back. Those who are concerned about skin changes should seek advice from a doctor. (This is analogous to promoting “breast awareness” rather than breast self-examination.)

Those at high risk of developing melanoma represent a small but important population group. There is broad agreement that individuals at high risk should be identified and offered surveillance. However, most surveillance recommendations have not been evaluated regarding their effect on incidence or mortality.

EDAG recommends that:

- an evidence-based approach to the development of guidelines for surveillance of melanoma be adopted in New Zealand
- comparative New Zealand studies be undertaken to measure sensitivity and specificity of diagnostic technologies in comparison with visual skin inspection
- genetic testing (for CDKN2A) should *not* be undertaken.

EDAG also recommends that:

- self-administered risk assessment tools for New Zealand be developed and tested
- a prognostic index or risk chart for melanoma in New Zealand conditions be developed.

Until the above recommendations can be implemented, EDAG recommends that:

- information for health professionals and consumers include reference to risk factors in relation to those at high risk
- consumers be advised to discuss with their GP or other doctor appropriate surveillance measures.

As detailed in its final recommendations, EDAG has also identified the need for action in relation to:

- the development of Trans-Tasman Guidelines for the Management of Melanoma
- recognition and management of skin cancer, particularly melanoma, in medical practice
- promptness and accuracy of histological diagnosis and reporting of melanoma
- data analysis.

In light of the above recommendations, and recognising that limited action has taken place in New Zealand to implement the 1993 recommendations of the Elwood and Glasgow report, EDAG recommends that:

- melanoma control in New Zealand be co-ordinated
- a database of who is working in the area of melanoma in New Zealand be developed
- national leadership for melanoma control in New Zealand be established
- relationships with overseas experts, especially in Australia, be established
- a national meeting on melanoma control in New Zealand be organised
- the above issues are brought to the attention of the Cancer Control Council.

INTRODUCTION

In New Zealand the age-standardised incidence and death rates from cutaneous malignant melanoma (melanoma C43) are among the highest in the world (IARC 2002). Since the publication in 1993 of a Cancer Society/Department of Health plan of action (Elwood and Glasgow 1993), the Cancer Society and a range of health professionals have actively promoted skin cancer prevention and early detection through a range of strategies. Such efforts are likely to have contributed to melanoma death rates becoming stable in New Zealand, despite its rising incidence.

According to recent research, interventions to promote early detection may have the potential to reduce deaths from melanoma (Minister of Health 2003). The question arises, however, as to which interventions are the most likely to have the greatest effect in preventing deaths.

Recognising the importance of this question, the SunSmart partnership (the Cancer Society of New Zealand and the Health Sponsorship Council), with funding from the Ministry of Health, established an Early Detection Advisory Group (EDAG) comprised of relevant experts and representatives of professional organisations and key stakeholder groups. This was also in response to an earlier specific recommendation made in the report commissioned to inform the Skin Cancer Steering Committee:

Recommendation 10

“as a matter of some urgency, a group which includes representation from clinicians, epidemiologists and health promotion researchers should be established and adequately resourced to investigate the need in New Zealand for further promotion, monitoring and research in the area of the early detection of skin cancers, in particular, melanoma” (Reeder 2004).

It was decided that the role of EDAG would be to review the 1993 plan of action, assess what had taken place to implement those recommendations and identify future evidence-based policy and strategies for the early detection of skin cancer, particularly melanoma.

This report provides the advice and recommendations arising from three EDAG face-to-face meetings, a teleconference and email communication. These should be considered within the broader context of a range of actions to control skin cancer, particularly melanoma, in New Zealand.

BACKGROUND

New Zealand Cancer Control Strategy and Action Plan

The New Zealand Cancer Control Strategy (NZCCS) is the first phase in the development and implementation of a comprehensive and coordinated programme to control cancer in New Zealand (Minister of Health 2003). The overall purposes of the NZCCS are to:

- reduce the incidence and impact of cancer
- reduce inequalities with respect to cancer.

In response to the identification in the report of the Cancer Screening and Early Detection Expert Working Group of the potential for survival from some cancers, such as melanoma, to be improved by early symptom identification, the NZCCS has as one of its objectives to “*establish a process to assess the value of early detection of cancer other than that obtained through organised screening*” (Goal 2: Objective 2). This complemented the identification of the need to address the primary prevention of skin cancer by the Primary Prevention Expert Working Group (Cancer Screening and Early Detection Expert Working Group 2003; Primary Prevention Expert Working Group 2003).

“The acknowledgement of skin cancer prevention and early detection as a priority in the NZCCS represents a significant advance. Not since the Public Health Commission’s Advice to the Minister of Health in 1994 identified melanoma prevention as a priority (Public Health Commission 1994), has there been such explicit, high-level acknowledgement of the need for coordinated national action on skin cancer control.” (Reeder 2004)

The NZCCS acknowledges that survival from melanoma may be improved by early symptom identification and treatment, and that delays in presentation remain common among some population groups in New Zealand. It also highlights the need for clarity around which intervention strategies to promote early presentation of symptoms, and thus referral for diagnosis and treatment, have the potential to improve survival and quality of life (Minister of Health 2003).

As highlighted in the NZCCS, early detection can involve strategies to promote early presentation, including education about signs and symptoms and improved access to primary care. They may also include endeavours to dispel myths, fears and negativity about cancer that may influence the likelihood of seeking medical advice. The NZCCS also acknowledges the need to assess the extent to which delays in early detection and diagnosis are occurring in New Zealand and the reasons for such delays (Minister of Health 2003). The NZCCS notes that early detection is only part of a wider strategy which includes primary prevention, diagnosis, treatment and follow-up, with its effectiveness being

dependent on the effectiveness and sustainability of other services along the cancer control continuum (WHO 2002).

The NZCCS Action Plan provides an explicit call for action, particularly in relation to melanoma. It states that survival decreases with increasing melanoma thickness and that there is very good prognosis (90 percent five-year disease-free survival) for tumours less than 1 mm thick (Cancer Control Taskforce 2005). In 1998/99 approximately 50 percent of invasive melanomas in New Zealand were diagnosed at < 0.75 mm. According to a recent analysis, a 10 percent shift in thickness distribution from ≥ 0.75 mm to < 0.75 mm would result in about 49 deaths prevented per year (Sneyd and Cox 2006). The NZCCS specifically calls for the development of a strategic approach to the early detection of skin cancer, including melanoma.

SunSmart Partnership

In 2001 the Cancer Society of New Zealand (CSNZ) and the Health Sponsorship Council (HSC) entered into a partnership to promote skin cancer prevention in New Zealand. As part of the partnership, a combined strategic plan to promote skin cancer prevention in New Zealand was developed in response to a commissioned background report (Reeder 2001).

In 2004 when the plan was being updated, the CSNZ and HSC convened a working group of experts and key stakeholders, the Skin Cancer Control Steering Committee (SCCSC), to provide advice on future direction for skin cancer control in New Zealand.

A Strategic Framework 2005-2008 was developed by the SCCSC and was adopted by CSNZ, HSC and the Cancer Control Taskforce. The goal of the Strategic Framework is to *“reduce the proportion of New Zealanders who develop and die from skin cancer”*.

The development of the Framework was informed by a second commissioned report (Reeder 2004). The Framework has four objectives.

1. To reduce harmful exposure to ultraviolet (UV) radiation.
2. To increase early detection of skin cancer.
3. To increase effectiveness of skin cancer treatment.
4. To increase investment in skin cancer control, research and evaluation.

The CSNZ and HSC acknowledged that primary prevention, early detection and treatment are all vital parts of the skin cancer control spectrum. The CSNZ and HSC had both been active in health promotion focused on prevention of skin cancer for many years. The CSNZ has maintained an interest in the early detection of skin cancer; however, in recent years the focus on early detection has been a smaller part of the Society’s overall work on skin cancer. The CSNZ

position statement on skin cancer prevention and early detection is attached as Appendix 1.

Early detection of skin cancer and effectiveness of skin cancer treatment are identified as core components of the SCCSC Strategic Framework. While the CSNZ and HSC do not have a leadership role in treatment of skin cancer, there are some aspects of treatment that are impossible to separate out from early detection. For this reason some treatment-related issues have been considered within the scope of this work.

Project rationale

Although the main CSNZ focus has been on primary prevention, there have been some limited activities at a national and divisional (regional) level to promote early detection (Watts et al 2002). In 1992-93 a national campaign promoting early detection was fronted by golfer Bob Charles. A new treatment booklet was distributed to general practitioners (GPs) and posters and leaflets were also available. Since this time CSNZ Divisions have taken more of a lead than the national body in early detection efforts, for example, running spot check clinics and educational sessions and awareness raising activities, such as cinema advertising (see the chapter entitled Early Detection Efforts in New Zealand for a fuller discussion of regional activities).

With the continuation of early detection activities at a regional level, CSNZ Divisions requested a review of the evidence base and the content of messages related to early detection. Specifically, the Divisions wanted to know who should be targeted and what should be the messages for early detection of skin cancer.

In response to the request from CSNZ Divisions, Recommendation 10 of the aforementioned report commissioned for the SCCSC (Reeder 2004) and the priorities identified in the Framework, the SunSmart Partnership facilitated the establishment of an expert advisory group to identify objectives and strategies for improved detection of skin cancer. The Ministry of Health provided funding for the advisory group through a contract with the Auckland Division of the Cancer Society. The objectives of the contract were to:

- review and evaluate the way in which the early detection messages have been communicated to the general public for the purpose of identifying and developing the most effective future strategies
- review and evaluate the strategies previously and currently utilised to communicate early detection messages as they relate to skin cancer, particularly melanoma
- establish an Early Detection Advisory Group (EDAG) (in consultation with the SunSmart Partnership project management team) which includes representation from clinicians, epidemiologists, health promotion practitioners and health promotion researchers
- conduct interviews with key stakeholders

- compile relevant information, including a literature review of the evidence regarding the various strategies for promoting early detection of melanoma
- develop a set of evidence-based best practice recommendations for the early detection of skin cancer, particularly melanoma, and identify the most effective strategies for future health promotion activities, monitoring and research in the area of the early detection of skin cancer, particularly melanoma.

The Early Detection Advisory Group (EDAG)

In June 2005 key stakeholders were contacted for their views regarding the establishment of the Early Detection Advisory Group for skin cancer, particularly melanoma (see Appendix 2 for EDAG terms of reference).

From the consultation it was decided that EDAG would be formed by the following selected organisations nominating a representative.

- Health Sponsorship Council
- Cancer Society of New Zealand
- Ministry of Health
- Royal New Zealand College of General Practitioners
- New Zealand Dermatological Society
- Royal College of Australasian Pathologists
- Australasian College of Surgeons
- New Zealand Association of Plastic Surgeons
- New Zealand Guidelines Group.

Expertise would also be sought with regard to the following areas.

- Epidemiology
- Health promotion
- Social and behavioural research
- Māori health
- Consumer representation
- Communications.

The purpose of EDAG was “*to develop evidence-based policy and strategies for the early detection of skin cancer, particularly melanoma, to reduce mortality*”. At its first meeting EDAG decided to use the 1993 report authored by Elwood and Glasgow (Elwood and Glasgow 1993) as a basis for its own recommendations.

Because EDAG chose to use the Elwood and Glasgow report as a basis for its work and also because of the limited time available, the initial emphasis was on

melanoma. This was supported by the focus in the terms of reference on reducing mortality. The relative seriousness of melanoma and the relative ease with which analyses derived from the Cancer Registry can be carried out were also factors in this decision.

However, EDAG also acknowledged the need to address issues related to non-melanoma skin cancer (NMSC). NMSC resulted in 96 potentially preventable deaths in 2001, which represented more than a third of all skin cancer deaths that year (i.e. including melanoma) (New Zealand Health Information Service 2005). An inclusive focus on early detection of all types of skin cancer is also consistent with the advice to the SCCSC in 2001 (Reeder 2001) and with existing primary prevention initiatives.

While acknowledging the importance of NMSC, EDAG noted that it may not be possible to identify early detection strategies for reducing mortality from NMSC. This is because, other than increasing age (42% of those who died from NMSC in 2001 were 85+) (New Zealand Health Information Service 2005) and immunosuppression due to organ transplant (up to 20% of organ transplant patients die of NMSC), little is known about those who are most likely to die from NMSC in New Zealand.

EDAG agreed that it was essential to define common terms so that everyone was clear about their meaning, particularly in relation to early diagnosis, screening, surveillance, skin checks, etc. However, as others have identified, one of the difficulties in using commonly accepted definitions as they relate to the early detection of skin cancer, including screening, is that visual examination is the tool which applies to all. Such distinctions, in practice, are therefore often difficult (Sneyd 1999).

Definitions used in this report

In developing its recommendations, EDAG has adopted and applied the following definitions to ensure clarity.

Early Detection

Detecting cancer prior to symptoms or as soon as is practicable after the development of signs or symptoms. In relation to skin cancer, early detection (outside of screening) involves visual recognition of a suspicious lesion either by an individual or a health professional.

Screening

Testing/checking of people at average risk of developing skin cancer, particularly melanoma, who are unaware of any signs or symptoms. Drawing upon definitions cited by Sneyd (1999), EDAG defines “unaware” as being:

- unaware of the lesion because it is hard to see
- aware of the lesion but not concerned about cancer
- aware and suspicious about a lesion but not concerned enough about cancer to have it checked properly.

For skin cancer, the screening test is a total skin examination by a health professional.

Population screening

Screening which is offered to large groups of people as part of an organised programme (where all activities along the screening pathway are planned, co-ordinated and evaluated).

Opportunistic screening

Screening which occurs in the absence of formal co-ordination, monitoring and evaluation, often when a person presents to the health system for another reason. Opportunistic screening occurs either because it is actively offered by a health professional or because it is requested by an individual. The term “case finding”, sometimes used in the literature, is considered by EDAG to be the same as opportunistic screening (although in some instances it has been used to refer to a diagnosis during an examination for another reason).

Presentation

Seeking medical attention for signs or symptoms.

Skin check programmes/clinics

Programmes/clinics outside of established medical practice principally designed for people to obtain an opinion on a lesion, though sometimes they provide screening and education about early detection and prevention. Also known as spot check programmes/clinics.

Diagnosis

Confirmation of disease through biopsy/histology.

Surveillance

Ongoing monitoring of those known to have had a cancer or to be at increased risk of a particular cancer, for example due to a personal or family history of cancer or a particular lesion(s) that require(s) monitoring. To be distinguished from screening for those who are at average risk.

Additional information requested by EDAG

EDAG requested that a number of activities be undertaken to inform its deliberations which include the following.

1. An analysis of New Zealand mortality and incidence data for melanoma since 1993.

This analysis was undertaken by Professor Ann Richardson (a member of EDAG) and Lyn Fletcher from the Department of Public Health and General Practice, Christchurch School of Medicine and Health Sciences, University of Otago. The analysis is included in the chapter entitled Skin Cancer in New Zealand.

2. A stocktake of early detection activities since 1993.

Information was collected by questionnaire and telephone interview from Cancer Society health promotion staff at regional and national levels and also from the HSC. Information was also requested from EDAG members. The data were collected and compiled by Quigley and Watts Ltd. Details of the stocktake are presented in the chapter entitled Early Detection Efforts in New Zealand.

3. A review of relevant early detection literature since 1993.

A rapid review of the literature was undertaken by New Zealand Health Technology Assessment. Relevant literature was sourced and abstracts, and in some cases full papers, were reviewed by Quigley and Watts Ltd. A summary of the literature review is presented in the chapter entitled Early Detection Efforts Internationally with further detail provided on the methods and findings in Appendix 3.

4. Melanoma in High-Risk Groups in New Zealand.

A report on melanoma in high-risk groups in New Zealand was funded by the HSC and undertaken by Dr Mary Jane Sneyd, Hugh Adam Cancer Epidemiology Unit, Department of Preventive and Social Medicine, Dunedin School of Medicine, University of Otago. The report identifies risk factors for melanoma and the characteristics of people at high risk of dying from melanoma in New Zealand. It also addresses the presentation and signs of melanoma (as distinct from those for non-melanoma skin cancer). Information from the report is included in the chapters, Skin Cancer in New Zealand and Advice for the Public on Early Detection.

Interpretation issues

Issues in relation to interpretation of data in the chapter on Skin Cancer in New Zealand are outlined as follows.

- Cancer registration was not compulsory in New Zealand until the introduction of the Cancer Registry Act 1993 which took effect on 1 July 2004. Therefore cancer registrations for 1994 are incomplete (as they include only six months of data following enactment of the legislation).
- Data provided by the Cancer Registry or available on the New Zealand Health Information Service (NZHIS) website for 2003 and 2004 are provisional and therefore subject to change.
- New ethnicity questions on death (and birth) registrations were introduced in September 1995, resulting in a significant increase in the numbers of deaths (and births) registered as Māori. Population estimates from the last quarter of 1995 use the new ethnicity data.
- Rates age-standardised to different standard populations cannot be compared.
- There is no universally agreed definition of “thick” melanoma. Contributors to the report (Richardson and Fletcher 2006; Sneyd 2006) have used different definitions. This should be considered when reading different results pertaining to “thick” melanoma.
- In the NZHIS data file of melanomas from 1994-2004, 13% are missing data on ethnicity.
- In the NZHIS data file of melanomas from 1994-2004, thickness information was missing for about 10% of melanomas which should have had thickness recorded. The distribution of missing information varied by ethnicity and whether the case was alive or dead. This could bias some analyses of thickness.
- Thickness information was missing for 53% of melanomas registered in 1994.

SKIN CANCER IN NEW ZEALAND

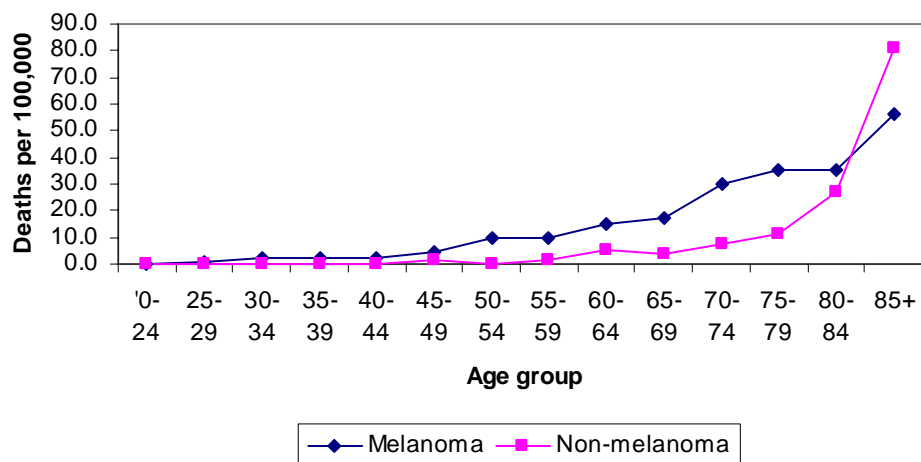
Skin cancer: an important health problem in New Zealand

Skin cancers are commonly classified into two main groups, namely melanoma and the non-melanoma skin cancers (NMSC). Non-melanoma skin cancers include mainly squamous cell and basal cell cancers. Although the incidence of NMSC in New Zealand is unknown, it has been estimated based on regional data that 50,000 or perhaps as many as 70,000 new cases occur each year. Overall nearly 350 deaths per year occur from all forms of skin cancer, with an estimated \$33M in direct treatment costs to the health system (O'Dea 2000). Melanoma is more likely to be fatal than NMSC because of its malignancy and potential to spread to other parts of the body, mainly via the lymphatic system.

Incidence data for most types of NMSC are not collected by the Cancer Registry because of resource considerations (New Zealand Health Information Service 2006). In contrast to melanoma, NMSC is very common, especially in the elderly. Although the case-fatality ratio is low compared to melanoma, NMSC can cause morbidity including disfigurement of prominent sites (e.g., the face and hands). In 2001 there were 62 deaths in men and 34 deaths in women from NMSC in New Zealand (New Zealand Health Information Service 2005). Based on 2001 data, death rates from non-melanoma skin cancer were much lower than those from melanoma among all age groups, with the exception of those 80 years and older (Figure 1).

Figure 1. Age-specific mortality rates for melanoma and non-melanoma skin cancer in New Zealand 2001

Source: Richardson and Fletcher 2006



In 2002 melanoma was the third most common type of cancer registration for both males and females (New Zealand Health Information Service 2006). Males and females had similar numbers and age-standardised rates of registration for melanoma, with 36.3 per 100,000 population for males compared to 33.6 per 100,000 population for females (Table 1). While registrations are relatively common, mortality is considerably lower, but with a significantly higher age-standardised mortality rate for men than women (New Zealand Health Information Service 2006).

Table 1: New registrations and deaths in 2002. Source: New Zealand Health Information Service 2006

	Male		Female	
	Number	Rate*	Number	Rate*
2002 new registrations	933	36.3	909	33.6
2002 deaths	149	5.5	86	2.8

* Rates per 100,000, age-standardised to Segi's world population.

The incidence of melanoma generally increases with age. Figure 2 shows age-specific melanoma registrations in New Zealand in 2001 (Richardson and Fletcher 2006). Nevertheless, it is reasonably common in younger age groups, with significant numbers diagnosed between 25 and 39 years of age in both men and women (Sneyd and Cox 2006). Although melanoma is the commonest cancer in adolescence, cancer is rare during that period of life. In 2002 the average age at diagnosis of melanoma for men was 61.2 years and for women was 57.1 years (Sneyd and Cox 2006).

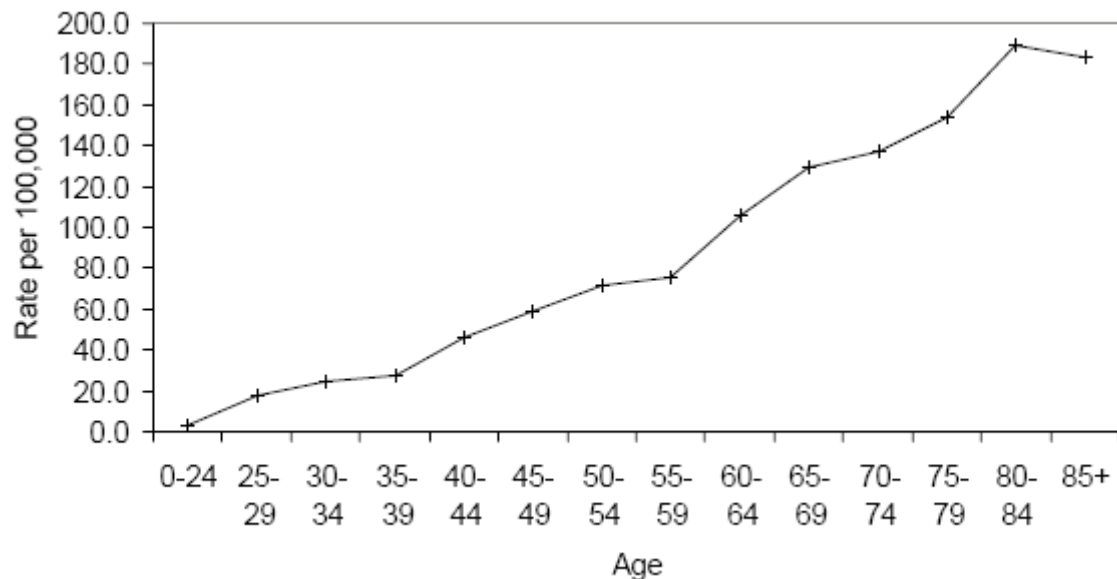


Figure 2: Age-specific melanoma registrations (5 year age groups) in New Zealand in 2001. Source: Richardson and Fletcher 2006

During the 1970s and 1980s there was a sharp increase in the incidence of melanoma in New Zealand followed by a levelling off in the early 1990s (Bulliard and Cox 1996). Although incidence and death rates of melanoma have increased in many developed countries over the past 30 years, Australia and New Zealand continue to have the highest incidence rates in the world (Sneyd and Cox 2006).

Melanoma has been legally notifiable in New Zealand since the Cancer Registry Act 1993 took effect in July 1994. As statutory notification greatly increased the number of melanomas registered, registration data from after 1994 cannot be compared meaningfully with earlier years (Richardson and Fletcher 2006). Figure 3 shows age-standardised registration and mortality rates for melanoma, 1995 – 2002 (New Zealand Health and Information Service 2006).

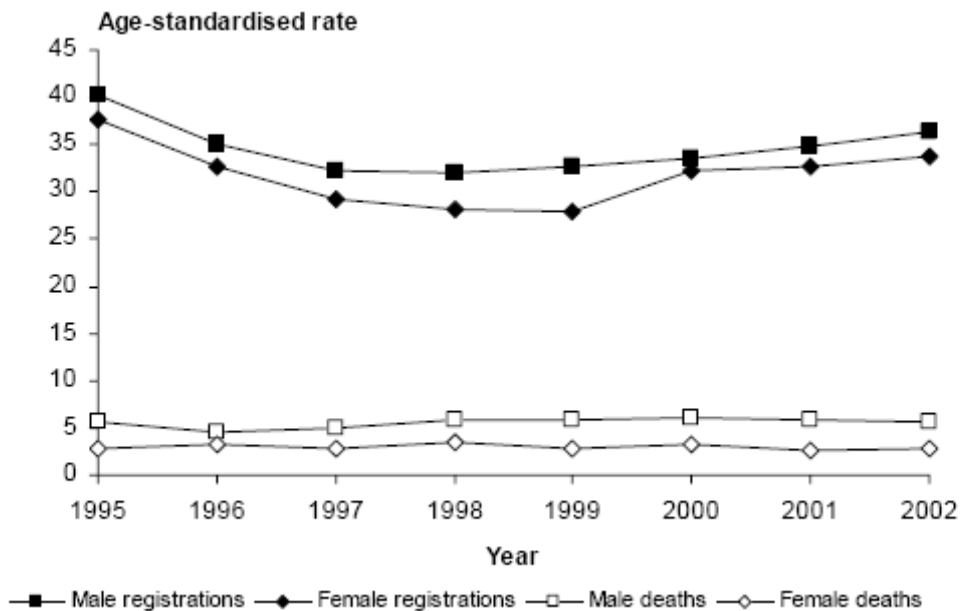


Figure 3: Registrations and deaths from melanoma of the skin, 1995-2002 (age-standardised rates per 100,000 standardised to Segi’s world population). Source: Ministry of Health 2006.

Table 2 shows age standardised registration rates by year from 1994 to 2004. The marked increase in incidence in 1994-95 reflects increased reporting following the introduction of the Cancer Registry Act, but no major increase in age standardised incidence subsequently (Richardson and Fletcher 2006).

Table 2: Age-standardised melanoma incidence rates and 95% confidence intervals 1994-2004 (Richardson and Fletcher 2006)

Year	Age standardised rate per 100,000*	95% confidence interval
1994	35.8	33.9 to 37.6
1995	40.3	38.3 to 42.2
1996	35.3	33.5 to 37.1
1997	33.6	31.8 to 35.3
1998	33.0	31.3 to 34.7
1999	32.9	31.2 to 34.5
2000	36.5	34.7 to 38.3
2001	37.0	35.2 to 38.8
2002	38.2	36.4 to 40.0
2003	37.4	35.6 to 39.1
2004	37.2	35.5 to 38.9

*standardised to the WHO world population

Based on 2001 Cancer Registry data, the cumulative risk of being diagnosed with melanoma before the age of 80 is 4%. The cumulative risk of death from melanoma before the age of 80 is 0.7%. These cumulative risks are compared with the cumulative risks for lung cancer, colorectal cancer, breast cancer and prostate cancer in Table 3 (Richardson and Fletcher 2006).

Table 3: New Zealand cumulative risks (to age 80). Source: Richardson and Fletcher 2006

Cancer	Diagnosis	Death
Lung cancer	5%	4%
Colorectal cancer	8%	3%
Breast cancer (females)	12%	3%
Prostate cancer (males)	21%	3%
Melanoma	4%	<1%

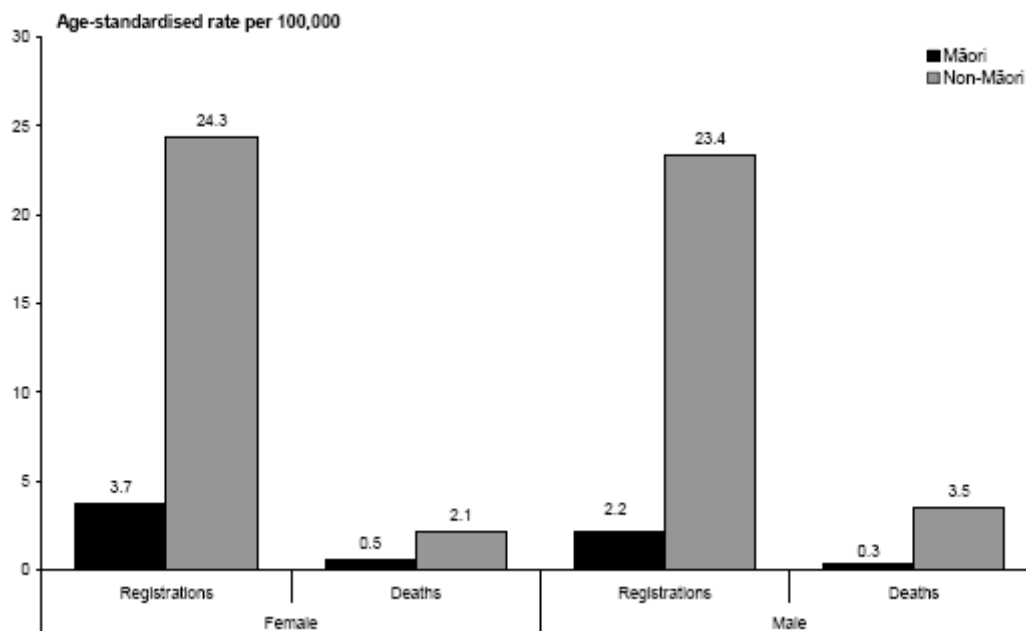
Incidence and mortality from melanoma of the skin is significantly lower among Māori than non-Māori. For the period 1996-2001, age-standardised Māori incidence rates for melanoma of the skin were 2.9 per 100 000, and mortality rates were 0.4 per 100 000, much lower than the equivalent rates for non-Māori (with an incidence rate of 23.9 per 100,000 and a mortality rate of 2.8 per 100,000) (Robson et al 2006). These rates were standardised to the average New Zealand Māori population which reduces the rates in comparison to using the WHO or Segi's standard populations. A comparison of Māori and non-Māori age-standardised incidence and mortality by gender is shown in Figure 4. In

2002 there were 1,823 melanoma registrations in non-Māori and 19 in Māori (New Zealand Health Information Service 2006).

For the period 1996-2001 there were no significant differences in survival for Māori and non-Māori diagnosed with melanoma of the skin, although this was based on only 15 deaths in Māori over the 6 years. Although most melanomas were diagnosed at an early stage (localised) for both Māori and non-Māori, Māori with melanoma were significantly more likely to be diagnosed at an advanced stage of disease (although overall numbers are small) (Robson et al 2006). In addition, analysis by Richardson and Fletcher (2006) has indicated that Māori who develop melanoma are more likely to have thick melanoma (>3 mm) than non-Māori with melanoma. Although the incidence rate of melanoma is much lower in Māori than non-Māori, the percentage of all melanomas diagnosed as thick (>3 mm) in Māori was 22.1% and in non-Māori the percentage of thick melanomas was 9.9% (Sneyd personal communication, October 2006).

These differences need to be considered in relation to early detection of melanoma. There also needs to be further consideration of the appropriateness and applicability of skin cancer messages for Māori, as well as the broader appropriateness of SunSmart messages.

Figure 4: Māori and non-Māori age-standardised melanoma incidence and mortality, 1996-2001 (standardised to the average New Zealand Māori population for 1996-2001). Source: Robson, Purdie and Cormack 2006)



Those at high risk of developing skin cancer, particularly melanoma, in New Zealand

Exposure of the skin to excessive ultra-violet radiation (UVR) is the main causal factor for the development of skin cancer. A recent analysis of melanoma in New Zealand estimated that of the 1842 new cases of melanoma in 2002, 328 were directly attributable to severe sunburn (Sneyd and Cox 2006). The authors concluded that the best avenues for reducing the burden of melanoma in New Zealand are prevention of excessive sun exposure and early diagnosis.

Recognising the importance of identifying people at high risk of melanoma in promoting its early detection, the SunSmart Partnership commissioned the report *Melanoma in High-Risk Groups in New Zealand* (Sneyd 2006) to inform EDAG's advice and recommendations. The report provides a summary of work in the field, although it does not include a systematic analysis of the quality of each study. It also notes that no original research on risk factors for melanoma in New Zealand could be found since the acceptance of the author's thesis (Sneyd 1999).

The report identifies three main types of risk factor associated with the development of melanoma in New Zealand: genetic, host and environmental factors. Genetic factors, often in combination with other risk factors, can confer a high risk of melanoma development. Host factors (number of naevi, dysplastic naevi, hair colour, eye colour, skin colour, skin reaction to sun) and environmental factors (excessive exposure to UVR) may also confer a higher risk. Many of these factors are interrelated and separating out the independent effects of each is difficult.

People at high risk of developing melanoma are those with a personal or family history of melanoma, classical atypical mole syndrome (CAMS), presence of atypical naevi, large number of naevi, previous non-melanoma skin cancer, and any combination of these risk factors. Transplant recipients and other immunosuppressed people are also at higher risk of developing melanoma (Table 4).

Table 4. Summary of risk factors

Very high risk	Personal history of dysplastic naevi + familial history of melanoma + >100 naevi. Personal history of melanoma Family history of melanoma in 1st degree relative CAMS
High risk	Atypical naevi Immunosuppression Large numbers common naevi Previous non-melanoma skin cancer
Modest risk	Blistering sunburns in childhood Fair skin, inability to tan Red or blond hair

As identified by Sneyd (2006), there is broad agreement that individuals at high risk should be identified and offered prevention and early detection strategies. Although these individuals are limited to a small subset of the population, the people potentially at high risk should be relatively easily identifiable (Meyskens and Ransohoff 2006).

A brief self-administered skin cancer risk assessment tool has been developed in the United States (Glanz et al 2003). Using a dichotomous risk measure, about 90% of people were correctly classified into high risk or low risk groups. This questionnaire asked about personal and family history of skin cancer, total body mole count, freckles, childhood residence, sunburn history, ethnicity, and phenotype (skin colour, hair colour, and tanning ability). Scoring was based on the relative risk of melanoma for each risk factor.

Austrian researchers also developed a self-administered questionnaire for the self-assessment of melanoma risk. They found no significant difference in accuracy between the self-assessment model and the physician assessment, but overall accuracy was low at about 40% (Harbauer et al 2003).

Other United States researchers developed an alternative model to estimate the chance of an individual developing melanoma over the next 5 years (Fears et al 2006). The risk factors for this model are easy to obtain during a clinical examination by a physician. This model is not intended for people with a previous diagnosis of melanoma or with a family history of melanoma.

Although these tools were not all specifically designed for melanoma, similar ones could be developed for local New Zealand conditions and might help better target preventive interventions to those who could benefit the most.

The development of a prognostic index or risk chart for melanoma in New Zealand conditions may also be appropriate as a useful aid for general practitioners and clinicians. This may be used to determine who should be considered for increased surveillance.

Those at high risk of dying from skin cancer in New Zealand

For melanoma, thickness is the strongest predictor of prognosis. In general, thinner lesions have a better outcome, with about 95% 5-year survival for tumours ≤ 1 mm thick (Balch et al 2001). Five-year survival for those with melanoma between 1.5 mm and 4 mm is approximately 70%; for those with melanomas thicker than 4 mm, survival is about 45% (Helfand et al 2001). Nevertheless, there are some thin melanomas that, if untreated, can result in death and some thick melanomas that do not.

Squamous cell cancers also have the potential to metastasise. A large primary tumour (>2 cm) is associated with an increasing risk of metastasis and therefore an increased risk of death.

According to a revised and validated staging system implemented for melanoma in 2003, both thickness and ulceration are major predictors of prognosis. The validation process found that although age, site and sex were prognostic indicators, these were of less significance than thickness and ulceration (Balch et al 2001). Survival decreased with increasing age, males had a poorer prognosis than females, and trunk, head and neck melanomas had a poorer prognosis than those on the extremities. One author has postulated that the differences in mortality between men and women may be related to site, possibly due to visibility (back vs. leg) and proximity to lymphatic system, which could mean greater likelihood of spread (Thomas and Giblin 2006).

Characteristics of people with thick melanoma in New Zealand

With its focus on reducing mortality from skin cancer, particularly melanoma, through early detection, EDAG identified the need for information on melanoma registrations and deaths in New Zealand to update the information provided in the Elwood and Glasgow report (Elwood and Glasgow 1993). In particular, EDAG required information on melanoma thickness, since this had been recorded by the Cancer Registry from 1994, and it was recommended in the 1993 report that the incidence of melanomas more than 0.76 mm thick be monitored.

An analysis of melanoma data 1994-2004 in relation to thick melanomas in New Zealand (with thick melanomas defined as those more than 3 mm) prepared for EDAG identified the following points (Richardson and Fletcher 2006).

- There is little difference in melanoma incidence rates according to gender in New Zealand.
- As in previous reports on melanoma in New Zealand, the site of melanoma varies according to gender (with the leg being the most common site in females and the trunk the most common site in males).
- Melanomas in non-Māori and non-Pacific people tend to be thinner at registration than for Māori and Pacific people.
- Older people have melanomas that are thicker at diagnosis than younger people.
- Older men are more likely to have thick melanomas than older women.
- Increasing awareness of melanoma and resulting early detection have been thought to partly explain the increasing incidence of melanoma in countries such as Australia, New Zealand and the United States in the 1970s and 1980s.
- Ideally, increasing awareness should lead to increasing incidence of thin lesions, and after a delay, a corresponding decrease in thicker lesions.
- Despite this expectation, a decrease has not been seen in Australia, leading to the hypothesis that some of the thin lesions are non-metastasing melanomas (Burton and Armstrong 1998).
- In New Zealand there has been no decrease in the rate of thick melanomas from 1994 to 2004.
- The most common types of melanoma recorded by the Cancer Registry from 1994 to 2004 were superficial spreading melanoma (44.2%), melanoma not otherwise specified (34.8%), nodular melanoma (9.8%) and lentigo maligna melanoma (6.8%).
- Nodular melanomas were significantly more likely than other melanomas to be diagnosed at 3 mm or greater.
- The incidence rate of thick melanoma increases rapidly with age.
- Although the incidence rate of melanoma is 8 times higher in non-Māori than Māori, Māori who develop melanoma are more likely to be diagnosed with thick melanoma than non-Māori who develop melanoma.
- Women who develop melanoma are less likely to be diagnosed with thick melanoma than men who develop melanoma.
- Nearly half (46.7%) of the thick (> 3 mm) melanomas were nodular; similar results have been found in Australia and the US (Chamberlain et al 2002; Demierre et al 2005).

An analysis of national data from 1994-2004 (11 years) yielded additional information in relation to those with deep melanomas in New Zealand (with thick melanoma defined as more than 4 mm thick) (Sneyd 2006). The key findings are listed as follows.

- A greater proportion of men than women were diagnosed with melanomas more than 2 mm thick.
- The proportion of thick melanomas increased with age, to over 20% in people aged 80 years or more.
- Many more head and neck melanomas were thick compared to other body sites.
- Almost 70% of nodular melanomas were more than 2 mm thick and 36% of acral melanomas were more than 2 mm thick.
- Although there is still controversy over nodular melanoma being a distinct melanoma type rather than the end-stage of the natural history of melanomas, recent research shows that it is quite unlike most melanomas with a radial growth phase (Carli et al 2004).
- Few Pacific people were diagnosed with melanoma over the 11 years but over 1/3 of them were thick.
- Almost 20% of melanoma in Māori were thick.
- The gender distribution of melanomas was different in Māori compared to Pacific people and other ethnicities: 2/3 were female in Māori and about half female in other groups.
- Morphology (melanoma type) varied by ethnicity. Although Pacific people have very few melanomas, more of them are acral melanomas (17.2%) than in other groups.
- Of those people with melanoma, nodular melanomas were more frequent in Māori and Pacific people and superficial spreading melanomas were most common in 'other' ethnicities.
- The most frequent classification in Māori and Pacific people was melanoma-NOS (type not specified) (42.5% and 44.8% of all melanomas, respectively). The different proportions of melanomas classified as not otherwise specified in different ethnic groups could bias the results presented.

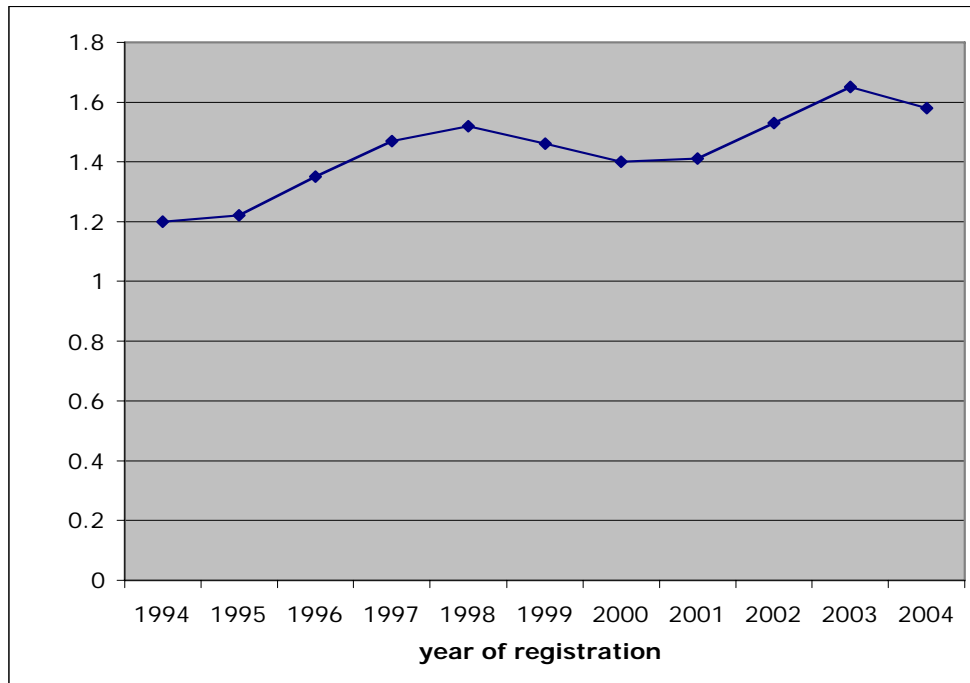
According to the report, between 1994 and 2004, 193 people were diagnosed with very thick melanomas ≥ 10 mm thick (Table 5) (Sneyd 2006). Most of these occurred in men and in people aged 70 years or older. Of all people with melanoma, men aged 50 years or older made up 37% of the total. Of all people with thick melanoma (>4 mm) men aged 50 years or more made up over half (52%) the cases and they contributed approximately the same proportion again (51%) of very thick (≥ 10 mm) melanoma. 102 of the 193 very thick melanomas were nodular melanomas and almost all of the remaining melanomas were classified as melanoma-NOS. Almost 10% of melanomas in Māori (10 cases) and Pacific people (only 2 cases) were very thick.

**Table 5. Characteristics of people with very thick melanoma (≥ 10 mm thick)
Source: Sneyd 2006**

		N	%	p value
sex	Male	114	1.4	0.014
	Female	79	1.0	
age	<30	4	0.5	<0.001
	30-39	5	0.3	
	40-49	13	0.5	
	50-59	23	0.7	
	60-69	36	1.2	
	70-79	57	1.8	
	80+	55	3.0	
site	head and neck	48	1.7	0.003
	Trunk	52	1.0	
	upper limb	37	1.0	
	lower limb	53	1.2	
morphology	Nodular	102	5.8	<0.001
	Acral	2	1.6	
	not otherwise specified	56	1.2	
	lentigo maligna	3	0.3	
	superficial spreading	9	0.1	
ethnic group	Māori	10	9.3	<0.001
	Pacific	2	9.5	
	Other	171	1.2	

The analysis also identified a statistically significant but small increase in average melanoma thickness from 1994 to 2004, of 0.03 mm per year; this requires further analysis (Figure 5). Internationally there is no evidence that the incidence of thick melanoma is decreasing (Sneyd 2006).

Figure 5. Average depth of primary melanomas at diagnosis, by year of registration.
Source: Sneyd 2006 (based on routine NZHIS national cancer incidence database)



The analysis also assessed predictors of melanoma thickness. The following characteristics were significantly associated with increasing melanoma thickness:

- morphology of melanoma (nodular and acral melanomas were thicker than other types)
- age (average thickness increased by 0.2 mm for every 10 year increase in age)
- site of melanoma (head and neck were thicker than other body sites)
- ethnicity (Pacific people had the thickest melanomas followed by Māori; “other” ethnicities were thinnest)
- gender (men having deeper melanoma than women)
- year of registration (on average, thickness increased by 0.03 mm for each year from 1994 to 2004).

In multivariate analysis (each factor adjusted for the others listed above) the factors which remained significantly associated with thickness of melanoma were:

- morphology
- site
- ethnicity
- age
- year of registration.

Once adjustment for the other factors was made, gender was no longer a determinant of thickness.

Although melanomas are rare in Māori and very rare in Pacific people, and so their absolute risk is low, after adjustment for gender, age, site, year of registration and morphology, the people who developed melanoma in these ethnic groups still had a significantly increased average melanoma thickness compared to other ethnic groups (Sneyd 2006).

Based upon the above analysis, recommendations were made as follows.

- Early diagnosis programmes should include information for Māori and Pacific people.
- Early diagnosis of nodular melanoma should be emphasised.
- The importance of melanomas of the head, neck and scalp should be accentuated.
- Older men should be targeted.

EARLY DETECTION EFFORTS IN NEW ZEALAND

In 1993 Mark Elwood and Helen Glasgow authored a report, *The Prevention and Early Detection of Melanoma in New Zealand*, on behalf of a Cancer Society of New Zealand/Department of Health Working Group (Elwood and Glasgow 1993). That working group was similar in many ways to EDAG. However, its brief was wider than just early detection and also included prevention, primary care, secondary care and therapy. Also, the scope was narrower, focusing only on melanoma, whereas EDAG has been responsible for considering skin cancer in general.

As part of the information requested to inform its deliberations, EDAG requested that a stocktake of activities related to early detection in New Zealand was undertaken. Information was collected from Cancer Society of New Zealand (CSNZ) health promotion staff and also from members of EDAG itself. The stocktake findings are summarised below under each of the italicised recommendations (numbered as per original report) from the Elwood and Glasgow Report.

Recommendations: actions taken on first suspicion

4.1 *High level of public knowledge: continue and develop current activities*

Continue and further develop education programmes to achieve a high level of public awareness about the early signs of melanoma and the importance of seeking medical opinion.

Promote the idea that close relatives and friends need to be aware of skin changes.

Acknowledge the valuable role of health professionals in promoting early detection of melanoma.

Assess programme by monitoring delays in recognition and in presentation.

Although the CSNZ focus has been on prevention there have been some limited activities at a national and divisional (regional) level to raise awareness about the early signs of skin cancer (Watts et al 2002). In 1992-93 a national campaign promoting early detection of melanoma was fronted by golfer Bob Charles. A new treatment booklet was distributed to GPs and posters and leaflets were also available.

The CSNZ has maintained an interest in the early detection of skin cancer; however, in recent years the focus on early detection has been a smaller part of the Society's overall work on skin cancer. Cancer Society Divisions have continued to promote a range of messages relating to skin cancer early detection, including:

- "Take time to spot the difference"
- "If you have a changing mole or freckle see your doctor immediately"
- "Know your body and what is 'normal'. Look for changes in your skin, moles or freckles. Have a doctor check any unusual spot without delay (If in doubt check it out)." ABCD criteria.

A variety of delivery channels have been used for early detection messages including:

- SunSmart presentations to community groups
- Professional education seminars and continuing medical education (CME) seminars for GPs
- Partnership with workplaces providing support and education
- Working collaboratively with other organisations to deliver messages
- Messages have been promoted by advertising through a variety of media including: newspapers, radio, cinema advertising, events; educational materials (*Take Time to Spot the Difference* pamphlets and posters) distributed through hospital outpatient clinics and doctors' surgeries; presentations/talks
- There has been little evaluation of the effectiveness of awareness raising/educational activities.

4.2 Targeting of the high-delay groups: continue and develop current activities; high priority

Focus on men over 40 years of age (as the group most likely to delay seeking treatment, to present with deeper melanoma and with poorer survival rates).

The national CSNZ campaign featuring Bob Charles in 1992-93 targeted older men with Bob Charles being interviewed and saying “because I had my melanoma treated early, I have had no more problems”.

More recently, regional Cancer Society public education strategies (workshops, resources and promotions) have been for the general population, although there have been some strategies targeted at older men.

4.3 Evaluation of speed of presentation of melanoma: research needed; high priority

Periodically survey melanoma patients, and those presenting to general practitioners with suspicious pigmented lesions, to monitor delay period between first recognition and gaining a medical opinion.

Despite attempts to gain funding for this work there has been no support for research in this area. There remains a clear need to look at the issues of delays in presentation and appropriate treatment for all types of skin cancer.

Recommendations: case finding and screening

5.1 Spot check programmes: monitor and assess; continue with careful evaluation

Continue existing locally initiated programmes (primarily because of their publicity and educational value); monitor carefully programmes and their mechanisms to ensure follow-up of people needing further attention.

For the most part, spot check programmes run by the Cancer Society have been discontinued; however, some centres continue to offer them.

A spot check programme has been running in Marlborough for a number of years.

Monitoring and assessment of spot check programmes has largely been unsystematic, although the Auckland Melanoma Project, which combined spot check clinics during Melanoma Awareness Week (now SunSmart Week) with a continuing medical education (CME) programme for GPs was evaluated. The project ran for 10 years between 1989 and 1999. During this time 14% of people presenting for a free spot check had a clinically suspected skin cancer (of which 1-2% were melanoma) (Boberg and Shaw 2001).

5.2 Encourage pilot programmes of self-referral and their evaluation: development and research needed; high priority

As a high priority, encourage establishment and evaluation of systematic self-referral pilot programmes integrated into routine primary care.

There appears to have been very few, if any, systematic self-referral programmes in routine primary care. EDAG knew of one GP with an interest in skin cancer who has outlined a proposal to his PHO, in which patients over a certain age will be informed of risk factors and invited to attend for skin check clinics.

5.3 Encourage pilot programmes of screening and their evaluation: research needed; high priority

Population screening for melanoma not recommended; as a high research priority, develop and evaluate pilot screening programmes involving general practitioners.

There have been no pilot screening programmes for those at average risk (i.e., programmes which actively invite those without symptoms to have a routine skin examination). The establishment on a commercial basis of MoleMap in New Zealand has yielded a large database of material. Evaluation of MoleMap in New Zealand has not been systematic to date and has proved difficult to achieve because of low yield of histology results.

Recommendation: early diagnosis in high risk subjects

6.1 Encourage pilot programmes and their evaluation: development and research needed; high priority

Encourage the establishment and evaluation of specific pilot programmes for early diagnosis that are specific to high-risk subjects.

There has been no evaluation of pilot programmes for early diagnosis of high-risk subjects. Funding to enable evaluation of MoleMap data could help determine the long term role of mole mapping in general and if it is proven to be clinically valuable.

In EDAG's view, many patients at high risk by reason of age, previous skin cancer, family history of melanoma and/or multiple atypical naevi are already undergoing some form of surveillance.

Recommendation: management of suspicious lesions in primary care

7.1 Encourage high level of knowledge and skills: continue and develop current activities

The Royal New Zealand College of General Practitioners, the Cancer Society of New Zealand and other bodies to continue educational programmes for general practitioners; these should cover management decisions and practical skills and give attention to decision-making and diagnostic skills and to practical skills regarding biopsies.

Regularly assess general practitioners' specific educational needs.

There is currently no nationally coordinated educational programme for the management of skin cancer in primary care in New Zealand. The 1992-93 CSNZ early detection campaign included a treatment booklet that was distributed to all GPs. General practitioners have readily available information on melanoma both in written form to which they can refer, or standard update courses for which they are personally responsible for accessing. DermNet NZ, the New Zealand Dermatological Society website, contains the interim Guidelines for Management of Malignant Melanoma along with a number of dermoscopy quizzes.

Dermoscopy training is offered to PHOs by some dermatologists.

There was an evaluation of GPs' and dermatologists' knowledge and skills in 1994 (McGee et al 1994), but to the best of EDAG's knowledge there have been no independent evaluations published since then.

7.2 Good biopsy and referral facilities: continue and develop current activities

General practitioners to have appropriate biopsy facilities available and, when undertaking biopsies themselves, to use approved techniques at an appropriate standard.

Assess existing referral system for patients with suspect lesions and make improvements where necessary to ensure clear and prompt referral.

In EDAG's view, there are excellent biopsy and referral facilities throughout New Zealand, the development of which naturally occurs in the climate of high-level observation of pigmented lesions.

Questions were raised by EDAG about how GPs manage to do biopsies and excisions in primary care, as it is difficult enough in specialist practice. Problems involve staff and facilities, knowledge of and compliance with medical and surgical standards and maintenance of equipment, as well as acquisition of appropriate skills.

7.3 Monitoring of primary care management: research needed

Establish a baseline figure for the delay interval from first contact with general practitioner to biopsy or referral from which improvements can be projected.

Obtain (once available) and apply baseline rates for the proportion of patients who have lesions that are either biopsied or referred and who do not have important disease and monitor improvements.

There is currently no systematic review of primary care management of skin cancer.

Unpublished data from Waikato Hospital evaluated the delay from referral to excision of melanoma at Waikato Hospital during 2002-3. Of the 113 cases included, 41% were detected incidentally (average Breslow thickness 0.57 mm) and the others were referred for that lesion (1.45 mm). The referred patients waited a mean of 26.5 days (range 0-94 days) for first specialist assessment and a mean of 24.2 days (range 0-81) for excision of the lesion.

Secondary care

Recommendations: management in secondary care

8.1 Accurate diagnosis and consistency of depth measurement: continue and develop; high priority

To ensure good management, establish ongoing auditing systems to monitor accuracy of diagnosis and changes in incidence and prognosis.

There is no systematic audit of accuracy of diagnosis in New Zealand. It is routine procedure, in most laboratories in New Zealand, for pathologists to have a countersignature or at least diagnostic validation of most primary malignancies and this includes melanoma.

There appears to be nothing formal in terms of audit; however, most pathologists engage in some form of peer assessment and continuing quality assurance.

Establish consistency in depth measurement.

Strive for consistency among pathologists in relation to borderline lesions.

As a high priority, set up a specific interest group or unit that could act as a referral centre for melanoma to assist with diagnostic problems.

There is no specific melanoma special interest group to act as a referral centre in New Zealand. In routine practice, if there is diagnostic contention over a specific lesion, after review by several "local (i.e., on site) or regional" pathologists, it is common to seek an opinion from an overseas expert with specific expertise in this area, although not necessarily working from a "melanoma referral centre". The choice of expert is up to the individual pathologist.

8.2 Evaluation of management in secondary care: research needed

Monitor the time interval from first referral for a secondary care opinion to definitive diagnosis and the institution of therapy.

Take steps to provide baseline information and to assess if improvements are needed.

Monitor and assess the number of biopsies for lesions that turn out to be benign, and the benign to malignant ratio of biopsied lesions.

There are currently no systematically collected data on the time interval from first referral for secondary care to diagnosis or treatment.

Many patients referred by GPs to dermatologists have benign lesions with no worrying clinical features, reducing the resources available to identify and treat high risk lesions. 35-40% of GP referrals to a dermatology clinic for skin lesions have the correct diagnosis. Removal of 6 benign lesions for every melanoma is a reasonable ratio. In reality the ratio is closer to 50:1 in New Zealand (A Oakley, personal communication, October 2006).

No systematic evaluation of management in secondary care currently exists.

The Departments of Dermatology and Plastic Surgery at Waikato Hospital are planning to establish a Cutaneous Oncology Service to cover primary, secondary and tertiary care of melanoma and non-melanoma skin cancer in the region within the next two years. An essential component of this service will be research, case review and audit.

Promptness of diagnosis

Recommendations: monitoring promptness of diagnosis

9.1 *Monitor and assess depth distribution: research development needed; high priority*

As a high priority, establish a national system of monitoring depth distribution, linked to quality control of diagnosis and depth distribution (with the appropriate target being to reduce, on a population basis, the incidence of deep melanomas, for example, those more than 0.76 mm deep).

9.2 *Reasons for late presentation: research needed; high priority*

As a research priority, set up studies in New Zealand to assess factors associated with late presentation of melanoma, assessed by deep lesions, and the reasons for such presentation. This should provide information on further action to increase the proportion of patients treated early (that is, who have thin lesions).

To the best of EDAG's knowledge, no action has been undertaken towards establishing a national system of monitoring depth distribution or assessing factors associated with late presentation. National data on the time period from initial recognition of lesion to diagnosis are needed.

In summary, it appears that very little and in some areas no action has been taken to address the Elwood and Glasgow recommendations in a systematic way. In EDAG's view, such inaction has been due to an absence of both leadership and a high-level coordinated approach to the control of skin cancer, particularly melanoma, in New Zealand.

EARLY DETECTION EFFORTS INTERNATIONALLY: REVIEW OF THE LITERATURE

An extensive and systematic search of the published scientific literature on early detection of skin cancer since 1993 was conducted by New Zealand Health Technology Assessment (NZHTA). A rapid review of abstract and full paper primary data was undertaken by Quigley and Watts Ltd. The Elwood and Glasgow Report (Elwood and Glasgow 1993) was used as a guide to categorise the evidence. Further details of the methodology and results are contained in Appendix 3.

Results Summary

Early detection: Public awareness and education

- There is strong evidence that public awareness and education campaigns focused on early detection increase awareness and knowledge about skin cancer and increase the number of people requesting skin checks (Baade et al 1996; Healsmith et al 1993; Hoffmann et al 1993; Lowe et al 1994; Mullan et al 1996; Rossi et al 2000; Tonks et al 1995).
- Early detection behaviour (skin checking) seems to be more conducive to change than primary prevention ('sun smart') behaviour such as wearing sun screen, seeking shade and covering up with clothing (Baron-Epel and Azizi 2003; Geller et al 2005).
- Research shows that older people, males and people in less affluent areas tend to be less responsive to public awareness campaigns (Roder et al 1995).
- Evidence is mixed as to whether public education campaigns reduce skin cancer morbidity or mortality (Cristofolini et al 1993a; Cristofolini et al 1993b; Melia et al 2001).
- One study concludes that in well-informed populations, campaigns for early diagnosis of melanoma may no longer have a major impact on prognosis, unless they are focused on subgroups with less access to information and medical care (Richard et al 1999).
- There is consistent evidence that public education campaigns lead to a greater number and proportion of thin lesions being detected (Howell and Cockerell 1996; MacKie et al 2003; Rossi et al 2000). However, only in South Australia has a corresponding reduction of thick melanomas been observed (Herd et al 1995; Melia et al 1995; Roder et al 1995; Tonks et al 1995).
- There are concerns that public education campaigns can lead to unnecessary doctors' visits and excisions (Del Mar et al 1997).

- Studies show how carefully worded and targeted campaign materials can improve specificity and cost effectiveness of campaigns (de Rooij et al 1995; Katris et al 1996).
- Ability to distinguish between benign and suspicious lesions improves modestly, if at all, as a result of educational interventions, e.g., brochures (Borland and Meehan 1995; Branstrom et al 2002; Brooks et al 2001; Chao et al 2003; Hanrahan et al 1995).
- There is debate about whether the ABCD (E) rule is the most effective public education message, as (a) many malignant melanoma do not exhibit these signs at an early stage (Bergenmar et al 2002; Carli et al 2004; Demierre et al 2005; Helsing and Loeb 2004; Levit et al 2000; Stante et al 2005) and (b) evidence suggests that experts rely on distinctiveness to correctly detect suspicious lesions (Gachon et al 2005), and that laypeople are also more accurate when using distinctiveness rather than ABCD (E) to distinguish suspicious lesions (Brooks et al 2001).

Early detection among high risk subjects

- Definitions of 'risk' vary. Risk factors for *getting* melanoma and risk factors for *dying from* melanoma are different. It is also important to make a distinction between high risk *groups* and high risk *individuals*.
- Evidence suggests that older people (Branstrom et al 2003), deprived groups and non-white populations may be at disproportionately higher risk of death. Inequalities are important to consider when 'high risk' groups are being targeted.
- Recent studies confirm that skin phenotype, presence of atypical naevi and family or personal history of melanoma are key individual risk factors for getting melanoma (Carli et al 2003; Giannotti and Carli, 2004; Kang et al 1994; MacKie et al 1993; Marghoob 1999; Sneyd 2001; Williams and Sagebiel 1994).
- It is not possible to identify with any accuracy the individuals who are most likely to get melanoma. The predictive value, sensitivity and specificity of risk-assessment tools remain low (Harbauer et al 2003; Massone 2005).
- The majority of melanoma patients are not defined as 'high risk' using typical tools for identifying high risk individuals (Harbauer et al 2003).
- Some studies of different methods of surveillance of very high risk individuals, generally in secondary care settings, suggest that any kind of regular follow-up (intervals 3 months - 18 months) leads to early detection and good prognosis (Carli et al 2003; DiFronzo et al 2001; MacKie 1993; Wang et al 2004).
- There is evidence that surveillance with the naked eye or photography can miss melanomas that more 'high tech' methods can pick up (Haenssle et al 2004; Mackie et al 1993). However, other studies have concluded that visual examination by a dermatologist is accurate and appropriate (Rampen et al 1995).

Skin check programmes/clinics and screening

Skin check programmes/clinics

- The quality of the evidence related to 'skin check clinics' is poor. Nearly all studies are cross-sectional, and results are difficult to draw conclusions from.
- Some studies claim that a programme was effective because it detected a small number of melanomas or other skin cancers (Carli et al 2003; McCormack et al 2002; Nikkels et al 2004; Vandaele 2000). However, others claim that since the pick-up rate of malignancy is low, other early detection methods may be more cost and time effective (Holme et al 2001).
- There is some indirect evidence that free skin check clinics may lead to earlier diagnosis, since a sizable portion of participants diagnosed with melanoma say they would not have considered having a physician examine their skin (Koh et al 1996).
- Skin check clinics directed at a high risk population, e.g., surfers (Dozier et al 1997) or elderly war veterans (Swetter et al 2003), produce higher 'hit rates' than self-selected populations.
- In New Zealand, those at higher risk of getting skin cancer are over-represented in skin check clinics (McGee et al 1994). However, studies have found that men, older people and deprived social groups are less likely to seek checks (Eiser et al 2000).
- The positive predictive value of 'skin clinic' screening for melanoma is between 4-17% (Carli et al 2002; de Rooij et al 1997a, 1997b; Jonna et al 1998).
- Practice based interventions to increase skin checking by GPs can dramatically increase opportunistic screening (Lowe et al 1999).
- Follow-up compliance after detection of suspicious lesions at a skin check clinic was reported in one study to be only 77% (Jonna et al 1998).

Screening

- There is no evidence that population screening for skin cancer reduces morbidity or mortality.
- Despite the lack of evidence, population screening is recommended in some countries.
- Although the evidence base is weak, screening for skin cancer is perceived as being of benefit by the public and many doctors (Geller et al 1999; Sladden et al 1999).
- There is some indirect evidence that screening of high-risk populations could reduce mortality from melanoma.
- Surveillance of high-risk populations may be cost-effective when compared to other screening initiatives.

- A community based randomised trial of a population screening programme for melanoma was initiated in Queensland, Australia.
- Many GPs do not have the capacity to undertake screening as part of their usual practice (Lowe et al 2004; Veronesi et al 2003).

Skin Self Examination (SSE)

- Rates of reported SSE vary substantially depending on the questions used to elicit this information (Weinstock 2004; Weinstock et al 1999).
- In New Zealand, SSE is fairly high. For example, 53% of 21 year olds reported checking their skin in the past year, with 20% noticing a change in a mole or freckle (Douglass 1998). SSE was lower (16%) in a more recent survey of a random national sample of the New Zealand adult population, but 55% overall had their skin checked by someone (including themselves) in the last 12 months (Reeder and Trevena 2003).
- Studies consistently show that women and younger people have higher rates of SSE (Carli et al 2003; Douglass et al 1998; Oliveria et al 1999; Weinstock et al 1999). Elderly people are less likely to report changes in moles at an early stage (Christos et al 2000).
- In New Zealand youth, tendency to self check was also associated with knowledge of melanoma and perceived risk of melanoma (Douglass et al 1998).
- Overseas, rates of SSE for groups considering themselves at high risk of melanoma (e.g. family members of melanoma patients) are much higher than in the general population (Manne et al 2004).
- Accuracy of SSE tends to be low (Titus-Ernstoff et al 1996). In one study of highly motivated at risk subjects, 25% could not detect an obvious change in a mole, and 38% detected a change when there wasn't one (Muhn et al 2000).
- Despite its low accuracy, there is some evidence that SSE may reduce melanoma mortality (Berwick et al 1996).
- Photographs of the skin improve the ability to detect changes and therefore the accuracy of SSE (Oliveria et al 2004).
- Educational brochures can improve the accuracy of SSE (Mickler et al 1999).

Primary care management of suspicious lesions

- Knowledge and skills of New Zealand and Australian GPs in detecting and managing suspicious lesions is excellent and high by international standards (Baade et al 2005; McGee et al 1994).
- Short training courses for GPs generally improve knowledge and confidence, and in some cases clinical practice was also modestly improved (Brochez et al 2001a; Carli et al 2005; de Gannes et al 2004; Dolan et al 1997; Girgis et al 1995; Harris et al 1999; Mikkilineni et al 2002).

- Patient-held baseline photographs have been shown to improve specificity of GP excisions, i.e., fewer excisions of benign lesions performed (Hanrahan et al 2002).
- A number of studies have tested the sensitivity and specificity of the ABCDE-rule, the 7-point checklist and the revised 7-point checklist with wide-ranging and often conflicting results (Argenziano et al 1998; Edmondson et al 1999; Whited and Grichnik 1998).
- Debate about tools and rules for discriminating between benign and malignant lesions continues, as does the development of new algorithms based on dermatologists' practice (Day and Barbour 2001; Gachon et al 2005).
- A number of studies describe the signs and attributes of melanomas that do not fit the ABCD rule (e.g. facial, nodular & subungual melanomas and melanomas of the sole) and recommended detection and management of these (Cerroni and Kerl 1998; Chamberlain et al 2003; Helsing and Loeb 2004; Levit et al 2000; Saida 2000; Stante et al 2005).
- Other health professionals, e.g., nurses and dentists, are well placed to notice the early signs of skin cancer (Kutcher and Rubenstein 2004; Maguire-Eisen 2003).

Promptness of presentation and diagnosis

- Studies examining the relationship between delay in diagnosis and thickness of melanoma have produced conflicting results. Some studies have found no association between thickness and delays (Brochez et al 2001b; Helsing et al 1997; Schmid-Wendtner et al 2002; Tyler et al 2005).
- Poor prognosis may be accounted for by aggressive rapidly growing tumours rather than by delays in diagnosis (Richard et al 1999).
- Thicker melanomas are not necessarily older, in fact the thickest lesions (the majority of which are nodular) are associated with shorter delays (Betti et al 2003; Richard et al 1999).
- The subtype of melanoma can affect both the likelihood of delay and the thickness. For example, nodular melanoma is associated with lower delay but higher thickness (Betti et al 2003; Carli et al 2004; Chamberlain et al 2003; Richard et al 1999). Amelanotic melanomas, plantar lesions and absence of pigmentation are associated with longer medical delays (Betti et al 2003).
- Factors associated with early detection include more frequent visits to the GP or dermatologist (Di Quinzio et al 2005; Richard et al 2000a), female gender (Schwartz et al 2002; Weinstock et al 1999), high level of education (Carli et al 2004), knowledge about skin cancer, awareness of being at risk (Oliveria et al 1999; Richard et al 2000a; Schwartz et al 2002), and an adequate supply of dermatologists and family physicians (Roetzheim et al 2000; Van Durme et al 2003).
- Thicker melanomas are consistently associated with increasing age (Hanrahan et al 1998; Osborne and Hutchinson 2001; Richard et al 2000a), male gender (Carli et al 2004; Osborne and Hutchinson 2001;

Richard et al 2000a), sites on the scalp, neck and back (Hanrahan et al 1998; Osborne and Hutchinson 2001), lower education level (Carli et al 2004; Montella et al 2002; Richard et al 2000a; Schmid-Wendtner et al 2002), low awareness of skin cancer (Richard et al 2000a), as well as the type of lesion.

- Several international studies report patient delay from first detection of a suspicious lesion to the first visit to a physician, which is often over a year (Brochez et al 2001b; Schmid-Wendtner et al 2002). New Zealand data on patient delay is not available.
- Amongst young people in New Zealand who had noticed a change in a mole or freckle, 45% sought medical advice. The most common reason for not seeking medical advice was cost (Douglass et al 1998).
- Internationally, the delay interval from the first visit to a physician to surgical treatment was short (< 1 month) in most patients (Richard et al 2000b; Schmid-Wendtner et al 2002).
- Physician delay seems to be attributed to misdiagnosis by GP and to a delay occurring during referral rather than delay in treatment (Blum et al 1999; Brochez et al 2001b).

ADVICE FOR THE PUBLIC ON EARLY DETECTION

Having considered strategies to date, evidence derived from the data analysis and results from the literature review, EDAG recognises two general approaches to promoting the early detection and diagnosis of skin cancer, particularly melanoma. These are:

- improved recognition and presentation by individuals; improved recognition and diagnosis by health professionals
- participation in screening for those at average risk and surveillance for those at increased risk.

EDAG recognises that such approaches are only part of a wider strategy including improved access to primary care and improved diagnostic processes.

Among efforts to date to improve early detection of melanoma in New Zealand have been public education strategies to promote early presentation. These strategies have acknowledged that survival from melanoma may be improved by early symptom identification and that delay in presentation is a key factor in the development of thick melanomas.

The extent to which delay in presentation of signs and symptoms of melanoma occurs in New Zealand, and the reasons for such delay, are currently unknown. Possible personal reasons could include, firstly, a lack of population awareness about (i) skin cancer risk, (ii) the increased risk associated with delay, and (iii) the efficacy of early treatment.

Yet in New Zealand there is evidence of high population awareness that melanoma is a serious skin disease (64% unprompted awareness) and 84% identified excess exposure to solar UVR as a risk factor. Furthermore, when population perceptions were compared with New Zealand cancer statistics, death from melanoma is perceived as being more common than it actually is (Reeder and Trevena 2003). Most people agree that survival is better if cancers are treated early (Reeder and Trevena 2003), although there is some evidence that NMSC is not viewed seriously by outdoor workers (McCool et al 2004).

A second possible reason for delay in presentation could be not checking regularly for skin changes. However, more than half of the population of young people report having had their skin checked, either by themselves or others in the past year (Reeder and Trevena 2003).

A third reason for delay could be lack of knowledge / confidence about what to look for. About half of young adults in New Zealand who noticed skin changes sought medical advice and another quarter said they intended to do so (Douglass et al 1998).

Fourth, there may also be structural barriers to early clinical presentation, such as issues of access, perceived appropriateness and cost. The main barriers to seeking medical advice seem to be perceived cost and uncertainty about what to do. According to findings from a 1988/9 survey, most GPs consider that patients who brought specific lesions to their notice were correct to do so (Elwood and Glasgow 1993).

The extent to which delay in presentation of signs and symptoms of melanoma is a factor in the proportion of thick melanomas occurring in New Zealand is also unknown. While superficial spreading melanoma (the most common type in New Zealand) and lentigo maligna usually develop over months and sometimes years before invasion, nodular melanoma may grow rapidly over a period of weeks or months. In some cases the rate of progress of some melanomas is too rapid to allow early diagnosis and cure (Thomas and Giblin 2006).

Furthermore, while some thick melanomas arise from thin melanomas, others, such as nodular melanomas, may arise *de novo*. Therefore, it cannot always be concluded that thick melanomas necessarily develop from thin melanomas or that all thick melanomas are due to delay in recognition, presentation and/or diagnosis.

Finally, it is possible that some thin melanomas are “histologically malignant but behaviourally benign”; that is, if they were not excised they would never have metastasised or may even have regressed (Burton and Armstrong 1998). No studies have established, however, whether this is the case (Helfand et al 2001).

Although delay in presentation may be associated with some thick melanomas which tend to have a poor prognosis, other factors need to be considered. Such factors are highlighted in a review of evidence on the consequences of delay in diagnosis summarised for the United States Preventive Services Taskforce (USPST) assessment of screening for skin cancer (Helfand et al 2001). The two largest studies examined, one from Scotland (Marghoob et al 1995) and the other from Australia (Hersey et al 1991), found no relationship between delay in diagnosis and tumour thickness. The Australian study found that male gender, nodular melanoma and location on the head and neck (but not delay) were associated with thick melanoma. Some of the other studies cited note that misdiagnosis was a common cause of delay in treatment, while others concluded that poor prognosis was due to rapidly growing tumours rather than delays (Helfand et al 2001).

In light of the above, EDAG recognises the need for research in New Zealand to identify the extent to which delays in presentation, as well as diagnosis and treatment, are factors related to melanoma thickness, among which groups such delays are occurring and the reasons for these.

Presentation and signs of melanoma

While acknowledging that further research is needed in relation to recognition and presentation by individuals, recognition by health professionals, access to primary care and diagnostic processes, EDAG supports ongoing efforts to educate the public about signs and symptoms.

As identified in the report *Melanoma in High-Risk Groups in New Zealand* (Sneyd 2006), in a recent Australian study, nearly half the melanomas (44%) were first noticed by the patient themselves and only one quarter were first noticed by a doctor (McPherson et al 2006). Compared to men, women were more likely to have noticed their own melanomas (57% versus 34%) whereas melanomas in men were more likely to be diagnosed by their partner (27% versus 8% in women). Overall, about 80% of melanomas detected by a doctor were thin (<0.75 mm) compared to 62% if detected by a lay-person.

The high contribution to the detection of melanomas made by women might suggest that education of women to detect melanomas earlier could be of most benefit.

As identified from original data from her PhD thesis, Sneyd (1999) found similar results for New Zealand as those outlined above for Australia. Of all invasive melanomas, nearly half (49%) were first identified by the patient and 30% by a relative or friend. For melanomas >1.5 mm thick, 58% were first identified by the patient and 29% by a relative or friend.

To reduce the number of deaths from melanoma the general public need to inspect their skin and recognise early melanomas when they see them. It has been shown that it is difficult for people to detect changes in skin lesions as they had difficulty remembering the appearance of lesions (Hanrahan et al 1997). Photographic records may help the detection of changing lesions (Hanrahan et al 2002).

Two main algorithms are promoted for facilitating the detection of early, thin melanomas: ABCD (E) and the 7-point checklist.

ABCD (E) rule: **A**symmetry, **B**order irregularity, **C**olour variation, **D**iameter >6 mm, and **E**levation (or sometimes **E**nlargement) above surrounding skin. Enlargement is bracketed as it is often not included in this rule. More recently, the 'E' in the ABCDE criteria has come to stand for evolution, referring to growth or change. The most common form of melanoma, superficial spreading melanoma, is usually flat and so strict adherence to this rule would miss these common lesions.

7-point checklist: 3 major signs (change in size, change in shape and change in colour) and 4 minor signs (inflammation, crusting or bleeding, sensory change or itch, and diameter ≥ 7 mm). These are

generally described as changes in size, irregular shape and irregular colour.

An Australian study found that a change in size, development of a new lesion and change in colour were most useful in distinguishing melanomas by patients (Liu et al 2005). The ABCDE rule failed to discriminate between melanoma and benign pigmented lesions.

In another study, which included a sample from the general public as well as patient groups from skin clinics (albeit with a low response rate), short instruction about ABCD criteria improved their immediate ability to decide the appropriate action for a given skin lesion (Branstom et al 2003). Whether this improvement persisted over time was not assessed.

Further, in other work, about 1/3 of melanomas were ≤ 6 mm in diameter so it is important to emphasise that the ABCDE rule is not absolute (Fernandez and Helm 2004).

A 2006 Australian study reported that the most common sign or symptom in patients with thin melanomas were a change in colour or size and brown or black pigmentation. The most common signs or symptoms in patients with thick melanoma were change in shape, bleeding/weeping, and a change in colour or size (McPherson et al 2006).

Nodular melanoma accounts for the majority of thick melanomas, followed by acral melanoma, and these types may be difficult to recognize early in their natural history as they often do not fulfil the ABCD criteria. Nodular melanoma does not tend to present with a change in shape or colour (major criteria of the 7-point checklist) but is more likely to present with bleeding and rapid growth (elevation) (Chamberlain et al 2003). A significant number are amelanotic and ≤ 6 mm. The thinner nodular melanomas change less obviously and are more often amelanotic in comparison to the thicker lesions. These characteristics are more likely to obscure early detection.

Encouraging familiarity with skin appearance among the general public and appropriate presentation to a doctor may increase the proportion of thin melanomas diagnosed (Sneyd 2006). However, it has not been shown that increased detection of thin melanoma is associated with a decreased incidence of thick melanoma and an improvement in survival (McPherson et al 2006). That nodular melanoma is so difficult to detect early is probably contributing to the stable rates of thick melanoma (Chamberlain et al 2003).

In the absence of definitive work on ABCDE versus the 7-point checklist (Argenziano et al 1998; Edmondson et al 1999; Whited and Grichnik 1998), Sneyd (2006) concluded that the ABCDE checklist is likely to be preferable for the public because of its simplicity and familiarity. However, for the identification of nodular and acral melanomas, information should address the following.

- Melanomas can occur on the soles of feet, palms of hands and under fingernails and toenails. These types are not common in white-skinned populations but are a more common form in darker skinned populations.
- Nodular melanoma may be a fast-growing lump which bleeds/weeps, but is not always dark coloured (unlike superficial spreading melanoma and lentigo maligna which tend to be dark).
- Nodular melanoma may not show obvious *change* in asymmetry, or borders or colour in the early stages, but will usually become elevated quite quickly or catch on clothing.

Screening and surveillance

In the context of this report, EDAG has defined screening as the testing/checking of people at average risk of developing skin cancer, particularly melanoma, who are unaware of any signs or symptoms. Surveillance is the ongoing monitoring of those known to be at increased risk of developing melanoma.

Skin cancer screening and surveillance involve a total body examination by a health professional. Recently, various technologies have been introduced, including digital photography and processes where suspicious lesions are mapped on a whole body image (mole mapping). These methods identify lesions which could be melanoma or other forms of skin cancer and that require further assessment by a doctor.

As highlighted in a recent Cancer Council of Australia publication devoted to melanoma, one of the most contentious issues with regard to skin cancer is whether to encourage or discourage routine screening of those at average risk (Elwood 2005). Although screening should in theory improve early detection and survival, there have not been any trials establishing its effectiveness in diagnosis and in reducing deaths.

A number of groups have developed criteria for assessing population screening, all of which build upon the World Health Organization principles of screening first proposed in 1968 (Wilson and Jungner 1968). Examples are the United Kingdom National Screening Committee (2000), United States Preventive Services Taskforce (2001), the Canadian Strategy for Cancer Control: Screening Working Group (2002) and the New Zealand National Health Committee (2003).

Drawing upon these examples, the Cancer Society of New Zealand developed criteria which address opportunistic as well as population screening in order to address individual consumer needs. The criteria relate to those at average risk; they do not apply to the surveillance of those at high risk, which requires a different assessment process.

Screening for skin cancer (particularly melanoma)

In considering its advice, EDAG applied the Cancer Society criteria to screening for those at average risk of skin cancer, with a particular focus on melanoma. The group's assessment and conclusions are provided in Appendix 4. Also included are the positions of some other overseas organisations.

EDAG concluded that although skin cancer, particularly melanoma, is an important health problem, population screening does not meet the Cancer Society criteria. Of particular significance is that:

- there is no high quality evidence from a randomised controlled trial that screening is effective in reducing mortality; therefore, its value is unknown
- it is not possible to conclude whether or not screening for skin cancer does more good than harm (possible harms including unnecessary biopsies and treatment).

As a result EDAG recommends that:

- population screening for melanoma, basal cell cancer or squamous cell skin cancer not be endorsed or promoted in New Zealand
- opportunistic screening by health professionals should not be encouraged as routine practice. In situations where it is undertaken it should be done on the basis of informed choice. Individuals should be informed about the potential benefits and risks of screening and the likely implications of a positive or negative result
- clinicians and other health professionals should remain alert for skin lesions with malignant features in the context of physical examinations performed for other reasons.

EDAG emphasises that the above recommendations apply to those at average risk of skin cancer, particularly melanoma. Recommendations for the surveillance of those at high risk of melanoma are addressed separately.

For those at average risk, EDAG also considered the evidence in relation to self-screening by individuals (skin self-examination), involving a thorough examination of the skin by following a particular technique. Although some evidence supports its value among those at high risk, its sensitivity as a screening tool is low and there is no clear evidence that it reduces morbidity or mortality.

As recognition of early signs and the early seeking of medical advice are key factors in early detection of skin cancer, particularly melanoma, EDAG recommends 'skin cancer awareness'. This is analogous to promoting 'breast awareness' rather than breast self-examination. People, particularly those over the age of 50, should regularly look at their skin (including skin not normally exposed to the sun) so that they will be aware of any changes; they should ask

for help from someone else to check difficult to see areas, such as their back. Those who are concerned about skin changes should seek advice from a doctor.

Surveillance of high risk groups

In considering the issue of surveillance of high-risk individuals, EDAG has based its recommendations on the report *Melanoma in High-Risk Groups in New Zealand* (Sneyd 2006). As highlighted in the report, most recommendations for such surveillance have not been evaluated regarding their effect on incidence or mortality.

According to the report, it is unclear what absolute risk in any individual should trigger increased surveillance, if at all (Meyskens and Ransohoff 2006). Surveillance of people identified as being at high risk of melanoma could include physician and self skin examinations, risk education and reduction of UV exposure. Genetic testing for CDKN2A mutations is not recommended as appropriate care can be delivered independent of the results of genetic tests.

As identified earlier, high risk groups include those people with a personal or family history of melanoma, classical atypical mole syndrome (CAMS), presence of atypical naevi, large numbers of naevi, previous non-melanoma skin cancer, and any combination of these risk factors (Table 4).

Many studies have shown that surveillance for melanoma in families results in thinner melanomas (Masri et al 1990; Vasen et al 1989). In very high-risk people, screening and interventions have resulted in earlier-stage diagnoses (Mackie et al 1993; Masri et al 1990).

An evidence-based approach to the development of guidelines for surveillance of melanoma is needed for New Zealand.

Self and physician skin examination for high risk groups

As noted earlier, screening by whole-body skin examination should in theory improve early detection and survival but this has not been proven. However, in some high-risk groups, surveillance including screening by skin self-examination has been shown to have some effect.

In an Australian study of skin self-examination (SSE) (Aitken et al 2004), older people at higher risk of melanoma examined their skin less often than younger people but there was a suggestion of increasing SSE with known risk factors for melanoma. The main difficulty people experience with self-detection of melanoma is their limited recall of skin appearance over time. Personal photographic records (a photo book) may be effective at detecting changes at longer intervals (Phelan et al 2003).

One study in the United States suggested that, although their response rate was low, about 59% of physicians were doing skin examinations of their high-risk patients (Geller et al 2004). Others have shown physician skin examination rates of about 50% in high-risk groups.

Photographic surveillance involves taking baseline whole body photographs in patients at high-risk. Comparisons are then made at periodic surveillance examinations. This may help identify changing or new skin lesions. Single-lesion photography may be used for people at lower risk but who have a single lesion which warrants monitoring. Although photography may be shown to be useful in the surveillance of high-risk patients with multiple naevi, these benefits have not yet been established. However, surveillance of patients with multiple dysplastic naevi is preferable to prophylactic excision of lesions (particularly since many melanomas arise *de novo*) and may result in detection at an earlier stage (Kelly et al 1997).

Digital photography (sometimes called digital dermoscopy) may be used to record lesions. Various systems are available that provide the dermoscopic digital camera, storage and retrieval systems; some have computer-aided diagnostic tools. Digital photography may improve the accuracy of melanoma detection and reduce the number of biopsies for benign lesions (CIGNA 2005).

Comparative New Zealand studies are needed to validate the relative sensitivity and specificity of photographic surveillance versus visual examination followed by surgical excision of suspicious lesions. Although sensitivity may be improved, specificity of photographic surveillance is reported as about 50%. Data are inadequate regarding computer-assisted analysis of dermoscopic lesions compared to conventional photographs (CIGNA 2005).

Risk education and reduction in sun exposure for high risk groups

Patients previously diagnosed with melanoma are at high risk of developing further primaries. Sun-protective measures may help reduce risk in these patients but there is as yet little evidence to support this.

It is well known that general information to alter sun-seeking behaviour increases awareness but does not necessarily translate into behavioural change (Boggild and From 2003; Jerkegren et al 1999; Theobald et al 1991). In a study of patients with dysplastic naevi (a high-risk group) (Brandberg et al 1996), despite being aware of increased risk, these people were still careless about sun exposure. A similar finding was made in relatives of patients with melanoma: habitual sun protection was relatively low (Manne et al 2004). In a Canadian study more patients stayed out of the sun and avoided peak hour sunshine and fewer sunbathed after the diagnosis of melanoma (Freiman et al 2004). The effect on subsequent melanoma development was not assessed.

Surveillance of high risk groups: Recommendations of other groups

International guidelines on surveillance of high risk groups lack consensus.

In Australia the National Health and Medical Research Council (NHMRC) clinical practice guidelines advise people at high risk of melanoma to be advised of the specific changes which suggest melanoma, encouraged to perform self-examination and offered a surveillance programme.

The Cancer Council Australia and the Australasian College of Dermatologists recommend that general practitioners develop surveillance programmes for those at high risk.

The American College of Preventive Medicine (ACPM) recommends that periodic total cutaneous examinations be performed, targeting populations at high risk for malignant melanoma. However, they find insufficient evidence to characterise periodicity of skin examinations more precisely (Ferrini et al 1998).

The National Cancer Institute encourages routine examination of the skin, with particular emphasis on high-risk groups.

The Canadian Task Force on the Periodic Health Examination finds 'fair' evidence to include inspection of the skin in the periodic health examination for those at high risk.

The U.S. Preventive Task Force, American Academy of Family Physicians, and American College of Obstetrics and Gynaecology recommend screening only for high-risk populations with a family or personal history of skin cancer, increased occupational or recreational exposure to sunlight, or clinical evidence of precursor lesions. e.g., dysplastic or congenital naevi.

RECOMMENDATIONS FOR EARLY DETECTION OF SKIN CANCER, PARTICULARLY MELANOMA

In developing these recommendations, EDAG used as a starting point the recommendations of the Elwood and Glasgow report (Elwood and Glasgow 1993), with additional information from subsequent New Zealand data analysis (Richardson and Fletcher 2006, Sneyd 2006), the stocktake of New Zealand activities and the literature review.

Strategies to provide high quality information

It is important to ensure that both health professionals and the general New Zealand public retain a high level of knowledge about skin cancer, particularly melanoma. EDAG therefore recommends strategies that will provide high quality information on skin cancer, particularly melanoma, comparable to the information programmes developed by the Cancer Society for prostate and breast cancers.

The programme should begin with the provision of information for health professionals and health workers in order to ensure that they have a good understanding of the risks, diagnostic processes and management of skin cancer, particularly melanoma.

The overall objectives of the programme would be to:

- provide information to assist health professionals in their understanding of the risks, diagnosis and the management of skin cancer, particularly melanoma
- increase knowledge about skin cancer, particularly melanoma, among other relevant health workers (e.g., physiotherapists)
- maintain a high level of knowledge about skin cancer, particularly melanoma, in people 50 years and over
- improve the quality of information currently available to people 50 years and over, including what to look for and specific information on nodular melanoma, as nearly half (46.7%) of thick (>3 mm) melanomas are nodular
- encourage people to consult a doctor about suspicious lesions.

Target audiences would be:

- intervention groups
 - health professionals and health workers
 - professional and public media
- population segment
 - people 50 years and older.

Research to better target future early detection strategies

In order to better target early detection strategies to reduce mortality from skin cancer, particularly melanoma, in New Zealand, EDAG recommends that research be undertaken to identify more specifically:

- who is most likely to develop which type of melanoma (e.g., nodular)
- who is most likely to develop thick melanoma
- who is most likely to die of melanoma
- the extent to which delay in recognition/presentation/diagnosis occurs in New Zealand and reasons for this.

Other early detection strategies

Skin check programmes/clinics

EDAG does not recommend the practice of skin check (sometimes referred to as spot check) programmes/clinics outside of established medical practice. This is because they have not been evaluated and because of concerns about the possibility of:

- inadequate follow up and referral
- inadequate lighting (which could result in a lesion being missed)
- lack of privacy
- examination of single lesions without a full body examination
- the risk of creating a false sense of security among consumers.

As recommended by Elwood and Glasgow (Elwood and Glasgow 1993), EDAG recommends monitoring and evaluation of existing skin check programmes/clinics, which would provide useful information about their effectiveness.

Screening for skin cancer

Although cancers of the skin, particularly melanoma, are an important health problem, screening does not meet the Cancer Society criteria for endorsement. Of particular significance is that:

- there is no high quality evidence from a randomised controlled trial that screening is effective in reducing mortality, therefore its value is unknown
- it is not possible to conclude whether or not screening for skin cancer does more good than harm (possible harms including unnecessary biopsies and treatment).

As a result, EDAG recommends that:

- population screening for melanoma, basal cell or squamous cell skin cancer should not be endorsed or promoted in New Zealand
- opportunistic screening by health professionals should not be recommended as routine practice. In situations where screening is undertaken, it should be done on the basis of informed choice. Individuals should be informed about the potential benefits and risks of screening and the likely implications of a positive or negative result.

EDAG also recommends that clinicians should remain alert for skin lesions with malignant features in the context of physical examinations performed for other reasons.

Skin cancer awareness

As recognition of early signs and the early seeking of medical advice are key factors in early detection and effective treatment of skin cancer, particularly melanoma, EDAG recommends the promotion of 'skin cancer awareness'. People, particularly those 50 years of age and over, should be encouraged to regularly look at their skin (including areas not normally exposed to the sun) so that they will be more aware of any changes; they should ask for help from someone else to check difficult to see areas, such as their back. Those who are concerned about observed skin changes should seek advice from their GP or another doctor.

Surveillance of high risk groups

Those at high risk of developing melanoma represent a small but important population group. Although there is broad agreement that individuals at high risk should be identified and offered surveillance, most surveillance recommendations have not been evaluated regarding their effect on incidence or mortality. EDAG's recommendations in relation to surveillance are outlined as follows.

Development of surveillance recommendations and assessment tools

EDAG recommends that:

- an evidence-based approach to the development of guidelines for surveillance of melanoma is needed for New Zealand
- comparative New Zealand studies are needed to measure sensitivity and specificity of diagnostic technologies in comparison to visual skin inspection
- genetic testing (e.g. for CDKN2A) should *not* be carried out.

EDAG also recommends that:

- self-administered, personal risk assessment tools for New Zealanders be developed and tested
- a prognostic index or risk chart for melanoma in New Zealand conditions be developed.

Advice for health professionals and the public

Until the above recommendations can be implemented, EDAG recommends that:

- information for health professionals and consumers include risk factors in relation to those at high risk
- consumers be advised to discuss with their GP or other doctor appropriate surveillance measures.

EDAG recommends that the above issues about surveillance and assessment be brought to the attention of those developing Trans-Tasman Guidelines for the Management of Melanoma.

Recognition and management in medical practice

As previously identified, EDAG recommends that GPs, dermatologists and others involved in the management of melanoma, including general surgeons, be provided with updated information in order to encourage a high level of knowledge and skills for the recognition and appropriate management of suspicious lesions in both primary and secondary (specialist) care.

In this regard, EDAG recommends that:

- national standardised guidelines for the recognition and management of suspicious lesions be developed
- until such guidelines become available, the interim New Zealand Dermatological Society guidelines on the DermNet website be recommended
- any primary care-based interventions to improve the recognition of melanoma and other skin cancers be evaluated
- the evidence be reviewed in relation to primary care-based interventions to improve the recognition of melanoma and other skin cancers
- the involvement of New Zealand be pursued in the current review of the Australian NHMRC Guidelines for the Management of Melanoma, to develop these into Trans-Tasman guidelines
- the potential for academic primary care units to assist with research and evaluation in the area of GP training also be explored.

Promptness & accuracy of histological diagnosis & reporting of melanoma

Data on melanoma thickness have been collected by the Cancer Registry since 1994. EDAG supports the ongoing collection of these data and recommends measures to increase the completeness of this reporting.

EDAG notes that the term thickness is now used rather than depth and recommends that:

- the appropriate target for thickness should be less than 1.00 mm thick rather than 0.76 mm (as stated in the Elwood and Glasgow report) to be consistent with the American Joint Committee on Cancer (AJCC) staging classification published in 2000
- Breslow thickness should be used by pathologists and the Cancer Registry in conjunction with Clark's level, as Breslow thickness has greater prognostic relevance.

EDAG recommends that the Cancer Registry consider adding melanoma in-situ to be reported to achieve improved completeness of data. This may require a change to the existing legislation. Reasons for such inclusion and other issues in relation to melanoma in-situ are as follows.

- Widespread opportunistic screening may lead to an increase in the detection of in-situ melanomas. Registration would enable monitoring of such screening and assessment of incidence of in-situ melanomas in relation to any trends in the incidence of thick melanomas.
- Melanoma in-situ (including lentigo maligna) may appear indistinguishable clinically from invasive superficial forms of melanoma (superficial spreading melanoma, lentigo maligna, acrolentiginous melanoma); histologically, these forms of invasive melanoma arise within areas of melanoma in-situ. Registration may help to encourage medical professionals to manage melanoma in-situ appropriately.
- As melanoma in-situ should be treated in the same way as invasive melanoma, i.e., it should be completely excised and the patient should be followed up, registration will help to ensure it is treated as cancer and not ignored.
- Melanoma in-situ should not be left untreated, except in rare circumstances (lentigo maligna has a low rate of conversion to invasive disease and acceptable management includes observation in the elderly where excision is going to be extensive and/or difficult). This decision should be made by an appropriate specialist, i.e., dermatologist or plastic surgeon.
- There are occasional reports of metastatic disease in patients without a history of invasive melanoma but who have had melanoma in-situ diagnosed and removed. This may be a reflection of the limitations contained within routine tissue sampling and sectioning or, uncommonly, due to diagnostic error. Registration will help to ensure there will be a record of the disease.

EDAG recommends the use of standardised synoptic reporting for both in-situ and invasive melanomas. This recommendation should be referred to the Ministry of Health Cancer Treatment Working Party.

EDAG supports the current development of a national cancer treatment database (the National Cancer Management Database) by the New Zealand Health Information Service. EDAG recommends that specific data in relation to melanoma be included and linked to the Cancer Registry

EDAG also recommends that standardised reporting guidelines be adopted, the need for which is highlighted by the number of unspecified melanomas (according to type) reported to the Cancer Registry.

EDAG notes that there are no national data in New Zealand on the time period from initial recognition of lesion to diagnosis, highlighting the need for a prospective study with retrospective questions to identify reasons for late presentation. EDAG recommends that such research be undertaken and that it is recognised as being an urgent priority.

Data analysis

EDAG concurs with the following needs identified in the report of Sneyd (2006) in relation to data collection and analysis in New Zealand.

- Detailed melanoma survival analysis is needed in New Zealand: thickness of melanoma and presence of metastases are only surrogate measures for death.
- Age-period-cohort modelling of trends in melanoma diagnoses is needed.
- Age-period-cohort modelling of trends in melanoma thickness is needed.
- Closer communication with the Cancer Registry is needed with respect to error checking.
- Ethnic differences in melanoma require more investigation.
- Discrepancies in use of melanoma NOS (type unspecified) classification require examination.

Strategic approach for the control of skin cancer, particularly melanoma, in New Zealand

In light of the above recommendations, and recognising that limited action has taken place in New Zealand to implement the 1993 recommendations of the Elwood and Glasgow report, EDAG recommends that:

- melanoma control in New Zealand be coordinated

- a database of who is working in the area of skin cancer in New Zealand be developed
- national leadership for melanoma control in New Zealand be established
- relationships with overseas experts, especially in Australia, be established
- a national meeting on melanoma control in New Zealand be organised
- the above issues be brought to the attention of the Cancer Control Council.

APPENDIX 1: POSITION STATEMENT OF THE CANCER SOCIETY OF NEW ZEALAND



POSITION STATEMENT

Skin Cancer Prevention and Early Detection

Skin cancer is the most common cancer in New Zealand with in excess of 50,000 new cases and around 300 deaths per year. Most are considered preventable. The Cancer Society aims to help reduce skin cancer incidence and mortality by promoting sun protective environments and practices and encouraging early detection.

Skin cancers fall into two main groups, namely melanoma (*cutaneous malignant melanoma*) and the non-melanoma skin cancers (NMSC), mainly *squamous cell carcinomas* and *basal cell epitheliomas*. Skin cancer is the most commonly occurring cancer worldwide, although the incidence of melanoma, alone, is fully documented.^[1] Melanoma is the type of skin cancer most likely to be fatal because of its malignancy and potential metastatic spread, mainly via the lymphatic system, to other body sites, in particular the lungs, liver and brain.

In New Zealand, overall, there are an estimated 50,000 or more new cases and around 300 deaths per year from all forms of skin cancer, which has an impact on many people and results in an estimated \$33M in direct costs to the health system.^[2] Skin cancer prevention is an acknowledged priority in the New Zealand Cancer Control Strategy.^[3]

Of the skin cancers, only melanoma and a small number of non-melanoma cases, such as dermatofibrosarcoma and Merkel cell tumours, are required to be registered in New Zealand. The less life-threatening and much more numerous NMSC cases are not registered because of resource considerations.^[4] Melanoma is New Zealand's fifth most

common registered cancer, accounting for approximately 1,500 new cases and 230 deaths a year.^[4] Melanoma is the most common tumour in young New Zealand adults, 20-39 years. New Zealand melanoma incidence and death rates are among the highest in the world,^[5] with the age-standardised incidence rate for the European population of Auckland, the most populous province, the highest reported world-wide (56.2/100,000).^[6]

Both incidence and mortality rates for melanoma appear to have stabilised and incidence may be declining in people under 50 years.^[7] Men older than 50 years tend to present with more advanced melanoma and have a higher mortality rate.^[8] The most recent, historically adjusted population projections indicate stable or declining melanoma incidence and mortality rates.^[9]

Prevention

Exposure to solar radiation may account for as much as 90% of all skin cancer cases.^[10] Although melanoma has a genetic component,^{[11][12]} most skin cancers are considered preventable through the avoidance of excess sun exposure, particularly that which results in sunburn (*erythema*). Episodes of acute, intermittent sun exposure, in particular during recreational activities and holidays, have been associated with increased risk of melanoma^[13] and there is evidence that this risk relates to sun burn at any age,^[14] although residence in a high UV radiation environment in early life is associated with the highest melanoma risk,^[15] which suggests that sun exposure early in life may be particularly important.^[16] The pattern for basal cell skin cancer is similar to that found for melanoma, being related to intermittent, acute sun exposure and showing little relation with total lifetime exposure or occupational exposure. Squamous cell skin cancers favour sites that are routinely exposed to the sun and tend to be associated with cumulative, long-term occupational and recreational exposures. Workers in agriculture, forestry, fishing, construction and similar outdoor occupations are, potentially, most at risk for this type of cancer.

Although the production of vitamin D₃ in the skin through sun exposure is required for healthy bone development and maintenance, for most people this exposure can usually be achieved during short periods outdoors such as normally occur in everyday life,^[17] with people having the darkest skin colour needing longest exposure. Only in particular circumstances is this everyday exposure likely to be inadequate, for example, among the elderly in residential care or those who habitually wear full body cover clothing, such as that worn by some Muslim women.^[18] There is no known health gain from levels of exposure that result in tanning or burning. The use of sun beds and sun lamps is not recommended as there is no evidence of any health benefits and there are risks. The hypothesis that sun bed use is associated with increased risk is consistent with the epidemiological data for melanoma^[19] and NMSC.^[20]

Despite differences in aetiology, the successful prevention of all types of skin cancer depends on reducing excess and harmful exposure to UVR at all ages, and on changing attitudes towards tanning so that harmful sun exposure and the incidence of sunburn can be reduced. Accordingly, the Cancer Society aims to reduce the burden of skin cancer incidence and mortality by promoting sun protective environments, for example, through

the use of shade, and by encouraging personal sun protective practices, early detection and appropriate treatment. These strategies are appropriate for the prevention of both melanoma and NMSC.

Current prevention recommendations to the public are:

1. To avoid the sun as much as possible at times when there are particularly high levels of solar ultra violet radiation (UVR), that is between 11am and 4pm during daylight saving months.
2. When sun avoidance during the hours of greatest risk in summer is not possible, the recommendations are to:
 - use appropriately protective clothing and a hat to protect the skin;
 - apply sunscreen on any unprotected skin.
3. The sunscreen used should be an SPF30+ broad spectrum, water-resistant product which meets the Australian / New Zealand Standard. It should be applied thickly and re-applied either when it has worn off through washing or rubbing or after about two hours.
4. To avoid tanning either in the sun or through the use of sun beds or sun lamps.

Early detection

Early detection and treatment is important for skin cancer control, most especially melanoma, and has the potential to reduce deaths. The trend in New Zealand towards stable melanoma mortality rates may be due to earlier diagnosis and treatment. The best indicator of the likely effectiveness of early diagnosis is a reduction in the incidence of melanomas that are more than 0.76 mm deep. National data on depth distribution have been collected since 1995, following legislation on cancer registrations, in order to monitor progress in controlling melanoma, however, a longer time series is required before trends can be observed in the age-standardised rates of thick melanomas.^[7] For NMSC, treatment before the invasive stage and, in rare cases, before any spread beyond the primary site is also important.

There is some evidence of benefit from self-screening.^[21] The greatest delay in treatment usually occurs before the first visit to the doctor, so encouragement of the recognition of early signs and the early seeking of medical advice are key factors in skin cancer control. There is some evidence that the level of knowledge and awareness about the early signs of melanoma is high among young New Zealand adults,^[22] although knowledge does not necessarily translate into appropriate protective practices. The main group to be targeted for early detection continues to be people over 50 years, particularly men, who are often less able to identify melanoma. Many patients are diagnosed with melanoma when being examined by a medical practitioner for some other reason. There are few data about the effectiveness of either population screening for melanoma^[21] or routine general skin examination by general practitioners. Informal skin check programmes have been useful for increasing public awareness of skin cancer and professional interest and expertise, however, these 'Spot Checks' are no longer recommended by the Society. The Cancer Society of New Zealand, along with the Cancer Council Australia^[23], does not support

large scale population-based screening, but recommends that people should visit their general practitioner if a freckle or mole is changing.

Recommendations

The Cancer Society of New Zealand and the Australasian College of Dermatologists:

- do not recommend mass or population-based screening for NMSC or melanoma
- recommend that General Practitioners develop surveillance programmes for patients at high risk (see Appendix 1)
- recommend that General Practitioners assess patients who are concerned and develop appropriate management programmes depending on their level of risk
- recommend that General Practitioners who identify risk factors for skin cancer in patients presenting for other reasons, inform patients about sun protection measures and offer them opportunity for a full body examination and an appropriate management plan (i.e. case finding with follow up)

Current early detection recommendations for the public are to:

1. be aware of skin changes and watch for new or changing freckles or moles;
2. consult a doctor immediately if a freckle or mole is either growing larger or changing in shape or colour.

Overall, the Cancer Society seeks to reduce the incidence of skin cancer through a health promotion programme, which includes:

- Working in alliances with other agencies involved in promoting sun protection, nationally and at regional level;
- Collaborating on the development of national standards for shade materials and guidelines for shade provision;
- Advocating for public health support of sun protection programmes;
- Regular monitoring of sun protection through a triennial national survey and a biannual primary school survey;
- Efforts of maintaining public awareness, nationally and at regional level;
- Promoting sun safe policies, environments and practices for schools and other agencies.

Statement of intent

- The Cancer Society of New Zealand regards primary prevention the most important area for skin cancer programmes and for research.
- At Cancer Society of New Zealand summer outdoor day functions, including all divisions and centres, shade will be provided and sun protective clothing and hats worn and provided.
- The Cancer Society will encourage people to have a whole skin examination by their

general practitioner when they notice any changes in a freckle or mole.

- The Cancer Society will use the media and speak out on sun protection issues and early detection of melanoma.
- The Cancer Society will liaise with agencies working for melanoma control both in New Zealand and overseas.

October 1999

Reviewed July 2003

Categories of skin cancer risk:

High risk

- have a family history of skin cancer/melanoma, have a large number of acquired or dysplastic naevi (moles), and/or have a previous history of melanoma
- have white skin, which burns rather than tans, are aged 50 or more and have solar keratoses
- are immunosuppressed or have xeroderma pigmentosa

Average risk

- have skin that burns or burns then tans and a history of sunburns
- have skin that burns or burns then tans and work outdoors
- have skin that burns or burns then tans and are aged 50 or over

Concerned individuals

- individuals who, in response to public education programmes, perceive themselves to be susceptible to developing skin cancer.

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APPENDIX 2: EDAG TERMS OF REFERENCE

Terms of Reference for the Early Detection (of skin cancer) Advisory Group

Group Name

The full name of the committee will be the 'Early Detection Advisory Group' (EDAG). In this document the Early Detection Advisory Group will be referred to as 'the group'.

Aim

To improve the health of the population by preventing and reducing illness, disability and death rates from skin cancer, particularly melanoma.

Purpose

To develop evidence-based policy and strategies for the early detection of skin cancers, particularly melanoma, to reduce mortality.

Tasks

The tasks of the group include, but are not limited to, the development of evidence-based policy and strategies for the early detection of skin cancer particularly melanoma.

Conflict of Interest

Members should formally document their conflicts of interest and identify any conflict of interest prior to a discussion of a particular issue. EDAG will then decide what part the member may take in any relevant discussion. Further guidance can be found in the *Conflict of Interest Protocols for Ministry of Health Advisory Committees*.

Chairperson

The chairperson will be elected from within the SunSmart Partnership project team. All meetings must be presided over by the chairperson or the acting chairperson in his/her absence. The SunSmart project team has suggested Betsy Marshall accept this role.

Meeting Frequency and Conduct

It is expected that EDAG will meet 2-3 times between October 2005 and April 2006 with a final report due on 30 June 2006.

Group Composition

The group will comprise of 10-15 members who have been appointed for their particular expertise in matters relating to skin cancer. The SunSmart project team will appoint members, after discussion with relevant stakeholder groups. If vacancies occur, the SunSmart project team will seek input from the group on

specific skills and knowledge required. The group may co-opt other member(s) as required to address any gaps.

Group members may also, at any time, resign by providing notice in writing to the Chairperson.

The EDAG will be formed by the following selected organisations nominating a representative.

- Health Sponsorship Council
- Cancer Society of New Zealand
- Ministry of Health
- Royal NZ College of General Practitioners
- NZ Dermatological Society
- Royal College of Australasian Pathologists
- Australasian College of Surgeons
- NZ Association of Plastic Surgeons
- NZ Guidelines Group.

Expertise will be sought with regard to the following areas.

- Epidemiology
- Health promotion
- Social and behavioural research
- Māori health
- Consumer representation
- Communications.

Reimbursement

There will be no meeting fee; however there will be reimbursement of costs to attend the meeting.

Confidentiality

The provisions of the Official Information Act 1982 also apply without exception to the activities of the group.

Period of the Group

The group shall be established for a period of 12 months beginning in September 05 and concluding at the end of September 2006.

APPENDIX 3: LITERATURE REVIEW

Methodology

This rapid review has collected primary data from a number of sources. While there was a lack of randomised controlled trial (RCT) research, findings were elicited from other studies such as non-randomised trials and experiments, observational studies and systematic reviews (but not literature reviews). This synthesis is not a systematic review of primary data as the time frames did not allow for such a comprehensive approach. We have not conducted a systematic search for grey literature. Again, this is not to discount the validity of such data – we believe they have an important place in the process of gathering evidence for making decisions about this area. However, methods to systematically search and gather such data were beyond the scope of this rapid review.

Identification of the relevant literature

An extensive and systematic search of the published scientific literature was conducted. The search strategy was devised in collaboration with New Zealand Health Technology Assessment (NZHTA) and an example of a search strategy is shown below. Key words were determined by the authors in conjunction with NZHTA. The following areas were included:

- Public awareness campaigns on early warning signs/detection
- Interventions that aim to increase awareness of the need to present suspicious spots for checking without delay
- Reasons for delay in presenting
- Services such as spot check clinics, mole mapping etc, including GP-run services and other case-finding interventions.

Sources Searched

Bibliographic databases

Medline
Embase
Cinahl
Current Contents
Index New Zealand
Te Puna- New Zealand Bibliographic Database

Review databases

Cochrane Database of Systematic Reviews
Database of Abstracts of Reviews of Effects
Health Technology Assessment Database
ACP Journal Club

Guidelines

Guidelines International Network <http://www.g-i-n.net/>
CMA Infobase Clinical Practice Guidelines <http://mdm.ca/cpgsnew/cpgs/index.asp>
NELH Guidelines Finder <http://libraries.nelh.nhs.uk/guidelinesFinder/>
US Guidelines Clearing House <http://www.guidelines.gov>

Other sources

Royal New Zealand College of General Practitioners <http://www.rnzcgp.org.nz>
New Zealand Family Physician <http://www.rnzcgp.org.nz/news/nzfp.php>
RNCZGP Research Unit (Auckland University) <http://www.gpresearch.auckland.ac.nz/>
RNZCGP Research Unit (Otago University) <http://www.gpresearch.otago.ac.nz/>
Royal Australian College of General Practitioners <http://www.racgp.org.au/>
Australasian College of Dermatologists <http://www.dermcoll.asn.au/>
Victoria Skin and Cancer Foundation <http://www.skincancer.asn.au/>
Cancer Council of Australia <http://www.cancer.org.au/>
Queensland Health <http://www.health.qld.gov.au>
Royal College of General Practitioners <http://www.rcgp.org.uk>
Australian Department of Health & Ageing publications <http://www.health.gov.au>
NSW Health <http://www.health.nsw.gov.au>
South Australia Department of Health <http://www.health.sa.gov.au>
Northern Territory Department of Health <http://www.nt.gov.au/health>
UK Department of Health publications
<http://www.dh.gov.uk/PublicationsAndStatistics/Publications/fs/en>
US Centers for Disease Control Skin Cancer Primary Prevention & Education Initiative
<http://www.cdc.gov/cancer/nscpep/awareness.htm>
American Association for Cancer Education <http://www.aaceonline.com/index.asp>
American Cancer Society <http://www.cancer.org>
American Academy of Dermatology <http://www.aad.org>
European Association for Cancer Education <http://www.eaceonline.com/>

Data handling process

Titles and abstracts of the 429 identified references were assessed for relevance by one reviewer (C Watts). The following inclusion criteria were used:

- English language only;
- January 1993 to January 2006;
- Human studies;
- Systematic reviews, syntheses, meta-analyses, interventions, observation studies, evaluations and commentaries;

The Elwood and Glasgow Report 1993 was used to categorise the evidence. Evidence relating to the following areas has been reviewed:

1. Early diagnosis in the general population
 - a. Public awareness and education
2. Early diagnosis among high risk subjects
3. Skin checks and screening
 - a. Skin checks
 - b. Population screening
 - c. Self-screening
4. Primary care management of suspicious lesions
5. Promptness of diagnosis

Evidence relating to the following areas has been excluded as it will be covered by the New Zealand group working alongside the NHMRC project reviewing the Australian clinical practice guidelines for the management of melanoma:

1. Secondary care
2. Therapy

Assessment of papers

The 203 abstracts of papers were reviewed by one of three authors (C Watts, J Ball or C Conland). The abstracts of the papers were appraised in terms of relevance and quality by the authors. Due to time constraints in some cases only the abstract of an article has been reviewed. All articles considered to make an important contribution to the body of evidence have been reviewed in full. Criteria to review in full included the type of study (randomised-controlled trial, case-control study or systematic review were all reviewed in full), level of evidence and the country where the study took place (New Zealand and Australian studies were reviewed in full). There is very little published evidence regarding the situation in NZ.

Reference lists of key papers have not been searched to identify further papers. All authors contributed to the writing of the report and all authors have final responsibility for the report.

Search strategies

Medline

- 1 exp Melanoma/ (49208)
- 2 exp Skin Neoplasms/ (62802)
- 3 1 or 2 (94672)
- 4 limit 3 to english (77090)
- 5 limit 4 to yr=1993-2005 (40457)
- 6 (public adj3 aware\$).mp. (2004)
- 7 (public adj3 campaign\$).mp. (858)
- 8 early warning.mp. (956)
- 9 spot check\$.mp. (103)
- 10 mole map.mp. (0)
- 11 case finding.mp. (1788)
- 12 (early adj3 detect\$).mp. (31830)
- 13 (increas\$ adj3 aware\$).mp. (6954)
- 14 ((delay\$ adj3 check\$) or (delay\$ adj3 present\$)).mp. (3703)
- 15 or/6-14 (46980)
- 16 5 and 15 (623)
- 17 from 16 keep (selected references)
- 18 Early Diagnosis/ (867)
- 19 Self-Examination/ (496)
- 20 (mole watch\$ or molewatch\$ or (skin check or skin clinic or lesion clinic or skin cancer day or skin cancer week or screening day)).mp. (188)
- 21 (early adj3 recogni\$).mp. (8717)
- 22 open access clinic\$.mp. (22)
- 23 (skinwatch or skin watch).mp. (2)
- 24 or/27-32 (10256)
- 25 5 and 24 (233)

- 26 26 not 16 (166)
- 27 from 26 keep (selected references)
- 28 mass screening/ (49281)
- 29 screen\$.ti. (59521)
- 30 (28 or 29) and 5 (306)
- 31 30 not (16 or 26) (205)
- 32 from 31 keep (selected references)
- 33 Advertising/ (8977)
- 34 Mass Media/ (5449)
- 35 Health Knowledge, Attitudes, Practice/ (27888)
- 36 Public Opinion/ (10337)
- 37 health education/ (37561)
- 38 or/33-37 (83815)
- 39 5 and 38 (425)
- 40 39 not (16 or 26 or 31) (294)
- 41 from 40 keep (selected references)
- 42 exp Melanoma/di or exp Skin Neoplasms/di (11569)
- 43 limit 42 to english (8219)
- 44 limit 43 to yr=1993-2005 (4704)
- 45 patient education/ (42989)
- 46 precancerous conditions/ (17188)
- 47 neoplasm invasiveness/ (27559)
- 48 or/45-47 (87269)
- 49 44 and 48 (211)
- 50 49 not (16 or 26 or 31 or 40) (160)
- 51 from 50 keep (selected references)
- 52 time factors/ (686440)
- 53 44 and 52 (141)
- 54 54 not (16 or 26 or 31 or 40 or 50) (104)
- 55 from 54 keep (selected references)

Embase

- 1 exp Melanoma/ (32753)
- 2 skin cancer/ (7394)
- 3 1 or 2 (38403)
- 4 limit 3 to english (34342)
- 5 limit 4 to yr=1993-2005 (27987)
- 6 (public adj3 aware\$.mp. (1476)
- 7 (public adj3 campaign\$.mp. (621)
- 8 early warning.mp. (798)
- 9 spot check\$.mp. (69)
- 10 mole map.mp. (0)
- 11 case finding.mp. (1627)
- 12 (early adj3 detect\$.mp. (22206)
- 13 (increas\$ adj3 aware\$.mp. (5314)
- 14 ((delay\$ adj3 check\$) or (delay\$ adj3 present\$)).mp. (3004)

- 15 or/6-14 (34212)
- 16 5 and 15 (517)
- 17 Early Diagnosis/ (27899)
- 18 Self-Examination/ (1240)
- 19 (mole watch\$ or molewatch\$ or (skin check or skin clinic or lesion clinic or skin cancer day or skin cancer week or screening day)).mp. (153)
- 20 (early adj3 recogni\$).mp. (5820)
- 21 open access clinic\$.mp. (17)
- 22 (skinwatch or skin watch).mp. (1)
- 23 or/17-22 (33867)
- 24 mass screening/ (7104)
- 25 screen\$.ti. (39826)
- 26 Advertising/ (3314)
- 27 Mass Media/ (4065)
- 28 Health Knowledge, Attitudes, Practice/ (18530)
- 29 Public Opinion/ (3360)
- 30 health education/ (18462)
- 31 or/26-30 (44445)
- 32 5 and 23 (607)
- 33 16 or 32 (923)
- 34 letter.pt. (300454)
- 35 33 not 34 (892)
- 36 from 35 keep (selected references)
- 37 exp melanoma/di (7157)
- 38 skin cancer/di (1246)
- 39 37 or 38 (7953)
- 40 limit 39 to english (6715)
- 41 limit 40 to yr=1993-2005 (5672)
- 42 exp health education/ or patient education/ (51739)
- 43 41 and 42 (105)
- 44 from 43 keep (selected references)

Cinahl

- 1 exp Melanoma/ (985)
- 2 exp Skin Neoplasms/ (1365)
- 3 1 or 2 (2058)
- 4 limit 3 to english (2056)
- 5 limit 4 to yr=1993-2005 (1810)
- 6 (public adj3 aware\$).mp. (520)
- 7 (public adj3 campaign\$).mp. (254)
- 8 early warning.mp. (179)
- 9 spot check\$.mp. (23)
- 10 mole map.mp. (0)
- 11 case finding.mp. (172)

12 (early adj3 detect\$.mp. (2350)
13 (increas\$ adj3 aware\$.mp. (1840)
14 ((delay\$ adj3 check\$) or (delay\$ adj3 present\$)).mp. (227)
15 or/6-14 (5266)
16 5 and 15 (75)
17 Early Diagnosis/ (0)
18 Self-Examination/ (0)
19 (mole watch\$ or molewatch\$ or (skin check or skin clinic or lesion clinic or
skin cancer day or skin cancer week or screening day)).mp. (34)
20 (early adj3 recogni\$.mp. (930)
21 open access clinic\$.mp. (1)
22 (skinwatch or skin watch).mp. (1)
23 or/17-22 (966)
24 mass screening/ (0)
25 screen\$.ti. (8503)
26 Advertising/ (2038)
27 Mass Media/ (1952)
28 Health Knowledge, Attitudes, Practice/ (0)
29 Public Opinion/ (1113)
30 health education/ (6087)
31 or/26-30 (10799)
32 exp Melanoma/di or exp Skin Neoplasms/di (430)
33 patient education/ (19657)
34 precancerous conditions/ (216)
35 neoplasm invasiveness/ (160)
36 or/33-35 (20020)
37 time factors/ (17108)
38 23 or 31 (11758)
39 5 and 38 (92)
40 16 or 39 (157)
41 32 and (36 or 37) (38)
42 40 or 41 (187)
43 limit 42 to yr=1993-2005 (181)
44 from 43 keep (selected references

Cochrane Central Register of Controlled Trials

- 1 exp Melanoma/ (586)
- 2 exp Skin Neoplasms/ (534)
- 3 1 or 2 (857)
- 4 limit 3 to english [Limit not valid; records were retained] (857)
- 5 limit 4 to yr=1993-2005 (576)
- 6 (public adj3 aware\$).mp. (21)
- 7 (public adj3 campaign\$).mp. (28)
- 8 early warning.mp. (24)
- 9 spot check\$.mp. (6)
- 10 mole map.mp. (0)
- 11 case finding.mp. (57)
- 12 (early adj3 detect\$).mp. (638)
- 13 (increas\$ adj3 aware\$).mp. (200)
- 14 ((delay\$ adj3 check\$) or (delay\$ adj3 present\$)).mp. (99)
- 15 or/6-14 (1054)
- 16 5 and 15 (14)
- 17 Early Diagnosis/ (21)
- 18 Self-Examination/ (38)
- 19 (mole watch\$ or molewatch\$ or (skin check or skin clinic or lesion clinic or skin cancer day or skin cancer week or screening day)).mp. (25)
- 20 (early adj3 recogni\$).mp. (88)
- 21 open access clinic\$.mp. (2)
- 22 (skinwatch or skin watch).mp. (1)
- 23 or/17-22 (173)
- 24 mass screening/ (1123)
- 25 screen\$.ti. (1889)
- 26 Advertising/ (49)
- 27 Mass Media/ (55)
- 28 Health Knowledge, Attitudes, Practice/ (1180)
- 29 Public Opinion/ (14)
- 30 health education/ (1266)
- 31 or/26-30 (2194)
- 32 exp Melanoma/di or exp Skin Neoplasms/di (49)
- 33 patient education/ (2504)
- 34 precancerous conditions/ (130)
- 35 neoplasm invasiveness/ (227)
- 36 or/33-35 (2855)
- 37 time factors/ (28740)
- 38 23 or 31 (2363)
- 39 5 and 38 (43)
- 40 16 or 39 (49)
- 41 32 and (36 or 37) (6)
- 42 40 or 41 (52)
- 43 limit 42 to yr=1993-2005 (52)
- 44 from 43 keep (selected references)

Current Contents

1. Melanoma OR skin cancer
2. (early SAME (detect* OR warning OR recognit* oR diagnosis))
3. (public SAME (aware* OR campaign))
4. mole watch OR molewatch OR lesion clinic OR skin watch OR skinwatch OR molemap* OR mole map*)
5. self examination OR spot check* OR skin check* OR skin clinic*
6. case finding
7. (increas* SAME aware*)
8. delay* SAME (diagnos* OR present* OR check*)
9. mass media OR adverti*
10. #1 AND (#2 OR #3 OR #4 OR #5 OR #6 OR #7 OR #8 OR #9)

Please note that the Current Contents and Citation Indexes databases do not have subject indexing and do not support the complexity of searching that is available on the other bibliographic databases

Other sources of information

All other sources of information were searched using simple searches according to the level of complexity supported.

APPENDIX 4: ASSESSMENT OF SCREENING FOR SKIN CANCER USING CANCER SOCIETY OF NEW ZEALAND CRITERIA

Introduction

A number of groups have developed criteria for assessing screening, all of which build upon the World Health Organization principles of screening first proposed in 1968 (Wilson and Junger 1968). Examples are the United Kingdom National Screening Committee (2000), the Canadian Strategy for Cancer Control: Screening Working Group (2002) and the New Zealand National Health Committee (2003).

Drawing upon these examples, the Cancer Society of New Zealand developed criteria that are specific to the role and responsibility of the Cancer Society, e.g., addressing consumer needs, responding to media requests for organisational views and participation in government policy working groups (Cancer Society of New Zealand 2005).

The Cancer Society's criteria are designed to assess screening of those who are at average risk of developing a particular form of cancer. The Cancer Society endorses screening for both individuals and populations that meet these criteria. The Cancer Society criteria do not apply to the ongoing surveillance of those known to be at increased risk of a particular cancer, for example, due to a personal or family history of that cancer.

In developing its policy recommendations, the Early Detection Advisory Group applied the Cancer Society's criteria to screening for those at average risk of skin cancer, with a particular focus on melanoma. The group's assessment and conclusions are provided in this document. Also included are the positions of some other overseas organisations.

For those at increased risk of melanoma, EDAG recommends that guidelines for the surveillance of melanoma be developed in New Zealand, using an evidence-based approach, and that self-administered, personal risk assessment tools be developed.

EDAG's assessment of screening for skin cancer is summarised under each of the Cancer Society criteria; an italicised synopsis of each criterion (sourced from the Cancer Society document) is also included.

Assessment by criteria

1. The cancer is an important health problem.

In this context the importance of a cancer as a health problem is a combination of its incidence and the potential for screening to benefit people with that cancer.

New Zealand melanoma incidence and death rates are among the highest in the World (Bulliard and Cox 1996). In 2002 melanoma was the third most common type of cancer registration for both females (909 new registrations) and males (933 new registrations) (Ministry of Health 2006).

While registrations are relatively common, mortality is considerably lower (149 male deaths; 86 female deaths). Although the incidence rate of melanoma is 8 times higher in non-Māori than Māori, Māori who develop melanoma are more likely to be diagnosed with thick melanoma than non-Māori who develop melanoma (Richardson and Fletcher 2006). For the period 1996-2001, although most melanomas were diagnosed at any early stage (localised) for both Māori and non-Māori, Māori with melanoma were significantly more likely to be diagnosed at an advanced stage of disease (although the overall numbers are small) (Robson, Purdie and Cormack 2006).

Incidence and mortality of melanoma increases with age, but less steeply than for many other cancers. About 10-30% of cases occur in young adults, 30-40% in middle age and the remaining 40-55% in old age (Ministry of Health 2002). As such, melanoma contributes significantly to years of potential life lost.

Table 1: New Zealand cumulative risks (to age 80). Source: Richardson and Fletcher 2006

Cancer	Diagnosis	Death
Lung cancer	5%	4%
Colorectal cancer	8%	3%
Breast cancer (females)	12%	3%
Prostate cancer (males)	21%	3%
Melanoma	4%	<1%

In contrast to melanoma, basal cell and squamous cell skin cancer (non-melanoma skin cancers, or NMSC) are very common, especially in the elderly. Although mortality is low compared to mortality from melanoma (62 deaths in men and 34 deaths in women in 2001) (New Zealand Health Information Service 2005) NMSC can cause disfigurement and morbidity.

Conclusion: Skin cancer, particularly melanoma, is an important health problem.

2. The cancer is appropriate for screening.

For a cancer to be appropriate for screening there needs to be a recognisable early stage, where treatment can provide a better outcome than treatment offered at a later stage.

For melanoma, thickness is the strongest predictor of prognosis. In general, thinner lesions have a better outcome, with prognosis worsening with increased thickness at diagnosis (Janda et al 2004). Five-year survival for those with melanoma between 1.5 mm and 4 mm is approximately 70%; for those with melanomas thicker than 4 mm, survival is about 45% (Helfand et al 2001). Nevertheless, there are some thin melanomas that, if untreated, can result in death and some thick melanomas that do not.

Melanoma can arise in an existing pigmented lesion or can develop *de novo*, both of which can be visible to the naked eye. Dysplastic naevi may be regarded as either risk markers (markers of individuals in the population who are at increased risk) or actual melanoma precursors (an early stage in the course of the disease) (Sneyd 1998). If risk markers, they can identify people who could be regularly assessed for melanoma development. If they are precursors, their detection and removal should reduce the incidence of melanoma. However, it is not yet possible to distinguish between those which will become malignant and the much higher number which will not (Sneyd 1998).

There are differences in the natural history of the common histological types of melanoma, with variation in the potential for and speed of metastasis. While superficial spreading melanoma (about 44% of melanomas in New Zealand) and lentigo maligna (about 7% of melanomas in New Zealand) usually develop over many years before invasion, nodular melanoma has no known precursor and is characterised by rapid growth over a period of weeks or months (Richardson and Fletcher 2006). According to the Richardson and Fletcher (2006) analysis, nearly half (46.7%) of thick (>3 mm) melanomas are nodular. Similar results have been found in Australia and the United States (Demierre et al 2005; Chamberlain et al 2002).

It is possible that some thin melanomas are “histologically malignant but behaviourally benign”; if not excised they would never have metastasised or may even have regressed (Burton and Armstrong 1998). Unlike prostate cancer, in which evidence exists of such non-aggressive cancers, no studies have established whether this is the case for melanoma (Helfand et al 2001).

Squamous cell cancer has the potential to metastasise. A large primary tumour (>2 cm) is associated with an increasing risk of metastasis.

In their review of evidence for screening for skin cancer, Helfand et al (2001) found no controlled studies of treatment in patients found by screening to have thin melanomas. They also concluded that studies of delay in diagnosis have conflicting results, and the ability of screening to reach individuals at high risk and to find aggressive tumours while they are still curable have not been established (Helfand et al 2001). It should also be noted that, as a rule, screening for cancer tends to detect those cancers which are slow-growing (over a period of years) rather than those which are aggressive.

With regard to non-melanoma skin cancer, Helfand et al (2001) concluded that while it is suspected that advanced locally invasive or metastatic non-melanoma skin cancer results from medical neglect, there have been insufficient studies of the rate of progression of non-melanoma skin cancers in the elderly (Helfand et al 2001). Although early treatment of basal and squamous cell carcinoma might reduce morbidity and disfigurement, the United States Preventive Services Task Force review found no studies which evaluated whether screening improves the outcomes of these.

Conclusion: The behaviour of the lesion is not always able to be predicted, so identifying a stage where screening could change the prognosis would be difficult. Nevertheless, as a proportion of thin melanomas progress to thicker melanomas, an argument can be made for excising thin melanomas, to prevent progression.

3. There is a suitable screening test.

The screening test must be acceptable and must have adequate sensitivity and specificity so that a high proportion of those with the cancer will be correctly identified, and so that false negative and false positive tests can be kept to a minimum.

To date, a visual full-body skin examination has been the primary test used for screening. Such examinations are non-invasive, accessible, inexpensive (as a test) and involve no special technologies. Their accuracy relies, however, on the skills of the examiner.

An assessment undertaken for the United States Preventive Services Taskforce (USPSTF) and published in 2001 examined two methods in its comprehensive review:

- total body skin examination in all patients in a primary care setting
- assessment of risk in all patients, followed by a total body examination among those found to be at high risk.

The accuracy of a visual examination was measured by two methods:

- examination of biopsy (with very few studies following patients to determine false negative rates of the examination)
- assessment of photos by examiners.

The USPSTF assessment concluded that:

- the accuracy of a total-body skin examination by primary care physicians in unselected patients may be low
- no study has determined the accuracy of risk assessment followed by total-body skin examination in selected patients as a screening method
- most studies have not examined the accuracy of a total-body skin examination or the ability of physicians to identify suspicious lesions in the setting of a screening programme (Helfand et al 2001).

More recently, the clinical outcome results of an Australian community-based randomised trial of population screening for melanoma, involving whole-body skin examinations by primary care practitioners, reported an estimated specificity of 86.1% (95% confidence interval = 85.6-86.6). Although the authors concluded that such specificity was comparable to that of other screening tests, including mammography (Aitken et al 2005), in the RCTs of mammography screening, specificity ranged from 95% to 97%.¹ Follow-up of participants with a negative screening examination (to determine sensitivity) was not conducted.

Recently other technologies have been introduced, e.g., digital photography and processes where suspicious lesions are mapped on a whole body image (mole mapping). To date there is no published evidence regarding the sensitivity and specificity of these modalities in the context of screening those at average risk.

With regard to acceptability of skin examinations, a telephone survey carried out in Australia before the planned RCT in Queensland (with a response rate of 70%) found that 25.9% of participants reported whole-body skin self-examination in the previous 12 months, and 79.1% reported that they or someone who was not a physician had deliberately checked at least part of their skin for early signs of skin cancer in the previous 12 months (Aitken et al 2004). In this same population, 11% of participants reported that they had had a whole-body skin examination by a GP in the previous 12 months (Janda et al 2004 (b)).

Conclusion: There is little information on acceptability and no evidence regarding sensitivity and specificity of skin examinations within a screening programme in a primary care setting.

¹ In December 2002, BreastScreen Aotearoa specificity was 96.8%.

4. There is high quality evidence, ideally from randomised controlled trials, that screening is effective in reducing mortality.

Using methods such as survival comparisons, observational studies or ecological studies to assess screening is misleading as they are vulnerable to biases. Only an appropriately designed and analysed randomised controlled trial can avoid these biases and determine whether screening for cancer really is beneficial.

To date there is no high quality evidence from a randomised controlled trial to establish the effectiveness of screening in reducing mortality from melanoma or from basal and squamous cell skin cancers. Although a trial involving 600,000 subjects and requiring nine years to complete was to have begun in Australia, it has now been abandoned due to lack of funding.

According to the Helfand et al review (2001), there are no case-control studies of screening for skin cancer. However, one case-control study has examined the effect of skin self-examination on mortality from melanoma. The results provide “suggestive, rather than definitive, evidence for the effectiveness of skin self-examination”. According to Elwood (2005), this result was confirmed recently in a survival analysis of the same group of melanoma patients, with 5.4 years’ median follow-up. A further unexpected result was a reduced risk of melanoma *incidence* in those doing self-screening (raising questions about the validity of other results). Also, those who practised self-screening most carefully had less benefit than those who used it only casually. According to Elwood, these results highlight the inherent difficulty of assessing screening by case-control methods (Elwood 2005).

A recent Australian study found that melanomas detected by doctors were more likely to be thin than those detected by the patient or other layperson. The authors acknowledge, however, that it has not been shown that the increased detection of thin melanoma corresponds to a reduction in the incidence of thick melanoma and an improvement in survival (McPherson et al 2006).

<p>Conclusion: There is no high quality evidence from a randomised controlled trial that screening is effective in reducing mortality.</p>

5. There is agreement on the most effective treatment for people who are diagnosed with cancer or a cancer precursor (pre-cancer) as a result of screening.

There should be evidence that treatment is effective, and treatment should be offered by appropriately qualified and experienced health professionals according to established guidelines.

Treatment for early melanoma is complete excision. In most cases, melanomas have a better outcome if detected and excised while still thin, with prognosis worsening with increased thickness. Treatment for advanced disease has limited effectiveness.

Conclusion: There is agreement on the most effective treatment.

6. Screening does more good than harm.

Ethically, screening should not be endorsed or promoted if the benefits do not outweigh the risks.

Population screening requires a large number of people to be screened in order to benefit a few. It is therefore important to identify the potential harms associated with screening, especially for those who will not benefit. With regard to screening for skin cancer, such harms include excising benign lesions (which is unnecessarily invasive, costly and leaves scars) and also missing malignant lesions.

The USPSTF concluded that although there are no serious risks from total-body skin examinations, these examinations may be embarrassing to some and inconvenient in some settings. The possible risks include:

- unnecessary treatment, either due to misdiagnosis or to detection of lesions that might not have caused clinical consequences
- detection of large numbers of benign skin conditions which are very common in the elderly and could lead to additional biopsies and unnecessary or expensive procedures.

In its overall assessment of screening for skin cancer, the USPSTF indicated that it could not determine the benefits and harms of periodic skin examinations. Helfand et al (2001) recommended that observational studies should address the potential harms of screening, including “mislabelling and unnecessary biopsies”.

A 1994 analysis of melanoma trends in Australia noted that although there was a high increase in the incidence of very thin melanomas, the incidence of thick melanomas increased as well (Burton and Armstrong 1994). A possible interpretation is that increasing checks in the population may detect a relatively “unimportant type of thin melanoma with little impact on mortality” (Helfand 2001).

Other potential harms of screening need to be taken into account. These include an increasing preoccupation with disease generated by screening promotion and increased levels of anxiety and fear of being found to have cancer. Also studies have shown that active promotion of cancer screening results in people significantly overestimating their risk of having or getting the disease.

Existing screening programmes in New Zealand have a lower proportion of Māori, Pacific and older participants. This means that the potential benefits of screening are less likely to be seen in these groups, thereby increasing inequalities. Furthermore, although melanoma in Māori, Pacific and older people are thicker at registration, there is no evidence that screening would reduce the incidence of thick melanomas in these population groups.

Sustainability is also an issue; while people may be persuaded to accept an initial offer of screening, many may opt not to participate in subsequent screening rounds or follow-up procedures for suspicious lesions. Of particular concern is the potential impact of screening and its subsequent pressure for services on people with signs of skin cancer, particularly melanoma, who may be subjected to additional delays in diagnosis and treatment.

Conclusion: Due to lack of evidence, it is not possible to conclude whether or not screening for skin cancer does more good than harm.

7. People with positive screening results will have access to timely and appropriate investigations and treatment.

Screening aims to detect cancer at a stage where treatment will be more effective than later treatment. If investigations are delayed, treatment may not be early enough to achieve this aim.

Based on anecdotal evidence, the current workforce has difficulty in coping with current demands and would be unable to meet any increased demands.

Conclusion: Current specialist services would not have the capacity to provide timely and appropriate investigations and treatment for screen-detected lesions.

8. Screening can be provided in a continuous manner in conjunction with necessary quality assurance and evaluation.

The best way to minimise the risks associated with screening is to deliver screening in an organised programme with appropriate quality assurance and evaluation of all aspects of the screening pathway.

At present there is no co-ordinated approach in New Zealand to the management of skin cancer, including melanoma. In the United Kingdom, recently developed guidance *Improving Outcomes for People with Skin Tumours including Melanoma* (National Collaborating Centre for Cancer 2006) has identified the need for two levels of multidisciplinary teams. According to the guidance, all

clinicians treating patients with any type of skin cancer should be members of one of these teams, whether they work in the community or in the hospital setting. Also, all should work to agreed protocols for referral, multidisciplinary team review, management and audit of skin cancer services. The planned involvement of New Zealand in the current review of the Australian NHMRC guidelines for the management of melanoma provides an opportunity to address these issues in New Zealand.

Conclusion: At present screening in New Zealand could not be provided in a continuous manner in conjunction with necessary quality assurance and evaluation. A more appropriate course of action is the development of agreed protocols and a multidisciplinary approach to the management of skin cancer, including melanoma. The involvement of New Zealand in the current review of Australian guidelines for the management of melanoma provides an opportunity to address these issues.

Conclusions

Although skin cancer, particularly melanoma, is an important health problem, screening for skin cancer does not meet the Cancer Society criteria for endorsement. Of particular significance is that:

- there is no high quality evidence from a randomised controlled trial that screening is effective in reducing mortality; therefore, its value is unknown
- it is not possible to conclude whether or not screening for skin cancer does more good than harm (possible harms including unnecessary biopsies and treatment).

As a result EDAG recommends that:

- population screening for melanoma, basal cell cancer or squamous cell skin cancer not be endorsed or promoted in New Zealand
- opportunistic screening by health professionals should not be recommended as routine practice. In situations where it is undertaken, it should be done on the basis of informed choice. Individuals should be informed about the potential benefits and risks of screening and the likely implications of a positive or negative result. (See page 93 for the Cancer Society of New Zealand position on screening as an informed choice and on rights and responsibilities in relation to cancer screening.)

EDAG also recommends that clinicians should remain alert for skin lesions with malignant features in the context of physical examinations performed for other reasons.

Recommendations for the surveillance of those at high risk of melanoma are addressed separately.

Advice of other organisations

US Preventive Services Task Force: The evidence is insufficient to recommend for or against routine screening for skin cancer using a total-body skin examination for the early detection of cutaneous melanoma, basal cell cancer or squamous cell skin cancer (US Preventive Services Taskforce 2001).

Cancer Council Australia and Australasian College of Dermatologists:

- Screening for non-melanocytic skin cancer (NMSC) does not meet the recognised criteria for the implementation of screening because the disease in the vast majority of cases is not life-threatening or serious enough to cause long term ill-health.
- Screening for melanoma does not meet the recognised criteria for the implementation of screening because:
 - research indicates that current diagnostic practices for melanoma are not optimal in terms of accuracy or cost-effectiveness (Burton 1996)
 - currently there is insufficient evidence that screening the general population for melanoma offers reduced morbidity and mortality.
- General practitioners should develop surveillance programmes for patients at high risk and develop appropriate management programs depending on their level of risk.
- Recommend that general practitioners who identify risk factors for skin cancer in patients presenting for other reasons, inform patients about sun protection measures and offer them opportunity for a full body examination and appropriate management plan.
- Do not recommend a specific self-examination technique or frequency of self-examination, as neither has been shown to reduce morbidity or mortality from skin cancer. However, as a significant number of melanomas are discovered by people themselves or by a family member (Koh et al 1992):
 - the general public, particularly men aged 50 and over, should be encouraged to check all areas of their skin, including skin not normally exposed to the sun, for changes described in the *How to Check for Skin Cancers* leaflet at least six-monthly. They should seek assistance from another individual to check difficult to see areas such as their back
 - individuals who are concerned about skin changes suggestive of skin cancer should seek advice from a medical practitioner (Cancer Council Australia 2004).

National Health and Medical Research Council (NHMRC) of Australia: The *Clinical Practice Guidelines for the Management of Cutaneous Melanoma* state that there are no data which show that screening of the general population for melanoma is an effective way of controlling melanoma mortality (NHMRC 1999).

Canadian Task Force on Preventive Health Care: The evidence is insufficient to recommend for or against skin cancer screening for the general population, but suggests that regular total-body skin examination may be prudent for a subgroup of very high-risk individuals (Freightner 1994).

American Cancer Society: recommends that for individuals undergoing periodic health examinations, a cancer-related check-up might include examinations of the skin, depending on a person's age (American Cancer Society 2006).

American College of Preventive Medicine: recommends total-body skin examination in high-risk individuals, including those with a family or personal history of skin cancer, predisposing phenotypic characteristics and increased occupational or recreational exposure to sunlight, or clinical evidence of precursor lesions (e.g., dysplastic or congenital naevi) but does not recommend routine screening (Ferrini et al 1998).

Cancer Society Position on Informed Choice, Rights and Responsibilities in Relation to Screening

Screening as an informed choice

As identified by the United Kingdom National Screening Committee (UKNSC), all those who choose to be screened (on an opportunistic basis or as part of an organised programme) should do so on the basis of informed choice, and they should appreciate that in being screened, there is a risk of an adverse outcome (National Screening Committee 2000). They should also be aware that they are not just consenting to a screening test but to the full screening pathway which includes the possibility of interventions as a result of screening (National Health Committee 2003).

Rights and responsibilities

In its role in relation to cancer screening, the Cancer Society of New Zealand acknowledges the following rights and responsibilities.

- a) The individual has the right to request a screening test and to be well informed by the provider about the test benefits, risks and limitations, including the implications of the test result².
- b) The Cancer Society has a responsibility to be an authoritative source of accurate information on screening.
- c) The Cancer Society has a responsibility to ensure that staff responsible for providing information are well informed and equipped to undertake this role.
- d) The Cancer Society has a responsibility to apply its screening criteria in a consistent and transparent fashion for the protection of the individual.
- e) According to the Medical Council of New Zealand, doctors have a “special duty of care” to make asymptomatic persons aware of the limitations of screening and the uncertainties, in particular the chance of false positive and false negative results. Before obtaining consent the doctor should explain, or give information to the patient that explains:
 - the purpose of the screening
 - the uncertainties
 - any significant medical, social or financial implications of the condition for which the screening is done
 - follow up plans, including availability of counselling and support services (Medical Council of New Zealand 2002).

² Health and Disability Commissioner (Code of Health and Disability Services Consumers’ Rights) Regulations 1996. Two rights of the Code of importance when considering screening – Right 6 (the right to be fully informed) and Right 7 (the right to make an informed choice and give informed consent).

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